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SCHOOL OF MEDICINE

DEPARTMENT OF PUBLIC HEALTH

RESEARCH REPORT

FACTORS AFFECTING ACCESS TO COMPREHENSIVE HIV CARE AMONG HIV POSITIVE CHILDREN (0-15YEARS) IN CHIPATA DISTRICT,EASTERN PROVINCE, ZAMBIA.

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DECLARATION

This dissertation is the original work of **Davie Simwaba.** It has been produced in accordance with the guidelines for Master of Public Health-Generic dissertation for the University of Zambia. It has not been submitted elsewhere for a degree at this or another University.

Signature……

Date…….

CERTIFICATE OF COMPLETION OF DISSERTATION

I, **Simwaba Davie** hereby certify that this dissertation is the product of my own work and, in submitting it for the Degree of Master of Public Health-Generic programme, further attest that it has not been submitted to another University in part or whole for the award of any programme.

Signature……

Date…….

I, **Dr. Selestine Nzala** having supervised and read this dissertation is satisfied that this is the original work of the author under whose name it is being presented.

I confirm that the work has been completed satisfactorily and is ready for presentation to the examiners.

Signature/Supervisor……..

Date……

Head of Department……

Date……

Department……

CERTIFICATE OF APPROVAL

The University of Zambia approves this dissertation of Davie Simwaba in partial fulfillment of the requirements for the award of the degree in Master of Public Health-Generic.

Examiner's signatures Date

1. …….. ……..

2. …….. ……

3. …….. ……...

DEDICATION

This dissertation is dedicated to my children Talusya, Naleli, Mpho, and my wife, Mampho for the continuous support rendered to me during the whole period of the programme. To my parents, family and colleagues for their tolerance, patience and spiritual support in prayers during my studies.

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Lastly, I wish acknowledge the Ministry of Health and Chipata District Medical Office for the financial support and my family for their unconditional love and support.

ABSTRACT

Background

This cross-sectional study described factors affecting access to antiretroviral therapy among HIV-positive children (0-15 years) out of the comprehensive HIV Care program using informal caregivers in Chipata district, Eastern Province of Zambia.

Methods

Data was collected between November, 2013 and March 2014. The study sampled162 respondents aged 18 years and above. These were the caregivers of HIV positive children out of the ART program from 30 Government clinics in Chipata. Data collection was done using a structured close-ended questionnaire. Data collected included among others socio-demographic factors, community factors, interpersonal and personal factors that affect access to comprehensive HIV care and treatment.

Results

The study revealed that N-301 (39%) children living with HIV were reported to be out of ART program and only 771 were on the ART program by 2012. Out of 162 respondents, 125 (77.2%) were aged between 24 and 39 years, 136 (84%) were biological parents with the 145 (89.5%) of respondents being females and 92 (57%) of respondents were married. 91 (56.2%) were from urban area, 98 (60.5%) had attained at least primary education, 87 (53.7%) respondents reported to be on ART program and accessing ART. In terms of level of knowledge score on basic pediatric HIV topic; 115 (71%) of the respondents were knowledgeable. HIV stigma was exhibited by 97 (59.9%) respondents after the stigma score test. Those found to be living more than 5km from ART services were 102(63%). Unadjusted regression model revealed that respondents in rural areas were less likely to have their children access HIV care because of perceived long distance and long waiting time than those in urban areas. OR: 0.26 (CI 95%) P-value < 0.001 and OR: 0.22 (CI 95%) P-value < 0.001 respectively which was significant. Those that perceived the waiting time to be more than 2 weeks before accessing ART were 112(69.3%). In terms of desired ART services for children, 128 (79%) respondents wanted a separate ART clinic for children.

Conclusion

Despite the study revealing that most children had stable family structures, parents of mature prime age group and relative good knowledge on HIV issues, access to ART among HIV positive children still remain a huge public health challenge in Chipata, Eastern province of Zambia. High burden of poverty, stigma among caregivers, long distance and long waiting time were factors which were highlighted as barriers to comprehensive ART care among HIV positive children out of the HIV program in rural areas. Therefore, there is need to urgently come up with strategies using health service structures to improve access such as integration of ART services at clinic level in rural areas.

Key words: Antiretroviral treatment access, HIV positive children out of program, factors.

DEFINITIONS AND KEY WORDS

- **ART Access:** refers to physical access to affordable, non-discriminatory ART care among children, including information about ART services.
- **Children:** defined age group of 0-15 years old**.**
- **Comprehensive HIV care for HIV positive children:** refers to earlier and compulsory initiation of ART in infants and children, attention to nutrition for children on ART, psychosocial support matters, adherence, screening for opportunistic diseases and monitoring of antiretroviral efficacy and toxicity.
- **Caregiver:** defined as unpaid personnel within the family, neighbourhood or community related or unrelated to HIV infected child and is responsible for the child's health needs**.**
- **HIV infected children out of the program:** children not registered in any ART program.
- **Paediatric antiretroviral therapy coverage**: Proportion of children 0-15 years on ART program out of the total adults on ART in the same area.
- **Current on ART:** refers to clients active on ART program who are receiving ARVs as scheduled.
- **Mobile antiretroviral therapy:** ART services at host Health facility with support from a supporting static accredited ART facility through a "Mobile ART Service Unit (MAS)" comprising of human resource, laboratory services and technical assistance.
- **Household food security:** ability to secure, either from production or purchase of food adequate to meet dietary needs of all members to the family to sustain a health and active life**.**

LIST OF ABBREVIATIONS AND ACRONOMY

AIDS	-	Acquired Immune Deficiency Syndrome
ART	-	Anti-Retroviral Therapy
CSO	-	Central Statistical Office
DCMO	-	District Community Medical Officer
DHMT	-	District Health Management Team
DHO	-	District Health Office
DHIO	-	District Health Information Officer
EID	-	Early Infant Diagnosis
GRZ	-	Government of the Republic of Zambia
HIV	-	Human Immune Virus
HMIS	-	Health Management Information System
IEC	-	Information Education Communication
MOH	-	Ministry Of Health
PMTCT	-	Prevention of Mother to Child Transmission
PLWHA	-	People Living with HIV/AIDS
UNAIDS	-	United Nations Program on HIV/AIDS
VCT	-	Voluntary Counseling and Testing
WHO	-	World Health Organisation
ZDHS	-	Zambia Demographic Health Survey

1.0 BACKGROUND

1.1 Epidemiology and history of HIV/AIDS in children

Human Immunodeficiency Virus /Acquired Immune Deficiency Syndrome (HIV/AIDS) continues to be one of the major global health problem with the others being malaria, tuberculosis and non Communicable diseases. The disease was first known to be caused by HIV agent of HIV/AIDS in 1984.The first HIV infected children was observed in the East African region in 1983-1985 periods. In the mid 1980s first longitudinal cohort studies on mother to child transmission (MTCT) and natural history started in the East African region. Factors contributing to high HIV prevalence in children in sub-Saharan Africa was highlighted as; high prevalence of infection in women of childbearing age, low coverage of PMTCT interventions, lack of male partner involvement and stigma.

Globally, an estimated 34 million people were living with HIV globally, including 3.4 million children less than 15 years in 2010. There were 2.7 million new HIV infections in 2010, including 390,000 among children less than 15 years. Ninety percent (90%) of global HIV/AIDS among children occur through mother to child transmission (MTCT) and constitute 14% (290,000) of deaths annually (World Health Organization, 2011).

Zambia faces significant challenges to maternal, infant and young child survival with the neonatal, infant and under five mortality rates at 34, 70 and 119 per 1000 live births for deaths, respectively.HIV remains one of the leading causes of death among under five children together with pneumonia, malaria and diarrhoeal. HIV continues to be a generalized and mature epidemic in Zambia with the HIV prevalence rate of 13% among 15-49 years old (Zambia demographic health survey, 2013-2014) and 16.4% of pregnant women attending antenatal clinic diagnosed with HIV (National antenatal care sentinel survey, 2012).

1.2 Global response to HIV/AIDS

Triggered by the WHO goal "3 by 5" of 2003, the global picture of the number of people receiving ART continues to increase with 6.65 million people getting treatment at the end of 2010, among them 456,000 children representing 23% coverage gap of adults. In 2013, 65% of eligible adults living with HIV had received treatment whilst only 34% of children got it. While HIV treatment, care, and support service give a child with HIV a chance to live a long and

healthy life, most of the 3.4 million children living with HIV did not have access to ART. (UNAIDS, Global report, 2013).In 2011, it was reported that global prevention of mother to child transmission coverage was at 48% and more than 50% of people eligible for treatment did not have access to ART, including many people living with HIV who were unaware of the HIV status. The children had much poorer access to ART than did adults, and attrition at each stage in the cascade of care had highlighted the need to strengthen links with HIV services and with other Health and Community System. (WHO, 2011)

1.3 Impact of HIV/AIDS on Children in Zambia

HIV infection is particularly aggressive in children. The virus multiplies rapidly, destroying their defenses against infections and facilitating the development of pneumonia, TB, diarrhea and other opportunistic infections. AIDS impacts children in many ways by increasing infant and childhood mortality, increasing number of orphaned children, increased deprivations in various forms; mental, psychological, school dropouts, physical and sexual abuse. (Zambia paediatric ART training curriculum, 2010)

WHO guidelines recommend immediate antiretroviral treatment for all children with HIV younger than five. However in Zambia, the guidelines recommend ART for all infants and children younger than two years are commenced on ART (Antiretroviral therapy guidelines for HIV infection in infants and children in Zambia, 2010). Without proper knowledge, care and support from families and communities, many children would die of HIV complications before or after it is diagnosed if access to comprehensive HIV care is not guaranteed through active family and community participation.

In 2007, Zambia had one million one hundred thousand People Living with HIV/AIDS (PLWHA) among which children (0-14 years) living with HIV ranged from 53000 to 250000. Perinatally exposed infants stood at 89,000 per year and 28,000 infants born were born with HIV per year according to Zambia demographic and health survey (ZDHS, 2007). In 2011, the national total clients current or active on ART for both adults and children was 415,685.Children coverage was 30,187 representing 7, 3% of total enrolment (MOH, 2011, unpublished). According to the United Nations General Assembly Special Session (UNGASS) of 2012, about 90% of adults in need of antiretroviral therapy were accessing ART whilst children sadly

represented only 28.1% of those in need of ART on the national program (UNGASS, 2012). This report complimented the WHO report on 22 priority countries which highlighted that Zambia had an estimated 90,000 children eligible for ART with 38% ART coverage among children in 2012 (UNAIDS, 2013). Eastern province had even recorded lower than the national level with 2,299 children on ART representing 6% (HMIS, 2011). Chipata district paediatric ART enrolment also stood at (771 children)7% (HIMS, 2011) of the total 10,511 adult ART enrolments against the district, provincial and national target of 12.5%. (MOH, 2007). There was also evidence suggesting that there was low uptake of pediatric ART services even in areas where the services were available and accessible (MOH, 2009 unpublished).

Chipata with a projected population of 508,361 people in 2015 (Central Statistics Office, 2010) had not been spared from the pandemic as the HIV prevalence rate was 21.6%, the highest in Eastern province (ZDHS, 2013-2014). HIV/AIDS continues to be among top ten causes of HIV related deaths among under 5 years old children in Chipata district (HIMS, 2010-2012). Although Chipata has scaled up antiretroviral therapy(ART) services to include 6 static and 10 mobile ART sites and prevention of mother to child transmission (PMTCT) of HIV services to 48 public health centres, challenges still existed of following up of pregnant mothers, postnatal mothers and their babies to effectively prevent mother to child transmission of HIV. HIV counseling and testing (CT) services were provided in all 48 health facilities. All these services are provided for free of charge in all public health facilities to the clients as per government policy in Zambia.

Even though Government had scaled up free HIV/ART services to health facilities in Chipata district with reasonable financial support from the government and partners, improved health logistical support, sustained information education and communication (IEC) on prevention of HIV/AIDS, training of staff in paediatric ART package, infrastructure development, improved diagnostic through early infant diagnostic (EID) of HIV, availability of palatable antiretroviral therapy for children, recognizable entry points for care and treatment, and predictable referral system; there was a still big challenge in accessing comprehensive HIV care among HIV positive children who remain underrepresented on these lifesaving ART program. In order to achieve universal access, improve quality of life and reduce mortality among HIV positive children, it

was imperative that community related factors affecting access to ART care are studied with special focus on children.

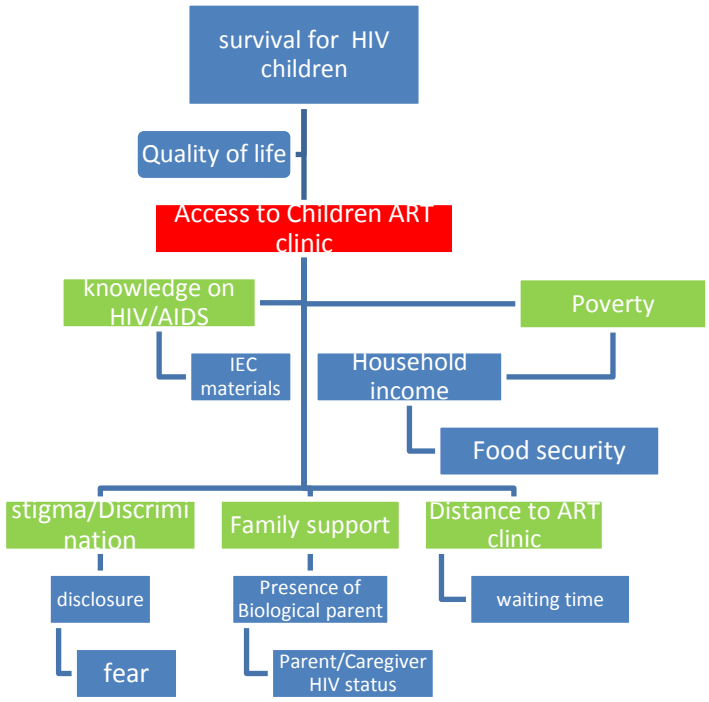
Literature reviewed from previous scholars in the area of access to HIV care among HIV positive children was very limited. The few studies reviewed were mostly qualitative in nature from different geographical, socioeconomic and cultural environments. These included a qualitative study using ethnographic research in São Paulo from 1999 to 2001 on "Experiences of Stigma and access to HAART in Children and Adolescents living with HIV/AIDS in Brazil", (Barrero**,**2005) which highlighted stigma and discriminations as challenges for children accessing HIV care in Brazil. Another qualitative study in South Africa focused on describing barriers and facilitators of uptake of HIV care among children using in-depth interview among caregivers and staff in Gauteng province of South Africa. This study revealed that lack of transport money, food, poor access to welfare grants, lack of access to treatment for opportunist infections, lack of coordination among caregivers, misperception about HIV, maternal guilt and fear of disclosure as important barriers to access HIV care among Children with HIV/ AIDS (Yeap and Hamilton, 2008). A review by Mariana et al., 2009 cited obstacles like lack of information about ART, perceived high cost of ART, stigma, long distance from health centre, lack of coordination across services and less community participation as barriers to access ART in Mozambique among the adult population whilst another study focusing on a qualitative study was conducted in Mozambique to identify motivators and barriers to improve uptake of and retention in HIV prevention, care and treatment services for HIV-exposed and HIV-infected children using in depth interviews and focused group discussions highlighted fear of disclosure, inefficiencies at point of care such as long waiting time and poor patient flow (De Schacht and Lucas, 2014) .

In Zambia, a similar study was conducted focusing on children already in care using a cross section analytical study on HIV infected children seeking care in rural Macha hospital in rural Southern province of Zambia cited long distance, taking long hours to the clinic, insufficient money for transport to the clinic and poor conditions of roads (Van Dijk and Sutcliffe, 2008).
Most of relatively similar studies reviewed have mainly focused on the adults like "Barriers to initiation of antiretroviral treatment in rural and urban areas of Zambia, cross-sectional study of

cost, stigma and perception about ART (Fox and Colleagues, 2010).Moreover, Kunihira et al., 2010 did indicate that research done in the past has neglected the existence of children as a group within society, thereby lacking effective advocacy on issues surrounding HIV care.

From the literature reviewed, it was evident that little has been gathered to review community related factors affecting HIV care in children infected with HIV in a programmatic set up using a problem solving tool in form of a problem tree diagram.

1.4 Problem analysis tree diagram



Problem tree diagram for ART program

Source: Own work

The problem analysis tree diagram was guided by the principle concept of accessibility encompassing four components namely non discrimination, physical accessibility, affordability and access to information (Elizabeth Glazier, 2009). Arising from the problem tree diagram, community related factors like HIV stigma and discrimination, basic knowledge on paediatric HIV/AIDS among caregivers, family support structure, waiting time and distance to ART clinic as key research questions to explore were identified.

Reflecting dominant ideological understandings of children as passive being in need of adult support and guidance, the adults view children as the problem ("the burden") and themselves as

the solution ("the burdened") (Hutchby and Moran-Ellis., 1998; James, 1998). This could entail that children are socially invisible and their identity shall always exists within the context of an adult who is responsible to providing basic needs and securing the child's health. It was from this background that the caregivers were interviewed to gather information.

2.0 RESEARCH FOCUS

2.1 Statement of the problem

HIV/AIDS continues to be among the top ten causes of mortality among children in Chipata district and (ART) antiretroviral therapy uptake among HIV infected children remain low at 6% of the total ART patient enrolments against the set target of 12.5% since 2007 (Chipata District Health Office,2011). Barriers to access antiretroviral therapy and care at program level remain unknown and literature on HIV infected children out of the program is very limited. This study will help accelerate access to ART program, improve quality of life and survival of HIV infected children in Chipata district.

2.2 Study justification

Zambia was a signatory to the millennium development goals (MDGs) to substantially reduce incidence of HIV/AIDS by more than 50% by 2015 and save the people of Zambia from the impact of HIV/AIDs by 2030 according to the vision 2030 for the country. In order to achieve this, Zambia is targeting 100% enrolment of HIV positive children on HIV care and at least 80% of HIV infected children to be enrolled on ART and improving PMTCT program by ensuring 100% protection among mothers and children born to them and ensuring access to quality care for infected clients; among them children. In addition, Zambia was signatory to the convention on the rights of the child, 1989, among them right to health and health care which is critical to preventing AIDS related stigma and discrimination. Therefore, the relevance of this study was to identify practical programmatic interventions for improving access to comprehensive HIV care among families with HIV infected children at public primary health care ART facilities in Chipata district.

2.3 Research question

What are the factors affecting access to comprehensive HIV care among HIV children out of ART program in Chipata district?

2.4 General objective

To describe factors affecting access to HIV care among HIV positive children out of ART program in Chipata district, Eastern Province, Zambia.

2.5 Specific Objectives

2.5.1 To determine level of knowledge among caregivers on basic HIV disease and management for children

2.5.2 To determine the distance to ART clinic and waiting time for enrollment on ART program for HIV infected children

2.5.3 To describe how presence of caregiver / biological parents influence access to ART.

2.5.4 To determine role of stigma and discrimination among caregivers in influencing children access to ART program.

3.0 METHODOLOGY

3.1 Study sites

A quantitative descriptive cross-sectional study was conducted in 30 government owned clinics of Chipata District, Eastern Province, Zambia. Indentified and listed HIV infected children not on ART (out of the ART program) were followed up by research assistants using caregivers or parents' addresses, villages and neighborhood health committee's structures.

3.2 Research Design

A cross-sectional study was applied to caregivers to generate information with a use of a structured close-ended questionnaire by way of a face-face interview. Data in form of counts, proportions, percentages, scores and crude odds ratios were used to describe factors and make inferences.

3.2.1 Inclusion criteria

Inclusion criteria: The study population comprised parents, guardians or caregivers aged 18 years and above of known HIV positive children out of the antiretroviral treatment program within Chipata district.

3.2.2 Exclusion criteria

Exclusion criteria: all parents, guardians or caregivers less than 18 years, caregivers with HIV positive children on the antiretroviral treatment program or on care within the HIV management program at the time of interview in Chipata district.

3.3 Sampling methods and sample size estimation

Identification of HIV positive children was done using the clinics secondary data (2009-2012) from voluntary counseling and testing (VCT) and baby follow up registers. With the assistance of health centre staff knowledge and information from registers, HIV positive children on ART, not known to be on ART and not on ART program were classified. Identification of health centres linking identified HIV positive children not ART program was then done with a purpose of identifying study sites after which, 30 conveniently selected government health centres out of the 48 health centres excluding Hospitals within Chipata district were identified using the volume of cases under study and geographical accessibility during the study (see list in annex). From this data set comprising children of interest, each child was linked to a caregiver and a total of (N-301) caregivers of HIV positive children formed the sampling frame. Lastly, a convenient sample size of (n-162) was randomly selected from the sampling frame (N-301) because the prevalence of HIV among children less than 15 years was unknown and so was the proportion of HIV positive children less than 15 years in and out of the ART program.

3.4 Data collection, entry and analysis

Data was collected by health centre staff through face to face interview using a close ended structured questionnaire. Thirty (30) health centre staff and community based volunteers from 30 health centres within Chipata were oriented to administer the questionnaire. Participants were offered verbal meeting schedules before the meeting in the health facility or their home. English and local languages were used during the interview. The study period was from November, 2013 to March, 2014.

Prior to administering the questionnaire, testing of the research questionnaire was done to five participants purposively selected at the ART site in Nyimba District.

3.5 Plan for data processing and analysis

Data was collected using a questionnaire and post coded thereafter; variables were entered manually in SPSS version 20. Descriptive statistics such as count, range, percentage, proportions, scores for level stigma/discrimination and level of knowledge variables, frequency tables, bar graphs and pie chart were used to describe collected information. Logistic regression model (crude odds ratios) was used for sub analysis to compare rural and urban respondents against distance and time taken to reach ART clinic variables.

3.6 Ethical Issues

Clearance was sought from the University of Zambia Biomedical Research Ethics Committee (Ref. No. 009-04-13) and permission was sought from MoH. Written informed consent was obtained from each respondent before participating in the research. No adverse psychological distress was observed during the interviews. All respondents were linked to ART sites by way of education and counseling on the need to seek care after the interviews.

4.0 RESULTS

4.1 Descriptive statistics

Table 4.1.1 Demographics of Respondents/participants

Demographics of Respondents/participants (N=162)

	n	%
Residence		
Rural	91	56.2
Urban	71	43.8
Gender		
Male	17	10.5
Female	145	89.5
Age		
18 ≤ 24	19	11.7
24 – 29	45	27.8
30 – 39	61	37.7
40 – 49	25	15.4
≥ 50	12	7.4
Marital status		
Single	21	13.0
Married	92	57.0
Divorced	14	8.6
Separated	16	9.9
Widowed	19	11.7
Tribe		
Ngoni	84	51.9
Chewa	53	32.7
Nsenga	13	8.0
Tumbuka	7	4.3
Others	5	3.1
Education		
None	28	17.3
Primary	98	60.5
Secondary	33	20.4
Tertiary	3	1.9
Income		
Less than K400	104	65.4
≥ K400	55	34.6

Table 4.1.1 describes the demographic characteristics of the respondents whose HIV positive children out of HIV/ART care. Majority of respondents were of reproductive age, females, married and of low income group.

Table 4.1.2 Respondent relationship and Knowledge on ART services

Respondent relationship and Knowledge on ART services (N=162)

	n	%
Relationship of caregiver with child		
Parent(s)	136	84.0
Other relative	26	16.0
Caregiver knows where to take child for HIV test		
Yes	121	74.7
No	41	25.3
Caregiver knows that child can take ARVs to prolong their lives		
Yes	140	86.4
No	22	13.6
Caregiver knows where the ART clinic for children is		
Yes	114	70.4
No	48	29.6
Caregiver knows that ART services are free of charge		
Yes	128	79.0
No	34	21.0

Table 4.1.2 describes proportions of respondents' relationship with HIV children out of the ART program and knowledge about the ART services available.84% respondents were either mother or father and knew the benefit of ART which were offered free of charge at ART clinic.

Table 4.1.3 Respondent Knowledge and Stigma score level

Respondent Knowledge and Stigma score level (N=162)

	n	%
HIV Knowledge level score (Total score = 6)		
Knowledgeable(4 or more)	115	71.0
Not Knowledgeable(3 or less)	47	29.0
HIV Stigma level score (Total score= 11)		
Has HIV stigma(6 or more)	97	59.9
Has no HIV Stigma(5 or less)	65	40.1

Table 4.1.3 showing high level of HIV stigma despite high level of knowledge among caregivers on the HIV topic in children and the benefit of accessing ART care.

Table 4.1.4 Respondents responses on IEC availability in the community

Respondents responses on IEC availability in the community (N=162)

	n	%
Availability of IEC on HIV in children		
Yes (enough)	69	29.0
No (Not enough)	93	71.0
Preferred medium of communication		
Radio	79	49.0
Inter & intrapersonal	82	50.0
TV/others	1	1.0

Table 4.1.4 showing little availability of information, education and communication among the respondents regarding HIV in children in the community.

Chart 1.0: Pie chart on proportion of respondents reporting being on ART program.

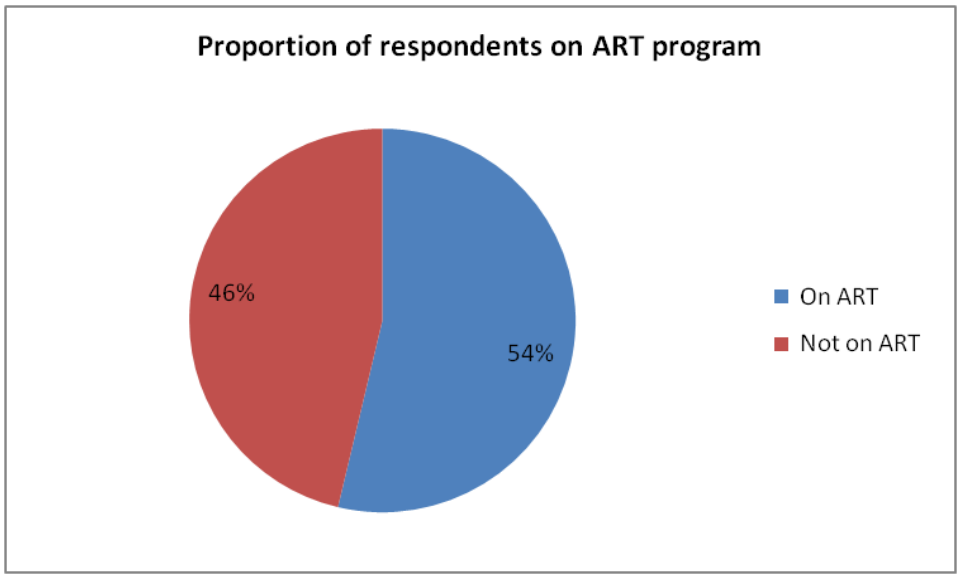


Chart 1.0 depicting proportions of caregivers of HIV children reported accessing ART services as reported by respondents.54% of caregivers reported to be on ART program in Chipata district.

Chart 2.0: Bar graph on respondents desired ART clinic setting

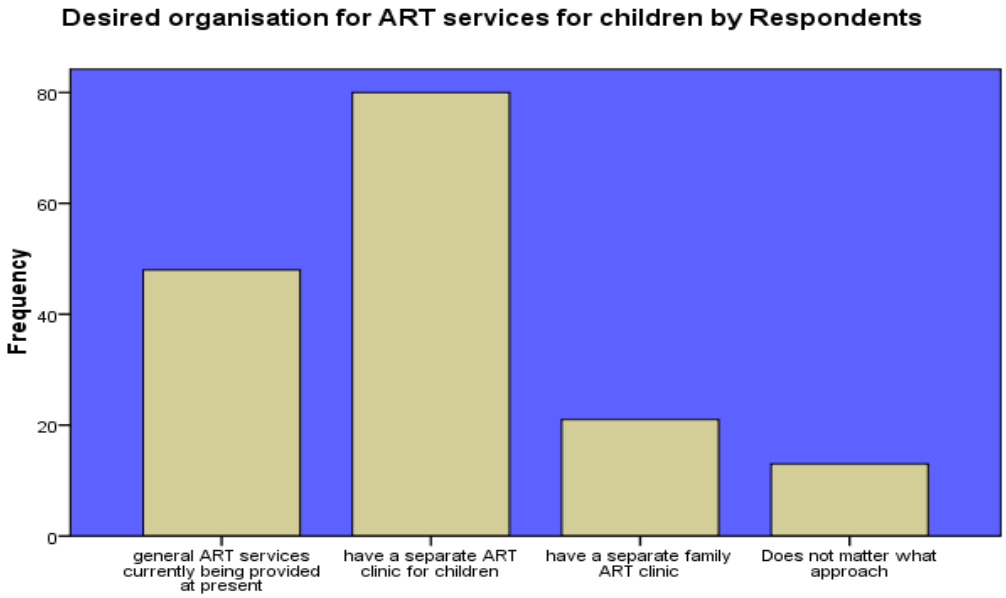


Chart 2.0 shows that the majority of caregivers desired a separate ART clinic for children.

Table 4.1.5 Perceived Distance and Waiting time

Perceived Distance and Waiting time (n=162)

	n	%
Distance to nearest ART clinic		
< 5km	60	37.0
5 – 27 km	87	53.7
>27	15	9.3
Perceived waiting time at ART clinic		
<2 weeks	50	31.3
2 – 4 weeks	48	30.0
4 – 6 weeks	47	29.4
6 – 8 weeks	11	6.9
>8 weeks	4	2.5

Table 4.1.5 depicts perceived distance taken to ART clinic and long waiting time as reported by respondents. Only 37% of caregivers perceived the distance to be within acceptable range of 5km radius whilst 31.3% perceived waiting time to be within acceptable range of less than 2 weeks before commencement of ART by children.

Chart 3.0: Comparison of Urban & Rural respondents on waiting time to enrolment on ART program.

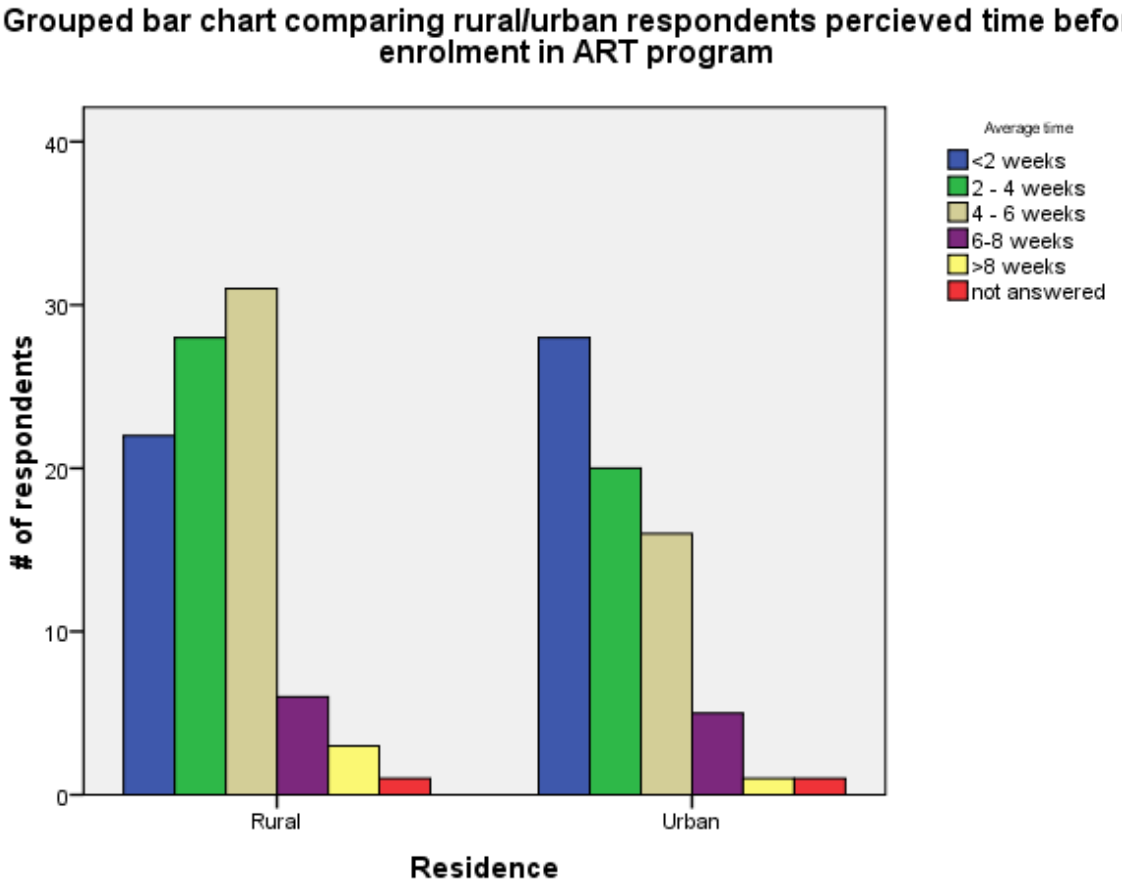


Chart 3.0 shows that generally rural respondents waited for longer time before they could access ART than their urban counterparts with the majority of caregivers in rural areas reporting the waiting time to be 4-6 weeks with the majority in urban areas reporting acceptable waiting time of 2 weeks or less.

4.2 logistic regression (univariate analysis)

Chart 4.2.1: Perceived distance taken to reach ART clinic in rural/urban communities

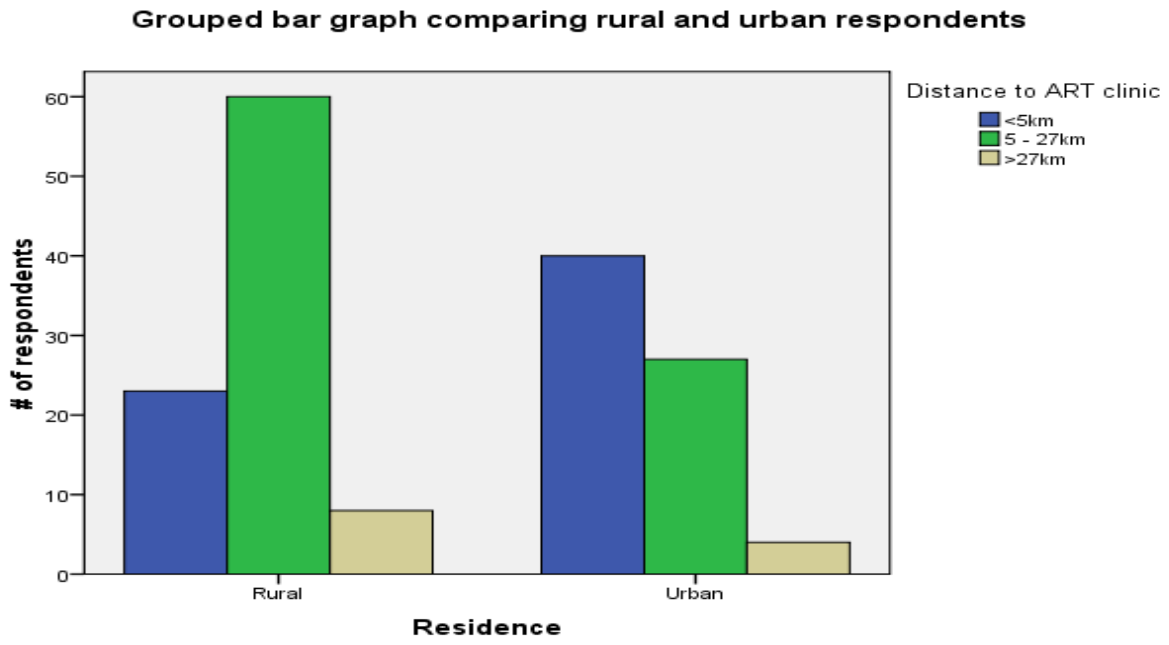


Chart 4.2.1 showing that rural respondents lived far from the ART clinic than urban respondents.

Table 4.2.2 univariate analysis of residence by distance

Variable	Distance (Km)	Distance (Km)	Total	Odds ratio	Chi Square	P-value
Residence	≤ 5km	≥ 5km				
Rural	23	68	91	0.26	16.365	<0.001
Urban	40	31	71			
Total	63	99	162			

Table 4.2.2 depicts logistic regression model of residence (dependant variable) and distance (independent variable) revealed that respondents in rural areas were less likely to have their children access HIV/ART care because of long distance than respondents in urban areas. (OR=0.26, CI 95%, 0.046-0.189) P- Value < 0.001 which was significant using chi square test.

Chart 5.0 Perceived time taken to ART clinic by caregivers

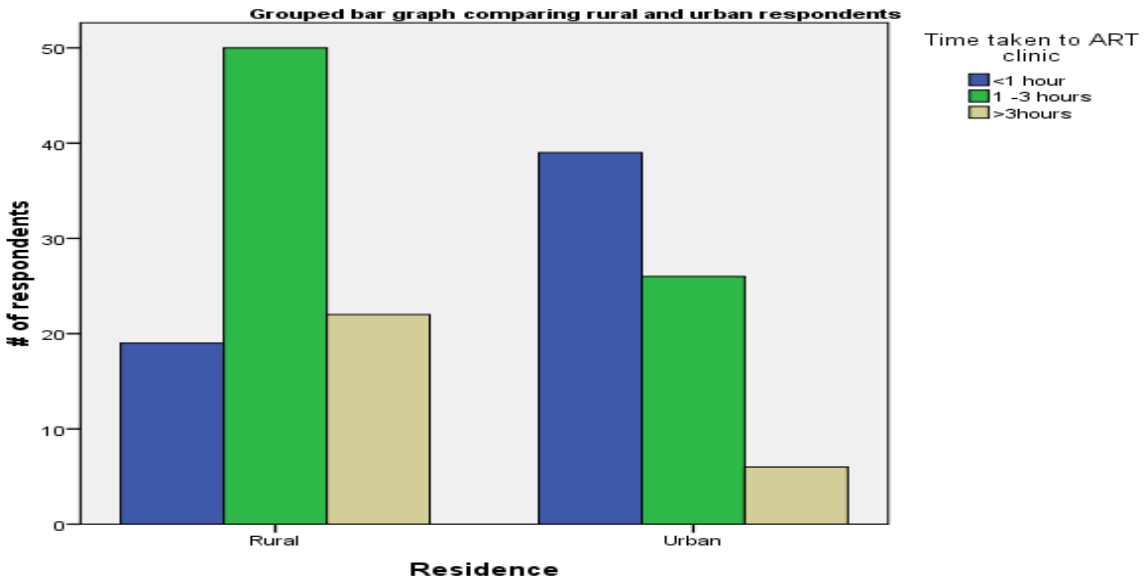


Chart 5.0 majority of rural respondents perceived long hours travelling to the ART clinic than urban respondents. This finding compliments charts 3.0 and 4.0 depicting rural respondents perceiving challenges to access ART.

Table 4.2.2 univariate analysis of residence by time taken to reach ART clinic

Variable	Time taken to ART clinic(hr)	Time taken to ART clinic(hr)	Total	Odds ratio	Chi Square	P- value
Residence	≤ 1 hour	≥ 1 hour				
Rural	19	72	91	0.22	21.477	<0.001
Urban	39	32	71			
Total	58	104	162			

Table 4.2.2 depicts logistic regression model of residence (dependant variable) and perceived waiting time (independent variable) revealed that respondents in rural areas were less likely to have their children access HIV/ART care because of perceived long waiting time than respondents in urban areas. (OR=0.22, CI 95%, P-value <0.001) which was significant using chi square test.

5.0 DISCUSSIONS

Factors affecting access to ART program still remain a huge public health challenge among families with HIV children not on the ART program in Chipata district. The study's preliminary finding revealed that during the year 2012, 301 known HIV positive children representing 39% of the total 771 children on ART program were not on HIV care and management program. This situation only represented children from the 30 health facilities of the 48 health facilities which may depict even bigger challenge children have to access ART in Chipata district.

Of 162 respondents, 125 (77.2%) were aged between 24 and 39 years, 136 (84%) were biological parents with the 145 (89.5%) of respondents being females and 92 (57%) of respondents were married. 91 (56.2%) were from urban area, 98 (60.5%) had attained at least primary education, 87 (53.7%) respondents reported to be on ART program and accessing ART (Table 4.1.1). In terms of level of knowledge score on basic pediatric HIV topic; 115 (71%) of the respondents were knowledgeable (Table 4.1.2). HIV stigma was exhibited by 97 (59.9%) respondents after the stigma score test (Table 4.1.3). Those found to be living more than 5km from ART services were 102(63%). Unadjusted regression model revealed that respondents in rural areas were less likely to have their children access HIV care because of perceived long distance and long waiting time than those in urban areas.OR:0.26 (CI 95%) P value < 0.001 and OR: 0.22 (CI 95%) P-value < 0.001 respectively which was significant. Those that perceived the waiting time to be more than 2 weeks before accessing ART were 112 (69.3%). In terms of desired ART services for children, 128 (79%) respondents wanted a separate ART clinic for children (Table 4.1.5).

A Family being a basic unit of health care support structure for any health system and children directly depended on adults within the family to access care and other necessities for their survival. 57% of respondents reported to be in married families and 84% were biological (mother or father) parents living with HIV infected children. These families had high levels of poverty manifested by low income levels at 65.4%, inadequate household assets and low levels of education (Table 4.1.2). Fifty four percent (54%) of respondents reported to be on receiving ART treatment which was relatively surprising result and reasons were not investigated which

limitation was arising from questionnaire design (Chart 1.0). This background is further compounded by high level of stigma which may negatively affect access to HIV care among children (table 4.1.3). Stigma and discrimination had even manifested itself in families with presence of stable family or biological parents among who could be already on ART program. This was despite many respondents showing high level of knowledge (71%) on topics surrounding HIV in children and knowing where to access HIV care and support. This phenomenon agrees well with the recent findings of population knowledge on HIV topic which is relatively high (ZDHS 2013-2014) but access to HIV services remained low. It was envisaged that with high knowledge, access to ART services would improve which may further reduce stigma among families living with HIV infected children. This finding compliments other studies done in Brazil by Barrero et al., 2005 (Experiences of stigma and access to HAART in children and adolescents living with HIV/AIDS in Brazil) which clearly indicated the stigma as barrier to ART services among HIV children. It should be recommended that other background demographic characteristics be incorporated in future analytical studies to ascertain the effect of confounding factors.

Even though Chipata District Community Medical Office had improved physical access to free HIV/ART care among the community through the established (16) sixteen static and mobile ART sites, many respondents highlighted long walking distance in accessing ART as only 73% respondents reported to be living above acceptable radius distance of 5km from ART clinic sites, with the majority taking more than (1) one hour to reach the ART clinic and perceived the waiting time to be longer than (2) two weeks before accessing ART/HIV care. Rural communities were less likely to access ART than urban communities. This finding agrees with the study in Macha, Southern Province of Zambia done by Van et al., 2009 (Barriers to the care of HIV-infected children in rural Zambia: a cross-sectional analysis) although it focused on HIV children already in care. This situation in Chipata could be attributed to non availability of information about the services being provided, the vastness of the area with sparsely populations, inadequate infrastructure, erratic and few static ART services as most of the rural communities are served via the mobile ART operated every two weeks per zone as opposed to daily ART static services. This quantitative study compliments knowledge generated from previous qualitative studies which highlighted stigma and discrimination among children living with HIV/AIDS in Brazil (Barrero, 2005) and Mozambique (Mariana, 2009) whilst long distance to

ART clinic were also cited in Macha, Zambia among children already accessing ART Zambia and South Africa (Yeap and Hamilton, 2008) as previously reviewed in the literature.

Even though this research has highlighted various challenges which may have a role in influencing access to HIV care among HIV infected children, this research design had limitations arising from the research design which was a descriptive cross sectional study focusing only on HIV children out of the ART program without any comparison group. The close- ended structured questionnaire also restrictive by design.

6.0 CONCLUSION AND RECOMMENDATION

5.1 Conclusion

Despite the study revealing that most children had stable family structures, parents of mature prime age group and relative good knowledge on HIV issues, access to ART among HIV positive children still remain a huge public health challenge in Chipata, Eastern province of Zambia. Therefore there is need to urgently come up with new strategies using health service structures to improve access, such as integrating ART services at clinic level in rural areas where there was notably low volumes of HIV positive children with little or no access to ART care. High burden of poverty manifested by low income levels, low educational level and HIV stigma among caregivers, long distance to ART clinic and long waiting time before enrolment on ART were other major factors highlighted as barriers to comprehensive ART care among HIV positive children out of the ART program in rural areas. Presence of families or biological parents and knowledge levels seemed not be among keys factors affecting access to HIV/ART care among HIV infected children out of the program.

5.2 Recommendations

Access to ART services among children with HIV still remain a challenging and complex phenomena.

1. We suggest further improvement of physical access to HIV/ART services to shorten the distance taken to ART sites by poor communities especially in the rural areas such as integrating ART services in the primary health care package at clinic level especially in rural areas of Chipata district.

2. We also suggest smart planning and coordination of mobile ART clinics to reduce on waiting time as reflected by needs of the clients but feasible within a local setting. Setting up separate static children ART clinic for urban population would also help as suggested from the respondents in the study.
3. We lobby for demand creation and advocacy on HIV care among children from stakeholders in protecting the rights of children to health care since they depend on parents and/or guardians noting high stigma which is prevalent event in families of parents/guardians with HIV.
4. We also suggest introducing a monitoring and evaluation mechanisms to follow up HIV children out of ART program to bridge the gap towards real universal access and such as estimations of the burden of HIV in children at population level through HIV prevalence survey for children below 15 years.
5. Lastly, we recommend that this baseline information be harnessed to undertake further analytical or intervention studies which may generate further important information to improve access to HIV care among HIV infected children , reduce mortality and improve the quality of life.

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Annexes

TITLE: FACTORS AFFECTING ACCESS TO COMPREHENSIVE HIV CARE AMONG HIV POSITIVE CHILDREN (0-15YEARS) IN CHIPATA DISTRICT, EASTERN PROVINCE, ZAMBIA

Questionnaire

Questionnaire number ☐☐☐☐☐

Date ☐☐☐☐☐☐☐☐ **YYYY/MM/DD)**

Residence:

Rural ☐ urban ☐

Participant No. ☐☐☐☐☐☐☐☐

Gender of caregiver

Female ☐ Male ☐

Age (in years) of caregiver

18-24 ☐
24-29 ☐
30-39 ☐
40-49 ☐
50-59 ☐
>60 ☐

Marital status of caregiver:

Single ☐ Married ☐ Divorced ☐ Separated ☐ Widow/Widower ☐

Relation of caregiver with the Child

Mother ☐ Father ☐ grandparent ☐ sibling ☐ Auntie/Uncle ☐

Is participant on ART program?

Yes ☐ No ☐

1. Does the participant have Children (0-15 years)?

Yes ☐ No ☐

If yes, how many children under 5 (<5) live in your house?

☐☐

How many children (5-15 years) live in your house?

☐☐

Are the children in school?

Yes ☐ No ☐

2. What is your Tribe?

Ngoni ☐ Chewa ☐ Nsenga ☐ Tumbuka ☐ Others ☐ Non-Zambian ☐

4. Education level of caregiver:

4.1 What is your level of education?

None ☐ Primary ☐ Secondary ☐ Tertiary ☐

5. Occupation of caregiver:

What do you do for a living?

Self-Employed ☐ NGOs/Private Employment ☐ Government/Security Employment ☐ Unemployed ☐ ☐

6. Social Habits of caregiver:

None ☐ Alcohol ☐ Smoking ☐ Alcohol & Smoking ☐

7. Level of Household income

< K400 ☐ K400 -2,000 ☐ K2, 000 -K4, 000 ☐ >K4000 ☐

8. Ownership of personal property (Proxy for wealth):

Radio ☐ Cell phone ☐ Bicycle ☐ Television ☐ Electric Stove ☐ Fridge ☐

9. Water and Sanitation

9.1 Water source

Individual Pipe Water ☐ Community piped water ☐ Community Borehole ☐ Shallow wells ☐

9.2 Type of Toilet

Flush Toilet ☐ Pit Latrine ☐ Bush ☐

10. Food security

10.1 Did your child have a meal last night?

Yes ☐ No ☐

10.2 Did your Child ever miss any meal last week?

Yes ☐ No ☐

10.3 Do you find food on the local market unaffordable for your family?

Yes ☐ No ☐

10.4 How often do you have nshima or starch/Vegetables/Meat or Kapenta /other protein/Fruits?

Never ☐ At least once per week ☐ Once per month ☐

11. Level of Knowledge of caregiver and perception about Health Care.

11.1 Where do you go when your child is ill?

Herbalist/Spiritual ☐ Government/Mission Health centre ☐ Private Health Centre ☐ Self-Treatment ☐

11.2. Do you know where you can have a Test for HIV?

Yes ☐ No ☐

11.3 Do you know that pregnant women are offered HIV test in ANC clinic?

Yes ☐ No ☐

11.4 How early can HIV test be done on children in Zambia?

At birth ☐
At 6 week ☐

At 6-9 months ☐

At 18 months & > ☐
I don't know ☐

11.5. Do you know that unborn children/breast feeding children can contract HIV from mothers with HIV/AIDS?

Yes ☐ No ☐

11.6 What are the other common ways children could get infected with HIV?

Sexual abuse of children ☐

Through injection with unclean needles ☐

Receiving contaminated blood ☐

Playing with an HIV infected child ☐

Through witchcraft in the community ☐

11.7. How can you tell if the children born to infected mother/parents have HIV?

It's difficult to tell ☐ By testing for HIV at appropriate age ☐ When they become ill on repeated times ☐ When admitted to hospital and diagnosed by a Doctor or Nurse ☐

11.8. Have you ever heard of where children can test for HIV?

Yes ☐ No ☐

If Yes where?

GRZ/Mission Health ☐ Private Clinic ☐ Community Outreach Services ☐ Hospital ☐

11.9 Could you be willing to have your child tested?

Yes ☐ No ☐

11.9.1 Could you be willing to have HIV test together with your child?

Yes ☐ No ☐

11.9.2 Who would make the decision to have your child tested?

Father ☐ Mother ☐ Guardian ☐ Both Father & Mother ☐

11.9.3 Do you know that like adults children can also take ARVs to prolong their lives and live a normal life?

Yes ☐ No ☐

11.9.4 .Do you know where the ART clinic for children is?

Yes ☐ No ☐

11.9.5 Do you feel ART services are enough for children?

Yes ☐ No ☐

11.9.6 Do you know that children can access ART services for free?

Yes ☐ No ☐

11.9.7 What health service provision could be ideal for providing ART services for children?

General ART services currently being provided at present ☐
Have a separate ART clinic for children ☐
Have a separate Family ART clinic ☐
Does not matter what approach ☐

12. Waiting time/Distance

12.1. How long is the nearest ART site/Clinic from your home?

<5 km ☐ 5 – 27km ☐ >27km ☐

12.2. How long can it you take to reach the ART clinic with your child?

<1 hour ☐ Between 1 to 3 hours ☐ >3 hours ☐

12.3. How long do you believe should be appropriate for a child to be attended to by health workers at ART clinic?

< 2 Weeks ☐ 2– 4 weeks ☐ 4– 6 weeks ☐ 6– 8 weeks ☐ > 8 weeks ☐

12.4. At what stage/area do you believe children delay in the ART clinic?

At Registration ☐ At Clinical Evaluation ☐ Waiting for Laboratory results/Complimentary results (like x-ray) ☐ Waiting to start ARVs/ Adherence Counseling ☐

At dispensing ARVs ☐ The whole process is quick/fast and efficient ☐ The whole process delays/takes a lot of time and inconveniencing. ☐

12.5. How do rate the services being offered to your child in this ART clinic?

Excellent 10-9 Very Good 7-9 Good 5-7 Fair 3-5 Poor <3

13. Stigma and Discrimination

13.1. How do you feel when you bring your child to the ART clinic?

Nothing ☐ Grateful that my child will receive care ☐ Fear that the child will be poisoned by ARVs ☐ Fear of your child being rejected by friends ☐

13.2. What is your biggest fear about your child's status?

Fear that the child will know about his/her HIV status ☐ Terrified that people will know your child's HIV status ☐

Fear of your child being rejected by friends ☐ Fear that your child will not access school ☐

Fear that your child will not look normal compared to other children ☐ Fear of your child dying soon despite being on ART care ☐

Nothing/No fear at all ☐

13.3. Would you reveal your HIV status to your child?

Yes ☐ No ☐

13.4. Would you reveal the HIV status to your Child to another caregiver?

Yes ☐ No ☐ Maybe ☐ Never ☐

13.5. If yes? At what age do you think would be ideal?

<3 Yrs ☐ 3-5 Yrs ☐ 5-10 Yrs ☐ Above 10 Yrs ☐

IEC

13.6. Do you think there are enough publicity/messages on Pediatric HIV and care in the community?

Yes ☐ No ☐

13.7 If yes which one?

Radio ☐ Television ☐

From Health talk from Health worker & Partners ☐ Drama/Meeting ☐

Posters ☐ Leaflets/Brochures ☐

Family/Friends ☐

13.8. What is the ideal form of message dissemination on issues of HIV/AIDS concerning children? ☐ ☐

Radio Television

From Health talk from Health worker & Partners ☐ Drama/Meeting ☐

Posters ☐ Leaflets/Brochures ☐

Family/Friends ☐

Consent form

Informed Consent Form

Cross Sectional Research Subject: Read this consent form carefully and ask as many questions as you like before you decide whether you want to participate in this research study or not. You are free to ask questions at any time before, during, or after your participation in this research.

Project Information

Project Title: Factors affecting access to ART Care among HIV positive children (0-15years) in Chipata District, Eastern Province of Zambia.	Project Number:009-04-13
Principal Investigator: Dr. Simwaba Davie	Organization: University of Zambia
Supervisors: Prof. Baboo Co-Supervisor: Dr Nzala Selestine	Phone:0977414826/0978774068/0962916221
Location: Chipata District	Location: Chipata District
Province/Country: Eastern Province, Zambia	Phone:+260 0216 221298

1. You are being asked to participate in a research study designed to find out challenges children infected with HIV/AIDS find in accessing ART care at our clinics within Chipata District. Few children unlike adults are accessing these health restoring and life prolonging Drugs leading to early deaths among HIV infected Children.

2. You will be asked a series of questions using a guided questionnaire and the interview will take 20 minutes of your time. Information provided will be solely used for the research purposes; i.e. improving ART services among children in Chipata and Zambia in General.

3. Some questions maybe be sensitive for you and you are free to stop and withdraw if you so wish. The project will provide you with assistants from our Counselors within the facility.

4. There will be no financial benefits. However, snacks and drinks will be provided to you for the time spent during the interview.

5. Your identity in this study will be treated as confidential. The results may be published for scientific purposes but will not give your name or include any identifiable references to you

AVAILABLE SOURCES OF INFORMATION

Any further questions you have about this study will be answered by the Principal Investigator:

Name:Dr.SimwabaDavie

Phone Number: 0977414826

AUTHORIZATION

I have read and understand this consent form, and I volunteer to participate in this research study. I voluntarily choose to participate.

Participant Name ……..……..

Date ……..

Signature……..

Research Assistance ……..

Date…….

Signature…….

List of Government health facilities in the study

1. Mchini health centre	16. Kwenje health centre
2. Namseche health centre	17. Kasenengwa health centre
3. Kapata health centre	18. Kamlaza health centre
4. Gondar health centre	19. Chiwoko health centre
5. Chinyaku health centre	20. Vizenge health centre
6. Chikando health centre	21. Rukuzye health centre
7. Champhande health centre	22. Chiparamba health centre
8. Chipangali health centre	23. Muzeyi health centre
9. Kapara health centre	24. Lunkhwakwa health centre
10. Mnoro health centre	25. Mwami hahc health centre
11. Munukwa health centre	26. Jerusalem health centre
12. Chinunda health centre	27. Kayeka health centre
13. Chipungo health centre	28. Chizenje health centre
14. Madzimawe health centre	29. Mafuta health centre
15. Madzimoyo health centre	30. Mkanda health centre

1

THE UNIVERSITY OF ZAMBIA

BIOMEDICAL RESEARCH ETHICS COMMITTEE

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IRB00001131 of IORG0000774

Ridgeway Campus
P.O. Box 50110
Lusaka, Zambia

6th September 2013

Your Ref: 009-04-13

Dr. Davie Simwaba
Chipata District Community Health Office,
P.O.Box 511025,
Chipata.

Dear Dr. Davie Simwaba,

RE: RE-SUBMITTED RESEARCH PROPOSAL: **"ACCESS TO COMPREHENSIVE HIV CARE AMONG CHILDREN (0-15 YEARS) IN CHIPATA DISTRICT, EASTERN PROVINCE, ZAMBIA. A DISCRIPTIVE CROSS SECTIONAL STUDY". (REF: 009-04-13)**

The above mentioned research proposal was re-submitted to the Biomedical Research Ethics Committee with recommended changes on 17th May 2013. The proposal is approved.

CONDITIONS:

- This approval is based strictly on your submitted proposal. Should there be need for you to modify or change the study design or methodology; you will need to seek clearance from the Research Ethics Committee.
- If you have need for further clarification please consult this office. Please note that it is mandatory that you submit a detailed progress report of your study to this Committee every six months and a final copy of your report at the end of the study.
- Any serious adverse events must be reported at once to this Committee.
- Please note that when your approval expires you may need to request for renewal. The request should be accompanied by a Progress Report (Progress Report Forms can be obtained from the Secretariat).
- **Ensure that a final copy of the results is submitted to this Committee.**

Yours sincerely,

Dr. J.C Munthali
CHAIRPERSON

Date of approval: 6th September 2013 Date of expiry: 5th September 2014

Telephone: 021-62 221298

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in Reply Please Quote

CPDHO/53/9/2

REPUBLIC OF ZAMBIA
MINISTRY OF HEALTH
DISTRICT COMMUNITY MEDICAL HEALTH OFFICE
EASTERN PROVINCE
P.O. BOX 511205
CHIPATA

6th February, 2013
Dr. Davie Simwaba
School of Medicine
Department of Community Medicine
University of Zambia.
Lusaka.

Re: Permission to conduct Research in the Chipata District-Yourself / MPH student.

I wish to acknowledge receipt of your request made to my office concerning the above mentioned subject.
Be informed that the permission to conduct research on "Access to comprehensive HIV care among HIV positive children (0-15 years) in Chipata District, Zambia.A descriptive cross sectional study" has been granted. You are advised to seek further clearance with Biomedical Research Ethical Committee and also strongly advised to update my office during and after on your research progress. The study sites have been informed accordingly for maximum support.
I wish you well. By copy, the Provincial Permanent Secretary, Chairperson - UNZA BREC and Provincial Medical Officer have been informed.

Yours faithfully,

Mr. Owen Zimba.
For/DISTRICT MEDICAL OFFICER

Cc: Provincial Medical Officer
Cc: Permanent Secretary-Eastern Province
Cc: Chairperson - UNZA BREC
Cc: File