International Journal of MCH and AIDS (2012), Volume 1, Issue 1, Pages 83-91

IJMA

INTERNATIONAL JOURNAL
of MCH and AIDS
ISSN 2161-864X (Online)
ISSN 2161-8674 (Print)

Available online at www.mchandaids.org

ORIGINAL ARTICLE

Social, Cultural, and Environmental Challenges Faced by Children on Antiretroviral Therapy in Zimbabwe: a Mixed-Method Study

Margaret Macherera, MSc[1,3] ✉; **Lindani Moyo**, BSc[1]; **Mkhanyiseli Ncube,** BSc[2]; **Angella Gumbi,** MSc[4]

[1] Department of Environmental Science and Health, National University of Science and Technology, Bulawayo, Zimbabwe.

[2] Department of Environmental Health, St Anne's Brunapeg Mission Hospital, Bulawayo, Zimbabwe.

[3] Africa Academy for Environmental Health, Sinoville, South Africa

[4] Department of Forest Resources and Wildlife Management, National University of Science and Technology, Bulawayo, Zimbabwe

✉Corresponding author e-mail: mmacherera@gmail.com

ABSTRACT

Objectives

Despite the advent of antiretroviral therapy (ART), many children, particularly in the rural communities of Zimbabwe, remain vulnerable. The purpose of this study was to determine the factors and challenges facing children on antiretroviral therapy (ART) in Brunapeg area of Mangwe District, Zimbabwe.

Methods

A mixed-method approach involving interviewer-guided focus group discussions and piloted semi-structured questionnaires was utilized to collect data from different key population groups. The data obtained were analyzed through content coding procedures based on a set of predetermined themes of interest.

Results

A number of challenges emerged as barriers to the success of antiretroviral therapy for children. Primary care givers were less informed about HIV and AIDS issues for people having direct impact on the success of antiretroviral therapy in children whilst some were found to be taking the antiretroviral drugs meant for the children. It also emerged that some primary care givers were either too young or too old to care for the children while others had failed to disclose to the children why they frequently visited the Opportunistic Infections (OI) clinic. Most primary care givers were not the biological parents of the affected children. Other challenges included inadequate access to health services, inadequate food and nutrition and lack of access to clean water, good hygiene and sanitation. The lack of community support and stigma and discrimination affected their school attendance and hospital visits. All these factors contributed to non-adherence to antiretroviral drugs.

Conclusions and Public Health Implications

Children on ART in rural communities in Zimbabwe remain severely compromised and have unique problems that need multi-intervention strategies both at policy and programmatic levels. Effective mitigating measures must be fully established and implemented in rural communities of developing countries in the fight for universal elimination of HIV/AIDS.

Keywords

Antiretroviral therapy • Challenges • Children • HIV/AIDS • Mangwe District • Zimbabwe

Introduction

For three decades, HIV and AIDS have affected the lives of many people at individual and family levels through illnesses and deaths of family members and has been a serious challenge medically, financially, and socially[1, 2, 3]. HIV and AIDS is of considerable and significant impact to children yet the attention given to this population is largely overshadowed by the large scale burden of the epidemic in the adult population, especially in Sub-Saharan African countries[2].

HIV and AIDS have caused untold suffering in the rural communities of Sub-Saharan Africa with children being the most affected. About 95% of the infected populations in the world currently live in developing countries, particularly in Sub-Saharan Africa[4]. Zimbabwe is one of the Sub-Saharan African countries burdened by high HIV infection prevalence. The country's population is estimated at about 13 million people with about 1.1 million HIV positive people, of which 151,749 are children below the age of 14[5]. By the year 2010, only 326,241 people in Zimbabwe were estimated to be receiving antiretroviral therapy (ART)[4].

Despite the increasing introduction of antiretroviral therapy, many children, particularly in the rural communities of Zimbabwe remain vulnerable. They are impacted by non-adherence ART regimen due to a number of factors. This includes inadequate access to food and nutrition which can be shown by the unbalanced diet and the number of meals they get per day, transportation problems, and long distance commute to hospitals, infrequent visits by the home based care givers (HBCs) and the prevalence of widespread stigma and discrimination[6, 7, 8].

Guardianship of children on ART is also crucial since it is directly correlated to the overall care and support provisioned by the primary care givers[6, 7]. Lack of adequate care and support has been noted in instances where the primary care givers are too old or too young.

A major treatment gap remains since by the end of 2010; many children who were eligible for treatment did not have access to ART. Access to treatment for the children is lower than that for adults since by 2009; only 28% of the registered children received ART whilst coverage for other age groups was 36%. Low ART coverage and access no doubt increases the vulnerability of children to HIV and AIDS[4, 9].

Antiretroviral therapy is an integral component in the quest to improve the well-being and health of children living with HIV and AIDS[10]. Its success is determined by factors that occur concurrently to the patients' health and social life during the course of the therapy. Antiretroviral therapy involves continual interaction between health staff and patients through on-going medical check-ups, prescription or drug refills, monitoring and adherence support[6, 7, 11].

Research on ART in developing countries is very new and tends to focus primarily on issues of non-adherence yet there are hosts of health, psychological, social and economic challenges which determine the success of ART in children[6, 7, 8, 12, 13]. The success rate of ART in rural communities of Zimbabwe is low with fewer children covered on therapy whilst those on ART have a poor health a situation worsened by the localities of the communities[14, 15].

The Mangwe district in Matabeleland South province of Zimbabwe has a widespread prevalence of HIV and AIDS in addition to highest levels of food insecurity, transportation problems, sanitation and health services challenges[15, 16]. It is such widespread inequalities, discrimination and poverty in the province which shape and worsen the HIV epidemic in the Brunapeg area of Mangwe district. There are several challenges with direct or indirect impacts on the success of ART in children. This includes the provision of good psychological counseling to the children; access

to adequate diet and nutrition; adequate access to health facilities, services and antiretroviral drugs; elimination or minimization of stigmatization and discrimination; and adequate knowledge and use of proper practices by caregivers, i.e. primary care givers and home-based care givers[8, 9, 13, 16, 17, 18]. Such challenges are profound in rural communities of Zimbabwe[14,15]. This paper explores the challenges faced by children on ART in the Brunapeg area of the Mangwe district in Zimbabwe.

Methods

Study Design

This study was conducted in the Brunapeg area of Mangwe District. The area has one diagnosing center for HIV and AIDS located at St. Anne's Hospital serving a population of approximately 78, 000 people. The hospital has an Opportunistic Infection (OI) clinic which provides HIV Counseling and Testing (HCT), prevention of parent to child transmission (PPTCT), ART and home based care (HBC).

A mixed-method study was designed utilizing both focus group discussions (FGDs) and semi-structured questionnaires to assess the challenges faced by children on ART looking at individual-level and group-level factors. The study also examined the consistency of information acquired through both tools. FGDs give group consensus information while questionnaires assess information from a personal level. The questionnaires were designed for the children and the caregivers and were piloted at Plumtree Hospital area, another hospital in the Mangwe district. For the community leaders, key informant interviews were only employed since they represented different levels of leadership.

Study Population and Sampling

This study focused on different sub-populations in the study district. A multi-stage sampling method was used to identify children (5-15 years) on ART registered at St Annes' Hospital OI clinic, their corresponding primary care givers, home based care givers registered with St Annes' Hospital and community leaders in the Brunapeg area.

Utilizing St Annes' Hospital registry for children on ART, 396 registered children were stratified according to wards. The Brunapeg area has 9 wards and a ward consists of 6-10 villages. Forty (10.1%) children (5-15 years) were purposively selected from all the wards according to their age ensuring that samples comprised of children. Four children were sampled from each of the wards 5, 6, 7, 8 and 9 whilst 5 children were sampled from each of the wards 10, 15, 16, 17 totaling 40 children in all.

The primary care givers were sampled corresponding to the selected 40 children. Among the 460 home based care givers (HBCs) registered in the St Anne's Hospital HBC program, 40 (11%) were randomly sampled for the study inclusive of those corresponding to the sampled children. It must be noted that unlike primary care givers, in Zimbabwe, HBCs cater for children from different homes.

In sampling the community leaders for the study, all three Chiefs (or village heads) who are overseers of the wards were selected. Out of the seven Headmen, four were selected, out of nine Councilors each corresponding to each of the wards, four were selected and out of 60 Village heads, 10 were selected. These community leaders were the key informants within their respective communities.

Data Collection

The sampled children, primary care givers, HBCs and community leaders were recruited into separate focus groups. Focus groups discussion guides with a set of carefully predetermined questions were used to collect data. The meetings were scheduled at selected outreach points for the wards concerned by making appointments with

the chiefs to mobilize other community leaders. The children on ART, primary care givers and HBCs were mobilized through the hospital staff. In addition, questionnaires were distributed to the respondents on the appointed days. The FGDs data was collected through note-taking until all key points and objectives were exhausted. Different FGD guides were designed for different focus groups for relevancy in drawing information. The data collected was analysed by the study team through content coding procedures and categorised based on pre-set themes of interest namely provision of clean water and hygiene, food access, ARV drug access, non-adherence, health services access, knowledge of primary care givers and HBC of HIV/AIDS, school attendance and stigma and discrimination. The questionnaires utilized were designed around these study themes. The data from the FGDs and questionnaires were integrated according to the pre-set themes and objectives to eliminate redundancy.

Results

The problems affecting the success of ART on children in the Brunapeg area of Mangwe district included inadequate access to food and nutrition, lack of access to adequate health services, stigmatization and discrimination and inadequate service provision by the care givers.

Access to Food and Nutrition

The primary care givers and HBCs highlighted the lack of access to adequate food and nutrition (Table 1) as a major challenge affecting the studied children on ART. It was found that the children on ART who were not having adequate access to food and nutrition were not coping well with the therapy whilst some of them ended up begging for food and avoiding the ARV drugs.

Table 1. Number of Meals Received by the Children on ART Per Day According to Primary Care Givers

No. of meals/day	No. of children affected	Children affected (%)
1	18	45.0
2	19	47.5
3	3	7.5

The study revealed that there was inadequate access to clean water, good hygiene and sanitation, which negatively affected the children on ART. This was worsened by the fact that the Mangwe district is located in drought prone area of Zimbabwe.

Access to Health Services and Provision of Care and Support

Home Base Care (HBC) respondents reported that most primary care givers (Table 2) were not the biological parents of the children (mostly orphaned by HIV/AIDS) on ART. They expressed concerns that the care and support obtained from the foster parents and guardians was not comparable to those that could be given by their biological parents. One primary care giver was quoted by the HBCs to have said to a child, *"Your people have arrived, and they want to see how you are taking your things"* implying that the HBCs have arrived, they want to assist you in taking your ARV drugs. Stigma is apparently implied in this statement and it translates to lack of ownership of the problem by the caregiver. This also impacted the frequency of taking the children to hospital to obtain health services, a situation also compounded by long distances and transportation problems to hospital in the Brunapeg area.

Table 2. Categories of Primary Care Givers for the Children on ART

Primary care giver	No. of children affected	Children affected (%)
Foster Parents	11	27.5
Single parents	8	20.0
Both parents	4	10.0
Child headed home	17	42.5

Impact of Age of Primary Care Giver on ART

Another challenge was that most primary care givers were either too young or too old to take care for the children on ART such that they had problems adhering to hospital dates and times or monitoring the children on ART during their drug administration (e.g. correct dosages). According to one older lady in the study: *"My bones are no longer strong to be moving up and down and I am frequently not feeling well"*. This indicates how old age and the individual characteristic of the care giver impacts the adherence of the children to their medication regimen.

It was also apparent that the primary care givers were not sufficiently trained on the issues surrounding ART and counseling for them to adequately support the children that they provide care for. Some primary care givers did not adequately provide care to the children due to the fear of being infected with HIV and AIDS following close interaction with the children living with HIV and AIDS. It was reported that some adult primary care givers took the drugs meant for children on ART for their own use due to the fear of disclosing their own status and going for individual treatments.

Lack of Disclosure of Status

Our study found that 60% of the children studied were not aware of the reasons why they were frequently visiting the health services since their HIV status had not been disclosed to them by their primary care givers. The children believed that they visited the hospital for minor ailments such as flu, headaches, and cough. This implies that some of the children would grow up and become sexually active without knowledge of their HIV status and will thus not reveal that to their partners. According to one of the children who had not formally had a disclosure of status said: *"My mum has never told me, but I know"*. This causes the children to mistrust their caregivers and may lead to lack of supportive family counseling. Children who became aware of their HIV status feared visiting the hospital due to fear of stigma. This is impacted by that there were no support groups for the children to reduce stigma after disclosure of status.

School Attendance Impacted by Stigma and Discrimination

We found that 70% of the children studied were of school-age yet only 39% of them were attending school (Table 3). This could be attributed to the fact that the children reported stigma and discrimination both at school and community or societal level and felt safer at home since they had been informed that they were HIV positive due to the noticeable signs associated with HIV infection. It was reported that the children had problems at school from other children ranging from verbal to physical abuse. A 14 year-old girl in the study said: *"Other children scold me at school, they say I am confused by the pills I am taking"*. In addition, the children could have been too unwell to be attending school.

Table 3. School Attendance of the 28 School Eligible Children (70%) on ART

School attendance	No. of children affected	Children affected (%)
Attending	11	39.3
Not attending	17	60.7

Discrimination and stigmatization is prevalent among these children outside the school settings. Children were not fully involved in social programs whilst those at adolescence stage end up going into relationships without disclosing their status for fear of losing their relationships. This is worsened by lack of knowledge of the existence of programs aimed at canvasing communal support for the children on ART. Another challenge faced by the children on ART was the infrequency of visits by the HBC givers (Table 4). We found that on the average, hospital visits by children on ART supervised by primary care givers were inadequate for close monitoring of the children and ensuring adherence to treatment protocols.

Table 4. Frequency of Visits to Children on ART by HBCs

Frequency of visits	No. of HBCs
Everyday	0
Once a week	2
Twice a week	9
After 2 weeks	5
After 3 weeks	7
After a month	13
As per need/ emergency	4

Another aspect found to compromise the service delivery of HBC givers to children was the verbal abuse they faced and the lack of support from other community members which discouraged them and thereby impacted their service delivery. One HBC recalled a discriminatory comment by a community member, *"What you know better is bathing people with AIDS"*.

Discussion

Data from different focus group discussions and semi-structured questionnaires indicate that the broad challenges faced by the children on ART can be categorized into food access, health service access and provision of care and support both at household and community levels. These findings are consistent with earlier studies on challenges faced by elderly guardians in sustaining adherence to ART in HIV-infected children and community relations and child-led microfinance[9, 13], HIV/AIDS-related stigma and discrimination[17] and food insecurity and nutritional barriers to ART[16]. Amongst the children (5-15 years), 42% were males whilst 58% were females demonstrating that girls were more affected by HIV and AIDS in the Mangwe district in Zimbabwe.

The primary care givers and HBCs reported food insecurity as a key challenge in the assistance of the children on ART despite the food aid provided by various donors. When providing food aid, the donors issued quantities targeted for children on ART, yet the food is often consumed by the entire family. This is because Mangwe district is in a drought-prone province resulting in low food access and poor nutrition for the children. Poor nutrition compromises the immune system and increases the virulence of HIV whilst also attenuating the efficacy of ARV drugs and magnifying the side effects, ultimately leading to non-adherence[6, 7, 11, 19]. The lack of access to clean water, hygiene and sanitation increases the susceptibility of the children to opportunistic infections[12, 15]. Lack of access to clean water and sanitation, inadequate food access, poor nutrition and food insecurity are key barriers to adherence and the success of ART on children in Brunapeg area concurring with the findings by Martin[16] who in turn linked this to stigma and discrimination. Lack of access to adequate food forces some children into begging for food in order not to starve to death. This disrupts the ART program as the children are not always at home and end up missing their drugs and even hospital visits. Begging exposes the children to sexual abuse and results in the spread

of the virus which would be resistant to some ARV drugs since they would be missing the drugs. The virus could resist the first line treatment leading to the second line drugs which are more expensive[6, 10].

According to earlier studies, the quality of life and health of HIV-infected children is also dependent on routine assessments for nutritional status, particularly after the initiation of ART[20]. Children on ART also require routine CD4 count tests, liver function tests and monitoring of weight and side effects. These assessments were not consistent in the Mangwe district. Symptomatic HIV-infected children have conditions requiring increased energy and nutrition such as TB, chronic lung disease and other chronic opportunistic infections[OIs] or malignancies. Those who are severely malnourished should be managed for severe acute malnutrition (SAM) and provided with 50–100% additional energy and receive one recommended daily allowance (RDA) of micronutrients daily and high-dose vitamin A[20, 21, 22].

Investigators have highlighted that people with HIV/AIDS are stigmatized more than other diseases[23]. In this study, stigma and discrimination were found to be predominant amongst the problems faced by the children on ART. This resulted in the children fearing to go to hospital, particularly for those who were aware of their HIV status. This was also attributed to the fact that the OI clinics were centralized and offered separate HIV treatment such that anyone frequently visiting them is implicated to be HIV infected and hence often stigmatized by the community[8]. Stigma and discrimination also had an impact on the school attendance of the children who were eligible for school since only 39.3% of these were found to be frequently attending school. This was also due to the fact that stigma and discrimination have been linked and correlated to low service utilization in rural areas[17, 23]. Social marginalization and discrimination restrict access to health and HIV-related services, food and nutritional support and other assistance programs and hence contributed and led to non-adherence[6, 7, 17, 23]. Such marginalization and discrimination were attributed[17, 23] to the lack of public awareness programmes and HIV specific support groups which improve adherence by minimizing stigma and discrimination and increasing communal and social support for the affected children. Studies have shown that expansion and decentralization of health service centers that give aid to the children on ART limits the impacts of social marginalization[6, 7].

Conclusions and Public Health Implications

Findings from this study showed that the HBCs and the primary care givers had inadequate knowledge on issues regarding HIV/AIDS and this affected the care they delivered to the children on ART particularly with drug administration, providing adequate care and food and nutrition. Policy states that there should treatment partners trained during pre-ART counseling of caregivers[14, 15]. The HBCs also faced inadequate availability of HBC kits and lack of support from other community members due to widespread stigma and discrimination against HIV and AIDS patients. This resulted in infrequent visits. In conclusion, the children on ART in the Brunapeg area of the Mangwe district are faced by lack of adequate food and nutrition and by widespread stigma and discrimination, in addition to inadequate support both at household and community levels. These factors severely lower the success of ART program since they have a negative impact on the children's health and quality of life.

Acknowledgements: We would like to express our sincere gratitude to the cutting-edge participants for their contributions and endeavors in this study. In particular, we appreciate the cooperation of the St Anne's Hospital OI clinic staff throughout the study and for the provision of statistical information on the children on ART. We would also like to thank Ms. Tumelo Nare, a technical assistant at the NUST Medical School for her constructive comments and for editing the manuscript.

References

1. Land H. Introduction. Journal of HIV/AIDS & Social Services. 2010; 9(4):323-326.

2. UNICEF/UNAIDS. Children and AIDS: Fifth Stocktaking Report; 2010.

3. Linsk LN. Thirty Years into the HIV Epidemic: Social Work Perspectives and Prospects. Journal of HIV/AIDS & Social Services. 2011; 10(3):218-229.

4. WHO/UNAIDS/UNICEF. Global HIV/AIDS Response: Epidemic update and health sector progress towards Universal Access 2011; 2011.

5. Joint United Nations program on HIV/AIDS and World Health organization. AIDS Epidemic Update. Geneva, Switzerland: Joint United Nations Program on HIV/AIDS; 2009.

6. Mullen J, Leech S, O'Shea S, Chrystie IL, Du Mont G, Ball C, Sharland M, Cottam F, Zuckerman M, Rice P, Easterbrook P. Antiretroviral drug resistance among HIV-1 infected children failing treatment. Journal of Medical Virology. 2002; 68(3):299-304.

7. Martin S, Elliott-DeSorbo DK, Wolters PL, Toledo-Tamula MA, Roby G, Zeichner S, Wood LV. Patient, caregiver and regimen characteristics associated with adherence to highly active antiretroviral therapy among HIV-infected children and adolescents. The Pediatric Infectious Disease Journal. 2007; 26(1):61-67

8. World Health Organization (WHO). Community home-based care in resource limited setting: a framework for action. Geneva, Switzerland: WHO; 2002.

9. Skovdal M, Campbell C, Madanhire C, Nyamukapa C, Gregson S. Challenges faced by elderly guardians in sustaining the adherence to antiretroviral therapy in HIV-infected children in Zimbabwe. AIDS Care. 2011; 23(8):957-964.

10. Paterson DL, Swindells S, Mohr J, Brester M, Vergis EN, Squier C, Wagener MM, Singh N. Adherence to protease inhibitor therapy and outcomes in patients with HIV infections. Annals of Internal Medicine. 2000; 133(1):21-30.

11. Castleman T, Seumo-Fosso E, Cogill B. Food and nutrition implications of antiretroviral therapy in resource limited settings. Technical Note No. 7. Food and Nutrition Technical assistance (FANTA). Academy of Educational Development, Washington DC; 2004.

12. World Health Organization (WHO). Antiretroviral therapy of HIV infection in infants and children in resource-limited settings: towards universal access recommendations for a public health approach; 2006.

13. Skovdal M. Community relations and child-led microfinance: a case study of caregiving in Kenya. AIDS Care. 2010; 22(2):1652-1661.

14. UNAIDS. Investing in Our Future Psychosocial Support for Children Affected by HIV/AIDS: A Case Study in Zimbabwe and the United Republic of Tanzania. UNAIDS case study best practice collection; 2001.

15. Zimbabwe Ministry of Health and Child Welfare. Zimbabwe National HIV and AIDS Estimates. ZMoHCW, Harare; 2009.

16. Martin A, Palar K, Derose PK, Adams J. Food Insecurity and Nutritional Barriers to Antiretroviral Therapy: Lessons from Latin America and the Caribbean. Journal of HIV/AIDS & Social Services. 2011; 10(2):194-214

17. Parker R, Aggleton P, Attawell K, Pulerwitz J, Brown L. HIV/AIDS-related Stigma and Discrimination: A Conceptual Framework and an Agenda for Action. Horizons Program; 2002.

18. Paranthaman K, Kumarasamy N, Bella D, Webster P. Factors influencing adherence to anti-retroviral treatment in children with human immunodeficiency virus in South India - a qualitative study. AIDS Care. 2009; 21(8):1025-1031.

19. Ivers L, Chang Y, Jerome J, Freedberg K. Food assistance is associated with improved body mass index, food security and attendance at clinic in an HIV program in central Haiti: A prospective observational cohort study. AIDS Research and Therapy. 2010; 7(33):1–8.

20. World Health Organization. Food security. 2010. Retrieved from: http:// www.who.int/trade/glossary/story028/en/.

21. Marston B, De Cock KM. Multivitamins, nutrition and antiretroviral therapy for HIV disease in Africa. New England Journal of Medicine. 2004; 351(1):78-80.

22. Hsu J, Pencharz PB, Macallan D, Tomkins A. Macronutrients and HIV/AIDS: A review of current evidence. Geneva, Switzerland: World Health Organization, Department of Nutrition for Health and Development; 2005.

23. Brems C, Johnson ME, Warner TD, Roberts LW. Health care providers' reports of perceived stigma associated with HIV and AIDS in rural and urban communities. Journal of HIV/AIDS & Social Services. 2010; 9(4):356-370.

24. Gahagan J, Rehman L, Barbour L, McWilliam S, The preliminary findings of a study exploring the perceptions of a sample of young heterosexual males regarding HIV prevention education programming in Nova Scotia, Canada. Journal of HIV/AIDS Prevention in Children & Youth. 2007; 8(1):135-153.

25. Dilorio CK, McCarty F, Pluhar E, Set the P.A.C.E.! Results of an HIV prevention intervention for mothers of young children. Journal of HIV/AIDS & Social Services. 2011; 10(3):290-310.

26. Centers for Disease Control and Prevention. HIV transmission rates in the United States; 2010.

