

An Assessment of the Experiences of Caregivers of Children with HIV and AIDS at a Children's Opportunistic Infections Clinic: Zimbabwe

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Abstract:

The purpose of the study was to assess the experiences of caregivers of children with HIV and AIDS at a Children's opportunistic infections clinic in Zimbabwe. The main objectives of the study were to determine the kind of relationships existing between the caregivers and the children, to establish the caregivers' level of knowledge of HIV and AIDS, the treatment modalities involved, to assess the caregivers' levels of adherence to ART, to establish the caregivers' support systems and to find out the problems faced by caregivers during their care giving roles. A mixed method approach was employed. A sample of ten caregivers, comprising 4 biological mothers, 3 female relatives, 1 male relative, 1 foster parent and 1 child caregiver was drawn from a population of 423 caregivers of children with HIV and AIDS. who had defaulted treatment and/or missed review dates. The main findings of the study were that, most of the caregivers were the children's biological mothers and female relatives, and they had known the children since birth. It was found that, prior to the initiation of ART, all the participants were trained to care for the children and were given guidelines on nutrition and drug therapy. Furthermore, all the participants showed knowledge of HIV and AIDS, its prevention and management. While participants mentioned that they received social support from family and friends, it was noted that the burden of care still fell hard on them as they were the ones who stayed with the children and had to be physically available to give care. The challenges faced by caregivers in adhering to ART were found to be financial constraints, living remotely from health care centers, transport problems, contradictory cultural beliefs and stigma. Recommendations included increasing staff compliment, step up sensitization campaigns through Health education programmes and disseminate research findings to stakeholders. Funds permitting, two year longitudinal studies be undertaken in Zimbabwe to ascertain ART adherence.

Key Words: caregivers, opportunistic infection, ART, stigma

I. INTRODUCTION

Anti-Retroviral Therapy (ART) is the combination of several Anti-Retroviral medicines used to slow down the rate at which HIV multiplies in the body. The drugs do not kill or cure the virus, but they prevent its growth (World Health Organization, 2012). Strict adherence to ART is therefore key to sustained HIV suppression and improved overall health. Poor adherence results in drug resistance and quick progression of the virus towards full-blown AIDS. Thus, it is imperative to promote strict adherence. The starting point is to determine the factors that may cause non-adherence in the patients and/or their caregivers. This study assesses the experiences of caregivers of children with HIV and AIDS at a selected clinic with a view to identifying factors that cause non-adherence to ART and making recommendations to address them.

II. BACKGROUND TO THE STUDY

During clinical practice, the researchers noted that caregivers of children with HIV and AIDS under 12 years of age attending the Opportunistic Infections Clinic, defaulted treatment and missed review dates occasionally, despite having undergone some training and counseling.

Before commencing Antiretroviral Treatment (ART), Clinicians ensure that caregivers understand the treatment modalities and become committed to the treatment. The patient's support systems are explored before the patient is commenced on ART. Treatment can be postponed or delayed until the patient and family are deemed ready for it.

Regionally, a study carried out by the World Health Organization (2014) to monitor the level of adherence to (ART) in Botswana, revealed that at least 20% of the study participants defaulted treatment by missing review dates and only 40% of the participants adhered well to the treatment modalities. The reasons cited for the non-compliance with ART were that of stigmatization and unaffordable transport costs due to poverty (World Health Organization, 2014).

Vree, Morris and Chester (2009) highlighted factors such as the child's age and household position, their relationship with their caregiver, adult openness regarding the child's HIV status, available resources, beliefs about HIV, stigma and access to health care services, as the main reasons for non-compliance to ART in Kenya.

In Zimbabwe, a similar study was undertaken by Haberer and Mellins (2009). It highlighted that while much has been written about how child-specific factors like psychosocial function, developmental stage, and regimen characteristics like drug formulation and changes to treatment plans impact children's ART adherence, little is known about social factors impacting children's ART adherence.

ART adherence has been shown to improve a person's health. However, Jackson (2012) suggested that lack of time and space for professional counselling of bereaved parents and the wide socio-economic gap between health professionals and the urban and rural poor, may block the professionals' recognition and caregiver expression of grief.

In Zimbabwe, assessments carried out by the Ministry of Health and Child Care (2015) on ART adherence at various hospitals showed that there was an adherence rate of 51,9%. The causes for such a relatively low adherence rate were that most of the children were orphans and would move from one relative to another whilst adolescents did not take the treatment seriously.

Statement of the Problem

The statistics for the year 2014 at the selected Children's Opportunistic Infections Clinic revealed that, of the 3099 registered children, the total number of defaulters was 423 (13.64%) and 14 deaths were registered. This is surprising as the caregivers would have been deemed ready and capable to adhere to ART following effective counselling. This prompted the researchers to investigate the experiences of the caregivers which led them to miss review dates and default treatment.

Purpose of the Study

The purpose of this study was to determine the experiences of the caregivers of children with HIV and AIDS which led them to default treatment and miss review dates.

Objectives of the study

The following were the objectives of the study:

- To determine the kind of relationship existing between the caregiver and the child.
- To establish the caregiver's level of knowledge of HIV/ AIDS conditions.
- To assess the caregivers level of adherence to ART.
- To establish the caregivers' support systems.
- To ascertain the problems faced by caregivers.

Significance of the Study

Timeliness

This study was well timed because for the past 10 years the incidence of non-adherence to ART in Zimbabwe was rising (Ministry of Health and Child welfare, 2012). Thus, there was need for immediate action to remedy the situation and to improve adherence to ART.

Contribution to Research and Education

The study results will contribute to existing knowledge on ART adherence and lead to a better understanding of the field and to the adoption of effective strategies to promote ART. It may also open the way for future studies.

Policy Formulation

It is hoped that the results from this study may help to map the way forward in addressing the challenges faced in promoting ART. Sound health translates into a world of productive people, which will inevitably lead to a well-developed global nation.

Methodology Used

The researchers used a mixed method approach. This means that both qualitative and quantitative techniques were used. The research population included the entire group of persons that were of interest to the researchers, and in this case, it meant all caregivers of children with HIV and AIDS attending the selected Children's Opportunistic Infections Clinic. Purposive sampling was employed, where the researchers selected individuals whom they felt would provide the information that was required. This method was chosen as the researchers were able to apply their knowledge and pick on the appropriate participants. The sample consisted of ten (10) caregivers of children with HIV and AIDS attending the selected Children's Opportunistic Infections Clinic. In the sample there were 4 biological mothers, 3 female relatives, 1 male relative, 1 foster parent and 1 child caregiver.

Ethical issues regarding informed consent, anonymity, confidentiality and protection from harm, were taken into consideration. The researchers explained the purpose of the study to the participants in detail, including what they were expected to do, what the information would be used for, the risks they could face, how they would be protected from harm and how their privacy and confidentiality would be respected (Best and Kahn, 2012). Questionnaires, document analysis and in-depth interviews were used to collect data.

III. RESULTS

Biographical Data

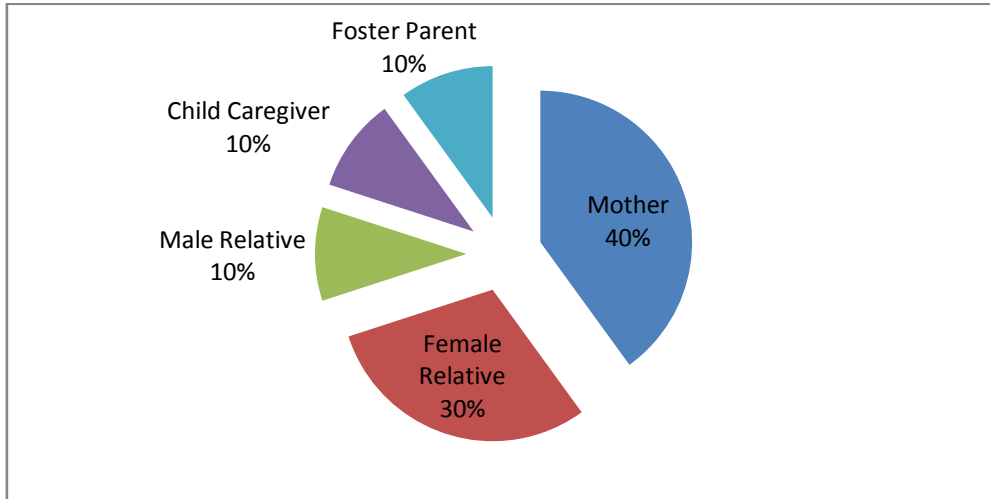


Figure 1: Caregiver's Relationship to Child

Data from the field revealed that 4 (40%) of the participants were the children's biological mothers, 3 (30%) were female relatives, 1 (10%) was male relative, 1 (10%) was child caregiver and 1 (10%) was a foster parent.

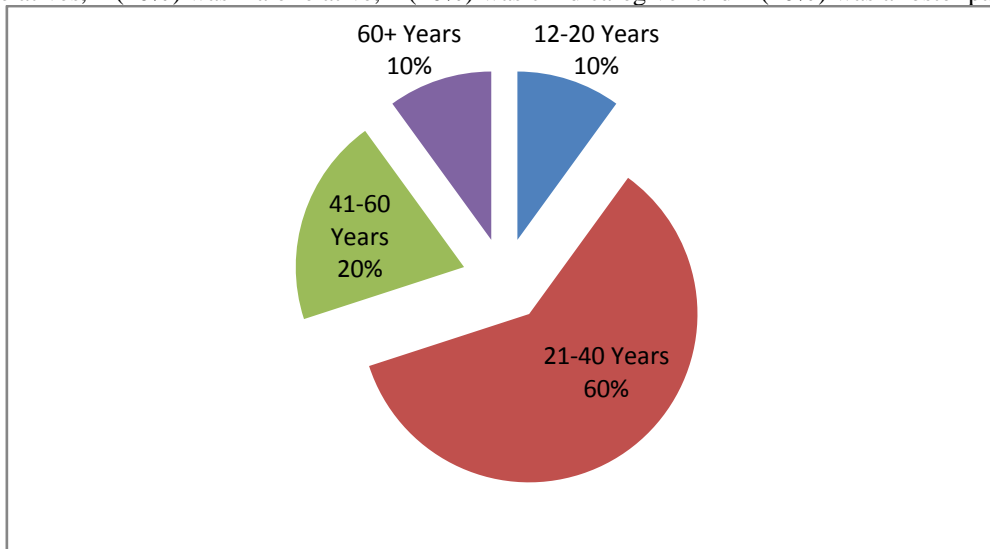


Figure 2: Participants' Age groups

The data collected revealed that 6 (60%) of the participants were aged between 21 and 40 years, 2 (20%) were aged between 41 and 60 years, 1 (10%) was aged above 60 years and 1 (10%) was below 20 years.

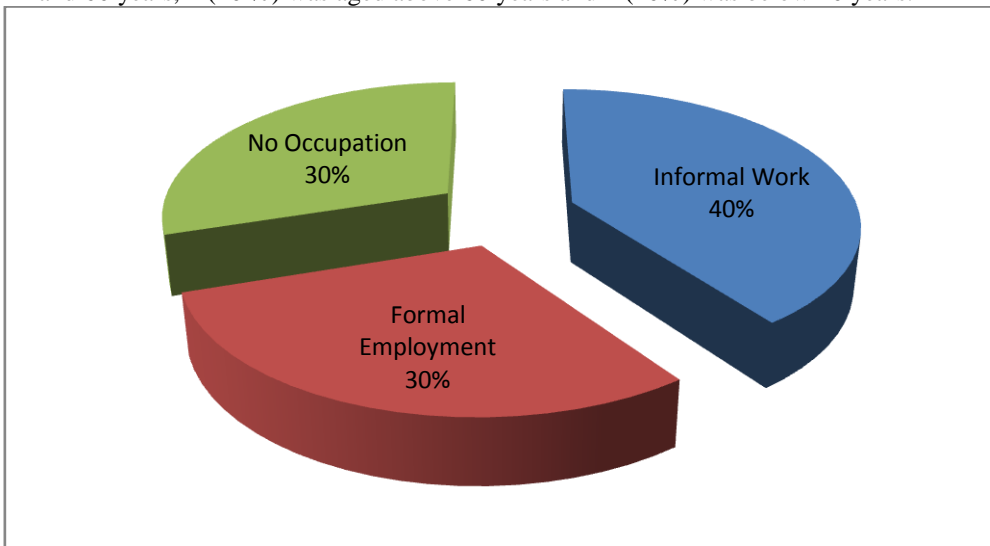


Figure 3: Participants' Occupation

Data from the field show that 4 (40%) of the participants were engaged in informal work, 3 (30%) were in formal employment and 3 (30%) had no occupation. In this research, informal work entails doing one's own income-generating projects in order to earn a living. Formal employment is whereby one works for an organization or under an employer.

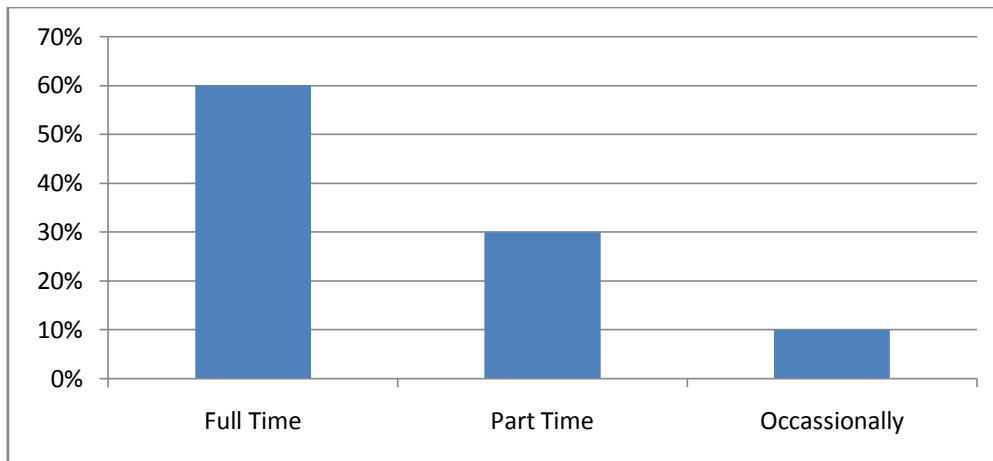


Figure 4: Type of Employment

Data show that 6 (60%) of those caregivers who were in occupation were on a full-time basis, 3 (30%) were on a part-time basis and 1 (10%) was only involved occassionally.

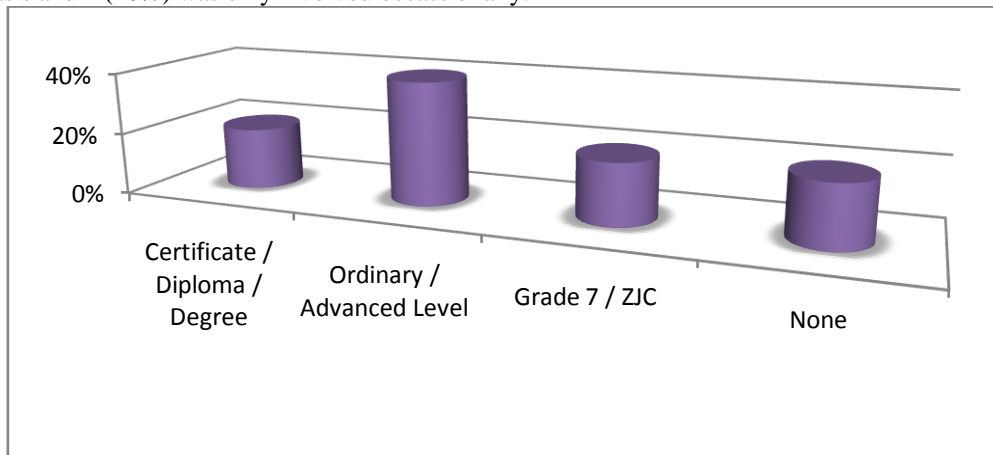


Figure 5: Participants' Level of Education

Four(40%)participants reached Ordinary/Advanced level of education, 2 (20%)had reached Certificate/Diploma/Degree level, 2 (20%) had reached Grade 7/ZJC level and 2 (20%)had never received any formal education.

Nine (90%) of the participants wre closely related to the children. Furthermore, it was noted that the caregivers had known the children for all their lives, as illustrated in the figure below.

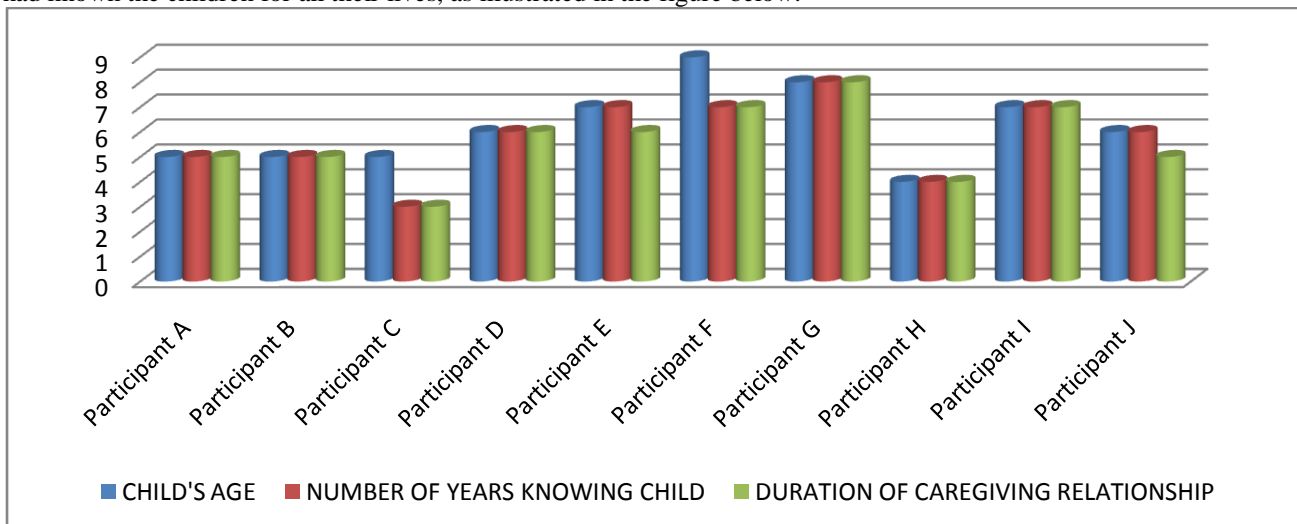


Figure 6: Duration of Caregiving Relationship

The chart above illustrates the duration of caregiving in terms of the child’s age, the number of years that the caregiver had known the child and the duration of the caregiving relationship in respect of each participant.
The table below shows the type of care given to the children.

Table 1: Types of Care given to Children

PARTICIPANT	PHYSICAL UPKEEP	SUPERVISING DRUG INTAKE	HOSPITAL VISITS	PSYCHOSOCIAL SUPPORT	MEETING OTHER NEEDS	MAKING MAJOR DECISIONS
Participant A						
Participant B						
Participant C						
Participant D						
Participant E						
Participant F						
Participant G						
Participant H						
Participant I						
Participant J						

Key: The “type of care” is given
The “type of care” is not given

Data show that all the participants were involved in the supervision of drug intake, hospital visits and providing psychosocial support for the child, 7 (70%) of the participants were involved in the physical upkeep of the child and meeting the child’s other needs and 3 (30%) could make major decisions for the child.

The researchers found the children’s attitudes to the care they are given to be as follows:

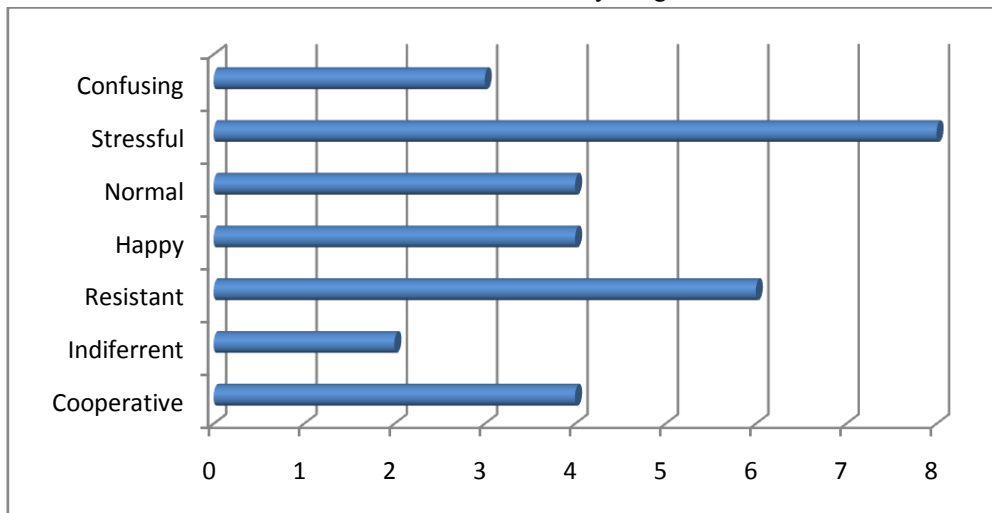


Figure 7: Children’s Attitudes to Care

Eight (80%) of the children found the ART process stressful, 6 (60%) were resistant to drug intake, 4 (40%) were cooperative, normal and happy, 3 (30%) found the whole process confusing and 2 (20%) were indifferent to ART.

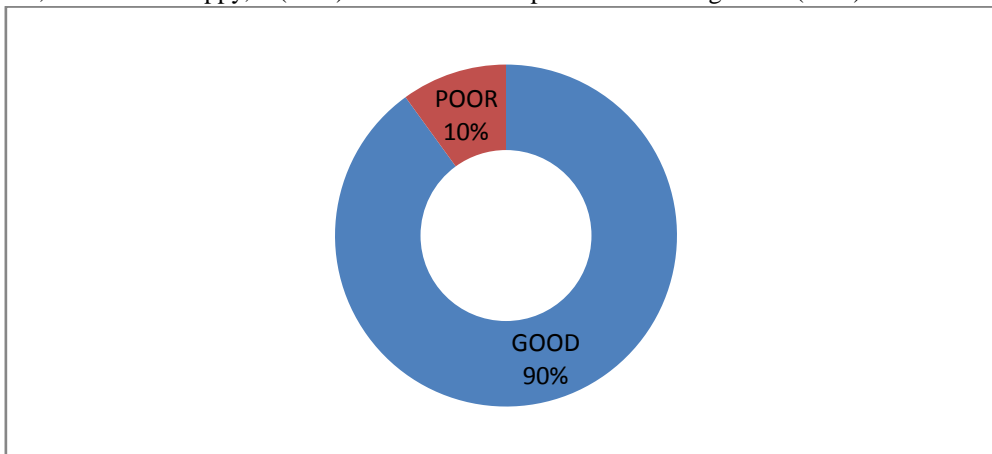


Figure 8: Caregivers’ Knowledge of HIV and AIDS

Data from the field show that 9 (90%) of the participants were knowledgeable about HIV and AIDS and 1 participant had poor knowledge of HIV and AIDS. Good knowledge about HIV and AIDS includes knowing how it is spread, how it can be prevented and how one can live positively after infection.

In summary, the following issues were pointed out as having been stressed on during the counselling sessions:

- the nature of HIV and AIDS;
- how to prevent the spread of HIV and AIDS;
- how to care for a child with HIV and AIDS;
- which drugs the child will be given and how to administer them;
- what to do in the event of defaulting treatment;
- how to act when an opportunistic infection occurs;
- the diet the child should follow; and
- when the next visit is scheduled.

IV. WHAT IS THE CAREGIVER'S LEVEL OF ADHERENCE TO ART?

Data obtained from document analysis revealed that all the participants in the study had, on more than one occasion, defaulted the child's treatment and/or missed review dates.

Seventy percent (70%) of the participants noted that the nurses at the Children's Opportunistic Infections Clinic assess ART adherence through pill counting and asking them to demonstrate dosage and administration of medication at each visit, and those that are doing things wrongly are immediately corrected so as to get back on the right track.

During follow up interviews, the participants noted that ART adherence is important for various reasons as paraphrased below:

- 100% noted that ART adherence makes HIV and AIDS treatment work;
- 80% noted that it prevents the children from getting into full-blown AIDS;
- 70% further postulated that it prevents opportunistic infections; and
- 50% pointed that it enables the children to live normal lives, with normal growth and development.

V. SUMMARY OF RESEARCH FINDINGS

In this study, 70% of the participants were biological mothers and female relatives and they had known the children since birth. Eight (80%) of the participants were aged between 21 and 60 years of age. It was noted that, 70% of the participants were involved in some form of occupation that generated income for them. However, 60% of them are involved on full time basis, which decreases the amount of time they spend with the children.

An 80% literacy rate was recorded amongst the participants. They showed knowledge of HIV and AIDS, its prevention and management. Prior to the initiation of ART, all the participants were trained to care for the children and were given guidelines on nutrition and pill taking. They all demonstrated knowledge of the negative consequences of defaulting ART. However, they were all found to have defaulted treatment and/or missed review dates at least more than once.

It was further noted that all the participants received some form of support from family, friends and/or the community. However, the burden of care still fell hard on the participants.

Financial constraints were the major challenge faced in ART adherence. The participants noted that there is a lack of funds for the child's up-keep, for provision of adequate nutrition and for seeking health services when needed. The problems faced by caregivers which lead them to default treatment and miss review dates were highlighted as living remotely from health care centers, transport costs, contradictory cultural beliefs and stigma.

Discussion

The objectives of the study were to determine the kind of relationship that exists between the caregiver and the child, to establish the caregivers' knowledge of HIV and AIDS conditions, to assess the caregiver's level of adherence to ART, to establish the caregivers' support systems and to find out the problems faced by caregivers during their care-giving roles. In this study, biological mothers and female relatives comprised 70% of the respondents.

In follow up interviews, participants highlighted that the children did not really have fixed attitudes to the care provided. It was noted that at one point a child may be happy and cooperative and at another point, especially when infections are raging, they may be withdrawn. As the children grew older, they became more tolerant to stressful issues.

Considering the extent of the issues emphasized on during the counselling sessions, the researchers noted that the caregivers had been fully equipped to care for the children and to adhere to their treatment regimen. This led the researchers to be more curious as to why the caregivers were then defaulting treatment and missing review dates.

The participants were chosen through purposive sampling because the researchers were curious to know the experiences of the caregivers that led them to default treatment and/or miss review dates. Information from actual experiences could only come from people who had defaulted treatment and missed review dates.

Vreeman (2009) notes that the consequences of interrupting the course of ART are:

- viral rebound;
- acute retroviral syndrome;
- increased risk of HIV transmission;
- decline in CD4 count;
- HIV disease progression;

- development of minor HIV-associated manifestations such as oral sores or thrush;
- Non-AIDS complications like renal, cardiac, hepatic or drug resistance; and the need for chemoprophylaxis against opportunistic infections like diarrhea, skin rashes, meningitis and encephalitis.

Defaulting once is already dangerous, and since records revealed that the participants in the study had defaulted more than once, their level of non-adherence was therefore considered to be high.

Data from the field showed that each of the caregivers received some form of social support from family and friends. However, they all echoed the same sentiments that physical upkeep of the children, supervision and administration of tablets including hospital visits were the most burdensome tasks and are usually left out for the caregivers' sole execution. However, caregivers are at times unable to perform the roles due to other commitments. Worldwide, financial constraints have been found to be a major challenge in ART Adherence (UNENABLE, 2003). Africa, in particular, is characterized by low incomes and high prevalence of diseases (Gureje and Alem, 2000).

In this study, 70% of the participants live in conditions that are below the poverty datum line. The following negative consequences of poverty on ART adherence were noted:

- ARVs need to be taken in conjunction with proper nutrition, without which harmful side effects occur. Therefore, most patients may stop taking the drugs and their illness will relapse and/or worsen.
- People living in poverty are more concerned about other issues such as food and shelter as compared to health issues.

Forty percent (40%) of the participants also pointed out that they live remotely from health-care facilities and these are inaccessible. This supports the World Health Organization statistics that an estimated 30% of the world population lacks regular access to existing drugs and that this figure reaches 50% in the poorest parts of Africa and Asia (Stevens, 2014:06).

The caregivers noted that, due to stigma, some family and community members are unwilling to help out in the child's physical upkeep. Culture also has an impact on how people respond to social issues, such as illness. The participants pointed out that culturally, HIV and AIDS are viewed in spiritual terms, and thus, spiritual remedies are sought. People are therefore resistant to scientific approaches such as medication and counselling. In this study, 50% of the participants hinted at culture as a factor to non-adherence.

Summary

HIV and AIDS are amongst the major public health concerns in the world. This has seen the introduction of Anti-Retroviral drugs in-order to mitigate the effects of the disease. Anti-Retroviral medicines slow the rate at which HIV multiplies in the body and strict adherence to ART is therefore key to sustained HIV suppression and improved overall health. Poor adherence results in drug resistance and quick progression of the virus towards full-blown AIDS. Thus, it is imperative to promote strict adherence. However, many cases of non-adherence to the treatment regimens have been noted especially in developing countries. Africa is a large continent, prone to strife and most of its countries are characterized by low incomes, high prevalence of communicable diseases, malnutrition, low life expectancy and poorly staffed services. As such, adherence to ART takes a lot of effort and requires more funding.

Zimbabwe has scaled up Anti-Retroviral Therapy by ensuring that all those who need it are catered for.

Literature from the field shows that ART adherence is still a major problem in Sub-Saharan Africa. The main factors that have been identified as deterring ART adherence include poverty, stigma and lack of comprehensive support systems.

VI. CONCLUSION

Based on the research findings, it was concluded that ART has been firmly established in Zimbabwe and more people are able to access ARVs free of charge. This includes both adults and children. Before commencing ART, the caregivers of children with HIV and AIDS are taken through extensive counselling and health education so that they are fully equipped to care for the affected child. Several factors highlighted in this study, that hinder child care, need to be addressed.

RECOMMENDATIONS

Based on the research findings and the conclusions drawn thereof, the researchers recommended that:

- Health Education programmes and support group meetings be intensified to ensure that the caregivers' issues are discussed and challenges are addressed timeously and continuously.
- Results of studies done at the Children's OI Clinics be disseminated to stakeholders
- Further Research be conducted focusing on the state of ART adherence in Zimbabwe as a longitudinal study, covering a considerable length of period.

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