The Adversities Faced By Female Adolescents On Antiretroviral Therapy In The Ethekwini District, South Africa

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ABSTRACT

Background: Adolescent females face many emotional and psychological challenges. They must be accountable, responsible, and head families when both parents are absent. This further becomes a challenge when they are infected with HIV at birth and are cared for by a sick parent, relative or a caregiver. Issues like stigma and a lack of support arises, resulting in psychological distress. For these reasons most female adolescents living with HIV are unable to adhere to antiretroviral treatment. The aim of the study was to understand the adversities faced by female adolescents on antiretroviral therapy in the eThekwini district.

Methods: Qualitative research method in the form of in-depth interviews were used for data collection and analysis. This was a phenomenology study which explored various experiences of HIV-positive female adolescents on antiretroviral therapy in the eThekwini District, South Africa. In-depth individual interviews were conducted with 15 purposively selected participants. Data was analyzed guided by the phenomenology framework for data analysis.

Results: Two themes emerged from the study: social impact of HIV and sources of support. It indicated variation on how living with HIV affected the lives of the female adolescents.

Conclusion: Female adolescents’ experiences vary regarding the social impact of HIV and sources of support. The varied experiences have an impact on adherence to treatment, which, in turn, affects the adolescents’ quality of life. Based on the findings, it is recommended the development of individualized support and relevant information to female adolescents on ART by healthcare professionals, family members, and teachers to promote adherence.

Keywords: Self-Regulated, Learning, Academic Stress.
INTRODUCTION

Of the estimated 38.4 million people living with human immunodeficiency syndrome (HIV) worldwide in 2021, 2.73 million were children aged 0–19. In 2021, an estimated 14.9 million children under the age of 18 had lost one or both parents to acquired immune deficiency syndrome (AIDS)-related causes. In South Africa, more than 5 million people are receiving antiretroviral therapy (ART) (1). In KwaZulu-Natal, an estimated 20,294,70 persons are infected with HIV (2). There are approximately 383,869 persons in the ART program out of the estimated 650,000 PLHIV in eThekwini (3). It is estimated that there are 720,000 HIV-infected youth aged 15-24 years in South Africa (4). South Africa is home to 20% of all adults living with HIV (ALHIV) globally, with young women disproportionately affected (5). ART adherence can help UNAIDS meet its new 95-95-95 testing, treatment, and viral suppression targets across all demographics, communities, and geographical contexts. The new targets will ensure that 95% of pregnant and breastfeeding women have access to HIV prevention, antenatal testing, and retesting; 95% of HIV-positive women achieve and maintain viral suppression before delivery and during breastfeeding; and 95% of HIV-exposed children are tested within two months of birth and, if HIV positive, receive optimised treatment (6). Adolescents living with HIV (ALHIV) had a higher chance of inadequate adherence, viral load progression, loss to follow-up, morbidity, and mortality when compared to adult populations living with HIV (7).

Adolescents typically have difficulty adhering to ART (8). Adolescents on ART must consequently be managed considering the complexities of biological and psychosocial changes that occur in their lives, as well as their implications on adherence (9). Infants born to mothers living with HIV are at risk of becoming infected if their mothers are not on effective treatment or retained in care. Adolescents who were infected with HIV from their mothers during the pre-, peri- or post-natal phases and whose parents or caregivers have not informed them about their HIV status (10). For these reasons, the defaulter rates in taking antiretroviral therapy remains high.

A lack of adherence is observed at one of its provincial hospital antiretroviral (ARV) clinics in the eThekwini District, where nine out of 328 adolescents have failed to complete their ARV treatments. Furthermore, 50% of adolescents lacked viral suppression. Several studies on the experiences of adolescents living with HIV in South Africa have been conducted (11) but none have focused on the eThekwini district. To fill this gap, this study focuses on the ART experiences of female adolescents in the eThekwini area. 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. Firstly, what are the experiences of female adolescents on ART in the eThekwini District? Secondly, what are the critical aspects that differentiate qualitatively varying ways of experiencing being on ART by female adolescents?

METHODS

A phenomenographic design was used for this study. The design emphasises qualitative understanding variances in how people experience, perceive, conceptualise, and comprehend a common event or topic.
The design was chosen as the researchers aimed to understand different perceptions of the female adolescents on ART in the eThekwini district.

The study population was adolescents attending an ART clinic at a regional hospital in the eThekwini district. In 2016, the clinic had 628 HIV-positive adolescents ranging in age from 10 to 19 years (13). The target population included 328 adolescents aged 13 to 17. All potential participants had to meet the following criteria: first, they had to participate voluntarily; second, they had to be in the above-mentioned age group; third, they had to have been on ART for at least two years; and finally, potential participants had to be physically and mentally healthy. The differences were mostly determined by age, parental status, treatment length, educational level, and socioeconomic situation.

From 1 November 2017 to 28 March 2018, data were gathered through in-depth interviews. The interviews helped the researcher understand and characterise the experience of being an adolescent on ART. The researcher used bracketing to reduce bias and direct participants’ responses in a predetermined manner. Each interview began with the following open-ended statement: "Please share with me your experiences as an adolescent on ART."

This statement was followed by the following probing questions, which directed the researcher's attention to the study's objectives: 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?

The researcher utilised prompts and probes to urge participants to comment on specific facts and discuss their experiences. Field notes were gathered in addition to audio recordings to acquire information that the recordings could not capture. Each interview was conducted until the individuals were unable to supply any new information, hence reaching data saturation.

Within 48 hours after each interview, the audio recordings were transcribed. The material was then examined using the data analysis phases for phenomenographic investigations provided by Marton, Carlsson, and Halasz (1992) in (14) The researcher categorised all linked descriptions based on differences and similarities. The categories were then subdivided into three groups that defined the differences in participants’ experiences and understanding of being an adolescent on ART.

ETHICAL CONSIDERATIONS

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 pamphlets addressed ethical issues such as voluntary participation, confidentiality, and respect, as well as the study's goal and risks and benefits. While more than 50 adolescents showed an interest in the study, only 15 were chosen because (13) states that 10 to 20 interviews are usually sufficient for accurately capturing variation.

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 themes 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.

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 researcher used pseudonyms to protect the identity of participants.

Table 1: Demographic characteristics of participants

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Gender</th>
<th>Grade</th>
<th>Available parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>16</td>
<td>Female</td>
<td>11</td>
<td>Mother</td>
</tr>
<tr>
<td>P2</td>
<td>17</td>
<td>Female</td>
<td>12</td>
<td>Mother</td>
</tr>
<tr>
<td>P3</td>
<td>13</td>
<td>Female</td>
<td>7</td>
<td>Mother</td>
</tr>
<tr>
<td>P4</td>
<td>15</td>
<td>Female</td>
<td>10</td>
<td>None</td>
</tr>
<tr>
<td>P5</td>
<td>13</td>
<td>Female</td>
<td>8</td>
<td>Both</td>
</tr>
<tr>
<td>P6</td>
<td>15</td>
<td>Female</td>
<td>8</td>
<td>Mother</td>
</tr>
<tr>
<td>P7</td>
<td>16</td>
<td>Female</td>
<td>10</td>
<td>Mother</td>
</tr>
<tr>
<td>P8</td>
<td>13</td>
<td>Female</td>
<td>6</td>
<td>Both</td>
</tr>
<tr>
<td>P9</td>
<td>16</td>
<td>Female</td>
<td>12</td>
<td>Mother</td>
</tr>
<tr>
<td>P10</td>
<td>13</td>
<td>Female</td>
<td>8</td>
<td>Mother</td>
</tr>
<tr>
<td>P11</td>
<td>16</td>
<td>Female</td>
<td>10</td>
<td>Mother</td>
</tr>
<tr>
<td>P12</td>
<td>13</td>
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<td>P13</td>
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<td>11</td>
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<td>Female</td>
<td>8</td>
<td>Mother</td>
</tr>
<tr>
<td>P15</td>
<td>15</td>
<td>Female</td>
<td>8</td>
<td>Mother</td>
</tr>
</tbody>
</table>

Source: Department of health (2017)

Experiences of female adolescents on ART

Two themes emerged from the data analysis, namely (a) Social impact of HIV (b) sources of support. This section indicates variation on how living with HIV affected the lives of the female adolescents. It highlights the societal barriers in their everyday lives.

Social Impact of HIV

This theme presents the social impact of living with HIV and being on ART. The theme addresses the aspects of stigma.

Stigma

There seems to be substantial anxiety among the participants that if their HIV status was revealed, they would face rejection. Some were concerned about other students gossiping about them at school. Other individuals were concerned that if their relatives discovered they had HIV, they would assume they got it from a sexual partner.

“I don’t want my aunt to know about me and I’m sick. I like her (aunty) a lot and I don’t her to tell me that I mustn’t come to her (aunty) house because I am sick”. (P3).

“I am afraid that the people will talk and my friends at school will not want to be around me. I hear of other children in my school that have HIV.”
Children laugh at them and say bad things. so, I don’t want other people to know”. (P6)

“I mean, that if I tell my friends that I have HIV, they will ask me how I get it and all that. I do not want my friends to know about this thing. Nowadays your friends talk bad about you and gossip with other people. I don’t want them to know about this”. (P7)

“I like my aunty cos she buys me nice things and the clothes. I love her. If she (aunty) finds out that I have HIV, she will think I am a bad girl”. (P8)

**Sources of support**

This theme focuses on the resources available to adolescents on ART. It addresses issues such as a lack of parental support and a low socioeconomic standing.

**Lack of parental support**

Adolescents suffer greatly because of a lack of parental support. Some participants stated that they do not receive any assistance from their parents, as evidenced by the following statements:

“My dad works, and he comes home very late sometimes. My mother is always busy at home, cleaning, cooking, taking care of my younger sister. She does not have time for me”. (P6)

“When my father comes from work he doesn’t talk to my sister and me. He does not ask how we are; he just goes eat then he goes into the room”. (P9)

**Poor Socioeconomic status**

Most participants mentioned that their parents were either unemployed or earning a minimum wage.

“I think that we are suffering like this because my mother doesn’t have a job. Because she does not have a job, then she does not have money to pay rent or buy the house. That is why we do not have a place to stay”. (P9)

“My mother collects a grant for herself and for me. We must pay the rent, water, and electricity and still buy food. Everything is very expensive these days”. (P5).

“My mother has no money, so we must stay there now. I hope that social grant which they give to us so we can go find another place”. (P8)

**DISCUSSION**

The findings show several differences and similarities in the experiences of adolescents on ART. The participants were diverse to ensure variation. The age range (13 to 17), educational level, and number of years on ART all contributed to the heterogeneity. Another variation was parental status, with adolescents participating who had both parents, one parent, and no parents.

The adolescents were filled with dread. They were afraid that if people found out about their HIV status, they would be rejected. Some said they were terrified to go to their aunt's house because if they found out they were HIV positive, they would not let them in again. The same sentiment was shared in a study by (15) stating that adolescents fear social rejection by their peers, family members, and community. Participants believed that if their friends discovered their HIV status, they would mock them. Discrimination was perceived as
isolating oneself from friends and relatives. The findings of the current study support findings by (16) who states that fear of disclosure and stigma by peers is the most prominent barrier to adherence among adolescents living with HIV.

Infected adolescents who care for sick parents face considerable stress. Most participants said their parents were either unemployed or earning minimum wage. Others stressed that they did not receive support from parents. The same sentiment was shared by a study by Richtie and Mofenson, economic deprivation, disrupted schooling, multiple losses, the uncertainty of the clinical course of parental HIV/AIDS, insufficient care, stigma, and social isolation are all potential stressors linked with parental HIV and AIDS.

CONCLUSIONS
The study's findings suggested that adolescents' experiences with antiretroviral therapy varied. Because there are parallels in experiences, there is a significant variance in how different adolescents respond to the same type of event. The findings necessitate the establishment of tailored and continuous assistance for female adolescents on ART. Carers should be given continuing training and support at the hospital so that they can cope with challenges related with HIV-infected adolescents. All adolescents who visit the hospital should receive support and education on how to care for the sick.

LIMITATIONS OF THE STUDY
The study was done only at a regional hospital of the eThekwini District in KwaZulu Natal; therefore, findings cannot be generalised to other settings. Another limitation is the study only focused on adolescents between the ages of 13-17 years. The sample size was also small with only fifteen participants who participated in the study. Another limitation of this study is willfully holding back valuable information due to the sensitivity of the research topic.

FINANCIAL SUPPORT AND SPONSORSHIP
Nil.

CONFLICTS OF INTEREST
There are no conflicts of interest

REFERENCES
5. Slogrove, A.L, Mahy M, Armstrong A, Davies, M.A. Living and dying to be counted: what we know about the epidemiology of the global adolescent


