

BEING A FEMALE ADOLESCENT ON ANTIRETROVIRAL THERAPY AT ETHIKWINI DISTRICT, SOUTH AFRICA: A PHENOMENOGRAPHIC STUDY

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Abstract

Adherence to antiretroviral treatment is an important strategy to reduce the spread of the Human Immunodeficiency Virus (HIV). However, most female adolescents living with HIV are unable to adhere to antiretroviral treatment. This phenomenographic study explores various experiences of HIV-positive female adolescents on antiretroviral therapy at eThekweni District, South Africa. In-depth individual interviews were conducted with 15 purposively selected adolescent living with HIV. Data were analysed guided by the phenomenographic framework for data analysis. Findings indicate that female adolescents' experiences vary regarding disclosure of HIV status, adherence to therapy, response to living with HIV, and taking treatment. The varied experiences have an impact on adherence to treatment, which, in turn, affects the adolescents' quality of life. Based on the findings, researchers recommend the development of individualised support and relevant information to female adolescents on ART by healthcare professionals, family members, and teachers to promote adherence.

Introduction

The Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) are still a major health threat. However, the introduction of antiretroviral therapy (ART) is assisting children born with HIV to live longer and undergo normal developmental stages, including adolescence (Joint United Nations Programme [UNAIDS], 2016). Adherence to ART can contribute to the achievement of the UNAIDS 90-90-90 targets for 2020, which are intended to be a key milestone towards ending the HIV epidemic by 2030 (UNAIDS, 2016). The targets are geared in ensuring that by the year 2020, 90% of all people living with HIV will know their status, 90% of all people tested HIV-positive will receive sustained ART, and that 90% of all people receiving ART will have viral suppression (UNAIDS, 2016).

However, for ARTs to be effective, adherence is required to prevent viral resistance (Kahana, Rohan, Frazier & Drota, 2013). Adherence to ART is usually challenging among adolescents (MacDonell, Naar-King, Huszti & Belzer, 2013). The source of challenges to adherence includes psychological status, physical symptoms related to HIV progression, the pressure of taking the ART, the use of substances such as alcohol, and discontinuation of schooling (Kahana et al. 2013). The exploratory nature related to the adolescent stage also hinders their adherence to ART (Lowenthal et al., 2014). Exploratory nature also makes the adolescents, who were taking the ART without being informed about their HIV status by the relatives or parents to discontinue taking treatment check what will happen. This usually happens to those adolescents who got HIV from their mother during natal (pre-, peri-or post-natal) phase whose parents or caregivers have not informed them about their HIV status (Lowenthal et al., 2014). The above-mentioned factors contribute to a high number of defaulter rates that defeat the gains of initiating a high number of people living with HIV to ART (MacDonell et al. 2013).

While the defaulter rate among adolescents is a global issue, research indicate that adolescents in sub-Saharan Africa have higher ART defaulter rates (Agwu & Fairlie 2013). Statistic South Africa (STAT SA 2019)' estimate that 7.97 million people are living with HIV in South Africa. This number translates to approximately 13.5% of the country's population. When this number is disaggregated according to age, 19.07% of people aged 15–49 years are living with HIV, which is an issue of concern as it includes teenagers aged 15 - 19 years. The fact that the HIV statistics are higher than that of the general population in South Africa, it means that in the province like KwaZulu Natal where the number of people living with HIV is 2029470, (approximately 18.23%) according to STAT SA (2019), the prevalence of HIV among people aged 15 to 49 years may be very high.

In the KwaZulu Natal province, though 92.46% who tested positive are on ART, only 61.43% have a low viral load due to poor adherence. A lack of adherence is seen at one of the its provincial hospitals ARV clinics at eThekweni District where nine out of 328 adolescents have defaulted on their ARV treatments. Furthermore, 50% of the adolescents were not showing viral suppression (eThekweni district health plan, 2016). Subsequently, this non-adherence may lead to the development of viral resistance (Kahana et al., (2013). Viral resistance in sub-Saharan Africa, where there are limited ART options may be catastrophic (Dube, Summers, Tint & Mayayise 2012).

Although several studies have been done on the experiences of adolescents living with HIV in South Africa (Taukeni & Ferreira 2016; Watermeyer, 2013), none of these were focused at the eThekweni district. In order to address this gap, this study focuses on the experiences of female adolescents on ART at the eThekweni district. The study has enabled the researchers to discover and describe variations in the experiences of female adolescents on ART. Additionally, it seeks to explore and address the following research questions: The research questions can be summarised as follows:

- i). Firstly, what are the experiences of female adolescents on ART in the eThekweni District?
- ii) Secondly, what are the critical aspects that differentiate qualitatively varying ways of experiencing being on ART by female adolescents?

Methods

The researchers have employed a phenomenographic design. The design focuses on qualitative understanding of variations on how individuals experience, perceive, conceptualise, and understand a common situation or phenomenon (Khan, 2014). The design was chosen as the researchers aimed to understand variations in the experiences of female adolescents on ART at the eThekweni district.

The study population was adolescents attending an ART clinic at a regional hospital in the eThekweni district. The clinic had 628 adolescents registered as HIV-positive in 2016 whose ages ranged from 10 to 19 years (KZN Department of Health, 2017). The target population was comprised of 328 adolescents aged 13 to 17 years. This age group was considered most relevant for the study for the following reasons: firstly, since they were teenagers, it could be assumed to have an understanding of their health; secondly, they have not yet fully matured and were therefore not able to give consent for their sexual activity. Consequently, children aged 10 to 11 (who were not yet teenagers) and those aged 18 to 19 (late adolescence) were excluded from the study. The researchers used purposeful, maximum variation sampling to recruit participants since it proved to be the most relevant approach (Patton, 2002). Furthermore, all potential participants had to meet the following criteria: firstly, they had to participate voluntarily; secondly, they had to fall within the prescribed age group mentioned above; thirdly, they had to be on ARTs for at least two years; lastly, potential participants had to be physically well and mentally sound. The variation was mainly based on age, parental status, duration on treatment, educational standard, and socio-economic status.

Ethical clearance was obtained from the Department of Health Studies Higher Degree Committee of the University of South Africa (Ethical Clearance Certificate HSHDC /709/2017). Permission to conduct the study was received from the KwaZulu Natal Provincial Department of Health, and the chief executive officer of the provincial hospital where data was collected. The researchers also requested permission from the Operational Manager of the ART clinics to gain access to the participants. During the recruitment phase, one of the researchers explained the study to the potential participants at the ARV clinic. Next, the researcher requested that those interested in participating give the consent form and information leaflets to their parents or guardians. This was a necessary step as all the participants were under the legal consent age of 18. The information leaflets covered ethical aspects such as voluntary participation, confidentiality, respect, the purpose of the study, and the risks and benefits. Keeping in mind both the financial status of such potential participants, these leaflets contained the contact numbers of the researchers. Interested participants were requested to send a “call back” (please call me) message to enable the researcher to call back to establish which venue, date and time the participant would feel most comfortable to be interviewed.

While more than 50 adolescents showed interest in the study, only 15 were selected since Åkerlind (2008) mentions that between 10 and 20 interviews are normally sufficient to accurately capture the variation. All participants chose to be interviewed at the ART clinic. Before the interviews commenced, the researcher collected the signed consent forms from the parents or guardians and once again explained all the ethical aspects

to the participants. This was done to obtain accent to participate. In accordance with ethical guidelines, the participants were identified by means of codes pseudonyms in order to ensure confidentiality. Furthermore, in the unlikely event that an unauthorised person gained access to the audio-recordings, it would be impossible for them to identify the participants from the audio-recordings. This additional precaution was undertaken due to the vulnerability of participants in terms of their HIV status and age, factors that categorise the study as high risk.

The data were collected through an in-depth interviews from 1 November 2017 to 28 March 2018. The interviews assisted the researchers to understand and describe the experience of being on ART as an adolescent. The interviewer (first author) practised bracketing to reduce biases and leading the participants to respond towards a pre-determined direction. Each interview was initiated from the following open-ended statement: “Kindly share with me your experiences of being an adolescent on ART”.

This statement was followed by the following probing questions, which guided the researcher to focus on the objectives of the study:

- How do you feel when you take ART?
- What affects your adherence to ART?
- What do you think should be done to help you take adhere to treatment?

Prompts and probes were used to encourage the participants to elaborate on specific information and to share their experiences with the researchers. Interviews were audio-recorded, and field notes were taken to collect information that the recordings could not capture. Each interview continued until the participants could not provide any new information (until the participants’ explanations were completely exhausted).

The audio-recordings were transcribed within 48 hours after each interview. The researchers then analysed the information guided by data analysis stages for phenomenographic studies, as described by Marton, Carlsson and Halasz (1992) in Yates, Partridge and Bruce (2012). The focus of such an analysis is provide better understanding of the participants’ experiences, the meanings they attach to them, and to identify similarities and differences in terms of various multifaced experiences. This type of analysis aims to determine the “where-and-when” alteration in conceptions occur , in relation to time and developmental states (McManus 2009).

Due to the facts mentioned above, phenomenographic analysis was relevant to study since the participants are female adolescents in different developmental phases. Since some have been on ARTs since birth, their understanding of being on antiretroviral treatment may have changed over time. The process highlighted in research by Larsson and Holmström (2009) guided the study’s approach to the analysis. This was done as follows: both researchers read all the transcripts, separately. They then re-read the transcripts, highlighting areas where the participants were providing information, especially in relation to the two research questions. Each researcher then provides a preliminary description of the participants’ experience and understanding of being on ART. Following this, each researcher group all related descriptions into categories focusing on differences and similarities. After this, both researchers met and discussed their identified categories and provided reasons for them. After these discussions, categories were further merged into three categories defining the variation in participants’ experiences and understanding of being an adolescent on ART.

Results

The results are presented in two sections. The first section of the results highlights the biographical data of the participants in a tabular form. The second section presents the categories related to the similarities and variations between participants. Direct quotations from study participants are used to highlight the variants and similarities noted in participants’ experiences.

Demographic characteristics of participants

Fifteen female adolescents, all of whom were attending school at the time of the study, participated. Table 1 below displays the demographic data of the participants. The researchers used pseudonyms to protect the identity of participants

Table 1: Demographic characteristics of participants

Participant	Age	Gender	Grade	Available parents
P1 Thembi	16	Female	11	Mother
P2 Erica	17	Female	12	Mother
P3: Thuli	13	Female	7	Mother
P4 Bonggi	15	Female	10	None
P5: Cindi	13	Female	8	Both
P6: Angy	15	Female	8	Mother
P7: Andile	16	Female	10	Mother
P8: Lindi	13	Female	6	Both
P9: Thandi	16	Female	12	Mother
P10: Esther	13	Female	8	Mother
P11: Elsie	16	Female	10	Mother
P12: Tomla	13	Female	8	None
P13: Melvina	16	Female	11	Mother
P14: Zethu	14	Female	8	Mother
P15: Zithelele	15	Female	8	Mother

Experiences of female adolescents on art

Three variants emerged from the data analysis, namely (a) disclosure of HIV status, (b) adherence to ART, and (c) the psychological effect of being on ART. Quotes from the transcripts support the presentation of each variation.

Variation 1: Disclosure of HIV status

This section indicates variation on how the adolescents were informed of their HIV status. It highlights the different processes on the way participants how the adolescents were informed about their HIV status and the informer. The variation in the experience during this process is the type of information where others were provided correct information while others were deceived.

“My grandmother told me sometimes ago when my mother got very sick and she [granny] told me that I have the same illness that my mother got. I was told that my mother had blood pressure, so I thought I have blood pressure too. I only realised very late that I might be having HIV when one of the people at the clinic asked me if I was also born with HIV like her”. (Thembi)

“Nobody from home told me that I have HIV. I just discovered that myself when the nurses were teaching us about HIV at school. The moment they start to talk about signs and symptoms, I realised that some of the signs they were talking about are the same as what I had seen with my mother before she died.” (Erica)

The differences in how participants discovered their HIV status also have an impact on adherence to ART.

Variation 2: Adherence to ART

Adherence to ART has an impact on viral suppression, the spread of HIV, and the quality of life of people living with HIV. This variation focuses on adolescents' adherence to ART. As noted earlier, a difference in adherence to ART depends on variables such as participants' knowledge of HIV, reminders to take treatment, socio-economic situations, and psychological factors. The variations focus on factors promoting and hindering ART adherence.

Factors that promote adherence to ART

This theme deals with factors that promote adolescents' adherence to ART. Participants highlighted the following factors that promote their adherence to ART: using reminders, having knowledge of the outcome of treatment, being encouraged by healthcare professionals, and, lastly, the fear of sickness and death.

“My mother reminds me to take the treatment every day at 06h30. When my mother is not around, as she is frequently admitted to the hospital, my grandmother takes the responsibility of reminding me by coming to my room every morning at about 06h30 to tell me to take my tablets.” (Thembi)

Some participants are adhering to treatment because they realise the importance of ART in the fight against HIV:
“I use an alarm, which reminds me to take the medication every time at the same time because it makes me feel better. I know that if I am taking treatment every time, it causes the HIV to be unconscious, and I know that I am not going to die soon.” (Bongi)

Some participants keep taking their ART because of the encouragement and information provided by healthcare professionals. Other participants adhere to treatment due to fear of sickness and death.

“I take the tablets every day on time because I want to stay healthy. My mother told me that if I do not take treatments, I will become sick and die like my father. Sometimes when I feel like I am tired of taking treatment every day, I just remember how my father was sick and take treatment. I do not want to look like him. I do not want to die and leave my mother alone” (Thuli)

However, the variation among participants is not only dependent on factors that enhance their adherence to treatment, but also factors which hinder it.

Factors that impede adherence to ART

There are various factors which hinder adolescents from adhering to ART. One of the factors is the fear of indirectly disclosing the status.

“When I visit my relatives during the school holidays, it is difficult for me to take treatment every day at a regular time. This is because I do not want them to see me taking treatment. I fear that people will know about my HIV status and start to mistreat me or chase me from their houses” (Zithelele).

Other adolescents do not adhere to the treatment regimen due to a limited understanding of how ART works. Poor knowledge among adolescents about HIV transmission is a serious concern since it can lead to opportunistic diseases resulting from their non-adherence to ART. The participants had limited knowledge about how ART works. They did not know the value of adherence to ART and assumed that there is no harm when a person skips a few doses of treatment.

“I have been taking treatment since I was born. So, my body is full of treatment. Now I do not take them every day because by now, HIV is dead in my body. I am healthy. I usually take when I feel like I am not feeling well. The virus knows me now. We are friends. I think that if I take it as long as I am taking the treatment most of the days, I will be okay.” (Lindi)

Other participants are prevented from adhering to treatment due to emotional states such as stress and depression.

“There are days when I feel so sad and not in any mood of taking treatment. I ask myself why I should keep on drinking pills because I will still die anyway. Last time one of my friends whom I met during the HIV clinic, who looks very healthy, just died. Like that, and she was gone. She was taking treatment every day and sometimes even telling us how treatments are helping her. She also had a boyfriend from the clinic, and I was looking forward to being like her.” (Angy)

Besides mental status, physical exhaustion also prevents other participants from adhering to ART.

“My mother is not well most of the time. When I come back from school, I clean the house and cook for everybody. There are days when I feel so tired in such a way that, even when I hear the alarm ringing, I do not get up to take my treatment. Some days I just slumber, and when I wake up in the morning, I realise that the alarm has rung until it went off without me hearing it.” (Elsie)

Some of the participants indicated that the side effects of ART make them reluctant to take it. The differences in adherence to ART is linked to how the adolescents are affected by living with HIV.

Variation 3: The psychological effect of being on ART

This section indicates the differences and similarities in how living with HIV (while on ART) affects the lives of adolescents. The frequently raised effects are psycho-social.

Fear

There seemed to be a strong component of fear among participants. However, its sources vary from person to person. To some, the main fear is premature death because of being HIV-positive, regardless of ART.

Sometimes I do not see why I need to continue with treatment. After all, I will still die. Whenever I go to the clinic, I find that some of the people I know use to collect medication with are not there. We are dying like flies. Every time if I feel not well, I think that I am dying. I feel so much afraid. (Melvina)

Other participants fear the progression of HIV from asymptomatic to the full-blown AIDS stage.

“What I am most afraid of is getting sick. I have read the stages of HIV and all the signs and illnesses for each stage. It is frightening. I have also seen how some of the people at our clinic look. They just lose weight like all the other people and also have sores all over my body. They are not looking good. Some have change colours and become very dark. some of them look very sick.” (Thembi)

With other participants, the source of the fear of stigma and discrimination

My fear is not being sick. I know people can be ill but also become well. Some of the people living with HIV are very healthy and beautiful. My fear is for people to know my status because the moment they see that you are positive, the friends disappear. Some relatives mistreat you. The schoolmates start to gossip about your condition. Because people do not even know that a person can be born with HIV, people will think that you have a boyfriend. (Elsie).

While other participants have accepted their HIV status, some of them are in denial.

Denial and acceptance

There is usually a dichotomy that exists between denial and acceptance. Denial is a typical response when a person finds out that he or she is HIV-positive. However, the issue of denial is not static, and someone may oscillate between denial and acceptance, depending on the situation.

“When the doctor told me that I am HIV-positive, I did not know what he was saying. I think maybe that was a mistake. How can I get HIV? I have not done anything wrong. I said to the doctor that he had made a mistake. But as time goes on, I accepted because my mother also told me. But sometimes I think it is not true. Most of the time, when people come to our school or the village for HIV testing, I always go for test. I sometimes think the test results are not true”. (Angy)

“At first, I did not believe that I am HIV-positive. I did not believe it because only my mother is HIV-positive, while my father is HIV negative. I thought that, because I am a virgin, I cannot be positive. But now, I have accepted that I have HIV. The good thing is that I am strong as all other people and live a normal people.” (Lindi)

While other participants showed acceptance, some participants showed anger.

Anger

The participants experienced and expressed anger in different ways. Some felt like running away from home; others just cried. While they expressed anger, they also displayed sadness during the interviews. The sources of such anger is also diverse. Some participants were angry with their parents for not disclosing their status and keeping it a secret.

“I was so angry with my mother and my father. They lied to me for so long. They told me that the treatment was taking was just vitamins, sometimes they said it is for asthma. I even teased and discriminated against other people with HIV while I was in a lower grade, not knowing that I also have HIV.” (Thandi)

While other participants showed anger, others blamed their parents for having infected them with HIV.

Blame

Blame is usually focused on one or both of their parents. Some participants blame their fathers for infecting their mothers with HIV.

“It is just that my father is also dead. If I know what I know about HIV, I would have killed him. He came to my mother knowing that his other wife died of HIV, just also to kill my mother. If it were not him, I would be healthy like other children without having to take this damn treatment for life.” (Tomla)

Other participants blamed their mothers for remaining with their fathers, who had extramarital relationships.

“When my mother finds out the first time that my father has a girlfriend, she should have left that time. But my mother was stupid. She [mother] still stays with that man and cares for him until he died.” (Thandi)

However, not all participants blamed their parents; others showed an appreciation of their parents.

Appreciation

Participants expressed appreciation towards their parents

"I am so grateful to my mother. She makes sure that I take treatment from early childhood. I think I would have been dead by now. I know that some people, if they get pregnant and are HIV, make an abortion. But my mother did not. She took excellent care of me. I know that she did not apply to be HIV-positive. It just happens to anyone. Even if I were not born with HIV, I would have got infected somehow if I was meant to live with HIV. Some people at the clinic said that they were raped and get AIDS. I love my mother a lot. Seeing her not well breaks my heart. I wish something will just happen for her to get well." (Thuli)

Although some participants seem to be coping, others displayed signs of depression (directly or indirectly).

Depression

From the participants' responses, it was clear that depression is one common psychological effect of being on ART. The difference is its source and the coping strategies they utilise.

"What depresses me more is when I start thinking of my future. I know that it will be difficult for me to have a wife. I will not have children. It means I am just wasting my time by being at school. When I think of this, I think of just leaving anything, including school, and just die like my parents. Even if I finish school and work well, for whom will I be working for? No husband, no child, no parent. Life is so unfair." (Bongi)

When other participants see no future, some participants are optimistic about life.

Optimism

It was clear that some participants were optimistic about living better lives and helping their parents. This optimism seemed to overcome the challenges they face in dealing with their HIV status.

"I am studying so hard so that I will soon pass Grade 12. I am going to study medicine and help other children. If I fail to study medicine because I heard people saying it is challenging. I will do nursing or Psychology. I want to help other children who are living with HIV. I also want to support my mother and my sisters. I want to have my car and a huge house." (Thuli)

Participants with a positive outlook about life also spoke and behave in a manner indicating that they are bargaining.

Bargaining

Bargaining is reflected in different ways by participants. Some participants bargain with God to look after them.

"Since I know that I am HIV-positive. When I feel bad, I always go to church. I always pray, telling God that If He stops HIV, I will be a good child. I am always behaving well as I know that, when behaving in a good manner, God will forgive my parents and me and have mercy on us. I know that He is God of miracles. If we keep on being good, our miracle will come soon. Some people are healed and become negative at our church." (Cindi)

Discussion

The results indicate several variations and similarities in the experiences of adolescents who are on ART. To ensure variation, the participants were heterogeneous. The heterogeneity was based on age (13 to 17), educational level, and the number of years on ART. Another variation was parental status, whereby adolescents with both parents, one parent, or no parents participated.

Three main variations emerged from the results. The first variation was how the adolescents found out about their HIV status and the person who told them. Thembi and Thuli were informed by their mothers or grandparents, while others like Erica, were never directly informed; they concluded that they might be HIV-positive when hearing of the signs and symptoms. Apart from the differences in how the participants were informed about their HIV status, the type of information differs. Some, such as Thembi were given incorrect information. This type of misinformation includes being told, "you have a similar disease as what your parents have." Because she knew that her mother was suffering from hypertension, she concluded that she also has it. Not disclosing their HIV status to children is sometimes based on the fear that a child's HIV status mostly reflects the biological parents (Bernays, Papparini, Seeley & Rhodes 2017). The same sentiment was shared by Mburu et al. (2014), who stated that caregivers might hesitate or avoid disclosing a child's HIV status due to the fear of exposing the child or

adolescent to stigma. As it may be difficult for the child to hide information about their condition to other children, it is vital to keep it secret from other close family members, including those with whom they live (Bernays et al., 2017).

The non-disclosure to the child may assist in protecting the child from stigma and discrimination. However, in this study, adolescents living with HIV who did not know their status, end up discriminating against other children living with HIV. Such finding implies that, although not telling children about their HIV status protect the child, not knowing the condition may be detrimental to the child's health and significant others. The situation may be worse during the adolescence stage as children may start to engage in unprotected sex; thus, they may spread the virus. This is a major concern as most adolescents start becoming sexually active during this phase, which explains the high incidence and prevalence of HIV in adolescents aged 15 years and above (Wang et al., 2016). Furthermore, the knowledge of their HIV status has an impact on their level of adherence to treatment, which is the second variation for this study.

Findings from the study indicate various differences in adherence to ART. The variations range from factors promoting adherence to those promoting non-adherence. For example, Thembi is reminded by the parents to take treatment daily at regular times. The method seems to be the most reliable one if the parent is also on medication. However, this approach can pose a challenge in terms of dependence, meaning that if the mother is not around due to sickness or in other instances, the adolescent can end up missing the treatment dosage. Depending on parents for taking treatment implies that the adolescent may not sleep out because, although the parent can make a call, there are some places where the network is a problem, especially in developing countries like South Africa. However, Bongi uses an alarm that reminds her to take her treatment, which gives her a sense of independence. A study by Barosso, Leblanc, and Flores (2017) shared the same findings, indicating that participants emphasise the use of phone applications or alarms. Based on the argument regarding the electricity challenges, the use of more than one reminder, such as setting alarms, using pillboxes, and having relatives remind them to take their medication may be useful, as highlighted in Barosso et al. (2017). The use of pillboxes was also highlighted by Mills and Cooper (2007) as a sustainable strategy in resources challenged environment.

The knowledge of the effect of ART, fear of getting sick and dying are among the motivators for teenagers to adhere to their treatments. Thuli is an excellent example of a teen that witnessed his father suffering from opportunistic infections and also how he died. The memory of that process instilled fear that acts as a motivator for adherence to treatment. The findings attest to Reda and Biadgilign (2012) documenting that the presence of family members living with HIV in the family, and emotional factors such as anxiety and fear, have an impact on adherence to treatment. The very same factors that promote adherence to HIV in some adolescents, also act as a hindrance to other participants. This was highlighted by one of the participants who witnessed parents being sick and dying of AIDS-related conditions while on ART, and concluded that there is no need to take the treatment religiously since people on treatment still die. Another hindrance to medication that was highlighted was the fear of stigma and discrimination by relatives. This fear causes some adolescents like Zithelele not to adhere to ART when visiting her relatives for fear of disclosing her HIV status. Zithelele believes that if people knew about her HIV status, she would be rejected. Others mentioned that they were afraid to go to their aunts' homes because if their aunts found out that they were HIV-positive, they would not allow them into their homes again. This corresponds to research by Demmer (2011), emphasising that disclosure remains particularly difficult because of the ongoing stigma attached to people who live with HIV. Another variation was identified in participants whose knowledge of the functioning of ART makes them take treatment intermittently. The very factors highlighted as their motivator for continuously adhering to treatment.

These differences indicate the variations of participants' experiences on ART in that although they may face similar situations, their responses differ. The variations in factors affecting adherence indicate the need for individualised, personalised support since the very thing that acts as a promoter for one person, may be interpreted as a prohibitor to another. Variations may occur, do not only in different individuals but also within one individual and thus affect his/her ART adherence. This was indicated in this finding where seeing other people dying of HIV makes participants adhere, whereas to others, the same incidence instills fear and discourages them from taking the treatment. An example of this is when Melvina feels that there is no need to continue treatment after seeing "healthy" peers that they met at the ART clinic dying. This attests to findings by Remien and Mellins (2007), who mention that adherence evolves, which necessitates the need for continuously supporting adolescence on ART. The findings also attest to Simoni et al. (2008), whose research mentions that

optimal adherence is challenging as it evolves depending on the physical, psychological, social, and economic situation of an individual. The same finding was documented by Reda and Biadgilign (2012) as determinants of adherence to ART. The above-mentioned variations reinforce the need for continually supporting adolescents living with HIV to ensure that they adhere to their ART. The support should also be focused, not only on adherence but should also emphasise the psychological impact of being an adolescent on ART, which is the third major variation in this study.

The findings revealed that various emotional stages that adolescents on ART undergo. Fear is identified as an emotion experienced by most adolescents living with HIV. The source of such fear is getting sick and or dying. This fear is real and rational as some participants, such as Thembi and Melvina, have witnessed the parents and peers living with HIV being sick and different kinds of opportunistic infections and death. To Elsie, the fear is based on potential stigma and discrimination that may result if people realise that they are living with HIV. The findings concur with that of Hogwood, Campbell, and Butler (2013), mentioning that people living with HIV have a fear of rejection and isolation, which may occur as some people have negative beliefs and perceptions concerning HIV. The fear has an impact on their adherence to ART, which may be both negative or positive.

While some participants present with fear, others like Angy and Lindi seem to oscillate within a dichotomy of denial or acceptance of their HIV status. This is a dichotomy because although adolescents may accept their situation, the same participants sometimes deny that they are HIV-positive, depending on their health and understanding. This causes Lindy to test for HIV continuously. The source of denial in others is based on their limited knowledge of HIV since some think that a lack of opportunistic infection and being a virgin, indicate an absence of HIV. During the denial phase, there is a possibility of non-adherence to treatment, which may result in the potential development of treatment resistance. There is also a possibility of spreading the virus as an adolescent may decide to engage in unprotected sex. Acceptance of HIV status to other participants leads to anger.

This anger is towards parents for various reasons, including for infecting them, not disclosing their HIV status, or for lying about the treatment (like Thandi where her parents say that she is taking vitamins. Thandi mentioned that not knowing her HIV status made her tease other learners living with HIV. In the case of Tomla, anger may be also be compounded by a feeling of guilt. To some people, guilty feelings may lead a person to blame others for their own negative behaviour. This may be the case as the findings also indicate that some participants like Tomla blame their parents, not only for non-disclosure of status. Tomla blames her father for infecting her mother, while others blame their mother who continue to stay with their fathers, even though they know that they are involved in extramarital affairs.

The differences in how adolescents experience living with HIV and being on ART differ because while some blame their parents, others, like Thuli, appreciate their parents. The appreciation is that the parents started the adolescents on ART early, which saved their lives. Thuli appreciates that her mother did not abort her but allowed her to live. This appreciative mode contributes positively to ART adherence. While others are appreciative of being alive, the most common emotion portrayed, either overtly or covertly, was depression.

Depression can be debilitating among adolescents. Participants who presented with depression indicated that they have no hope of living. For example, Bongi mentioned that she saw no need to take ART or to study as, even if she succeeds, she will not marry because she cannot have children, and does not even have parents. The value of living or studying is considered fruitless. Richter and Mofenson (2014) also recorded depression among adolescents caused by stressors such as the loss of parents, disrupted schooling, multiple losses, the uncertainty of regarding clinical course HIV/AIDS, inadequate care, stigma, and social isolation. Such negative mental states may further lead to their non-adherence to ART. While other participants present with such demotivation, being on ART makes other participants optimistic about the future.

Optimism seems to help them overcome the challenges some of them face, an excellent example of which is Thuli mentioning the need for working very hard to support his parents and other children living with HIV. His dream is to have a car and a big house. Therefore, optimism can act as a motivator to ensure that people adhere to ART.

While some are optimistic, other participants, like Cindi, bargain with God. The motive for bargaining is for God to forgive both her and her parents, have mercy on her family and cure them as other people living with HIV in her church are already healed. The bargain is in the form of prayer and ethical behaviour. Although bargaining may be beneficial, it can be dangerous, especially in churches where the pastors do not thoroughly understand HIV or assume that people with faith should not take treatment because they are going to be healed miraculously.

Conclusion

The findings of the study indicated variation in the experiences of adolescents on antiretroviral. The variations are interlinked as the emotional status of a person may impact their adherence to ART. This adherence (or lack of) may also be affected by whether the person knows their HIV status, which then may have a positive or negative effect on their psychological response. The findings necessitate the development of individualised and continuous support for female adolescents on ART because, although there are similarities in experiences, there is a considerable difference in how different adolescents respond to the same type of situation. The same experience may motivate different adolescents differently, and influences how (and if) they adhere to ART. On the one hand, it may encourage adherence in some, while discouraging it in others. The same exposure also results in varied emotional responses to female adolescents and also to an individual participant.

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