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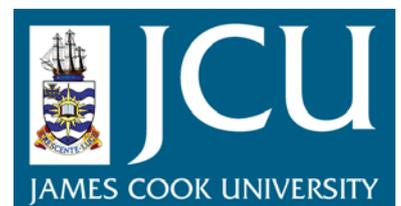
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The Child Friendly Schools Project for AIDS Affected
Children: An Evaluative Assessment in Northern Thailand

By

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(B Psych)

This thesis is presented for the degree of Doctor of Philosophy
of James Cook University Cairns

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*“Everyone has changed, people have become very apprehensive about being near me. I want the government to provide more concern and more money to purchase medicines. More importantly, I want society to provide encouragement because it is the best medicine for people with AIDS”. -
Female 25 years Chiang Mai*

The Child Friendly Schools Project for AIDS Affected Children: An evaluative Assessment in Northern Thailand

Abstract

HIV/AIDS is one of the greatest threats to child development in many parts of the world. In the countries most affected by HIV/AIDS, all children are touched by the epidemic and their lives are affected in unprecedented ways. Families may experience a range of emotional reactions including fear of contagion, anticipatory grief, shame, and perceived helplessness, which can impede coping and create disruptions and relationship problems. Further challenges, such as dealing with loss, uncertainty about the future, anxiety, sadness, anger, financial worries, and interpersonal stress, and an uncertain health support system are also common. Sadly, the struggle against real or perceived discrimination within their communities and even within families often reinforces their invisibility. Most children affected by HIV/AIDS tend to have limited access to health, education and welfare services. For the most vulnerable children, those whose parents are infected with HIV, care and support needs to start before children are orphaned. Their psychological support and acceptance in a non – discriminatory environment is just as important as their material needs. When considering the needs of children affected by HIV/AIDS, it is vital to recognise the importance of a supportive environment for a child's survival and development. Effective interventions seek to listen to children and their families. They work to strengthen the capacities of children, families and communities to respond effectively.

This research is an inquiry into the effectiveness of a project that aimed to create prototype replicable models of rights-based, 'Child-friendly', schools that respond to the special needs of children in distress, develop psychosocial competencies, and promote healthy lifestyles and resilience in children and youth affected by AIDS in three districts of upper northern Thailand. Emphasis was placed on building the self-esteem and effectiveness of children, as they are crucial components for optimal growth and development. One of the aims of this research was to provide an understanding of the lives and needs of children affected by HIV/AIDS, particularly within Thai culture.

It is a thesis with two parts. In part one, pilot research highlighted the psychosocial problems that occur in a familial unit affected by HIV. This research was intended to provide a holistic insight into how HIV disrupts key areas that underpin a child's development and social acceptance. Interpersonal relationships, grieving issues, communication, disclosure rates, acceptance in schools, orphan outcomes and the effects of AIDS stigma were investigated in-depth. Results suggest AIDS affected children suffer from a large array of problems that affect their wellbeing. Stigma and the sense of hopelessness associated with HIV/AIDS have the potential to greatly undermine the provision of care to children infected/affected by HIV/AIDS. Recommendations suggest that support for children must be an integral part of programmes reaching parents with HIV/AIDS. Focus should not only be on orphaned children, it should be on all children who are vulnerable. The implementation of more child centred programmes is also recommended, as effective child-centred interventions do not focus on children alone, but consider the social context of their communities, the relationships within their families, as well as the structures and services that are in place to provide support to children. Effective child-centred approaches are underpinned by a set of principles that view the child as a whole person, rather than as a set of separately defined needs.

The second part of the thesis presents a child centred intervention, the 'Child Friendly Schools' project (CFS) that aimed to alleviate the psychological problems experienced by AIDS affected children. An evaluative assessment was undertaken on this project utilising a combination of both qualitative and quantitative techniques. Focus group discussions and art therapy sessions provided first hand, qualitative feedback. ¹The case studies of

¹ All The names of the people researched in this thesis are fictional. Names and details have been left out to protect the identity of the individuals who participated in this research.

three HIV affected children containing the stories of the families and communities are presented to further highlight the complexities experienced, and to provide personal feedback on the project.

Pre and post-test screens for depression and self-esteem provided an important situational analysis and a useful quantitative measure for determining if the project was effective in lowering depression and enhancing self-esteem. The results of the screening suggest a very noticeable improvement in the depression and self esteem levels of the children after a one-year period of project implementation. Overall results from both qualitative and psychological testing suggest that the CFS intervention had played a major role in improving the psychosocial wellbeing of AIDS affected children and those in difficult circumstances.

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Last but not least, special gratitude goes towards my family, particularly my little daughter Katelyn, who has endured many boring weekends of dad working away on the computer. I promise to make this time up to you.

CHAPTER 1

Introduction

At the start of the 21st century, despite renewed global commitment to the realization of human rights, women and children are still frequently discriminated against, their rights violated on a daily basis. Children in particular are an extremely vulnerable group needing special care and attention. They are born with fundamental freedoms and the inherent rights of all human beings, and are entitled to the fullest achievement of their rights to life, health care, education, nutrition and a basic standard of living and to special measures for their protection. Although gender inequality and the exploitation of women and children exist in most societies, some of the worst manifestations are found in parts of developing nations (Kawewe & Dible, 1999). In many resource poor countries, children are often exposed to a variety of negative experiences and hardships that often deny them their rights and needs intrinsic to healthy development and active participation in their society. Far too many children around the globe die every day — 11 million each year- from largely preventable causes (UNICEF, 2000). Poverty, endless conflicts, the debt burden, sexual abuse, exploitation and HIV/AIDS are devastating and endangering women's and children's survival and access to important services such as education.

UNICEF recently commissioned an empirical study to look at how children in developing countries are affected by severe deprivations in seven areas: adequate nutrition, safe drinking water, decent sanitation facilities, health, shelter, education and information. The study used a more strict interpretation of 'severe deprivation' than is normally employed in such investigations. For example, a child severely deprived of an education means here a child who has never attended school, rather than the more widely used concept of 'non-completion of primary education'.

The researchers relied on these highly restrictive definitions to ensure that they measured deprivation at a level that undeniably undermines children's rights. The study concluded that over 1 billion children – more than half the children in developing countries – suffer from at least one form of severe deprivation. The fact that every second child is deprived of even the minimum opportunities in life is alarming. Moreover, using these criteria, the

study found that about 700 million children suffer two or more forms of severe deprivation (UNICEF, 2005).

Today, worldwide, over 120 million children of primary school age do not attend school; of these, roughly two-thirds are girls (UNICEF, 2005). There is an unmistakable correlation between education and mortality rates, especially child mortality. The implications for girls' education are therefore particularly critical (UNICEF, 1999). Girls are at particular risk of exclusion from school and comprise around 60 per cent of the children worldwide who do not attend primary school (ILO, 2002). In South Asia alone, one in three school-aged children are out of school — in total, an estimated 44 million children. In developing countries, child labour is increasing despite several international agreements against it or that seek to limit it. The number of working children in the developing world (aged 5 to 14) has reached 211 million. The International Labour Organisation has determined that 186 million of these children are engaged in child labour in its worst forms (ILO, 2002).

Asia is home to the largest concentration of child labour with some 127.3 million working children (ILO, 2002). How many children are working full time or combining their economic activity with schooling, and how many have had their education suffer because of their work is difficult to estimate. Far from being static, children's involvement in the labour market is constantly changing. Individual children move in and out of school and work, and between different types and intensities of work depending, for example, on the season, the immediate cash needs of the family, and where income opportunities are perceived to exist (ILO, 2002). School performance is bound to suffer as a result of attendance made irregular by child labour.

The 1997 financial and economic crises that hit Asia resulted in a sharp increase in the numbers of child labourers and school dropouts. Governments and other agencies recognised the threats that the crisis might pose to the development of children. Economic downturns make children potentially vulnerable in terms of inadequate nutrition, health services and education. Post-crisis forecasts included dramatic increases in poverty, the deterioration of public services and the flow-on problems of malnutrition, threats to public health and education, and increasing family and community dislocation.

These threats to the substantial gains in child well-being achieved over the last two decades spurred both concern and action. To date, the impacts of the crisis on poverty and on children have been serious, but fortunately less severe than originally anticipated (UNICEF, 2004). However, the greatest impacts have been on the especially vulnerable within society. These includes children with HIV/AIDS, children whose parents have died from HIV/AIDS, children in families where one or both parents are HIV positive, hill tribe children, and the invisible poor that includes some school drop-outs, urban slum dwellers and children of the small minority or, other families that are acutely marginalised within society. The forecast for these minority groups in many Asian countries is gloomy. The economic downturn has pressured even more families into sending their children into the labour force to increase familial income. In many instances, children are pushed into employment where they are at high risk of sexual and moral exploitation. Rates of HIV infection are escalating due to the desperation of young, impoverished women and children being coerced, or deceived into prostitution that, in turn, reduces their ability to protect themselves from sexually-transmitted diseases and HIV (Levine, Michaels & Back, 1996). For women and adolescent girls, the consequence of AIDS can be particularly dire (Bharat & Aggleton, 1999). In some countries women have been "blamed" for HIV disease even in circumstances where they have been infected by (remaining faithful to) their male partner (Bharat & Aggleton, 1999). Evidence also suggests that women are less likely to receive the kind of care and support made available to male household members (Warwick et al., 1998). Moreover, where the male head of household has died, there may be loss of social support for young women, ostracisation from the community, and a lack of legal right to inherit land and property (Levine, Michaels & Back, 1996).

AIDS is emerging as a disease of poverty, globally and within individual societies. In resource poor settings, the AIDS epidemic and the resulting social crisis is eroding all of the hard won achievements in health provision, poverty alleviation and education. AIDS poses risks to each of the three fundamental aspects of children's rights — survival, development and protection — adding to the abuse and neglect of children that continue to exist in many cultures despite worldwide articulation of concern for children (Kawewe & Dibie, 2000) and the United Nations Convention on the Rights of the Child.

AIDS is a socially destructive disease that produces a heavy human toll. Indiscriminate of race, religion, colour, gender or age, AIDS carries a heavy stigma that is damning in many

societies. Families affected by AIDS experience a decline in family nutrition and deterioration in economic status. Children are frequently pulled out of school — particularly girls — leading to an eventual de-education of the labour pool. The psychosocial problems experienced by each affected family are horrendous, with the AIDS stigma ensuring that surviving family members carry on the legacy of being touched by AIDS. Worse, HIV cases are rising rapidly among women and children in many previously unaffected areas.

In the past few years, as the demographics of people with HIV/AIDS shifted, more attention has been given to the youngest people affected by this virus and their unique needs, particularly in relation to rights and access to education. Globally, AIDS is a significant obstacle to children achieving universal access to primary education by 2015 a key target of UNESCO's Education for All Initiative and the UN's Millennium Development Goals.

The International Commission for Education of the Twenty-First Century considers education to be the most indispensable asset to overcome disparity, exclusion and social injustice (International Commission for Education, 1996). UNICEF also recognises education as a “basic human right” that is enshrined in several international conventions and declarations including the Convention on the Rights of the Child (1989), the World Children's Summit Declaration (1990) and the Jomtien Declaration (1990). The Convention on the Rights of the Child states that every child has the right to quality education that is relevant to her or his individual development and life (UNICEF, 1999). The Jomtien Declaration further reaffirmed that education is not only a fundamental human right but also a prerequisite for development and the elimination of poverty. The principal goal expressed by the signatories that attended the international Education for All (EFA) conference in Jomtien, Thailand in 1990 was to achieve universal basic primary education for all children. Emphasis was placed on the five contemporary bases for development in education: *access, quality, equity, efficiency and relevance* (UNICEF, 1999).

In the Asia-Pacific region, enrolment figures in primary school have improved significantly with steady progress being made towards the goal of universal primary education. The region appears to be on track to meet the 2015 goal of universal primary education (UNICEF, 2002). But although progress in these regions has been good, it has, however, been uneven (UNICEF, 2002). And despite significant progress in providing education and

meeting the EFA goals, there are still close to one billion illiterate people worldwide, two-thirds of whom live in Asia. In the East Asia Pacific region there has been some very good progress in education with 97 percent of children attending school but six million children are not in school. Six out of 10 of those are girls and most are from ethnic minorities (UNICEF 2001).

Education has been given so much importance because it is considered a vehicle for cultures and values that create an environment for socialisation to take place (International Commission for Education, 1996). Yet, in many environments, it has also become the primary cause of exclusion and disparity. Increases in primary school enrolments often cover up the growing disparity of access within the larger society. Rural areas, geographically remote communities, ethnic minorities and the generally less advantaged register slower or no progress as compared to more accessible target populations (International Commission for Education, 1996). Dropout rates and inaccessibility to education remain high in many Asian countries with large numbers of children leaving school before mastering basic literacy and numeracy. Lack of educational resources, poorly-trained insensitive teachers and equally insensitive teaching practices, outdated curricula and inflexible schools systems have all made the classroom irrelevant and inaccessible to children of poor and marginalized groups such as the AIDS affected (UNICEF, 2004).

However, it is not enough to simply ensure that children attend school. The quality of education is also of paramount concern (UNICEF, 2004). Experts foresee that a balance must be struck between the drive for expanded capacity and the improvement of the school system's internal efficiency in providing quality education and the ability of schools to retain students (UNICEF, 2004). Governments and education departments have a responsibility to provide an optimal learning and socialization environment for all children regardless of their race and economic status or whether they may be AIDS affected. The capacity and roles of teachers also need to be enhanced with training in child rights and the development of a curriculum that incorporates life skills, experiential learning and multiple intelligence techniques that may nurture the growth and development of all students. By universalising this *"child friendly approach"*, schools could be an integral key

in reversing the negative trends that have been experienced in child rights for large numbers of poverty stricken and marginalized children.

The structure of the thesis is as follows. Chapter one and two provide an introduction and general global overview of the HIV/AIDS pandemic and then narrow down to the infection rate in Thailand with reference to numbers of AIDS orphans. Chapter three highlights how HIV/AIDS affects children and details how psychosocial issues such as depression and self esteem, discrimination and stigmatization impact on a child's ability to adjust and grieve adequately when they lose a loved one. Protective factors and resilience are also discussed. Chapter four details pilot research that was undertaken to determine how parental HIV status affects orphan outcome. This chapter provides an in-depth analysis on psychosocial issues that affect children and families affected by HIV/AIDS.

Chapter five aims to provide an insight into community and child centered approaches and provides background information and objectives of the Child Friendly Schools project. Useful predictive models developed from the pilot research provide an insight into the problems experienced and strategies utilized by the CFS project to negate these. Chapter seven is the main study methodological section and details the qualitative and quantitative instruments utilized in the research. Chapter eight provides information on the Rainbow Camps conducted as one of the main CFS activities. This section also provides qualitative results which complement the main study results section in chapter seven. Chapter nine describes three case studies which provide a personal insight into the lives of three AIDS affected children. Chapter ten discusses the positive qualitative and quantitative results of the research and provides recommendations for future action.

CHAPTER 2

A Global Overview of the AIDS Epidemic

The AIDS pandemic is widely referred to as the most dramatic of the world's health problems, causing innumerable social and economic problems in countries around the world (UNAIDS, 2004). At present, global statistics suggest that there are approximately 39.4 million HIV-infected people including adults and children; a rise from 35 million in 2003 (see figure 1). Over 20 million people have died since the first cases of AIDS were identified in 1981 (UNAIDS, 2004).

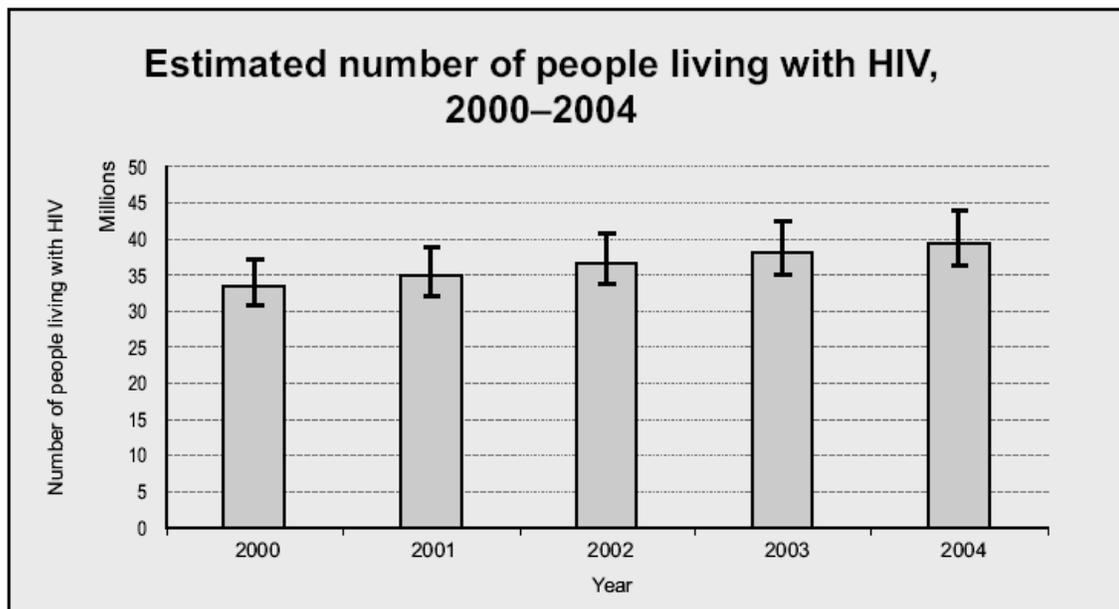


Figure 1: Estimated Number of People Living with HIV Globally 2000-2004

Source UNAIDS Update, December 2004

Sub-Saharan Africa is home to just over 10% of the world's population – and almost two-thirds of all people living with HIV, approximately 25 million. The epidemic in Asia is expanding rapidly. This is most evident with sharp increases in HIV infections in China, Indonesia and Vietnam. National HIV infection levels in Asia are low compared with some other continents, notably Africa. The populations of some Asian nations are so large that even low national HIV prevalence means large numbers of people are living with HIV. Latest estimates show some 8.2 million people were living with HIV at the end of 2004, including the 1.2 million people who became newly infected in the past year. AIDS claimed

some 540 000 lives in 2004. Among young people 15–24 years of age, 0.3% of women and 0.4% of men were living with HIV by the end of 2004 (UNAIDS Update December, 2004).

The AIDS predicament is worsening and primarily concentrated in resource poor countries. At present, 95 percent of people with HIV live in the developing world, a proportion that is likely to grow as infection rates rise due to poor health systems, poverty and limited resources — all of which assist the spread of the virus (Rivers & Aggelton, 1999). Globally, five to six million people need antiretroviral medicines now; yet only 7% in low- and middle-income countries have access to these drugs—fewer than 400, 000 people at the end of 2003 (UNAIDS, 2004).

Women and Young people

Women typically have limited access to reproductive health services and are often ignorant about HIV, the ways in which it can spread and prevention options. Social and cultural norms often prevent them from insisting on prevention methods, such as the use of condoms in their relations with their partners (UNAIDS, 2004). As of December 2003, women accounted for nearly 50% of all people living with HIV worldwide, and for 57% in sub-Saharan Africa. Similar factors are threatening women in South and South-East Asia, but the overall impact in the region is much lower because the epidemic in most countries is concentrated among injecting drug users and other key populations. At the end of 2003, women accounted for 28% of infections, a slight increase compared to end-2001 estimates. In South Asia, women's low economic and social position has profound implications. Congruence between indicators of women's poor status and their HIV vulnerability suggests a close link between patriarchy and HIV in South Asia (UNDP, 2003).

Young people (15–24 years old) account for half of all new HIV infections worldwide; more than 6000 contract the virus each day (UNAIDS Update, December 2004). Socio-cultural, political and economic forces, such as poverty, migration, war and civil disturbance, increase the risk of HIV infection for young people in developing countries (Sweat and Denison 1995). Young people may also face the increased risks of HIV infection by virtue

of their social position, unequal life chances, rigid and stereotypical gender roles, and poor access to education and health services (Rivers and Aggelton, 1999).

Numbers of AIDS Orphans Globally

By 2003, 15 million children under the age of 18 had been orphaned by HIV/AIDS; just two years earlier, the figure stood at 11.5 million. Eight out of ten of these live in Sub-Saharan Africa. It is estimated that in 2010, over 18 million African children under the age of 18 will have lost one or both parents to HIV/AIDS, and the number of double orphans, children whose mother and father have died, will increase by about 2 million over the same period (UNICEF, 2005). Although the orphan crisis is located mainly in Africa at the moment, countries in other regions (especially the Caribbean and Asia) are expected to experience large increases in the number of children orphaned by AIDS (UNAIDS, 2004). While HIV prevalence remains low, absolute numbers of orphaned children are much higher in Asia, which has almost four times more children. In 2003, there were 87.6 million orphans due to all causes in Asia, double sub-Saharan Africa's 43.4 million (UNICEF, 2004). There is, however, insufficient information in Asia to provide figures for the number of AIDS orphans in individual countries. UNAIDS, WHO and UNICEF define AIDS orphans as children who lost their mother to AIDS before reaching the age of 15 years. Some of these children have also lost, or will later lose, their father to AIDS (UNAIDS, 2004).

As the epidemics of HIV and AIDS develop over time, key health agencies have recognised just how much of an impact social inequalities and power relations have on HIV transmission. Factors such as poverty, migration and urbanisation play a very significant role in facilitating HIV infection (Sweat & Denison, 1995). UNAIDS researchers believe that up to 95 percent of people infected with the HIV virus in developing countries probably do not know they are carriers, making investment in preventing the virus from spreading crucial (UNAIDS 2001).

HIV/AIDS in Thailand



Figure 2: Map of Thailand and neighbouring countries

Source- United Nations

UNAIDS and UNICEF have estimated that there are at present 900,000 HIV-infected persons in Thailand (2 to 3% of the adult population). Latest estimates suggest that to date 7,500 children have been infected via vertical transmission ². Approximately 13,000 children are born at risk for mother-to-child transmission annually. Without interventions, 4,000 children will become infected each year, about one seventh of all new infections (UNICEF, 2004).

² HIV transmission from mother to child during the birth process

In stark contrast to the UNICEF and UNAIDS figures, the Bureau of Epidemiology in the Thai Ministry of Public Health reports state if that, by the end of 2003, an estimated 570,000 adults and children were living with HIV/AIDS in Thailand, and 65,178 adults and children were estimated to have died in 2003, with most deaths occurring in the 20-39 year age range (MOPH, 2003). The overall HIV prevalence rate for adults is estimated to be 1.5%. Among countries in Asia and the Pacific, Thailand (see figure 2) has the second highest reported adult HIV prevalence. More than 82% of HIV transmission is through sexual intercourse, and 38% of the reported cases are female. In 2003, a survey among men who have sex with men in Bangkok found an HIV prevalence of 17%. HIV prevalence among injection drug users (IDUs), in Thailand remains high (47%) (MOPH, 2004). In 2003, 1.2% of women attending antenatal clinics were found to be infected with HIV. With Thailand's effective national program for the prevention of mother-to-child HIV transmission (PMTCT), the transmission rate is 9%, so there are approximately 900 HIV-infected infants born each year (MOPH, 2004). In 2003 AIDS accounted for twice the number of deaths due to traffic accidents, and is the leading cause of death in Thailand (UNDP, 2004). The main route of HIV infection in Thailand is via heterosexual transmission (see figure 3).

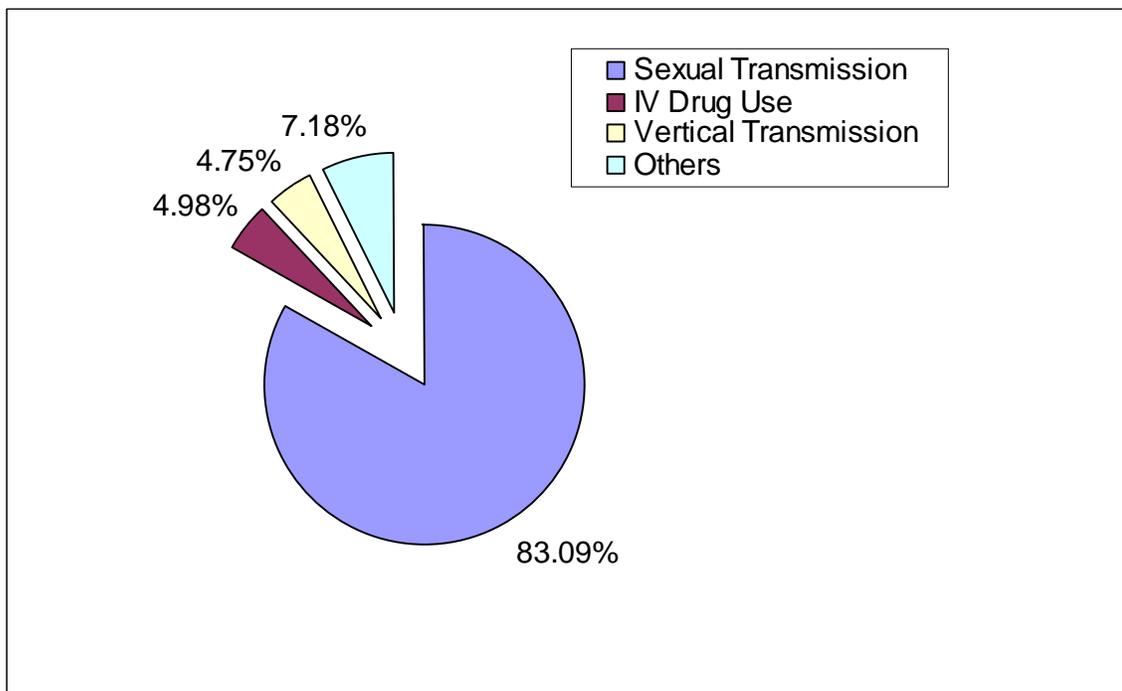


Figure 3: HIV Transmission Mechanisms in Thailand

Source: Data obtained from Epidemiology Division, MOPH, (2000).

Since a major shift in national AIDS policy in 1991, the Thai government has helped to generate and maintain a high profile for HIV/AIDS, and has followed a clear policy of strategic collaboration between governmental and non-governmental agencies in facing the challenge presented by the disease (UNICEF, 1997). The country's response to the HIV/AIDS epidemic over the last few years has become a model for other developing nations and, from an epidemiological perspective, is one of the most extensively documented (Phoolcharoen, 1998). The result has been a levelling out and subsequent downturn in the rate of new infections, which is now in a clear decline since 1995 (Wongchoosri et al, 1998). This success is apparently due to the willingness of the government to alter strategies and policy as knowledge of the extent of risk behaviour grew and the social, economic, and cultural roots of the epidemic were understood (Phoolcharoen, 1998). The number of new infections has fallen from a peak of around 140,000 a year in 1991, to around 21,000 in 2003 (UNAIDS, 2004).

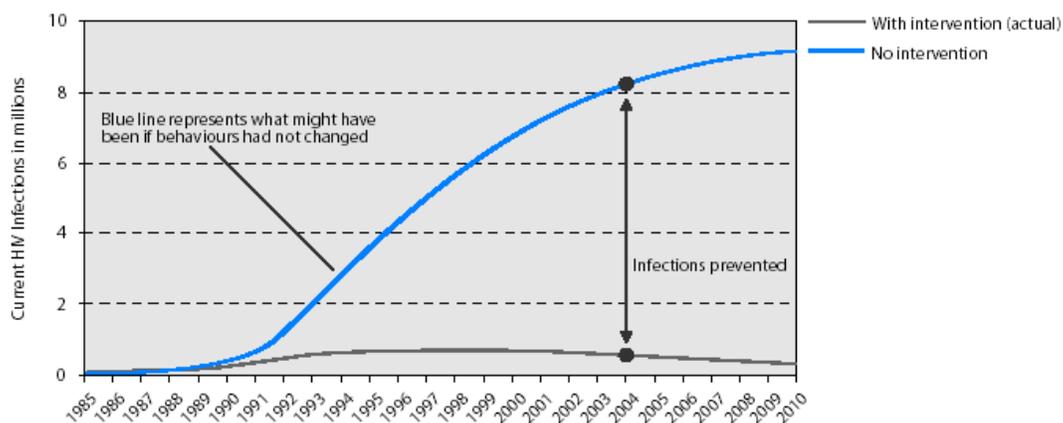


Figure 4: Millions of infections averted
Source: Brown, (2003).

Although Thailand has shown HIV prevention successes (see Figure 4) through strong political commitment and the promotion of a multi-sectoral approach, the country still faces the socio-economic and epidemiological impact of the epidemic. AIDS has become a leading cause of death and a growing number of people living with HIV/AIDS (PLWHA) require effective treatment. The Government aimed to address this need by making 50,000 antiretroviral treatments available at the end of 2004. Unless preventive efforts are sustained, the epidemic could quickly grow, especially within new and existing vulnerable groups such as spouses of sex workers clients, young people, mobile populations and drug users. Challenges for the country include reviving intensive HIV prevention efforts,

providing care and support to people living with HIV/AIDS, and maintaining political commitment at the highest level and in every government ministry (UNAIDS 2004).

HIV in Thailand today is spreading to more diverse populations than those that were infected ten years ago. Current prevention efforts and interventions have not kept pace with this evolution of the epidemic in Thailand; public information and education campaigns, once ubiquitous, are now barely perceptible. Public concerns about personal risks of HIV infection, once a cornerstone of the Thai success, have ebbed to worrisome levels, particularly among Thai youth (UNAIDS, 2004).

The double standard in sexual behaviour among Asian men and the thriving sex industry have been blamed for the rapid spread of the disease in Thailand (Weniger & Brown, 1996). In many instances, males who became infected through prostitutes often passed on the infection to their wives and unborn children. Due to this, preventive programs have placed a large emphasis on modifying sexual behaviour and changing social attitudes that condone male patronage of prostitutes (AIDS Weekly Plus, 1997). Still, the ignorance, complacency and stigma attached to the disease are proving to be potent killers today (UNAIDS, 2004). Twelve years ago, approximately 90% of HIV transmission in Thailand was occurring between sex workers and their clients. Projections show that by 2002, an estimated 50% of new infections were between spouses, as current or former male clients of sex workers transmitted the virus to their wives (Thai Working Group on HIV/AIDS Projections, 2001).

There is no room for complacency. Although there is a reduction in the numbers of young Thai men visiting brothels, for example, there is also an increase in casual sex. Behavioural surveillance between 1996 and 2002 shows a clear rise in the proportion of secondary school students who are sexually active with low levels of condom use (UNAIDS, 2004).

AIDS Orphans in Thailand

Up to date statistics on AIDS orphans in Thailand are lacking. An early study conducted in 1999 jointly by the Royal Thai Government Ministry of Health and the Global Orphan Project attempted to determine the exact numbers of children in Thailand under the age of 14 orphaned, or at risk of being orphaned, and displaced by the HIV/AIDS epidemic. The report indicated that there were at that time 21,294 women of reproductive age living with AIDS and a further 5,122 women of reproductive age already deceased and who had left children behind. It was estimated that at the end of 2000 there would be approximately 63,000 children infected with HIV, of which 47,000 children would die of AIDS. Reported cases of children born of HIV-infected mothers annually had increased from 3,100 in 1993 to 7,000 in late 1999. A proportion of these children would also be infected with HIV.

These statistics however, have historical underestimation problems, and more emphasis was placed at that time on the results of the sentinel surveillance report that indicated that 1.43 percent to 2.15 percent of all women of reproductive age were living with HIV (Global Orphan Project, 1999). A common problem that hinders the ability of researchers to accurately predict the true extent of the overall numbers of HIV-infected persons is the issue of disclosure and unawareness of HIV infection.

The Global Orphan study described the three phases of risk: tertiary, secondary and primary stages of being orphaned and displaced by AIDS. As of January 1999, 34,372 children under the age of 14 in Thailand had lost their mothers to AIDS or an AIDS-related disease. An additional 57,049 children were facing the considerable risks and hardships that come with having mothers who are suffering from an AIDS-related disease. More significantly, there were 420,731 children under the age of 14 who were living with an HIV-positive mother who was as of yet asymptomatic (Global Orphan Project, 1999).

Although accurate up to date statistics on the numbers of children orphaned by HIV/AIDS are not readily available from UN agencies or the Thai ministry of Public Health, unofficial reports from NGOs agree with Brown and Sittitrai (1995; see figure 5) and the Global Orphan Project (1999) projections .

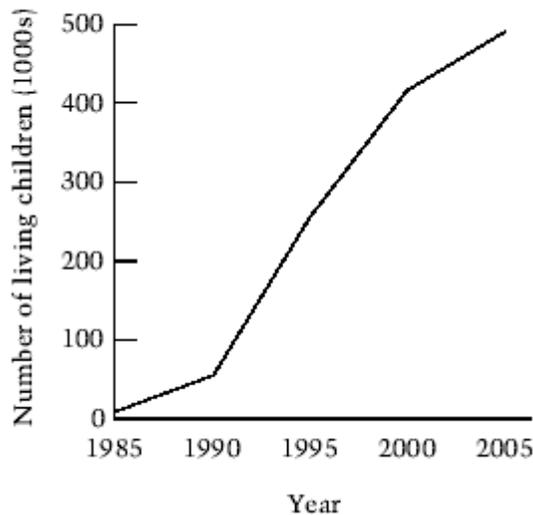


Figure 5. Living children under 15 years old whose mothers are positive for HIV or have died of AIDS: trends and projections. Source: Brown and Sittitrai (1995).

HIV/AIDS in Northern Thailand

The northern region, particularly the six provinces of the upper north, has so far borne the brunt of Thailand's AIDS epidemic. In Chiang Mai province, at the epidemic's peak in 1993, HIV prevalence amongst adults reached 8-10 per cent, three to four-fold higher than national prevalence in the same year. Some surveys indicate that as many as 15 per cent of the men aged 18-50 have died in the villages of this region. On several other fronts, the impact in Chiang Mai has been far more severe than national indicators would suggest. Life expectancy at birth has fallen by nearly five years, in contrast to a two-year reduction nationally. Death rates for young adults have risen 120 per cent in the province compared with 90 per cent nationally. The proportion of children orphaned by AIDS is three times higher in Chang Mai than the national average, as is the rate of increase in tuberculosis cases (UNAIDS & ADB, 2004). In Chiang Mai, 41% of households affected by AIDS reported having sold land, and 24% were in debt (UNAIDS, 2004).

These figures illustrate the seriousness of the social problem that faces Thailand with regards to the massive numbers of HIV-free surviving children that are AIDS affected. It is quite evident and alarming that Thailand has only seen the tip of the "iceberg." The true

extent of the AIDS orphan problem will become increasingly evident over the next decade. The advanced status of the epidemic in the Upper North has given high visibility to the suffering of people with HIV and AIDS and their families. Attention to the plight of affected children, in particular, has grown enormously since 1997, helped by the global campaign "Children Living in a World with AIDS" (UNICEF, 1999). Very few studies, however, have actually attempted to understand the complex issues and problems that complicate a child's ability to adequately deal with parental death from AIDS.

CHAPTER 3

"We cannot begin the 21st century with a generation of children lost to abandonment, despair and hopelessness" (Atwood, 1997).

How AIDS Affects Children

Thailand has one of the most successful and well-studied AIDS prevention programs in the world, however many of the social consequences of the epidemic, including its effects on children, have not been well-researched. Most research into the psychological effects of AIDS affected children to date has taken place in Western countries and Africa. Asia differs greatly from Western countries and Sub-Saharan Africa, socially and culturally, and, therefore, the factors contributing to children's vulnerability to the effects of HIV/AIDS and the violation of their rights may differ.

The consequences of HIV/AIDS can be far-reaching for young people. Not only does it cause terrible consequences for the individual, such as serious illness and eventual death, it also has the potential to trigger negative social reactions (Auer, 1996; Malcolm et al., 1998). The problems that children face as a result of HIV/AIDS begin long before their parents die because they live with sick relatives in households where problems are compounded by the financial drain of HIV/AIDS. Economic pressures and the need to replace lost adult labour often force children to drop out of school. Girls, whose education is traditionally considered less important than that of boys, are often forced out first. Because this leaves them practically unskilled and poorly educated, the employment opportunities open to them are narrow. Commercial sex work may, tragically, be seen as the only way for them to support their families and themselves (Levine, Michaels & Back, 1996). Children orphaned by AIDS are vulnerable in almost all aspects of their lives (Haworth et al., 1993; Foster et al., 1995; Foster et al., 1997; Hunter & Williamson, 1997; see table 1). HIV-positive parents and their children experience psychosocial distress because of the uncertainty about the children's future. Children may suffer depression or develop behavioural problems at school (Hunter & Williamson 1997).

Table 1: The potential impact of AIDS on children, families and communities

Potential impact on children	Potential impact on families and households	Potential impact on communities
<ul style="list-style-type: none"> • Loss of family and identity • Depression • Reduced well-being • Increased malnutrition, starvation • Failure to immunize or provide health care • Loss of health status • Increased demand in labour • Loss of educational opportunities • Loss of inheritance • Forced migration • Homelessness, vagrancy, crime • Increased street living • Exposure to HIV infection 	<ul style="list-style-type: none"> • Loss of members, grief • Impoverishment • Changes in family composition, and family and child roles • Forced migration • Dissolution • Stress • Inability to provide parental care for children • Lack of income for health care and education • Demoralisation • Long-term pathologies • Decrease in middle generation in households, leaving the old and young 	<ul style="list-style-type: none"> • Reduced labour • Increased poverty • Inability to maintain infrastructure • Loss of skilled labour, including health workers and teachers • Reduced access to health care • Elevated mortality and morbidity • Psychological stress and breakdown • Inability to marshal resources for community-wide initiatives

Source: Hunter and Williamson (2000, 2002).

The issues associated with progressive HIV infection in a parent are particularly complex as each different stage of HIV illness - diagnosis, illness progression, late-stage illness, death, and family reconfiguration - presents a different challenge.

Upon diagnosis and often throughout the course of illness, parents must confront issues of disclosure of their HIV status to children, adolescents, and extended family. They also need to plan for the placement of children after parental death. With progression of parental HIV illness, children and teenagers witness the physical and mental deterioration of their parent and are often forced to cope with these changes in the absence of clear information about their parent's health status. In some cases, HIV-associated dementia can impair an adult's capacity to function in a parental role, leaving children without adequate care or forcing older children and adolescents into parental roles (Dane & Miller, 1992).

Children who lose a parent to AIDS suffer grief and confusion, like any other children who experience the death of a parent. But there are special differences. For one thing, the psychological impact can be even more intense than for children whose parents die from more sudden causes, such as in armed conflict or as a result of an accident. HIV ultimately

makes people ill but it runs an unpredictable course. There are typically months or years of stress, suffering or depression before a parent dies. And in developing countries, where the epidemic is concentrated, effective pain or symptom relief is often unavailable to alleviate a parent's suffering.

Emotional suffering is perhaps the most acute effect of AIDS in the family, though this fact is not always sufficiently valued. Psychosocial distress begins well before the parent actually becomes physically ill, as knowledge of the parent's HIV-positive status can debilitate the family. Children may suffer lingering emotional problems from attending to dying parents and from witnessing those parents die. The death of one parent may be made that much more painful by the knowledge that the other is bound to follow in a relatively short period of time (Dane & Levine, 1994). In the worst affected countries, traditional coping mechanisms, such as adoption by extended families, are severely stressed. The act of permanency planning, the process by which a parent makes arrangements for the placement of his or her children after their death, is restricted due to the stigma and misconceptions surrounding HIV/AIDS. Successful execution of this process requires selection of future caregivers, disclosure of HIV serostatus to these individuals, and efforts to finalize the legal transfer of guardianship.

AIDS has seen the emergence of grandparent and sibling headed households. Unlike able-bodied, productive adults, grandparents and siblings often lack resources to provide adequate care for AIDS orphans (UNAIDS, 1997). With parental death, children and adolescents move into reconfigured families, most commonly into extended families also grieving the loss of loved ones.

Furthermore, with parental death, the supports available to the children and the family by virtue of the parent's AIDS diagnosis generally diminish or disappear. Most commonly, children and adolescents orphaned by AIDS are moving from one situation of poverty to another, with their care assumed by already financially limited families (UNAIDS, 2004).

Psychosocial Issues

The psychological and social issues associated with HIV are compelling. Children affected by HIV have higher rates of depression and anxiety, and some have been labelled

"autistic-like" because of severely withdrawn behaviour (Dane & Levine, 1994). HIV forces the child to confront an abbreviated life of chronic illness, including fear of death, loss of abilities, social stigma, plus the likelihood of others at home with the same disease. The effects parental illness and death have on a child's mental health and ability to cope are complex, and depend upon the child's developmental stage, resilience and culture. Consequently, psychological and emotional effects are less obvious and often go unnoticed or neglected. Changed behaviour may be dismissed as a mere transitional stage, a temporary disorder that will pass, rather than an indicator of psychological trauma with possible long-term implications.

Depression and Self –Esteem

Developmental research suggests that children who are orphaned through AIDS pass through a series of difficult adjustments as their parents pass through the successive stages of HIV disease, suffering psychological difficulties in addition to increased household demands and stresses from outside the household (Brown & Sittitrai, 1996). They are traumatized during the most critical period of their lives; when assumptions about self, others, and about the world are being formed; when their relations to their own internal states are being established and when coping and affiliate skills are first acquired. Due to the complexities surrounding HIV infection, the loss of maternal care and bonding may begin well before the mother has actually deceased. The impact of this maternal neglect on young children may have dire consequences for children's psychological adjustment and maturation, leading to potential problems in later life. According to Brier (1992), post traumatic reactions can easily have an impact upon subsequent psychological and social maturation, leading to atypical and potentially dysfunctional development. The effect of maternal HIV on infant development is a major concern because the virus has become so widespread among women of childbearing age. According to a United Nations report (UNAIDS, 2004), half the new cases of HIV infection that occur across the world each year are among 15–24 year olds. This group, constituting two and a half million people, are the next generation of parents.

It has been well established in studies not involving HIV/AIDS that maternal depression and lack of social support have adverse effects on children's development. Postnatal depression, particularly in disadvantaged communities, has been shown to be associated

with impairments in the child's growth and his or her social, emotional, and cognitive development (Murray & Cooper, 2003). By school age, children of women who suffer postnatal depression are at risk for showing externalising and internalising behavioural problems, and they have lower social skills and academic achievement (Forehand, Biggar & Kotchick, 1988). A key way in which maternal depression affects children's development is by disrupting the mother-infant relationship as well as routine parenting functions. Two studies have shown that HIV infection is associated with similar disturbances in mother-child interactions (Kotchick, Forehand, & Brody, 1997; Johnson & Lobo, 2001).

More than 59 years ago, Spitz (1946) described a form of depression in infants who had been separated from their mothers following hospital admission. He referred to the apathy, withdrawal, lack of interpersonal responsiveness, and visible sadness of these children as "anaclitic depression" and suggested it was the absence of maternal nurturance and the contact that produced such severe dysphoria (cited in Briere, 1992). Brier (1992) states that forms of deprivation may provide a vast store of negative childhood experiences that, in turn, have significant, yet overlooked, impacts on the later mental health of millions of people. Emotional neglect is difficult to determine. Not only do its parameters vary according to who is defining it and in what culture it occurs, it may also be subsumed under a more general definition of psychological maltreatment (e.g., the denial of essential stimulation, emotional responsiveness, or availability; Schakel, 1987).

Longitudinal research by Egeland and colleagues further supports the connection between early emotional neglect and immediate and longer-term depressive mood (e.g., Egeland & Sroufe, 1981; Egeland, Sroufe, & Erickson, 1983; Erickson, Egeland, & Pianta, 1989). Cohen and Syme (1985) also suggest that there is good evidence that interpersonal relationships have health related consequences. Some of the most persuasive evidence comes from epidemiological studies that show greater morbidity and mortality in people with fewer close relationships. Epidemiological and immunological data suggest that both the quality of relationships and their disruption are important (Bloom, Asher, & White, 1978).

Research conducted in the U.S. has suggested that children of HIV-infected parents – particularly those with symptomatic illness – experience higher rates of grief, depression,

dysphoria, anxiety, post-traumatic stress disorder, irritability, social withdrawal and impaired cognitive performance than others (Forehand et al., 1998; Forsyth et al., 1996). Forehand et al, (1988) compared the psychosocial adjustment of 87 inner-city African American children, 6-11 years old, whose mothers were HIV infected with that of 149 children from a similar socio-demographic background whose mothers did not report being HIV infected. Children were not identified as being HIV infected. Mother reports, child reports, and standardized reading achievement scores were used to assess 4 domains of adjustment: externalizing problems, internalizing problems, cognitive competence, and pro-social competence. The results indicated that, on average, children from both groups had elevated levels of behaviour problem scores and low reading achievement scores when compared with national averages. Relative to children whose mothers were not infected, those whose mothers were HIV infected were reported to have more difficulties in all domains of psychosocial adjustment. The primary analyses suggested that maternal depressive symptoms play a moderating, but not a mediating role, as the direction of the relationship between maternal depressive symptoms and child depressive symptoms differed between HIV-infected and non-infected groups.

Forsyth et al. (1996) study aimed to assess the mental health of children of mothers infected with the human immunodeficiency virus. Parents completed the Child Behaviour Checklist and the children completed the Revised Children's Manifest Anxiety Scale and the Children's Depression Inventory. Controlling for confounding variables, subjects were found by the Child Behaviour Checklist to be significantly more withdrawn and to have more problems with attention than controls, although total Child Behaviour Checklist scores were not significantly different. Compared with control children, the subject children reported more depression on the Children's Depression Inventory but were not more anxious. However, compared with children of asymptomatic mothers, the children of symptomatic mothers were reported to be significantly more anxious and/or depressed on the Child Behaviour Checklist and the children reported more anxiety on the Revised Children's Manifest Anxiety Scale. This study focusing specifically on uninfected children in families affected by the human immunodeficiency virus demonstrates some of the psychological ramifications of this disease.

Although scarce, research in developing countries shows similar mental health and psychosocial problems in children from families and communities affected by HIV/AIDS.

For example, Congolese children of infected parents show high rates of depression, anxiety, irritability, hyperactivity, and antisocial behaviour (Makaya et al., 2002). A study of Tanzanian children orphaned by AIDS found higher rates of suicidal ideation and internalizing disorders among 10 – 14 year olds compared to demographically matched non-orphans (Makame et al., 2002). Other studies show that bereavement and trauma are associated with witnessing declines in parental health (Sengendo & Nambi, 1997). In Uganda, researchers investigated the nature of emotional problems of school-sponsored orphans. In comparing the feelings of children orphaned by AIDS to feelings of non-orphans, investigators found that non-orphans showed more optimism: they expected to live longer and they imagined themselves staying in school, working, and wanting children. The children orphaned by AIDS were significantly less able to envision a future (Sengendo & Nambi, 1997).

A study found that healthy African-American children living in households with a parent or sibling diagnosed with HIV/AIDS struggle with emotional and social stressors that threaten to interrupt their psychosocial development. This study was designed to compare selected mental health variables and behaviours, depression, anxiety, somatization, and external problem behaviours, of inner-city, African-American children who live in a family where their mothers are infected with HIV/AIDS, and children who lived in non-AIDS infected families. Findings from this study indicated that there was not a statistically significant difference in levels of depression, anxiety, somatization, and external problem behaviours in AIDS-affected children when compared to children who did not live in the home with a parent or caregiver who was infected with HIV/AIDS. However, the results of this study did indicate that a statistically significant difference existed between AIDS-affected and non-AIDS-affected children with respect to the percentage of children who exhibited statistically significant levels of depression, anxiety, and somatization.

Kiirya (1993) found that orphans generally tended to evaluate themselves negatively, psychologically and emotionally. Kusimba et al. (1996) found that AIDS orphans are likely to suffer ostracism, especially when the extended family members and the community at large know that parents have died of AIDS. Those who are looked after by either widows or aging grandparents are disadvantaged in many ways including schooling and nutrition. Sengendo and Nambi's (1997) research further stated that children orphaned by AIDS had lower self - esteem and higher rates of depression. A high percentage of children were depressed, externally oriented, and showed evident signs of unresolved grief.

A study in Zambia found that 82% of those caring for children noted changes in their behaviour during parental illness. Caregivers noted that children became worried and sad and that they tried to help more in the home and stopped playing so as to be close to their parent (Poulter, 1997). In another study in Uganda, orphans were found to internalise behaviour changes, such as depression, anxiety and decreased self-esteem, rather than to exhibit acting out or sociopathic behaviour, such as stealing, truancy, aggression, and running away from home or school. Supporting children in such situations towards improved emotional well-being is critical to mitigate the long-term potentially negative impact of AIDS on children (Foster et al., 1997).

Parental coping with HIV infection and disease, which may include feelings of guilt, depression and anxiety, has a direct effect on child adjustment (Hough et al., 2003). These adverse effects may be preventable. Intervention research conducted in the U.S. has demonstrated that improvements in mental health and behavioural outcomes may be derived from psychosocial interventions for bereavement due to AIDS (Rotheram-Borus et al., 2000).

To date, little research has been conducted in high prevalence, low-resource countries to develop, implement, and evaluate theoretically-based interventions to minimize adverse mental health and psychosocial outcomes in children from 'hard hit' communities. Larger studies are required to identify factors that contribute to the vulnerabilities and resilience of such children. Attention needs to focus on ameliorating these adverse effects on the children of the acquired immunodeficiency syndrome epidemic (Forsyth et al., 1996).

The question that most urgently needs to be addressed is what can be done to help infected women and their young children and, in particular, what intervention strategies are necessary to minimise the impact of maternal HIV? There is good reason to believe that early psychosocial interventions in this population have the potential to enhance infant development. Psychosocial interventions in disadvantaged communities (without HIV), delivered during pregnancy and early childhood, have been shown to provide long-term benefits to children and their families. Interventions need to be evidence based and carefully formulated. Furthermore, they need to be culturally and locally appropriate.

Grief process

The death of a parent(s) means children are deprived of affection, attention, love and interpersonal and environmental stimulation, which is damaging and traumatic. They experience grief, sorrow and feelings of loneliness and isolation and suffer psychological distress that can have long lasting effects (Devine & Graham, 1999). Their self-esteem and view of themselves as individuals can also be affected. Since bereavement in children and adolescents may result in a number of emotional, cognitive, behavioural and physical problems, the resolution of grief is extremely important. Grief following a death by AIDS can be compounded by the stigma attached to the disease by some people. Family and friends may feel uncomfortable revealing that their loved one died of AIDS, making it difficult to talk honestly about their feelings. These are the "hidden grievers" who often suffer more damage due to the thoughtless and discriminatory attitudes of friends, family, and community. Some survivors are actively shunned when the truth about the death comes out (Dane & Levine, 1994).

When a family member dies, children react differently from adults. Children at different ages have very different concepts of death (Siegel & Freund, cited in Dane & Levine, 1994). Very young children may have little appreciation of the permanent quality of death (Levine, 1994). Hoagland (1984) points out that one of the most important discoveries about bereavement is that the symptoms tend to follow a predictable course over time. One must go through grief work, grieving for ones losses in order to heal ones wounds. When the wound is healed, there will be a scar, but it will be a healed psychological wound (Levine, 1994). Bowlby and Parkes (1979) describe four phases of the mourning process: (1) shock and numbness, (2) yearning and searching, (3) disorientation and disorganisation, and (4) resolution and reorganisation. All four dimensions are usually present when the mourner learns of death. It is the resolution of the conflicts brought on by the death, not the passage of time, by which the mourner achieves resolution of the process. A child surviving when family members die may often feel guilty (Dane & Levine, 1994). An important principle in this process is that children do not know how to verbalize or express guilt in the same fashion as adults. Guilt, as expressed in children, may often be best observed in behaviours and emotions which are related to self-hatred and self-destruction. The child will likely not be able to articulate that survivor guilt is intimately related to their sense of worthlessness, self-abusive or destructive behaviours. The amount of guilt a child feels may often be related to the degree to which they develop and

maintain false assumptions about the event (Bowlby & Parkes, 1979). Preschool children usually perceive death as temporary and reversible, a belief reinforced by cartoon characters who “die” and “come to life” again. Children between five and nine begin to think more like adults about death, yet they still believe it will never happen to them or anyone they know.

Bereavement clearly ranks high among stressful life events (Holmes & Rahe 1967; Lopata, 1979; Sanders, 1980; Vachon et al. 1980; Raphael, 1983). The loss from AIDS of a cherished and significant relationship can have both overt and inner psychological effects. Dane (1994) describes six salient features of an AIDS death that can have an influence on grieving and adjustment. They are (1) overall cultural response to death and the mourning process (2) socially unspeakable death, which tends to carry stigma, fear of contagion, discrimination, and secrecy (3) relationship to the deceased; (4) the child’s and adolescent’s understanding of death (5) survivor guilt; and (6) social supports.

According to child and adolescent psychologists and psychiatrists, it is normal during the weeks following the death for some children to feel immediate grief or persist in the belief that the family member is still alive (Dane & Miller 1992; Dane & Levine, 1994). Long term denial of the death or avoidance of grief is unhealthy and can later surface in more severe psychological problems (Dane & Miller 1992; Dane & Levine, 1994). The suffering of children ranges from the emotional trauma of watching one or both parents slowly die, to the double stigma of “AIDS” and “Orphan”, to profound insecurity and deprivation. Death is a part of everyday life, and children, at some level, are aware of it. If we permit children to talk about death, we can give them needed information, prepare them for a crisis, and help them when they are upset. We can encourage their communication by showing interest in and respect for what they have to say. We can also make it easier for them to talk to us if we are open, honest, and comfortable with our own feelings (Dane & Levine, 1994).

One common intervention identified for massive scale-up in Africa is the use of memory books, which are collections of family memorabilia (e.g., photos, letters, stories) believed to strengthen families' capacities to cope with grief, plan for the future, and disclose HIV-positive serostatus. Yet, little evidence exists to show for what age groups, under what circumstances, and to what extent such interventions reduce adverse short- and long-term mental health and psychosocial problems. Unintended effects of these interventions may

be more pronounced among children of different age groups or youth exposed to the physical, emotional, and mental deterioration of dying parents (Saldinger et al, 2003).

The social environment in which HIV/AIDS affected Thai and minority hill tribe children, as orphans, experience their grief is of great significance. This has direct implications concerning the support, both formal and informal, that is available and how they are able to manage their emotional reactions and practicalities of their care. Individuals working in care and support programs often express concern about how to address issues affecting these children such as emotional distress, worry, depression, and loss (Gilborn et al, 2001). Acharakup (1992) describes how many HIV/AIDS affected children experience a state of emotional deprivation that leads to depression and a general lack of interest in the surrounding environment (cited in Pitayanon et al 1996). Methods for assessing psychosocial wellbeing in these settings have so far been quite limited.

Discrimination/Stigmatization

Children face many uncertainties when their parents die from AIDS. The stigma attached to death from AIDS magnifies the emotional trauma experienced by bereaved children by damaging the network of family, friends and social support. It is common for these children to experience feelings of abandonment, helplessness and frustration in reaction to their parent's death from AIDS. Research has shown that children's adjustment may be worsened by aspects of the social environment, including HIV-associated stigma, social ostracism, and availability of resources and support (Sunpuwan, 2001).

Save the Children UK (SCUK) conducted a study to explore the socio-economic impacts on HIV infected and affected children in Vietnam. The research found that the HIV/AIDS epidemic has had a negative impact on a number of children's rights. Key impacts included: children dropping out of school; children starting work at an earlier age, sometimes in high-risk jobs such as sex work; and abandoning of children suspected to be HIV-positive. The research also highlighted a number of economic, social and cultural factors that contribute to poverty, discrimination and stigma, while increasing vulnerability to HIV/AIDS, lack of protection, and encouraging migration. Many children infected or affected by HIV/AIDS had migrated to other cities to find work and escape from stigma and discrimination (Save the Children UK, 2004)

Sunpuwan (2001), in her research, looked at social distance and acceptance of AIDS orphans in Phayao, Northern Thailand. She found that there was a distinct difference between AIDS orphans and non-AIDS orphans in regards to how they were accepted by the community. Discrimination against AIDS orphans was rampant, with many affected families and children experiencing economic hardships, emotional problems and an inability to ensure basic needs. Some of the factors that affected community acceptance were child health status, appropriate behaviour of the child, cause of parental infection, social status, and knowledge and understanding of HIV/AIDS. Im-em and Sasipen (1999) also found that the level of social acceptance of infected persons by the community was dependent on the behaviour of the person before becoming ill. Ratanalangkarn et al., (2004) conducted research in Khon Kaen province, Thailand, into the needs, self-esteem and health impact of AIDS on orphans in Thailand. The research findings suggest that AIDS orphans are more vulnerable and have a lower standard of living than children orphaned through other means. Findings further suggest that having a parent infected with HIV/AIDS impacted on children's health, needs, self-esteem, and also contributed to the development of social and psychological problems due to stigmatization and ostracism.

Discrimination on the basis of HIV seropositivity causes serious drawbacks in the campaign against HIV/AIDS. HIV/AIDS affected children's distress is often compounded by the prejudice and social exclusion directed at individuals with HIV and their families. For example in the north of Thailand, a 1994 study of 116 households affected by HIV found that in 48% of these, stigmatization, due largely to incorrect beliefs about HIV transmission, was widespread in everyday life. Fifteen percent of these families stated that other family members were also subject to some form of discrimination. Twenty percent of HIV/AIDS affected families with children stated that other children in the area were forbidden to play with their own (Pitayanon et al., 1996). There is an urgent need to legally protect orphans of HIV/AIDS and provide for their needs, ranging from education to economic, social and public health (UNICEF, 1997). Children in particular need to be protected by the law, especially in as far as their (or their parents) HIV status is concerned. They do not have to be infected in order to be affected by it. The mere knowledge that there is an infected member in their household can trigger fear and prejudice directed against children in and out of school, resulting in social exclusion, or even denial of access to schooling and health care.

Orphan Acceptance

It is likely that psychosocial distress among both HIV-positive parents and their children can be reduced by making provisions and plans for the children future. The earlier a parent's infection status is known, the more time he or she will have to plan for the children's future, in particular, to find another family or person who can care for and shelter them. Meeting psychosocial and developmental needs of children is based on a healthy bond between parent and child, the quality of the attachment, and the interaction between a growing child and the adults that shape a child's future. If we can safeguard a healthy attachment or bond between children and the adults caring for them, their chances of survival and a better quality of life are significantly improved. In protecting children affected by HIV/AIDS, so much depends on the families' capacity to support themselves in times of personal crisis, typically against a backdrop of long-term deprivation of basic survival needs. Who constitutes a family unit varies tremendously and often changes to meet the needs of its more vulnerable members. Although exact statistics are lacking, the majority of children in the countries most affected by HIV/AIDS live within their extended family and community.

Dhammadhikul's study (cited in Sunpuwan, 2001) in Chiang Mai, Thailand, looked at community acceptance of children orphaned by AIDS and found that most of the children who were not infected, or who could not be identified as being affected, would generally be accepted. These children could attend school or child care centres without fear of discrimination. Children who showed signs of infection faced discrimination and were not permitted to attend school or child care centres. These children were not permitted to play with other children in the community. Stimulation for these children primarily came from grandparents. Another study in Northern Thailand by Pittayayanoda (cited in Brown & Sittirai, 1995) found that 15% of community members held resentful feelings towards households that were affected by HIV/AIDS. Paninoi's (1998) research, also in Northern Thailand, found a direct correlation between acceptance and prevalence of HIV/AIDS in the community. Higher levels of community exposure to HIV/AIDS resulted in higher levels of acceptance (cited in Sunpuwan (2001)).

A fundamental response to HIV/AIDS must be to strengthen the capacity of families and communities to protect and care for children so they remain within the care of the families and communities. Children formulate personal identity on the basis of their interactions

with the people caring for them. They learn how to interact socially and to express feelings and thoughts by watching family members. More importantly, they gain a sense of themselves by how parents act towards them; how parents encourage them, make them feel safe in the world, and reflect the value the children have in the family. Families show children how to get along in the world. Throughout childhood, children mimic the interactions of those around them through observation and practice. Without a sense of self-confidence in their abilities, children are not able to venture out to practise social connections. This hampers their development in a profound way (Williamson, 2002). The developmental needs of children are best met in a stable, consistent, protective environment in close contact with the same caregivers throughout childhood. Children require a sense of stability and safety to be able to attend to the task of childhood, which is the integration of intellectual, emotional, physical, and social growth.

The longer a parent can work and the longer he or she can be helped to stay well and nurture and raise the children, the less pain and trauma the children will experience. The parent will also have more time to pass on their skills and knowledge to them, and to help the children be able to support themselves. Knowing their infection status when they are well will help the parents prepare their children and themselves emotionally for their deaths.

The wellbeing of all children affected by AIDS depends in great part on the capacity of the community to support and raise them. Hunter and Williamson (1997) state that the first and most important responses to the problems caused by HIV/AIDS come from the affected children, families, and communities themselves. The efforts of governments, NGOs, and donors are significant, largely to the extent that they help children, families, and communities cope more easily with these problems, yet, few programs have focused on preparing and supporting willing guardians to take on additional child-care responsibilities (Gilborn et al, 2001). Donahue (2002) recognizes the family and the community as the primary safety nets for children made vulnerable by AIDS.

The way forward

The need to bolster preventive interventions for communities in low-resource countries is becoming increasingly clear, as parental illness and premature death due to HIV infection worsens economic hardship and may result in loss of succession, social isolation,

discrimination, and stigmatization. In addition to straining extended families' capacities to serve as safety nets for affected youth, AIDS and related stigma may exacerbate the effects of war, famine, disasters, and poverty that together may threaten mental health and functioning of future generations, weaken the social fabric that stabilizes communities, prolong cycles of poverty, and imperil long-term economic development of low-resource countries. Although a family member's death from AIDS may be a catalyst that propels children into escalating trouble, the psychosocial needs of children are too often perceived as somehow less important than their economic necessities (Foster & Williamson, 2000).

Arguments associating orphanhood with delinquency are clearly alluding to the probability that children orphaned through AIDS will have poor psychosocial health. There are very good reasons why we should seriously consider the ways in which children are affected by parental illness and death, not to mention the economic and social trauma faced by households and communities. Moreover, there is a real danger that the emotional and psychological impacts of the virus are overlooked in the rush to understand and respond to the social and economic issues (Devine & Graham, 1999; Foster & Williamson, 2000).

In her research on southern African children affected by HIV/AIDS, Wild (2001) states that negligible research has been conducted on the way in which children experience and respond to illness and death in the family. She further states that there is no reference point from which to understand the implications of AIDS-related parental death for children's short- and long-term well-being (Wild, 2001). She concludes that "we do not yet have a definitive answer to the question of whether losing a parent to AIDS places children at increased risk for psychosocial adjustment difficulties" (Wild, 2001, p. 16).

Some research does point to heightened levels of emotional and behavioural problems amongst children who have lost parents to AIDS-related illnesses relative to a comparison sample from the same community (Forsyth, Damour, Nagler & Adnopoz, 1996; Reyland, McMahon, Higgins-Delassandro & Luthar, 2002, p 313-329). Studies of American children living with a mother who is HIV-infected reported problems including feelings of helplessness, a sense of isolation, regressive dependency or, alternatively parentification, and psychological disturbance (Reyland et al., 2002; Siegel & Freund, 1994; Stein et al., 1999). In addition, American adolescents who had lost a parent to AIDS have shown more emotional stress, conduct and problem behaviours, and lower self-esteem than unaffected

teens (Rotheram- Borus, et al., 2001). Silver (2001, p 22-24) points out that children react to stress by:

1. Internalizing stress: When children react with depression and/or anxiety to a stressor or trauma.
2. Externalizing stress: When children react to stress or trauma with disruptive behaviour, anger, clowning or passive dependency.
3. Somatizing stress: When children develop abdominal cramps, stomach-aches, headaches, diarrhoea or frequent urination or bowel movements.

A study in Uganda of 577 children attending a primary school, 68 children attending a reform school and 61 children attending an outpatient clinic showed no significant link between disturbed behaviour and parental death. There was, however, a correlation between children's disturbed behaviour and coming from a home that had been broken by divorce or desertion. This study was carried out, however, before the onset of the AIDS epidemic (Minde, 1977). Poulter's (1995) paper draws on two studies of children in urban Lusaka, Zambia, that examined psychological and social adjustment. The Orphan study was of orphans living with members of their extended family. The Family study was of children living with one or two parents who had been diagnosed as being HIV positive. Results of this analysis showed that children of sick parents were significantly more likely to show behaviour which is depressive in nature, rather than that which is anti-social. Once a child is bereaved this behaviour is exacerbated.

Some studies reviewed also demonstrate that orphaned children will not invariably be dysfunctional, and suggest that family process variables and the supports available to children may be more important predictors of children's adjustment than the parent's illness or death per se (Woznick & Goodheart, 2002; Mellins et al., 2003). In the light of this finding, it is clearly inadequate to simply assume a direct relationship between the parent's AIDS-related illness or death and the psychosocial health of children. When considering the psychological impact of orphanhood and its implications for individual children and society, it is worth looking at long-term studies done with other children in so-called 'difficult circumstances' (Rutter, 1998). These have shown that they respond to traumatic situations in different ways. While some experience severe impairment in their overall development, others are resilient and adapt quickly to the new situation.

Research on resilience in children has examined the conditions under which social and psychological well-being are maintained, even when stress is severe, and the factors that increase the ability to recover quickly and completely after severe trauma. One of the conclusions reached is that more than one factor is responsible for impairing a child's intellectual, psychological and social development (Mellins et al, 2003). For this reason, the context in which the traumatic experience takes place can be as important, or perhaps more important, than the experience itself. If favourable conditions can be created, then there is a good chance that a child will be able to successfully overcome the trauma of losing a parent. The question therefore is whether the presence of certain securities (such as shelter, a consistent caregiver, friendships, or an income source) make a critical difference to the impact of parental death on children.

Children have different tolerances for stress and the ways in which they respond are also varied. Factors which will affect these differences include the stage of his or her intellectual and social development, his or her character, antecedent events, and the reactions of those around them. Studies of Thai children and their responses to various life stressors have characterized them as tending more frequently towards problems of over-control (fears, feeling guilty, somatic concerns) – similar to those reported in African children – rather than under-control (arguing, disobedience, cruelty to others), which are characteristic of American children (Weisz et al., 1993).

When discussions emphasize "children at-risk," the task of removing all of the factors that can create significant stresses for children seems overwhelming. Theorists such as Benard, (1991), Luthar and Zigler (1991) and Rutter (1985) believe that stresses are part of children's lives, and we must move beyond a focus on the "risk factors" and problems in order to create the conditions that will facilitate children's healthy development.

Researchers and care givers alike have tended to be caught up in the pathological model of looking at children, focusing on the identification of problems instead of the self-righting factors or strengths that protect children from developmental obstacles. The concept of resilience in contrast has, in the last decade, begun to change the way that we look at the lives of children. Research and interventions that focus on resilience point to what should be added to children's lives to give them better tools for coping with diverse, stressful settings. While not ignoring the social circumstances that make modern life more difficult

for children, it emphasizes more careful efforts to improve the conditions that most directly affect a child's ability to cope.

Recognition of children's competencies and resourcefulness can encourage a move away from a focus on child pathology and towards recognition of children as social actors with valid insights and skills. The examination of these strengths, and the acknowledgment that everyone has strengths and the capacity for transformation, gives the prevention, education, and youth development fields a clear sense of direction, informing us about what works and providing a new paradigm for practice. The belief that children are competent and resourceful and have the potential to help others and their surrounding communities is not new (Aichon, 1935; Konopka, 1970; Makarenko, 1955; Vorrath & Brendo, cited in Laursen, 2000). Resilience is an inside-out process that begins with one person's belief and emanates outward to transform whole families, classrooms, schools and communities. (Fullan, 1993). It should be emphasised that children can survive adverse conditions with little or no ill effects if there are supportive factors present.

In Summary

When reviewing the literature, it is apparent that AIDS orphans face a number of extremely traumatic experiences beginning with the onset of HIV within their family unit. It is hard enough for a child to lose a parent, but when AIDS is the killer, the pain is all the more profound. The stigma of AIDS causes many families to keep the cause of death quiet. The surviving children are isolated in their shame, if they know, they usually do not tell anybody. The silence takes its toll, leaving children with no acceptable outlet for their rage or grief (Hinshaw, 2005). Stigmatization, unresolved grief, poverty, exclusion from society and educational facilities are but a few of the problems experienced by AIDS affected children. The loss of a friend, the slow debilitating illness and death of a parent – these are the ripple effects of AIDS on children, even if they themselves are spared from being infected with HIV. Children are the last link in the chain of HIV infection and their psychological and welfare needs are frequently overlooked. The specific nature of their needs have not been fully researched and, as a result, very few government institutions have developed services that are responsive to these needs.

CHAPTER 4

“AIDS takes advantage of some of humanity’s most intractable problems such as poverty and discrimination. It is an opportunistic disease. It exploits ignorance, prejudice, fear, fatalism and the very human tendency to hide from difficult or threatening truths in the hope that they will simply go away”
(UNAIDS, 1997).

Pilot Research - Parental HIV Status as Variable Associated with Orphan Outcome in Northern Thailand.

After seeking advice and guidance from UNICEF and other key players, pilot research was undertaken in 20 provinces in Chiang Mai and northern districts (see figure 6) in an attempt to provide a greater insight into the psychosocial issues that affect Thai children and families who are affected by HIV/AIDS. The main objectives of the research were two-fold, to determine if HIV orphaned children experience a different post-bereavement outcome compared to non-HIV orphaned children, and to assess the potential moderating influence of parent/child communication and futuristic planning. This research specifically attempted to identify the psychosocial problems that were unique to, hampered, or acted as barriers for AIDS affected children’s physical, emotional, and social development and functioning in everyday life. The care for AIDS affected children was becoming an emergent issue and at that time there had been limited research undertaken that covered these issues.

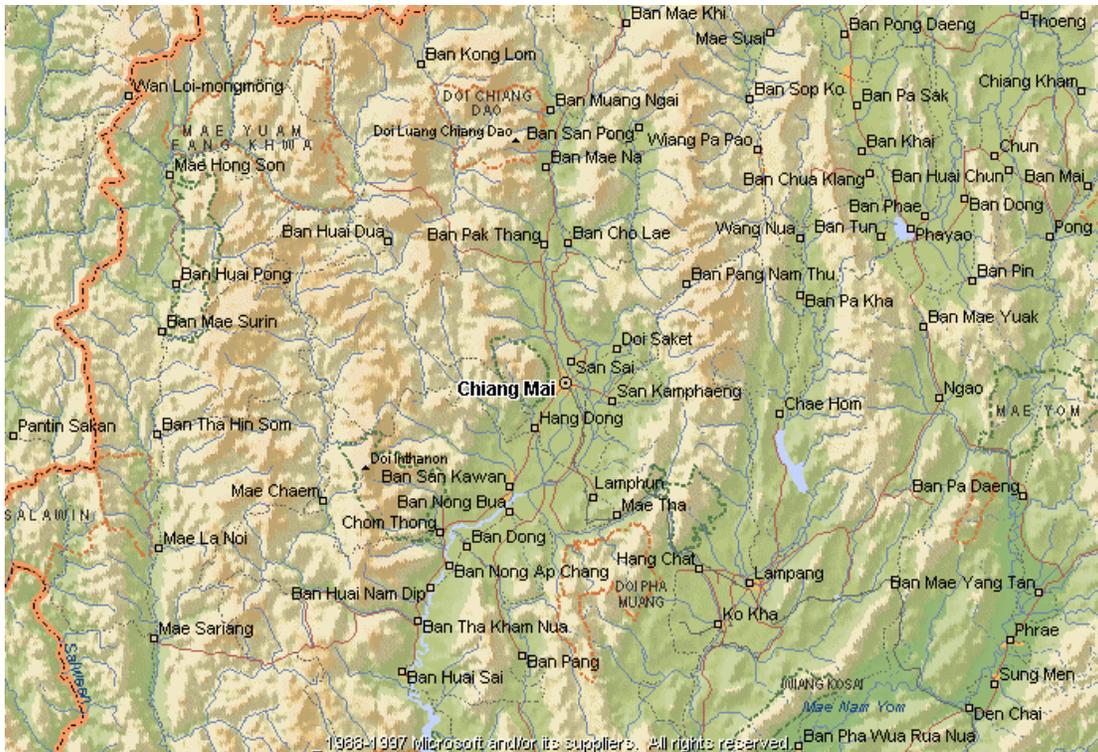


Figure 6 Map Showing Chiang Mai and Surrounding Provinces

PROVINCES INCLUDED IN STUDY

*Mae Taeng *Mai Jam *Mai Rim *San Sai *Sankamphaeng *Mae Wang *Chiang Dao *Samoeng *Sanpatong * Mae-on *Phrao *Chaiprakarn *Saraphi *Mai Ai *Hang Dong *Muang *Hod * Doi Saket

Methodology

Participants

TABLE 2. Research population breakdown

	HIV Positive Parents	AIDS Orphans	Non AIDS Orphans
Sex			
Male	26.8% (11)	51.5% (34)	50% (15)
Female	73.2% (30)	48.5% (32)	50% (15)
Total	100% (41)	100% (66)	100% (30)

TABLE 3. Mean Age of research population

Age	Male	Female
HIV Positive Parents	25.09 (19-37)	30.96 (18-39)
AIDS Orphans	11.26 (6-17)	11.93 (6-17)
Non AIDS Orphans	12.33 (6-18)	12.13 (6-17)

The sample consisted of 66 AIDS affected orphans, 33 non-AIDS related orphans and 41 HIV infected parents (see tables 2 & 3 for gender and age breakdowns) drawn from the Bahn Vieng-Ping community outreach program for HIV/AIDS infected and affected people in Chiang Mai and northern districts. The subject selection was purposeful and primarily based on availability³. The Community Outreach Program (COP) was designed to address the needs of AIDS affected people at the village level. Visitations to affected areas by orphanage welfare staff occur on a regular basis to provide direct assistance and psychosocial support to AIDS affected individuals and families and to facilitate educational sessions that help villagers overcome their fears and misconceptions relating to HIV/AIDS. The non AIDS orphan sample was drawn from another program initiated and implemented by Bahn Vieng –Ping that provides general assistance to all orphaned

³ Subject selection was based on COP recipients' willingness to participate in the research. The researcher aimed to attain the largest sample size possible.

children. Once again subject selection was based on the child's and their guardian's willingness to participate in the research. Outreach workers provided the researcher with information on potential subjects and made the initial contact with subjects to provide information on what would be required from them if they were available and willing to participate. A further follow up visit was made prior to the interviews to allow potential subjects time to confirm their availability.

Materials

Detailed information was gained from HIV infected parents, AIDS and non-AIDS orphans through the use of structured interviews and questionnaires that were designed specifically for this project (see appendix 1 & 2). The questionnaire design relied heavily on information derived from in-depth interviews and consultation with local health care professionals with extensive working experience and knowledge of the psychosocial impact of HIV/AIDS on communities. The questionnaire was aimed at gaining information that provided a more comprehensive understanding of the psychosocial problems experienced by AIDS affected children from the onset of a parent/s HIV infection to the eventual breakdown of the familial unit and orphaning of the child.

The researcher held several meetings with Thai social workers working with AIDS affected children and other mental health professionals from the department of psychology Chulalongkorn university Bangkok. The purpose of these meetings was to discuss the main themes that would determine the content of the questionnaire to be used. As a result of these discussions it was established that stigma, parent/child communication and disclosure issues were dominant themes affecting Thai children affected by HIV/AIDS. Discussions also took place with child protection officers from UNICEF to elaborate on what issues were of major importance to UNICEF in their work with children in difficult circumstances. Access to education for AIDS affected children was an issue of major importance to UNICEF as this remained a critical problem in Northern Thailand.

Structured interviews with HIV positive parents provided the researcher with a powerful insight into the familial dynamics, social, cultural experiences and psychosocial problems experienced by an AIDS affected family. A further comparison between non-AIDS and AIDS related orphans experience was made to identify outcomes unique to AIDS affected children. Interviews were conducted in the Thai language negating any possible language

barriers or misunderstandings. All information collected from the interviews was translated into English by Thai health care professionals adept in both languages. Translations were then re-checked by a professional translation service to verify their accuracy.

Content

Questions for HIV positive parents focused on: a) determining the current level of parent/child communication⁴, b) the child's understanding of the situation as perceived by the parent, c) demonstrated futuristic planning for the child's welfare. Questions for AIDS and non-AIDS affected children focused on the same areas as HIV positive parents but were specifically designed to gain information that was based on these children's personal life experiences.

Procedure

The research received ethics approval number H962 from James Cook University Cairns Australia.

HIV Positive Parents

Data were collected through focused in-depth individual interviews that were open ended in reference to time. Informed consent was obtained from each subject prior to the commencement of the interview. The average duration for each interview was approximately 30 minutes. The variation in interview length was primarily dependant on each person's responsiveness and ability to talk about this sensitive subject. Issues such as the parent's reasoning, beliefs (cultural) and current concerns were discussed during the interviews. Subjects were also given the opportunity to express their views, and make suggestions as to how to improve general living conditions and existing services. Information gained from the interview was transcribed onto the structured questionnaire. Data was then categorized for analysis by the researcher and social workers.

AIDS & Non-AIDS Orphans

The data collection for AIDS and non-AIDS orphans was of a qualitative nature with data for analysis being collected by focused, in-depth, individual discussions. The discussion group consisted of the researcher, a professional social worker, and a single subject. The subjects were interviewed on an individual basis for two important reasons; to allow the

⁴ How much open discussion took place between the parent and child regarding everyday issues and more specifically issues relating to the parents HIV status and opportunistic illnesses

researcher to facilitate the discussion more adequately, and to reduce the incidence of peer pressure and confidentiality concerns. The discussion primarily focused on the children's experiences and feelings during the course of the illness and after their parent's death. Consent was gained from both the respondent and their guardian via the consent form attached to all questionnaires (see appendix 3). The interviews were open ended in reference to time with the average duration for each being approximately 30 minutes. The variation in interview length was determined by each child's responsiveness and ability to talk about this sensitive subject. A number of questions (See appendix 2) were carefully developed to be used as a loose guide for discussion, children however, were and encouraged to decide on the pace and the topics to be raised. If at any stage this became distressing for the subjects, the discussion ceased immediately. A social worker was present during the discussions to monitor and moderate any adverse distress, however, during the course of the interview period no child experienced any serious adverse distress. It was noted that, on the whole, the majority of children were quite open about their experiences and minimal distress occurred due to the discussion. Information gained from the interview was transcribed onto the structured questionnaire. Data was then categorized for analysis by the researcher and social workers.

During the interviews both HIV positive parents and AIDS orphans had the opportunity to provide extra information on the questions that they were asked. It was not the researchers intention to just derive just a "yes" or "no" response from participants. Most participants also found that this was an ideal opportunity for them to express their feelings and problems to someone who was willing to listen with empathy. Many people affected by HIV/AIDS as mentioned in previous chapters have great difficulty finding someone to listen to their problems without casting negative aspersions about them or their families. The following quotes in the results section were derived from the extra information provided by subjects during the interviews. The intention behind the inclusion of these quotes was to provide the reader with a more personal understanding of the experiences of people affected by HIV/AIDS.

PILOT STUDY RESULTS AND DISCUSSION SECTION

HIV/AIDS impacts on families and individuals in several ways. It can debilitate families both economically and socially enforcing impoverishment, exclusion, and in many cases causing psychological distress to the infected and their families. Being HIV/AIDS infected and being a parent further complicates an already stressful situation with the added responsibilities of deciding on the future care of their children after they themselves become physically disabled or die. AIDS and HIV infection present the additional stressors that stem from discrimination, stereotyping, and social ostracism. The death of a parent is a uniquely stressful life event that compromises children's short-term and long-term psychosocial development. Bereaved individuals may have to face a double burden. The first is that associated with the loss, and the second is with the stigma (Sherr, 1995). The findings have suggested that the majority of HIV positive parents participating in the study reported that they lacked any hope for the future (see table 21 appendix 6) and in many cases this has led to severe depression although this issue was not studied closely in this research.

"I am very tired and cough a lot I recently stayed in hospital. I am afraid, worried about my children and parents, health & finances. I am living a life which is short, medicine can only give me a last life. I am bored with being sick and coughing, I have to lie down a lot to feel any good. I am bored and annoyed at new symptoms which make me feel lonely & sad. Work makes me tired, its difficult when you can't stop the itching, headaches & coughing".
A 32 year old single mother from Chiang Rai.

These feelings of helplessness and hopelessness stemmed from two main factors. Firstly, the lack of funds to purchase medicines, and, secondly, the inability to provide permanency planning (i.e. secure future care and education) for their children. Whenever poverty and HIV infection coexist, antiviral therapies and even simple medications to treat opportunistic diseases are often unavailable. It is also important to note that stress and depression may contribute to life threatening conditions in immune compromised individuals. Children are affected by the changes in their parent's emotional and physical state. They may not know what is happening to the parent and become confused and frightened. The uniquely painful features of parental HIV/AIDS are of course of deep concern to the adults themselves.

Only 29% of HIV positive parents had disclosed their HIV positive status to their children. A further 32% of HIV positive parents were unaware as to who informed their children of their status (see table 22 appendix 6). Although a low parental disclosure rate was evident in this study, a large number of children (74.2%) knew how their parents had died. The chi-square statistic was used to examine the difference between respondents regarding their knowledge of what caused their parents death. The non-significant chi-square value $\chi^2(1, N=96)=.188, p < 1.00$ shows that AIDS orphans and non AIDS orphans were equally aware of how their parents had died (see table 23 appendix 6). Some (44%) were very perceptive and frequently diagnosed the cause of parental illness through reading, observing symptoms and asking medical staff questions whilst parents were receiving treatment. Other key informants included extended family (24%) and community members/neighbours (17%) (see table 24 appendix 6). A large number of children knew all along that their parent was HIV positive and were keeping this a secret to protect the parent. Having to keep this secret deprives children of the opportunity to discuss the situation with the parent and to prepare for future bouts of illness and the prospect of the parent's death.

Several factors such as societal views and the parent/child relationship become evident and determine the likelihood of HIV disclosure to children. The most reported reasons for non-disclosure were that parents were scared (31.7%) and that they thought their children would not understand (29.3%) their situation. A large number of parents feared that their children might be heavily influenced by societal perceptions of HIV/AIDS and would think badly of them (see table 25 appendix 6). Gender differences were further examined for reasons of parental non-disclosure. The significant chi-square value $\chi^2(1, N=41)=10.146, p < .05$ shows that there was a significant gender difference in the reasons for non disclosure. The majority of females stated that being scared prevented disclosure. Comparatively, the belief that their children would not understand prevented disclosure for males (see table 25 appendix 6). A number of important issues were brought forward that directly influenced each parent's decision to openly talk with their children about the disease. Some parents refused to talk with their children about HIV out of shame and self-hatred and a fear of rejection, or concern that the child would insist on giving up his or her own life to take care of the parent.

“I feel dejected but I will stay for my child, I did the wrong thing but I did it myself. I am worried about my child and his future and who will take care of him. How can I tell him, it will hurt him very much”.- Male 32 years old Chiang Rai

“My children know I have AIDS and they won’t stay near me. I never stop them from doing this but it hurts me very much”.-Female 27 years old Chiang Rai

Others hid their status from their children and community to preserve the dignity and self-respect of the family, and prevent discrimination in housing, employment, and medical care.

“If they find out everyone will hate me. There were others in the village that had HIV and I saw what happened to them. One woman used to sell food and her business was very profitable. When people found out she had HIV everyone was scared to buy food from her”. - Female 25 years old Chiang Mai district

Family stress and dysfunction can result when a family member is infected with HIV/AIDS. A high number (29%) of HIV positive parents stated that they felt isolated and received little or no support from family and outside agencies when they discovered they were HIV positive (see table 26 appendix 6). A further 78% stated that friends and relatives become apprehensive to be near them and that they had lost many close friendships during this time. Stigma and being ostracized by extended family members and friends was evident upon knowledge of their positive status (see table 27 appendix 6). Family breakdown and fragmentation is an increasing factor contributing to neglect, abuse and exploitation of children. Attendance at pre and post-test counselling is an important factor that can significantly reduce anxiety and misinformation about HIV/AIDS. A high rate of males and females attended pre and post-test counselling in this research. The non-significant chi-square values for pre test $\chi^2(1, N=41)=.503$, $p < 1.00$ and post test $\chi^2(1, N=41)=3.19$, $p < 1.00$ reveal no gender differences in attendance at pre and post test counselling (see table 28 appendix 6).

“Everyone has changed; people have become very apprehensive about being near me. I want the government to provide more concern and more money to purchase medicines

and society to provide encouragement because it is the best medicine for people with AIDS”.- Female 25 years Chiang mai

A key factor that may act as a protective factor that enhances the resiliency of a child from being adversely affected is the quality of the parent child relationship and their ability to communicate effectively. The research found that there was a discrepancy in the quality of relationships as reported by HIV + Parents and AIDS orphans. Eighty percent of HIV positive parents reported having a good relationship with their children. Comparatively, (50%) of AIDS orphans responded as having a poor relationship and communication with their parent's (see tables 29 & 30 appendix 6). Although these findings are not based on interviews with the HIV positive parents actual children, because of ethical and disclosure reasons, the results from surviving children do suggest that there is a possible discrepancy between HIV + parents perceived and actual relationship status with their children and they consequently may not be in touch with their children's true feelings. A barrier to an effective relationship was the parent's inability to overcome their fear of rejection by the child once their status was disclosed (see table 31 appendix 6).

“I am very scared to tell my sons that I will soon die. They are too young to know and will not understand. This makes me feel very sad”. A 28 year old male from Chiang Mai district.

Both HIV positive parents (20%) and AIDS orphan (50%) groups also reported having had, or presently do, experience poor communication levels. Comparatively, 73.3% of non - AIDS related orphans reported having good communication with their parents (see tables 29 & 30 appendix 6). Differences between AIDS and non AIDS orphans ability to communicate with parents before they become orphaned were also examined. The significant chi-square value $\chi^2(1, N=96)=4.59, p <.05$ (see table 32 appendix 6) shows that non AIDS orphans experienced better communication levels with their parents than AIDS orphans. Gender differences in AIDS orphans communication with their parents about their symptomatic state were further examined. The significant chi-square value $\chi^2(1, N=96)=3.926, p <.05$ shows that there was gender differences in AIDS orphans ability to talk with their parents when they become ill (see table 33 appendix 6). A large number of AIDS orphans were unable to discuss this issue openly with their parents. Females were less likely than males to discuss health issues with their parents. It was evident that this

lack of communication compounded the psychological trauma experienced by both groups. This finding shows how HIV/AIDS stigma can be potentially damaging and act as a barrier to an infected person's ability to communicate effectively with family members.

"My son changed a lot, he didn't want to study and would not accept that I was sick".

"I don't want my children near me because I am afraid I will infect them".

"I clean myself and try to not make my children afraid of me".

"I have a good relationship with my children but I really don't want it"

- Collective responses from personal interviews with HIV positive parents

Many HIV+ parents expressed a wish to disclose their status and discuss HIV with their children but were afraid to do so out of fear and concern for their child's coping ability and level of understanding. A high number (69.7%) of AIDS orphans also reported that they never openly discussed with their parents their HIV infection (see table 33 appendix 6). Because a parent's HIV infection is generally shrouded in secrecy, children may have concluded that it is something that they should not talk about and is something that should be avoided. This situation invariably creates a potentially psychologically damaging and stressful environment for both parents and their children. Wiener's (1998) study showed that those parents who chose not to reveal their illness to their children were more depressed than those who did. None of the parents who spoke honestly with their children about their disease and inevitable death regretted having done so. Comments made by children whose parents did not disclose the nature of their disease suggest that these children nevertheless understood the cause of the illness.

"I knew by myself because I studied about it and could see by my parents the symptoms"

"He looked thinner, had spots and diarrhoea"

"When my parents were sick and staying in hospital my grandmother would stop me from being near them"

"I knew from the time they started receiving treatment"

- Collective responses from personal interviews with AIDS orphans

Eventually the parent will pass away leaving children with unresolved issues. Parents in these situations often deny the child the right to prepare for death and to say their farewells. Previous research (Siegel, Mesagno, & Christ, 1990; Weizman & Kamm, 1985)

suggests that in order to prevent a child's self blame, fear and confusion, the child should be allowed to talk directly with the dying loved one, so that they can share their feelings and say loving farewells. Open communication with children about death and HIV/AIDS should be promoted instead of being typically avoided by adults. The research has identified that there is an urgent need to incorporate the disclosure process into HIV/AIDS family treatment in order to facilitate healthier communication and relationship patterns and increased quality of life for HIV positive mothers and their children. The findings of the research illustrated that disclosure strategies depend largely on the quality of relationship parents have with their children, parents' level of social support, parents' own feelings of guilt regarding their infection, and parents' perceptions of children's coping abilities. Further research needs to be implemented to assess the benefits of open dialogue about HIV/AIDS within the family unit and to explore the link between parent/child relationships and communication and children's future adjustment and resiliency to psychological problems.

"Nobody said anything, but I observed that he was sick so I kept an eye on him"

"My parents never told me, they would get fevers regularly, but say they would be better soon"

"Mother told me that father had AIDS and would leave us, and then it will be her turn"

"I knew because I studied the symptoms at school and eventually the doctor told me"

- Collective responses from personal interviews with AIDS orphans

Thailand acted swiftly in 1991 to combat HIV/AIDS by introducing an extensive educational and awareness campaign in the early stages of the HIV epidemic (Phoolcharoen, 1998). Although successful overall, there are still groups of people who were not reached by this campaign and remain virtually uneducated about HIV/AIDS. An additional problem that needs attention is the fact that knowledge about HIV/AIDS does not always translate into safer behaviours as indicated in past research (Van Landingham, Grandjean, Suprasert & Sittitrai, 1997). The research found that HIV positive parents reported low attendance rates (46%) at HIV/AIDS courses and a limited knowledge of HIV/AIDS (see table 34 appendix 6). Parents did however, as mentioned earlier, have a high attendance rate at pre (87.8%) and post-test (87.8%) counselling which would normally have an educational component (see table 28 appendix 6). This finding questions the quality of and structure of counselling being provided to these individuals. More research is needed in this area.

Seventy three percent of the HIV positive parents with children that were aware of their status reported that their children had a poor knowledge of HIV/AIDS. These children were experiencing adjustment problems and difficulty in accepting the eventual path the disease takes. Parents had observed distinct behavioural changes in their children since they had become aware of their parents HIV status (see table 35 appendix 6). It was found however, that 74% of AIDS orphans exhibited a competent knowledge base of HIV/AIDS along with 77% of non- AIDS orphans. A high rate (91%) of AIDS orphans also indicated that AIDS was a prominent social problem in their respective communities (see table 36 appendix 6). These children stated that they were educated about HIV primarily via media sources (see table 37 appendix 6). This suggests that AIDS orphans are being educated about HIV/AIDS after the parent has actually deceased, further indicating that a large percentage of HIV positive parents and their children really do not comprehend the nature and complexities of the disease. This situation can be extremely stressful and traumatic for both parents and children. Problems arise from a lack of understanding, such as rejection, poor communication, and isolation. Individuals are also more prone to be influenced by societal stigma.

Surviving children also face numerous problems and hardships due to their parent's lack of permanency planning for their future care and support. Although future care for their children was the greatest concern for HIV+ parents (see table 38 appendix 6), a high number (66%) had made no formal plans or decisions as to their children's future care (see table 39 appendix 6). Not infrequently, in Thailand, large numbers of elderly grandparents become guardians by default when the mother dies. Godfrey's (1996) research in Sanpatong district, Chiang Mai, found that one third of those who care for people with HIV/AIDS are above the age 60.

"I prepare my mind and tell my children to take care of themselves"

"When I get sick I don't want my children to take care of me. I will take them to public welfare"

"I will tell my child to go and live with her grandmother"

"I have no plan because I have nothing to give them. I don't have any money or property"

- Collective responses from personal interviews with HIV positive parents

A large number of AIDS orphans (63.6%) in this research stated that they reside with their grandparents (see table 40 appendix 6). In Thai society grandparents are in most cases supported by their own children if they are not well off economically. Life for the elderly without the support of their children is extremely difficult, with the added burden of the care of their grandchildren often crippling them financially and forcing them to engage in some form of menial employment that will help them survive. The effect of AIDS on the elderly is also an area that has received insufficient attention and should be the focus of more intense research. Most children that were residing with grandparents expressed a lot of love for them, but they did feel at times that they had some difficulty with their communication and relationships due to the large generation gap.

"I like where I live now but if there is a better place I will go"

"Grandmother and grandfather love me and don't reject me like other people"

"Grandmother and grandfather are kind but they don't understand me"

"I am afraid about my future education because my grandparents can't afford it"

"I can't talk with my grandmother because she is so old"

- Collective responses from personal interviews with AIDS orphans

In many cases AIDS orphans are rejected by extended family. This may be due to economic factors, but in most cases it is a fear of contagion or the drawing of unwanted stigma upon the family that prevents adoption or care. The research has highlighted that a lack of parental permanency planning in most of these cases resulted from denial, a fear of disclosure, and a lack of any formal counselling or education. It is important that interventions be implemented prior to parental death to help parents with permanency planning, dispelling misconceptions and myths of contagion and to reinforce health-inducing behaviours. It is also vitally important that they receive assistance in communication and disclosure strategies with their children. Any programmatic intervention aimed at AIDS affected children should be age appropriate HIV/AIDS education, as children's ability to understand illness and death depends largely on their stage of cognitive development. For example, young children typically cannot grasp concepts such as causality nor understand the finality of death (Schaefer & Lyons, 1986). Previous research (Nicholas & Abrams, 1992) has also indicated that AIDS affected children often engage in high risk behaviours such as early and unsafe sexual practices and experimentation with drugs that may increase their susceptibility to HIV infection.

The findings suggest that AIDS orphans are experiencing problems in the resolution of the grief process and adjustment problems. The study revealed that children living in an AIDS affected family and children who have been orphaned due to AIDS suffer similar problems at school and in the community. The study shows that 95% of AIDS orphans were attending school and of these, 50% experienced some difficulties due to being AIDS affected. The significant chi-square value $\chi^2(1, N=96)=14.08, p < 0.001$ shows that AIDS orphans experienced more problems than non AIDS orphans at school (see table 41 appendix 6). The relationship between knowledge of what caused their parents death and problems experienced at school by AIDS orphans was also examined. The non-significant chi-square value $\chi^2(1, N=96)=.0793, p < 1.000$ shows that knowledge of parental death from AIDS was not a predictor for problems at school (see table 41 & 42 appendix 6).

Some of the problems experienced by AIDS affected children at school included learning difficulties (19%), constant fighting with other children (29%) and loneliness (35%) (see table 43 appendix 6). Several children (6) did report that they were either banned from attending or expelled from school because other parents and teachers had complained and demanded their immediate expulsion. AIDS orphans expressed their eagerness to attend school and participate in classroom activities, however it was, evident that stigmatisation and social isolation restricted their active participation and inclusiveness in the classroom and playground (see tables 43 appendix 6). This stigma came in the form of teasing from other children, and uncaring and at times physically abusive treatment from teachers. Instead of being a place that provides a nurturing and caring environment that facilitates learning and development, the school to these children is a cold uncaring place that at times they feared.

“Some friends of mine at school said my parents were bad so I fight often”

“My teacher blames me for everything”

“One school did not let me attend because they feared I would spread HIV”

“I continually get in trouble at school because I don’t do my homework”

“I am always punished by the teacher and my friends always tease me”

- Collective responses from personal interviews with AIDS orphans

A large number of HIV parents did report that they had noticed distinct behavioural changes in their children from an early stage. Parents expressed concern over how their children had become more emotionally withdrawn and socially introverted. The research findings reflect that a large majority of AIDS orphans seem to be experiencing difficulty in processing and progressing through the grieving stages. The findings reinforce the fact that the grieving and bereavement process may commence well before the parent has actually deceased. Grief is not simply a reaction to a loss but may be triggered as a process in anticipation of a loss. Anticipatory grieving, for example, has been shown to trigger a diverse range of emotions in those involved in grieving (Dane & Levine, 1994). The notion of anticipatory grieving suggests that the prolonged illness prepares the survivor for the loss in a way that eases the grief once the death occurs (Dane & Miller, 1992). Opportunity for anticipatory grieving however, is totally dependent on the individual accepting the potential death and not entirely denying its approach (Dane & Miller, 1992). Unfortunately, as noted in the research, the facilitation of this crucial process is totally reliant on factors such as the disclosure of infected parents HIV+ status, susceptibility to associated stigma, and the quality of the interpersonal relationship between parents' and their children.

"I have seen many changes in my son, he has become very withdrawn"

"My son has stopped studying, he is an orphan now"

"Before they would come and visit me a lot, now they rarely come"

"I have noted many changes in their personality since they became aware that I am sick"

"He will not talk anymore, and has problems with learning"

"He has a broken heart"

- Collective responses from personal interviews with HIV positive parents

Bereavement reactions of children and adolescents are very strongly influenced by the dynamics of social attitudes prior to parental death and the dynamics of the grieving process itself. Dane (1994) coined this process as "stigmatised grief", where children of AIDS infected parents become entwined in a conspiracy of silence that is reinforced by HIV positive parents who hide their diagnosis to avoid discrimination. Biller and Rice (1990) also described social stigma as a "barrier to successful mourning". A child's grieving is painful and potentially harmful to his or her future psychological and social development. AIDS is a highly stigmatised condition that tends to cut the bereaved off from

their natural grieving process especially by the need of the bereaved to remain silent or lie to counterbalance the stigma (Sherr, 1995). There is a growing body of literature (Doka, 1989; Mallinson, 1997; Brown, & Powell-Cope, 1993) that points to the key role that social support plays in an AIDS related bereavement process and the problems that may be incurred when it is lacking or not available. It is evident that social support was lacking for the majority of HIV affected families and orphans interviewed in this study. A high rate (78%) of HIV parents stated that they had experienced stigmatisation from community members once their HIV status was exposed (see table 27 appendix 6).

“They would always gossip about us”

“I wish they would understand, nobody wanted to be my friend”

“I was treated very poorly by everyone

- Collective responses from personal interviews with AIDS orphans

The study found that a high number of HIV + parents feared exposing their children to HIV infection and were very concerned that their children would hate them (see table 31 appendix 6). These parents were very apprehensive about having their children in close proximity to them and in a number of cases, the children were actually relocated to live with extended family or grandparents. This coping strategy, although possibly psychologically traumatic for the children, was the best option that was available to these parents and was reflective of their low level of understanding of HIV/AIDS transmission. AIDS orphans also reported that their parents were reluctant for them to be physically near. This was particularly traumatic for children as the experience of loss and isolation was reported to begin well before parental death. An alarming number (36%) of AIDS orphans stated emotional support was unavailable to them when their parents' died (see table 44 appendix 6). Fifty three percent further stated that presently they remain emotionally isolated without support or the opportunity to share their problems with a significant other (see table 45 appendix 6). What is believed to be essential for mental health is that the infant and young child should experience a warm, intimate, and continuous relationship with their parents in which both find satisfaction and enjoyment.

“ I would not dare tell a stranger, I am afraid and embarrassed if anyone knew”

“I don't like to talk with anyone, I like to be alone”

“If I talk with anyone they may feel an aversion towards me”

"I don't talk with anyone because I fear they may feel disgusted that my parents had AIDS"

"I can't talk about this because I will start crying"

"I miss my parents very much and I pray for them every night"

"I am very lonely, I want my parents back"

- Collective responses from personal interviews with AIDS orphans

Children, who live in families affected by AIDS and HIV infection, are vulnerable to high levels of psychological distress. They experience numerous separations from parents, changes in the nature and predictability of emotional nurturing, concerns about loss, disruptions in routine and contact with peers, and economic hardship. The research found that a large number of HIV+ parents and their children had been the focus of some form of discrimination by community members and neighbours (see table 27 & 46 appendix 6). When asked how people from their community treated them, 65.2% of AIDS orphans reported that they were treated badly. Comparatively, a high number of non AIDS orphans (93.4%) reported that they had never experienced any negative problems whilst residing in their communities (see table 46 appendix 6). An alarmingly high number of AIDS orphans stated that they internalised their problems and feared confiding in their peers. These children had great difficulty creating and maintaining existing friendships. A large number of children reported that they were lonely and without any significant other to share their emotions and problems. Biller & Rice's (1990) research illustrated that survivors of multiple losses to AIDS tend to turn inward, which may have long term irreparable effects. AIDS orphans were frequently ostracized at a time when they most needed social support. The grief experience of AIDS orphans is a very silent, secretive and commonly unfulfilled process. The findings of this study stress that certain factors are critical to the child's management of the grief process.

The availability of the family, the support network, both informal and professional, and the development needs of the child, all contribute to the eventual resolution. Helping children cope with grief entails knowledge of their perception of death and an understanding of personality, temperament, and their previous experience with death. Children are also significantly influenced by the reactions of those in their immediate surrounding and the responsiveness of other close adults (Wilfelt, 1983). It becomes evident that how others are handling the death may be critical to how a child will cope.

“Society is unhappy; people look down upon the affected and are disgusted”

“Yes it is a big problem; if you are affected then everyone will hate you”

“Increasing numbers of orphans, children’s minds are affected and there is a lack of warmth for them”

“Yes, the village will change. Nobody likes to visit you and so many people will die”

“In the beginning nothing happens, then their skin gets swollen. They then get thinner and thinner and then their skin goes dark and then they die”

“Yes it kills a lot of young people so our country lacks labour”

“People in our community don’t understand about AIDS so they are not careful about their behaviour”

- Collective responses from personal interviews with AIDS orphans about the affect of HIV/AIDS on society

Research Limitations

Certain limitations impact on the results and were evident in the implementation of this research project. Firstly, it suffers from a low sample size for HIV positive males and non-AIDS orphans. Secondly, the fact that the interview process may draw unnecessary attention and possible discrimination prevented more compliance. It was also particularly hard to access orphaned children that have not been affected by AIDS in some respect. Thirdly, inconsistencies in children's real and perceived memories may have occurred due to the age of the child at the time of parental death. Fourthly, due to ethical problems concerning disclosure, AIDS affected children with surviving parent/s were not included in the sampling. Further research needs to be undertaken with this group as it has been found that it is at this stage that children are extremely vulnerable and interventions should commence to prepare the child for parental death and to facilitate the grieving process. Further research also needs to be implemented to ascertain if increased parent/child communication decreases both parental and child anxiety rates.

Summary Conclusion

The findings from this study suggest a range of adverse psychosocial factors occur in AIDS bereavement. The interviews conducted suggest that parental death as a result of AIDS, have major psychosocial impacts on the children left behind. These factors include: multiple loss, social ostracism, low levels of social support prior to, and after parental death, discrimination in all areas of life, unresolved grief, extreme loneliness, exclusion

from education, learning difficulties, and a high rate of concealment as to the cause of parental death. These are but a few problems that perpetuated throughout their lives. Most of these children are living in poverty and have a whole range of unmet social, educational and health needs. It is evident that AIDS adds a new dimension to the problems experienced by a child that is left to survive without parental support.

This study differs from previous research because it examined and compared issues from both the HIV+ parents and AIDS orphans perspectives. It elucidated reasons and issues affecting disclosure, lack of permanency planning, poor parent/child communication, isolation, and the grief process for children. The findings suggested that AIDS related stigma was the primary contributing factor to these problems. AIDS stigma has created a vast army of hidden sufferers, destroying the lives of many innocent children. The results from this research highlighted the need for two types of interventions to be developed and implemented. Firstly, HIV educational programs need to commence prior to parental death; emphasis should be placed on interventions being pro active rather than reactive. Secondly, and most importantly, there is an urgent need for programs to be implemented to help the mass of hidden sufferers already in existence in the resolution of the grief process. There is a dire need for interventions that focus on making schools and communities more nurturing to the needs of these children, rights based, and more 'friendly' and accepting to children and families affected by AIDS. School attendance gives stability at a time when life may be very unsettled at home and gives hope of a better standard of living in the future.

CHAPTER 5

"Without education, AIDS will continue its rampant spread. With AIDS out of control, education will be out of reach" - Peter Piot, Director of UNAIDS.

Community and Child Centred approaches: Background and Rationale

Figure seven shows the cycle of problems experienced by HIV/AIDS affected families and children. This was originally developed by Williamson (2000) to reflect the situation in a number of Africa countries but modified slightly by the researcher based on results of pilot research to reflect the Thai context. In an ideal situation the optimal time to commence an intervention to assist families and children would be based upon knowledge of their infection but unfortunately this is largely dependent on the individual's acknowledgement of their risk behaviour and the systems in place to assist them once testing takes place. Stigma both within communities and the medical profession, has been proven to restrict disclosure and health seeking opportunities. Due to this, to date, programs to assist families and children affected by HIV/AIDS have generally been reactive, attempting to minimize the trauma already experienced by surviving children.

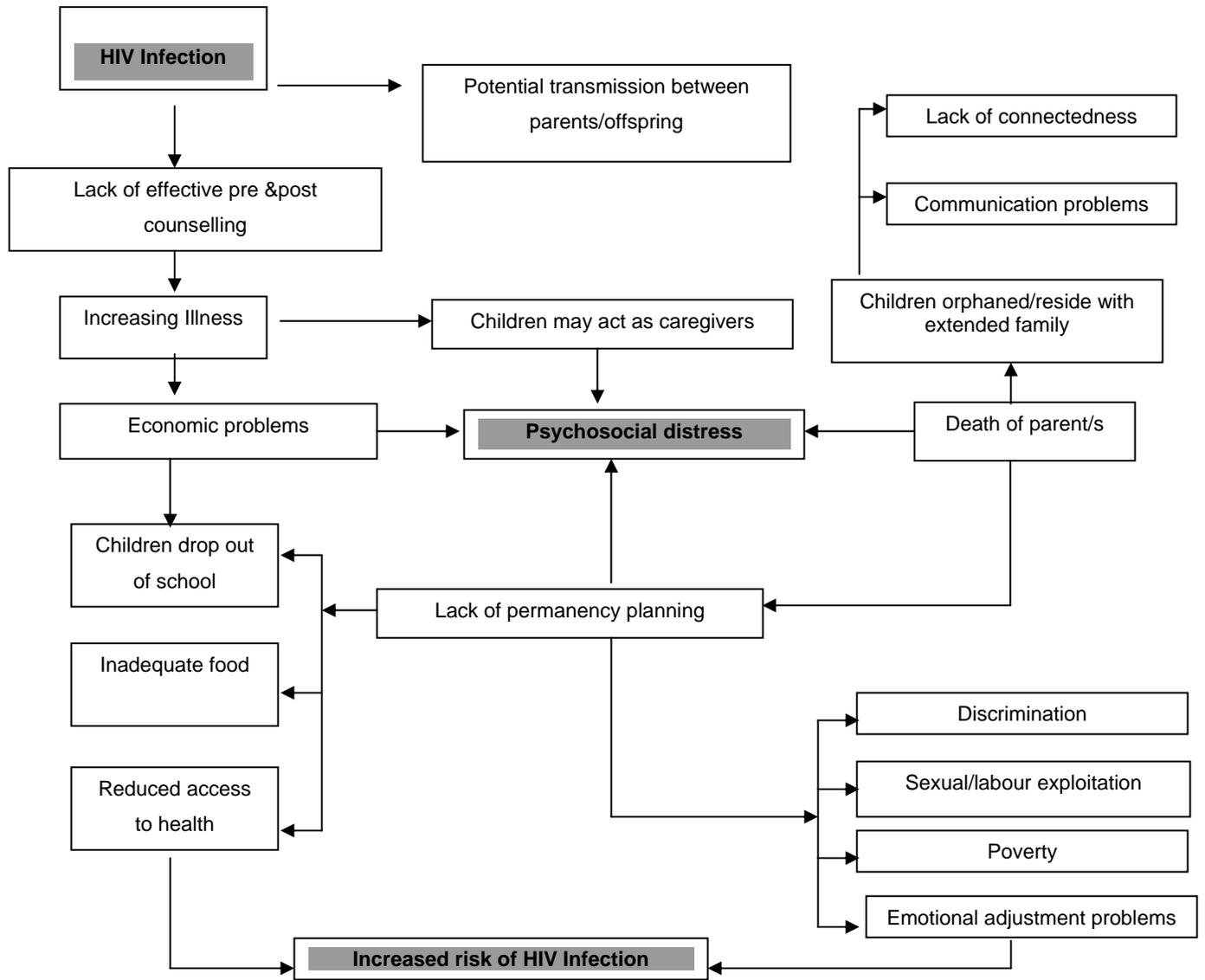


Figure 7: Problems experienced by families and children affected by HIV/AIDS (adapted from Williamson, 2000).

A family and community-focused approach means that the critical and primary roles of the family and the local community to protect and ensure the development of children are acknowledged. Initiatives that support the enhancement and financial viability of the family,

such as income-generating activities for caregivers and vocational education for older orphans, should be encouraged because caregivers take on the responsibility of caring for increasing numbers of orphaned children. Programs that offer caregiver training, respite care, and other types of support become essential. Research (Hunter, 2000) has shown that home-based care programs and community day care centres are preferable to orphanages, which are difficult and costly to sustain, and tend to isolate children, leaving them ill-prepared for community life. Child development specialists have also recognized that institutional care generally fails to meet many children's developmental needs, such as those for attachment, social integration, and acculturation. However, residential care can sometimes provide a critical service, especially for acutely ill and abandoned HIV-infected children and as a transitional care facility leading to placement in the community.

A human rights-based approach means that we recognize children as rights holders, rather than as mere recipients of services. We look for programs that offer leadership opportunities for children and initiatives that give children a voice in the decision-making processes that affect them. Orphan children are generally poorer, less educated and much less healthy than other children. The burden of care for this impoverished youth is falling to families in the communities who themselves are extremely poor. Traditional coping mechanisms are being overwhelmed by this crisis. There is no doubt, that caring for children in community settings is consistent with most social and cultural norms.

While there is no single best-practice that fits all countries, all children and all needs, it is safe to say that the extended family or other families within the kinship network as the primary caregivers for orphans and vulnerable children is the best means of support. In addition to extended family-centred care some will propose orphanages, children's villages and other institutional arrangements. No doubt, where there is no family or community to care for a child, institutional arrangements must be made available to guarantee the well-being of that child. But institutional care should be a last resort as the policy of building the capacities of families and communities is the most effective response to the needs of these children.

All of the studies on this subject have shown that institutional care is very expensive. A study by the World Bank (1992) found that institutional care at one facility in Tanzania costs a thousand dollars per child per year, a figure six times more expensive than the average cost of family care in that country. Institutional care should be seen as a last resort as it is potentially psychologically harmful for children and much more expensive than the care provided within the family structures. Children who grow up in families develop better social skills and are psychologically better adjusted than those who grow up in institutions because they receive more affection and attention and develop a better sense of personal identity. Orphans are more likely to cope if they can live in surroundings that are familiar, stable and as nurturing as possible. If possible, orphans should be cared for in family units through extended family networks, foster families and adoption. At the very least, siblings should not be separated (Richer et al., 2004; Safman, 2004).

Another key challenge in developing effective action for orphans and vulnerable children is the lack of monitoring and evaluation techniques. An inventory or needs assessment can provide an initial picture of the situation of children in families affected by HIV. A system for monitoring needs and measuring the impact of interventions over time needs to be established. Assessment and monitoring are most effective when they are participatory processes, actively involving people from the communities most affected. Participation in assessing and monitoring needs also creates local awareness and engagement. It is important therefore to balance the rights of the individual, in this case the child, with the implementation of HIV prevention and control programs (Levine, 1996).

To deal with the problem of orphans and vulnerable children, we must deal with the wider context in which they live. That means investing in communities, in schools and in clinics, in self-help, and in income generating projects. It is imperative, that we help families provide the social and economic protection for their children and create thriving communities where children can flourish and grow. There are no quick fixes to any of the challenges brought on by AIDS, and problems associated with the large numbers of orphans are no exception. First and foremost, national governments have a responsibility to create an environment where children can exercise their rights, including those to survival and development, to the highest attainable standards of health, to education and to protection from abuse and neglect. Since AIDS has wide-ranging effects on a country's

education and social welfare systems, religious institutions, agricultural production, private businesses and community groups, coping with its impact requires the cooperation of many sectors. It is essential that policies, technical support, information campaigns and health and social services be coordinated among the actors.

The Intervention- The Child friendly Schools Project (CFS)

Background Information

Programs or interventions should not single out children affected or orphaned by AIDS, as targeting specific groups or categories of children can promote stigmatisation and discrimination and in turn, deny other groups of children in the community who may have profound needs. With this in mind, Save the Children United States began developing a child-friendly schools initiative in March 1998 in collaboration with UNICEF and the Thai Office of the National Primary Education Commission (ONPEC), with encouragement from the World Health Organisation (WHO). Central to the notion of child-friendly schools, is the belief that the school can and should be a positive experience for all children.

The child friendly school's goal is to contribute to society by working to achieve the ideals described in the UN Convention of the Rights of the Child - that is for a school which promotes peace, dignity, tolerance, freedom, equality and solidarity. In August 1998, the Office of the National Primary Education Commission approved the launching of a multi-year Child Friendly Schools Program to be implemented in 16 provinces as a national education reform pilot project with funding from the Royal Thai Government, UNICEF, and Save/US. The Life Skills Development Foundation a Chiang Mai based non-government organization (NGO), was the primary collaborating and implementing agency in 5 Northern provinces.

The main objective of the project was to create prototypical replicable models of rights-based 'Child Friendly' schools that respond to the special needs of children in distress, develop psychosocial competencies, and promote healthy lifestyles and resilience in children and youth affected by AIDS in three districts of upper northern Thailand. The child-friendly schools initiative aims to encourage schools to contribute to the socio-emotional development of all children by becoming child-friendly. This project provided a

strong link between the UNICEF supported district-based approach for Children Affected by AIDS and the Child-friendly Schools Program, by focusing on sites with high concentrations of orphans and children affected by AIDS to develop specific school and community child development centre-based measures to respond to the psychosocial developmental needs and problems of children and youth affected by AIDS.

Child-Friendly Schools Defined

Schools are traditionally looked upon as places for serious learning pursuits, but rarely as places for children to enjoy their rights, express themselves freely, have fun and take part in enjoyable learning activities and be involved in decisions that affect them. One of the goals of the Child-Friendly Movement is to make the schools and the administrative system that supports schools, child-friendly. A child-friendly school system is one which recognizes and respects children's rights and responsibilities, allowing children to exercise their rights in schools, and helps ensure such an environment extends into children's homes and into the larger community of the school.

To transform existing pilot schools into child-friendly schools requires that the school system expand its perceived role and influence beyond the school into children's homes and the larger community. The school system must likewise expand its targets to include all school age children, whether inside or outside the school system, and even endeavour to influence the preparation of preschool children who are its future students. Furthermore, the school system also needs to relate and work more closely with other non-education sectors and stakeholders who are also engaged in meeting the needs and recognising the rights of children. What characterizes a rights-based child-friendly school system? A child-friendly school is effective with, healthy for, gender-sensitive, inclusive and protective of children. It is also importantly, family-focused and community-based (see table 4).

Table 4 – Four Pillars of the Child Friendly Schools Project

Effective with children	Healthy for children	Gender-sensitive, inclusive and protective of children	Involved with families and communities
<ul style="list-style-type: none"> • promotes quality learning environment and outcomes • children master the essential skills of writing, reading, speaking, listening, mathematics and life skills • children think critically, ask questions and express opinions • children as active learners learn by doing and working cooperatively in pairs and in groups • children are able to express their opinions about school work and school life • children work together to solve problems and achieve learning objectives • children's creativity through music, arts, drama, etc are encouraged and supported • child-centred and encourages child participation 	<ul style="list-style-type: none"> • promotes physical health • guarantees healthy, hygienic, safe environment, with adequate water and sanitation facilities • promotes healthy school policies and practices • serves as venue for health services • provides positive experiences for all children and promotes psychosocial development, self-esteem and self-confidence of children • no bullying nor any form of violence in school, no corporal punishment and teachers use non-aggressive styles of discipline instead of physical punishment • explicit school policy of non-tolerance for bullying • clear guidelines for conduct between students, and between students and teachers • children are protected from substance abuse, 	<ul style="list-style-type: none"> • promotes tolerance of diversity and caring for children • equality between boys and girls and between children of different ethnic, religious and social groups • eliminates gender stereotypes in biases • teachers model supportive behaviour towards children in distress • no children are excluded from activities by peers • schools adjust to meet the 	<ul style="list-style-type: none"> • establishes connections between school and family life of children • parents are involved in decisions about the school activities, methods and policies • parents regularly discuss children's learning experiences with teachers • parents are encouraged to put into practice at home what children learn in school • teachers are concerned with children's health and nutritional status and general well-being • teachers are concerned with what happens to children before they enter school and after they leave the classroom

<ul style="list-style-type: none"> • curriculum corresponds to the learning needs of children as well as the learning objectives of the education system • curriculum and learning methods are appropriate to the child's developmental level, abilities and learning styles • the needs of children are considered first over the needs of others • enhances teacher capacity, morale, commitment and status • ensures that teachers have adequate pre-service training , in-service support and professional development, status and income • provides education that is affordable and accessible, especially to families and children most at-risk 	<p>sexual exploitation and all forms of abuse</p>	<p>differing needs and circumstances of children</p>	<ul style="list-style-type: none"> • community-based and flexible system • encourages local partnerships in school-based management • acts in the community for the sake of children
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Main Objective of the CFS Project

To create prototypical replicable models of rights-based 'Child-friendly' schools that respond to the special needs of children in distress, develop psychosocial competencies, and promote healthy lifestyles and resilience in children and youth affected by AIDS and to create an enabling policy and programme environment and a network of support for the child-friendly school system in three districts of upper northern Thailand. The aims, specific

objectives and strategies as set out in the actual CFS project design document (PDD) are described in table 5. Figure eight shows the schedule of implementation for the main project activities.

Table 5. Aims, Specific Objectives and Strategies of the CFS Project

Aims	Specific Objectives	Strategies
<ol style="list-style-type: none"> 1. Enhance the health and well-being of children 2. Encourage school enrolment and completion 3. Raise teacher morale and motivation 4. Ensure higher achievement and academic success 5. Guarantee safe, protective spaces for children 6. Encourage child participation in school and society 7. Mobilize community support for education 	<ol style="list-style-type: none"> 1. To increase school-community awareness and understanding of the rights, psychosocial needs, and problems of children in emotional distress, orphans, and specific needs of children affected by AIDS. 2. To improve the child-friendliness of schools and child development centres by providing a caring and nurturing environment and emotional and psychosocial support for children in distress and children affected by AIDS. 3. To enhance the capability of teachers, community child development centre caregivers, and parents/guardians to interact with children, including those affected by AIDS, in supportive and nurturing ways that promote psychosocial development and increase resilience. 4. To develop and demonstrate a life-cycle approach (pre-school to grade 9) for active participatory learning to 	<ol style="list-style-type: none"> 1. Implement participatory child rights sensitization processes involving children, parents, community leaders, teachers, and other stakeholders in community child development centres and schools. 2. Involve children, adult community leaders, teachers/centre caregivers in local generation of criteria/indicators for child-friendliness and use in combination with external criteria/indicators. 3. Establish participatory assessment, analysis, planning, and action systems for continuous improvement of the child-friendliness of schools/community child development centres, including providing emotional and psychosocial support for children in distress and children affected by AIDS. 4. Create a learning exchange network of core trainers, model teachers/centre caregivers, and supervisors to promote and model supportive behaviour and nurturing ways to interact with children in distress, including those affected by AIDS. 5. Develop and implement processes for school-based participatory learning situation analysis by children, with involvement of parents, caregivers, community leaders and teachers, to identify local social environmental risk factors, protective factors, psychosocial needs and problems of children in distress, including children affected by AIDS. 6. Determine local priorities for specific positive developmental and preventive life skills

	<p>develop psychosocial competencies (life skills) including specific coping skills for children affected by AIDS, health promoting behaviour, and resilience.</p>	<p>education for school children affected by AIDS.</p> <p>7. Develop locally relevant applications of life skills curricula to respond to the social environmental risk factors, risk behaviour and problems of students in their everyday lives, including the special needs of children affected by AIDS.</p>
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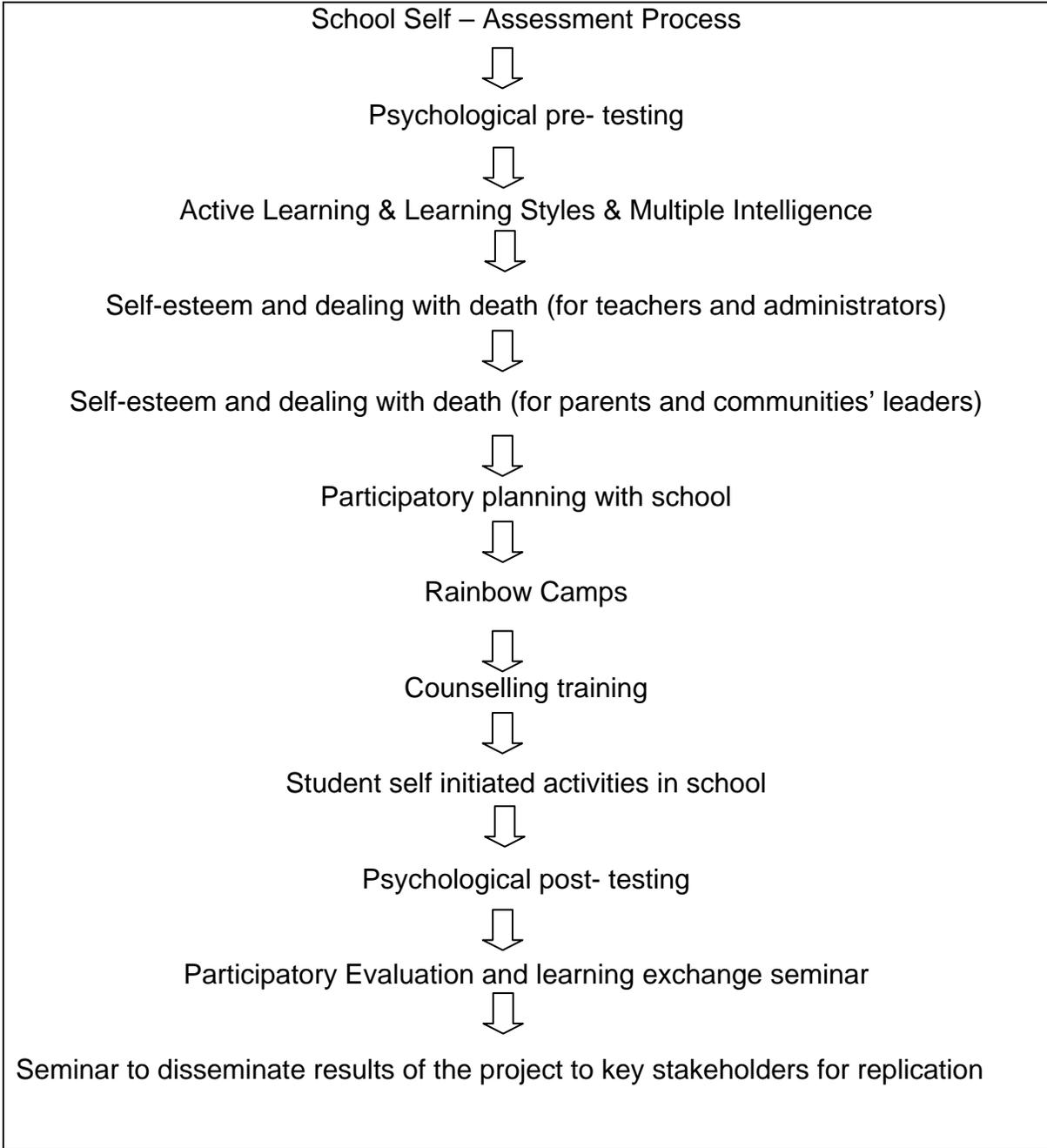


Figure 8. Timeline reflecting CFS Implemented Activities and Training

The Importance of Self-esteem building in Students

One of the main objectives of the CFS project was to conduct activities and infuse new child centred concepts into schools that would assist in enhancing children's self esteem. Self-esteem is the degree to which children feel accepted and valued by adults and peers who are important to them. The development of a sense of self is very complex. It is developed from within a person and shaped as well by the people around them (Katz, 1996). Kaplan (1975) states that programmes that enhance self-esteem can act as a social vaccine in reducing the incidence of many of the problems experienced by children experiencing grief and loss.

Much research in the area has been done in schools. Reasoner (2000) states that evidence supports the fact that most schools are not conducive to self-esteem since the level of self-esteem declines for most students the longer they are in school. Several studies have found that there was a significant relationship between self-concept and academic achievement (Brookover et al, 1965; Purkey, 1970; West and Fish, 1973). Coopersmith (1967) reported that children's self-concept predicted a child's ability to read in first grade.

Wylie (1974) found that there is considerable empirical evidence that self-concept predicts and influences achievement in school. Kelley (1978) found a correlation between delinquency and low self-esteem. When programs to raise self-esteem were implemented, delinquency decreased. Kaplan (1975) found that pupils with lower self-esteem were more likely to adopt deviant behaviour, as low self-esteem frequently becomes a source of anger and hostility. Covington's (1989) study found that as the level of self-esteem increases, so do achievement scores; and as self-esteem decreases, so does achievement. Furthermore, and perhaps most important, he concluded that self-esteem can be modified through direct instruction and that such instruction can lead to achievement gains.

TABLE 6. Problems affecting AIDS Orphans Identified through Pilot Research and Responsive CFS Activities

Manifestations	Immediate Causes	Underlying Causes	Basic Causes	CFS Activities Responding to Issues
Depression	<ul style="list-style-type: none"> • Lack of parental love and attention • Discrimination • Social Ostracisation • Loneliness 	<ul style="list-style-type: none"> • Lack of understanding of HIV transmission • Stigma • Lack of familial protection • Vulnerability due to social isolation • Family breakdown 	<ul style="list-style-type: none"> • HIV/AIDS • Parental illness • Poverty • Death of parent • Lack of permanency planning 	<ul style="list-style-type: none"> • Identification through depression and self esteem tests • School and community sensitization to the needs of children affected by HIV/AIDS • Grief counselling training for teachers • Rainbow camps
Learning Difficulties & Behavioural problems	<ul style="list-style-type: none"> • Depression and grief 	<ul style="list-style-type: none"> • Ineffective teaching techniques • Lack of understanding of children in difficult circumstances • Misinterpretation of behaviours exhibited by children in difficult circumstances 	<ul style="list-style-type: none"> • Teachers lack training in CRC, life skills and child centred learning methods • Teachers lack training that aids them in identifying children in difficult circumstances • Poor teacher/community relations 	<ul style="list-style-type: none"> • Participatory learning • Local curriculum development • Child rights and life skills education training • School based management information system to support child learning
Exclusion from education	<ul style="list-style-type: none"> • Lack of understanding of HIV transmission • Poverty 	<ul style="list-style-type: none"> • HIV/AIDS Stigma • Parental illness 	<ul style="list-style-type: none"> • Lack of government commitment to child rights in education • Lack of government policy regarding HIV and education • Ineffective support mechanisms 	<ul style="list-style-type: none"> • Sensitization in child rights for teachers and school administrators • School self assessment for child friendliness • School self-improvement through participatory planning/action process
Community Stigma	<ul style="list-style-type: none"> • Lack of understanding of HIV transmission 	<ul style="list-style-type: none"> • Lack of community education on HIV/AIDS 	<ul style="list-style-type: none"> • Poor HIV/AIDS policy • Lack of government commitment 	<ul style="list-style-type: none"> • School –community mobilization to support child development and child rights

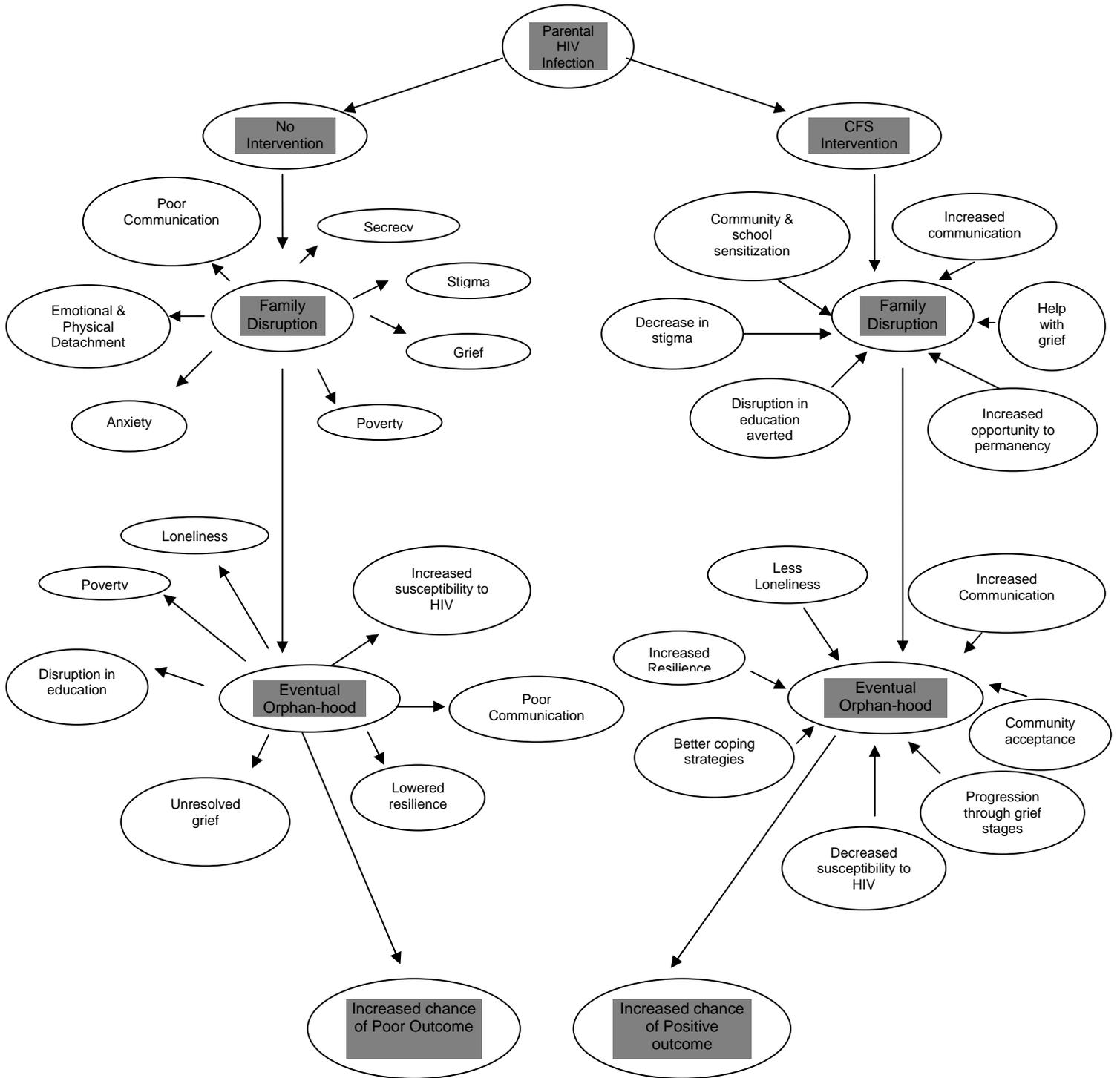


Figure 9 shows how the CFS activities attempt to reduce family disruption, increase coping strategies, enhance educational opportunities and decrease stigma for children affected by HIV/AIDS.

CHAPTER 6

Main Study Methodology Section

Participants

The sample consisted of 591 students attending the three pilot Child Friendly project schools in northern Thailand. A number of children participating in the study were currently experiencing psychosocial problems as a result of HIV/AIDS or other social disorders⁵ or in many cases a combination of both. Information on these children was provided by teachers and other key informants from the community such as monks or persons who have positions of influence in the village such as the village headman. It was however recognised by the researcher, that this may have only been the tip of the ice berg and many more children could possibly be experiencing difficulties unbeknown to these persons.

The interim period between pre and post testing was approximately one year. This allowed a sufficient time frame to explore any changes pre and post intervention in children's depression and self-esteem score. It also merged well with the monitoring and evaluation framework for the intervention. The research methodology differed from traditional pre and post designs as no control was used. The reasons underpinning the decision to follow this path were complex and were not taken lightly. It was very difficult at the time to convince the bureaucracy of the pilot schools to allow this type of testing let alone use another school which was not benefiting from any project activities. Discussions with peers and other key persons also questioned whether it was ethical to provide assistance to some children and not to others who may be identified in the control sample and may be in desperate need. It can also be argued that the results of the pilot research go a long way in highlighting the predicament of AIDS affected children both in societal and academic environments. A thorough situational analysis was gained from the results of this initial pilot research and this information was incorporated into the main study.

⁵ Drug and alcohol or gambling addictions

Quantitative Evaluation Instruments

The Children's Depression Inventory (see Appendix 4)

The inventory was developed by Maria Kovacs and translated by Professor Umaporn Trangkasombat, M.D. Child Psychiatry Division Chulalongkorn University and Professor Dusit Likanapichitkul, M.D. Yuwaprasat Hospital Bangkok. The CDI is a 27-item symptom-oriented scale that was designed for school age children and adolescents. It quantifies an array of depressive symptoms including disturbed mood, hedonic capacity, vegetative functions, self-evaluation, and interpersonal behaviour. Besides measuring current levels of depressive symptomatology, it has been used as a screen to differentiate symptomatic individuals or potential cases of depressive disorders from normal individuals (Trangkasombat & Likanapichitkul, 1996). The self-rated device is one of the most widely used modalities in psychological assessment. It is important to evaluate depression because affective states are likely to manifest in subjective evaluation of one's own experiences. Items in the CDI describe various feelings or problems that any child may experience and are not culturally specific.

Reliability

The reliability of the Thai version of the CDI was measured by analysis of correlation between each item and between each item and total score. The corrected item- total score correlation was 0.09-0.58. The internal consistency or the extent to which all items on the depression scale actually measured the same underlying dimensions was assessed with Cronbach's coefficient alpha. The value of the alpha obtained was 0.83 (Trangkasombat & Likanapichitkul, 1996).

Validity

Mean CDI scores were examined to determine the extent to which the scale differentiated contrasting groups. CDI scores were significantly higher among subjects rated during interviews as having depressive symptoms as compared with those rated as evidencing no symptoms (mean = 18.5, SD = 6.1 and mean = 9.3, SD=4.1 respectively, $p < .001$). Individual CDI responses were analysed to examine differences in reported symptom severity. The mean score of each item was calculated. Previously identified depressed children endorsed higher severity ratings on 26 of the 27 items. These results suggest that

the CDI, Thai version, has a good degree of discriminant validity. The choice of the optimal cut off score was derived from data plotted in a Receiver Operating Characteristic (ROC) curve. The examination of the ROC curve suggested that optimal screening cut-point for depression is 15. At this cut-point the CDI Thai version had a sensitivity of 79 percent, specificity 91 percent, accuracy 87 percent, positive predictive value (PPV) 82 percent, and negative predictive value (NPV) 89 percent (Trangkasombat & Likanapichitkul, 1996). The Coopersmith Children's Self-esteem Inventory - School Form (see Appendix 5). Coopersmith Self-Esteem Inventory—The School Form (SEI) (Coopersmith, 1981). Range School Form: 8 - 15 years. Time - untimed; about 10 minutes. This measure consists of 58 items, eight of which comprise a lie scale. The remaining items are scored on a dichotomous scale (“like me” or “not like me”) to provide a global measure of self-esteem. Higher scores indicate higher self-esteem. This measure was translated by Dr Chumpon Faculty of Psychology Chulalongkorn University Bangkok.

The Coopersmith Self-Esteem Inventory was developed through research to assess attitude toward oneself in general, and in specific contexts: peers, parents, school, and personal interests. This is a brief, self-report questionnaire originally designed for use with children, drawing on items from scales that were previously used by Carl Rogers. Acceptable reliability (internal consistency and test-retest) and validity (convergent and discriminant) information exists for the Self-Esteem Inventory (see Blascovich & Tomaka, 1991). Although this psychological instrument has not been normed in Thailand, it has been widely used in many minority cultures in western countries (Herz and Gullone, 1999; Kimball, 1972; Trowbridge, 1972; Stodtbeck, 1972; Reed, 1972; Owens and Gustafson, 1971; Simon and Bernstein, 1971; Ketcham and Morse, 1965 cited in Coopersmith, 1981).

Academic Records

Academic records for each child participating in the CFS project schools were collected by the researcher before and after the intervention from comparative purposes. Because the CFS schools were government run, the subjects taught in each school were the same (see table 14). The techniques and format utilised by teachers for marking and recording of students grades is also a standardised process in each school. These records provided valuable feedback when used in conjunction with other qualitative measurements such as focus groups, with teachers and students, to evaluate the projects effectiveness in enhancing the academic performance and learning of students.

Art Therapy and Focus Groups

Structured art therapy sessions were conducted during camp one focusing on opening communication lines between children and their guardians. Positive feedback was received from participants and it was obvious to the researcher that this was an effective tool in opening communication lines and connectedness (see chapter 6).

Focus groups were held on two occasions, during a therapeutic camp for children in difficult circumstances and after the end of the project implementation period (see tables 7, 19 & 20). The focus groups on both occasions had a funnel structure and were conducted in a relaxed and supportive environment. The group size was always limited to eight persons and the average time for the session was 30 minutes to one hour depending on the receptiveness of participants to discuss issues. Professional social workers facilitated each focus group session on both occasions.

The theme of the first focus group session held during Rainbow camp two revolved around relationships and communication between teachers, guardians and children. Children's thoughts on the rainbow camp and CFS activities and the infusion of knowledge learnt from these into their daily life was also explored. A number of questions were developed by the researcher, TLSDF team and social workers to provide a guide to aid the flow of discussion for both children and guardian groups (see appendix 6). These questions were designed to move the discussion from the general at the start to be narrower and focused at the end. A designated person took detailed notes. The on-site summaries were used to synthesize themes across all groups which were then sorted by the researcher for analysis and tabulation.

The theme of the second focus group sessions which was held after the completion of the CFS activities focused on how children perceived their school before and after the CFS project implementation period. Participants included children from the three pilot schools. The main themes explored were the school environment, participatory methods, and teaching methodologies. A number of questions were developed by the researcher and TLSDF team to provide a guide to aid the flow of discussion (see appendix 6). A designated person took detailed notes. The on-site summaries were used to synthesize

themes which were then sorted by the researcher and TLSDF staff for analysis and tabulation.

Procedure

The research received ethics approval number H962 from James Cook University Cairns, Australia.

Psychological Testing

Data were collected through the administration of the CDI and the Coopersmith self-esteem inventory to all students from grade 1 to grade 9 in the participating pilot schools. Informed consent was obtained through a consent form (see Appendix 3) from each subject and parent/guardian prior to the commencement of the testing. Due to the large numbers of students involved in the research it was necessary for teachers to assist with the distribution of the tests under the direct supervision of the researcher. The researcher was responsible for the administration of the testing instruments as well as answering any questions -via a translator from the children. Prior to the testing periods a considerable amount of groundwork was undertaken by the researcher.

A seminar was held with all involved teachers from the pilot schools to inform them of the researcher's intentions and the testing methodology, and to answer any queries that teachers might have concerning the use of psychological instruments. Some teachers were initially quite apprehensive about having such tools used in their classrooms, primarily because this was new to them and an air of unwarranted stigma and trepidation often surrounds psychological testing. It took a considerable amount of patience and explanation to convince teachers that the results would not reflect poorly on their ability to teach effectively, or their qualifications to be a role model for their students. The researcher, a registered practising psychologist in Australia, put forward the argument that the use of such psychological instruments, when administered by a mental health professional, could potentially be a useful and effective tool in screening for at risk students well before their problems take on a more severe form. It must be noted that prior to this research there is little evidence that mental health issues have received any considerable attention in the educational sector in Thailand.

The average duration for each testing period was approximately 30 minutes. Children were informed that their participation in this research was voluntary and they could withdraw their consent at any stage without incurring any reprisals or punishment from teachers or anyone else. The emotional state of each child was monitored and given the highest priority, fortunately no adverse problems were experienced by children during the testing period. Arrangements were made however, for teachers to be on hand to assist any children if they showed any signs of emotional distress. Professional help was also offered in the event that some children might experience some future distress. Due to language difficulties a number of younger minority hill-tribe children sought assistance from teachers regarding some more complex questions. This problem was monitored closely and caution was taken to reduce the incidence of coaching. The results from the psychological testing acted as a situational analysis and a baseline measure as well as allowing direct post- test comparison of the effectiveness of the project in building self-esteem through life skills development and child centred interactive teaching techniques.

CHAPTER 7

Rainbow Camps

The Rainbow Camps was an important activity in the CFS project and provided the researcher with an opportunity to derive qualitative information on the CFS activities as well as to conduct art therapy exercises. The qualitative results outlined in this chapter aim to compliment and add weight to the quantitative results highlighted in chapter eight.

People whose lives are affected by AIDS are faced with many emotional difficulties, unique to their own situations, which make life burdensome. They need a way to examine and explore their thoughts and feelings, and help with coping with the physical, emotional and social distresses of their condition. The stigma and secrecy of HIV/AIDS result in an interactive style of communication involving denial, distortion, deception and isolation. Children end up questioning their judgment and perceptions of reality and they become suspicious of others. Guilt, shame and blame are prominent factors in their lives (Weiner et al., 1998).

In an attempt to address these issues two therapeutic camps were conducted during the year of project implementation for sixty high-risk children and a designated caretaker of their choice in most cases these were older siblings or grandparents. The objectives of these camps were to provide an element of fun, while at the same time, to provide a number of special coping skills. A number of camp activities focused on building communication skills, connectedness, HIV education, instilling group support, destigmatization of HIV/AIDS for children caregivers and teachers, strengthening familial relationships and the development of a school-based older-to-younger child support networks. Participant selection was based on the baseline depression (children who had very high indicative scores) and self esteem tests and from teachers' own observations of children with behavioural problems in the classroom. Communities in Thai culture are generally close knit and most information about families is well known by everyone. The benefit of this is that early assistance can be provided, whereas the down side is that it can lead to unwarranted stigmatization which is commonly the case in communities with poor support networks.

During the first Rainbow camp it was the researcher's responsibility to conduct a number of art therapy exercises to enhance relationships and communication between children and their caregivers (see figures 10,11,12 & 13). None of these children had any prior bereavement counselling which would have helped them to develop coping skills to deal with the stress that AIDS brings. Bereavement counselling may, if it was available, support and encourages the child's capacity for resilience and the ability to understand what is happening. In an ideal setting counselling would have commenced well before the parent had deceased.



Figure 10. Guardian and child discussing their strategy to conduct an exercise



Figure 11. Art therapy group work and communication exercises

Art therapy techniques were chosen because they allow people to evaluate themselves, document their experiences in a non-directive, contemplative manner, while freeing themselves from inhibitions caused by social conditioning. It helps people reflect on personal meanings, and hold together fragmented and chaotic feelings. Art programs have been found beneficial in improving mental health and positive behaviours in behaviour disordered children (Rosal, 1993), traumatized children (Pifalo, 2002; St. Thomas & Johnson, 2002; Gil, 2003; Chapman, Morabito, Ladakakos, Schreier & Knudson, 2001), children living with HIV and AIDS (Willemsen & Anscombe, 2001), emotionally disturbed children (Thyagarajan & Kapur, 2000), children with anxiety disorders (Crenshaw, 2001), children with Autism (Gabriels, 2003), and children with ADHD (Safran, 2003).

Art has been used in some early intervention and after-school programs (Garcia, 1999; Saunders & Saunders, 2000) and has been shown to be beneficial to both children and their families. Art therapy, by emphasising a spontaneous approach to art, breaks down psychological defences. It is especially effective with young children traumatised with AIDS or HIV, or whose parents are afflicted (Willemsen & Anscombe, 2001). Because these children are unable to share with others their pent-up emotions, through art therapy, they have the opportunity to express themselves imaginatively through their drawings.

When children are not given an opportunity to talk about death and dying, their imagination and fear take over in response to the emotions they see around them and they may assume responsibility, or feel powerless and angry with themselves for having caused this problem. Not dealing with grief makes it harder for the child to cope with their circumstances (Willemsen and Anscombe, 2001). Coping difficulties could result in problem behaviour that may impede scholastic development and other areas of the child's life and could have far reaching consequences into adulthood. They need a way to examine and explore their thoughts and feelings, and help with coping with the physical, emotional and social distresses of their condition (Willemsen and Anscombe, 2001).



Figure 12 Child and guardian drawing a picture together on their present home situation

Initially children were asked to draw a picture about their current home life and their dream occupation, basically- 'where they saw themselves in the future'. Guardians were also asked to do a similar activity focusing on the present situation at home and what they wished for their children. After completion, children and their guardians were asked to sit together and briefly present their work. During these discussions it became clearly evident that both guardians and children had vastly different perceptions on their present and future wishes.

Often the guardians in contrast to the children, played down or failed to recognize the problems experienced by the children. Most children aspired to go on with higher education and eventual employment in a professional field such as a doctor or teacher. Guardians tended to have a less ambitious employment path planned for their children with an evident desire for them to leave school as soon as possible to be employed in more menial tasks. Further prodding of guardian's motives behind this revealed that there was a desire for more quick material goods such as televisions or a new vehicle. Less concern was placed on the possible long-term financial gains if the child entered more professional types of positions. Following this, a long open group counselling session was then held to discuss the needs and desires of both groups. It was a good opportunity to remind guardians of child rights and the importance of effective communication in the family. One of the main problems experienced by orphaned children, as outlined in the pilot research and by other studies is a lack of communication and poor relationships between children and their caregivers who are frequently grandparents.



Figure 13. Grandfather and grandson working together on their “ideal future” picture

Children and guardians were requested to work together on a picture depicting their “ideal future”. These activities were very successful in building relationships and opening communication lines between guardians and children. Both guardians and children expressed pleasure and a revitalised drive to work together with respect of each others

rights and dreams after these sessions. A commitment was made to follow up on their progress through focus group discussions during camp two as one participant noted:

“I have really enjoyed my time at the camp. Before I came here I could not talk with my grandmother- she just does not understand me. I wish to become a teacher and I am hoping to get a scholarship to do this. I now feel more confident when talking with her about my future”- 12 year old female

The second camp that was held monitored behaviour change and knowledge learnt since camp one. Activities in this camp also focused on skills such as self-awareness, sustaining relationships, dealing with emotions, effective communication, life planning and child rights. A key result from this camp was to learn that camp one participant's were able to apply the skills and knowledge they had learnt into their daily life. Parents and children had learnt to respect and accept each other's opinions more openly and were now spending much more quality time together. These camps were considered to be very successful activities in helping HIV affected children and their parent/s or guardians deal more effectively with their present predicament.

During camp two a number of focus groups were held by the implementation team with technical assistance provided by the researcher to evaluate the amount of knowledge retained and integrated into daily life. The results of these focus group discussions are highlighted in Table 7.

Results Focus Groups- Rainbow Camps

TABLE 7. Children's opinions after attending the rainbow camp

Camp Objectives	Main Skills Learnt	Summary of Feedback from participants
To support and improve family relationships and to create new friendships.	<ul style="list-style-type: none"> • Friendship and relationship building 	<ul style="list-style-type: none"> • Enjoyed participating in activities with other people • Established new relationships • Enjoyed drawing, exercising and playing games, doing activities with guardians
To improve the self-esteem of participants.	<ul style="list-style-type: none"> • Communication skills • Self confidence building • Self awareness raising 	<ul style="list-style-type: none"> • Children report that they now have the skills and self-confidence to express their feelings and have a greater understanding of how to maintain an open relationship with their guardians. • Children state that they have a better understanding of their emotional state and now have better coping skills. • Children now feel they have the confidence to ask for help when they are experiencing difficulties.
To create a greater understanding of child rights.	<ul style="list-style-type: none"> • Understanding of child rights 	<ul style="list-style-type: none"> • Children reported that they learnt a number of useful skills from the camps activities e.g. drawing, self-awareness, building self - confidence, assertiveness and child rights. • They have learnt that they are valued individuals, with rights and opinions that should be respected by others.
To encourage life planning	<ul style="list-style-type: none"> • Planning skills 	<ul style="list-style-type: none"> • They now know how to assist themselves in times of crisis and have the knowledge and confidence to conduct life planning.
To broaden participants knowledge on HIV/AIDS and risk behaviour.	<ul style="list-style-type: none"> • HIV/AIDS education 	<ul style="list-style-type: none"> • Participants have a competent understanding of HIV/AIDS- particularly how it is transmitted. • Now have more awareness about the dangers of illicit drug usage.

Sustainability of Knowledge Learnt		<ul style="list-style-type: none"> • Overall, guardians and children now state they have a much improved relationship. • Generally there is now more agreement in their opinions. • Children now feel they have the skills and ability to communicate more freely with their guardians. • Both groups now state they are able to express their feelings more freely with each other.
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Summary Conclusion

Overall, more than 95% of children and their guardians, when questioned through the focus group discussions, reflected that they now have more moral support from each other and have learnt how to live together as a functioning familial unit. They expressed their willingness to change some of their behaviours in accordance with their life plan. Activities that enhanced communication, family values, and self-esteem were useful to participants in improving familial integration and relationships. One of the main findings from the pilot research (chapter 4) was that many children have great difficulty in communicating with their parents or guardians particularly when the family is affected by HIV/AIDS. The results from this focus group session are very positive and encouraging. If people are taught through simple activities how to communicate and respect each others opinions, then they are able to deconstruct many barriers that compromise their wellbeing and relationships with others. Whilst these initial results are positive, there remains a need for a longitudinal evaluation to take place to measure any sustainable behaviour change.

CHAPTER 8

Results Main Study

The pre and post test quantitative results outlined in this chapter provide support to the qualitative results from focus groups outlined in chapter 7

Characteristics of Target Population

TABLE 8. Distribution of Sample by School and Gender

School	Gender	
Huarin	Male	80
	Female	63
	Total	143
Bornamrawn	Male	158
	Female	188
	Total	346
Pat Thai	Male	47
	Female	55
	Total	102
Total	Male	285
	Female	306
	Total	591
Percent	Male	48.2
	Female	51.8
	Total	100

Table 8 shows the subject population and gender breakdown for the three pilot schools. In total 591 children participated in this research. Bornamrawn school, because of its size, had the highest number of children (346) involved in the research. The gender distribution was fairly even with 48.2% males and 51.8% females taking part in the research.

TABLE 9. Distribution by Grade

Grade	Frequency	Percent
1-3	338	57.2
4-7	121	20.5
8-9	132	22.3
Total	591	100.0

Table 9 shows the distribution of the subject population by grade. The majority the children sampled (57.2%) were in the lower grades 1-3.

TABLE 10. Distribution by Age

Age	Frequency	Percent
5-7	156	26.4
8-11	203	34.3
12-17	232	39.3
Total	591	100.0

Table 10 shows the distribution of the subject population by age. . It is important to note that in many rural settings, grade and age are not always closely linked as they are in central areas and in many other countries. The reasons for this include the poor higher grade retention rate and the unavailability of classroom positions. Many children therefore have to wait longer to start school hence the high proportion of older students in lower grades.

Significance testing

TABLE 11

Pre & Post-test Depression and Self-esteem mean Scores

		N	Mean	SD	Min	Max
Pre	test	591	15.66	7.542	1	44
Depression						
Pre	test	591	61.46	13.292	8	98
esteem						
Post	test	591	13.51	6.387	1	44
depression						
Post	test	591	66.04	13.593	14	98
esteem						

Analysis of test mean scores reveals a reduction of depression (pre- test M 15.66, post-test M 13.51) and an increase in self esteem (pre-test M 61.46, post-test M 66.04) indicating that the intervention may have had a positive affect on children.

TABLE 12

Number of Children Scoring Over 15 in the Pre Test Depression Screening

	Frequency	Percent	Valid Percent
Score			
0-14	288	48.7	48.7
Over 15	303	51.3	51.3
Total	591	100.0	100.0

A significant number of children (51.3%) recorded depression scores above the cut point of 15 during the pre testing period.

TABLE 13.

Number of Children Scoring Over 15 in the Post Test Depression Screening

	Frequency	Percent	Valid Percent
Score			
0-14	361	61.1	61.1
Over 15	230	38.9	38.9
Total	591	100.0	100.0

Post test depression screening revealed a reduction in the numbers of children (38.9%) scoring above the cut point of 15.

TABLE 14 Gender Differences in Mean Depression and Self esteem Pre and Post test scores

	Gender	N	Mean	df	SD	t	Sig tailed	(2 tailed)
Pre test depression	Male	285	15.91	589	7.479	.763	.446	
	Female	306	15.43		7.605			
Pre test self esteem	Male	285	61.25	589	12.997	-.369	.712	
	Female	306	61.65		13.580			
Post test depression	Male	285	13.55	589	6.668	.133	.894	
	Female	306	13.48		6.125			
Post test self esteem	Male	285	66.22	589	13.513	.311	.756	
	Female	306	65.88		13.687			

Independent-samples t-tests compared gender differences in depression and self-esteem scores. Results revealed no significant gender differences in depression (pre-test $t(589)$

=.763, $p=.446$, post-test $t(575)=-.133$, $p = .894$) or self-esteem (pre-test $t(589) = -.369$, $p = .712$, post-test $t(589) = .311$, $p = .756$) scores. To keep the probability of a type 1 error fixed at 0.05 a Bonferoni adjustment was made to adjust the significance level for each of the 4 tests $0.05/4$ ($P=0.01$).

TABLE 15. Mean Depression and Self esteem Pre and Post test scores Between Children Identified as Having/not Having Problems

	Problems	N	Mean	df	SD	t	Sig (2 tailed)
Pre test depression	No	478	15.08	589	7.467	-3.922	.001
	Yes	113	18.13		7.385		
Pre test self esteem	No	478	62.16	589	13.450	2.640	.009
	Yes	113	58.50		12.225		
Post test depression	No	478	13.29	589	6.357	-1.710	.088
	Yes	113	14.43		6.458		
Post test self esteem	No	478	66.20	589	13.422	.569	.570
	Yes	113	65.39		14.355		

An independent-samples t-test compared the depression and self-esteem scores for children identified as having and not having problems. There was a significant difference in depression $t(589) = .76$, $p<.001$ and self-esteem $t(589) = 2.640$, $p<.009$ scores after pre test screening. Post-test screening revealed no significant differences between these groups in depression $t(589) = -1.710$, $p<.088$ and self-esteem $t(589) = .569$, $p<.570$ scores. To keep the probability of a type 1 error fixed at 0.05 a Bonferoni adjustment was made to adjust the significance level for each of the 4 tests $0.05/4$ ($P=0.01$). Table 11 also shows that 113 children out of 478 were identified by teachers as having psychosocial problems.

TABLE 16. Differences Between Pre and Post Depression Children's Depression Inventory Item Scores

		N	Mean	SD	t	Sig
Negative Mood	Pre test	591	3.08	1.988	.213	.831
	Post test	591	3.07	1.737		
Interpersonal Problems	Pre test	591	1.12	1.200	1.797	.073
	Post test	591	1.04	1.096		
Ineffectiveness	Pre test	591	3.23	1.648	16.673	.001
	Post test	591	2.21	1.239		
Anhedonia	Pre test	591	4.25	2.049	-437	.663
	Post test	591	4.29	2.022		
Self Esteem	Pre test	591	3.98	2.142	14.128	.001
	Post test	591	2.86	1.606		

A paired samples t-test determined if differences exist in the pre and post-test mean item scores. One of the main objectives of the intervention was to enhance children's self-esteem and effectiveness. A significant difference between the item 'ineffectiveness' occurred, pre-test ($M=3.23$, $SD=1.648$) and post-test ($M=2.21$, $SD=1.239$), $t(590) = 16.673$, $p < .001$. The eta squared statistic (.32) indicated a large effect size. A significant difference also occurred between the item 'self-esteem' pre test ($M=3.98$, $SD=2.142$) and post test ($M=2.86$, $SD=1.606$), $t(590) = 14.128$, $p < .001$. To keep the probability of a type 1 error fixed at 0.05 a Bonferoni adjustment was made to adjust the significance level for each of the 5 tests $0.05/5$ ($P=.01$). The eta squared statistic (.25) indicated a large effect size.

A meeting was organized by the researcher with teachers from the participating schools to discuss the results of the psychological pre-testing. Causal reasons for the high levels of depressive symptomatology were discussed and strategies to negate the psychosocial problems experienced by their students were explored (see table 17).

TABLE 17. Possible Causes of High Levels of Depression in Students as Reported by Teachers

Psychosocial Problems	<ul style="list-style-type: none"> • Parental death • Loneliness • Ostracism • AIDS affected • Divorce • Parent/Guardian Imprisonment • Parent/Guardian - Domestic violence • Parent/Guardian - Gambling • Parent/Guardian - Drug addiction or dealing • Parent/Guardian - Migratory labour etc
Economic Problems	<ul style="list-style-type: none"> • Families/guardians have large financial debts • Poor living conditions • Low familial income
Academic Problems	<ul style="list-style-type: none"> • Poor access to education • Attention deficits caused by psychosocial problems • Learning difficulties • Low self-confidence • Class retention
Health problems	<ul style="list-style-type: none"> • Disease • Poor nutrition • Skin irritations • Poor hygiene
Problems with teachers at school	<ul style="list-style-type: none"> • Some teachers lack reasoning skills • Some teachers are not kind and unfair • Some teachers frequently disclose student's problems/situation to others • Some teachers are insensitive to student's problems.

Teachers discussed several activities that they could implement to assist children experiencing psychosocial problems. These included organizing a home visit program to assist children, a counselling program, and an effort to be more attentive and more flexible in their teaching processes. These activities were included into the school plan and implemented as part of the overall project. Specialized training in counselling and child centred teaching techniques were delivered to teachers by the implementing agency.

TABLE 18. Scholastic Performance Pre and Post Project Implementation by school

Subjects	School	Semester	Mean	Std	Df	F	Sig
Thai Language	Huarin	1	66.6667	5.80141	1	.104	.754
		2	67.5050	2.62843			
	Bornamrawn	1	71.3333	4.32049	1	.495	.498
		2	73.3333	5.46504			
	Pat Thai	1	68.1250	5.52069	1	.329	.579
		2	65.8583	7.95102			
Mathematics	Huarin	1	69.6367	7.05366	1	1.370	.269
		2	64.8600	7.08433			
	Bornamrawn	1	73.8333	5.15429	1	.197	.666
		2	72.5000	5.24404			
	Pat Thai	1	70.3300	.99158	1	.254	.625
		2	68.6100	8.30196			
Social Skills	Huarin	1	64.5383	7.98217	1	.017	.898
		2	65.1233	7.43793			
	Bornamrawn	1	72.3333	6.86052	1	.022	.886
		2	72.8333	4.70815			
	Pat Thai	1	71.1033	2.84461	1	.003	.959
		2	70.8533	11.29392			
Health	Huarin	1	75.1483	5.14868	1	.073	.793
		2	74.4200	4.14970			
	Bornamrawn	1	78.1667	3.92003	1	.018	.896
		2	77.8333	4.62241			
	Pat Thai	1	77.5567	3.32183	1	.296	.599
		2	75.9783	6.28633			
Vocational Skills	Huarin	1	76.1767	5.43458	1	.211	.656
		2	77.5583	4.97882			
	Bornamrawn	1	78.3333	2.80476	1	.638	.443
		2	76.667	4.27395			
	Pat Thai	1	81.3917	6.13404	1	.586	.462
		2	79.1500	3.71752			

A one way between groups analysis of variance was conducted to compare academic scores for the three pilot schools pre and post project implementation. Overall, no

significant differences in academic scores were found between pre and post testing suggesting there was no increase in academic performance during the period of project implementation.

Summary

The results show that there was an overall improvement in depression and self-esteem scores over the course of the project implementation period. A breakdown of the CDI factor scores shows the greatest improvements to be in the self-esteem and ineffectiveness domains. Children identified as having problems exhibited higher depression and lower self-esteem scores in the pre-testing in comparison to other children. Post-testing scores however, revealed no differences in the depression and self-esteem scores of these two groups. No gender differences were evident in self-esteem and depression pre and post testing. Academic records reveal that there was no significant improvement in academic performance over the course of project implementation. A number of possible reasons for this will be offered in the main discussion. The results of the depression and self-esteem pre-testing were discussed with teachers from the three pilot schools in focus groups to provide insight into teachers' perceptions regarding the causes of their student's high depression and low self-esteem scores.

Results Focus Groups- CFS Project

A series of focus groups were undertaken after the completion of the project implementation period with children and teachers (see chapter 6 for details). The purpose of these focus groups was to derive qualitative data on the effectiveness of the project in meeting its initial objectives as well as to verify if knowledge learnt was sustainable. Prior to the CFS intervention many basic physical and psychosocial needs remained unmet, and the school was not perceived as a child-friendly environment proactively promoting and supporting the best interests of the child. The main results of these appear in the following tables.

TABLE 19. Pre CFS Intervention- Children's feelings toward teachers and School Environment

School Environment	<ul style="list-style-type: none"> • Teachers were very cruel and used many forms of punishment. • Emotionally unsupportive. • Student's lacked discipline. • Teachers physically punished students. • A unhygienic school environment • Teachers held no respect for child rights. • Students had no knowledge or understanding of child rights.
Participatory Methods	<ul style="list-style-type: none"> • A distinct lack of understanding existed in relation to the respective needs of teachers and students. • Schools were very formalised - strict rules were instigated from the top down without any participatory input from students.
Teaching Methodologies	<ul style="list-style-type: none"> • Teachers only used rote learning techniques which often excluded children with learning and behavioural problems.

TABLE 20. Post CFS Intervention- Children's feelings toward teachers and School Environment

School Environment	<ul style="list-style-type: none"> • A more friendly relationship now exists between teachers and students. • A better physical school environment is evident. • There is more discipline in the school. • There is now more understanding of student's needs and interests. • No longer do teachers or school staff use threatening or physical punishment.
Participatory Methods	<ul style="list-style-type: none"> • New school rules and orders were developed based on student opinions and input.

	<ul style="list-style-type: none"> • Students now have input into school processes
Teaching Methodologies	<ul style="list-style-type: none"> • Child centre learning approaches based on child rights have been incorporated into the school curriculum. • There is now more freedom in the learning process with more individual research work being undertaken that is driven by the personal interests of students.

Summary conclusion

The results of the focus groups suggest that the CFS project activities have been very effective in changing the school environment from a place where children endured harsh environment and learning conditions to a safe place that offers them the opportunity to potentially thrive both academically and emotionally. The infusion of child rights and child centred techniques into the school curriculum and the training of teachers in grief counselling along with other participatory methods have, as reported by children, changed the nature of the project schools to be a more inclusive and caring place. Major efforts and investments have been made to improve access to and quality of school education, concentrating on what seems to be the most pressing needs for facilities and equipment, curriculum development, and teacher training.

CHAPTER 9

Three Short Case Studies

The purpose of the following case studies is to provide a brief personal insight into the lives of three AIDS affected children that have attended and benefited from the CFS project. The case studies illustrate the lives of the children, as well as those of the people who supported them. This kind of research offered an intimate and detailed way of learning about the children and their worlds. Their stories are quite similar and reflect the lives of many children affected by HIV/AIDS in Thailand. Stigmatisation, trauma and loneliness are some of the obstacles that challenge these children. HIV typically destroys the fundamental human attachments that are essential to normal family life and development. On a more positive note, many of these children show a very resilient streak. By creating a more caring environment conducive to their needs, they are able to deal more effectively with their situations. Even though these parents and children voluntarily agreed to these interviews their names have been changed to protect their identity.

Case Study one

Kan's Story

Kan is a 15 year old girl who lives in Sanpatong district in a small rural village called Huarin. She lives in a modest house with her grandfather and mother who has AIDS but is currently asymptomatic. Kan's family is quite poor. She attended Huarin school which is one of the three pilot Child Friendly schools. The Huarin community suffers from a number of societal problems including HIV /AIDS, drug and alcohol abuse and gambling. The majority of people residing in the village are employed in the agricultural industry (growing and harvesting rice) for approximately 3 months of the year. For the rest of the year, most are employed in labouring positions on construction sites or in factories outside of the Sanpatong district.

As in many Buddhist societies, the Wat (temple) plays an important central role in the community. The head monk is very active in psychosocial issues in the village. He has instigated a number of projects that provide assistance to people experiencing problems, particularly women and children.

“In the past in Sanpatong district and especially in one particular village there were a lot of places (brothels) that prostitutes worked in. These establishments are often frequented by males from the village and other areas. Now things have changed and today prostitutes are readily found in many restaurants and karaoke bars” (Phra Daeng)

Because of the window period between infection and illness many others were infected in the village possibly from these people. He began to campaign to protect people against HIV when the infection rates began to rapidly rise. He believes the major problem is that young people leave the village to find work without any real understanding of HIV/AIDS. Without this knowledge, many became infected and unknowingly passed it on to others.

“A group of men travelled to Rayong (2-3hrs away from Bangkok) to work and when they returned something unusual happened in the village. They started getting sick and it was later found that many had contracted AIDS from visiting prostitutes”.

Culture is also a precipitating factor. In Thai society women are expected to be submissive and to abide by their husbands wishes. Large numbers of women in the village feel powerless and have low self-esteem, they know their husbands visit prostitutes but are afraid and say or to do anything about it. This lack of power also flows into their home sex life where women are afraid to ask their husbands to wear condoms. There currently is a group (NGO) that has close ties with the Wat and is very active in the village called “women against AIDS” this group seeks to reverse this situation and empower women both in the home and in the community.

Kan’s mother was very frank and open about telling her story of how she acquired HIV. She was married early at the age of 19 and had a daughter. This marriage ended in divorce with both parties going their separate ways. In 1995 she remarried to a man who was much younger than her. Before they were actually married they went to a local medical clinic and both underwent blood tests for HIV and both test results returned negative. Both were employed as labourers on construction sites at this time. After a few years her husband begun getting sick and after consultation with a doctor at the government hospital in Sanpatong they both agreed to be tested again for HIV. The tests again returned negative, but her husband became increasingly ill with skin disorders and

other minor problems. He was later diagnosed with a respiratory problem and admitted into the hospital for treatment. They declined to stay, and it was at this stage that she became suspicious and doubtful of the doctors diagnosis and she decided to ask him if her husband was suffering from AIDS related illnesses. The doctor declined to answer and told her to consult another doctor who was at that time in a meeting and unavailable.

Her husband's condition was deteriorating rapidly and he was experiencing severe headaches which had become unbearable. He was however, still able to continue working and supporting his family. Kan's mother sought advice from several of her friends in the community and they advised her to visit the government hospital in city of Chiang Mai. They took heed of this advice and visited Suandoc hospital and were both yet again tested for HIV. While waiting for these test results the husband fell very ill and she took him back to Sanpatong hospital to see the original consulting doctor. He was immediately admitted into the intensive care unit with a brain related disorder. The doctor then asked her how she would feel if she knew her husband had AIDS. She said that she would be very sad but would accept the situation.

At this point both of them knew that he had AIDS and she tried desperately hard to smile and to pacify her husband telling him that this could happen to anyone. After this they both travelled back to Suandoc hospital to receive their HIV test results. The doctor handed her the results without uttering a word, no attempt at counselling was made or any offers of assistance made. They travelled back to their home in Sanpatong and finally built up enough courage to open the test results to find that they were both HIV positive. She began to cry but wanted to be strong for her daughter; she told her mother who was very shocked and devastated. She asked her daughter how she felt about her mother having HIV, her daughter replied "I am not shy, but I am very sad". Close friends of hers in the community suggested that she not tell anyone and warned her that it would cause her many problems if people found out.

After her husband died in 1998 her sister in-law suggested that she join the HIV women's group (loosely translated as "join with open arms"). Not wanting to stay alone and let her problem frustrate her she joined the group and received the emotional support she needed. On reflection, she believes that her husband had become HIV positive from

visiting prostitutes prior to their marriage. She wants to tell this story so other people may learn from her experiences.

At the time of the research there were about 45 women in the HIV support group of these about 7 or 8 work in the Wat most days. They produce several items such as clothing to sell to raise revenue. Some of the money (10,000-20,000 Bht) generated from the HIV women's group Wat activities is donated each year to children's scholarships, National Children's Day, and World AIDS Day. The sewing machines utilized by the HIV group in the Wat belong to the non-formal education department.

The Wat also acts as the non-formal education centre in the community and is accessible to several groups of women children and the elderly. The HIV women's group also provide home visits and counselling to newly HIV infected persons and to general patients recuperating from an illness or accident. The group is well accepted by the community. There does not seem to be a large AIDS related stigma problem in the community probably because there are so many infected persons. Kan's mother said that some people feel stigma when they refuse to disclose and accept their positive status when everyone else in the community already knows. The group really focuses on helping these individuals come to terms with their predicament and provide positive alternatives. The head monk stated that he was planning to take the HIV women's group to see the ocean as he believed that for most it would be the first and last time they would be able to do this before they died.

Kan's mother is extremely proud of her daughter and this is very obvious as she becomes teary eyed when she talks about her being a constant source of strength and encouragement for her. She told how she gave up hope after the death of her husband, she stayed in bed and had no motivation to go to work or even go outside. She said that Kan helped her greatly during this period and eventually she began to have some hope.

Kan graduated from Huarin school a year before most children her age. She is currently undertaking a three year general course in cooking, dress-making, interior decorating and floral arrangement at a government vocational college. She had the opportunity to specialize in either of these four courses but chose to undertake the general course to gain experience in all areas. She is a very high achiever scoring 8th out of well over a

hundred in the entrance examination. She hopes to graduate from vocational college and then pursue a bachelor's degree at university, possibly in floral arrangement. She hopes to find part time employment whilst studying at the vocational college and has already made several contacts that may provide her with some work in the flower business. Her eventual aim in life is to own her own floral arrangement business. She became interested in floral arrangement when she was in grade 5. There was a garland making competition for students being held at her school but the teacher would not let her participate because she was being very naughty.

Eventually the teacher consented and let her enter and she won first prize out of all schools in the sub-district and district region. At present she assists the head monk at Wat Huarin with all floral orders (weddings, funerals, festivals etc) as she is the only one that has the ability to undertake such a task. Sometimes she has to work until 2 or 3 in the morning if they receive a large order. Most days she is found assisting in some way at the local Wat and she is very happy to do so. She is very determined to help her mother financially as she knows her mother works hard and does her best to support the family. Kan has one very close friend but she is able to mix well in groups of other children.

Kan was very appreciative that she was able to attend a "Child Friendly" school and she believes that she gained a lot of strength, motivation and assertiveness from the rights based activities that were conducted in the school and at camps held specifically for children in difficult circumstances. Initially, when her mother told her about being HIV infected she was very sad but with the support from the school and some organizations in the community she was able to overcome her fears and regain hope for the future. Initially there were problems and a lot of teasing, but she was able to rise above it and continue to be strong and supportive of her mother. Having a very close relationship with one of the female teachers at the school has been extremely helpful and enhanced her ability to cope. Kan's teacher, Ms Ratre, has provided strong support for her, including regular home visits, from the time her mother's HIV status was confirmed. Although Kan has left the school, Ms Ratre's support continues; she is always there for her when she is feeling down or has a problem.

Kan's story is a very common one amongst children in Huarin and Sanpatong district as there are many children whose lives are touched by HIV/AIDS. A while back Kan entered

a writing contest in a local newspaper that wanted people to write about ways to help other people. She wrote about her life experiences and how she was able to motivate herself to achieve, and to live life to its fullest. She used her experiences as a guide to motivate other people, especially those that may have similar problems to her.

Case Study Two

Sam's Story

Sam is a ten year old boy from Chiang Rai province. Both Sam and his mother provided information for this case study. Sam's mother provided most of the information for the case study because Sam still had difficulty talking about his father and what had happened. For this reason Sam was only asked questions relating to the activities undertaken by the CFS project. One of the guiding principles of the CFS project was to avoid overtly targeting specific groups. All children received the same attention and were able to be involved with all CFS activities in the school. Inclusion rather than exclusion was promoted heavily. School ownership of the project was also highly encouraged.

Sam's mother states that Sam's father was a trader in Mai Sai a town on the Thai/Burma border. Mai Sai is a bustling border town which is a notorious location for many vices such as prostitution, drugs, and people trafficking – particularly young women and children. Sam's father frequently travelled between Burma and Thailand buying and selling goods.

For a number of months Sam's father was repeatedly falling ill and it was becoming increasingly hard for him to conduct his business. One day he fell ill and was hospitalised. Due to the repetitive nature of his illnesses, on advice from the doctor, a test for HIV was undertaken. To the shock and dismay of Sam's parents this came back positive. A year after his diagnosis Sam's father silently passed away. The extended family had refused to help or acknowledge Sam's parents throughout the course of his father's sickness. Sam's mother states that the extended family would not talk with her and would not help in any way. This incident had apparently brought tremendous shame on the family.

Sam's mother could not speak more highly of the CFS project. She stated that it was like a great weight being lifted from her shoulders. *"My family don't want to know me and I have*

for a long time been unable to confide in anyone. I always feared that people will treat my son poorly, and they did at times but he was too young to understand why. Now it is different, I can now talk with teachers and others like me in the community. I am very grateful for what this project is doing for the children”

Sam also states that he is enjoying the activities and he feels that the teachers have become more caring. He has in the past been teased by other children and at times teachers have treated him harshly. Sam seems to think that the school is trying to change and the headmaster is really focused on helping children. After school activities and livelihood training have also helped create friendships and bonding amongst students.

Sam's mother is now very much involved with activities in the school. She attended the school assessment process which included children, teachers and the community. She is very happy to be able to contribute her time to the school when needed. It is evident during the interview that Sam's mother was very appreciative of the project. Unfortunately, HIV/AIDS stigma can force people to become reclusive if they are affected and this is obviously what has happened to her in the past. She now has the opportunity to be a part of her son's education which would normally be a fundamental right of every parent.

Case Study 3

Somchai's Story

The following case study is about a 16 year old teenager called Somchai. This case study illustrates that some children are capable, with a little assistance, of being resilient despite experiencing numerous obstacles. He is a quiet spoken individual but when questioned he answers with an air of assertiveness and it is clear that he is a confident individual.

Somchai describes his young life so far as being extremely difficult. He has experienced excessive stigma and endured things that a child should not be put through. He has and is currently experiencing a form of “double stigma” because of his ethnicity (Lahu Daeng which is a minority group in northern Thailand) and the fact that he has lost both parents to AIDS.

Somchai attends a CFS school and is currently in Mor 4 which equates to grade ten. His home town is Chaiprakan Bahn Pang Makham Bom, which is in northern Thailand, not far from the Burmese border. Somchai was able to describe in detail his life history. When he was young his parents divorced for unknown reasons and he ended up staying with his father. Some time later, Somchai's father was arrested and incarcerated by local authorities for drug related offences. At the time Somchai had limited contact with his mother but he later learnt through others that she had died from AIDS, so he had no one to stay with. Whilst his father was away the local temple was willing to take him in and provide care and schooling for him. When his father was released from prison he remarried but failed to resume care of his son. This had effectively left Somchai permanently orphaned and in the care of the local temple. A few years later his father fell ill and also died from AIDS.

Somchai states that it is his ambition in life to go to university and study law. The driving force behind this career path is the fact that he has experienced many unnecessary difficulties which stem from stigma and an infringement of personal rights. An example of this was his treatment by government officials. When he was young both he and his father moved a lot due to his father's transitional occupation as a labourer. Unfortunately, on one of these occasions his father misplaced their citizenship documents so they had to go through the complicated process of re-applying for Thai citizenship. Both were born in Thailand and had lived there all of their lives but this is no guarantee that citizenship will be granted. A lack of citizenship and subsequent rights makes minority groups extremely vulnerable to all forms of exploitation.

When they went to renew their citizenship the government official could not find any copies or their original citizenship papers. He states "the official really did not care and he did not try to find our papers; he kept telling us to come back later". He felt abused because he felt he was discriminated against because of his ethnicity and because he was from a poor village. It took many frustrated attempts to finally renew his papers.

"I want to study law to help protect minority group's rights because most of them don't know the law so they are discriminated against". "I come from a poor village, when the government support budget is approved, we are frequently left out".

Somchai has in the past experienced a lot of problems at school particularly with other children who tease him about his parents dying from AIDS. He feels he is not liked by other students but he is a high achiever academically and desperately wants to succeed in school.

"I have been in many fights and I won't back down when someone is giving me a hard time"

Somchai believes that children should have the right to make decisions, suggest ideas and opinions and he would like it if adults accept these. The CFS project he believed is a great opportunity for students in similar positions to himself. It has given them more rights in the school and has helped educate teachers and other students to be more sensitive to the needs and emotions of children in difficult circumstances. He stated that stigma generally stems from ignorance or a lack of understanding of something, so the more you educate and sensitise people on issues such as HIV/AIDS, the better it will be for those that are affected by it. He believes that the project has promoted inclusiveness both inside and outside of the class room. Somchai stated the school has come a long way but there is much more to be done.

"We need acceptance and the chance to show that we can achieve. The government must support people like myself because we are the next generation of leaders. I am one of the lucky ones that has had the chance to benefit from this project.....many others don't have this opportunity and they remain helpless"

Somchai's story briefly illustrates that some children have an innate resilience that can be tapped and directed when given the opportunity. The CFS project provides children such as Somchai with this opportunity to be accepted for who they are and not what they have been labelled as. Somchai believes the project has helped him a lot and made the path ahead easier. Although his parents have died he adamantly believes they are watching him and helping him achieve his dreams.

CHAPTER 10

Main Discussion

"Without education, AIDS will continue its rampant spread. With AIDS out of control, education will be out of reach"

- Peter Piot, Director of UNAIDS.

As the AIDS epidemic unfolds, the proportion of cases involving women, children, and families has increased dramatically. HIV/AIDS will continue to affect the lives of several generations of children. The unpredictable nature of the virus introduces uncertainty into every aspect of a family's life. Its variability threatens the routine and structure that are essential to well-being, healthy growth and a basic sense of security. Children are especially vulnerable because they are extremely dependent on the family and the way it functions.

The demands of HIV/AIDS are compounded by major demographic vulnerabilities- education and work opportunities decline, nurturing and support systems are eroded, and mortality rises. Children's distress is often compounded by the prejudice and social exclusion directed at individuals with HIV and their families. This stigma may translate into denial of access to schooling, health care and of the inheritance rights of orphaned children. In this respect, girls may be at a further disadvantage. A final cruel difference from other parental diseases is that HIV is likely to have spread sexually between the father and mother. Thus the child's chances of losing a second parent relatively quickly are high. In the absence of caring adults to protect them, children struggle to survive. Many surviving family members have been known to exhibit symptoms of a post- traumatic stress disorder although this is not entirely an accurate term since these issues are generally ongoing (Dane, 1992). While AIDS has garnered a significant amount of attention, little consideration has been directed towards this population.

A clear shift of programmatic priorities has become evident in Thailand. Programs on HIV/AIDS and children in Thailand have in the past been focused primarily on prevention. However, due to the growing crisis which now sees thousands of children enduring the impact of HIV/AIDS in their families and communities, more emphasis is now on assisting

the survivors. The CFS project was implemented by the The Life Skills Development Foundation (TLSDF), a non government organisation based in Chiang Mai, in collaboration with the Office National Primary Education Commission (ONPEC), with funding from UNAIDS and UNICEF. TLSDF are technically very experienced in the development and implementation of rights based participatory projects in health and education sectors. It was TLSDFs aim to pilot this project, evaluate its effectiveness, and then ONPEC would replicate it nation wide as part of the current ongoing education reform process in Thailand.

People with HIV and those close to them are subject to numerous stressors that can affect their mental health. HIV-affected individuals are challenged to find ways of coping with stress, anxiety, and feelings of depression throughout the course of HIV disease. A person's history of coping with adversity or illness, the amount of social and emotional support they receive from friends, family, and community organizations, and their ability to access mental health services can all be important protective factors for an HIV-affected person's mental health. Professional psychological knowledge about bereaved children, to date, has largely been developed in a Western context, so there is a gap in information on HIV-specific grief and depression among Thai and Asian children. For this reason, this research has several important roles a) to profile how HIV/AIDS affects the familial unit; b) to analyse eventual orphan outcomes; c) to discuss whether losing a parent to AIDS places children at increased risk for psychosocial adjustment difficulties; and finally d) to evaluate the effectiveness of a participatory, child centred, rights based intervention that aims to build self-esteem and resilience in AIDS affected children.

It is vital, when considering the needs of children affected by HIV/AIDS, to recognise the importance of a supportive environment for a child's survival and development. Social support systems can act as a buffer to some of the HIV/AIDS related stressors but often many families fail to take advantage of them. A fear of disclosure and stigma associated with HIV/AIDS, forces many families to isolate themselves from their extended family and communities to protect themselves and their children from maltreatment. Effective child-centred interventions such as the CFS project, do not focus on children alone, but consider the social context of their communities, as well as the structures and services which support children. The CFS project was participatory and child & community centred in nature, with teachers, children, parents/guardians and communities being involved in the entire process. Several participatory planning and evaluation sessions were undertaken

throughout the project implementation period to ensure that activities were culturally relevant, focused and in the best interests of children in difficult circumstances (see table 4).

Depression in AIDS affected children can occur for many reasons—low self-esteem, anticipatory, realistic or unresolved grief, the daily anguish of living with the virus, powerlessness, anger, and the illness orientation that characterizes the families. Mental health disorders have an intertwined relationship with HIV, yet are often overlooked when AIDS interventions are planned and implemented. With this fact in mind, the researcher decided to use a combination of measures in an attempt to get a wholistic picture of the mental health situation of the subject population. Western based research (Egland & Sroufe, 1981; Egland, Sroufe & Erickson, 1983; Forsyth, 1996; Forehand et al., 1998) and African studies (Sengendo and Nambi, 1997; Makaya et al., 2002; Makame et al., 2002;) have found a direct correlation between HIV and heightened levels of depression in affected children.

The research took place in three schools (see table 8) that were selected to pilot the Child Friendly Schools project for AIDS affected and disadvantaged children. The project sites were selected due to their high numbers of AIDS affected children, their willingness and commitment to change, and their ability to dedicate staff and resources. The majority of subjects (57.2%) were in grades one to three (see table 9) yet the average age of the population (39.3%) was in the 12 to 17 age bracket (see table 10). This finding is common in many communities suffering social and economic problems and is consistent with other studies such as Bicego et al., (2003) who found that an orphan is less likely to be at his/her proper educational level than a child who has both parents living. Furthermore, double orphans are less likely to be at their proper level than are single orphans. For single orphans, a mother's death causes more deterioration in education at the primary school ages as compared to a father's death.

The CFS project aimed to address a number of psychosocial problems experienced by children through a series of focused activities (see table 5 & figure 8). The results of the pilot research assisted in the development of strategies to assist children and provided a map of potential outcomes if certain issues are addressed by the project (see figure 9). Previous research has highlighted that children living in AIDS-affected households are more likely to suffer exclusion, start school at a late age, or drop out of school because

remaining family members cannot afford to pay fees, or the child may be needed to care for other relatives or siblings, or to work. Studies in Africa suggest that after the death of one or both parents, the chance of orphans going to school is halved, and those who still attend school spend less time there (UNAIDS 2000). The CFS project aimed to transform the schools both environmentally and physically to be friendlier to all children regardless of their predicament. By doing this, exclusion from education from both inside and outside the classroom will be reduced. For obvious reasons this project would not be able to address economic problems per se, besides offering some vocational training to students, but it does reduce the likelihood of children being stigmatised against and being refused entry into school (see figure 8). It also attempts to keep children in school for as long as possible. By involving families and the community the CFS project was able to ensure local ownership which is crucial to the sustainability of any development project.

Psychological Testing

Chatterji et al (1995) study emphasises that given the possible adverse psychological consequences on a child of a parent's illness and death, program implementers desperately need reliable and valid methods to measure the psychological well-being of children and determine their needs. In this research the Child Depression Inventory (CDI) and the Coopersmith Self-esteem Inventory (CSI) (see appendix 4 & 5) were used, along with qualitative methods such as focus groups (see tables 19 & 20) to evaluate the effectiveness of the CFS intervention.

The results of the research suggest that overall the project did have an impact on childrens depression and self esteem levels over the course of the implementation period. An overall increase in self esteem levels and a lowering of depression rates was evident between pre and post testing (see table 11). This finding agrees with research conducted in the United States and Africa that suggest that children of HIV-infected experience higher rates of grief, depression, dysphoria, anxiety, post-traumatic stress disorder, irritability, social withdrawal and impaired cognitive performance than others (Forsyth et al., 1996; Sengendo & Nambi, 1997; Forehand et al., 1998; Makaya et al., 2002). The results revealed that a significant number of children (51.3%) recorded depression scores above the clinical cut point of 15 (see chapter six) during the pre testing period. Post test depression screening revealed a reduction in the total numbers of children (38.9%) scoring above the cut point of 15 (see tables 12 & 13).

A further examination reveals that there were no gender differences in pre and post depression and self-esteem scores (see table 14). This finding agrees with Trangkasombat & Likanapichitkul's (1996) Thai study which also found no significant gender differences in depression scores. Literature on HIV/AIDS has indicated that girls are at greater risk of being excluded from education and potentially more exposed to HIV through unsafe work environments. In Pat Thai school which has predominately Lahu Daeng children the headmaster informed the researcher that girls started leaving school around the age of 11 or 12 to be married. The practise of pre arranged marriage was still in use in many of these communities and it was generally the older and wealthier men that had the choice of these young girls. One could speculate that not being able to complete their schooling and being forced to marry a person possibly not of their choice may cause girls to have higher rates of depression. This was not however an area that was looked at by this research. Further research needs to be done to explore this gender issue.

Young children affected by AIDS, like all children, need caregivers with whom they are attached or they emerge poorly socialized and alienated from their communities. AIDS affected children are at risk of developing psychosocial trauma and distress due to hardships that they face. Psychosocial trauma involves a disconnection between the way children have understood the world to be and the way they experience it. Psychosocial distress is caused by experiences that are fundamentally inconsistent with how the child has come to expect the world and his/her place in it. Children who are stigmatised and ostracised by people, that they otherwise expected to receive support and care from, are more likely to experience social disconnectedness and heightened insecurity due to lack of trust.

A further breakdown of the depression results reveals that the project had the most affect on children who were identified prior to the pre-testing period by teachers and peers as having psychosocial problems. There was a significant difference in depression and self-esteem scores after pre test screening. Post-test screening revealed no significant differences between these groups in depression and self-esteem scores (see table 15). This finding is very positive as it appears as though the project has been effective in assisting children known to be experiencing problems from being AIDS affected but without a control group and further evaluation, this can not be proven beyond a doubt.

A further breakdown of the CDI factor scores shows the greatest improvements to be in the self-esteem and ineffectiveness domains. A main objective of the CFS intervention was to enhance children's self-esteem and effectiveness. This finding was extremely positive reflecting the targeted nature of the intervention activities. Self –esteem is seen as one of the main protective factor that makes people more resilient when faced with adverse experiences. Self-esteem is generally considered the evaluative component of the self-concept, a broader representation of the self that includes cognitive and behavioural aspects as well as evaluative or affective ones (Blascovich & Tomaka, 1991). Self-esteem has been related to virtually every other psychological concept or domain, including personality (e.g., shyness), behavioral (e.g., task performance), cognitive (e.g., attribution bias), and clinical (e.g., anxiety and depression) concepts (Blascovich & Tomaka, 1991). Low self-esteem is linked to depression (Tennen & Herzberger, 1987), alienation (Johnson, 1973), and social anxiety (Leary, 1983). The reason for the greater increases in self-esteem and effectiveness domains could be due to the introduction and infusion of child centred learning techniques into the schools which empowered children and gave them more say in their schools curriculum development.

The use of discovery learning techniques help build a child's self esteem by opening up their creativity and giving them new skills. An example of this is where children in one pilot school learnt about malaria by going into the community and interviewing local health organisations. Children after gathering all of the facts, presented their results back to the community. As a result of this activity children gained more confidence in their abilities and learnt more about preventative measures for a dangerous health problem and at the same time transfered this knowledge to their peers. These innovative techniques aim to give children more responsibility and control over how they learn and and their physical environment. Increases in the other domains may be expected over time as the project activites become more entrenched in the schools.

Focus group sessions were held with teachers to discuss the results of the depression and self-esteem pre-testing and possible reasons for the high depression and low self-esteem ratings of many students in their schools (see table 17). Reasons such as a poor familial environment and poverty were brought forward, but it was obvious at this stage, prior to

any project sensitization training, that their understanding of HIV was lacking and there was an air of stigma surrounding their perception of HIV infected/affected persons.

It is obvious from the literature that many children may suffer from the social, economic and psychological consequences of the epidemic several years prior to death of a parent, as they live with prolonged or recurrent parental illness. They may not know what is happening to the parent and become confused and frightened. Many mental health issues transcend economic, political, and cultural boundaries as young people vulnerable to the vicissitudes of this disease in their parents become embroiled in a downward spiral of stigma, shame, secrecy, and losses. Some studies (Brown and Sittitrai, 1996; Murray and Cooper, 2003) suggest that the severity of the epidemics impact on a child may be greater before he or she is orphaned than it is in later years.

Most children show psychological reactions to parental illness and death such as depression, guilt, anger and fear. Furthermore, the recurrent impact of AIDS at the household level can be associated with continuous traumatic stress syndrome and a second generation of problems such as alcohol and drug abuse, severe depression, violent behaviour and suicide (Straker, 1992). There is a real need for more research to be conducted on children's mental health issues prior to the death of their parent/s from AIDS.

Unfortunately for some AIDS affected children, a vicious psychological cycle may result from a depressive reaction initially triggered by loss, or ineffectiveness. The depressive reaction may cause more difficulties resulting in a greater depressive reaction resulting in more difficulties- finally resulting in a maladaptive behavioural pattern. In this regard, it is important to determine factors that protect bereaving youth from experiencing impairing psychological distress. Art therapy exercises and other activities (see Ch7 & table 5) that help enhance communication and relationships with peers can be valuable tools. The Rainbow Camps provided a unique opportunity to enhance relationships and communication between AIDS affected children and their guardians. Art therapy exercises broke down barriers and enabled children and their guardians to communicate their feelings in a constructive and fun way. For many children open communication with their grandparents or older siblings was impossible due to cultural beliefs that respect must be shown to older persons. Being able to express their feelings and needs in a picture was an extremely successful way to communicate their opinions and needs. There is no doubt that

the Rainbow Camps were an important CFS activity for both therapeutic and evaluative purposes.

Caregivers, community leaders, volunteers, and school personnel can all make contributions to a child's well-being by recognizing problems and involving young people in group activities. Children affected by HIV/AIDS live in a world shrouded by secrecy and isolation. For children dealing with grief from a loss of a parent/s in a stigmatised environment can be an almost impossible task without the open support of family and friends. Children need to feel like they are important individuals and that they have a future. It is extremely important, in the first instance, to make the "invisible" child "visible".

Academic Performance

A review of academic records shows that there were no significant differences in academic scores between pre and post-testing suggesting there was no increase in academic performance during the period of project implementation (see table 18). Improving the school environment so that it was conducive to learning and psychosocial wellbeing of students was the main priority of the CFS project. Achieving an improvement in academic performance was of course important, but is viewed as a longer term goal of the project. By providing a psychological environment conducive to learning, this goal is now seen as more attainable.

Focus group discussions with children and teachers on this particular topic suggested that a possible reason for non significant increases in academic performance may be related to the fact that teachers were frequently absent from the classroom to attend training and project planning sessions. This was an unforeseen problem, but inadvertently also led to a more participatory classroom style. Children believed that overall, the school and classroom environment had dramatically improved (see tables 19 & 20) but their tuition had suffered due the unavailability of teachers. It is likely however, that academic performance would improve once teacher's absenteeism was reduced and both teachers and children become more accustomed to the new child centred participatory teaching methodologies. Children frequently remarked during focus group discussions that they were very pleased and empowered by the new learner friendly environment in the classroom (see table 20). An improvement in self-esteem and a lowering of depression, as indicated by many other studies (Brookover et al, 1965; Purkey, 1970; West & Fish, 1973) would in due time enhance the academic performance of students.

Another encouraging result from the training that teachers had received was the fact that their ability to identify children in trouble was enhanced remarkably. Prior to pre-testing teachers identified 113 children as having psychosocial problems due to being AIDS affected or from other familial problems (see table 15). Although exact numbers were not recorded, teachers reported that they were able to identify considerably more children in distress after the post-testing period. Their confidence to assist, and their knowledge about psychosocial issues surrounding HIV that affect children was boosted remarkably.

“Some students would behave very poorly in the classroom and were disruptive to other children. I put this down to the fact that they were not good students. I now realise there was more behind their behaviour. Some of these children were experiencing many emotional problems due to their family’s predicament. The grief and counselling training has been very useful for me as a teacher. I am now more aware of how my students are feeling and I have the skills to assist them more”.- Grade 6 teacher Chiang Rai

Prior to the project teachers had frequently interpreted children’s behavioural patterns incorrectly. A combination of poor coping skills and an unfriendly environment increases the likelihood that children suffering from an AIDS related depression become withdrawn or act out in a sometimes violent fashion. Instead of assisting or being sensitive to their situation, teachers would frequently punish these children (see table 19) thereby worsening the situation and decreasing the likelihood of the child adapting and being accepted by other children in the classroom.

A common theme reflected throughout the pilot research and the focus groups was the fact that many children were being ostracised or isolated at a time when they were in most need for support. The stigma and secrecy of HIV/AIDS result in an interactive style involving denial, distortion, deception and isolation. Children end up questioning their judgment and perceptions of reality and they become suspicious of others. Guilt, shame and blame are prominent factors in their lives (Weiner, 1998). As noted in the pilot research (see Ch4) parent/child and sibling relationships are also disturbed by the impact of HIV/AIDS. Attachment disorders and compromised parenting are common. Family dynamics are damaged in both subtle and dramatic ways (Dane, 1992). Many of the

responses that are adaptive in HIV affected homes prove to be highly maladaptive in the outside world. It may be argued that the resulting cognitive dissonance further diminishes their fragile sense of competence and identifies them as impaired to others.

Young people need a safe and supportive environment. This requires sensitive attitudes, policies and legislation at family, community and national levels. Strong and effective education systems are important. Yet, in many countries, those systems are in disarray. They need to be repaired and boosted with innovative teaching approaches. School attendance enables children to retain a semblance of normal life, even if there are major changes at home.

Children have the right to freedom from discrimination in education. This right flows from the non-discrimination provisions of the Convention on the Rights of the Child, the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, the Convention on the Elimination of All Forms of Discrimination Against Women, and the International Convention on the Elimination of All Forms of Racial Discrimination. It is explicitly guaranteed in the Convention against Discrimination in Education, which had ninety states party to it as of July 2001. As Schafer (1994) states “the education system must also adapt to the impact of HIV and AIDS by altering the content - knowledge, skills, and values - of what it teaches and the methods it uses for teaching”. Taking action to prevent HIV/AIDS and to mitigate the impact of HIV/AIDS on orphans and other vulnerable children, also contributes to improved quality of education and the overall learning environment. Despite the many challenges HIV/AIDS poses to the educational systems, access to primary education is a basic need and right of every child.

In Summary

The growing demand for care and support of orphans and vulnerable children at the community level has strained traditional coping mechanisms to a crisis stage in the most heavily affected countries. An increasing number of communities and government structures are struggling to harness the impact of AIDS on children and their families. The psychosocial needs of children continues to be one of the most neglected areas of

support. If children are to develop the resilience to deal with the challenges in their lives, their psychosocial needs must receive proper and prompt attention.

The consequences of HIV/AIDS for children are complex and multiple, many of which have serious implications for their psychological well-being. The HIV epidemic has increased the urgency to address psychological problems of children in an equal proportion to other interventions. Psychosocial support interventions recognise that growing children need more than just basic material provision. They also need social stimulation and support, nurturing, affection, and guidance from stable, caring adults. Through appropriate psychosocial care and stimulation, children develop positive self-esteem, decision-making capabilities, skills for daily living, flexibility and adaptability, social capacities, and the ability to manage their emotions appropriately. Without proper support mechanisms upon the death of a parent children experience a profound sense of loss, grief, hopelessness, fear and anxiety. Long-term consequences can include psychosomatic disorders, chronic depression, low self-esteem, low levels of life skills, learning disabilities, and disturbed social behaviour. In the absence of support, there will be long-term developmental impacts on children and a very negative impact on society.

Despite the recognition of the magnitude and significant health, economic, social, and psychological consequences of this problem, and increasing attention and resources devoted to these children, little evidence exists about which children are most in need of assistance and what types of interventions would be most effective in helping them. It is therefore crucial that evaluative research such as this takes place to inform and provide evidence based feedback on project effectiveness. Many projects targetting children in difficult circumstances have ineffective monitoring and evaluation frameworks built into their design. Psychological instruments are useful tools that can provide a baseline situational analysis and comparative data for evaluative purposes. Because of their often precarious economic and social circumstances orphaned children and youth are particularly vulnerable to HIV infection - as are all children from families affected by HIV/AIDS – highlighting the importance of effective, well evaluated, prevention strategies. Young people are key to controlling HIV/AIDS. They have the right to knowledge and skills that reduce their vulnerability and enable them to protect themselves and each other against the epidemic.

Experiences show that HIV/AIDS programmes that respect and involve young people, while being sensitive to their cultures, are more likely to succeed. Large-scale, long-term efforts are needed to cope with these harsh new realities. National policies and legislation affecting children are also key factors in the creation of a supportive environment for children affected by HIV/AIDS. Projects need to be based on a permanency planning model which recognizes not only the traditional legal needs of families but also the mental health, social support, educational, and care coordination needs. The way in which a parent's illness and death are handled within the family are critical to a child's future.

Potential Problems and Recommendations

The research would clearly have benefited from the use of a control group for comparative purposes so that any observed changes in children's depression and self esteem levels could be attributed to the CFS intervention. Further research also needs to be conducted in a more controlled way to look at ways to further enhance the resilience of AIDS affected children. Reasons why some children have better outcomes than others in similar situations needs to be further explored.

The researcher foresees replication and sustainability as being the most obvious challenges to the CFS project not its content or design. Effective and quality replication relies heavily on the technical skills of the implementation team. It is the researcher's understanding that ONPEC rely heavily on each school's ability to implement and adapt each of the activities to their own situational circumstances. It is questionable whether schools can do this effectively without ongoing quality technical assistance. Sustainability is the key aim in the development field, yet it is often not adequately incorporated into monitoring and evaluation frameworks. The researcher believes that the project evaluation process should be an ongoing process as it is difficult to get a true indication of how effective a project is in such a short period of time. More longitudinal research is also needed to examine the long term affects of this project on the development and resilience of children in vulnerable circumstances.

Another area that needs further exploration in the Thai context is the impact of maternal deprivation on children's coping. The question of whether losing a parent to AIDS places children at increased risk for psychosocial adjustment difficulties still requires further exploration although studies to date tend to suggest that it does. Another potential downfall of the project is the inconsistency in school staffing. For example if a headmaster is replaced by one that is not committed to the project then there is an increased likelihood that the project would lose momentum or even cease. It is hoped, however, if a situation like this occurs, that certain aspects of the project would remain en-cultured within the school. The researcher believes that the majority of the activities need to be followed in order to get maximum effects from the project.

The CFS project was well designed, focused, and flexible in its approach (see figure 9) which is crucial in working with diverse cultures and differing communities. This is extremely important as the constraints believed to affect orphans' and other vulnerable children's access to primary education are numerous and differ in magnitude from one community to another. There are also substantial differences in the needs of children of different ages and how programs should effectively address each group.

The results of this research suggest that the CFS project has been effective in reducing depression and increasing self esteem in children attending the pilot schools. It is however, extremely difficult to pinpoint the exact reason for its success. It is the researchers' belief that all CFS activities contributed to its success. HIV/AIDS can permeate into all areas of a person's life. It is therefore extremely important that an intervention takes this into account and provide a comprehensive and wholistic response. The case studies (see chapter 8) also give a personal insight into how the CFS project has assisted three children. The multi modal model is clearly a strength when aiming to achieve a nurturing and healing environment for all children. Data on children orphaned by AIDS and vulnerable children needs to be systematically collected to offer valuable insight into the effects of HIV/AIDS on children, especially with respect to their access to education. Unfortunately, there is not one solution that can solve all of the psychosocial problems that hinder an AIDS affected family. This project does however, go a long way in regards to recognizing that mental health issues cannot be ignored and have a place in any form of programmatic intervention for children in vulnerable circumstances.

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APPENDICES

APPENDIX 1

QUESTIONS FOR HIV/AIDS POSITIVE PARENTS PILOT STUDY

1. How are you feeling?
2. Are you experiencing any symptoms of HIV/AIDS?
3. Was pre-test and post test counselling made available to you?
4. If yes, did you undertake counselling?
5. If no, why not?
6. Who provided support for you at this time?
7. Do your children know of your HIV/AIDS status?
8. If no, what are your reasons for not telling them? - Then proceed to question 13.
9. If yes, how did your child first find out about your positive status?
10. Does your child understand the outcome of this disease?
11. If no, do you intend to tell them?
12. Have you noticed any changes in your children's behaviour since they became aware of your status?
13. What are your main fears for your children?
14. Do you think that you have a good understanding of HIV/AIDS and how it can be transmitted?
15. Have you and your children received any education about HIV/AIDS?
16. Have you talked to your child about HIV/AIDS?
17. Is your extended family aware of your positive status? If yes, proceed to question 19.
18. If no, please explain reasons for choosing not to tell them?
19. Do you think that you have changed much in regards to your relationship with your family and other people since you become aware of your positive status? If no, go to question 21.
20. If yes, what changes have you noticed?
21. Do you think you have a good relationship with your children? If yes, proceed to question 23.

22. If no, what reasons do you think are causing this?
23. Is there anything that you think could improve the relationship?
24. Do you discuss everyday problems with your children?
25. Do your children help you with everyday chores?
26. Are your children attending school?
27. If no, please provide reasons?
28. If yes, have they experienced any problems at school?
29. Are the people in your community aware of your positive status?
30. How have you and your child been treated by your local community?
31. Are you currently working?
32. If not, how do you support your family?
33. How will you provide for yourself and your children if you become sick?
34. Who will take care of your children if you become too sick?
35. Have you been able to make any plans for your child's future in regards to accommodation and financial support?
36. If no, please provide reasons why?
37. Does your family provide help?
38. Do you receive any assistance from government and non government agencies?
39. If yes, what type of assistance do they provide?
40. What do you think are your main needs?
41. In your opinion how can this service be improved?
42. What do you believe are the main problems affecting you in everyday life?
43. Is there anything that you want to discuss?

QUESTIONS FOR HIV/AIDS POSITIVE PARENTS IN THAI

1. คุณมีความรู้สึกอย่างไรในขณะนี้
2. คุณรู้หรือมีประสบการณ์เกี่ยวกับอาการของโรค AIDS หรือไม่
3. คุณได้รับคำแนะนำก่อนหรือหลังการตรวจหรือไม่
4. ถ้าได้รับ คุณปฏิบัติตามคำแนะนำหรือไม่
5. ถ้าไม่ปฏิบัติตาม ช่วยบอกสาเหตุว่าทำไม
6. ใครเป็นผู้ให้ความช่วยเหลือแก่คุณในครั้งนี้
7. ลูกหลานของคุณรู้หรือไม่ว่าคุณติดเชื้อ HIV/AIDS
8. ถ้ายังไม่รู้ทำไมคุณถึงไม่บอกเขา-ข้ามไปตอบข้อ 13
9. ถ้ารู้แล้ว เขารู้ได้อย่างไร
10. ลูกหลานของคุณรู้ถึงผลของการติดเชื้อหรือไม่
11. ถ้าไม่รู้ คุณตั้งใจจะบอกพวกเขาหรือไม่
12. .ลูกหลานของคุณมีพฤติกรรมที่เปลี่ยนแปลงหรือไม่
ตั้งแต่พวกเขา知道你ติดเชื้อ HIV แล้ว
13. สิ่งสำคัญที่คุณหวาดกลัวเกี่ยวกับลูกหลานของคุณในขณะนี้คืออะไร
14. คุณคิดว่าคุณมีความรู้เกี่ยวกับโรค HIV/AIDS ดีพอหรือไม่
และรู้หรือไม่ว่าโรคนี้สามารถแพร่ได้อย่างไร
15. คุณและลูกหลานของคุณเคยได้รับการศึกษาเกี่ยวกับ HIV/AIDS หรือไม่
16. คุณเคยพูดคุยกับลูกหลานของคุณเกี่ยวกับ HIV/AIDS หรือไม่
17. ญาติๆของคุณรู้หรือไม่ว่าคุณมีเลือดบวก ถ้ารู้แล้ว ข้ามไปทำต่อ ข้อ 19.
18. ถ้ายังไม่รู้ กรุณาบอกสาเหตุว่าทำไมถึงยังไม่บอกเขา
19. คุณคิดว่าคุณเปลี่ยนไปมากหรือไม่ในเรื่องความสัมพันธ์กับครอบครัวและ
คนอื่นๆตั้งแต่คุณทราบว่าคุณมีเลือดบวก ข้ามไปทำข้อ 21.

20. ถ้าเปลี่ยน การเปลี่ยนแปลงใดที่คุณสังเกตเห็น
21. คุณคิดว่าคุณมีความสัมพันธ์ที่ดีกับลูกหลานของคุณหรือไม่ ถ้าใช่
ข้ามไปทำข้อ 23
22. ถ้าไม่ใช่ อะไรที่เป็นสาเหตุ
23. คุณคิดว่ามีสิ่งใดที่สามารถทำให้ความสัมพันธ์กับลูกหลานดีขึ้นได้
24. คุณพูดคุยปัญหาในชีวิตประจำวันกับลูกหลานหรือไม่
25. ลูกหลานช่วยคุณทำงานบ้านหรือไม่
26. ลูกหลานของคุณไปโรงเรียนหรือไม่
27. ถ้าไม่ได้ไป ทำไมถึงไม่ไป
28. ถ้าไป พวกเขามีปัญหาเกี่ยวกับทางโรงเรียนหรือไม่
29. คนในชุมชนของคุณรู้ว่าคุณมีเลือดบวกหรือไม่
30. ชุมชนที่คุณอยู่ปฏิบัติต่อคุณและลูกหลานอย่างไร
31. คุณยังทำงานอยู่หรือไม่
32. ถ้าไม่ ค้นหาเลี้ยงครอบครัวได้อย่างไร
33. คุณได้เตรียมอนาคตให้ตัวเองและลูกหลานอย่างไร
ถ้าคุณป่วยทำงานไม่ได้แล้ว
34. ใครจะเป็นคนดูแลลูกหลานแทน ถ้าคุณป่วยมาก
35. คุณได้วางแผนอนาคตให้ลูกหลานหรือไม่ เช่น เรื่องที่อยู่อาศัย
หรือเรื่องการเงิน
36. ถ้าไม่วางแผน กรุณาบอกสาเหตุด้วย
37. ครอบครัวของคุณให้ความช่วยเหลือหรือไม่
38. คุณได้รับความช่วยเหลือจากทางราชการหรือเอกชนบ้างหรือไม่
39. ถ้าได้รับ เป็นความช่วยเหลือแบบไหน

40. ความต้องการหลักของคุณคืออะไร
41. ตามความคิดของคุณ บริการนี้ควรทำอะไรถึงจะดีขึ้น
42. อะไรที่คุณคิดว่าเป็นปัญหาสำคัญที่กระทบถึงคุณในชีวิตประจำวัน
43. มีอะไรที่คุณอยากจะพูดอีกบ้าง

APPENDIX 2

QUESTIONS FOR AIDS ORPHANS

1. Do you know what caused your parents death? If no, go to question 4.
2. If yes, when and how did you find out about it?
3. Did you talk much with your parents? If no, why not?
4. Did your parents talk to you about their illness?
5. What did you enjoy doing most with your parents?
6. Who do you talk with when you are feeling sad?
7. What problems did you have?
8. Were you able to talk to anyone about how you felt when your parents died?
9. How did your friends and people in the community treat you?
10. Were you going to school? If no give reasons.
11. Did you have any problems at school?
12. If no, did you enjoy going to school?
13. Who takes care of you now?
14. Do you like where you are living now?
15. What do you want to be when you grow up?
16. Do you understand about HIV/AIDS?
17. If yes, how did you find out about it?
18. Do you think HIV/AIDS is a big problem in your community?

QUESTIONS FOR AIDS ORPHANS IN THAI

1. รู้หรือไม่ว่าอะไรเป็นสาเหตุที่ทำให้พ่อหรือแม่เสียชีวิต ถ้าไม่รู้ข้ามไปทำข้อ 4
2. ถ้ารู้ รู้เมื่อไรและอย่างไร
3. ได้พูดคุยมากหรือไม่ ถ้าไม่ เพราะเหตุใด ไม่ได้พูดคุยกับพ่อแม่
4. พ่อแม่เคยพูดเรื่องการเจ็บป่วยให้ฟังหรือไม่
5. ชอบทำกิจกรรมต่างๆกับพ่อแม่หรือไม่
6. ชอบทำอะไรมากที่สุดกับท่าน
7. ความรู้สึกของตนเองสามารถพูดให้คนอื่นฟังได้หรือไม่
8. ถ้าไม่สบายใจจะพูดคุยกับใคร
9. มีปัญหาเรื่องอะไรบ้าง
10. เคยไปโรงเรียนหรือไม่ ถ้าไม่ ให้เหตุผลด้วย
11. คุณมีปัญหาที่โรงเรียนหรือไม่
12. ถ้าไม่ ชอบไปโรงเรียนหรือไม่
13. ใครเลี้ยงดูตัวเราอยู่ตอนนี้
14. ชอบที่อยู่ตอนนี้หรือไม่
15. โตขึ้นอยากเป็นอะไร
16. เข้าใจเกี่ยวกับ HIV/AIDS หรือไม่
17. ถ้าเข้าใจ เข้าใจได้อย่างไร

18.คิดว่า HIV/AIDS เป็นปัญหาใหญ่ในชุมชนที่อาศัยอยู่หรือไม่

QUESTIONS FOR NON AIDS ORPHANS

1. Do you know what caused your parents death?
2. Did you talk much with your parents?
3. Did you enjoy doing things with your parents?
4. What did you enjoy doing most with your parents?
5. Did you get angry with your parents much? If yes, why?
6. Who do you talk with, if you are feeling sad?
7. What do you think your main problems are?
8. Do you have many friends?
9. How do people in your neighbourhood treat you?
10. Are you going to school? If no, give reasons why?
12. Do you have any problems at school? If yes, what are they?
13. If no, do you enjoy going to school?
14. Do you like where you are living now?
15. What do you want to be when you grow up?
16. Do you think HIV/AIDS is a big problem in your community?
17. Do you understand about HIV/AIDS?
18. If yes, how did you find out about it?

QUESTIONS FOR NON AIDS ORPHANS IN THAI

- 1.ทราบหรือไม่ว่าทำไมพ่อแม่ถึงได้เสียชีวิต
- 2.ได้พูดคุยกับพ่อหรือแม่มากไหม
- 3.ชอบทำกิจกรรมต่างๆร่วมกับพ่อแม่หรือไม่
- 4.ชอบทำกิจกรรมอะไรกับท่านมากที่สุด
- 5.เคยโกรธพ่อแม่มากหรือไม่ ถ้าเคยทำไมถึงโกรธท่าน
- 6.จะพูดคุยกับใคร ถ้ารู้สึกไม่สบายใจ
- 7.คิดว่าปัญหาที่สำคัญ ๆ ของตัวเองคืออะไร
- 8.มีเพื่อนมากหรือไม่
- 9.เพื่อนบ้านปฏิบัติกับเราอย่างไร
- 10.จะไปโรงเรียนหรือไม่ ถ้าไม่ ให้เหตุผลด้วย
- 11.มีปัญหาที่โรงเรียนหรือไม่ ถ้ามี คืออะไร
- 12.ถ้าไม่มีปัญหาที่โรงเรียน ชอบไปโรงเรียนหรือไม่
- 13.ชอบที่อยู่ตอนนี้หรือไม่
- 14.โตขึ้นอยากเป็นอะไร
- 15.คิดว่า HIV/AIDS เป็นปัญหาใหญ่ในชุมชนที่อาศัยอยู่หรือไม่
- 16.เข้าใจเกี่ยวกับ HIV/AIDS หรือไม่
- 17.ถ้าเข้าใจ เข้าใจได้อย่างไร

APPENDIX 3

CONSENT FORM

Thank you for giving to the time to participate in this research. It is important that you read and sign the following-

I am participating in this research purely on a voluntary basis without inducement nor benefit. I recognize the right to withdraw my participation at any stage if I wish to do so. I also acknowledge that personal counselling and support will be provided if I experience any adverse psychological stress due to my participation in the research.

Signature

Signature of Guardian

CONSENT FORM (Thai)

ข้าพเจ้าสมัครใจที่จะร่วมในการทำวิจัยโดยไม่หวังผลตอบแทนจากการวิจัยนี้ซึ่ง
ข้าพเจ้าเข้าใจว่าข้าพเจ้ามีสิทธิ์ยกเลิกการวิจัยเมื่อใดก็ได้อันเนื่องมาจากเหตุผล
ส่วนตัวของข้าพเจ้าหรือถ้าข้าพเจ้าได้รับผลทางความเครียดทางจิตใจอันอาจจะ
เกิดจากการร่วมการวิจัยซึ่งข้าพเจ้าสามารถยกเลิกการเข้าร่วมในครั้งนี้ได้
และข้าพเจ้าสามารถเข้ารับการบำบัดทางจิตใจได้ด้วย

APPENDIX 4

CDI Thai Version

ต่อไปนี้เป็นความรู้สึกที่เกิดขึ้นได้ในบุคคลทั่วไป ไม่มีข้อใดผิด หรือ ข้อใดถูก
จงเลือกข้อที่ตรงกับความรู้สึกของท่านมากที่สุด ในช่วง สองสัปดาห์ที่ผ่านมา
โดยทำเครื่องหมาย (X) บนข้อ ก, ข หรือ ค

1. ก) ฉันรู้สึกเศร้ามานานๆ ครั้ง
 - ข) ฉันรู้สึกเศร้าบ่อยครั้ง
 - ค) ฉันรู้สึกเศร้าตลอดเวลา

2.
 - ก) อะไรๆ ก็มีอุปสรรคไปเสียหมด
 - ข) ฉันไม่แน่ใจว่าสิ่งต่างๆ จะเป็นไปด้วยดี
 - ค) สิ่งต่างๆ จะเป็นไปด้วยดีสำหรับฉัน

3.
 - ก) ฉันทำอะไรๆ ได้ค่อนข้างดี
 - ข) ฉันทำผิดพลาดหลายอย่าง
 - ค) ฉันทำอะไรผิดพลาดไปหมด

4.
 - ก) ฉันรู้สึกสนุกกับหลายสิ่งหลายอย่าง
 - ข) ฉันรู้สึกสนุกเฉพาะกับบางสิ่งบางอย่าง
 - ค) ไม่มีอะไรสนุกสนานเลยสำหรับฉัน

5.
 - ก) ฉันทำตัวไม่ดีเสมอ
 - ข) ฉันทำตัวไม่ดีบ่อยครั้ง

ค) ฉันทำตัวไม่ดีนานๆ ที

6.

- ก) นานๆ ครั้งฉันจะคิดถึงสิ่งไม่ดีที่อาจเกิดขึ้นกับฉัน
- ข) ฉันวิตกว่าจะมีสิ่งไม่ดีเกิดขึ้นกับฉัน
- ค) จะต้องมึ่สิ่งเลวร้ายเกิดขึ้นกับฉันแน่ๆ

7.

- ก) ฉันเกลียดตัวเอง
- ข) ฉันไม่ชอบตัวเอง
- ค) ฉันชอบตัวเอง

8.

- ก) สิ่งเลวร้ายทั้งหมดที่เกิดขึ้นเป็นความผิดของฉัน
- ข) สิ่งเลวร้ายหลายสิ่งที่เกิดขึ้นเป็นความผิดของฉัน
- ค) สิ่งเลวร้ายที่เกิดขึ้นมักไม่ใช่ความผิดของฉัน

9.

- ก) ฉันไม่คิดจะฆ่าตัวตาย
- ข) ฉันคิดถึงการฆ่าตัวตาย แต่ฉันจะไม่ทำเช่นนั้น
- ค) ฉันต้องการฆ่าตัวตาย

10.

- ก) ฉันรู้สึกอยากร้องไห้ทุกวัน
- ข) ฉันรู้สึกอยากร้องไห้บ่อยครั้ง
- ค) ฉันรู้สึกอยากร้องไห้นานๆ ครั้ง

11.

- ก) ฉันรู้สึกหงุดหงิดใจตลอดเวลา
- ข) ฉันรู้สึกหงุดหงิดใจบ่อยครั้ง

- ค) ฉันรู้สึกหงุดหงิดใจนานๆ ที่
- 12.
- ก) ฉันชอบอยู่กับคนอื่น
- ข) ฉันไม่ค่อยชอบอยู่กับคนอื่น
- ค) ฉันไม่ต้องการอยู่กับใครเลย
- 13.
- ก) ฉันไม่สามารถตัดสินใจอะไรต่างๆ ด้วยตนเอง
- ข) ฉันตัดสินใจเรื่องต่างๆ ได้ลำบาก
- ค) ฉันตัดสินใจเรื่องต่าง ๆ ได้ง่าย
- 14.
- ก) ฉันเป็นคนหน้าตาดี
- ข) ฉันเป็นหน้าตาไม่ค่อยดี
- ค) ฉันเป็นคนหน้าน่าเกลียด
- 15.
- ก) ฉันต้องใช้ความพยายามอย่างหนักทุกครั้งที่ทำกรบ้าน
- ข) ฉันต้องใช้ความพยายามอย่างหนักบ่อยครั้งที่ทำกรบ้าน
- ค) การทำกรบ้านไม่ใช่ปัญหาใหญ่สำหรับฉัน
- 16.
- ก) ฉันนอนไม่หลับทุกคืน
- ข) ฉันนอนไม่หลับหลายคืน
- ค) ฉันนอนหลับสบาย
- 17.
- ก) ฉันรู้สึกเหนื่อยนานๆ ครั้ง
- ข) ฉันรู้สึกเหนื่อยบ่อยครั้ง
- ค) ฉันรู้สึกเหนื่อยตลอดเวลา
- 18.

- ก) มีหลายวันที่ฉันไม่รู้สึกรอยากกินอาหาร
- ข) มีบางวันที่ฉันไม่รู้สึกรอยากกินอาหาร
- ค) ฉันกินอาหารได้ดี

19.

- ก) ฉันไม่กังวลกับการเจ็บป่วย
- ข) ฉันกังวลกับการเจ็บป่วยบ่อยครั้ง
- ค) ฉันกินอาหารได้ดี

20.

- ก) ฉันไม่รู้สึกรเหงา
- ข) ฉันรู้สึกรเหงาบ่อยครั้ง
- ค) ฉันรู้สึกรเหงาตลอดเวลา

21.

- ก) ฉันไม่รู้สึกรสนุกเลย เวลาอยู่ที่โรงเรียน
- ข) ฉันรู้สึกรสนุกนานๆ ครั้ง เวลาอยู่ที่โรงเรียน
- ค) ฉันรู้สึกรสนุกบ่อยครั้ง เวลาอยู่ที่โรงเรียน

22.

- ก) ฉันมีเพื่อนมาก
- ข) ฉันมีเพื่อนไม่กี่คน และอยากมีมากกว่านี้
- ค) ฉันไม่มีเพื่อนเลย

23.

- ก) การเรียนของฉันอยู่ในขั้นใช้ได้ดี
- ข) การเรียนของฉันไม่ค่อยดีเหมือนเมื่อก่อน
- ค) การเรียนของฉันแย่มาก

24.

- ก) ฉันทำอะไรไม่ได้ดีเท่าคนอื่น

- ข) ฉันทำอะไรได้ดีเท่าคนอื่น ถ้าฉันพยายาม
 - ค) ฉันทำได้ดีพอๆ กับคนอื่นอยู่แล้ว ในขณะนี้
- 25.
- ก) ไม่มีใครรักฉันจริง
 - ข) ฉันไม่แน่ใจว่ามีใครรักฉันหรือเปล่า
 - ค) ฉันรู้สึกว่ามีคนรักฉัน
- 26.
- ก) ฉันทำตามคำสั่งที่ได้รับเสมอ
 - ข) ฉันไม่ทำตามคำสั่งบ่อยครั้ง
 - ค) ฉันไม่เคยทำตามคำสั่งเลย
- 27.
- ก) ฉันเข้ากับคนอื่นได้ดี
 - ข) ฉันทะเลาะกับคนอื่นบ่อยครั้ง
 - ค) ฉันทะเลาะกับคนอื่น

- | | | |
|------------------------------------------------|--------------------------|--------------------------|
| 7. ฉันต้องใช้เวลาานานที่จะทำให้คุ้นกับสิ่งใหม่ | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. ฉันเป็นที่นิยมชมชอบของกลุ่มคนวัยเดียวกัน | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. พ่อแม่คำนึงถึงความรู้สึกของฉันเสมอ | <input type="checkbox"/> | <input type="checkbox"/> |
| 10. ฉันยอมแพ้อย่างง่ายดาย | <input type="checkbox"/> | <input type="checkbox"/> |
| 11. พ่อแม่คาดหวังฉันมากเกินไป | <input type="checkbox"/> | <input type="checkbox"/> |
| 12. เป็นตัวฉันนี้มันยากพอดู | <input type="checkbox"/> | <input type="checkbox"/> |
| 13. ชีวิตฉันยุ่งเหยิงไปหมด | <input type="checkbox"/> | <input type="checkbox"/> |
| 14. เพื่อนๆ มักคล้อยตามความคิดของฉัน | <input type="checkbox"/> | <input type="checkbox"/> |
| 15. ฉันรู้สึกว่าคุณตัวเองต่ำต้อย | <input type="checkbox"/> | <input type="checkbox"/> |
| 16. หลายครั้งที่ฉันอยากหนีออกจากบ้าน | <input type="checkbox"/> | <input type="checkbox"/> |
| 17. เมื่ออยู่ที่โรงเรียนฉันหงุดหงิดบ่อยๆ | <input type="checkbox"/> | <input type="checkbox"/> |
| 18. ฉันหน้าตาไม่ค่อยดีเมื่อเทียบกับคนส่วนมาก | <input type="checkbox"/> | <input type="checkbox"/> |

- | ข้อความ | เหมือนฉัน | ไม่เหมือนฉัน |
|------------------------------------------|--------------------------|--------------------------|
| 19. ถ้าฉันมีอะไรจะพูดฉันมักจะพูดออกมาเลย | <input type="checkbox"/> | <input type="checkbox"/> |
| 20. พ่อแม่เข้าใจฉัน | <input type="checkbox"/> | <input type="checkbox"/> |
| 21. คนส่วนมากได้รับความนิยมนมากกว่าฉัน | <input type="checkbox"/> | <input type="checkbox"/> |
| 22. ฉันรู้สึกอยู่เสมอว่าพ่อแม่ผลักดันฉัน | <input type="checkbox"/> | <input type="checkbox"/> |
| 23. ที่โรงเรียน ฉันรู้สึกท้อแท้บ่อยๆ | <input type="checkbox"/> | <input type="checkbox"/> |
| 24. บ่อยครั้งที่ฉันอยากจะเป็นคนอื่น | <input type="checkbox"/> | <input type="checkbox"/> |
| 25. ฉันไม่สามารถเป็นที่พึ่งของใครได้ | <input type="checkbox"/> | <input type="checkbox"/> |
| 26. ฉันไม่เคยกังวลเกี่ยวกับสิ่งใดเลย | <input type="checkbox"/> | <input type="checkbox"/> |
| 27. ฉันค่อนข้างมั่นใจในตนเอง | <input type="checkbox"/> | <input type="checkbox"/> |
| 28. ฉันชอบอะไรง่ายๆ | <input type="checkbox"/> | <input type="checkbox"/> |
| 29. ฉันกับพ่อแม่มีสิ่งสนุกสนานร่วมกัน | <input type="checkbox"/> | <input type="checkbox"/> |

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|-------------------------------------------|--------------------------|--------------------------|
| 30. ฉันใช้เวลาฝึกกลางวันมากทีเดียว | <input type="checkbox"/> | <input type="checkbox"/> |
| 31. ฉันอยากเป็นเด็กกว่านี้ | <input type="checkbox"/> | <input type="checkbox"/> |
| 32. ฉันทำสิ่งที่ถูกต้องเสมอ | <input type="checkbox"/> | <input type="checkbox"/> |
| 33. ฉันภูมิใจกับงานด้านการเรียนของฉัน | <input type="checkbox"/> | <input type="checkbox"/> |
| 34. ต้องมีคนคอยบอกฉันว่าฉันต้องทำอะไรบ้าง | <input type="checkbox"/> | <input type="checkbox"/> |
| 35. ฉันมักเสียใจกับสิ่งที่ทำไปแล้ว | <input type="checkbox"/> | <input type="checkbox"/> |
| 36. ฉันไม่เคยมีความสุขเลย | <input type="checkbox"/> | <input type="checkbox"/> |
| 37. ฉันจะทำอะไรเต็มความสามารถ | <input type="checkbox"/> | <input type="checkbox"/> |
| 38. ฉันสามารถดูแลตนเองได้ | <input type="checkbox"/> | <input type="checkbox"/> |
| 39. ฉันค่อนข้างมีความสุข | <input type="checkbox"/> | <input type="checkbox"/> |
| 40. ฉันชอบที่จะเล่นกับคนที่เด็กกว่าฉัน | <input type="checkbox"/> | <input type="checkbox"/> |
| 41. ฉันชอบทุกคนที่ฉันรู้จัก | <input type="checkbox"/> | <input type="checkbox"/> |
| 42. ฉันชอบให้ถูกเรียกตอบในชั้นเรียน | <input type="checkbox"/> | <input type="checkbox"/> |
| 43. ฉันเข้าใจตนเอง | <input type="checkbox"/> | <input type="checkbox"/> |
| 44. ที่บ้านไม่มีใครใส่ใจกับฉันมากนัก | <input type="checkbox"/> | <input type="checkbox"/> |
| 45. ฉันไม่เคยถูกดุเลย | <input type="checkbox"/> | <input type="checkbox"/> |

ข้อความ

เหมือนฉัน

ไม่เหมือนฉัน

- | | | |
|-----------------------------------------------|--------------------------|--------------------------|
| 46. ที่โรงเรียนฉันทำอะไรได้ไม่ดีเท่าที่อยากทำ | <input type="checkbox"/> | <input type="checkbox"/> |
| 47. ฉันตัดสินใจได้เองและมั่นใจกับสิ่งนั้น | <input type="checkbox"/> | <input type="checkbox"/> |
| 48. โดยแท้จริงฉันไม่อยากเป็น (ชาย หญิง) | <input type="checkbox"/> | <input type="checkbox"/> |
| 49. ฉันไม่ชอบรวมกลุ่มกับผู้อื่น | <input type="checkbox"/> | <input type="checkbox"/> |
| 50. ฉันไม่เคยประหม่าเลย | <input type="checkbox"/> | <input type="checkbox"/> |
| 51. บ่อยครั้งที่ฉันรู้สึกอายตนเอง | <input type="checkbox"/> | <input type="checkbox"/> |
| 52. เพื่อนๆ จับผิดฉันบ่อยมาก | <input type="checkbox"/> | <input type="checkbox"/> |
| 53. ฉันพูดความจริงเสมอ | <input type="checkbox"/> | <input type="checkbox"/> |

54. ครูทำให้ฉันรู้สึกว่าคุณไม่ดีพอ
55. ฉันไม่แน่ใจว่าอะไรจะเกิดขึ้นกับฉัน
56. ฉันเป็นคนล้มเหลว
57. ฉันหงุดหงิดง่ายมากเมื่อถูกดู
58. ฉันรู้อยู่เสมอว่าควรพูดอะไรกับผู้อื่น

APPENDIX 6.

FGD Questions for Children

1. Did you enjoy participating in CFS activities?
2. What areas do you think have improved the most in your school?
3. What activities are still being undertaken in the school after the completion of the CFS project?
4. What other innovative activities have been implemented by your school?
5. Do you believe conditions have improved in your school? What else do you think can be done?
6. Does the school now have closer ties with the community?
7. Do you think that teachers are now more understanding of children's problems?
8. If you have a problem what do you do now to solve it?
9. Do you think your communication has improved with your guardian/parent?
10. Is there anything else you would like to mention regarding the CFS Project?

FGD Questions for Guardians

1. Did you enjoy participating in CFS activities?
2. What areas do you think have improved the most for your child in their school?
3. What activities are still being undertaken in the school after the completion of the CFS project?
4. What other innovative activities have been implemented by your child's school?
5. Do you believe conditions have improved in your school?
6. Does the school now have closer ties with the community?
7. Do you think that teachers are no more understanding of your children's problems?
8. Do you think your communication has improved with your child after participating in the activities?
9. Are you actively participating now in school activities?
10. Is there anything else you would like to mention regarding the CFS Project?

FGD Questions for Children post CFS Project

1. Did you enjoy participating in the CFS project?
2. What changed in the school if you compare it before and after the CFS activities?
3. Do you think teachers have changed? If so in what areas?
4. What has changed in their teaching techniques?
5. What has improved in the school?
6. Are you now able to be more involved in school activities?
7. Is the school a better place now?

APPENDIX 7.

RESULTS PILOT STUDY

TABLE 21. Reported Health Problems and Main Concerns for HIV + Parents

Sex	Suffering poor Health		Have Hope		Scared/Worried		Financial Worries	
	Yes	No	Yes	No	Yes	No	Yes	No
Male	55% (6)	45% (5)	0% (0)	100% (11)	100% (11)	0% (0)	73% (8)	27% (3)
Female	70% (21)	30% (9)	26.7% (8)	73.3% (22)	100% (30)	0% (0)	90% (27)	10% (3)
Total	66% (27)	34% (14)	20% (8)	80% (33)	100% (41)	0% (0)	85% (35)	15% (6)

Table 21 shows that 80% (33) of respondents expressed a lack of hope for the future. A further 66% (27) currently were suffering from health problems. Of these 100% stated they were very scared about their predicament.

TABLE 22. Informant of Parental HIV + Status

SEX	Parent Informed	Family member	Medical Staff	Neighbour	Extended family	Other	Unknown
Male	27.3% (3)	0% (0)	0% (0)	36.4% (4)	0% (0)	9% (1)	27.3% (3)
Female	30.1% (9)	3.3% (1)	3.3% (1)	20% (6)	6.6% (2)	3.3% (1)	33.4% (10)
Total	29% (12)	2.5% (1)	2.5% (1)	24% (10)	5% (2)	5% (2)	32% (13)

Table 22 shows that a low 29% (12) of parents disclosed their HIV positive status to their children. A further 32% (13) of parents were currently unaware if their child knew of their positive status.

TABLE 23. Orphans Knowledge as to Cause of Parental Death

Knowledge	Yes	No	Total
AIDS Orphans	74.2% (49)	25.8% (17)	100% (66)
Non AIDS Orphans	70% (21)	30% (9)	100% (30)
Total	72.9% (70)	27.1% (26)	100% (96)

The chi-square statistic was used to examine the difference between respondents in regards to their knowledge of what caused their parents death. The non-significant chi-square value $\chi^2 (1, N=96) = .188, p < 1.00$ shows that AIDS orphans and non AIDS orphans were equally aware of how their parents had died.

TABLE 24 AIDS Orphans Informants as to Eventual Cause of Parental Death

Sex	Parents	Family	Neighbours	Medical Staff	Noticed Symptoms	Other
Male	5.8% (2)	20.6% (7)	11.8% (4)	0% (0)	52.9% (18)	8.9% (3)
Female	6.2% (2)	28.1% (9)	22.1% (7)	9.3% (3)	34.3% (11)	0% (0)
Total	6% (4)	24% (16)	17% (11)	4.5% (3)	44% (29)	4.5% (3)

Table 24 shows that a high number 44% (29) of respondents became aware of their parent's HIV+ status by observing their parent's symptoms. A further 24% (16) were told by their extended family.

TABLE 25. Gender Differences in Reasons for Non Disclosure for HIV Positive Parents

HIV + Parents	Scared	Too Young	Not Understand	Indifferent	Unknown	Total
Male	0% (0)	9.1% (1)	45.5% (5)	18.1% (2)	27.3% (3)	100% (11)
Female	43.3% (13)	13.3% (4)	23.3% (7)	16.7% (5)	3.4% (1)	100% (30)
Total	31.7% (13)	12.2% (5)	29.3% (12)	17% (7)	9.8% (4)	100% (41)

The chi-square statistic was used to examine the gender differences for reasons of non-disclosure. The significant chi-square value $\chi^2(1, N=41) = 10.146$, $p < .05$. shows that there was a significant gender difference in the reasons for non disclosure. The majority of females stated that being scared prevented disclosure. Comparatively, the belief that their children would not understand prevented disclosure for males.

TABLE 26. Support Network Accessed by Parents after Confirmation of their HIV+ Status

Doctor/Hospital	Family/Ext Family	Friends/Neigh	HIV Group	Government Agencies	Nobody
12%	17%	12%	10%	20%	29%
(5)	(7)	(5)	(4)	(8)	(12)

Table 26 indicates the support network/s utilized by parents upon confirmation of their HIV positive status. A high percentage 29% (12) accessed no, or received no support during this period. A low percentage 17% (7) of respondents received support from their immediate family.

TABLE 27. Community Knowledge of Parental Infection and Stigmatisation Experienced

Sex	Community Knowledge of parents HIV +Status		Stigmatisation Encountered	
	Yes	No	Yes	No
Male	73%	27%	82%	18%
	(8)	(3)	(9)	(2)
Female	97%	3%	77%	23%
	(29)	(1)	(23)	(7)
TOTAL	90%	10%	78%	22%
	(37)	(4)	(32)	(9)

Table 27 shows that 90% (37) of respondents reported that their HIV positive status was common knowledge in the community. Of these 78% (32) reported experiencing forms of stigmatisation as a result of this disclosure.

TABLE 28. Gender Differences in HIV Positive Parents Attendance at Pre and Post test Counselling

HIV + Parents	Pre-test		Post-test	
	Yes	No	Yes	No
Male	81.8% (9)	18.2 % (2)	72.7% (8)	27.3% (3)
Female	90% (27)	10% (3)	93.3% (28)	6.7% (2)
Total	87.8% (36)	12.2% (5)	87.8% (36)	12.2% (5)

The chi-square statistic was used to examine the gender differences in attendance at pre and post-test counselling. The non-significant chi-square values for pre test $\chi^2 (1, N=41) = .503, p < 1.00$ and post test $\chi^2 (1, N=41) = 3.19, (n.s)$, reveal no gender differences in attendance at pre and post test counselling. A high rate of males and females attended pre and post-test counselling.

TABLE 29. Parent/Child Relationship and Communication

Sex	Good parent/child relationship		Good parent/child communication		Room for improvement		Do children help with everyday chores		Experienced Personality Changes		Experienced Stigma	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
Male	73% (8)	27% (3)	55% (6)	45% (5)	82% (9)	18% (2)	36% (4)	64% (7)	27% (3)	73% (8)	63% (7)	27% (3)
Female	83% (25)	17% (5)	47% (14)	53% (16)	87% (26)	13% (4)	67% (20)	33% (10)	27% (8)	73% (22)	83% (25)	17% (5)
TOTAL	80% (33)	20% (8)	49% (20)	51% (21)	85% (35)	15% (6)	59% (24)	41% (17)	27% (11)	73% (30)	78% (32)	22% (9)

Table 29 shows that 80% (33) of respondents reported having a good relationship with their children. A high figure of 51% (21) reported an inadequate level of communication with their children. Of these 85% (35) believed that their relationship and communication levels could be improved. A further 27% (11) of respondents reported experiencing personality changes due to their HIV infection. A high number 78% (32) stated that people were apprehensive about being near them, and that they had lost a number of friends.

TABLE 30. Reported Parent/Child Relationship and Communication

Sex	Did You Talk Much With Your Parents			
	AIDS Orphans		Non AIDS Orphans	
	Yes	No	Yes	No
Male	56%	44%	67%	33%
	(19)	(16)	(10)	(5)
Female	47%	53%	80%	20%
	(15)	(17)	(12)	(3)
Total	50%	50%	73%	27%
	(33)	(33)	(22)	(8)

Table 30 shows that 50% (33) of AIDS orphan's reported experiencing a poor relationship and communication level with their parents. In comparison 73% (22) of the total non - AIDS orphans reported a good communication level with their parents.

TABLE 31. Barriers to Parent/child relationship and communication

Children are afraid	Parents scared child will hate them	Fear of HIV Transmission from Parent to child	Unable to provide financial support
17%	39%	34%	10%
(7)	(16)	(14)	(4)

Table 31 shows that 39% (16) of parents stated they become very detached from their children fearing that their children would hate them because of their HIV positive status. A further 34% (14) were concerned that they may infect their children.

TABLE 32. Differences in Communication with Parents between AIDS and Non AIDS Orphans

Communication with parents	Yes	No	Total
AIDS Orphans	50% (33)	50% (33)	100% (66)
Non AIDS Orphans	73.3%(22)	26.7% (8)	100% (30)
Total	57.3% (55)	42.7% (41)	100% (96)

The chi-square statistic was used to examine the difference between respondents in regards to their communication with parents before they become orphaned. The significant chi-square value $\chi^2 (1, N=96)= 4.59, p < .05$. shows that non AIDS orphans experienced better communication levels with their parents than AIDS orphans.

TABLE 33. AIDS Orphans Communication with Parents regarding their Illness

AIDS Orphans	Yes	No	Total
Male	41.2% (14)	58.8% (20)	100% (34)
Female	18.8% (6)	81.2% (26)	100% (32)
Total	30.3% (20)	69.7% (46)	100% (66)

The chi-square statistic was used to examine the gender difference in AIDS orphans communication with their parents about their symptomatic state. The significant chi-square value $\chi^2 (1, N=96) = 3.926, p < .05$. shows that there was gender differences in AIDS orphans ability to talk with their parents when they become ill. A large number of AIDS orphans were unable to discuss this issue openly with their parents.

TABLE 34. Parental Knowledge of HIV/AIDS

	Attended HIV Educational Course		Children received counselling regarding HIV/AIDS		Extended Family Aware of Positive Status	
	Yes	No	Yes	No	Yes	No
Male	45%	55%	27%	73%	73%	27%
	(5)	(6)	(3)	(8)	(8)	(3)
Female	47%	53%	30%	70%	80%	20%
	(14)	(16)	(9)	(21)	(24)	(6)
TOTAL	46%	54%	29%	71%	78%	22%
	(19)	(22)	(12)	(29)	(32)	(9)

Table 34 shows that 54% (22) of respondents had not attended HIV/AIDS educational courses. A high number of parents 71% (29) stated that their children had no access to HIV/AIDS counselling. The majority of parents 78% (32) stated that their extended family knew their HIV + status.

TABLE 35. Children's Knowledge and Understanding of Parents HIV + Status and Reported Behavioural Changes in Children

	Child knows of parents + Status		Child Understands Outcome of Parents + Status		Parents Observed any Behavioural Changes in Child	
	Yes	No	Yes	No	Yes	No
Male	55%	45%	27%	73%	64%	36%
	(6)	(5)	(3)	(8)	(7)	(4)
Female	57%	43%	27%	73%	67%	33%
	(17)	(13)	(8)	(22)	(20)	(10)
Total	56%	44%	27%	73%	66%	34%
	(23)	(18)	(11)	(30)	(27)	(14)

Table 35 shows that 56% (23) of parents reporting that their children are aware of their HIV positive. Of these 73% (30) believed that their children had no real comprehension or understanding of the course the disease takes. Parents had also witnessed a very high rate (66%) of behaviour change in their children

TABLE 36. Understanding of HIV/AIDS and Perception of HIV/AIDS Problem in the Community

Sex		Do You Understand About HIV/Aids		Do You Think HIV/AIDS is a Problem in Your Community	
		Yes	No	Yes	No
AIDS Orphans	Male	65%	35%	91%	9%
		(22)	(12)	(31)	(3)
AIDS Orphans	Female	84%	16%	91%	9%
		(27)	(5)	(29)	(3)
AIDS Orphans	Total	74%	26%	91%	9%
		(49)	(17)	(60)	(6)
Non AIDS Orphans	Male	87%	13%	73%	27%
		(13)	(2)	(11)	(4)
Non AIDS Orphans	Female	67%	33%	67%	33%
		(10)	(5)	(10)	(5)
Non AIDS Orphans	TOTAL	77%	23%	70%	30%
		(23)	(7)	(21)	(9)

Table 36 shows that 74% (49) of AIDS orphans believe that they a competent understanding of HIV/AIDS. Ninety one percent (60) believed stated that HIV/AIDS is a significant problem within their community/village. Comparatively, 77% (23) of non-AIDS orphans stated they have a good understanding of HIV/AIDS and how it is transmitted. Seventy percent (21) of these respondents also believed that HIV/AIDS is a considerable problem in their community.

TABLE 37. Source of HIV/AIDS Education

	Sex	School/Ai ds Course	Parent	Reading/Me dia	Neighbours/ Community	Don't Understand
AIDS Orphans	Male	15% (5)	3% (1)	44% (15)	18 % (6)	20% (7)
	Female	16% (5)	0% (0)	40% (13)	22% (7)	22% (7)
	Total	15% (10)	2% (1)	42% (28)	20% (13)	21% (14)
Non- AIDS Orphans	Male	20% (3)	0% (0)	47% (7)	20% (3)	13% (2)
	Female	20% (3)	0% (0)	40% (6)	13% (2)	27% (4)
	Total	20% (6)	0% (0)	43% (13)	17% (5)	20% (6)

Table 37 shows that 42% (28) of AIDS orphans became aware of HIV/AIDS through reading and the media. A high number (21%) stated having a limited understanding of HIV/AIDS. A low 15% (10) reported they had received HIV/AIDS education from school. Comparatively, 43% (13) of non-AIDS orphans reported gaining HIV/AIDS knowledge through reading and media. A further 20%(6) stated that they had no knowledge at all.

TABLE 38. Main Fears of HIV Positive Parents for their Children

Sex	Education	Health	Future Care	Feel Aversion	Other
Male	36% (4)	36% (4)	28% (3)	0% (0)	0% (0)
Female	20% (6)	13% (4)	30% (9)	27% (8)	10% (3)
Total	24% (10)	20% (8)	29% (12)	20% (8)	7% (3)

Table 38 shows that 29% (12) of respondents were concerned about their child's future care. A further 24% (10) were concerned about their child's access to education. Twenty percent (8) reported that they were concerned about their child's health and possible infection with the HIV virus.

TABLE 39. Future Care Providers for Children and Incapacitated Parent

Grandparent	Siblings/Ext family	Welfare	Don't Know	No Financial Planning
76% (31)	10% (4)	2% (1)	12% (5)	66% (27)

Table 39 shows that 76% (31) of HIV + parents will rely on their own parents to provide care for them and their children once illness has incapacitated them. Sixty six percent (27) of the total respondents reported that they had not initiated any form of permanency planning (savings or income generation) for their children's future financial support once they have deceased.

TABLE 40. Reported Satisfaction with Current Residence

		Grand Parents	Orphanage	Adopted	Extended Family
AIDS Orphan	Male	64.7% (22)	35.3% (12)	0% (0)	0% (0)
	Female	62.5% (20)	34.5% (12)	0% (0)	0% (0)
	Total	63.6% (42)	36.4% (24)	0% (0)	0% (0)
Non AIDS Orphan	Male	26.7% (4)	20% (3)	13.3% (2)	40% (6)
	Female	26.7% (4)	33.3% (5)	20% (3)	20% (3)
	Total	26.6% (8)	26.6% (8)	16.6% (5)	30% (9)

Table 40 shows that 63.6% (42) of AIDS orphans currently reside with their grand parents. A further 36.4% (24) live in an orphanage. No AIDS orphans reside with extended family. Comparatively, 30% (9) of non-AIDS orphans reported that they were currently living happily with extended family.

TABLE 41. Problems Experienced at School by AIDS and Non AIDS Orphans

Problems at School	Yes	No	Total
AIDS Orphans	50% (33)	50% (33)	100% (66)
Non AIDS Orphans	10% (3)	90% (27)	100% (30)
Total	37.5% (36)	62.5% (60)	100% (96)

The chi-square statistic was used to examine the difference between respondents in regards to experiencing problems at school. The significant chi-square value $\chi^2 (1, N=96) = 14.08, p < 0.001$ shows that AIDS orphans experienced more problems at school than non AIDS orphans.

TABLE 42. Impact of Parental Death on School Experience for AIDS Orphans

Knowledge of Cause of Death	Problems at School		
	Yes	No	Total
Yes	51% (25)	49% (24)	74.2% (49)
No	47.1% (8)	52.9% (9)	25.8% (17)
Total	50% (33)	50% (33)	100% (66)

The chi-square statistic was used to examine the relationship to between knowledge of what caused their parents death and problems experienced at school by AIDS orphans. The non-significant chi-square value $\chi^2 (1, N=96) = .0793, p < 1.000$ shows that knowledge of parental death from AIDS was not a predictor for problems at school.

TABLE 43. Types of Problems Experienced by AIDS Orphans at School

Fighting/Teasing	Learning Difficulties	Health Problems	Problems with Teachers	Lack of Friendship
29%	19%	3%	14%	35%
(19)	(13)	(2)	(9)	(23)

Table 43 shows that 35% (23) of AIDS orphans stated that loneliness and a lack of friendship as their major problem at school. A further 29% (19) reported that they were constantly fighting with, and being teased by other children at school. It was also evident that a number (19%) of these children's learning was directly affected by their situation.

TABLE 44. AIDS Orphans: Person Who Provided Emotional Support When Their Parent Deceased

Sex	Family	Friends	Doctor / Welfare Workers	Other	No one
Male	47%	6%	0	6%	41%
	(16)	(2)	(0)	(2)	(14)
Female	63%	3%	3%	0	31%
	(20)	(1)	(1)	(0%)	(10)
TOTAL	55%	5%	1%	3%	36%
	(36)	(3)	(1)	(2)	(24)

Table 44 shows that 36% (24) of children had not received, or had rejected any form of emotional support when their parent died.

TABLE 45. Present Confidant for Children

	Sex	Family	Friend	Doctor/Welfare Worker	Teacher	No one
AIDS Orphans	Male	30%	5%	3%	6%	56%
		(10)	(2)	(1)	(2)	(19)
	Female	31%	9%	0	9%	51%
		(10)	(3)	(0%)	(3)	(16)
	Total	30%	8%	1%	8%	53%
		(20)	(5)	(1)	(5)	(35)
Non-AIDS Orphans	Male	40%	40%	0	0	20%
		(6)	(6)	(0%)	(0%)	(3)
	Female	33%	20%	0	40%	7%
		(5)	(3)	(0%)	(6)	(1)
	Total	37%	30%	0%	20%	13%
		(11)	(9)	(0)	(6)	(4)

Table 45 shows that a high number 53% (35) of AIDS orphans stated they had no person to confide in when they were feeling sad or depressed. Comparatively, 37% (11) of non-AIDS orphans were able to talk with their family or friends 30% (9) when sad or depressed.

Table 46. AIDS and Non AIDS Orphans Acceptance in Their Community

The following table shows the differences in levels of community acceptance for AIDS and non- AIDS orphans

		Good	Badly	Unknown
Sex				
AIDS Orphans	Male	32.3% (11)	61.7% (21)	6% (2)
	Female	28.3% (9)	68.7% (22)	3% (1)
	Total	30.3% (20)	65.2% (43)	4.5% (3)
Non AIDS Orphans	Male	93.4% (14)	0% (0)	6.6% (1)
	Female	93.4% (14)	6.6% (1)	0% (0)
	TOTAL	93.4% (28)	3.3% (1)	3.3% (1)

Table 46 shows that 65.2% (43) of AIDS orphans stated that they were treated badly by people in their community. In comparison 93.4% (28) of non-AIDS orphans reported that the people in their community treated them well.

APPENDIX 8

JAMES COOK UNIVERSITY Townsville Qld 4811 Australia Tina Langford, Ethics Administrator,
Research Office. Ph: 07 4781 4342; Fax: 07 4781 5521

ETHICS REVIEW COMMITTEE Human Ethics Committee APPROVAL FOR RESEARCH OR TEACHING INVOLVING HUMAN SUBJECTS					
PRINCIPAL INVESTIGATOR		Sean Devine			
SUPERVISOR		Graham, Deborah			
SCHOOL		Psychology			
PROJECT TITLE		Art Therapy as an intervention for AIDS affected children. An evaluation assessment in Chiang Mai			
APPROVAL DATE	1 Sep 1999	EXPIRY DATE	1 Mar 2002	CATEGORY	2
This project has been allocated Ethics Approval Number with the following conditions:				H	962
<p>1. All subsequent records and correspondence relating to this project must refer to this number.</p> <p>2. That there is NO departure from the approved protocols unless prior approval has been sought from the Human Ethics Committee.</p> <p>3. The Principal Investigator must advise the responsible Ethics Monitor appointed by the Ethics Review Committee:</p> <ul style="list-style-type: none"> ◆ periodically of the progress of the project; ◆ when the project is completed, suspended or prematurely terminated for any reason; ◆ if serious or adverse effects on participants occur; and if any ◆ unforeseen events occur that might affect continued ethical acceptability of the project. <p>4. In compliance with the National Health and Medical Research Council (NHMRC) "National Statement on Ethical Conduct in Research Involving Humans" (1999), it is MANDATORY that you provide an annual report on the progress and conduct of your project. This report must detail compliance with approvals granted and any unexpected events or serious adverse effects that may have occurred during the study.</p>					
ASSESSED AT MEETING				Date: <i>1 Sep 1999</i>	
Tina Langford Ethics Administrator Research Office					

