CARE AND SUPPORT OF CHILDREN LIVING WITH HIV/AIDS IN AIZAWL, MIZORAM

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Chapter-1

Introduction

The situation of Children Living with HIV/AIDS (CLHIV) depends much upon the care and support they receive from their family and the society at large. According to UNAIDS (2000), care and support can help CLHIV and their carers cope more effectively with each stage of the infection and enhance quality of life. HIV infection often results in stigma and fear for those who are infected, as well as for those caring for them, and may affect the entire family. For children, care and support can improve the quality of their lives and r arrest further transmission of HIV infection. Care and Support helps CLHIV away from stigma and discrimination in the society. And guide them to become good member in the society. It can further help CLHIV from vulnerable population and provide sustainable care and support for them.

According to Deeks, Lewin & Havlir (2013), the care and support model was restricted only to hospital-based care of symptomatic patients, home-based care, palliative care and end-of-life care. Presently, we are moving towards clinic- and hospital-based integrated care cascade and because of various development taking place in the care and support of HIV/AIDS related field the future model will be a community-based and clinic based integrated HIV care model with speciality HIV cure services. A point-of-care technology will be widely used and informing patient decentralised care with a routine viral load monitoring services (In UNAIDS, 2016).

The provision of care and support services also acts as an important aspect of managing persons with HIV/AIDS. These include care, day cone, domiciliary care and care provided by family, friends and partners. Because of its fast growing rate, it is the social and moral responsibility of every citizen to play roles so as to lessen the challenges that has crept up due to HIV/AIDS (Dokwal, 1999). However, Sherr and Mueller (2008) reported that many children are orphaned by HIV/AIDS because death clusters within the families. As such, CLHIV suffer from poverty, no or lack of social support services, because of which they become more or less abandoned.

According to UNAIDS & WHO (2006), CLHIV have multiple challenges. Apart from their infection, accessibility to medical care such as provisions of antiretroviral drugs and other appropriate drugs is highly abysmal because of high prices of the drugs and lack of healthcare

providers who are trained to treat children. Another challenge they face is the drug being in a tablet form, which is difficult for younger children to consume. Further, CLHIV who live with their parents or family members that are HIV positive also experience stigmatization and discrimination from their extended families, friends and communities that greatly affects their mental wellbeing. Vranda & Mothi (2013), stated that in spite of the fact that children with chronic illness, in general, are found to be a greater risk for psychiatric problems, including depression, anxiety and feelings of isolation there are very few studies addressing the impact on the mental health of children either affected or infected with HIV/AIDS in India.

According to UNAIDS (2001), the statistics about the impact of HIV/AIDS world-wide are overwhelming. Estimates of the United Nations Agency for AIDS (UNAIDS) shows that over 40 million people were living with HIV/AIDS in 2001, and nearly 25 million people died of AIDS since the disease was first discovered in the early 1980's, and further, more than 15.6 million children under 15, have lost either their mother, their father, or both parents as a direct result of AIDS.

Children living with HIV/AIDS have special needs for good nutrition, immunization and regular health care to avoid complications. If the father and mothers are also infected, home care visits might be needed. If the children lose their parents, teachers and caregivers to HIV/AIDS, they need special care and understanding (Zhao, 2011). Good quality training on HIV/AIDS for teachers and peer educators can increase understanding and compassion and lessen discrimination of children living with HIV/AIDS or with families affected by HIV/AIDS. Among the school-aged children, information on HIV/AIDS and life skills should be provided (Islam, Minichiello & Scott, 2014).

UNICEF (2004) states if the increasing trend continues, the number of AIDS orphans could reach 40 million by 2020.In 2008, it was found that there are 21 million children in the world living with HIV/AIDS. Approximately 430,000 children were infected with HIV in 2008. Every hour, 31 children around the world die because of AIDS. There are 2-3 million people in India living with HIV/AIDS. It is estimated that 70,000 children below the age of 15 infected through mother to child transmission**.** The Government of India (2009) estimates that about 2.40 million Indians are living with HIV (1.93-3.04 million) with an adult prevalence of 0.31 per cent

(UNICEF, 2010).The Orphan Project, New York reports that in the year 2000 approximately 72,000 to 125,000 children had been orphaned by AIDS in the US (Webb, 2003).

In 2003, almost five million people became newly infected with HIV, the greatest number in any one year since the beginning of the epidemic. At the global level, the number of people living with HIV continues to grow-from 35 million in 2001 to 38 million in 2003. In the same year, almost three million were killed by AIDS; over 20 million have died since the first cases of AIDS were identified in 1981. India has the second highest national total of persons living with HIV/AIDS after the Republic of South Africa. According to National Aids Control Organization (NACO), there were an estimated 0.55 lakh HIV infected 0-14 year old children in India in 2003. UNAIDS, however, puts this figure at 0.16 million children (In MSACS, 2005).

Number of people living with HIV/AIDS (PLHIV) in the year 2011 in India was estimated to be 20.9 lakh. Children less than 15 years of age accounted for 7 per cent (1.45 lakh) of all infections and 86 per cent were between 15-49 years of age. The estimated number of PLHIV in India reducing from 23.2 lakh in 2006 to 20.9 lakh in 2011. Fifty three per cent of prevalence was reported from four high prevalence States of South India (Andhra Pradesh, Karnataka, Maharashtra and Tamil Nadu). A case control study on quality of life was conducted by Gupta et al in 2013 on HIV infected children and other chronic ailments (40+40) at the referral hospital in Northern India. A significantly improved quality of life of HIV infected children was observed among children with chronic illness than among children with HIV. The study concluded that the quality of life was better in HIV infected children than those suffering from chronic illness (Bharathi, Pai&Nayak, 2014).

The National Aids Policy talked about equal access to education, hundreds of cases like those of ‘Ben and Bency’ took place over all the country and the infected and affected children were denied permission to attend the school. Similarly, there was nothing for the treatment of children who were suffering from HIV/AIDS either as a result of mother-to-child transmission or blood products infected with HIV (In Varma, 2010).

A study of HIV/AIDS in women and children in India stated that management of HIV in India has significantly improved with many international and local programmes supporting prevention and treatment. However, there are areas in India where women and children living

with HIV endured a myriad of medical, psychological and social challenges (In Mothi, Mamatha & Tappuni, 2016).

According to a publication of NACO (National Aids Control Organization) and MPWD 2015, there are 2-3 million people in India living with HIV/AIDS. It is estimated that 70,000 children below the age of 15 infected with 21,000 children being infected through mother-child transmission every year. HIV infection in extremely young children is especially fatal. Children living with the disease experience a great deal of social stigma and discrimination. This results in children being marginalised from essential services such as education and health (In NACO & MWCD, 2008).

The National Aids Control Programme declared Mizoram status in the year 2005 from 1990 to March 2005, there were 1087 in total (666-male & 421-female). Due to sexual contact, 497 were transmitted, 481 were because of Injecting Drugs, 37 were due to Prenatal and the rest 72 were not specified. According to the survey of Mizoram States Aids Control Society (2005), in Mizoram, since October 1990-March 2004, there were 159 children who are living with HIV/AIDS. Among these, there were 77 male and 82 female in number. The common transmission was due to prenatal and breast feeding. Mizoram State Aids Control Society (MSACS) had reported that since October 1990 to March 2016, there were a number of 3,52,737 Blood Tested and among these 11374 were HIV positive. An age group less than 14 years were 433 (3.81%) and between 15 to 24 age group, they were 2488 (21.87). The mode of transmission among children was usually from prenatal and breast feeding (MSACS, 2017).

1.1 Child

The United Nations Convention on the Rights of the Child (UNCRC) 1989, defines a 'child' as a person below the age of 18, unless the laws of a particular country set the legal age for adulthood younger. In this study, children shall mean those children between the ages of 11-18 years who are living with HIV/AIDS.

1.2 HIV/AIDS

According to Bor & Elford (1998), HIV (Human Immunodeficiency Virus) is a very small fragile virus and soon dies outside the body. Consequently, it is not contagious and cannot be passed from person to person easily like a cold or the flu virus, or by ordinary social contacts. It is a member of a group of viruses called retroviruses. Retroviruses are simple microscopic organisms dependent on a host for reproduction. These microscopic organisms lack an independent metabolism and cannot grow without energy and nutrients supplied by a host cell.

They also state that AIDS is an acronym made up of the first letter of the words Acquired Immune Deficiency Syndrome. The word acquired was chosen because the illness was neither genetically determined nor, the result of other conditions. In other words, it was acquired during a period of normal life. It is a disease in which the body's immune system breaks down and is unable to fight off infections, known as 'opportunistic infections' and other illnesses that take advantage of a weekend immune system. AIDS is a medical condition. A person is diagnosed with AIDS when his or her immune system is too weak to fight off infections. It was in 1981, that unusual opportunistic infections were identified in a number of homosexual men in the United States of America. These men died ultimately as the infections responded poorly to any therapy. Several years lapsed between the identification of the virus that caused AIDS and the first report of AIDS cases. The virus that caused AIDS is known to be "Human Immunodeficiency Virus"(HIV).

1.3 Care and Support

According to UNAIDS (2016), 'Care and support is a comprehensive set of services, including medical, psychosocial, physical, socioeconomic, nutritional and legal support. These services are crucial to the well-being and survival of people living with HIV and their caregivers and orphans and other vulnerable children. Care and support services are needed from the point of diagnosis throughout the course of HIV-related illness, regardless of ability to access antiretroviral therapy'. It also states that care and support includes key non-antiretroviral therapy clinical services, prevention and treatment of HIV-related infections, and non-clinical services that in combination with antiretroviral therapy contribute towards the reduction of rates of ill health and HIV-related deaths among, and increase the well-being of, people living with HIV. Care and support is important because it facilitates immediate access to treatment when a person is diagnosed with HIV and supports adherence to treatment to attain viral suppression for people

living with HIV, for the sake of their own health and to prevent infecting other people with HIV. It also enhances the prevention and management of HIV-related infections and coping with the challenges of living with HIV. Further, it goes on to say that care and support extends beyond medicines and formal health-care systems and requires adoption of new strategies that take into account the comprehensive and different needs of people living with HIV.

HIV Care and support is intended not only for people living with HIV, but also for all those directly affected by HIV. Those affected by HIV include the families, friends, children and those who provide care and support from the community. According to the definition produced by UNAIDS and WHO in 2004, there are five interrelated domains of HIV care and support:

a) **Psychosocial**: This includes counselling, emotional support and spiritual support, reduction of stigma and discrimination, positive living.

b) **Clinical:** This includes testing, prevention of opportunistic infections, symptom control and pain management, treatment of AIDS-related illnesses and opportunistic infections including TB, treatment adherence support and information, alternative/traditional medicine.

c) **Social and economic**: This includes social protection, targeted financial support, income generation and employment opportunities, capacity building and advocacy support, food and nutrition assistance and appropriate agricultural inputs and services, education, orphan support, adoption services, help in the home and child care.

d) **Human rights and legal:** This includes legal aid, support and information, human rights legislation, advocacy training and rights awareness-raising.

e) **Family & community:** This includes psychosocial and medical, socio-economic and legal care and support for families, care-providers and children infected or affected by AIDS (In HIV Care and Support Working Group, 2008).

UNAIDS (2016) has also highlighted various services under the Care and support programmes such as:

a) Universal Services which include linkage to care for immediate initiation of antiretroviral therapy for people newly diagnosed with HIV, with clinical and laboratory monitoring, including viral load monitoring, tuberculosis screening, cotrimoxazole prophylaxis, optimization of retention in care and adherence to antiretroviral therapy.

b) Contextual Services which include clinical care, physical care, social support, pain and symptom management and end-of-life care, mental health and substance (including alcohol) abuse services, nutrition assessment, counselling and support and legal support.

1.4 Causes and Consequences

According to Bor & Elford (1998), there are five (5) modes of transmission in which a person can become infected with HIV such as unprotected sexual intercourse with an infected person, contact with an infected person's blood, use of infected blood products, sharing of in sterilized needles/syringes and from HIV infected mother to child.

Web (2001) states that HIV infection is caused by the human immune deficiency virus. One can get the virus from contact with infected blood, semen or vaginal fluids. Most people get the virus by having unprotected sex with someone who has HIV. Another common way of getting it is by sharing drug needles with someone who is infected with HIV. The virus can also be passed from a mother to her baby during pregnancy, birth or breastfeeding. Since HIV does not survive well outside the body, it cannot spread by casual contact like kissing or sharing drinking glasses with an infected person.

According to Foster & Williamson (2000), highlights the impact of HIV/AIDS on children, their families and the communities at large. They state that the impact is compounded by the fact that many families lives in communities which are already disadvantaged by poverty, poor infrastructure and limited access to basic services. To get a clear picture of its impact, they have categorised the impact of HIV/AIDS which are as under:

a) Economic Impact

Economic factors include those related to poverty. CLHIV from developing countries face more challenges. Because of poverty, children are abandoned and orphaned. If care and support services become abysmal, children as young as 5 years old resort to work. Besides this, the workload of children affected by HIV/AIDS starts to increase when parents become sick and increases when the children becomes an orphan.

b) Education

Studies reveal that education is often disrupted when parents become sick, especially older girl children who are required to take over household and care giving chores. Studies from several countries also confirmed significantly less enrolment rates in orphans than non –orphans and identified risk factors such as girl orphans, children orphaned by AIDS, rural or poor households and orphans living in households headed by men.

c) Health and Nutrition

There is a close relationship between child morbidity and the quality of parenting. Itv was found that foster children in West Africa experienced higher mortality than other children because of poorer care, malnutrition and reduced access to modern medicine.

d) **Psychosocial impact**

The mental wellbeing of CLHIV is neglected especially in developing countries, where the social and economic factors are considered more important. Where basic needs are not met, it is difficult for agencies to concentrate on addressing less immediate or obvious psychological need. In some contexts, a blanket and food may be more appropriate than counselling.

1.5 Statement of the Problem

Children who are infected with HIV/AIDS have low self-esteem in the society and it can affect their education, mental and even their social life. They need support to develop their mental health and to have a good relationship with the society. Stigma and discrimination are universally experienced by persons living with HIV/AIDS. Children living with HIV/AIDS are in lack of social support especially in Mizoram. They also face problems of protection and nutrition from their family and the society. As such, there is a need to understand the situation of children living with HIV/AIDS and the levels and dimensions of care and support they receive from the society at large.

There are few study/research specifically related to care and support and children living with HIV/AIDS. This study will fill this gap. Further this research will also highlight the social demography, dimensions, quality, quantity and accessibility of care and support which is missing in Mizoram. It also into the challenges faced by children and their coping strategies.

1.6 Objectives

1. To profile the socio-demographic characteristics of Children Living with HIV/AIDS in Aizawl District.
2. To find out the availability, adequacy and quality of care and support given to Children Living with HIV/AIDS.
3. To find out the dimensions of care and support given to Children Living with HIV/AIDS.
4. To find out the challenges and coping strategies of Children Living with HIV/AIDS.
5. To suggest measures for Social Work intervention and policy making for Children Living with HIV/AIDS.

1.7 Chapter Scheme

Chapter I	:	Introduction
Chapter II	:	Review of literature
Chapter III	:	Methodology
Chapter IV	:	Results and discussion
Chapter V	:	Conclusion

Chapter-2

Review of Literature

Literature helps the researcher to understand the theoretical background and findings of different scholars in various aspects. A review of literature also helps in identifying research gaps as well as the differences and commonality of various studies in relations to the problem under investigation also helps to understand and support more of the present study.

UNAIDS reported that for 2007, the total number of people living with HIV in December 2007 was 33.2 million, out of which 15.4 million were women. 2.5 million children under 15 years, and 15.4 million men. The 2007 Global Overview on AIDS reported that, in Sub-Saharan Africa, the total number of CLHIV between 2001 and 2007 increased from 1.5 million to 2.5 million but the new infection rate declined during the period. Deaths among children increased between 2001 and 2005 but since then have been declining. The number of such children is the highest in India ranging from 4 to5.75 lakhs, followed by Brazil (1-5 lakhs), USA (3 lakh) and Thailand and China (2 lakhs each). According to an estimate in Sub-saharan Africa, nearly 20 lakh children below the age of 14 were living with HIV in 2007 an eight fold increase in new HIV infection and death among children since 1990 and about 370 thousand became newly infected and 270 thousand died. 12 million children who had lost their parents are vulnerable to poverty and require support, the support offered by the local community and voluntary organizations is far short of requirement of such children. According to UNAIDS, about 50 thousand children below the age of 15 years are infected with HIV/AIDS in India every year. There is no long term plan for them, neither any material, physical or health care plan for them nor any psychosocial support is exclusively available to them (In Varma, 2010).

It is estimated that 15 million children under 18 years have lost one or both parents to AIDS, with the vast majority, 12 million, and resident in sub-Saharan Africa. The number of orphaned children as a result of AIDS is projected to exceed 25 million by the end of the decade, and the number of children in sub-Saharan Africa who have lost both parents to AIDS may rise to 8 million from 5.5 million in 2001, according to estimates (UNICEF, 2006).

According to Global Summary of the HIV/AIDS epidemic December 2004, the numbers of children living with HIV/AIDS under 15 years were 2.2 millions, children below 15 years

who were newly infected with HIV in 2004 were 6,40,000 and 5,10,000 children under 15 years died due to AIDS in 2004 (In MSACS, 2005).

Islam, Minichiell & Scott (2004) also states that in 2007, 4,20,000 children were infected with HIV and 3,30,000 died of an AIDS-related illness. Without treatment, most children will die before their 5th birthday and while children account for only 8 per cent of overall HIV infections, they represent 19 per cent of all AIDS-related deaths. Over 90 per cent of children infected with HIV live in sub-Saharan Africa, where there is least access to paediatric treatment.

In the US, researchers estimate that in 2006, about 34 per cent of all new HIV infections in the United States occurred among young people between 13 to 29 years old, majority of them are acquired through sexual transmission. Within the age group women, men having sex with men and African Americans are particularly affected by HIV/AIDS. From 2004 to 2007, the majority of new HIV/AIDS cases among male adolescents and young adults to 13 to 24 years old were attributed to male to male sexual contact. African American adolescents13 to 19 years old accounted for only 17 per cent of the total population but 72 per cent of new diagnosis of HIV/AIDS (Fraser &Jensen 2011).

The Irish Aid of Briefing Paper (2010) found that AIDS is one of the primary factors forcing children to drop out of school and enter the labour market. Child labour is also filled with numerous risks including sexual exploitation and HIV infection and either to assist their families or provide for themselves, many orphaned and vulnerable children are forced into labour or sexually exploited for cash to obtain protection, shelter or food (In UNICEF, 2006).

According to Bharathi, Pai & Nayak (2014), among 50 CLHIV, 46.1 per cent of the them belonged to the age group of 16-18 years; 56 per cent of them were males and majority (62%) of the children's fathers and 32 per cent of the children's mother's cause of death was AIDS. Majority of the children were diagnosed of HIV between the age group of 1-6 years.

Doku, Dotse & Mensah (2015), studied the socio-demographic profile of CLHIV/AIDS. The study was conducted with291 children. They found that the mean age was 13.03 years, with age range 10–18 years. Majority (81.8 %) of the children were currently attending school and 75 per cent had attained primary or junior secondary level education and 12.7 per cent vocational or

technical education. There were 62 per cent of all the children who had changed residence between two or more times. Majority (62 %) of the parents and caregivers worked mainly in farming, driving, trading or as artisans (carpentry, masonry, bead making). Among the children 56 per cent of the children indicated that they were Christians, 11 per cent Islam, 20.3 per cent Traditional/African beliefs and 12.7 per cent belonging to other faith.

According to Bharathi, Pai & Nayak (2014), 1299 rural children suffering HIV/AIDS in central China, the perceived social support (PSS) was highly correlated with psychosocial well-being of children and there was a strong association between PSS and psychosocial outcomes among children affected by HIV/AIDS. Doku, Dotse & Mensah, (2015) also states that the strong association between PSS (Perceived Social Support) and psychosocial outcomes underscores the importance of adequate social support to alleviate stressful life events and improve psychosocial wellbeing of children affected by HIV/AIDS. PSS is highly correlated with children's psychosocial wellbeing and such correlations vary by functions and sources of the PSS as well as different psychosocial outcomes.

Social support is also found to be associated with psychiatric and mental health outcomes, it can also be a cost effective critical resource that buffers the effects of mental illness among children. Social support system is usually sustained by family relatives, neighbor and friends (Islam, Minichiello & Scott, 2014).

UNAIDS 2001 conducted study of parental caregivers of HIV infected adult offspring in Thailand. IT was found that older parents were seen as being greatly motivated and dedicated to improve the wellbeing of their children and acted as major caregivers. Among the HIV children, social stigma and fear are not in Thailand as compared to the other countries. Financial demands also accumulate till the point where the child and parents resources are exhausted. Parents displayed strong will to help their children as much as possible (D'Cruz 2004).

Because of the severe HIV/AIDS epidemic in sub-Saharan countries such as Zimbabwe, there are a growing number of orphans requiring care and support and have been absorbed within the extended family but this is becoming more difficult because of the large number of young adults dying(Drew, Makufa & Foster, 1998).

According to Joseph & Bhatti (2004), high levels of HIV-related worry have been reported to occur among HIV-positive who do not disclose their sera-status. Bruyn (2002) found that the impact of HIV/AIDS stigma obviously has an effect on the psychological well-being of women.

Islam, Minichiello & Scott (2004) also states that HIV-infected parents have poor quality relationships with their children compared to non-infected mothers while high quality mother–child relationships are important for the enhancement of psychosocial functioning of children. A study of children aged between 11 and 16 years with HIV-positive mothers showed that these children had more difficulties in their relationship with their mother. Studies have identified that a poor parent–child relationship can also lead to psychological problems among children with HIV-infected parents.

In Thailand, the children eventually become orphans after the death of one or both parent, some of them are themselves living with HIV, thereby subjecting them to daily hardships. According to UNAIDS, by the end of 2001, there were 325,000 orphans aged 0 to 14 years living in South East Asia countries except in India. Asia has a higher number of both orphans and AIDS orphans than Africa, while percentage of AIDS orphan to total number of children in Asia is steady over years at approximately 3 per cent throughout the period, Africa shows an alarming increase from 0.4 per cent in 1990 to an estimated level of 5.8 percent in 2010 (In Narain, 2004).

Parental deaths and illnesses are childhood traumatic events that are associated with several physical, psychiatric and psychosocial health problems. Children orphaned by AIDS are at risks for a range of adjustment difficulties including emotional problems, behavioural difficulties, self-esteem, suicide ideation, anxiety, conduct problems, post-traumatic stress disorder, delinquency problems.HIV/AIDS also results in loss of social and family support with direct consequences for children (Doku, Dotse & Mensah, 2015).

Stigma and discrimination can exacerbate the material and psychological problems children face in the context of HIV and AIDS, children affected and infected with HIV experience considerable psychological disadvantage as a result of HIV and AIDS-related stigma. Children whose parents are ill with AIDS or who have died of an AIDS-related illness, report

being marginalized and isolated from other children, being teased and gossiped about, while presumed to be HIV positive, and not in receipt of care. The jury is largely out on this issue because it is difficult to separate causal factors for stigma and discrimination in societies where poverty or orphan hoods are stigmatizing states in themselves (UNICEF, 2006).

Further Zhao (2011) states that children born into HIV-affected families have reported numerous psychological and physical problems including fear, isolation, depression, anxiety, grief, low self-esteem and trauma. They identified social stigma as the key determinant of negative outcomes for children in HIV affected families.

A survey in Uganda demonstrated that 26 per cent of children living with HIV positive parents attended school less often, citing the need to stay at home and care for sick parents. Children orphaned by AIDS are significantly more likely than non-orphans to experience hunger and are less physically healthy. The death of a parent has a critical impact on early life and development and studies demonstrate that the survival of children less than 3 years AIDS has made a dramatic difference in child mortality rates (Bharathi, Pai & Nayak, 2014).

Children living with HIV/AIDS will have special needs because they are not able to get access and help themselves in the same way. Most of them get from their parents, and it is best for them to looked after by those they know and make them feel safe. The caregivers has to be the main target for support and training to make sure the child receives proper care (Zhao, 2011).

In India, there were approximately 2.5 million people living with HIV/AIDS in 2006 with a national adult HIV prevalence of 0.36 percent. Adults and children living with HIV were 2.4 million. India, out of an estimated 9 lakh sex workers, 30 percent are children. The number of such children is growing by 8-10 percent per annum (Varma, 2010).

GOM (2007), conducted a study on 'Communication Needs Assessment (CNA) on HIV/AIDS/STD' in 2001. The findings reveal that 81 per cent of the rural population and 92percent of the urban population had heard about HIV/AIDS. Of these, 90 per cent (rural) and 91 per cent (urban) knew the modes of transmission.

Family care in the field of HIV/AIDs has become very important because of the uniqueness of the disease that involves various new challenges relating to stigma. There is limited literature in the area of care and support in India that necessitates for reliance of western sources. He further highlights the challenges parents go through in looking after their children living with HIV/AIDS. 'They experience a disruption in the natural order of families, resuming a long discarded role as guardian or decision maker for their child. They also go through the pain of having to watch their offspring die and of having to outlive their child. (Brennan and Moore 1994; Sewpaul and Mahlalela 1998; wiener et al. in D'Cruz, 2004).

Children belonging to the poorer sections of the society, especially from SC's and ST's, are the least empowered groups in India. Among the children, boys are slightly more advantaged than girls. The health care system, especially in the rural areas, does not meet even the remotest need of children with special illnesses, both physical and mental. Apart from the lack of attention by the administrative system, there is a total lack of political support (Mahmud, 2004).

According to MSACS (2005), the first HIV case in Mizoram during October 1990-January 1991 were a total of 164 samples were tested (103-IDUs, 31 CSW/STDs, 6 Blood donors and 64 others) and 9 were found positive, and were all IDUs. Further, in Mizoram since October 1990-March 2004, 37 children have HIV positive cases. The age group was less than 14(20 male and 17 female). There were 122 children (57 male and 65 female) which were in the age group between 15-19 years.

Chapter- 3
Methodology

The Study was exploratory in design and will adopt mixed method i.e. both qualitative and quantitative methods.

3.1 Sources of Data Collection

Data were collected from both primary and secondary sources. Primary source include data collected from Children Living with HIV/AIDS(CLHIV) and their caregivers. Secondary source include those collected from Government and Non-Governmental records.

3.2 Sampling Procedure

The unit of study is a child living with HIV/AIDS and adults involved in their care. All children living with HIV/AIDS in Mizoram and all adults involved in their care constitute the population of the study. A Multi-stage sampling procedure was adopted.

In the first stage, Aizawl Municipal area in Aizawl District,was purposively selected. In the second stage, all lists of children living with HIV/AIDS were collected from Mizoram State Aids Control Society (MSACS), Vihaan (Care and Support Centre), Peace Home, Gan Sabra, and World Vision. In the third stage, only children living with HIV/AIDS belonging to 11-18 years of agewere selected from the list. In the final stage, from the selected list, 80 children living with HIV/AIDS, who gave their mutual consent, formed the final sample.

3.3 Tools of data collection

A semi-structured interview schedule formed the tool for data collection. The tool was constructed based on domains of care and support given by UNAIDS and WHO (2004), review of literature and pilot studies. The tool was child centric where active participation from the children was sought. The tool included information regarding the social demographic characteristics of HIV/AIDS, the domains of care and support provided to them, the availability, adequacy and quality of care and support provided to them across domains and the challenges and coping strategies of children living with HIV/AIDS in Aizawl. Separate tool (Semi

Structured Interview Schedule) was also made for caregivers to find out their perceived quality of support across domains, their challenges, coping strategies and suggestions to improve care and support for CLHIV. Qualitative and Participatory techniques such as in-depth interview, focus group discussion and Daily activity schedule of children were conducted to gather additional information. Pre-testing of the tool wasdone to check the reliability and necessary changes to suit the children were made accordingly to maintain ethical standards in research.

3.4 Data Processing and Analysis

The data shall be analyzed using Microsoft excel and SPSS package. Descriptive statistics, case vignettes and focus group discussion were analyzed in order to find out the socio-demographic characteristics of children living with HIV/AIDS, the availability, adequacy and quality of care and support and the dimensions of care and support. The challenges facedand the coping strategies of children living with HIV/AIDs and the caregivers were analyzed. Further, the perceived quality of caregivers was also analyzed. Kendall's Coefficient of Concordance was also used to find out the level of scorers agreement with respect to the children'sperceived adequacyand quality of care and support given by the agents.

3.5 Ethical Consideration

The topic of HIV/AIDS is a sensitive issue that requires confidentiality. Informed consent were sought from the concerned authorities, caregivers and the children. Only those who have given consent formed the final sample. The names of the children and their address were also kept confidential.

3.6 Operational Definition and Concepts

In this study, children living with HIV/AIDS refer to those children living with HIV/AIDS between the ages of 11-18 years.

In this study, care and support means the fivedomains of care and support given by UNAIDS & WHO (2004).

In this study, caregivers refer to parents, guardians and institutional authorities involved in the care, support and rehabilitation of children living with HIV/AIDS.

Agents of care and support in this study includes family, peers, community (Young Mizo Association (YMA), Mizo Hmeichhe Insuihkhawm Pawl (MHIP), Mizo Upa Pawl (MUP) and church organisations, government and NGOs (Agencies directly involved in HIV/AIDs).

Chapter-4

Results and Discussions

4.1 Socio-Demographic Profile

This section will highlight the socio-demographic background of Children Living with HIV/AIDS (CLHIV) that includes their age group, gender, sub-tribe, denomination, educational status, type of family, form of family, socio-economic category, occupation and monthly income. This will help in understanding the personal characteristics and background of the children.

Table 1: Age Group

Sl.No	Age Group	Frequency	Percent
1	11-14 years	43	53.8
2	15-17 years	37	46.3
	Total	80	100.0

Source: Computed

Table 1 presents the children according to their Age Group. The table shows that more than half (53.8%) are from the age group 11-14 years while less than half (46.3%) of the children belong to the age group 15-17 years.

Table 2: Gender

Sl.No	Gender	Frequency	Percent
1	Female	43	53.8
2	Male	37	46.3
	Total	80	100.0

Source: Computed

Table 2 shows the respondents according to their Gender. From the table, we see that more than half (53.8%) of the children are females while less than a half (46.3%) of them are males.

Table 3: Sub-Tribe

Sl.No	Sub Tribe	Frequency	Percent
1	Lusei	50	62.5
2	Hmar	9	11.3
3	Others	8	10.0
4	Paihte	6	7.5
5	Lai	5	6.3
6	Mara	2	2.5

	Total	80	100.0

Source: Computed

Table 3 highlights the children according to their Sub-tribe. The table shows that more than half (62.5%) of them are from the Lusei tribe, followed by more than a tenth (11.3%) who are from the Hmar tribe and a tenth (10%) of them from the Others category consisting of children from Myanmar and Tripura. Less than a tenth (7.5%) of the children are from the Paihtetribe followed by a close 6.3 per cent from the Lai tribe and a small 2.5 per cent from the Mara tribe.

Table 4 Denomination

Sl.No	Denomination	Frequency	Percent
1	Presbyterian Church	27	33.8
2	Catholic Church	23	28.8
3	Baptist Church	10	12.5
4	United Pentecostal Church	7	8.8
5	The Salvation Army	6	7.5
6	Local Christian Denominations	4	5.0
7	Seventh Day	3	3.8
	Total	80	100.0

Source: Computed

Table 4 shows the distribution of children according to their Denominations. From the table, we can see that Presbyterian Church takesthelead at 33.8 per cent of the children from the denominationfollowed by those (28.8%) who belong to the Catholic Church and more than a tenth (12.5%) of the children who belong to the Baptist Church . Less than a tenth (7.5%) of the children are from United Pentecostal Church followed by another 7.5 per cent of them from the Salvation Army. Few (5%) of the children are from the Local Christian denomination while the fewer (3.8%) of them belong to the Seventh Day.

Table 5: Educational Status

Sl.No	Educational Status	Frequency	Percent
1	Middle School Level	36	45.0
2	High School Level	26	32.5
3	PrimarySchool Level	12	15.0
4	Higher SecondarySchool Level	6	7.5
	Total	80	100.0

Source: Computed

Table 5 represents the Educational Status of the children. Almost half (45%) belong to Middle school level followed by those (32.5%) who studied till the High school level. Fifteen per cent of the children belong to Primary school level while less than a tenth (7.5%) belong to the Higher Secondary school level.

Table 6: Type of Family

Sl.No	Type	Frequency	Percent
1	Joint family	52	65.0
2	Nuclear family	28	35.0
	Total	80	100.0

Source: Computed

Table 6 shows the distribution of children according to their Type of Family. This table highlights that more than half (65%) of the respondents are from Joint family while more than a third (35%) of the respondents are from Nuclear family.

Table 7: Form of Family

Sl. No	Form	Frequency	Percent
1	Broken Family	37	46.3
2	Stable Family	27	33.8
3	Reconstituted Family	16	20.0
	Total	80	100.0

Source: Computed

Table 7 shows the children according to their Form of Family. From the table, we see thatalmost half (46.3%) of the childrenare from broken family followed by children (33.8%) from stable family while a fifth (20%) of them come from reconstituted family.

Table 8: Socio-economic Category

Sl. No	Category	Frequency	Percent
1	BPL	45	56.3
2	Don’t know	15	18.8
3	APL	13	16.3
4	AAY	7	8.8
	Total	80	100.0

Source: Computed

Table 8 exhibits the socio-economic category of the children. The table shows that more than half (56.3%) of the respondents are from the BPL family while less than a fifth (18.8%) do

notknow their socio-economic category. A sixth (16.3%) of the respondents are from the APL category while less than a tenth (8.8%) are from AAY category.

Table 9: Occupation of Children

Sl.No	Occupation	Frequency	Percent
1	Student	77	96.3
2	Daily Labour	2	2.5
3	Petty Business	1	1.3
	Total	80	100.0

Source: Computed

Table 9 highlightsthe children according to their Occupation. From the table, we can see that majority (96.3%) of the respondents are students. Surprisingly, few children worked as a daily labourer and were involved in petty business.

Table 10: Monthly Income

Sl. No	Monthly Income	Frequency	Percent
1	Dependent	77	96.3
2	Rs. 2001-Rs. 4000	3	3.8
	Total	80	100.0

Source: Computed

Table 10 represents the monthly income of those children who worked. The table clearly shows that among those who worked, they earned a monthly income of Rs. 2001- Rs.4000.

4.2 Testing and mode of Transmission

This section will cover the children's knowledge about where their blood were tested, year of testing, age of the children when they tested and the mode of transmission.

Table 11: Testing Centre

Sl. No	Place	Frequency	Percent
1	Don't Know	54	67.5
2	ICTC	19	23.8
3	Private Hospitals	7	8.8
	Total	80	100.0

Source: Computed

Table 11shows the distribution of children according to their Testing Centre. From the table, we see thatmore than half (67.5%) do not know their centre while less than a fourth

(23.8%)of the children were tested at ICTC and less than a tenth (8.8%) were tested in private hospitals.

Table 12: Year of Testing

Sl. No	Year	Frequency	Percent
1	2000-2005	50	62.5
2	2006-2010	14	17.5
3	2011 and above	10	12.5
4	Don't Know	6	7.5
	Total	80	100.0

Source: Computed

Table 12 represents the distribution of children according to the year of testing. The table shows that more than a half (62.5%) weretested between the years 2000-2005 followed by those children (17.5%) who were tested in the years2006-2010. More than a tenth(12.5%) of the children weretested in the years 2011 and above while less than a tenth (7.5%) does not know the year of testing.

Table 13: Age when tested

Sl. No	Age	Frequency	Percent
1	At Birth	65	81.2
3	1-5 years	5	6.3
4	6-10 years	5	6.3
5	11-15 years	3	3.8
6	15 years and above	2	2.5
	Total	80	100.0

Source: Computed

Table 13highlights the children according to their Age when tested. The table shows that most of the children(66.3%) did not know their age when they were tested followed by 15 per cent of the respondents who were tested at birth. Less than a tenth (6.3%) each were tested when they were between 1-5 years of age and 6-10 years of age, while a few (3.8%) were tested when they were between the age 11-15 years. Very few children (2.5%) were tested when they were 15 years and above.

Table 14: Mode of Transmission

Sl. No	Mode	Frequency	Percent

1	Mother to Child	75	93.8
2	Don't Know	3	3.8
3	Sexual intercourse	2	2.5
	Total	80	100.0

Source: Computed

Table 14 represents the distribution of respondents according to their mode of transmission. The table clearly shows that majority (93.8%) of the respondents were infected from mother to child while a few (3.8%) did not know how they were infected. A very few (2.5%) of the children were infected because of sexual intercourse.

4.3 Care and Support

This section discusses the availability of care and support from different agents, perceived adequacy of care and support from different agents, perceived quality of care and support across the dimensions given by the agents. It shall also analyze Kendall's Coefficient of Concordance to find out the level of scorers agreement with respect to perceived availability and quality of care and support.

Table 15: Availability of Care and Support

Sl. No	Agents	Frequency	Percent
1	NGOs	80	100.0
2	Government	78	97.5
3	Family	73	91.3
4	Community	58	72.5
5	Peers	40	50.0

Source: Computed

Table 15 represents the distribution of children according to the availability of Care and Support. From the table, we see that all children (100%) reported as having been cared for and supported by NGOs followed by majority (97.5%) of the children as having been cared for and supported by the Government. Most of the children (91.3%) also reported as getting care and support from the family and 72.5 per cent of the children also reported as having been cared for and supported by the community. Half of the children (50%) indicated that they were cared for and supported by their peers.

Table 16: Perceived Adequacy of Care and Support

Sl. No	Agents	Mean
1	NGOs	1.88
2	Family	1.84
3	Government	1.51
4	Community	.90
5	Peers	.59
	Mean	1.34
	Kendall's W[a]	.528
	Chi-Square	169.071
	Df	4
	Asymp. Sig.	.000
Kendall's Coefficient of Concordance		

Source: Computed

Table 16 shows the perception of children on the adequacy of care and support given by the agents. Adequacy was measured based on a four point scale ranging from 0 Very Inadequate, 1 Inadequate, 2 Adequate and 3 Very Adequate. To assess the inter scorer reliability, Kendall's W[b] were also worked out. The table shows that care and support given by NGOs, Family and Government is adequate while care and support given by Community and Peers is inadequate. The overall score is however found as inadequate. However, we see that there is high level of agreement among the scorers on adequacy of care and support from Kendall's Coefficient of Concordance.

Table 17: Perceived Quality of Care and Supportand Domains

Sl. No	Agents	Domains of care and support					Mean
		Psychosocial	Clinical	Human rights and legal	Family and Community	Social and economic	
1	NGOs	2.15	2.12	2.21	2.34	1.96	2.16
2	Government	1.56	1.91	1.88	1.91	1.29	1.71
3	Family	1.9	1.83	1.35	0.99	1.62	1.54
4	Community	1.31	1.1	1.17	1.16	0.8	1.11
5	Peers	0.76	0.66	0.29	0.28	0.3	0.46
	Mean	1.54	1.52	1.38	1.34	1.19	1.39
	Test Statistics						
	N	80	80	80	80	80	80.00

	Kendall's W[a]	.421	.460	.635	.637	.707	.538
	Chi-Square	134.862	147.088	203.236	203.703	226.186	1032.953
	df	4	4	4	4	4	24
	Asymp. Sig.	.000	.000	.000	.000	.000	.000
Kendall's Coefficient of Concordance							

Source: Computed

Table 17 shows the perception of children on the quality of care and support across different domains given by various agents such as the family, peers, community, government and NGOs. The quality of care and support given by the agents were measured based upon five domains of care and support given by UNAIDS and WHO (2004). Each domain had different services and these services were rated based upon a 4 point scale viz, 0Very Bad, 1 Bad, 2 Good and 3 Very Good. To assess the inter scorer reliability, Kendall's W[b] were worked out for each of the dimensions. All the coefficients were significant at 1 per cent level. On the whole, the inter scorer agreement on the quality of care and support was significant at 1 per cent level. The Kendall's W (0.538)indicates that there is high level of agreement on the ranking of agents of care givers and supporters. Likewise, among the domains, there is high level of inter scorer agreement among the respondents in Human rights and Legal dimension, Family and Community domain and Social and Economic domain. However, the inter scorer agreement is low in case of Psychosocial and Clinical domains of care and support.

From the table we can see that the score given to NGOS on the quality of care and support across the domain is highest followed by the government and then the family. Quality of support given by the Community is reported as low and Peers are scored as lowest by the children. Overall, the quality given of care and support given by the agents is scored at only 1.39.

Among the domains, we also see that quality of care and support in Psychosocial domain which include counseling, emotional support, spiritual support, reduction of stigma and discrimination and positive living is highest followed by Clinical domain which include testing, prevention of opportunistic infection, symptom control and pain management, treatment of AIDs related illnesses and opportunistic infection. The score on the quality of care and support becomes lower in the Human Rights and Legal domain which include legal aid, support and information, human rights legislation, advocacy training and rights awareness raising followed by Family and Community domain which include psychosocial and medical, socio-economic and legal care and support for families, care providers and children infected or affected by AIDs. The quality of care and support becomes more lower in the Social and Economic domain which

include social protection, targeted financial support, income generation and employment opportunities, capacity building and advocacy support, food and nutrition assistance and appropriate agricultural inputs and services, education, orphan support, adoption services, help in the home and child care.

From the table we see that the care and support given by NGOs are adequate, followed by family and the government. However, adequacy of care and support given by community and peers is scored as low. We also see that Inter scorer concordance is high and significant.

4.4 Challenges, Coping Strategies and Suggestions

This section discusses the various challenges faced by the children, the coping strategies they use and the suggestions they made to improve care and support.

Table 18: Challenges of CLHIV

Sl.No	Challenges	Frequency	Percent
1	Physical Health	74	92.5
2	Education	59	73.8
3	Mental Health	57	71.3
4	Family Problems	47	58.8
5	Financial	36	45.0
6	Fooding	24	30.0
7	Stigma and Discrimination	16	20.0
8	No proper guardian	10	12.5
9	No proper treatment centre to improve health	5	6.3
10	Suicidal Ideation	4	5.0

Source: Computed

Table 18 shows the distribution of children according to the challenges they face. The table shows that the children face multiple challenges. Majority(92.5%) of the children face physical health challenges followed bythose children (73.8%) who face challenges related to education and children (71.3%) who reported as having mental health challenges. More than half (58.8%) of the children face family problems and 45% of them also face financial problems while 30 per cent of them face problems related to fooding and a fifth (20%) of them face challenges related to stigma and discrimination and more than a tenth (12.5%) have no proper guardian look after them. Less than a tenth face challenges such as absence of proper treatment centre to improve health and a few even have suicidal ideation.

Table 19: Coping Strategies of CLHIV

Sl. No	Coping Strategies	Frequency	Percent
1	Telling family/guardians	65	81.3
2	Praying	53	66.3
3	Suffer alone	53	66.3
4	Crying	26	32.5
5	Tell friends	23	28.8
6	Indulging in intoxicants	12	15

Source: Computed

Table 19 represents the distribution of children according to their coping strategies. From the table, we see that majority of the CLHIV (81.3%) cope by telling their family about their problems and more than half (66.3%) coping by praying followed by another 66.3 per cent who suffer alone. Less than a third(32.5%) of the children cope by crying and more than a fourth of the children cope by telling their friend while more than a tenth (15%) coping by indulging in intoxicants.

Table 20: Suggestions of CLHIV

Sl. No	Suggestions	Frequency	Percent
1	More regular medicine and nutritional service	11	13.8
2	More financial support	7	8.8
3	Identification of services for sustainable jobs	6	7.5
4	More regular health services by NGOs	5	6.3
5	Recreation Programs for CLHIV	2	2.5
6	More awareness on Stigma and Discrimination	7	2.5

Source: Computed

Table 20 highlights the distribution according to the suggestions given by children to improve care and support of CLHIV. The table shows that very few children gave suggestions. However, among those who gave, more than a tenth of the respondents (13.8%) suggested for regular medicine and nutritional service while less than a tenth (8.8%) suggested for better financial support for CLHIV. Other suggestions included more financial support, identification of services for sustainable jobs, more regular health services by NGOs, recreation programs for CLHIV and more awareness on stigma and discrimination.

4.5 Care Givers

This section covers information regarding the caregivers perceived quality of their care and support to CLHIV/AIDS across the various dimensions, the challenges they face as caregivers, their coping strategies and their suggestions to improve care and support of CLHIV/AIDS.

Table21: Perceived Quality of Care and Support

Sl. No	Domains	Mean
1	Clinical care and support	2.4
2	Socio-economic care and support	2.4
3	Psychosocial care and support	2.3
4	Family and Community care and support	2.3
5	Human Rights and Legal care and support	2.2
	Mean	2.3

Source: Computed

Table 21 shows the perception of caregivers on their quality of care and support across the domains. Similarly, the perceived quality was rated from different services included ineach domainwhich were rated according to a 4 point scale viz, 0 Very Poor, 1 Poor, 2 Good and 3 Very Good. From the table, we see that their perception on the quality of care and support given to CLHIV by them is good across the domains.

If we compare the scores of the children on their perceived quality of care and support across domains, we see that the scores they made in family is lower than the scores made by the caregivers on their care and support to children living with HIV/AIDS.

Table 22: Challenges of Caregivers

Sl. No	Challenges	Frequency	Percent
1	Financial	18	90
2	Family Problem	15	75
3	Mental Health	13	65
4	Physical Health	11	55
5	Fooding	9	45
6	Stigma and Discrimination	8	40
7	Education	4	20

8	No proper place of care	2	10
9	No proper guardian for children	1	5

Source: Computed

Table 22 shows the distribution of caregivers according to their challenges faced. From the table, we see that majority(90%) of them mentioned financial problems as a main challenge followed by those (75%) who reported family problem and 65 per cent who face mental health related challenges. More than half (55%) face physical health challenges while less than half (45%) of the caregivers have problems related to fooding and 40 per cent of them suffer from stigma and discrimination. Twenty per cent of the care givers reported that it effects their education and a tenth of them highlighted that the children have no proper place for care and a few(5%) reported that the children have no proper guardians

Table 23: Coping Strategies of Caregivers

Sl. No	Coping Strategies	Frequency	Percent
1	Praying	16	80
2	Suffer alone	11	55
3	Telling family/Guardian	11	55
4	Telling friends	6	30
5	Crying	2	10
6	Indulging in Intoxicants	2	10

Source: Computed

Table 23 represents the coping strategies of caregivers. From the table, we see that majority(80%) of the caregivers cope by praying while more than half (55%) of them cope by suffering alone. Another 55 per cent cope by telling their family and a fifth (20%) of the caregivers cope by telling their friends. Tenth per cent each cope by crying and indulging in intoxicants and another 10 per cent tell their colleagues.

Table 24: Suggestions of Caregivers

Sl. No	Suggestions	Frequency	Percent
1	Awareness on HIV/AIDS in the community	4	20.0
2	Financial and more community based support	3	15.0
3	Equal opportunity in society and Church	2	10.0
4	Regular counselling and nutrition service	2	10.0
5	ART services must be more accessible	1	5.0

Source: Computed

Table 24 shows the distribution of caregivers according to the suggestions for improving care and support to CLHIV. The table shows that a fifth (20%) of the respondents suggested for

more awareness on HIV/AIDS in the community and more than a tenth (15%) suggested for more financial and community based support. A tenth (10%) of the respondents each suggested for equal opportunity in society and church and regular counselling and nutrition service while a few (5%) of the respondents suggested for more accessible ART services.

4.6 Participatory Techniques

Participatory techniques were conducted to make sure that the children participated in the research process and also gather qualitative data to provide any additional information that could achieve the objectives of the study.

4.6.1 Focus Group Discussion

Focus Group Discussion was conducted among the CLHIV on various topics such as the causes of infection, its consequences, the challenges they face, the coping strategies they utilize and the suggestions to improve care and support of Children Living with HIV/AIDS. The findings are as follows:

a) According to the children, the main cause of infection was mother to child transmission.
b) Their challenges include poverty, broken family, problem in physical health and problems in education because of poverty.
c) When they face such challenges the children usually tell their family or guardians and also pray to cope with their challenges.
d) To improve care and support, the children suggested for more financial support, free regular check-up and free medicine and nutritional service.

4.6.2 Daily Activities Schedule

This activity was conducted to understand the daily routine of the children and provide information about what they do in weekdays and in weekends. This activity was conducted with children living with their parents or relatives in communities.

Table 25: Daily Activities in Weekdays

Time	Activities
5:30am	Wake up
5:45am-6:30am	Study hour
6:30am-8:30am	Prepare for school Eating morning meal
8:30am-2:30am	School hour
3:00pm	Going home from school
3:30pm-4:30pm	Study hour and doing home work
4:30pm-5:00pm	Leisure time Helping parents/relatives with household chores
5:00pm-6:00pm	Dinner
6:00pm-9:00pm	Study hour
9:00pm	Sleep

Table 26: Daily Activities in Weekends

Time	Activities
6:30am	Wake up
7:30am	Eating morning meal
8:00am-10:00am	Watching television
10:00am-12:00pm	Eating afternoon snacks Helping parents with household chores, Going to church service
12:30 pm - 4:00 pm	Taking a bath Playing games (football, computer games) Going to church service if it is Sunday Helping parents with household chores
4:00pm-6:00pm	Prepare dinner, Watching Television
6:00pm	Eating dinner
7:00pm-9:00pm	Rest Study, Watching Television
9:00pm	Sleep

4.6.3 In-depth Interview

In-depth interview was also conducted to highlight cases that gave qualitative information about the lived experience of the children. Three cases are highlighted to have a more in-depth understanding of CLHIV/AIDS.

4.6.3.1 Case 1

Mami (fictitious) is a 14 years old girl who was born out of wedlock. She lives with her mother, stepfather and three younger half siblings (2 boys and 1 girl). They come from a low economic background and belong to the BPL category. Both her mother and stepfather are daily labourers and her stepfather is an alcoholic. She was infected with HIV from her mother at birth. As her parents earned very few income, Mami's childhood was filled with financial related problems. She and her siblings needs were not met and she even had to discontinue her studies due to poverty. Her stepfather often abuses her emotionally when he gets drunk and this makes Mami very suffer from anxiety. When such kind of abuses takes place, her father would always mention that she was not his real daughter. Her stepfather would also often physically and emotionally abuse her mother. With no emotional support from her mother and half-siblings, she would tell her maternal grandparents who lives in their locality to cope with her predicament. Though she wants to live with her grandparents who invite her to do so, her mother would not allow her to live with them.

When luck seemed to have run out, an NGO that works in the area of HIV/AIDs identified their family and sponsored the family financially. This support has helped her parents in looking after the basic and health needs of the children besides their education. Beside the support that they receive from the NGO, they also receive financial support from the community and the church because of their low economic background.

At present, Mami is studying inclass8and she is one of the brilliant student in her class. As far as her health is concerned, Mami has no major problems or challenges and she takes regular ART from the NGO. She also faces no challenges related to stigma or discrimination at present. The abuses from her step-father has decreased but, at times he would still emotionally abuse her. Mami is very resilient about her health status and lives normally like every children. She loves to draw and paint and wishes to be a teacher when she grows up.

Analysis of Case 1

The case of Mami reveals multiple challenges that children living with HIV/ASIDS face. Firstly, she was infected with the virus from birth, a result of her parents and secondly, we see how poverty affects provisions of basic needs such as health and education for Mami. We also see that she was discriminated by her stepfather and abused emotionally since childhood with no or little support from her mother. This has caused a sense of fear in Mami and even wishes to leave her home and be with her grandparents who is her source of coping and security. We also see a resilient nature on Mami and is not affected much by her health status.

Though the case illustrates the poor conditions of CLHIV/AIDS, we also see that care and support also exist externally from the NGOs, community and the Church that gives financial support to poor families as well as families affected by HIV/AIDS

4.6.3.2 Case 2

Lala (fictitious) is a 12 years old boy studying in class 7. He lives with his mother and younger sister. They come from a low economic background and belong to the BPL category. Lala was infected with HIV from her mother through breastfeeding. When Lala was only a month old, his parents divorced but after a year they were remarried again. During his parents' divorce, his father was infected with HIV and this was how it was transmitted to his mother and then eventually to him. When Lala was only 7 years, his father died and since his death, his mother took care of him and his sister by earning a small income from their petty shop.

Soon after, an NGO that worked in the area of HIV/AIDS identified their family and sponsored the family financially. The NGO also helped by giving free second hand clothes to his mother for them to sell and have all the profit. This provided opportunities for them to live a decent life and for the children to go to school without financial difficulties.

Lala is one of the smartest student in his class, however, due to his skin rashes, his school mates use to make fun of him. At times, he would wish to drop out because of this and at times he spends less time with his friends to avoid his hurt. His skin rashes gives him an inferiority complex.

Lala loves reading books and watching news in Television and dreams of becoming a police officer when he grows up.

Analysis of Case 2

The case of Lala is almost similar to the case of Mami with regards to poor economic background and mode of transmission. As far as social support is concerned, Lala's family also get such support from an NGO which improved their lives. However, in this case physical symptoms is seen as the cause of creating inferiority complex and also challenges in the school. One positive indication in this case is that Lala is not much affected mentally and hopes for a better future for himself.

4.6.3.3 Case 3

Rini is a 17 years old girl who was married and divorced. She lives with her one year oldchild. She comes from low economic background and belongs to the BPL category. When she was only 16 years old, she got married without knowing that her husband was HIV positive.

It was only after she delivered her child that she knew she was positive. Her husband abandoned her and their child even before a year lapsed from the day of their marriage. Since then she has been looking after herself and the child by selling clothes and sometimes working as a daily labourer. Her trade was not enough to fulfill their basic needs and sometimes it became difficult for Rini to manage herself and her child. When all hopes seemed lost, one NGO working in the area of HIV/AIDS identified her and supported her in kind and money. She and her child are undergoing antiretroviral therapy through the NGO and she continues her business for her sustenance.

Rini is not accepted by her family because of her health status and suffers from stigma and discrimination. Sometimes she feels so stressful that she even thinks of committing suicide. However, the thought of her 1 year old child gives her strength to carry on and have hope. She hopes that with the help of the NGO, she and her child will have a better tomorrow.

Analysis of Case 3

The case of Rini is a peculiar one as she was married as a minor. Her problems increased when she found out that her husband was the reason behind her and her child being positive. It became worse when she was abandoned by her husband soon after their marriage. So at a very young age, Rini had to experience what people don't usually experience which was made more

sever because of poverty. Apart from these challenges, this case also illustrates stigma and discrimination that exist even within families that creates severe mental trauma and emotional imbalances.

Like the other two cases, we also see in this case the proactive work done by NGOs in the care and support of children or families infected with HIV/AIDS. Their care and support clearly shows how the children and the families develop in spirit, work and in health.

Chapter-5

Conclusion

This chapter summarizes the study by highlighting the whole gist of the research and its major findings. It also includes suggestions suggestion for social work intervention and policy making in the area of care and support of Children Living with HIV/AIDS.

Care and support to CLHIV/AIDS is very much essential for their overall development.It truly enhances their quality of life because it covers all aspects of bio-psycho social and spiritual realms of the person. Because of their vulnerability, children are often more subjected to ill treatment, stigma and discrimination and as such they are likely to suffer more as human beings. Therefore, form a rights based approach, it becomes imperative for scholars to delve into research in the area of the most vulnerable population, i.e Children Living with HIV/AIDS for this matter.

According to UNAIDS and WHO (2004), care and support is characterised by five interrelated domains which are Psychosocial (counselling, emotional support and spiritual support, reduction of stigma and discrimination, positive living); Clinical (testing, prevention of opportunistic infections, symptom control and pain management, treatment of AIDS-related illnesses and opportunistic infections including TB, treatment adherence support and information, alternative/traditional medicine); Social and economic (social protection, targeted financial support, income generation and employment opportunities, capacity building and advocacy support, food and nutrition assistance and appropriate agricultural inputs and services, education, orphan support, adoption services, help in the home and child care); Human rights and legal (legal aid, support and information, human rights legislation, advocacy training and rights awareness-raising) and Family & community (psychosocial and medical, socio-economic and legal care and support for families, care-providers and children infected or affected by AIDS) (In HIV Care and Support Working Group, 2008).

The need for the care, protection and providing opportunity for Children Living with HIV/AIDS is necessary in today's world especially in our society. There is very few research on Children Living with HIV/AIDS in Mizoram and it is hoped that this research will fill the gap and highlight their social demography, how they were infected,whether care and support are available, adequate and qualitative across different dimensions and what agents supports them across the dimensions.It will also attempt to find out the challenges and coping strategies of the children and will also highlight their suggestions for improvement of care and support. Further, this study will also highlight the perceptions of caregivers on their care and support, the challenges they face and their coping strategies. Lastly, it will also highlight suggessions made by the caregivers to improve care and support of CLHIV/AIDS.

In this study, children living with HIV/AIDS refer to those children living with HIV/AIDS between the ages of 11-18 years. Care and support means the various domains of care and support given by UNAIDS & WHO (2004). Further, caregivers will refer to parents, guardians and institutional authorities involved in the care, support and rehabilitation of children living with HIV/AIDS .Lastly, agents of care and support in this study will include family, peers, community (Young Mizo Association (YMA), MizoHmeichheInsuihkhawm Pawl (MHIP), Mizo Upa Pawl (MUP) and church organisations), government and NGOs (Agencies directly involved in HIV/AIDs).

The study is exploratory in design and cross-sectional in nature. Both quantitative and qualitative method of research was used to gather data. It was conducted within the Aizawl Municipal area, Mizoram. The study was conducted in the Aizawl city only. With the help of NGO's, children living with HIV/AIDS were found out but only those who are registered in NGOs. Children who registered only in Gan Sabra, MSACS, World Vision, Vihaan (care and support) and Peace Home were selected. A number of 80 children were selected those who are between the age of 11-18 years. In the meantime, among the caregivers, 20 of them were selected. So, overall the sample size were 100 (80 children and 20 caregivers). The study collected data from primary source and secondary sources.Primary source include data collected from CLHIV/AIDS through a structured interviewed schedule conducted during the study and information gathered from in-depth interview the children and their caregivers.Secondary source include data collected from Government and Non-Governmental records.

A semi-structured interview schedule formed the tool for data collection. The tool was constructed based on dimensions of care and support given by UNAIDS and WHO (2004), review of literature and pilot studies. The tool was child centric where active participation from the children was sought. The tool included information regarding the social demographic characteristics of HIV/AIDS, the domains of care and support provided to them, the availability, adequacy and quality of care and support provided to them across domains and the challenges and coping strategies of children living with HIV/AIDS in Aizawl. Separate tool (Semi Structured Interview Schedule) was also constructed for caregivers to find out their perceived quality of support across domains, their challenges, coping strategies and suggestions to improve care and support for CLHIV. Qualitative and Participatory techniques such as in-depth interview, focus group discussion and cause and effect diagram were conducted to gather additional information. Pre-testing of the tool was conducted to check the reliability and necessary changes to suit the children were made accordingly to maintain ethical standards in research.

The data shall be analyzed using Microsoft excel and SPSS package. Descriptive statistics, case vignettes and focus group discussion were analyzed in order to find out the socio-demographic characteristics of children living with HIV/AIDS, the availability, adequacy and quality of care and support and the dimensions of care and support. The challenges faced and the coping strategies of children living with HIV/AIDs and the caregivers were analyzed. Further, the perceived quality of caregivers was also analyzed. Kendall's Coefficient of Concordance was also used to find out the level of scorers agreement with respect to the children's perceived adequacy and quality of care and support given by the agents.

Informed consent was taken from the respondents (children and caregivers) and from the NGOs i.e. MSACS (Mizoram State AIDS control society), World Vision, Peace Home and Gan Sabra. Only those who give consent were interviewed. Keeping in view the sensitiveness of HIV/AIDS in Mizoram, confidentiality was maintained with utmost priority.

5.1 Major Findings

The research observed the following findings:

- More than half of the respondents are between the age group 11-14 years.
- More than half of the respondents are female.

- Majority belong to Mizo Sub-Tribe and only a few of the respondents belong to Non-Mizo Sub-tribe.
- All the respondents are Christian and a large number of the respondents belong to Presbyterian denomination.
- Nearly half of the children are from the middle school level.
- Majority of the respondents belong to Joint Family.
- Nearly half of the children comes from a Broken family.
- More than half of the children are fromthe BPL category.
- Majority of the respondents are school going and there were few who dropped out and worked as a daily labourer and petty businessman. Among those who worked their income ranged from Rs.2001-Rs.4000.
- Majority of the students did not know where they were tested. Among those who knew, majority of them were tested in ICTC and fewer in Private Hospitals. Majority of the children were tested between the years 2000-2010 where more children concentrated between 200-2005. Majority of them were tested at birth and mother to child formed the major mode of transmission.
- For most of the children, care and support was available from all the agents and availability was highest from NGOs followed by Government, Family, Community and Peers. Perceived care and support given by NGOs, Family and Government was found to be adequate while perceived care and support given by Community and Peers were found as inadequate. The overall perceived adequacy of care and support given by all the agents was however, inadequate.
- Perceived quality of care and support given by NGOs, Government and family were rated as good while quality of care and support given by Community and Peers were rated as bad. The overall quality of care and support given by all the agents was found to be bad.
- Among the domains, quality of care and support was perceived as good in the psychosocial and Clinical domain while the quality of care and support was perceived as being bad in the Human Rights and Legal domain, Family and Community domain and Social and Economic Domain.
- Majority of the children had challenges relating to their physical health, education and mental health while a significant number of children had challenges relating to family

problems and poverty and other challenges includes fooding, stigma and discrimination, no proper guardian, no proper treatment centres to improve health and suicidal ideation.

- Majority of the children tell their family/guardians to cope with their challenges and a significant number of the children pray and suffer alone to cope with their challenges. Other coping strategies of the children include crying, telling friends and indulging in intoxicants.
- Suggestions of the children to improve care and support includemore regular medicine and nutritional service,more financial support,identification of services for sustainable jobs, more regular health services by NGOs, recreation programs for CLHIV/AIDS andmore awareness on stigma and discrimination.
- The perceived quality of care and support given by the caregivers across the domains was found to be good.
- The challenges faced by caregivers include financial problems, family problem, mental health problems, physical health problems ,fooding problems, stigma and discrimination, problems in education, no proper place of care and no proper guardian for children.
- Coping strategies of caregivers includepraying,suffer alone,telling family/guardian,telling friends,crying andindulging in intoxicants.
- The suggestion of caregivers to improve care and support of CLHIV/AIDS include awareness on HIV/AIDS in the community,financial and more community based support,equal opportunity in society and Church, regular counselling and nutrition service and ART services must be more accessible

5.2 Suggestions

From the research findings, following are the suggestions for social work intervention for policy for the person involved and uninvolved in care and support of children living with HIV/AIDS.

- Awareness programme regarding HIV/AIDS should be strengthened in the community.Focus should be made on awareness in stigma and discrimination especially in the schools and community.

- Community should take active steps in supporting the family who are living with HIV/AIDS.
- Government should take active steps in supporting and caring for children living with HIV/AIDS through education service and proper nutrition service.
- Comprehensive policies and services are needed to support BPL families, socially, psychologically and economically across the life course.
- More regular medicine, nutritional services and regular health services by NGOs and the government.
- Greater awareness in maintenance of confidentiality and acceptance is the need of the hour.
- Policies and programmes related to Care and Support of Children living with HIV/AIDS should be introduced specifically.
- ART medicines must be more accessible.

CERTIFICATE

This is to certify that the dissertation 'Care and Support of Children Living with HIV/AIDS in Aizawl, Mizoram' submitted by C. Hmingthansangi for the award of Master of Philosophy in Social Work is carried out under my guidance and incorporates the student's bona fide research and this has not been submitted for award of any degree in this or any other university or institute of learning.

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Date: December' 2017

Place: Aizawl, Mizoram

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DECLARATION

I, Ms C. Hmingthansangi, hereby declare that the subject matter of this dissertation is the record of work done by me, that the contents of this dissertation did not form bias of the award of any previous degree to me or to do the best of my knowledge to anybody else, and that the dissertation has not been submitted by me for any research degree in any other University/Institute.

This is being submitted to the Mizoram University for the degree of Master of Philosophy in Social Work Department.

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Dated: 13th December, 2017 (C.HMINGTHANSANGI)

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Contents

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ABBREVIATIONS

AAY	Antyodaya Anna Yojana
AIDS	Acquired Immunodeficiency Syndrome
APL	Above Poverty Line
ART	Anti-Retroviral Therapy
BPL	Below Poverty Line
CLHIV	Children Living with HIV
FGD	Focus Group Discussion
HIV	Human Immunodeficiency Virus
MSACS	Mizoram State Aids Control Society
NACO	National Aids Control Organisation
NGO	Non-Governmental organization
PLHIV	Person's Living with HIV
PSS	Perceived Social Support
SEC	Socio-Economic Category
SPSS	Statistical Package for Social science
UNAIDS	United Nations AIDS
UNICEF	United Nations International Children Emergency Fund
WHO	World Health organization

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FIELD-WORK EXPERIENCE

- **Community Health Action Network (CHAN)-** was placed for a period of 26 days and practice to conduct case-studies and Focus-group discussion under the community project and conducting group work with the children and women who are from the low economic background and Home-Visits.
- **Centre for Peace and Development (CPD)-** was placed for a period of 26 days and study one of the setting of CPD i.e., Family Counselling Centre (FCC). Different cases and process of the domestic violence in Aizawl were studied and visit the victim and the accused.
- **Community based Field-Work at Lungbial Community-** was placed a community fieldwork during 3rd and 4th semester, conducted a survey on "Substance abuse and HIV/AIDS among the Youth" at Lungbial community with 40 respondents.

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CHAPTER 1

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