

EXPLORING THE EXPERIENCES OF ADOLESCENTS ON HIGHLY ACTIVE ANTIRETROVIRAL THERAPY IN TEMBISA: A PILOT STUDY

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ABSTRACT

This study was aimed at exploring the experiences of adolescents who are on long-term Highly Active Antiretroviral Therapy (HAART) treatment in Tembisa, Gauteng province. The study is based on a qualitative research method using in-depth semi-structured open-ended interviews and a focus group for data collection. The sample consisted of three adolescents as this was a pilot study. Thematic data analysis method was used to analyse data. The study findings cover the negative and positive experiences and the perceived role of HAART treatment over a longer period of time. The predominant themes identified from participants were disclosure of HIV-positive status and the stigma surrounding a positive status, early childhood experience of parental death, challenges of taking HAART treatment, factors influencing adherence and non-adherence to HAART treatment, and lastly, the impact of religion on HAART treatment adherence. The findings suggest that adolescents who are on HAART treatment over an extended period of time experience drug fatigue. Drug fatigue has far-reaching implications for the health of adolescents, as it has a higher likelihood that poor adherence or even complete refusal to take HAART treatment will occur. Poor adherence or refusal to take HAART treatment will most likely lead to cross infection and further spread of HIV and AIDS. A recommendation was made to include the establishment of a youth and adolescent-friendly centre by the hospital – one that is designated for the provision of tailored adolescent services and sensitive to adolescent developmental stages so as to minimise the likelihood of infected adolescents falling through the healthcare cracks. The introduction of a hospital-based school, an education unit run by dedicated and qualified facilitators focusing on aiding hospitalised learners with catch-up scholarly programmes, was a further recommendation.

Keywords: Adolescents; experience; Highly Active Antiretroviral Therapy (HAART); HIV/AIDS; Tembisa



INTRODUCTION

Adolescence is a formative period in a young person's life during which physical, emotional, and mental processes as well as sexual identity are evolving and maturing. The term was a derivative of the Latin word *adolescere*, which means to grow up or to grow into maturity and spans the ages from 12-19 years (Sigelman & Rider, 2009). UNICEF (2012) also describes adolescence as a time of transition from childhood to adulthood in which the youth take risks, and the period when many young people begin to explore their sexuality, so access to sexual and reproductive health information and services is necessary for their well-being. Further, the social environment and responses of peers and parents have to be constantly integrated into this evolving concept of self (Li, 2009).

Due to risky behaviours and sexuality tendencies, adolescents become susceptible to sexual diseases. HIV/AIDS is a major potential health hazard the young person is expected to respond to. It is especially challenging for youth who are facing marginalisation and stigma related to their sexual orientation, poverty, desperate living situations, abuse, as well as disparities in the provision of prevention and healthcare services, based on race and ethnicity. The face of HIV/AIDS is increasingly young, and adolescents are equally impacted. HIV/AIDS has a tremendous impact on adolescents, both those infected by the virus, as well as those affected by the illness of their loved ones.

Pharoah (2004) states that the negative impact occurs in a number of overlapping and interdependent domains that affect their psychosocial development. It is often difficult to determine the full impact of HIV/AIDS on infected adolescents. They may experience a wide range of impacts including but not limited to poor health and nutrition, economic need, reduced levels of care, new responsibilities and school dropout. As children and adolescents infected with HIV continue to live longer, normal developmental milestones and educational needs will take on new significance. Many children will continue to be adversely impacted by non-HIV factors such as poverty, inadequate medical services, and a lack of social support (Lam, Seekings & Sparks, 2006).

Adolescents go through a myriad of physical, psychological, neuro-behavioural, hormonal and social developmental changes. Given the social taboos often surrounding puberty, the lives of millions of adolescents worldwide are at risk because they do not have the information, skills, health services and support they need to go through the enormous, rapid changes that adolescence brings.

The impact of HIV/AIDS on the development of adolescents who grow up with HIV/AIDS is still in its infancy. HIV/AIDS-infected adolescents represent a unique, yet diverse, population requiring specialised medical and psychosocial HIV/AIDS care. Infected adolescents often have differing therapeutic needs, but may share common

difficulties, including medication non-adherence, high-risk sexual behaviour, and psychosocial stressors. The impact of HIV/AIDS on the functioning of adolescents is multifaceted and affects all aspects of the adolescent's life. The impacts are immense insofar as they compel adolescents to battle with adult responsibilities for which they are not adequately prepared. Given the potential public health implications of their reproductive decisions, better understanding of factors influencing the decision-making process is needed to help inform the development of salient treatment and prevention interventions (Fair, Wiener, Zadeh, Albright, Mellins, Mancilla, Tepper, Trexler, Purdy, Osherow, Lovelace & Kapetanovic, 2013).

Psychological Issues

Li (2009) revealed that the psychosocial issues associated with HIV infection in adolescents coalesce around five central themes: knowledge and understanding about personal sero-status; mental health; networks of support; treatment management; and healthy behaviour. These issues present challenges to HIV-positive adolescents in the present, and also affect their outlook on the future. Findings reveal that despite the fact that young seropositive South Africans live in a country where social contexts, available resources and healthcare systems differ markedly from those in developed countries, they share similar concerns and face many of the same challenges as other HIV-positive young people around the world (2009). Disclosure is often the central issue that determines if, when, and how a child living with HIV receives the services and support he or she needs. Lack of readiness and willingness both on the parent/caregiver side (e.g., reluctant to disclose their own HIV status) and the child's side can be significant barriers to ensuring a child's well-being.

Religion and Spirituality

Religion and spirituality are often interchanged. In essence, they encompass one's belief in the existence of a supernatural or high power to escape to when faced with overwhelming challenges (Lippman & McIntosh, 2010). HIV/AIDS forms part of such overwhelming challenges. Adolescents might resort to religion and spirituality to help them cope or simply explain challenges for themselves. Spirituality as a protective factor for coping with HIV has been understudied in adolescents. However, a mixed picture prevails regarding the role of religion/spirituality in adolescent living with HIV is concerned.

Spirituality is difficult to define. It involves looking within and having an awareness that there is something sacred. Spirituality and religion are often central issues for patients dealing with chronic illness. Cotton, Puchalski, Mrus, Peterman, Feinberg, Pargament, Justice, Leonard & Tsevat, (2006) revealed that most patients with HIV/AIDS belonged to an organised religion and use their religion to cope with their illness.

Patients with greater optimism, greater self-esteem, greater life satisfaction, minorities, and patients who drink less alcohol tend to be both more spiritual and religious.

Religion or spirituality may play a positive role among adolescents with HIV. It might help to decrease risky behaviours, provide support, act as a coping mechanism, and generate hope and comfort. According to McCree, Wingood, Di Clemente, Davies and Harrington (2003), adolescent spirituality is associated with less anxiety and depression and adaptive coping with a chronic illness. Having strong religious beliefs has been shown to be a protective factor against many risk behaviours, including tobacco, alcohol, drug use, violence, and initiation of sex.

Spirituality is one of many ways teens with HIV and their families cope with the burdens of HIV (Cotton et al., 2006). Religion may protect youth from risky behaviours (McCree et al., (2003). Spirituality is often a central issue for them and their families (Lyon, Garvie, Kao, Briggs, He, Malow, McCarter, & D'Angelo, 2011).

In Tennessee, United States of America, Garvie, He, Wang, D'Angelo and Lyon (2012) found that about 68% of HIV-positive teens rated themselves as religious/spiritual, about 72% reported regular attendance at religious services, and about 80% indicated that religion/spirituality helped them face their fears. Furthermore, it emerged that although important areas of congruence emerged, equally important areas, such as the timing of these conversations and adolescents' end-of-life needs and wishes, are not known by their families. Families need help initiating conversations to assure their adolescents' end-of-life wishes are known to them.

Some negative elements may arise regarding religion and spirituality. For example, Bernstein, D'Angelo and Lyon (2013) inform that religion or spirituality may be a negative or painful factor, especially if it is viewed as a punishment, leading to worsened outcomes. Some patients believe or feel that their disease is a punishment from God, which negatively affects their coping with illness. Youth living with HIV/AIDS (YLWHA) are more likely to wonder "whether God has abandoned me". The research by Family Centered (FACE) Advance Care Planning study hypothesised that a) high spirituality would predict high medication adherence and stage of illness; and b) belief "HIV is punishment from God" would decrease medication adherence. Religious beliefs can increase spiritual distress. HIV-positive teens were more likely to report "God abandoned me," than HIV-negative teens (Bernstein et al., 2012). The belief that HIV was a punishment from God was associated with poor medication adherence among HIV-positive teens (Lyon et al., 2011).

The number of adolescents living with HIV/AIDS in South Africa is increasing (Jaspam, Li, Johnson & Bekker, 2009). However, it is not known how adolescents on Highly Active Antiretroviral Therapy (HAART) experience the pandemic, with particular focus to their subjective experience of HAART. Adolescents' experiences of living with HIV/AIDS are influenced by various factors, most of which are beyond the control of adolescents, as such understanding these factors might better enhance the degree to which the adolescents adhere with treatment.

METHODS

Study Setting

The study was conducted at Tembisa Hospital's Masakhane Clinic, which is the HAART roll-out centre. Tembisa Hospital is located in the township of Tembisa, near Kempton Park town in the Ekurhuleni Metropolitan Area of the City of Johannesburg, Gauteng, South Africa.

Participants

Three adolescents aged between 10-19 years who are living with HIV/AIDS and that have been on HAART for at least a period of two years participated in the study. A balance in terms of gender was preferred in order to analyse the role of gender on the narratives of being on HAART. It also included those able to articulate their experiences in the language that they feel comfortable.

Design

The study employed qualitative methodology to capture the experiences of adolescents who were on HAART. This was an exploratory design using the phenomenological approach. Creswell (2006:58) explains that the straightforward purpose of phenomenology is to reduce individual experiences with a phenomenon to a description of the universal essence and help to understand the phenomenon from the perspective of people who have experienced the phenomenon. Phenomenological approach is based on the assumption that in order to understand humans, it is best to discover their meaning world and experiences which can be captured through the use of interviews (Wertz et al., 2011).

This study aimed to gain an understanding and to describe the experiences of adolescents on HAART. Phenomenology is concerned with the study of experience from the perspectives of the individual, 'bracketing' taken-for-granted assumptions and usual ways of perceiving. Epistemologically, phenomenological approaches are based on a paradigm of personal knowledge and subjectivity and emphasise the importance of personal perspective. As such, they are powerful for understanding subjective experience, gaining insights into people's motivations and actions, and cutting through the clutter of taken-for-granted assumptions and conventional wisdom (Wertz et al., 2011). Although phenomenological researchers seek targeted experiences, they also want to explore the diversity of individual experiences (Polit & Beck, 2006; Husserl, 1970).

Phenomenology is a philosophy which puts essences back into existence and does not expect to arrive at an understanding of man and the world from any starting point other than that of their 'facticity.' However, it is also a philosophy that the world is

always ‘already there’ before reflection begins, as an inalienable presence, and all its efforts are concentrated on re-achieving a direct and primitive contact with the world and endowing that contact with a philosophical status. It is the search for a philosophy which shall be a rigorous science, but it also offers an account of space, time and the world as people ‘live’ them. It endeavours to give a direct description of a person’s experience as it is, without taking account of its psychological origin and the causal explanations which the scientist, the historian or the sociologist may be able to provide (Merleau-Ponty, 1962).

Furthermore, in-depth interviews formed an integral part of data collection in this study. Such method is regarded by prominent researchers as the predominant mode of data collection. Thematic analysis approaches were applied, which shared the aim of identifying and describing the central ideas occurring in data.

Sampling Procedures

Convenient and purposive sampling methods were used to draw a sample from the population of Tembisa hospital. Welman and Kruger (1999) inform that purposive sampling is a vital method of non-probability sampling to identify the participants by selecting only those who have knowledge of the phenomenon under investigation. The sample in this study included adolescents who had been on HAART for at least a period of two years.

Ethical Considerations

The researcher ensured strict compliance with ethical standards. These included standards which were relevant to protecting the rights of the participants as well as institutions where data was collected and scientific integrity was maintained throughout the study. Approval was sought and obtained from both the Tembisa Tertiary Provincial Hospital as well as the Unisa Ethics Committee before data collection commenced.

Theoretical Orientation

Theoretical frameworks used for this study were the Health Belief and the Biopsychosocial Models. The Health Belief Model (HBM) is a modern framework for explaining people’s health-related behaviour, such as healthcare utilisation and adherence to a medical regimen (Polit & Beck, 2006). The model hypothesises that individuals’ motivation to act depends on the perceived threat to their health and their belief that action will mitigate the threat. Individuals are first convinced that they are personally susceptible, the disease has serious consequences, the recommended health action will prevent these consequences and the benefits of the new behaviour will outweigh the

costs. Faced with a threat to their health, individuals evaluate all alternatives that can reduce the threat.

The Health Belief Model is still very current to this present day. Adherence with HBM is seen as a preventive health action. Patients adhere more to treatment if they believe that they are susceptible to a disease they perceive as serious and that the treatment will be effective, provided the benefits outweigh the costs (Mayer, 2007). HBM suited this study as it provided a framework for understanding adolescents' experiences of HAART and subsequent health-related decisions, such as adhering to treatment. As such, the extent to which adolescents' adherence to HAART is influenced by their personal perceptions about the seriousness of HIV/AIDS, their perceived benefits as opposed to perceived barriers will also be explored.

The bio-psychosocial model (BPSM) is juxtaposed alongside the HBM in order to render a comparative description of models in describing the unique experiences of adolescents as far as HAART is concerned. Williams, Holmbeck and Greenlay (2002) describe the BPSM as a model that emphasises the biological, psychological and social changes of the adolescent developmental period.

The BPSM is a generic approach positing that biological, psychological (entailing thoughts, emotions, and behaviours) and social (socio-economical, socio-environmental, and cultural) factors play a significant role in human functioning in the context of an illness. Health is a blend of biological, psychological and social factors, not only biological. This contradicts the biomedical model of medicine (BM) that suggests every disease process can be explained in terms of an underlying deviation from normal function such as a virus, gene or developmental abnormality, or injury. BM applies in medicine, nursing, health psychology and sociology, and in specialist fields such as psychiatry, health psychology, family therapy, chiropractic, clinical social work, and clinical psychology. The BPSM is also a technical term for the 'mind-body connection' which addresses more philosophical arguments between the bio-psychosocial and biomedical models, rather than their empirical exploration and clinical application. Behavioural issues, through their effect on adherence, often lie at the root of antiretroviral failure. If not addressed, they might jeopardise the success of any future treatment. BPSM therefore enables behavioural issues to be contextualised (Soloway & Friedland, 2000).

Data Collection and Analysis

All the data collection processes were conducted at Tembisa Hospital. The researcher collected the data herself through the use of individual semi-structured interviews. This involved in-depth interviews where an interviewer and an interviewee discuss specific topics in depth (David & Sutton, 2011). In this study the researcher followed a flexible interviewing guide. Interviews were audio recorded because the analysis focuses on the speech rather than visual channel.

Thematic analysis approach was applied, which shares the aim of identifying and describing the central ideas (usually referred to as themes or categories) occurring in data. Thematic analysis attempted to identify themes from the material under study. This material is derived from the interview data. The researcher normally analyses the material inductively, that is, the themes are derived from the data, rather than derived beforehand (Wertz et al., 2011). Themes were organised in a hierarchical structure, with higher order themes and subthemes. In a sense, thematic analysis is a qualitative analog of the statistical approaches of factor analysis or cluster analysis, both of which aim to describe a complex data set in terms of a number of dimensions or groupings (Cooper et al., 2012).

Analysis in this study was a process of reading and looking for themes and patterns of meaning. The researcher read and re-read the transcripts to identify emerging themes and sub-themes that reflect the experiences of adolescents on HAART and a code list was developed which defined the identified themes. Furthermore, the computer program, Atlas.ti.7 was co-applied in the creation of codes and subsequent generating of themes.

FINDINGS

Recognition of adolescents' evolving capacity for self-determination could be maximised to improve chances of HAART adherence by first giving them full disclosure of their HIV status. Experiences of adolescents living with HIV/AIDS are influenced by numerous factors across individual, family, peer relationships as well as the healthcare system. In order to improve the quality of life of HIV-infected adolescents, an improvement of above-mentioned structures cannot be emphasised enough. The issue of disclosure comes up as having a significant bearing on acceptance of HIV status and later on, adherence to HAART.

Participants

Three participants, two girls (14 and 15 years of age) and a boy of 17 years participated in the pilot study. The older girl's mother died in 2001, and three years later in 2008 at age 11, she started taking the ARVs. The younger girl started taking ARVs at seven years of age in 2006. Her mother died in 2010. The participants have now become orphans and are cared for by guardians who are blood relatives. There were indications that the patients were also following up on their tests and monitoring sessions.

The girls seemed to be more willing to provide information for this study while the boy was very reserved. Even though he insisted that he wanted to participate, the questions seemed to be too sensitive for him. He was not free to disclose information as it hurt him, as he claimed. He was also crying when asked about his HIV status. In addition to initiation, several follow-up and re-initiation sessions were attended by the patients. These showed that the patients were highly committed to the treatment.

Knowledge about HAART use

All the participants knew that they were treated with ARVs because of their HIV-positive status. Doctors and parents/guardians had informed them. Sometimes the patients were denied the information on why they were using ARVs but insisted on being told.

Means of Infection

They did not know who had infected them. However, they suspected that since their mothers died of the disease, they must have been the ones who infected them. More confusion occurred as to who would have infected others at first in the case of a father who had also died of the disease. The source of HIV infection cannot always be detected with accuracy, since several sources are available to effect infection.

Effects of Illness

The younger girl dropped out of school as a result. She reported that she was not enjoying it and was not coping. Despite dropping out of school she had the ambition of helping other sick people when she grows older, hence she wanted to become a medical doctor. The mothers were still missed though, despite the comfort provided by grandmothers' guardianship. Failure at school was blamed on the parent's death.

Coping Mechanisms

The company of friends and companions in some cases seemed to comfort the HIV-positive participants. There were also claims of using drugs as well as dagga in order to cope. Some guardians were supportive, encouraging, and also provided comfort to the patients and this seemed to help them to cope. They also found it difficult to disclose their status to their friends due to lack of trust and the fact that their friends would criticise them for being HIV positive.

Adherence to the Treatment

The participants seemed to adhere to treatment, as they all claim that 19h00 is the time that they take their medication. The participants indicated that they got annoyed when the doctors did not believe that they adhered to their medication.

Effects of Treatment

Participants believed the treatment was beneficial even though only some could feel it was working while others did not feel the positive effect at the time. The HAART treatment was sometimes tiring to the participants, but there was consolation and hope

that it keeps them alive and they will grow to be useful adults. This shows that the treatment was perceived as having long-term positive effects in HIV treatment.

Feelings about the HIV Status

Participants reported feelings of anger as a result of their HIV-positive status. Others were saddened by the death of their parents due to HIV/AIDS. They were also scared that the same fate is awaiting them. They eventually had to accept their HIV-positive status in order to focus completely on the treatment.

Impressions about the Treatment

Participants believed that the HAART treatment keeps them alive. That is, if they were not using it, they believed that they would have died. They alluded that their mothers died because they were not enrolled to the HAART programme.

Treatment by the Guardians

Some guardians treat the orphans well while other orphans claimed to be not properly cared for. The encouragement reports were also said to have been experienced from some guardians.

Sexual Experience

The girls were younger (14 and 15 years old), had no boyfriends, were not sexually active and not necessarily eager to start. The boy was 17 years old, had a girlfriend and was sexually active. He claimed to use a condom when engaging in sex with his girlfriend. The girls stated that when they start to be sexually active, they would insist on using condoms with their sexual partners. They reported that they would leave the boyfriends who disliked using a condom.

DISCUSSION

The patients indicated that they adhered to treatment and believed they would improve their health. However, they were concerned about their current condition and the way others would treat them if their HIV-positive status was to be disclosed. Some guardians took good care of them. However, poverty seemed to play a role in how well the participants reported satisfaction with their guardians. Participants who came from a poor background reported less satisfaction with their caretakers.

The participants reported that they took their treatment consistently and they trusted the medication. There was a sense of awareness on why they took this specific treatment. However, they were unacquainted as to where they got the infection. They could only

suspect it could have been from parents who had died of the disease. However, it was inconsequential to them. Their focus was on improving their health through the HAART treatment.

Emotionally, the participants reported that the disease initially evoked feelings of anger and sadness but they eventually accepted their HIV-positive status. Some of the patients had to drop out of school because they could not cope with school work and were not supported. However, they still had ambitions for their future, and were hoping to become helpers in professions such as medicine.

The participants in the study used different coping mechanisms such as hanging out with friends, but dangerous methods of ‘coping’ such as drugs and dagga use were also mentioned. Despite participants’ general adherence, doctors sometimes estimated incorrectly that they had defaulted. The lack of trust displayed by doctors angered them as they were adamant that they honoured the prescriptions. Their attitude in thinking about sexual play was impressive. They all considered condom use as the only option when they become sexually active. They would neither open up to reinfections nor infect others, even when the partners did not know. The participant who was already sexually active reported unflinching condom use.

LIMITATIONS

The context-specific features of the research setting have limited the generalisation of the research study results. The study was based at a clinical unit in Tembisa with a homogeneous population. Therefore, its findings cannot be generalised to other races, provinces or other diverse biographical populations. However, other areas in South Africa may experience similar characteristics.

A further limitation of the research study is the duration of the study data collection. A longitudinal study would have produced an additional set of results in comparison to the cross-sectional study. Data for the individual adolescents was collected within a period of three months, while that of parent, guardian and caregiver participants was within two weeks. HCPPs returned the questionnaire within a period of two weeks, while the focus group met only once.

The sample size for parent, guardian and caregiver participants was limited to three due to poor willingness and withdrawal from participation. This sample was identified based on phenomenological research principles which recommend smaller sample sizes. However, for future research, more participants could be included. The focus group size was planned to be between six and eight participants. However, only three participants arrived for the scheduled interview and were willing and open to participate. Bigger samples would have resulted in more diverse responses and findings. Conducting the interviews in a mixture of English and the participants’ vernacular language and then transcribing and translating into English can be considered as a limitation, as some meaning might have been lost during the process.

RECOMENDATIONS

It is recommended that:

- A large-scale study be conducted with more responses;
- A study be conducted on how the health workers involved with these patients conduct their work and how they find the progress with their HIV patients under HAART; and
- A research study be conducted to determine how the patients' wishes could be improved in their HAART programme.

CONCLUSION

The study demonstrated that supportive environments for adolescents living with HIV/AIDS contribute to the favourable subjective experience of HAART. Understanding these environments will further empower adolescents, provided they are adolescent-centred.

BIOGRAPHICAL NOTES



MUSA MASETSHABA is a clinical psychologist and Head of Clinical Psychology Department at Tembisa Provincial Tertiary Hospital. She recently graduated for her PhD in Psychology with the University of South Africa. The title of her research project was: 'Adolescents' experiences of the Highly Active Antiretroviral Treatment (HAART) in Tembisa.'

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