"Accepting 'Eternity' of Antiretroviral Drugs": A Pillar in Improving Adherence to Antiretroviral Drugs among a Selected Population of HIV Positive Patients in a Semi-Urban Region in Kenya - A Qualitative Analytic Study

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Abstract

Purpose: The objective of this research was to ascertain perspectives on suboptimal adherence and ways to improve optimal adherence to antiretroviral drugs (ARVs) among Human Immunodeficiency Virus (HIV) positive patients attending selected HIV Care Centres in Kibwezi West Sub-county, Makueni County, Kenya.

Methodology: Six Focused Group Discussions (FGD) homogeneously stratified by age and gender and four Key Informant Interviews (KII) were conducted. Each FGD consisted of 8 study participants recruited by purposive sampling technique.

Findings: Focus group discussions identified fear, stigma, defiance, ignorance on reasons for medication, not believing in oneself, participating in activities that hinder adherence such as drinking alcohol, retrogressive religious beliefs, lack of self-love and denial as the main causes of sub optimal adherence to ARVs. However the discussions also identified one-on-one educational counselling sessions, seeking advice, group education with similar infected people, adherence counselling support by health workers, acceptance of one's status, social and family support as means to improve adherence to ARVs. It also identified knowing one's status, acceptance, personal discipline on adherence and reminders such as clock alarms or a trusted person as means to improve adherence to ARVs. However, the discussions revealed gender and age differences, attributed to different life's challenges and perspectives in the different cohorts thus interventions should be targeted rather than lump sum. Key informant interviews identified ignorance, stigma, busy work schedule and lack of social support as patient level factors that would hinder adherence to ARVs. They also noted long waiting time, distance, poor attitude by health service providers and drug stock outs contributing to poor adherence to ARVs at the facility level. However, they identified community dispensing, support groups, health talks with mentors, psychosocial support, drug availability, outreach, encouraging disclosure, distribution of patients to nearest satellite clinics and directly observed therapy (DOT) by a trusted relative as ways to improve adherence to ARVs.

Unique Contribution to Theory, Practice and Policy: interventions need to be tailored to the specific population and individual needs; thus, adopting better and informed strategies. The study adds to the pool of knowledge that factors affecting adherence are dependent on populations under investigation due to varied socio-demographic, socio-cultural and socio-economic factors locally, regionally and globally. The findings of the study will inform the local county government of Makueni and Kibwezi West Sub-county administrators in formulating local economic and health policies and by-laws that would aid in improving optimal adherence to ARVs.

Keywords: *Adherence, Stigma, Acceptance, Social Support*

INTRODUCTION

Suboptimal adherence to ARVs is a significant public health concern in the management of HIV infection. Understanding predictors of suboptimal adherence to ARVs is key in addressing challenges on adherence. The general objective of the study was to determine the factors associated with adherence to antiretroviral drugs among HIV positive patients aged 15 years and above attending selected CCCs in Kibwezi West sub-county, Makueni County, Kenya. Globally, an estimated population of 38 million people were infected with HIV by 2019 (UNAIDS, 2021). Out of those on ART, only 59% were virally suppressed (UNAIDS, 2021) which is a proxy indicator of adherence to ARVs. This is a far cry from the UNAIDS goal of 95-95-95 by 2030 (UNAIDS, 2021). Most people living with HIV are in low and middle income countries (UNAIDS, 2021), Kenya being one of them. A meta-analysis of 50 years research studies show an annual rate of 24.8% non-adherence to any prescribed medication (DiMatteo, 2004). Another meta-analysis of Africa and Asia reveals an adherence of more than 70% among adolescents and young adults living with HIV with comparatively lower rates of 50-60% in Europe and North America (Kim *et al*., 2014). In sub-Saharan Africa, a systematic review of 4052 research studies on adherence to ARVs show an adherence estimate of 72.9%% (Heestermans *et al*., 2016).

In Kenya, a recent laboratory-based study conducted on Kenyans aged 15-64 years indicate that less than 10% of Kenyans are not adhering to ARVs reflecting a significant success in retention to care and treatment response (Mukui *et al*., 2016). However, the study points to the need for targeted intervention among the rural population and young persons (Mukui *et al*., 2016). According to Kenya Population-based HIV Impact Assessment (KENPHIA) 2020 report, 90.6% of HIV infected adults aged 15-64 years were adherent to treatment by 2018 (Ministry of Health, 2020). Counties in Kenya have varying levels of adherence rates among HIV infected adult population on ARVs. Makueni County houses the longest stretch of the busy Mombasa-Nairobi Highway. Kibwezi West sub-county has major administrative and commercial towns along the Mombasa-Nairobi highway that contribute significantly to the national burden of HIV/AIDS. The towns are also stop-overs for long-distance truck drivers; a key population in contributing significantly to high HIV prevalence along the transport corridor (Strauss *et al.,* 2018).

The Joint United Nations Strategy on AIDS (UNAIDS) targets at 95% of those on treatment adherent to ARVs in combating HIV epidemic by 2030 (Joint United Nations On AIDS [UNAIDS], 2021), yet data on adherence levels has not been established. Adherence to medication is the single most important predictor of viral suppression; (Rosenblum *et al.,* 2009) consequently predicting morbidity and mortality among HIV positive patients. Notably, Makueni County has rolled out free universal health care dubbed MakueniCare (Government of Makueni County, 2017) through an affordable insurance programme breaking financial barriers in accessing healthcare services (Daily Nation, 2016). Further, the national government's robust efforts in routine HIV screening, increasing access to ARVs and comprehensive management have scaled up diagnosis and enrolment into care and treatment (National AIDS Control Council, 2016). However, adherence to ARVs by patients has still remained a challenge.

Makueni County Strategic Direction 4.4.2 in the Makueni County HIV, Aids, and TB Strategic Plan 2015/16-2018/19 aims at 90% of all people on ARVs adhere to medication (Government of Makueni County, 2016). The county's strategic plan on HIV/ AIDS is in line with the Kenya

Aids Strategic Framework (KASF) priority intervention areas in linkage, enrolment, and treatment (Ministry of Health [MoH], 2014). NACC avers that there is a need for improvement in achieving the unmet gaps of 90 % (National AIDS Control Council, 2016). Kenya's Vision 2030 describes HIV as one of the greatest threats to achieving socio-economic development (National AIDS Control Council, 2016). Poor adherence to ARVs further makes socioeconomic development a mirage as it is associated with worse health outcomes. Notably, HIV/AIDS ranked as number one cause of most death and disability combined (DALYS) in Makueni County by the end of 2019 (Institute for Health Metrics and Evaluation, 2019). Poor adherence accelerates progression to AIDS; thus, undermining United Nations' Sustainable Development Goal (SDG) 3.3 that aims at ending AIDS epidemics by 2030 (World Health Organisation [WHO], 2020). In a US study, adherence was better among females (Tandon *et al*., 2019). In a Nigerian study, females had poor adherence(Hanif *et al*., 2013). This shows differences in adherence between the two genders. However, there is consensus in most studies that having social support group portends better adherence (Rouhani *et al*., 2017); (Grieb *et al*., 2018); (Falang *et al*., 2012). Different studies show varied association of adherence with age (Agbaji *et al*., 2015); (Nozaki *et al*., 2011); (Adejumo *et al.,* 2015); (Semvua *et al.,* 2017).

The above studies majorly relate adherence to quantifiable factors such as gender, income, level, and occupation et cetera. However, non-quantifiable patient experiences and perspectives that hinder adherence have not been widely studied since they are population-specific and not generalizable. Such factors in Kibwezi West Sub-county have not been investigated. Thus this study attempted to address this identified research and knowledge gap.

Conceptual Framework
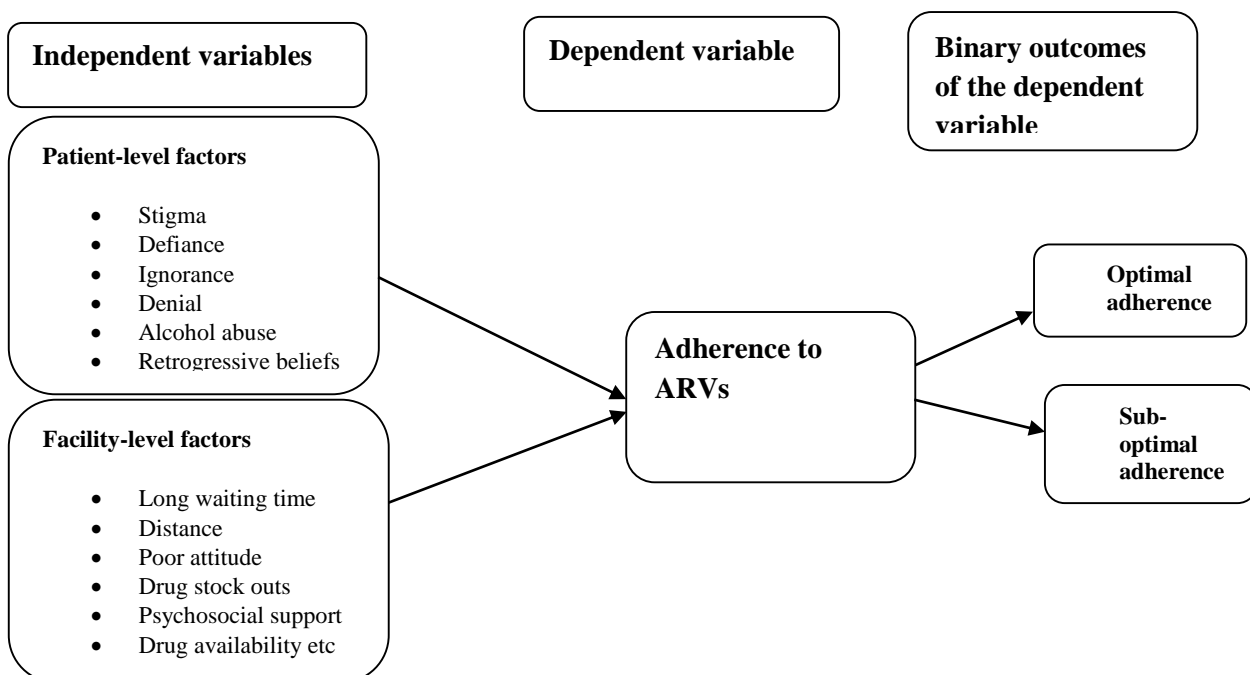**(Non-quantifiable Determinants of Adherence to ARVs)**

Figure 1: Conceptual Framework

Theoretical concept: individual patient beliefs, practices and perspectives affect adherence to ARVs despite their availability, access and uptake.

MATERIALS AND METHODS

We conducted a qualitative cross-sectional analytic study in selected HIV care centres in Kibwezi west sub-county. The study population was HIV positive patients aged 15 years and above who met the inclusion criteria and were recruited by convenience sampling technique. Two HIV Care centres: Makindu Sub-County hospital and Emali model health centre were recruited by purposive sampling. Makindu town is majorly an administrative center whereas Emali town is majorly a commercial hub thus providing a more diverse picture in the study. Ethical clearance was obtained from Kenyatta National Hospital ethics and review committee before data collection (Ref: KNH-ERC/A/322). Upon obtaining informed consent, six FGDs and four KIIs were conducted. Each FGD consisted of eight study participants; thus forming a total of forty-eight discussants. Recruitment of FGD participants and their classification was predetermined purposively. Selection of the participants was homogenous taking into consideration gender and age. KII involved the HIV Testing and Counselling Service provider or the in-charge of the HIV care centre. Only study subjects who had been adequately informed and voluntarily consented to participate were recruited. The study involved participants less than 18 years; thus an assent form was provided to this particular group. Thematic discussion was conducted guided by the FGD and KII guide, information recorded in a script and audio-taped using a phone recorder taking into consideration gestures and facial expression. Qualitative data was obtained up until data saturation. Discussions were held in Kiswahili with translations into Kiswahili where necessary and transcribed verbatim into English. Qualitative data from FGDs and KII was transcribed into Microsoft Word, pass-word secured and exported to computer-assisted qualitative data analysis software (CAQDAS) software – Code Analysis Toolkit (CAT) for coding and qualitative analysis based on thematic and core analysis and conclusions drawn.

RESULTS

Focus Group Discussion Results

Forty-eight discussants in stratified homogeneous groups of eight were interviewed.

Male focus group discussion identified stigma, fear, participating in activities that hamper adherence such as drinking alcohol, denial and not believing in oneself as the main causes of suboptimal adherence to ARVs.

Participant number 3 observed, 'There are many ways. The first is not believing in oneself. Second is fear. Fear to be seen…seen taking drugs."

The discussion also identified reduced immunity, increase in frequency and severity of opportunistic diseases, family-social consequences, increased viral load, and ultimately death as consequences of suboptimal adherence to ARVs.

Participant number 10 said, "People can develop very many diseases...viral load goes up."

Nevertheless, the group identified group education with similar infected people, seeking advice, one-on-one educational counselling sessions, and social support as means to improve adherence to ARVs.

Participant number 18 suggested, "It is through being brought closer to people with HIV so that they can be counselled and educated."

Female focus group discussion identified lack of self-love, denial and retrogressive religious beliefs as the main reasons of suboptimal adherence to ARVs.

Participant number 23 averred, "Stigma and refusing to abandon things that one is told may interfere with proper adherence to medication such as…drinking alcohol, sex without condom. Those are the reasons that can make one not to take medications appropriately."

The group also identified frequent hospitalisation and an increase in severity of opportunistic infections as the main consequences of suboptimal adherence to ARVs.

Participant number 27 posited, "Viral load goes up, immunity goes down. Diseases here and there."

Nonetheless, it identified social and family support, acceptance of one's status and adherence counselling support by health workers as means to improve adherence to ARVs.

Participant number 30 suggested, "To improve adherence, one must accept the eternity of ARVs early enough until God's appointed time."

Adolescent focus group discussion identified denial, defiance, ignorance on reasons for medication, stigma and fear as reasons for suboptimal adherence to ARVs.

Participant number 34 noted, "Disclosure. You are given the drugs but you are not taking them. Stigmatization. Like in school, you don't want to be seen taking the drugs."

The group also identified morbidity, death, hospitalisations and increased frequency of diseases as consequences of suboptimal adherence to ARVs.

Participant number 45 observed, "Poor health. You can be weak. Immunity can go down. Diseases like tuberculosis and malaria can follow you. And you might end up dead since you don't have immunity to boost your health."

However, the group noted that, personal discipline on adherence, acceptance, reminders such as a trusted person or clock alarms and knowing one's status are ways to improve adherence to ARVs.

Participant number 48 suggested "You can get somebody who can guide you. Who can remind you when to take medication, buy a watch that has an alarm when time reaches to take medication it reminds you. And accepting yourself that you are sick and you take medications well."

Key Informant Interview Results

Four key informants (the in-charges involved in primary care of HIV positive patients) from respective HIV care centres were interviewed. They identified ignorance, busy work schedule, stigma and lack of social support as patient level factors that would hamper adherence to ARVs.

KI 1 opined, "Stigma, lack of understanding, some lack social support, basically those."

On facility level factors they identified distance, drug stock outs long waiting time and poor attitude by health service providers contributing to suboptimal adherence to ARVs.

KI 3 averred, "You know the attitude of the staff, how you handle the client. Some clients don't want to pick drugs from their areas."

On how to improve adherence to ARVs, they identified encouraging disclosure, support groups, health talks with mentors, drug availability, psychosocial support, outreach, distribution of patients to nearest satellite clinics, directly observed therapy (DOT) by a trusted relative and community dispensing.

KI 2 suggested, "Well, there is this thing...we have not implemented it yet…where we do community dispensing instead of the client coming here for treatment because of this distance, we do the community dispensing."

Discussion

The male and female FGDs were in concurrence about predictors of poor adherence to ARVs with variation in males' view of harmful practices that hamper adherence such as heavy alcohol consumption as opposed to females' perspective of lack of self-love and religious beliefs. This compares to a study done among rural women living with HIV in Eswatini that identified hunger, personal stress, alcohol use, forgetfulness, persona stress and lack of disclosure of one's HIV status and side effects as barriers to optimal adherence. (Nozipho *et al.,* 2020). This shows gender differences in perspective.

In improving adherence, the male group identified one-on-one counselling as opposed to group counselling by the female group. Perhaps an indicator of the extra effort needed to improve adherence among the male cohort. It was noted that the adolescent group differed from the adult group citing unawareness on reasons for medication and defiance to doctor's recommendations as causes of suboptimal adherence. This compares to a South African study that shows strained teacher-learner relationship, ill treatment by non-biological care givers, negative household dynamics and treatment fatigue as contributors to suboptimal adherence (van Wyk & Davids, 2019).

This points to the role of emotional and psychological maturity on adherence to ARVs, need for linking to a peer counsellor and determination of the appropriate age to have a discussion on HIV diagnosis and care to an adolescent. . Adolescent group differed with the adult group noting the need for reminders and personal discipline to take medication in improving adherence to ARVs. This compares to studies that show that life goals and ambitions as well as social support predicted better adherence to ARVs (van Wyk & Davids, 2019); (Ankrah *et al.,* 2016). This points to unique developmental challenges affecting adherence since adolescence is a tipping point into adulthood and if not well addressed may portend challenges in adherence even into adulthood.

KIIs identified distance, drug stock outs long waiting time and poor attitude by health service providers as facility level factors contributing to sub-optimal adherence to ARVs. This relates to drug-related side effects, work-related demand, HIV-related stigma and human resource-related factors contributing to suboptimal adherence to ARVs in two studies in Sub-Saharan Africa (Chirambo *et al.,* 2019); (Adeniyi *et al.,* 2018). Stigma is is a biased perception of HIV being a product of a 'deviant behavior' thus people are presumably responsible for their HIV acquisition. Kibwezi West Sub-County being an arid and semi-arid area (ASAL), most residents are busy in various economic activities fending for themselves and/or their dependants thus may miss out on their scheduled clinic appointments. KIIs pointed to novel ideas to improve adherence such as community dispensing, health talks with mentors, support groups, drug availability, outreach, psychosocial support, distribution of patients to nearest satellite clinics, encourage disclosure and directly observed therapy (DOT) by a trusted

relative. Studies show that support from health care providers remains key in facilitating adherence to ARVs(Ankrah *et al.,* 2016); (Chirambo *et al.,* 2019). Primary health care givers are the first point of contact and focal persons in continuum of care thus their attitude and amiable nature is key in facilitating and sustaining adherence.

Conclusion

As lifelong adequate and consistent use of antiretroviral drugs (ARVs) is key in optimum management of HIV, determining non-quantifiable predictors to sub-optimal adherence is important in informing socio-anthropologic approaches to improve adherence - key in addressing the HIV menace.

Recommendations

From the study findings, we recommend gender-informed approaches in improving adherence and further studies on the role of psycho-emotional maturity on adherence to ARVs among adolescents. Finally, we recommend community dispensing, distribution of patients to nearest satellite facilities and introducing Directly Observed Therapy (DOT) to improve adherence to ARVs.

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