Sri Lankan component of the regional study on the situation assessment of women and children infected and affected by HIV/AIDS in the SAARC region – Afghanistan, Nepal and Sri Lanka.

A SITUATION ASSESSMENT OF WOMEN AND CHILDREN INFECTED AND AFFECTED BY HIV/AIDS IN SRI LANKA

2015

National STD/AIDS Control Programme, Sri Lanka.
The SAARC TB and HIV/AIDS Centre, Nepal.

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National STD/AIDS Control Programme,
Ministry of Health,
Sri Lanka.

The SAARC TB and HIV/AIDS Centre,
Nepal.

Conducted by : National STD/AIDS Control Programme, Sri Lanka in collaboration with and the SAARC TB and HIV/AIDS Centre, Nepal.

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1. Introduction

1.1. Global, regional and Sri Lankan situation of HIV

Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) has been a well-recognized pandemic throughout the world nearly over the past two decades. Both men and women are affected by HIV/AIDS in all parts of the world. Globally, an estimated 35 (32.2–37.2) million people were living with HIV in 2013 and 16.0 [15.2–16.9] million among them were women. This is an increase from previous years as more people are receiving the life-saving antiretroviral therapy. There were 2.1 (1.9–2.4) million new HIV infections globally, showing a 33% decline in the number of new infections from 3.4 (3.1–3.7) million in 2001. At the same time the number of AIDS deaths were also declining with 1.6 (1.4–1.9) million AIDS deaths in 2012, down from 2.3 (2.1–2.6) million in 2005. Over the past decade, rapid expansion of Anti-Retroviral treatment in many parts of the world has reduced HIV morbidity and mortality drastically thereby transforming HIV into a stage of chronic illness (1).

Globally, AIDS-related illnesses are the leading cause of morbidity and mortality among women of reproductive age. In areas such as Western and Central Europe and Australia, women account for a relatively low percentage of people living with HIV. However, in regions such as sub-Saharan Africa, South and South East Asia and the Caribbean, the percentage is significantly high.

The world HIV/AIDS figures show the extent of children (defined by UNAIDS as under-15 years of age) directly affected by the epidemic. Nearly 3.2 million children were living with HIV around the world at the end of 2013 and 240,000 children became newly infected with HIV in year 2013, alone. Sub Saharan region is the mostly affected area with 91% of children with HIV live. Only limited number of children (about 24%) needing antiretroviral treatment have received appropriate

medications. Finally 190,000 children died of AIDS and related illnesses during 2013. In addition, millions of children are indirectly affected by the impact of the HIV epidemic on their families and communities every year (1).

Sri Lanka is part of the region of South and South-East Asia, where the second biggest epidemic of HIV is being experienced at present. HIV/AIDS continues to be a major public health problem in the SAARC Region. All eight member states of the SAARC region are designated as low prevalence countries. On the basis of latest available information, this region is home for an estimated number of 2.24 million HIV infected people. Three countries, namely India, Nepal and Pakistan account for majority of the regional burden.

The Democratic Socialist Republic of Sri Lanka Government and UNAIDS classified Sri Lanka as a country experiencing a low prevalence HIV epidemic. According to UNAIDS, the estimated number of people living with HIV was 2900 (1,800 -5,300) in 2013. The estimated number of HIV infection in adult women (15-49) was less than 1000 in Sri Lanka. An estimated less than 100 children (0-14 Years) were living with HIV in 2013. The total reported number of HIV infected persons up to end of 2013 was 1845 with a male and female ratio of 1.5:1. Among all reported cases, 740 cases were females and 71 were children. The cumulative number of AIDS related deaths was 310 for the same period. Adult mortality rate has resulted an increase in number of orphan children. In Sri Lanka, HIV epidemic is largely driven by sexual transmission, accounting for more than 85% of the total HIV infection in the country (2).

HIV prevalence among women and children is relatively low in Sri Lanka compared to other Asian countries. Some of the factors that may be contributing to the low prevalence of HIV/AIDS among women in Sri Lanka are its cultural context that strongly emphasizes moral values, high literacy

level, better health care and increased accessibility to health institutions including those for sexually transmitted infections (STIs) and PMTCT initiatives.

However, Sri Lanka is in midst of flourishing economic development and hence multiple social, cultural and economic changes are taking place in the country. In spite of this economic boom, there are certain dangers lurking beneath the surface. Risk of HIV/AIDS can be stated as one such important public health issue especially in relation to women and children.

1.1.1. HIV affected women

Biologically, women are more likely to become infected with HIV through unprotected heterosexual intercourse than men.

The HIV epidemic impact upon women has been exacerbated by certain roles within society. The responsibility of caring for people living with HIV and orphans is an issue that has a greater effect on women. Additionally, millions of women have been indirectly affected by the HIV and AIDS epidemic through issues such as mother-to-child transmission (MTCT) of HIV.

In many parts of the world there exist major inequalities between women and men in all aspects of living from employment opportunities and availability of education, to power inequalities within relationships. These gender roles can confine women to positions where they lack the power to protect themselves from HIV infection.

In most of the South Asian countries, women have few rights within sexual relationships and the family. This power imbalance means that it can be more difficult for women to protect themselves from HIV acquisition. For example, a woman may not be able to insist on the use of a condom and infected individuals may not disclose their sero status to their female sexual partners. Marriage does not always protect a woman from becoming infected with HIV. Many new infections occur within marriage or long-term relationships as a result of unfaithful male partners (3).

Caring for ill parents, children or husbands is unpaid and can increase a person's workload by up to a third. Women often struggle to bring in an income whilst providing care and therefore many families affected by HIV suffer from increasing poverty. In Sri Lanka where a family's livelihood mainly relies on males and their occupation, the death can lead to variety of social impacts and economic crisis within the family which in turn affect women.

However, in Sri Lanka a very strong maternal & child health service has been routed into the primary health care system for a long time. HIV affected women and children are also provided with comprehensive care through this system.

1.1.2. HIV affected Children

HIV infection among adult has caused immense impact on children. The children whose parents are infected also stigmatized and discriminated. Many children living with HIV experience tough life events that could impact their psychosocial well-being, such as losing caregivers to AIDS-related illness, stigma, shock about their status and not understanding the importance of adhering to treatment.

Affected children's rights within the family and society should be ensured. This includes not only the treatment and HIV medical care, but also the right of education, food, shelter, safety from violence, gender equality and lack of stigma. They have the right to born with free of HIV, live without stigma caused by parent's sero status.

Reduced household income combined with increased expenses (for example for treatment, transport, funerals) can push families into poverty, which has negative impact on children in terms of nutrition, health status, education and emotional support. By reducing household's economic vulnerabilities and crisis, children benefit from better nutrition, the opportunity to go to school instead of work and better access to healthcare services.

Supporting the family holistically and efficiently can be the best way to ensure a good quality of life for the affected child. This should include social protection schemes that provide external assistance to poorer affected families. Some of those schemes are now demonstrated a valuable part of improving the lives of children affected by HIV in certain parts of the world.

Proper monitoring and care for children living with HIV can enable them to live a normal life. However, a lack of necessary motivation and resources for adequate testing and prevention programmes mean children continue to suffer the consequences of the epidemic.

Many caregivers delay disclosing children about their HIV status, because they are anxious about the child's well-being, are concerned about being blamed, and are worried about stigma from the family and the community. It is important for a healthcare worker or a care giver to disclose the child's status to them, to prevent the child feeling isolated and finding out their status accidentally, or in public. It is thought that disclosure gives the child greater mental stability and health.

On the other hand testing and treatment opportunities for children need to be optimized to bring them along with the adult HIV infected individuals.

Apart from this, there needs to be greater access to the drugs that can prevent MTCT, HIV testing, linkages to care and treatment services. Support for the family members/ relatives and community services that provide the material, social, and emotional foundation for a child's development also equally important.

Justification

The National STD/AIDS Control Programme (NSACP) spearheads the national response to HIV/AIDS in Sri Lanka. NSACP is the focal point for planning and implementation of HIV/AIDS National Strategic Plan and AIDS Policy together with all stakeholders.

The government of Sri Lanka has developed successive policy document, guidelines, manuals and training packages to guide the HIV response in Sri Lanka with the goal of halting and reversing the spread of HIV by 2015. The current National HIV Strategic Plan 2013-2017 was developed using an inclusive and consultative process with all stakeholders (4).

The major impact of AIDS includes discrimination, social stigma, distress, destitution and lack of care. Major inequalities exist between women and men in all aspects of living – from employment opportunities, availability of education, accessibility to care services to power inequalities within relationships. This become more pronounce in HIV affected females. Many children living with HIV experience tough life events that could impact their psychosocial well-being, affect their education and restrict their accessibility to care facilities.

Studies done on accessibility and availability of services to HIV affected women and children are sparse in Sri Lanka. Therefore, National STD/AIDS Control Programme of the ministry of health is planning to collect information on HIV/AIDS in women and children. The purpose of the study is to obtain the information that can help government and non-governmental organizations in designing and strengthening HIV/AIDS prevention, treatment, care and support programmes. This will serve as the benchmark for assessing the impact of their programmes in future.

This study proposal is financially and technically supported by SAARC Tuberculosis and HIV/AIDS Centre (STAC) as part of the regional study involving Afghanistan, Nepal and Sri Lanka.

Objectives of the study

General objective

To assess accessibility and availability of education and health care services to Women and Children infected and affected with HIV/AIDS in Sri Lanka.

Specific objectives

1. To describe the socio-demographic and socio-economic information of women and children infected and affected by HIV/AIDS.

2. To assess the accessibility to education and to health care services including reproductive health and HIV care services among HIV infected and affected women

3. To assess the accessibility to education and to health care services including nutritional, immunization, HIV care among HIV infected and affected children

4. To determine health status of women and children infected and affected with HIV

5. To ascertain the level of stigma and discrimination faced by HIV affected and infected women and children in Sri Lanka and their coping strategies.

2. Review of literature

2.1. Situation assessment of HIV affected people in the region

A similar study was carried out in Nepal to assess availability and accessibility of health care, education, economic and psychosocial support services for HIV affected children below the age of 17 years. The study interviewed total of 435 HIV infected and affected children and a similar number of comparison group. A structured questionnaire was used as data collection tool like in present study. Approximately 56% of the sample were orphaned (lost either one or both parents) and out of them 7% had lost their both parents and the cause of death of parents for most respondents was AIDS related (81%). Farming was reported as main source of income in both study groups (54% in HIV affected households and 61% in comparison group). The percentage households falling under "poor" category among HIV affected was twice that of comparison group (31%). The study reported high levels of school enrollments among both HIV affected children (93%) and comparison group (95%). However, enrolling among male children was high.

Further, the Nepal study reported that higher percent of boys (64%) than that of girls (44%) had received health care services and the rate was higher among educated households. Both study groups reported rating of health care provider as encouraging (52%). On the other hand one in sixth (17%) considered health care provider's behavior as impolite.

This study also assessed stigma and discrimination among HIV affected children. The common forms of discrimination experienced by many were avoidance, insult/ disgracing remarks, separation of beds, dining plates and utensils and asking to sit separately. The study further reported that the HIV affected children faced discrimination from the community (49%) and from their peers (28%).

The psycho- social issues among the HIV affected children in Nepal study were fear and isolation when left alone; girls (76%), boys (56%). More girls (76%) than boys (56%) tend to experience fear and isolation when left alone (5).

Social protection systems are important components to the HIV affected. The Nepal study analyzed the knowledge on available organizations working for the HIV affected among the study group and found that it was low; 49% among affected children, 11% among caregivers and 23% among comparison community. Only few children (13%) were members of these organizations. This study further reported that nearly 60% of affected children were unaware about a place for psychological support. One third reported NGO as a place for support, one eighth reported hospital and a small proportion reported private clinics, youth clubs as source for support.

2.2. Situation assessment of HIV affected people in Sri Lanka

Studies done on accessibility and availability of services for HIV affected women and children are sparse in Sri Lanka. However, HIV stigma index survey carried out in Sri Lanka (2010) revealed some interesting information about HIV positive women in Sri Lanka (6).

This survey gathered information on accessibility to work, health care and educational services as well as knowledge on testing, diagnosis, treatment, family planning, rights, laws and policies. Furthermore, it studied issues on disclosure, confidentiality and extent of stigma and discrimination faced by HIV infected people. Random sample of HIV infected women were selected from the network of HIV positive people's organizations.

Majority of women (86%) were within the age group of 30-50 years and 62% had been living with HIV for less than 5years. The respondents were mainly from the low socio economic community with poor educational status and were unemployed; depend on state or other NGOs for their

daily needs. Moreover considerable number was migrant workers (gave a history of work in a foreign country).

Approximately 12% reported verbal harassment and 5% physical assault due to their HIV status. Among the 11% who lost their jobs the main reason was ill health. About 3% of respondents in this survey reported that their children were dismissed, suspended or prevented from educational activities. It was further reported that the low level of stigma and discrimination was due to non-disclosure of HIV status.

Quality of health care services was also assessed in this survey. Forty nine percent respondents claimed that they did not have constructive discussion with health care providers about HIV treatment options.

The HIV stigma index survey reported internalized stigma; 37% decided not to have sex any more, 56% not to marry, 77% not to have children and 32% experienced suicidal feelings.

3. Methodology

There were 1845 reported cases of HIV at the end of year 2013 of whom 730 were women and 71 were children. Up to end of June 2014, 772 patients were registered at care services in Sri Lanka. Almost all these patients were registered and being followed up at seven main ART centers; Colombo, Ragama, Kandy, Galle, Anuradhapura, Kalubowila and Kalutara.

3.1 Study setting

This study was conducted in Colombo, Ragama, Kandy, Galle, Anuradhapura, Kalubowila and Kalutara which are the main ART centers in the country. HIV clinic, Colombo is the main HIV clinic of the country which had been in existence since HIV care services started in Sri Lanka. All the other centers provide specialist services for PLHIV including ART. The principal investigators and other investigators are staff members having experience in the setting for more than five years. The data collecting of the study was commenced on 1st November 2014 and completed on 31st January 2015.

3.2 Study design

This study was a descriptive cross-sectional study, carried out among infected and affected women and children with HIV. The study consisted of two components; quantitative and qualitative parts.

3.3 Study Population

Study population was women and children living with HIV and affected by HIV in Sri Lanka.

3.4 Sample size

Total of 300 women and 70 children were selected as the sample for entire study. The sample size was determined on the basis of availability of study participants and the suggestions given by the SAARC research centre who drafted the methodology for this regional study involving three countries in the SAARC region (Afghanistan, Nepal and Sri Lanka).

3.5 Study sample

The study sample consisted of 200 HIV infected women, 100 affected women, 35 infected children and 35 affected children. Almost all HIV infected women and children who were attending the above ART centers were included in the study. People living with HIV (male 50 and female 50) were explained about the study and were asked to name one affected woman in the household to get 100 affected females. Similar method was used to select 35 affected children. Table 1 shows the number of HIV infected women and children seek care at each center and table 2 shows the number enrolled to the study from each center.

TABLE 3.1 TOTAL NUMBER OF HIV INFECTED WOMEN AND CHILDREN ATTENDING THE MAIN ART CENTERS BY 30TH OF JUNE 2014

ART center	Women 18 yrs. or older	Children less than 15yrs.
Colombo	158	26
Kandy	19	7
Ragama	23	4
Kalubowila	4	0
Kalutara	3	0
Anuradhapura	6	0
Galle	14	0
Total	**227**	**37**

Following were excluded from the study.

a) Patients who were too sick to be interviewed
b) Patients who were defaulted and unable to trace for last 3 months
c) Patients who were diagnosed with in last 2 weeks

Operational definitions

HIV infected woman – A woman, 18 years or older and having confirmed HIV infection. HIV, western blot test was used to confirm the diagnosis of HIV infection.

HIV infected child – A child less than 15 years and confirmed as having HIV infection. Both male and female children were included. HIV, DNA PCR test was used to diagnose HIV infection in child less than 2 years of age.

HIV affected woman – A woman, 18 years or older who was uninfected with HIV but having a family member with HIV infection living in the same household.

HIV affected child – A child younger than 15 years old who was uninfected with HIV but having a family member with HIV infection in the same household. Both male and female children were included.

Data collection instruments

a. Quantitative data

An interviewer administered, structured questionnaire was used to collect data. The questionnaire was worded in simple language for ease of understanding irrespective of the educational level of the respondants. As far as possible close ended questions were used to minimise intra and inter

observer variation. Data onsocio-demographic status, socio economic situation, accessibility to health care services/education, stigma experienced and coping strategies were obtained using this questionnaire. Data extraction sheet was used to collect information on morbidity and mortality situation of the infected women and children through clinical records. Details on eligibility criteria for ART and laboratory data were also obtained through same way.

b. Qualitative Data

Key Informant Interview and In-depth interviews were carried out to obtain qualitative data. More detailed information on accessibility to health care services, accessibility to education and availability of supporting services for HIV infected people were collected by adapting this method.

Training of interviewers

Discussions with the PLHIV attending clinics indicated that they prefer interviewers to be medical officers as they were highly concerned about disclosing HIV status to nonmedical personnel. Medical officers who had more than one year experience in providing sexual health services were used as interviewers as they had a reasonable understanding related to issues involving the HIV infected and affected people.

All the research team members were given an extensive training on basic introduction on child rights issues, objectives of the study, methodology and the best ways of administering the questions. The study team was adequately trained in each research instrument and on the administration of specific questions. The training included conducting lectures, mock interviews, role-plays and field trials. Officials from NSACP were involved in the training program.

The field team was closely supervised by the research team members from NSACP in order to ensure the quality of the work.

Data Collection

a. Quantitative data collection

HIV infected women and children attending for services from 1st of November 2014 were included in this part of the study till the required sample size was completed. Selected HIV affected women and children were informed about the study and once they visited the clinic, data collection was done.

A face-to-face interview was conducted with the women affected and infected by HIV using standard semi-structured questionnaire to collect data. Caregivers of children were interviewed using similar questionnaire if they were below 12 years. The interview method was used to obtain information as this method also offered opportunity for counselling where necessary. Data collection has been done at the clinic as most PLHIV did not want others to visit their homes.

The interviewees were informed in detail the purpose of the study. A friendly atmosphere was developed before starting the interview while maintaining privacy and confidentiality.

The interviewees were explained the importance of the study to improve facilities in relation to health services. Further it was emphasized that their inputs were used in future planning to improve service provision. This helped them to talk about deficiencies which need to be addressed in future without fear.

The interview commenced after getting the informed consent and during the introduction, study participants were asked to skip any question they would not wish to answer. All the responses were

entered by the interviewers according to the previously defined way. At the end of interview they were given the opportunity to make comments or ask any questions from the interviewers.

b. Qualitative data collection

Two types of detailed interviews were conducted to collect qualitative data.

a. **Key Informant Interview**: Eight Key Informant Interviews were conducted with the key personnel involved in STD/HIV prevention activities of the country. The interviewees were Director of NSACP, HIV care coordinator of NSACP, a representatives from UNAIDS, a representatives from UNICEF, a representative from a PLHIV group, a representative from a NGO, a school principle and a representative from child protection authority.
b. **In-depth interview**: Twelve in-depth interviews with selected HIV infected and affected women were conducted.

Key Informant Interviews and in depth interviews were conducted by a team lead by a senior consultant working at NSACP.

Data management and analysis

All completed questionnaires were re-checked each day in the evening by the interviewers to check for any discrepancy. All the completed forms were handed over to the data analysis team. These were further reviewed and then they were edited and coded. The data were double entered separately into Epidata data entry form and subsequently transferred into SPSS for analysis. Stepwise univariate, bivariate and multivariate analysis were done using SPSS and test of significance was applied wherever applicable.

Ethical considerations

Ethical guidelines developed by the World Health Organization were followed throughout the study and beyond. Participants of the study were fully informed about the nature and the purpose

of the study, the study objectives, and the confidentiality of the data. There were no personal identification details in the questionnaire to maintain anonymity and confidentiality.

The potential benefit of participating in the study was explained to all the study participants. The consent form has been formulated in simple local languages. This was read out to the respondents and verbal consent was obtained. No written consent had been taken as it would have negative effect since the participants tend to be afraid of any implied commitment resulting from signing a form. Data were collected only from the people who gave consent to participate the study.

Ethical clearance for the study was obtained from the Ethical review Committee of the Faculty of Medicine, University of Colombo, Sri Lanka. Permission to conduct the study was obtained from the Director, National STD AIDS Control Programme, Sri Lanka.

4. Results

4.1 Results of the quantitative component

The number planned to be enrolled in the study is given in table 4.1.

TABLE 4.1NUMBER PLANNED TO ENROLL IN THE STUDY FROM EACH CENTER

Clinic	Infected Women	Affected Women	Infected Children <15	Affected Children <15	Total
Colombo	148	45	25	15	233
Kandy	15	15	6	5	41
Ragama	18	20	4	7	49
Kalubowila	2	5	0	2	9
Kalutara	2	5	0	2	9
Anuradhapura	5	5	0	2	12
Galle	10	5	0	2	17
Total	**200**	**100**	**35**	**35**	**370**

The actual sample taken for the study consisted of 206 HIV infected women, 62 affected women, 27infected children and 27 affected children.

TABLE 4.2 ACTUAL NUMBER ENROLLED TO THE STUDY FROM EACH CENTER

Clinic	Infected Women	Affected Women	Infected Children <15	Affected Children <15	Total
Colombo/Gampaha/ Kurunegala/Rathnapura	148	50	22	20	240
Kandy	14	02	0	0	16
Ragama	23	4	5	2	34
Kalubowila	2	3	0	2	7
Kalutara	3	2	0	2	7
Anuradhapura	9	1	0	1	11
Galle	7	0	0	0	7
Total	**206**	**62**	**27**	**27**	**322**

Socio demographic and socioeconomic status of infected and affected women and children.

Socio demographic characteristics of women infected with HIV

TABLE 4.3 SOCIO-DEMOGRAPHIC CHARACTERISTICS OF WOMEN INFECTED AND AFFECTED BY HIV

		Infected with HIV=206		Affected by HIV=62	
		Number	%	Number	%
Age	Mean (years)	43.0	n/a	42.3	n/a
	SD	10.0		12.4	
	Median	42		43	
	Range	20-67		17-67	
Age group	-24	8	3.9	5	**8.1**
	25-34	33	16.0	11	**17.7**
	35-44	82	39.8	16	**25.8**
	45-54	54	26.2	23	**37.1**
	55 +	29	14.1	7	**11.3**
Ethnicity					
	Sinhala	139	**67.5**	45	**72.6**
	Tamil	46	**22.3**	7	**11.3**
	Muslim	21	**10.2**	9	**14.5**
	Burgher	0	**0.0**	1	**1.6**
Religion					
	Buddhist	114	**55.3**	37	**59.7**
	Hindu	35	**17.0**	5	**8.1**
	Islam	20	**9.7**	9	**14.5**
	Christian	23	**11.2**	6	**9.7**
	Catholic	14	**6.8**	5	**8.1**
Civil Status					
	Married	118	**57.3**	57	**91.9**
	Single	6	**2.9**	2	**3.2**
	Divorced/Separated	29	**14.1**	2	**3.2**
	Widow	46	**22.3**	1	**1.6**
	Living together	7	**3.4**	0	**0.0**
Currently living with					
	Partner/Spouse	98	**47.6**	46	**74.2**
	Family/relative	81	**39.3**	16	**25.8**
	Friends	2	**1.0**	0	**0.0**
	Alone	15	**7.3**	0	**0.0**
	PLHIV	6	**2.9**	0	**0.0**
	Others	4	**1.9**	0	**0.0**

Cont., Table 4.3

Permanent residence	Infected with HIV		Affected by HIV	
	Number	%	Number	%
Colombo	51	**24.8**	21	**33.9**
Gampaha	40	**19.4**	15	**24.2**
Puttalam	15	**7.3**	3	**4.8**
Galle	11	**5.3**	3	**4.8**
Kalutara	10	**4.9**	4	**6.5**
Kandy	13	**6.3**	1	**1.6**
Kurunegala	10	**4.9**	1	**1.6**
Jaffna	9	**4.4**	0	**0.0**
Anuradhapura	8	**3.9**	0	**0.0**
Ratnapura	4	**1.9**	4	**6.5**
Matara	4	**1.9**	3	**4.8**
Matale	4	**1.9**	1	**1.6**
Trincomalee	4	**1.9**	0	**0.0**
Vavuniya	3	**1.5**	1	**1.6**
Ampara	2	**1.0**	1	**1.6**
Badulla	2	**1.0**	1	**1.6**
Batticoloa	1	**0.5**	2	**3.2**
Monaragala	3	**1.5**	0	**0.0**
Hambantota	3	**1.5**	0	**0.0**
Kegalle	3	**1.5**	0	**0.0**
Mulativ	2	**1.0**	0	**0.0**
Nuwaraeliya	1	**0.5**	1	**1.6**
Polonnaruwa	1	**0.5**	0	**0.0**
No Response	2	**1.0**	0	**0.0**

The sample consisted of 206 infected females and 62 affected females. Majority of the infected females were in the age group 35-44 years (39.8%) followed by 45-54 years (26.2%). Only 3.9% were young females in the age less than 24 years.

The sample had females in all four major ethnic groups. As expected highest number was Sinhalaese followed by Tamils and Muslims in infected female group. Reflecting the ethnic composition 55.3% were Buddhists, 17.0% Hindus and 9.7% were Muslims.

More than half of the infected women were married (57.3%) but only 47.3% of them lived currently with partner or spouse. A reasonable number were divorced /separated or widowed (36.4%).

Close to 40% were living with family or relatives. Around 13% of infected women did not ave any family assistance and lived either alone or with friends (1.0%), PLHIV support groups (2.9%) or others (1.9%).

As expected more infected females were from districts of Colombo and Gampaha. Other important districts were Puttlam, Kandy, Galle, Kurunegala, Jaffna and Anuradhapura.

Socio demographic characteristics of women affected with HIV

There was no difference in the age range or mean age of the infected and affected females. However, among the affected females highest number was in 45-54 age group indicating older females are affected more due to HIV. Most of the affected women lived with their partner/spouse (74.2%) and others had family assistance. More affected women were seen in Colombo and Gampaha followed by Kalutara, Ratnapura, Puttlam, Galle and Matara.

TABLE 4.4 FREQUENCY DISTRIBUTION OF FEMALES ACCORDING TO EDUCATIONAL LEVEL

	Infected with HIV		Affected by HIV	
	Number	%	Number	%
Highest level of education				
Grade 1-5	28	**13.6**	5	**8.1**
Grade 6-9	53	**25.7**	12	**19.4**
GCE O/L	73	**35.4**	24	**38.7**
GCE A/L	39	**18.9**	14	**22.6**
Diploma or higher	5	**2.4**	5	**8.1**
Not attended school	7	**3.4**	2	**3.2**
No response	1	**0.5**	0	**0.0**
Ability to read or write				
Yes	186	**90.3**	58	**93.5**
No	17	**8.3**	3	**4.8**
No response	3	**1.5**	1	**1.6**

Among infected women 56.7% had education up to GCE OL (year 11) or more. Only 3.4% had never been to school. However, in the sample 8.3% infected women admitted inability to read or write.

Affected women had higher educational level than infected women with 69.4% had education up to GCE OL or more. More affected women (93.5%) could read or write than infected.

TABLE 4.5 SOCIO ECONOMIC DATA OF WOMEN INFECTED AND AFFECTED BY HIV

	Infected with HIV No:206		Affected by HIV No:62	
	No:	%	No:	%
Current Employment				
House wife	74	**35.9**	41	**66.1**
Employed	85	**41.3**	16	**25.8**
Unemployed	41	**19.9**	5	**8.1**
No Response	6	**2.9**	0	**0.0**
Monthly individual average income				
<5000	25	**12.1**	2	**3.2**
5000-9999	22	**10.7**	2	**3.2**
10000-19999	37	**18.0**	11	**17.7**
20000+	29	**14.1**	8	**12.9**
No income	93	**45.1**	39	**62.9**
Mean	18,492.8		21,815.8	
Median	10,000		16,000.0	
SD	43,077.8		21,107.7	
Monthly Family average Income				
<5000	19	**9.2**	4	**6.5**
5000-9999	23	**11.2**	3	**4.8**
10000-19999	63	**30.6**	22	**35.5**
20000+	80	**38.8**	29	**46.8**
No response	21	**10.2**	4	**6.5**
Mean	26,762.8		32,375.0	
Median	18,000.0		18,000.0	
SD	45,053.0		36,948.3	

Most of the infected women were unemployed or house wives (55.8%). Close to 41.3% of infected women had an individual income through employment. However, only 32.1% had individual income more than LKR 10,000. The median income was LKR 10,000.

Median family income was LKR 18,000. Only 38.8% had average monthly family income more than LKR 20,000. The non-response rate was 10.2% for this question.

In the affected group less number of women were employed and 62.9% had no income of their own. Median individual income for affected women was much higher LKR 16,000 and median family income was LKR 18,000.

TABLE 4.6 WOMEN INFECTED AND AFFECTED BY HIV ACCORDING TO MONTHLY EXPENSES CATEGORY

	Infected with HIV No:206		Affected by HIV No:62	
	No:	%	No:	%
Monthly Expense for food in family				
<Rs 5000	25	**12.1**	1	**1.6**
>Rs 5000	179	**86.9**	60	**96.8**
No response	2	**1.0**	1	**1.6**
Mean	13,961.00		16,051.30	
Median	10,000.00		15,000.00	
SD	10,386.00		7826.9	
Monthly expense for Education				
None	145	**70.4**	40	**64.5**
<5000	37	**18.0**	7	**11.3**
>5000	15	**7.3**	14	**22.6**
No response	9	**4.4**	1	**1.6**
Mean	7442.5		4461.7	
Median	5000		5000	
SD	6893.4		3387.6	

Among infected women 12.1% spent less than LKR 5000 monthly for food. Median expense for food was LKR 10,000. There were no expenses for education in 70.4%.

Among affected only 1.6% spent less than LKR 5000 monthly for food with median expenses LKR 15,000 and 64.5% did not spend for education.

Socio-demographic characteristics of infected and affected Children

TABLE 4.7 EDUCATION LEVEL OF CHILDREN INFECTED AND AFFECTED BY HIV

	Infected with HIV		Affected by HIV	
	No:	%	No:	%
Children >5yrs.				
Yes	19 /27	**70.4**	21 /27	**77.8**
No	8 /27	**29.6**	6 /27	**22.2**
Ever attended school				
Yes	19 /27	**70.4**	2(/27	**74.1**
No	8 /27	**29.6**	7 /27	**25.9**
Currently attending school				
Yes	19 /27	**70.4**	20 /27	**74.1**
No	8 /27	**29.6**	7 /27	**25.9**
Highest level of education				
Primary	11 /19	**57.9**	13 /20	**65**
Secondary	6 /19	**31.6**	4 /20	**20**
No response	2 /19	**10.5**	3 /20	**15**
Can read or write?				
Yes	16 /19	**84.2**	18 /20	**90.0**
No	3 /19	**15.8**	2 /20	**10.0**

Being a low prevalent country Sri Lanka has identified 71 children with HIV infection from 1987 to 2014. Of these only 48 children survive by end 2014. ART services were initiated in Sri Lanka in 2004.

Among the infected children in the sample (n=27) 70.4% were above 5 years and all of them were attending school at the time of the study. The literacy rate is 84.2%. This is probably due to children being in early school going age group. 57.9% were in primary classes while 31.6% were in secondary classes. 84.2% of children above 5 years could write or read.

Most affected children were more than 5 years old and 20 out of 21 children were attending school. Most of these children were having primary education.

TABLE 4.8 SOCIOECONOMIC INFORMATION OF CAREGIVERS OF THE INFECTED AND AFFECTED CHILDREN

	Infected with HIV N=27 No:	%	Affected by HIV N=27 No:	%
Are you currently Employed?				
Yes	14	**51.9**	11	**40.7**
No	13	**48.1**	16	**59.3**
Family monthly average income				
<10000	12	**44.4**	6	**22.2**
10-200000	7	**25.9**	14	**51.9**
>20000	7	**25.9**	5	**18.5**
No response	1	**3.7**	2	**7.4**
Mean	17,516.7	na	22,000.0	na
Median	16,500.0	na	20,000.0	na
SD	15,093.5	na	18,435.70	na

Infected children: Half of the care givers were employed. For 44.4% the family monthly average income was less than LKR 10,000. Only 25.9% had monthly family income more than LKR 20,000. Median family income was LKR 16,500. Families with infected children had spent less money for food with 22% spending less than LKR 5000 per month for food. Median monthly expenses for food was LKR 9000. For schooling, median amount spent per month was LKR 2000.

Affected children: Forty one percent of care givers of affected children were employed. Family monthly median income was LKR 20,000. Affected children's families spent more for food and education with median value for food LKR 11,000 and for education LKR 2750.

TABLE 4.9 MONTHLY EXPENSES OF CARE GIVERS OF INFECTED AND AFFECTED CHILDREN

	Infected with HIV N=27		Affected by HIV N=27	
	No:	%	No:	%
Monthly expenditure for food				
<5000	6	**22.2**	3	**11.1**
≥5000	21	**77.8**	24	**88.9**
Monthly expenditure for food				
Mean	14,250		12,125	
Median	9,000		11,000	
SD	11,281.00		6,751	
Monthly expenditure for schooling				
<5000	26	**96.3**	21	**77.8**
≥5000	1	**3.7**	6	**22.2**
Mean	2710.5	na	4062.5	na
Median	2000	na	2750	na
SD	2354.8	na	2713.3	na

Infected children: Families with infected children had spent less money for food with 22% spending less than LKR 5000 per month for food. Mean value of expenditure for food was LKR 14,250 and median was LKR 9,000. For schooling the median amount spent per month was LKR 2000.

Affected children: Affected children's families spent more for food and education.

The second specific objective is to assess the accessibility to education and to health care services including reproductive health and HIV care services among HIV infected and affected women.

TABLE 4.10 ENTRY POINT TO HIV CARE OF INFECTED WOMEN

Entry point to HIV care	No:	%
Contacts of known HIV cases	56	**27.18**
Visa screening done locally	32	**15.53**
Inpatient (ward) referrals	25	**12.14**
PMTCT screening	14	**6.8**
Private sector referrals	12	**5.83**
Visa screening done abroad	12	**5.83**
Voluntary screening	11	**5.34**
Outpatient referrals	9	**4.37**
Screening patients with TB	5	**2.43**
Self-referred with a HIV positive report	3	**1.46**
Blood donor screening	3	**1.46**
Others	24	**11.65**
Total	206	**100.00**

Most of the infected females were identified as having HIV due to screening of them as contacts of already identified PLHIV (27.2%) followed by visa screening local and abroad (21.4%). 18.9% were identified when they presented with symptoms (inpatient/outpatient/TB). Only 5.3% of females were identified through voluntary STI screening. PMTCT screening helped to identify 6.8% of females.

TABLE 4.11 ACCESSIBILITY TO HIV HEALTH SERVICES OF INFECTED WOMEN

	Infected with HIV	
	n/N	%
Distance to nearest HIV clinic in km		
Mean	44.6	na
Median	22.0	
SD	55.0	
<25km	125 /206	**60.68**
≥25Km	81 /206	**39.32**
Are you Visiting the nearest HIV clinic		
Yes	115 /206	**54.37**
No	91 /206	**45.63**
Reason for avoiding nearest clinic		
Fear of identification	69 /91	**75.82**
Stigma	5 /91	**5.49**
Other*	17 /91	**18.68**
Satisfaction on available services		
Satisfied	160 /206	**77.67**
Very satisfied	36 /206	**17.48**
Neither satisfied/Unsatisfied	5 /206	**2.43**
Unsatisfied	5 /206	**2.42**
Time to discuss medical problems		
Yes	202 /206	**98.06**
No	4 /206	**1.94**
Time to discuss social problems		
Yes	195 /206	**94.66**
No	11 /206	**5.34**

The closest HIV clinic was less than 25 km away for 61% of infected females. However, only 54% used the nearest STD clinic for HIV services. Those who did not use the closest clinic revealed the reason for avoiding the closest STD clinic was due to fear of being identified by known people in the village (75.8%).

Among infected females 17.5% were very satisfied with services at the STD clinic and 77.7% were satisfied. Close to 5% were not satisfied. Majority were clear that they had time to discuss medical problems. However, 2% were of the view that they did not have enough time to discuss their medical problems.

Similarly though 95% agreed that they had time to discuss social problems 5% were of the opinion that time was not adequate.

TABLE 4.12 ACCESSIBILITY TO HIV HEALTH SERVICES OF WOMEN AFFECTED BY HIV

	Women affected by HIV	
	No:	%
Have you ever done HIV test?		
Yes	54/62	**87.1**
No	8/62	**12.9**
Place of the test done		
STD Clinic	47/54	**87.04**
Private hospital	7/54	**12.96**

Majority of affected women had undergone testing for HIV. Most tests were done from STD clinics (87%) and 13% from private hospital. 13% of affected women have never done HIV test.

TABLE 4.13 WOMEN INFECTED AND AFFECTED WITH HIV ACCORDING TO EFFECT ON ECONOMIC LEVEL DUE TO HIV

	Infected with HIV No:206		Affected by HIV No:62	
	No:	%	No:	%
Reduction of income due to HIV				
Yes	109	**52.9**	34	**54.8**
No	89	**43.2**	27	**43.5**
No response	8	**3.9**	1	**1.6**
Spend more due to HIV				
Yes	167	**81.1**	43	**69.4**
No	35	**17.0**	18	**29.0**
No response	4	**1.9**	1	**1.6**
Financial assistance for HIV				
Yes	64	**31.1**	7	**11.3**
No	142	**68.9**	55	**88.7**
Monthly Expense for Health				
None	39	**18.9**	10	**16.1**
<1000	113	**54.9**	21	**33.9**
>1000	52	**25.2**	24	**38.7**
No response	2	**1.0**	7	**11.3**
Mean	3294.6		2107.7	
Median	1500		1000	
SD	6182.9		2853.9	
Compelled to take Loan due to HIV				
Yes	35	**17.0**	13	**21.0**
No	171	**83.0**	49	**79.0**
Sold assets due to HIV				
Yes	53	**25.7**	13	**21.0**
No	153	**74.3**	49	**79.0**

More than 50% of infected women admitted that their income was affected due to the diagnosis of HIV infection. In addition to the reduction of income, infected women had to spend more due to HIV status (81.1%). Among infected women 31.1% received some financial assistance. Twenty five percent spent more than LKR 1000 as monthly expenses for health among the infected. Close to 20% did not have to spend money for health services and 55% spent less than LKR 1000. HIV was a financial burden to infected women. Among infected 17% had to get loans due to HIV and 25.7% had to sell assets.

Among the affected women 54.8% indicated reduction of income due to the diagnosis of HIV infection of a family member. In the affected group close to 70% had to spend more due to HIV status. More affected women admitted getting loans and close to 21% sold assets to find money for needs created by HIV diagnosis of their family member.

TABLE 4.14 ACCESSIBILITY TO REPRODUCTIVE HEALTH SERVICES OF WOMEN INFECTED AND AFFECTED BY HIV

	Infected with HIV No:206		Affected by HIV No:62	
	No:	%	No:	%
Currently on Contraception				
Yes	102/206	**49.5**	23/62	**37.1**
No	104/206	**51.5**	39/62	**62.9**
Main Method of Contraception				
Hormonal	9/102	**8.8**	2/23	**8.7**
Condoms	34/102	**33.3**	11/23	**47.8**
IUCD	14/102	**13.7**	4/23	**17.4**
LRT	30/102	**29.4**	5/23	**21.7**
Depoprovera	15/102	**14.7**	1/23	**4.3**
Place of getting Contraception				
Gov. Hospital	45/102	**44.1**	10/23	**43.5**
NSACP/STD	38/102	**37.3**	9/23	**39.1**
Pvt. Hospital	11/102	**10.8**	3/23	**13.0**
Other	8/102	**7.8**	1/23	**4.3**
Health facility usually visit for medical problems				
Gov. Hospital	91/206	**45.0**	25/62	**41.0**
NSACP/STD	79/206	**39.1**	34/62	**55.7**
Pvt. Hospital	28/206	**13.9**	2/62	**1.6**
Other	8/206	**2.0**	2/62	**1.6**

Among the infected women 49.5% used modern methods of contraception. Of them 33% used condoms for contraception. 30% had undergone LRT 13.7% were using IUCD and 8.8% were on Norplant/ OCP. Most infected women were getting contraceptive services from government clinics including STD clinics. Only 10.8% had contraceptive services from private health services. Most infected women received medical services from government hospitals including STD clinics.

Among affected women most used condoms for contraception (47.8%) A reasonable number was using IUCD and hormonal methods. Twenty two percent had undergone LRT.

TABLE 4.15 ACCESSIBILITY TO HIV HEALTH SERVICES OF CHILDREN INFECTED AND AFFECTED BY HIV

	Infected with HIV N=27		Affected by HIV N=27	
	No:	%	No:	%
Health care institution usually visit for child's illnesses				
Gov. Hospital	16	**59.3**	16	**59.3**
Pvt. Hospital	2	**7.4**	3	**11.1**
General Practitioner	3	**11.1**	8	**29.6**
HIV clinic	6	**22.2**	0	**0.0**
Distance to the health care institution				
<25 km	16	**59.3**	25	**92.6**
>25 km	11	**40.7**	2	**7.4**
Mean	32	na	15.8	na
Median	15	na	5	na
SD	46	na	36	na
Is that institution, the nearest one?				
Yes	11	**40.7**	21	**77.8**
No	16	**59.3**	6	**22.2**
Why avoid the nearest institution?				
Fear	5	**18.5**	1	**3.7**
Stigma	3	**11.1**	0	**0.0**
Poor Quality	1	**3.7**	2	**7.4**
Other	6	**22.2**	2	**7.4**
No response	12	**44.4**	22	**81.5**

Among infected children only 22.2% visited HIV clinic for all health issues of the child. They took treatment from the closest hospital or general practitioner as well.

Close to 60% had to travel less than 25 km distance to seek health care services related to HIV.

According to the caregivers, 59% of infected children did not obtain healthcare services from the nearest health care institution. Main reasons were fear of meeting known health care workers (18.5%) and stigma (11.1%).

Among affected children majority seek health care services from the government hospitals and 30% from the general practitioners. More than 90%, visit the nearest health care institution.

TABLE 4.16 EXPENDITURE FOR HEALTH CARE SERVICES OF INFECTED AND AFFECTED WITH HIV

	Infected with HIV N=27		Affected by HIV N=27	
	No:	%	No:	%
Spending in the last visit				
<5000	25	**92.6**	15	**55.6**
>5000	0	**0.0**	2	**7.4**
No response	2	**7.4**	10	**37.0**
Mean	1053.3	na	1980.9	na
Median	1250	na	1500	na
SD	654.2	na	2069	na
Management of cost in last time				
On my own	12	**44.4**	na	
With NGO support	9	**33.3**	na	
Did not buy medicine	1	**3.7**	na	
No response	5	**18.5**	na	
Satisfaction of available services				
Satisfied	24	**88.9**	na	
Very satisfied	3	**11.1**	na	
Enough time to discuss medical problems				
Yes	26	**96.3**	na	
No	1	**3.7**	na	
Enough time to discuss social problem				
Yes	26	**96.3**	na	
No	1	**3.7**	na	

The care givers of infected children stated that they had to spend money for the last clinic visit for HIV services with median LKR 1250. Out of them 33% received NGO support. Most (89%) were satisfied with services received at the STD clinic. Among the care givers 96% mentioned that the time spent by doctors to discuss medical and social problems was satisfactory.

TABLE 4.17 EFFECT OF HIV ON EDUCATION LEVEL OF CHILDREN INFECTED AND AFFECTED BY HIV

	Infected with HIV		Affected by HIV	
	No:	%	No:	%
Change of school due to HIV				
Yes	2 /19	**10.5**	1 /20	**5.0**
No	17 /19	**89.5**	19 /20	**95.0**
School attendance				
>80% of days	18 /19	**94.7**	16 /20	**80.0**
<80%of days	1 /19	**5.3**	4 /20	**20.0**
Is anyone in school knows child's HIV?				
Yes	5 /27	**18.5**	na	
No	14 /27	**51.9**	na	
No response	8 /27	**29.6**	na	
Involvement in extracurricular activities				
Yes	11 /19	**57.9**	14 /20	**70.0**
No	7 /19	**36.8**	2 /20	**10.0**
No response	1 /19	**5.3**	4 /20	**20.0**

Infected Children: Two children out of 19 had to change the school due to HIV status. Only one child missed more than 20% of school days. Most of the school authorities were not aware of the child's status, but in 5 children (18.5%) the school was aware of the child's HIV status. However,

they could continue studies in the schools without problems. Fifty eight percent of infected children were getting involved in extracurricular activities in schools.

Affected children: One child had to change the school due to family member's HIV status. Twenty percent of affected children missed school more than 20% of school days. Out of all 70% were involved in extracurricular activities.

TABLE 4.18 NUTRITION RELATED INFORMATION ON INFECTED AND AFFECTED CHILDREN

	Infected with HIV N=27		Affected by HIV N=27	
	No:	%	No:	%
Daily eating pattern in last 1 month				
>3 times/week	5	**18.5**	5	**18.5**
<3 times/week	22	**81.5**	22	**81.5**
Food source in last 6 months				
Out	1	**3.7**	1	**3.7**
Home	26	**96.3**	26	**96.3**
Protein rich food in last 7 days				
Daily	11	**40.7**	8	**29.6**
>3 times/week	10	**37.0**	10	**37.0**
<3 times/week	6	**22.2**	9	**33.3**
Fruit consumption in last 7 days				
Daily	8	**29.6**	6	**22.2**
>3 times/week	7	**25.9**	6	**22.2**
<3 times/week	12	**44.4**	10	**37.0**
Never	0	**0.0**	5	**18.5**
Vegetable consumption in last 7 days				
Daily	22	**81.5**	23	**85.2**
>3 times/week	3	**11.1**	3	**11.1**
<3 times/week	2	**7.4**	1	**3.7**
Additional vitamins -Currently				
Yes	12	**44.4**	1	**3.7**
No	10	**37.0**	24	**88.9**
No response	5	**18.5**	2	**7.4**
Assistance for food currently				
Yes	3	**11.1**	1	**3.7**
No	24	**88.9**	26	**96.3**
Eating difficulty				
Yes	3	**11.1**	na	
No	22	**81.5**	na	

Most of the infected and affected children were given home cooked food. Twenty two percent of infected children received proteins less than 3 times per week. Vegetable consumption was satisfactory and 44% received additional vitamins. Only 11% received assistance for food.

The specific objective 4 is to determine health status of women and children infected and affected with HIV.

TABLE 4.19 ANTHROPOMETRIC DATA OF INFECTED WOMEN.

	Infected with HIV No:206	
	n/N	%
Height of infected females		
Mean	150.38	na
Median	152	na
SD	14.46	na
<150cm	73 /206	**35.4**
≥150cm	119 /206	**57.8**
Missing data	14 /206	**6.8**
Weight of infected females		
Mean	51.3	na
Median	50	na
SD	10.13	na
<50kg	93 /206	**45.2**
≥50kg	103 /206	**50.0**
Missing data	10 /206	**4.8**
BMI of infected females		
Mean	22.43	na
Median	21.76	na
SD	7.25	na
<18	23 /206	**11.2**
18-25	117 /206	**56.8**
>25	36 /206	**17.5**
Missing data	30 /206	**14.5**
Haemoglobin level of infected females		
Mean	12.25	na
Median	12.35	na
SD	1.73	na
<8 g/l	5 /206	**2.4**
8-10 g/l	13 /206	**6.3**
>10g/l	173 /206	**83.9**
Missing data	15 /206	**7.3**

Fifty seven percent of infected women were within normal range of BMI. Mean haemoglobin level was 12.25 mg/dl but 9% had haemoglobin less than 10 mg/dl. Mean height was 150 cm and mean weight 51.3 kg. However 45.1% infected women had weight less than 50 kg.

TABLE 4.20 NUTRITION RELATED DATA OF WOMEN INFECTED AND AFFECTED BY HIV

	Infected with HIV No:206		Affected by HIV No:62	
	No:	%	No:	%%
Daily eating pattern, last month				
<3 meals/week	38	**18.4**	6	**9.7**
≥3 meals/ week	168	**81.6**	56	**90.3**
Source of cooked food last,6months				
Outside	7	**3.4**	0	**0.0**
Home cooked	199	**96.6**	62	**100.0**
Protein rich food ,past 7 days				
Daily	84	**40.8**	31	**50.0**
≥ 3 times/week	55	**26.7**	17	**27.4**
<3 times/week	63	**30.6**	13	**21.0**
Never	4	**1.9**	1	**1.6**
Fruit consumption				
Daily	72	**35.0**	24	**38.7**
≥ 3 times/week	45	**21.8**	13	**21.0**
<3 times/week	78	**37.9**	24	**38.7**
Never	11	**5.3**	1	**1.6**
Vegetable consumption				
Daily	188	**91.3**	59	**95.2**
≥ 3 times/week	15	**7.3**	2	**3.2**
<3 times/week	3	**1.5**	1	**1.6**
Additional vitamins				
Daily	153	**74.3**	9	**14.5**
≥ 3 times/week	8	**3.9**	0	**0.0**
<3 times/week	6	**2.9**	0	**0.0**
Never	34	**16.5**	50	**80.6**
No response	5	**2.4**	3	**4.8**
Additional vitamins last 6m.				
Yes	163	**79.1**	8	**12.9**
No	43	**20.9**	54	**87.1**
Assistances for food currently				
Yes related to HIV	8	**3.9**	0	**0.0**
Yes ,not related to HIV	87	**42.2**	39	**62.9**
No	111	**53.9**	23	**37.1**

Eighteen percent of the infected had less than 3 meals per day. Most of the infected women had home cooked food. Thirty one percent of infected consumed proteins less than 3 times a week. Almost all had vegetables in their diet regularly and 74% had daily additional vitamins. Fruit consumption was fairly low with 38% having fruits less than 3 times per week. Assistance for food was received by 46.1%. Among them 42.2% received assistance not related to HIV status. Majority of affected women (90%) had 3 meals per day. Most had home cooked food with 21% having proteins less than 3 times a week. Fruit consumption was fairly low with 38% having fruit less than 3 times a week. Assistance for food was obtained by 62.9% which was mainly related to HIV.

TABLE 4.21 CLINICAL DETAILS AT BASE LINE AND AT TIME OF STUDY OF THE HIV INFECTED WOMEN

		Base line N=206		Last visit N=206	
		No:	%	No:	%
Clinical stage of the patient					
	WHO stage 1	140	**68.0**	192	**93.2**
	WHO stage 2	13	**6.3**	5	**2.4**
	WHO stage 3	26	**12.6**	4	**1.9**
	WHO stage 4	26	**12.6**	4	**1.9**
	Not known	1	**0.5**	1	**0.5**
Performance scale					
	Normal activity	172	**83.5**	202	**98.1**
	Bed ridden <50%	27	**13.1**	1	**0.5**
	Bed ridden >50%	6	**2.9**	2	**1.0**
	Not known	1	**0.5**	1	**0.5**
CD4 levels	Mean	350	na	568	na
	Median	323	na	528	na
	SD	248	na	312	na
CD 4 level	<=200	61	**29.6**	13	**6.3**
	201-349	46	**21.3**	35	**17.0**
	350-500	45	**21.8**	44	**21.4**
	>500	51	**24.8**	108	**52.4**
	Unavailable	3	**1.5**	6	**2.9**
Viral load	Mean	55007	na	3379	na
	Median	4140		0	
	SD	166238		11438	
	Undetectable	10	**4.9**	120	**58.2**
	<1000	11	**5.3**	8	**3.8**
	>1000	37	**17.9**	26	**12.6**
	Unavailable	148	**71.8**	52	**25.2**

Most of the HIV infected women were in stage 1 at the time of diagnosis (68%) and one fourth of the sample were in the clinical stages 3 and 4 (25.2%). At the last visit 93.2% were in stage 1 after receiving appropriate HIV care services.

At the time of diagnosis 16% were in WHO performance scale B and C and with HIV care services it had come down to 1.5%. Mean CD4 count has increased from 350 to 568 and median CD4 count from 323 to 528. At the time of diagnosis, 50% were having CD4 count less than 350, and out of them 30% had CD4 count less than 200 cells/µl. However, at the last visit only 6.3% had CD4 count less than 200.

Unavailability of regular viral load testing facilities made it difficult to interpret the viral load response. Among the 154, who were offered viral load testing, 128 showed satisfactory response (with undetectable viral loads or viral loads less than 1000 copies) in their last visit.

TABLE 4.22 INFECTED WOMEN ACCORDING TO STATUS OF ART

Currently on ART?	No:	%
ART	169	**82.1**
Pre ART	37	**17.9**

In the sample 82% of infected women were on ART.

TABLE 4.23 OPPORTUNISTIC INFECTIONS BEFORE STARTING ART

Opportunistic infections	Patients on ART No:169	
	No:	%
Tuberculosis	12	**7.1**
Candidiasis	50	**29.6**
Diarrhea	2	**1.2**
Cryptococosis	1	**0.6**
PCP	15	**8.9**
CMV	1	**0.6**
HZV	6	**3.6**
Genital herpes	2	**1.2**
Total	169	**100.0**

The common opportunistic infections diagnosed before starting ART were Candidiasis, PCP pneumonia and Tuberculosis.

TABLE 4.24 ART RELATED INFORMATION

	Patients on ART No:169	
	No:	%
Eligibility criteria's to start ART		
CD4 count	101	**59.76**
WHO clinical stage	42	**24.85**
Other	20	**11.83**
TB	4	**2.37**
Sero-discordant	2	**1.18**
Current ART regimen		
AZT+3TC+EFV	62	**36.69**
TDF+FTC+EFV	56	**33.14**
AZT+3TC+NVP	20	**11.83**
AZT+3TC+LPV/r	10	**5.92**
TDF+FTC+LPV/r	9	**5.33**
TDF+FTC+NVP	2	**1.18**
ABC+3TC+EFV	2	**1.18**
Other	8	**4.73**
Total	169	**100.0**

Most infected females were on AZT+3TC + EFV or TDF+FTC+EFV. Efavirenz was used as they had completed family and most were on family planning methods.

ART was started mainly due to low CD4 count (59.7%) or presence of clinical symptoms (24.9%) in stage 3 or 4.

TABLE 4.25 ADHERENCE TO ART

	Patients on ART	
	No:	%
Adherence		
Satisfactory-missed<3doses last 30 days	160	**94.7**
Unsatisfactory-missed >3-12 doses	5	**2.9**
Highly unsatisfactory Missed >12 doses	3	**1.8**
Not known	1	**0.6**
Total	169	**100.0**

Majority of the infected females had satisfactory adherence.

Children infected with HIV

TABLE 4.26 ENTRY POINT OF HIV CARE AMONG CHILDREN

	Infected with HIV	
	No:	%
Reason for attendance		
Mother identified as positive	10	**37.0**
In ward patients	6	**22.2**
Pediatrics	4	**14.8**
Contact	2	**7.4**
Self-referred	1	**3.7**
Blood	1	**3.7**
Other	3	**11.1**
Total	27	**100.0**

Thirty seven percent of children were identified as their mothers were diagnosed as having HIV during subsequent pregnancies.

TABLE 4.27 FREQUENCY DISTRIBUTION ACCORDING TO MORBIDITY STATUS OF CHILDREN

		First visit		Last visit	
		No:	%	No:	%
WHO stage	1 st stage	17	**62.9**	26	**96.3**
	2 nd stage	6	**22.2**	1	**3.7**
	3 rd stage	3	**11.1**		
	4 th stage	1	**3.7**		
Performance scale					
	Normal	23	**85.2**	27	**100**
	bed <50%	2	**7.4**	0	**0**
	bed> 50%	2	**7.4**	0	**0**
CD4 count					
	CD4 percentage	16	**59.3**	0	**0**
	<200	1	**3.7**	4	**14.8**
	≥200-349	0	**0.0**	0	**0**
	350-499	2	**7.4**	2	**7.4**
	>=500	8	**29.6**	21	**77.8**
	Mean			902.59	
	Mode			890	
	SD			576.65	
Viral load					
	<1000	1	**3.7**	12	**44.44**
	>1000	26	**96.3**	15	**55.56**
	Mean	248,802.6	na	8972.5	na
	Mode	92861	na	200	na
	SD	303,334.6	na	22,255.8	na

Most of the children were either in the WHO clinical stage 1 or 2 at the time of diagnosis. Out of infected children 85% had satisfactory performance scale and 81% were on ART at the time of the study.

TABLE 4.28 ART RELATED INFORMATION OF INFECTED CHILDREN

	Infected with HIV (N=27)	
	No:	%
Currently on ART /not?		
Yes	22	**81.48**
No	5	**18.52**
ART eligibility criteria		
WHO	10	**45.45**
CD4	8	**36.36**
TB	1	**4.55**
Other	3	**13.64**
Current ART regimen		
AZT+3TC+NVP	7	**31.82**
AZT+3TC+EFV	7	**31.82**
AZT+3TC+LPV/R	5	**22.73**
TDF+FTC+LPV/r	2	**9.09**
ABC+3TC+LPV/r	1	**4.55**
Adherence to ART		
Satisfactory	21	**95.45**
Not known	1	**4.55**
Opportunistic infections before starting ART		
Tuberculosis	1	**4.5**
Candidiasis	2	**9.1**
Diarrhea	1	**4.5**
Pneumocystis jiroveci Pneumonia	1	**4.5**
Herpes Zoster	1	**4.5**
Toxoplasmosis	1	**4.5**

Of 22 children on ART, 95% had satisfactory adherence. Seven children has had opportunistic infections before starting ART. Most of the children were on AZT, 3TC, NVP or EFV regimens.

TABLE 4.29 NUTRITION RELATED INFORMATION ON INFECTED AND AFFECTED CHILDREN

	Infected with HIV N=27		Affected by HIV N=27	
	No:	%	No:	%
Hemoglobin				
<10 g/dl	4	**14.8**	1	**3.7**
>10 g/dl	21	**77.8**	6	**22.2**
Missing	2	**7.4**	20	**74.1**
Mean	11.83	na		
Median	11.75	na		
SD	1.5	na		

Majority (78%) of the infected children had haemoglobin level over 10g/dl. This information was not available for majority of affected children.

The specific objective 5 is to ascertain the level of stigma and discrimination faced by HIV affected and infected women and children in Sri Lanka and their coping strategies.

TABLE 4.30 PSYCHOSOCIAL DATA OF FEMALES INFECTED AND AFFECTED DUE TO HIV

	Infected with HIV No:206		Affected by HIV No:62	
	No:	%	No:	%
Fear of being gossiped				
Yes	115	**55.8**	34	**54.8**
No	91	**44.2**	25	**40.3**
No response	0	**0.0**	3	**4.8**
Fear of being verbally insult				
Yes	78	**37.9**	19	**30.6**
No	126	**61.2**	39	**62.9**
No response	2	**1.0**	4	**6.5**
Fear of being physically harassed				
Yes	33	**16.0**	9	**14.5**
No	169	**82.0**	49	**79.0**
No response	4	**1.9**	4	**6.5**

Among infected women 55.8% were concerned about being the target of gossip and 37.9% were worried about verbal insult. The percentage having fear of being physically harassed was 16%. Affected women too had similar concerns as infected women. They were worried about being gossiped about (54.8%), being verbally insulted (30.6%) and physically harassed (14.5%) due to HIV status of the partner or family member.

TABLE 4.31 PSYCHOSOCIAL DATA AMONG INFECTED AND AFFECTED CHILDREN

	Infected with HIV No:206		Affected by HIV No:62	
	No:	%	No:	%
Felt ashamed due to HIV				
Yes	121	**58.7**	28	**45.2**
No	83	**40.3**	29	**46.8**
No response	2	**1.0**	5	**8.1**
Felt guilty				
Yes	74	**35.9**	6	**9.7**
No	129	**62.6**	47	**75.8**
No response	3	**1.5**	9	**14.5**
Felt of blaming self				
Yes	62	**30.1**	7	**11.3**
No	141	**68.4**	47	**75.8**
No response	3	**1.5**	8	**12.9**
Felt of blaming others				
Yes	61	**29.6**	20	**32.3**
No	140	**68.0**	35	**56.5**
No response	5	**2.4**	7	**11.3**
Felt low self esteem				
Yes	86	**41.7**	14	**22.6**
No	113	**54.9**	39	**62.9**
No response	7	**3.4**	9	**14.5**
Felt suicidal				
Yes	36	**17.5**	2	**3.2**
No	160	**77.7**	50	**80.6**
No response	10	**4.9**	10	**16.1**

Close to 59% of infected women have felt ashamed due to the diagnosis of HIV status during the last 12 months. Thirty six percent of infected women felt guilty and 30% of infected females blamed themselves for HIV status. Only 29.6% of infected females blamed others for their HIV status. Out of infected 41.7% had issues with low self-esteem due to HIV. Among infected women 17.5% felt suicidal at some point during the last one year.

The data for affected women has to be considered with caution as more than 10% have not responded to these questions. Among affected women 45% felt ashamed due to the diagnosis of HIV status of the family member. As expected only 10% of affected women felt guilty and 11.3% blamed themselves.

Among affected women 22.6% had feelings of low self-esteem due to HIV status of family member. Suicidal ideas were not common, still 3.2% had suicidal ideas.

TABLE 4.32 EXPERIENCE OF STIGMA BY WOMEN INFECTED AND AFFECTED BY HIV

	Infected with HIV No:206		Affected by HIV No:62	
	No:	%	No:	%
Stigma from neighbors				
Yes	16	**7.8**	4	**6.5**
No	129	**62.6**	33	**53.2**
No response	61	**29.6**	25	**40.3**
Stigma from friends				
Yes	10	**4.9**	3	**4.8**
No	133	**64.6**	36	**58.1**
No response	63	**30.6**	23	**37.1**
Stigma from family				
Yes	26	**12.6**	4	**6.5**
No	136	**66.0**	38	**61.3**
No response	44	**21.4**	20	**32.3**
Stigma from health staff				
Yes	27	**13.1**	3	**4.8**
No	149	**72.3**	38	**61.3**
No response	30	**14.6**	21	**33.9**
Stigma from Co-workers				
Yes	2	**1.0**	2	**3.2**
No	139	**67.5**	36	**58.1**
No response	65	**31.6**	24	**38.7**
Denied health services due to HIV				
Yes	18	**8.74**	na	
No	184	**89.32**	na	
No response	4	**1.94**	na	

Among infected females 7.8% have experienced stigma or discrimination from neighbours due to HIV status. The high percentage of no response indicate that the neighbours are not aware of HIV status therefore question is not relevant. Only few indicated stigma from friends and again non response rate was high. Friends may not be aware of HIV status. More infected women felt stigmatized by the family. However, here again the non-response rate was high. Stigma or

discrimination at workplace was minimum. Obviously more infected women had experienced stigma from health staff (13.1%) and according to 8.7% they were denied health services due to HIV status. Among affected females issues related to stigma were much less.

TABLE 4.33 CARING EXPERIENCE OF WOMEN INFECTED AND AFFECTED BY HIV

	Infected with HIV		Affected by HIV	
	No:	%	No:	%
Are you caring for a HIV infected person?				
Yes	82/206	**39.8**	60/62	**96.8**
No	111/206	**53.9**	2/62	**3.2**
No response	13/206	**6.3**	0/62	**0.0**
Type of the person you provide caring				
Child	18/82	**22.0**	3/60	**5**
adult	64/82	**78.0**	57/60	**95**
Experience of burnout due to caring				
Yes	17/82	**20.7**	11/60	**18.3**
No	60/82	**73.2**	45/60	**75**
No response	5/82	**6.1**	4/60	**6.7**

TABLE 4.34 CARING EXPERIENCE AND BURNOUT EFFECT ACCORDING TO TYPE OF PLHIV

	Child with HIV No:21			Adult with HIV N=121		
	n/N		%	n/N		
Experienced of burnout						
Yes	7	/21	**33.3**	21	/121	**17.4**
No	13	/21	**61.9**	92	/121	**76.0**
No response	1	/21	**4.8**	8	/121	**6.6**
Has anybody supported?						
Yes	16	/21	**76.2**	46	/121	**38.0**
No	4	/21	**19.0**	73	/121	**60.3**
No response	1	/21	**4.8**	2	/121	**1.7**

Close to 40% of infected women were caring for another HIV infected person with 22% of them caring for a child. Twenty one percent experienced burn out effect due to the burden of caring.

Majority of affected women (96.8%) had to provide care services to infected adult (95%) or a child (5%). Among affected women 18.3% experienced burn out effect.

Women who looked after children had more burn out effect (33.3%) than who looked after an adult (17.4%). Those who cared for infected children had more support than those who cared for infected adults.

TABLE 4.35 COPING STRATEGIES OF HIV INFECTED AND AFFECTED WOMEN

	Infected with HIV n = 206		Affected by HIV n = 62	
	No:	%	No:	%
Disclosure of HIV status				
Yes	172	**83.5**	na	
No	30	**14.6**	na	
No response	4	**1.9**	na	
To whom disclosed?				
Spouse/partner	92	**44.7**	na	
Children	35	**16.9**	na	
Family & Friends	45	**21.8**	na	
No Response	34	**16.5**	na	
Response following diagnosis				
Accepted	63	**30.6**	na	
Couldn't accepted	75	**36.4**	na	
Thought it was a wrong	18	**8.7**	na	
Felt life is worthless	34	**16.5**	na	
Felt neutral	9	**4.4**	na	
No response	7	**3.4**	na	
Any difficulties in coping up the results				
Yes	167	**81.1**	43	**69.4**
No	35	**17.0**	9	**14.5**
No response	4	**1.9**	2	**3.2**
Did you have to withdraw children from school?				
Yes	6	**2.9**	1	**1.6**
No	189	**91.7**	52	**83.9**
No response	11	**5.3**	9	**14.5**
How did your sexual life affected due to HIV?				
Completely avoided sex	95	**46.1**	15	**24.2**
No change	13	**6.3**	5	**8.1**
Reduced	43	**20.9**	15	**24.2**
Continued with condom	43	**20.9**	13	**21.0**
No response	11	**5.3**	14	**22.6**

Among infected women 14.5% had not disclosed HIV status to anyone. 22% had disclosed to anyone other than nuclear or extended family. Most had disclosed to spouse or partner. Many

could not accept the diagnosis (36.4%) while 16.5% felt life is worthless. Only 30.6% of infected women were able to accept the diagnosis. More infected women (81.1%) had faced difficulties when coping with HIV result. Close to 3% of infected women had to withdraw children from school. The diagnosis has affected the quality of sexual life. More number of (46%) infected women completely avoided sexual exposure. Very few had continued sexual exposures without change. However, only 20.9% of infected women mentioned that they are using condoms.

Out of affected women 69.4% had difficulties in accepting the diagnosis of the family member. One child had to change school due to the diagnosis of HIV. Among affected women 24.2% completely avoided sex. Only 21% continued sexual life with condoms.

TABLE 4.36 DETAILS OF AFFECTED WOMEN

	Affected by HIV N= 62	
	No	%
Relationship to the patient		
spouse/Partner	52	**83.9**
Family	9	**14.2**
Other	1	**1.6**
Ever had fears of contracting		
Yes	27	**43.6**
No	32	**51.6**
No response	3	**4.8**

Most of the affected women had a HIV positive partner (83.9%). Fifteen percent had to look after HIV infected family member. Some affected women were worried about contracting HIV.

TABLE 4.37 HIV TESTING STATUS OF CHILDREN AFFECTED BY HIV

Affected children	No	%
Ever tested for HIV?		
Yes	18/27	**66.7**
No	9/27	**33.3**
Place of HIV test done		
Gov. facility	17/18	**94.4**
Pvt. facility	1/18	**5.6**

Sixty seven percent of affected children were tested for HIV. All children whose mothers were positive have been screened.

TABLE 4.38 PSYCHOSOCIAL INFORMATION OF CARE GIVERS OF CHILDREN INFECTED AND AFFECTED BY HIV

	Infected with HIV N=27		Affected by HIV N=27	
	No:	% %	No:	% %
Fear of being gossiped				
Yes	13	**48.1**	6.0	**22.2**
No	14	**51.9**	20.0	**74.1**
No response	0	**0.0**	1.0	**1.9**
Fear of verbal insult				
Yes	8	**29.6**	5.0	**18.5**
No	19	**70.4**	21.0	**77.8**
No response	0	**0.0**	1.0	**3.1**
Fear of physical harassed				
Yes	2	**7.4**	2.0	**7.4**
No	25	**92.6**	24.0	**88.9**
No response	0	**0.0**	1.0	**3.7**
Fear of physically assault				
Yes	2	**7.4**	2.0	**7.4**
No	25	**92.6**	24.0	**88.9**
No response	0	**0.0**	1.0	**3.7**
Ashamed of child's HIV				
Yes	8	**29.6**	na	
No	19	**70.4**	na	
Feel guilty of child's HIV status				
Yes	10	**37.0**	na	
No	17	**63.0**	na	
Blame myself for child's HIV status				
Yes	9	**33.3**	na	
No	18	**66.7**	na	
Blame others for child's HIV status				
Yes	9	**33.3**	na	
No	18	**66.7**	na	

Among care givers of infected children 48% were worried about being gossiped and 29% were concerned about Verbal insult. But only 7.4% were worried about physical harassment. Thirty

seven percent were feeling guilty of the child's HIV positive status and 33% blamed themselves for child's HIV status.

TABLE 4.39 EFFECT OF STIGMA OF CARE GIVERS OF CHILDREN INFECTED AND AFFECTED BY HIV

	Infected with HIV N=27 No :	%	Affected by HIV N=27 No:	%
Low self-esteem for child's HIV status				
Yes	6	**22.2**	na	
No	21	**77.8**	na	
Feel suicidal				
Yes	2	**7.4**	na	
No	25	**92.6**	na	
No response	0	**0.0**	na	
Ever experienced of stigma from neighbours				
Yes	2	**7.4**	0.0	**0.0**
No	25	**92.6**	26.0	**96.3**
No response	0	**0.0**	1.0	**3.7**
Ever experienced of stigma from friends				
Yes	2	**7.4**	0.0	**0.0**
No	25	**92.6**	26.0	**96.3**
No response	0	**0.0**	1.0	**3.7**
Ever experienced of stigma from family members				
Yes	2	**7.4**	4.0	**14.8**
No	25	**92.6**	23.0	**85.2**
Ever experienced of stigma from health staff				
Yes	6	**22.2**	1.0	**3.7**
No	21	**77.8**	25.0	**85.2**
No response	0	**0.0**	1.0	**3.7**

The care givers experienced low self-esteem due to child's HIV status (22%). Seven percent felt suicidal as well. Stigma from neighbours, family members and friends were less. However, stigma from health care workers was more 22%.

TABLE 4.40 CARE GIVING EXPERIENCE OF CARE GIVERS OF CHILDREN INFECTED AND AFFECTED BY HIV

	Infected with HIV N=27		Affected by HIV N=27	
	No:	% %	No:	%
Burnout due to caring of HIV infected child				
Yes	6	22.2		na
No	21	77.8		na
Has anybody ever supported?				
Yes	21	77.8		na
No	6	22.2		na

Among care givers 22% experienced burn out effect while looking after an infected child. However, according to 78% they had support to look after the child.

TABLE 4.41 COPING STRATEGIES OF CARE GIVERS

	Infected with HIV N=27	
	No:	%
Disclosed child's HIV status to him/her?		
Yes	9	**33.3**
No	18	**66.7**
Your response for diagnosis of child's status		
Accept	5	**18.5**
Not accepted	9	**33.3**
Felt life is Worthless	8	**29.6**
Other	5	**18.5**
Any difficulty in coping up?		
Yes	20	**74.1**
No	6	**22.2**
No response	1	**3.7**
Withdraw child from school following diagnosis		
Yes	4	**14.8**
No	22	**81.5**
No response	1	**3.7**

Nine care givers had disclosed HIV status of the child. Many could not accept the HIV status of the child and 74% had difficulties in accepting the diagnosis. Four had to withdraw child from the school due to diagnosis.

4.2 Results of the qualitative research component

Availability, accessibility and quality of education system for HIV affected and infected women and children of Sri Lanka

All of them admired the free education system in Sri Lanka where every child can get education free of charge. When considering the responses given by the infected women and care givers for infected children (including infected mothers) almost all of them felt that, if the status was divulged there would be problems. As far as it is kept a secret to the school, there are no problems in accessibility. But they pointed out that children who are ill are getting discriminated in few settings. The teachers ask the other children to keep away from the sick children even if they are not sick at that moment. Most of the children are being labelled as a sick child. The explanations they have given to the schools are that the child is having a heart disease. That answer is the safest. The advice given by doctors in STD clinics regarding how to overcome these problems is not satisfactory. Most of the mothers and care givers were having severe concern about the confidentiality and repercussions if anything happens.

Some of them appreciated the NGO help given for school bags and books. Few of them didn't like to go and get exposed to NGOs to get bags and books. They were concerned about the way NGOs addressed them "HIV infected children" in meetings or gatherings. They clearly showed their displeasure for the reason the child also can understand and he/she will get the idea of being a sick child; an HIV infected child. The request was, if anything is given, not to ask the children to come and to give it without any publicity.

Only one mother was scared that the other children will get infected. Few of them were concerned about participation in dances and sports, because of the liability of getting injured.

Most of them pointed out the education of teachers and the other parents on the transmission and non- transmission modes will reduce the problems.

One mother said that, when they were diagnosed with HIV (mother, father and daughter) the villagers came to know about that through the estate doctor. There was lot of resistance from the school. Later when the husband recovered from illness and the child looked healthy with treatment, the villagers thought that they are not sick and now they do not have any problem. The help given by NGO s was appreciated but she also didn't like to attend meetings organised by them with the child.

When the discussion was done regarding the opportunities for education for women who are infected or affected, they all were in the idea that if divulged, the opportunity will be lost. But they were concerned about the economical obstacles to get any education. And the fact that they have to look after their husbands or children has affected their capacity to get education.

When they were asked about the educational level of women infected and affected, almost all said they were uneducated. Although they knew very few people are having a good educational level, they said they will not come to the front and work for the population for the reason of stigma and discrimination.

In summary, there is lot of stigma in the background of educational institutes. The NSACP has to take initiatives to educate all school teachers on modes of transmission and non-transmission in order to avoid discrimination.

Assessment of availability and accessibility of healthcare services to women and children affected by HIV/AIDS

Morbidity and mortality related to HIV/AIDS

All of them were on the same view that the availability of ART has significantly reduced the morbidity and mortality of women and children affected and infected with HIV. A significant number of them were concerned about the availability of ART without interruption.

> I very well know that my child and I are living because of the drugs given from the clinic. But sometimes the drugs are given only for one week. I get scared because the drugs are not available even in a pharmacy. I don't mind about myself but my child should live. The government has to take all the steps necessary for us to live.

Most of them knew about the possible infections and the availability of treatment to them. They were thankful to doctors for treating them well giving education.

Few of the respondents compared the situation 10 years back with the present and they all said the conditions have improved a lot. The health care staff has improved immensely with their knowledge and attitudes on HIV infected. Some of them said it is good to have a well-equipped hospital which caters only for HIV positives but the majority did not have a clear idea where they should get admitted for care.

> "I can remember the nurses pushed me to a trolley in 2002, in Polonnaruwa (A district Hospital) saying that I will be killed at IDH by an injection. But the IDH treated me very well. I am alive today because of the doctors and the nurses at IDH. But I can see now they are treated in a good manner. I am very happy."

Some respondents were worried about the HIV positives having children. Most of them thought they should not have children to suffer. Few of them knew that ART given to the mother and to the baby after delivery can significantly reduce the transmission.

"I am happy to see a young mother whom I met in the clinic who was positive getting an uninfected child"

Almost all said that people should come and get tested. For that the society and the health care staff should change their attitudes.

Availability and accessibility of HIV testing and counseling services

Almost all of them knew about STD clinics providing counselling services after and before diagnosis. Only a few named some NGO s providing services. A fair number was satisfied with the services provided by the NSACP and other clinics. But two of them had very critical ideas regarding the services provided mainly the attitudes of some doctors regarding giving counselling.

"I feel I have done something wrong when the doctor talks to me. There are new doctors coming to central STD clinic every day. I don't like to talk with them. They always ask whether I had sex during the last month. I have no husband. Most of us do not like that question I think. If they say it in a kind way, it is good. But they are like police. The space is not enough"

Some of them said that there should be a good place not inside the hospital to do counselling for testing as the hospital environment can scare them out of services. The media should ask the people to come out for testing was another idea. They all felt that young people should be tested. The husbands will reach services but not the females as they are scared of getting the blame.

As for children, the parents and medical staff should be educated on the possibility of mother to child transmission and symptoms and signs of the disease to identify early.

"The Sri Lankans are scared of hospitals. They do not like blood drawing. I have heard about a test done by pricking the finger and giving the result same time. It is very good to go out and test.

A leader of a NGO who works for the HIV positives said that health care staff is not concerned about their privacy while counselling. Some of them just open doors and come in to the room. No respect for us"

Overall idea was they do believe in the testing and counselling done in STD clinics but some had the idea that services given by NSACP is not enough. It should be widely spread and integrated in to other services in the public and private sector.

Availability and accessibility of STI services

Almost all of them knew that STI care is mainly provided by the central and other provincial STD clinics in Sri Lanka. Most of them said that the services were enough and adequate. But they had some queries about provincial STD clinics according to what they heard from other patients.

"I am satisfied with the services provided by STD clinics. But the people in the country do not know about the available services. Other doctors in the hospitals have no idea about sexually transmitted infections"

Availability and accessibility of ART services and management of opportunistic infections

Almost all were satisfied with the availability of ART free of charge. But they were concerned about the non-availability of investigations and treatment for some OIs. The national hospital of Sri Lanka is refusing many investigations. But the condition in Negambo, Kandy and Ragama are good. They all praised the NGO s for giving money for investigations and treatment.

Almost all had the concern of non- availability of ART time to time and they knew that their lives are dependent on the drugs.

"The rate of other diseases is less now compared to 10-15 years back, but still we hear that people die at end stages of the disease. That is a mistake of the doctors rather than patients. I don't understand why the doctors do not know the features of the disease. But it is much better now"

Knowledge and consumption of nutrients

Most of them said the doctors explain what to eat and what not to eat. But they were concerned about not getting the food pack as given earlier. Few people said that no advice is given and the doctors do not say how to prepare a meal which is less expensive. The availability of a nutritionist was mentioned by few people.

"We eat what we have. Food is expensive. Now nobody talks about the food pack. Earlier we could at least sell the stuff because the quality was good. We sold oil and bought rice. But now we don't get anything"

Assessment of psycho-social problems and support services including coping strategies for infected and affected families

The social and psychological problems faced by HIV affected women and children

Many were not satisfied with the way they are treated. They didn't know where to go. They knew only about NGOs. They were very worried about the confidentiality of the disease. Some were actually harassed by the society especially many years back. They were worried about the future of their children. Their schooling, marriages and their employment.

They showed the need of trained counsellors in the clinics to address their social and psychological issues. Psychiatric referrals are done by the NSACP. But the doctors in the clinics are only concerned about diseases not as an individual.

Most of them were not satisfied with the services available for dealing with psychosocial problems. They are of the view that STD clinic doctors do not have enough time to give the services. NGOs also pay their attention when they are new. But later they forget about the past members. Some people were worried about males approaching them as their husbands are not alive.

"The society thinks that we should suffer. We have done some wrong. If we are happy also they don't like us. Specially the relatives"

"I went to a hospital to get treatment with a referral letter given by NSACP. I was asked to sit in the bench without showing me to the doctor. I saw the doctor in the clinic. They did it purposely"

"When my husband died many years back the neighbours displayed a poster telling that- **This dog may attain Nibbana".**

"As nobody knows my disease, I live without any problem. If they come to know, that will be a disaster"

UNICEF country representative:

"Psychosocial support is not satisfactory. Although the services are available, linking the patients to those services are very poor. The care providers do not think much about their psychosocial problems. They are limited to providing clinical care. That may be the reason why a significant proportion of patients are not linked to the services after the diagnosis"

Stigma and discrimination in the family, community or in healthcare settings

Almost all were concerned about the stigma and discrimination mostly prevailing in the health care settings. But all of them said that the conditions are much improved now. Some hospitals are really good. Why they get discriminated is the lack of knowledge among health care workers regarding the modes of spread and some thinking patterns the society has given them. In the hospitals there are problems when the minor staff and cleaning service people come to know about the HIV status.

"Some hospitals get ready for caesarean sections like for a war. They don't know how many HIV positive people they handle without their knowledge"
"Sometimes I don't divulge the status of my child to doctors even when I go to the private sector even though the doctors in STD clinics have advised me to do so. I have faced many bad consequences. So I don't tell"

Most of them praised IDH hospital for not discriminating them due to HIV.

When they were asked about the family setting, some had god understanding families but they said most of them were reluctant to divulge to family members also due to the possible problems.

"I am looking after my son's child for many years. I have not told about my condition or about my husband to them as they may separate us from the child. The doctors educated me on how to look after the child taking precautions. I am very healthy at 67 years also. I can work. I am very happy about my status with drugs"

Inputs given by the Key Informants involved in providing services for the HIV infected and affected women and children in Sri Lanka.

Availability, accessibility and quality of education system for HIV affected and infected women and children of Sri Lanka

Director NSACP mentioned that there is a clear policy for free education in Sri Lanka and it applies to HIV positives as well. There had been few incidents where the children as well as the parents were reluctant to send their children to schools. We need to be vigilant about such instances and intervene where necessary.

Director Research, AIDS Foundation Lanka was in the opinion that there are ample opportunities for the women and children in our country to learn; education is provided free of charge. Privacy and confidentiality is maintained to a greater extent. Even if the HIV status is disclosed, with good explanation, the children are accepted by majority of institutions. Discrimination is very much less when compared with earlier days.

UNAIDS Country Representative held a similar view related to the above topic. He highlighted the negative impact of the element of self-stigma which prevails in majority, on their education.

Assessment of availability and accessibility of healthcare services to women and children affected by HIV/AIDS

Morbidity and mortality related to HIV/AIDS

Director NSACP was on the opinion that the care provided for HIV positives is satisfactory and the longevity has improved as a result of it. Patients who were started on ART about 10 -12 years ago are still live with good quality of life. If the patients neglect themselves, early death may not be preventable.

Representative from AIDS Foundation mentioned that currently the HIV related deaths are less when compared with earlier days and it is attributable to provision of ART. When patients are

detected early and retained in care the mortality would go down as evident at present. This is true for both adults as well for children.

Country Representative of UNAIDS shared with us a slightly different view. He mentioned that there is a problem with the treatment cascade at present. Late diagnosis, defaulting clinic follow ups, not using ART as prescribed are some of the problems. The positive-living programmes are not tailor made. The advice provided following diagnosis is not comprehensive though a fair proportion of details are shared with the patients.

Availability and accessibility of HIV testing and counseling services

Director NSACP was on the view that though services are available, awareness given to their existence is not satisfactory. This is especially for the people with high risk behaviours. When it comes to women, majority of women do not know their risk of getting HIV as they do not engage in risk behaviours. As strengths, there is a well-established network of STD clinics in the country and they are manned by trained staff; ART and other main services are given free of charge. The services are integrated.

Director Research, AIDS Foundation mentioned that, HIV testing and counselling services are accessible and available to public, including to women and children. But need more publicity to increase the uptake of testing

UNAIDS Country Representative was on the opinion that though the services are available for children the accessibility is an issue due to need for getting parental consent etc

Availability and accessibility of STI services

Director NSACP mentioned that good STI services are available in the country and the STI services are linked to HIV services which is a positive feature. The clinic utilization has improved over the

years. AIDS Foundation representative opined that qualified doctors are working in the STD clinics and guidelines are available for patient management.

Country Representative UNAIDS was on the view that good quality services are available and the staff has adequate clinical competencies. Accessibility of services is an issue to a certain degree to a set of individuals in the community.

Availability and accessibility of ART services and management of opportunistic infections

Director NSACP mentioned that adequate ART services are available in the country. Since 2004 ART was given free of charge. For treatment of opportunistic infections there is adequate provision for drug purchase allocated by the government.

Director Research from AIDS Foundation Lanka also believed that unavailability of ART in the private sector as a negative feature. Also she mentioned that unavailability of most of the laboratory investigations in the clinic setting as another negative concern which need to be addressed soon. As most patients are compelled to do them from private places which creates undue financial burden on them. Presence of Post Graduate trained doctors at the Central clinic is a major plus point for patient management and as a result more patients are managed in the central clinic.

UNAIDS Representative also agreed on the good service provided for HIV positive patients by the STI clinics.

Knowledge and consumption of nutrients

Director NSACP was on the view that though the services are available related to above they are not enough and need to be scaled up.

Director Research, AIDS Foundation Lanka was on the opinion that the HIV positives are fairly well informed about these by the government as well as by the NGOs. Information on balanced diet is given clearly for them.

UNAIDS Country Representative mentioned that there is a scarcity of programmes addressing the nutrition need of the affected community. Involving of other specialists such as nutritionists in the main programme is a felt need

Assessment of psycho-social problems and support services including coping strategies for infected and affected families

The social and psychological problems faced by HIV affected women and children

Director NSACP was of the view that psychosocial issues are not being addressed to the extent expected Director Research AIDS Foundation Lanka also shared a similar view and mentioned that there are many social problems. Some women are left alone and there are few families with single parents. To address psychological needs of these patients a very few services are available and many do not wish to attend to such services. Adding on to this economic support should be provided to the affected as well as infected patients at National Level. Country Representative UNAIDS was of the opinion that there are multitude of social problems for children.

Stigma and discrimination in the family, community or in healthcare settings

Director NSACP was on the view that the prevailing stigma in health care settings has improved when compared with the past. Stigma and discrimination shown at family level depends on many factors and level of education, social status, economical status, the social role the person has played in the family and the respect towards the infected person among the others in the family are some of the determinants. In the community level still there is stigma but the situation is improving now.

Director Research AIDS Foundation Lanka stated that stigma and discrimination is very much less when compared with the past. Usually the women are blamed for HIV in the past but that situation is improving now. Even for children the environment is more favourable at present.

UNAIDS Country Representative also shared a similar view to Director, AIDS Foundation

5. Discussion

Discussion on infected women

The main objective of the study was to determine the social, economic, psychological, nutritional and physical impact of HIV positive status on infected women in Sri Lanka. The study was carried out among women registered for services for HIV from main STD clinics throughout the country. Previously no study has been done in the country to understand the status of women in relation to HIV diagnosis. Women are important as the main support of the family and also as a link to the society. Any effect on women directly influences the family and especially children.

The infected women were identified through the registers at the STD clinic. When selecting women with HIV, ideally the sample should have been collected from the community. However, with HIV infection the issues of confidentiality and linked concerns reduces the ability to approach people living with HIV in the communities. Further, it is not possible to identify a representative sample as there may be many unidentified women in the community. Therefore, the only option was to select the sample from women who are already diagnosed as having HIV. In Sri Lanka most of the women diagnosed with HIV are referred to the STD clinics of the National STD AIDS Control Programme. They are routinely registered at the government STD clinics and provided health services free of charge. Some of them have links with PLHIV groups. Accessing infected and affected women through PLHIV support groups would have been more convenient. However, the number of women linked to support groups were few. By end 2014, the total number of women identified with HIV in Sri Lanka is 796 and out of this 524 have registered for services at STD clinics.

The first Sri Lankan with HIV was diagnosed in 1987. ART services were initiated in Sri Lanka in 2004. From 1987 to 2014, a reasonable number of females may have died of which 171 deaths of

infected females have been reported to the NSACP. Since 1987, out of infected females registered, 104 have defaulted of which 83 defaulted records are available at the main HIV clinic in Colombo (2). (Annual report 2014) These defaulters too need to be considered to understand the accessibility of health services. At STD clinics defaulter tracing is carried out routinely. Letters are sent to all of them requesting to attend for services. Further effort is taken to contact them through phones. Failing both steps some are visited at the given address. As these defaulters could not be traced through these methods their socio-demographic data were evaluated based on the clinic records to understand whether they differed from the women who continued to attend for services.

Selecting the required number of women randomly from the identified STD clinics would have given a representative sample of all women with HIV registered for services at STD clinics. As a country with low prevalence of HIV it is difficult to identify the required sample size through random selection. A convenient sample within a given time period had to be considered to overcome this issue.

The instrument which was used to collect data was an interviewer administered pre-coded structured questionnaire given in the Annexures. A self-administered questionnaire would have been more convenient as well as would have maintained confidentiality and anonymity. But the varying levels of education among the infected or affected women prevented using a self-administered questionnaire. The questionnaire included several sections on socio demographic data, socio economic data, accessibility to health care services and nutrition related data. Further the psychosocial data and coping strategies were assessed to understand the effect of HIV on the woman.

The objectives of the study were considered when identifying the sections of the questionnaire. The content of the questionnaire was checked by a team of Venereologists and clarity of the questions were checked by PLHIV. Improvements were done according to the suggestions of the PLHIV. (Placeholder1)

Questions were mostly closed ended and proper interview techniques were used to prevent any possibility of bias. Respondents were not allowed to guess the answer if they were not sure of the answer. In these instances the answer was marked as no response. Few pretests were conducted before finalization of the questionnaire and modifications were done accordingly.

Clinical check list was used to understand the morbidity and mortality related data. These data were collected by going through the case records of the patients.

In the preliminary stages of the study, discussions with the PLHIV attending clinics indicated that they prefer interviewers to be medical officers as they were highly concerned about disclosing HIV status to a nonmedical personnel. This was more so with women who were not linked to support services. Therefore, the interviewers selected were medical officers. Medical officers who were not working in HIV clinics at the time of the study period were identified as interviewers to reduce the possible bias.

Being medical officers they had previous knowledge on research principles. Further they had adequate experience in the setting. Women, children or guardians were comfortable to discuss various issues with medical officers. The interviewers had a thorough training before commencing the study to ensure complete and accurate collection of data and to minimize interviewer bias.

The disadvantage of having medical officers as interviewers was the possible reluctance of women with HIV to reveal issues on accessibility, acceptability or quality of health services. The

interviewees were explained that it is important to understand the strengths and weaknesses of the existing system to improve the currently available facilities for HIV care services. Further it was emphasized that their inputs are necessary for future planning. This helped them to talk about deficiencies of health care system without fear.

It was decided to conduct interviews at the clinic as most people living with HIV (PLHIV) do not feel comfortable when others visit their homes. Only in few instances women and children were visited at homes after ensuring confidentiality, privacy etc.

Several steps were adapted to improve the accuracy of the responses. Prior to the interview the interviewers explained the purpose of the study to the patients and assured that complete confidentiality would be maintained. The aim was to put the subject at ease and to minimize bias. Care was taken to interview individuals in private out of the ear shot of others.

In addition to the quantitative study among women, few infected and affected women were subjected to in-depth interviews to understand the real issues they experience which cannot be covered by the quantitative study. Further the morbidity status was also assessed by extracting data from the case records maintained at the STD clinic. A pretested coded questionnaire was used to extract data from the case records.

Socio-demographic and socio-economic information of women infected by HIV/AIDS.

The median age was 42 years and most were in the age group 35-54 years (66%). There were only very few in the young age group <25 years (3.4%). This may be due to infection occurring in latter part of life or due to late diagnosis. As HIV has a long latent period women may be getting diagnosed later in life. Among the infected women 55.8% were in the reproductive age group 25-

45 years indicating the possible risk of paediatric infections through mother to child transmission. (Table 4.3)

As expected more infected were Sinhalese followed by Tamils and Muslims in concordance with the country statistics. The recent census data in the year 2012 shows the distribution of ethnic groups as Sinhalese 74.9%, Sri Lankan Tamil 11.2%,Muslims 9.3%,Indian Tamils4.1%,Others 0.5% (6). However, there were more percentage of Tamils and Muslims among infected women when compared with the figures given in the census data.

More infected females were married at the time of the survey (57.3%). A high percentage of widows, divorced or separated (36%) can be accepted among infected women as their husbands may have died due to AIDS. This may have led to the diagnosis of HIV among women. Though we did not try to explore reason for transmission in this study the data available from previous studies (unpublished clinic data) show most of the women are infected through their husbands. Divorce or separation may be due to HIV diagnosis or it may have led to HIV status through unprotected sexual exposures. The recent census data in the year 2012 shows 67.8% married, 25.5% Unmarried and 6.7% divorced or separated. This population seems to be different from the general population according the marital status.

The family assistance was obviously low for infected women. Though 57.3% admitted married only 47.6% lived with the partner at the time of the study. A high number 7.3% lived alone or with friends (1.0%) while another 2.9% were living in the homes run by PLHIV support groups.

Highest percentage of infected women were from Colombo and Gampaha districts which has high population densities. However, Puttlam having a reasonable number of infected women and affected women need to be taken seriously. The existence of CSW establishments or employment

abroad may have contributed to these increased numbers. The districts of Kandy, Galle , Kurunegala, Jaffna and Anuradapura had more women with HIV. As shown in the annual report of 2014 the HIV high prevalence districts are similar to this pattern. The exceptions were districts of Jaffna and Anuradapura. (Map annual report vs. study areas)

The low literacy rate may be exposing these women to risk through lack of opportunities. Though the sample who not attended school was only 3.4 %,(Table 4.4)

close to 8.3% of infected women could neither read nor write. Of the sample 39.3% had not reached up to GCE OL education (grade 11) in the school. According to UNICEF survey in 2013 the literacy rate of the country is 91.2% and is compatible with the figure identified in the study.

Among infected women 41.3% were employed. However, only 14.1% of them had income LKR 20,000 per month. (Table 4.5)

Although 45% of the infected did not have any income of their own most infected women admitted that they have a family income to support their needs. Still, close to 20% of infected received less than LKR 10,000 income. Many studies have proven that poverty affects entry in to care.

In Sri Lanka health services are provided free for all and health insurance is not an issue affecting services. However, infected women had to spend for transport and sometimes spent for investigations. Although adequate nutrition is an important area in HIV care services 12.1% spent less than LKR 5000 for food per month.

Many women did not spend for education may be as they did not have school going children. Other possibility is due to financial problems children's education may have got affected. This

possibility can be excluded as only 2.9% admitted withdrawing children from school due to HIV status.

Accessibility to health care services including reproductive health and HIV care services among HIV infected women

Most infected females were identified as contacts (27.2%) due to presence of infection in the husband. (Table 4.10)

Mandatory visa screening for purposes of Middle East employment also identified many unsuspecting females; locally (15.5%) and abroad (5.8%). These women may have contracted HIV abroad and may have been detected while trying to reenter the country. As these women leave their husbands alone for two or more years the possibility of them getting infected through the husbands who stay in Sri Lanka also cannot be excluded. Women do not consider themselves as at risk of HIV. Voluntary screening is very low. Late presenters have been identified with symptoms in late stage of the disease (18.9%). (Table 4.10)

Many infected women were not seeking services at the closest STD clinic. Median distance to the closest HIV clinic was 22 km (Table 4.11). Though the closest STD clinic was less than 25 km away for 61% of infected females, of them 45% avoided the closest STD clinic mainly due to fear of identification by known staff members coming from their village or town. Over the years many programmes have been conducted for hospital workers to reduce stigma and discrimination and to change the attitude of the health care workers. Still, as HIV is not a common diagnosis in Sri Lanka the attention paid to infected people may be more. The 'Stigma index' identified high level of self-stigma among infected people (6). Other studies identify transport cost, economic and psychological factors as important factors affecting access to care services (5).

As medical officers were involved in collecting data the possibility of infected and affected women giving biased answers to make the doctors happy was considered. It was explained to them the study was conducted to identify the deficiencies in the services to give better quality of services. They were assured of confidentiality. Their names were not included in the questionnaire and the completed questionnaires were handed over to the data analysis department end of each day to prevent access by others. Further the doctors involved in the study as interviewers were not managing PLHIV in the regular setting during the period of the survey.

Therefore the high rate of satisfaction regarding clinic services can be accepted as unbiased. In Sri Lanka each PLHIV is seen in the STD clinic by a qualified and trained medical officer. Mostly these are postgraduate qualified doctors having more than 4 to 6 years of training on STI and HIV. The clinics are dedicated clinics only for STI and HIV. PLHIV gets preference and more time is expected to be allocated for each patient as health care providers need to pay attention to the social and psychological issues in addition to medical problems. Majority were clear that they had time to discuss medical problems. Though 95% agreed that they had time to discuss social problems, 5% were not satisfied with services and felt they need more time to discuss their issues (Table 4.11).

The findings of the qualitative study indicated that doctors at STD clinics do not have enough time to give services other than clinical care services. The need of trained counsellors at STD clinics too was highlighted by some. The need to improve psychosocial services has to be considered when improving services.

In Sri Lanka all infected men and women are referred for specialized care services at the STD clinics manned by specialists. However, geographical distribution of specialist services is not satisfactory. Infected women may have to spend more for transportation due to this fact. None

indicated lack of specialist care services as an important reason for seeking services in peripheral STD clinics. The medical officer in charge of STD clinic is expected to get regular training at the central clinic of the National STD AIDS Control Programme on comprehensive care services for PLHIV. However, frequent transfers of health care workers affect continuity of quality services.

The qualitative part of the study indicated that infected women having the feeling that availability of ART has significantly reduced the morbidity and mortality. One infected woman was concerned about getting drugs for one week in one instance. According to some the situation has improved within last 10 years.

In the qualitative study a fair number were satisfied with the psycho social services. But two women had critical ideas regarding counselling and services provided. One was reluctant to talk on recent sexual encounters with doctors. It is very important to assess the risk of possibility of transmission of a different type of HIV or other STI to the patient through unprotected sexual exposures. Similarly the aim of providing all the services is to achieve prevention of HIV transmission through infected people by introducing responsible behaviour. During each follow up visit the PLHIV is encouraged to talk on matters related to sexual life. Sometimes PLHIV are not happy to discuss. This may be due to the sensitive nature of the topic as they feel embarrassed or they feel guilty as they continue risk practices.

Although the ART services were free of charge the women had to spend for transport, some investigations etc. The mean amount spent at the last clinic visit is Rs.1053 with median figure of LKR1250. Half of the sample managed the cost of last visit through their own funds while another 33% had support from PLHIV organizations. (Table 4.13)

Infected women agreed that the diagnosis of HIV status affected their income (52.9%). This may be due to ill health affecting working days as well as more expenses due to medical costs and cost to visit clinics (Table 4.13.)

As shown in many studies HIV diagnosis is a burden to the individual and family. It was obvious, in addition to the reduction of income, infected women had to spend more due to HIV status (81.1%). However only 31% received some financial assistance.

When it comes to real expenses for HIV services only 25% spent more than LKR1000 as monthly expenses among infected. Close to 20% did not spend money for health services and 55% spent less than LKR1000. In spite of having free health services in Sri Lanka and provision of free ART for all eligible, the infected women sometimes had to bear the cost of investigations due to stock out of reagents or breakdown of machines. The transport cost was also high due to the fact some preferred to visit a clinic far from their hometown due to confidentiality reasons.

The financial burden of HIV is obvious as some had to get loans (17%) and some had to sell assets (25.7%) to manage expenses related to HIV care. This may be due to lack of income due to ill health which leads to obtain loans and selling assets to cover family needs. Possibility of higher expenses for HIV related matters too need to be considered here.

It was alarming to realize that 33% of infected women used condoms as the only method of contraception. (Table 4.14) Condom failures are not uncommon and may lead to an unwanted pregnancy. As mentioned earlier most of these women were in the reproductive age group with 86% in the age group less than 45 years. This indicates the possible risk of mother to child transmission which needs to be eliminated. Infected women are expected to practice dual methods of contraception with a modern method and condom to prevent reinfection with HIV or

other STI. However, 30% of infected women who used modern contraceptive method used condoms alone for contraception leaving room for pregnancies during condom rupture or failure.

Health status of women infected with HIV

Most of the infected women had reasonable BMI with 88.9% having more than 18 BMI. Most of the women were in care services for many years and were doing well. Height of an individual is mainly determined by the genetic and nutritional factors during growing age. This may not get affected due to HIV status as all women acquired HIV during adulthood. Median height was 152 cm. There were 35.4% having height less than 152 cm. (Table 4.19)

Weight is affected due to HIV infection. HIV itself can cause HIV enteropathy. HIV suppresses immunity and the infected person is prone to infections. Repeated infections can affect weight gain. Oral and oesophageal involvement of infections can reduce intake of food. Intestinal infections lead to malabsorption. Further the drugs taken to cure infections or ART drugs can reduce appetite. In this group 41.5% had weight less than 50 kg.

Anaemia is a common problem among PLHIV. However, in this group 83.9% had haemoglobin level more than 10g/dl. (Table 4.19)

Food intake was satisfactory in the group. However, 18.4% had less than three meals per day which is not acceptable. (Table 4.18) Close to 30% had proteins less than 3 times per week. Fruit consumption too was low with 37.9% reporting less than 3 times a week. Most of the infected women (79%) were getting additional vitamins. All PLHIV are routinely prescribed vitamins at the STD clinic. Therefore, 20.9% of women attending for services not taking additional vitamins is a concern.

Among the group 42.2% were receiving assistance for food. This was not due to HIV status. They are eligible for the government food subsidiary as they are from the lower socio economic level.

Few years back World Food Programme (WFP) organized a food package for PLHIV in Sri Lanka. However, the programme was suspended in two years. With better services for HIV the infection is identified as a chronic disease similar to diabetes or hypertension. Therefore the expectation is to make infected people healthy through early initiation of ART and assist them to lead their normal lives. This includes them continuing their employment, earn their living without being a burden to the family and society.

At the time of entry in to services three fourth of the infected women (74.3%) were in WHO stage 1 or 2 indicating early diagnosis opportunities. (Table 4.21) Close to 25% were in stage 3 or 4 with 16% resenting in the bed ridden status. However, 29.6% had less than 200 CD4 level which indicated advanced immunodeficiency. Median CD4 level at the point of entry in to care services was 323 cells / microlitre.

The quality of services in a country can be assessed by the response to treatment. In Sri Lanka all infected people are offered comprehensive care services including screening for infections, opportunistic infections management, ART and routine monitoring including follow up. Counseling services are offered throughout on various related aspects including adherence, nutrition and prevention of infections. Services are usually offered by specialists or trained medical officers. In Sri Lanka guidelines are in place for management of PLHIV. In the sample 82% received ART in addition to other services. (Table 4.22)

With services infected women have shown marked improvement with 93.2% being in WHO stage 1 at the last visit. Similarly, 98.1% were having normal activity. Median CD4 level increased to 528 cells/µl. Only 6.3% had CD4 less than 200 cells/µl at the last visit. (Table 4.21)

Oral Candidiasis was the most common opportunistic infection among this group before starting ART. (Table 4.23) Pneumocystis Jeroveci Pneumonia infections (8.9%) and Tuberculosis (7.1%) were other common infections. According to the annual report of the NSACP 2014 a similar presentation of OI was seen among the PLHIV.

According to the Sri Lanka guidelines for ART, the eligibility criteria includes CD4 count less than 500 cells/µl (up to 2013 CD4 <350 cells /µl was considered), WHO stage 3 or 4, Pregnancy, sero-discordant status, female sex worker and tuberculosis (9).

In this group most were started on ART based on the CD4 count less than 350 or being in WHO stage 3 or 4. Two women were started ART as they had sero-negative partners to prevent infection in the partner. Diagnosis of Tuberculosis is considered under an eligibility criteria in the recent WHO guideline for ART use. Two percent of the study population were started on ART as they were diagnosed with TB. (Table 4.24)

WHO consolidated guideline on ART use released in 2013, recommends TDF+FDC+EFV as the choice for first line ART regimen. Most of these women were diagnosed before 2013 and they are currently doing well on AZT+3TC+EFV. Therefore among women on ART most were on AZT+3TC+EFV (36.7%) followed by TDF+FDC+EFV (33.1%). TDF+FDC+EFV is a fixed dose combination which has to be taken once daily and has better adherence due to convenience. However, few PLHIV experience depression, drowsiness and sleeplessness which affects quality of life. Nevirapine is the

choice available in these instances. Nevirapine may cause problems among women with higher CD4 counts. Among women on ART, 11.8% of women were on NVP.

Satisfactory adherence is essential to prevent emergence of resistant virus. This is important for the individual as well as for the community. In the sample 94.7% of women on ART had satisfactory adherence. This has been achieved through regular adherence counselling during each visit. Service providers pay attention to the importance of adherence during each consultation. The satisfactory adherence was further proven by the clinical improvement, increase in CD 4 count and decrease in viral load. (Table 4.25)

Viral load testing is routinely offered to patients free of charge, once in six months in the first year after initiation of ART and then annually. However, unavailability of regular supply of viral load testing makes it difficult to interpret the viral load response. 120 had undetectable viral load at the last visit and another 8 had <1000 copies/ml.

Psychological issues

The level of stigma and discrimination faced by HIV infected women

The findings indicate that 44% of infected women had no fear of being gossiped about. This may be due to the reason as no one other than few close people are aware of their infected status. Therefore this cannot be interpreted as due to acceptance of PLHIV in the community. Similarly 38% were concerned about being verbally insulted. (Table 4.30)

The number indicating possible physical harassment was much lower than verbal harassment. However, 16% of infected females admitted possible physical harassment due to HIV status.

The diagnosis of HIV causes immense psychological disturbance and the impact of diagnosis remains with the infected person for lifetime. The extent of self-stigma plays an important role in a

person's ability to adjust to life with HIV. More infected women had negative feelings. Close to 60% felt ashamed due to HIV status during the last 12 months. These women included women who were diagnosed many years back as well. (Table 4.31)

The mode of transmission or who brought the infection may have influenced women to feel guilty of HIV status. Many infected women were not feeling guilty. This may be because they got infected from their husbands.

Similarly many infected women (68%) did not blame themselves as they were not responsible for the infection. Though we would expect more women to blame others only close to 30% of infected women blamed others for their status. This may be because after living with HIV for many years the women have accepted the fact and stopped blaming others.

HIV diagnosis changes life forever for some women. Forty two percent of infected women had problems due to low self-esteem following the HIV diagnosis. This affects their family and social interactions and may cause adverse impact psychologically.

Among infected women 17% were feeling suicidal at some point during the last one year. This may be linked to several reasons. Inability to cope with the diagnosis or recent diagnosis, problems in caring for other infected family members or stigma and discrimination by others may have led to these feelings.

In the qualitative part of the study it was revealed that the care services for psycho social concerns need to be improved. Though they reach PLHIV support groups seeking assistance support groups too are not in a position to provide much services. According to the qualitative study findings these NGO s pay attention to infected when they are newly identified. Later the NGO forgets about the past members.

Seventeen percent have not disclosed to others. (Table 4.33) As others are not aware they may not be getting exposed to HIV related discrimination.

Infected females experienced stigma or discrimination from neighbours due to HIV status (7.8%). (Table 4.32) The high percentage of no response indicate that the neighbours are not aware of HIV status, therefore question is not relevant. In the previous question on disclosure, the infected and affected women indicated that they did not want to disclose HIV status to neighbours. Only few indicated stigma from friends and again non response was high. Friends may not be aware of the HIV status of these women.

More infected women felt stigmatized by the family. More had disclosed the HIV status to family members. However, here again non response rate was high.

Infected women have frequent contacts with health care workers and most of the instances the health care workers are aware of the HIV status. More women stated that they had not experienced stigma from health staff. However, it is worth to note that 13% of infected women had experienced stigma by health care workers.

In the qualitative study almost all were concerned about the stigma and discrimination in health care settings. But all mentioned that the conditions have improved now.

Since the commencement of HIV care services in Sri Lanka from 1986, many programmes have been conducted for health care workers to reduce stigma and discrimination in health care setting. The country policy has been informed to the health services through a circular in 1993 encouraging managing PLHIV in general wards as other patients to prevent isolation and discrimination. The programmes have improved the attitude of many health care workers and currently PLHIV do receive services in many hospitals without much issues.

Still there may be few health care workers who did not get the opportunity for training or who cannot change their attitude. The training programmes need to be continued as there is high turnover of staff due to transfers etc.

It is interesting to note that stigma or discrimination at workplace was minimum. This may be due to coworkers being unaware of the woman's sero status. Many programmes are currently being conducted for workers through the ministry of labour on HIV at workplace. There may be some contribution through these programmes.

Being infected, women needed somebody to care for them. But 40% of infected had to care for another infected adult or child. (Table 4.33) HIV causes infections in families by infecting partners and children. The burden of caring for the infected family falls on the woman. If the woman in the family is also infected this creates a huge burden on the woman. She has to look after herself while providing services for others; mainly children. However, in this group only few infected women had to look after children.

As one would expect women looking after children experienced burn out effect more (33.3%). This was 17.4% for among women who look after adults.

At the same time more women admitted receiving support when caring for a child than caring for an adult. It was not analyzed from where they had support. However, this may be from immediate family or extended family. (Table 4.34)

Disclosure is an issue which affects provision of comprehensive management for PLHIV. Among infected women 14.5% had not disclosed HIV status to anyone. (Table 4.35)

Women may be worried about the violence in the family. Mostly women who had HIV through exposures other than with husband may be worried about disclosure to husbands or partners.

Widows, separated and single women or those who may not be having suitable trustworthy people to disclose may be reluctant to disclose.

Disclosure is important in management of the PLHIV as disclosed person may have more support than non-disclosed. This is helpful to maintain adherence and also in managing side effects.

Majority of women had difficulties when coping with HIV result. (Table 4.35) Being a low prevalence country the diagnosis of HIV is not even heard of as a possibility for most women. The perception of the people that they are at risk of HIV is minimal. In this background to grasp the fact that the person is infected with HIV is unthinkable.

HIV diagnosis brings with itself several changes to life. It is a turning point in life for many. The life would not be same after the person learns about the diagnosis.

The diagnosis has affected the quality of sexual life. Many factors can affect the sexual life. Psychological changes with the diagnosis, fear of infection or possibility of infecting other partner, guilty feeling, worthlessness all these might affect the life style of the individual including sexual life. Close to 50% of infected women completely avoided sexual exposure (46%). Very few had continued sexual life without change.

PLHIV are encouraged to use condoms to prevent reinfection with HIV or to prevent other STI. In this sample there may have been sero-discordant as well as sero-concordant couples Low use of condoms is a concern as there is risk of infection to the individual and to others as well.

Discussion for Affected women

The main objective of this component of the study was to determine the social, economic, psychological and nutritional or physical impact on women affected due to HIV in Sri Lanka. The study was carried out among women affected due to HIV diagnosis of a partner of family member. Women who were affected due to the HIV positivity of spouse, child or family member were assessed to understand the effect of HIV status to women as careers. Previously no study has been done in the country to understand the status of affected women in relation to HIV diagnosis. Women are important as the main support of the family, and also as a link to the society. Any effect on women directly influences the family and children.

The affected women were identified through the PLHIV registered for services at the STD clinic. People living with HIV (50 males and 50 females) were explained about the study and were asked to name one affected woman in the household to get 100 affected females. When selecting women with HIV, the definition used was to identify a woman nominated by the PLHIV, 18 years or older who was uninfected with HIV but having a family member with HIV infection living in the same household.

It is not possible to identify a representative sample of affected women as there may be many unidentified affected women in the community. Therefore, the only option was to select the sample through the PLHIV who were already diagnosed. In Sri Lanka most of the PLHIV diagnosed with HIV are referred to the STD clinics of the National STD AIDS Control Programme. Hundred women were identified through PLHIV and every effort was taken to contact them. However only 62 of them could be reached due to many unavoidable reasons. Some who agreed to participate at the beginning were reluctant to welcome STD staff at their places. Though a transport allowance was arranged for all the participants they refused to attend STD clinic. Some

were willing to attend but their family commitments prevented them from getting involved in the study. Further the short period through which we had to collect data according to the protocol provided by the SAARC secretariat, hindered getting more numbers of affected women in to the study sample. Therefore non response rate was fairly high in this component.

All affected women were identified through PLHIV receiving services currently. The issues of women affected due to death of a family member or a PLHIV who defaulted services would have been different. However, as we had to get the consent of the infected person to identify the affected woman we had to limit to the PLHIV receiving services currently.

The instrument which was used to collect data was an interviewer administered pre-coded structured questionnaire. The questionnaire included several sections on socio-demographic data, socio economic data, accessibility to health care services and nutrition related data. Further the psychosocial data and coping strategies were assessed to understand the effect of HIV on the woman.

The objectives of the study were considered when identifying the sections of the questionnaire. The content of the questionnaire was checked by a team of Venereologists and clarity of the questions were checked by PLHIV. Questions were mostly closed ended and proper interview techniques were used to prevent any possibility of bias. Few pretests were conducted before finalization of the questionnaire and modifications were done accordingly.

In the preliminary stages of the study, discussions with the PLHIV attending clinics indicated that they prefer interviewers to be medical officers as they were highly concerned about disclosing HIV status to nonmedical personnel. This was more so with the women who were not linked to support services. Therefore the interviewers selected were medical officers.

Women were comfortable to discuss their concerns with medical officers. The interviewers had a thorough training before commencing the study to ensure complete and accurate collection of data and to minimize interviewer bias.

Interviews were conducted when they accompanied PLHIV adult or child to the clinic. Most affected women were not comfortable to see STD clinic staff visiting their homes. In few instances women were visited at homes after ensuring confidentiality, privacy etc.

Several steps were adapted to improve the accuracy of the responses. Prior to the interview the interviewers explained the purpose of the study to the women and assured that complete confidentiality would be maintained. The aim was to put the subject at ease and to minimize bias. Care was taken to interview individuals in private, out of the ear shot of others.

Socio-demographic and socio-economic information of women affected by HIV/AIDS.

The median age of affected women was 42 years. However the age ranged from 17-67 years. Among the affected women most were in older age group (45-54 age group). Young women had to care for infected husbands and parents. Women who were in their sixties had to care for infected husbands or children or in few cases for orphaned grandchildren.

As expected more females were Sinhalese followed by Tamils and Muslims in concordance with the country statistics. Most of the affected women were married and widowed or divorced number was few. They had partner or family living with them. However, as they have to care for one or more infected adults or children, the status of these affected women cannot be considered to be better than infected women. (Table 4.3)

Highest percentage of affected women were from Colombo and Gampaha districts which has high population densities followed by Kalutara, Ratnapura, Puttlam, Galle and Matara.

Education level was satisfactory in this group with most women having education up to GCE OL or more (69.4%). Those who did not attend school was 3.2% and 93.5% could read or write. Among affected women though many were unemployed, 46.8% had monthly family income more than LKR 20,000 per month. Affected women had more financial support from spouse. (Table 4.4)

Most women agreed that the diagnosis of HIV status of the family member affected their income. This may be due to ill health of the PLHIV family member affecting working days as well as more expenses due to medical costs and travel to visit clinics. (Table 4.13)

As shown in many studies, HIV diagnosis is a burden to the individual and family. It was obvious in addition to the reduction of income, they had to spend more due to HIV status.

When it comes to real expenses for HIV services the affected women stated that they had to bear the cost of investigations sometimes due to stock out of reagents or breakdown of machines. The transport cost was also high due to the fact some PLHIV preferred to visit a clinic far from hometown due to confidentiality reasons.

The financial burden of HIV is obvious as some had to get loans and some had to sell assets to manage expenses.

The mean amount spent at the last clinic visit is LKR 1223 with median figure of LKR 1000. Three fourths of the sample managed the cost of last visit through their own funds while another 14% had support from PLHIV organizations.

It was alarming to realize that only 37.1% of affected women used modern methods of contraception. These affected women included partners, mothers, grandmothers or daughters. This may be the reason for low contraceptive use. Further a reasonable number has passed the reproductive age group. However, 47.8% of affected women who used modern contraceptive

method, used condoms alone. It was not clear whether this was to prevent infections and pregnancy both. All affected women identified in the study were sero-negative and it is important to use condoms for each sexual encounter. (Table 4.14)

Psychological issues

The findings indicate that 40% of affected women have no fear of being gossiped about. This may be due to the reason as no one other than few close people are aware of their family members infected status. Therefore this cannot be interpreted as due to acceptance of PLHIV in the community. About 31% of affected women were worried about being verbally insulted due to HIV status of the family member. The number indicating possible physical harassment was much lower than verbal harassment. However, 15% of affected females admitted possible physical harassment due to HIV status. (Table 4.30)

The diagnosis of HIV causes immense psychological disturbance and the impact of diagnosis remains with the infected or affected person for lifetime. Among affected women 45% had felt ashamed due to a family member being positive for HIV.

It was not clear why 9% of affected women felt guilty and 11% blamed themselves for family members infection. Though we would expect more women to blame others only close to 30% of affected women blamed others for their status. This may be because after living with HIV for many years the women have accepted the fact and stopped blaming others. (Table 4.31)

HIV diagnosis changes life forever for some women. 22% of affected women had problems due to low self-esteem following the HIV diagnosis. This affects their family and social interactions and may cause adverse psychological impact.

Six percent of affected people have experienced stigma or discrimination from neighbours due to HIV status. The high percentage of no response indicate that the neighbours are not aware of HIV status. Therefore, question is not relevant. The affected women did not want to disclose HIV status to neighbours. Only few indicated stigma from friends and again non response rate was high. Friends may not be aware of HIV status. (Table 4.32)

As expected the diagnosis has affected the quality of sexual life. Many factors can affect the sexual life. Fear of infection might affect the sexual life. Among affected women (24.2%) completely avoided sexual exposure. Very few had continued sexual contacts without change. (Table 4.35)

When it comes to affected women most had HIV positive partner. It is a concern that only 21% continued sexual life with protection. Being sero-negative they were worried about contracting HIV. This may have led to the situation where 24% completely avoided sex.

Discussion for Infected Children

The main objective of this component of the study was to determine the social, economic, psychological and nutritional or physical impact on infected children due to HIV in Sri Lanka. The study was carried out among children with HIV. Previously no study has been done in the country to understand the status of infected children women in relation to HIV diagnosis.

The infected children were identified through the list of children registered for services at the STD clinics. When selecting children with HIV, the definition used was to identify a child less than 15 years and confirmed as having HIV infection. Both male and female children were included. HIV, DNA PCR test was used to diagnose HIV infection in children less than 2 years of age.

Being a HIV low prevalent country, Sri Lanka has identified 72 children with HIV infection from 1987 to 2014. Of these only 48 children survive by end 2014. ART services were initiated since 2004.

The sample size was very small (n=27) as the identified number of infected children was less. Further all infected could not be interviewed during this period. As most children were young had to get most details from the care givers. The care givers of infected children included parents and other relatives of the nuclear or immediate extended family such as aunts and grandmothers. The care givers interviewed varied depending on the fact whether parents were alive or not. Therefore interpretation of some of the facts should be done with caution as the interviewees do not come from a similar sample. Further the findings cannot be generalized to others due to varied nature of the interviewees.

Among the infected children in the sample (n=27) 70.4% were above 5 years and all of them were attending school at the time of the study. Sri Lanka has free education services and a child above 5 years has to be enrolled in the school (10). Literacy rate for the country is 91.2% according to the UNICEF data conducted in 2013. In this sample the literacy rate of 84.2% is low. This is probably due to children in early school going age group. 57.9% were in primary classes while 31.5% were in secondary classes. 84.2% of children above 5 years could write or read. (Table 4.7)

Two children in the study sample, out of 19 school going children had to change the school due to HIV status. Only one child missed school for more/less than 80% days. Most of the children's school authorities were not aware of the child's status. But in 5 children (18.5%) the school was aware but still they could continue studies in the schools without problems. 57.9% of the school going children were getting involved in extracurricular activities. They may not have faced issues due to nondisclosure. Disclosing the status of the child is a dilemma most parents experience. Being responsible citizens they are worried about other children getting exposed if child sustains

an injury. Teachers and children do not pay attention to infection control practices when a child needs help. Further being a low prevalent country the general population downplay the possible risk due to HIV infection.

Having one or more infected children in the family is a financial burden. Situation was worse as most of these children came from poor families. Only half of the care givers were employed. For 44.4% the family monthly average income was less than LKR 10,000. Only 25.9% had monthly family income more than LKR 20, 000. (Table 4.8)

Five children (18.5%) of the sample had lost one or both parents. In the study done in Nepal (n=435) 56% of the sample were orphans. Twenty two children in the study lived with one or both parents.

Median family income was LKR 16,500. However, the SD was very large indicating the wide range of income. There were very poor families as well as rich families affecting the mean value. Similar study done in Nepal indicates 31% of infected children to be from poor families. However, as median or mean income was not given in the Nepal study values cannot be compared.

Sixty three percent of care givers admitted to spend more due to child's HIV status. The mean monthly expenditure for health was LKR1665.90 and median was LKR 1000. Among infected children 48.1% care givers admitted getting some financial assistance mostly through NGO or PLHIV support groups. Parents have to spend more to provide medical services to children. With HIV infected children the cost for health services is more.

Gender bias is much lower in Sri Lanka when compared to other South Asian countries. Though Nepal observed more services for male children not much difference was observed in the study. However, as the sample size of children was small this cannot be stated clearly.

Families with infected children had less money for food, 22% spending less than LKR 5000 per month for food. Mean value was LKR 14,250 and median was LKR 9,000. This may have been due to the fact that they spent more on health services and transport to visit to clinic.

For schooling the median amount spent per month was LKR 2000. The care givers of 70.4% of infected children had to spend more for transport visit the clinic for HIV services. The median amount spent was LKR 1000. (Table 4.15)

Close to 60% had to travel more than 25 km distance to seek health care services related to HIV. 59% agreed it is not the nearest health care institution. Many reasons including fear of meeting known health care workers (18.5%) and stigma (11.1%) affected them seeking services at the nearest health care institution. The high cost of transport was mainly as they were worried to visit the known health care setting due to stigma. (Table 4.3)

Only 22.2% of infected children visited HIV clinic for all health issues of the child. Others sought treatment from the closest hospital or general practitioner as well. Though parents were reluctant to use the closest medical unit for HIV related services they had no problem in receiving services for other medical issues. We cannot assess the level of discrimination here as HIV status was not disclosed when they received services from other institutions.

Stigma is a fact which affects throughout the life when a person gets to know that the child is infected with HIV. There are two aspects to stigma. It may be external stigma due to discrimination by others due to HIV status. In addition most HIV infected are affected due to self-stigma as revealed in the stigma index report. When it comes to infected children self-stigma does not play a role as most children are not aware of the HIV status. (Table 4.32)

When an infected child visits the STD clinic, the patient has to wait to trace the file, to get registered, to check the completeness of the file with reports and to weigh the child. STD clinic provides services to all patients with STD and a reasonable time has to be spent with each patient to provide quality comprehensive services. These units are tertiary care centres and services are provided to cover most of their medical and psychological needs such as counselling, prevention, adherence, assess nutritional issues and ART related problems. Most care givers need time to talk to medical officers and nursing officers regarding their issues as they cannot discuss these with others due to disclosure and confidentiality issues. Each patient takes a long time sometimes extending to 45 minutes. 96% stated that they have enough time to discuss their problems with the medical staff.

The care givers of infected children stated that they had to spend money for the last clinic visit for HIV services. Mean expenditure was LKR 1053 and median value was LKR 1250.

Among infected children 33% received NGO support for transport cost while 44% managed on their own. One care taker did not buy extra medicine (cough syrup) from pharmacy as she did not have enough finances.

In this group 89% were satisfied with services but only 11% were very satisfied. The difference between satisfied and very satisfied needs to be explored as this is subjective and cannot be quantified. Overall there is consensus that patients were satisfied with services but still there is room for improvement. (Table 4.11)

Most infected children showed issues related to growth. The height and weight cannot be compared as children were in different age groups. The weight of each child was compared with the standard figures given in child health development record of Sri Lanka and WHO NCHS figures.

Only six children had satisfactory weight. This indicates definitely that HIV status has affected the growth of the child. (Table 4.11)

Anaemia is a common nutritional problem of children in low socio economic levels with country figures amounting to 36.1% (<11g/dl) in 2011 among children (8). In this study 14.8% of infected children had haemoglobin <10g/dl. (Table 4.19)

Most of the infected and affected children were given home cooked food. Though children needed more food including proteins for growth, 22% of infected children received proteins less than 3 times per week. Vegetable consumption was satisfactory.

All infected children are expected to receive vitamins from the clinic. However, only 44% consumed additional vitamins in the infected group.

As expected the care givers of infected children were worried about being gossiped (48%). Less number 29% were concerned on verbal insult. Care givers did not have much worries about physical assault. Here the care givers were worried about possibilities of being abused. This does not indicate that they have been abused earlier. (Table 4.30)

When it comes to interpreting these questions we need to understand that caregivers comprise of a different population. Irrespective of wrong doing any mother or father would feel guilty for giving infection to the child. In this sample 36% were feeling guilty of the child's HIV positive status.

However, 33% blamed themselves for the child's HIV status. This may be related to linking their behaviour to the child's HIV status. This feeling can affect the mental health of the infected parent and can affect the immunity as well. The self-stigma of having HIV can reduce the self-esteem of the individual. The care givers experienced low self-esteem due to child's HIV status (22%). Having

7.4% who felt suicidal at one point of time due to child's HIV status indicates the importance of psychological health services to care givers. (Table 4.31)

Stigma from neighbours, family members and friends were less. But this was mainly due to non-disclosure. The care givers continue to suffer having the insecure feeling if others get to know about the infection. This same finding has been observed in the study on stigma index done among HIV positive women (Table 4.33) (6).

However, stigma from health care workers was more (22%). This does not indicate higher stigma in health care settings. Disclosure is 100% when it comes to health care settings. This shows there was no stigma in 88% cases. However, 22% stigma from health care workers is not acceptable. There need to be programmes to improve the stigma level.

Looking after a person with HIV is a difficult task and it is more so with a child with HIV infection. Twenty two percent of care givers experienced burn out effect while looking after an infected child. However, 78% had support to look after the child. It is relieving to understand that they have assistance within the nuclear family or from the extended family to look after the infected child.

When it comes to HIV infection in children the most difficult topic is disclosing the HIV status to the child. Most of the children were small and were not in a stage to understand the condition. It is important to introduce the subject gradually to the child as the child grows as during adolescence the child has to understand his or her condition. This is important as the child has to live with HIV during lifetime. This affects their future options of identifying partners and marriage also. In this study nine care givers had disclosed HIV status to the child. (Table 4.36)

Many could not accept the HIV status of the child. 74% had difficulties in accepting the diagnosis. Four care givers revealed that they had to change the school due to diagnosis.

Most of the children were either in the first or second stage at the time of diagnosis and 85% had satisfactory performance scale. At the time of the study 81% were on ART. Of 22 children on ART 95% had satisfactory adherence.

Discussion of affected children

The sample size was very small (n=27) as the identified number of affected children was less. Further all affected could not be interviewed during this period. As most children were young had to get most details from the care givers. The care givers for affected children included parents and other relatives of the nuclear or immediate extended family such as aunts and grandmothers. Interpretation of some of the facts should be done with caution as the interviewees do not come from a similar sample. Further the findings cannot be generalized to others due to varied nature of the interviewees.

Among affected children more were above 5 years of age. Twenty out of 21 affected children in school going age were attending school. Being young, most of these children were in primary education. Eighteen out of 20 school going children could read or write. One affected child had to change the school due to family members HIV status. More affected children were involved in extracurricular activities indicating that there is no restriction from the school based on family members HIV status. However, as most have not disclosed HIV status to schools they may have been accepted as other children (Table 4.15).

Less percentage of care givers of affected children were employed (40.7%). Family monthly average income was reasonable in affected children's families with mean income LKR 22,000 and median LKR 20,000. Affected children too had to spend a reasonable amount for health with mean monthly expenditure for child's health LKR 1236 and median LKR 1000.

Affected children's families spent more for food and education. However, as care givers were infected they had to spend more money for transport to visit the clinic. Among affected children 30% received proteins daily. However, 33% had proteins less than 3 times per week. This is a concern as children need more proteins for growth.

There are four PLHIV support groups currently offering services to PLHIV in Sri Lanka. STD clinics display information regarding services provided by the PLHIV support groups and patients are expected to voluntarily seek services at these centers.

Conclusions

HIV infected women

- The low literacy rate may be exposing these women to risk through lack of opportunities. In the sample close to 8.3% of infected women could neither read nor write.
- Voluntary screening is very low among women and some were identified in late stage of the disease. However, at the time of entry in to services three fourth of the infected women (74.3%) were in WHO stage 1 or 2 indicating early diagnosis opportunities.
- There is high rate of satisfaction regarding HIV clinic services.
- Though the HIV services are free of charge a reasonable amount had to be spent by PLHIV. Diagnosis of HIV status affected their income and some had to get loans or had to sell assets.
- Though infected women in reproductive age group were expected practice dual contraception the practices were not satisfactory.
- Most of the infected women had reasonable BMI with 88.9% having more than 18 BMI. Food intake was satisfactory in the group. However, 18.4% had less than three meals per day.
- At the point of entry in to care services median CD4 level was 323 cells / microlitre. 29.6% had less than 200 CD4 cells/µl which indicated advanced immunodeficiency.
- With services infected women have shown significant improvement. At the last visit with 93.2% in WHO stage 1, 98.1% were having normal activity and median CD4 level increased to 528 cells/µl.

- Common opportunistic infections before starting ART were oral Candidiasis, Pneumocystis Jeroveci Pneumonia infections and Tuberculosis.
- Among women on ART most were on the first line regimen. AZT+3TC+EFV followed by TDF+FDC+EFV.
- Adherence to ART was satisfactory (94.7%). The satisfactory adherence was further proven by the clinical improvement, increase in CD4 count and decrease in viral load.
- Infected women had negative feelings with 17% feeling suicidal at some point during the last one year.
- The societal stigma is high though there is an improvement over the years. Many avoided the closest STD clinic mainly due to fear of identification. More infected women felt stigmatized by the family. Some infected women had experienced stigma by health care workers. Some infected women were reluctant to disclose HIV status to anyone. Majority of women had difficulties when coping with HIV result. The diagnosis has affected the quality of sexual life. Close to 50% of infected women completely avoided sexual relationships.
- Women looking after children experienced burn out effect more than an adult.

Affected women

- Most affected women had education up to GCE OL or more.
- Most women agreed that the diagnosis of HIV status of the family member affected their income.
- HIV diagnosis caused a financial burden and some had to get loans and some had to sell assets to manage expenses.
- Only 37.1% of affected women used modern methods of contraception.

- Some affected women had concerns about stigma and discrimination.
- Low self-esteem was observed among one fourth of affected women.
- Among affected women few had continued sexual contacts without change.

Infected children

- The opportunities for education for children is available free of charge but divulging HIV status may cause problems for them by the school authorities and other parents.
- Most care givers were in low socio economic backgrounds.
- Five children (18.5%) of the sample had lost one or both parents.
- Most care givers admitted to spend more due to child's HIV status and had less money for food.
- Most seek health care services related to HIV avoided the nearest health care institution due to fear of stigma (11.1%).
- Majority were satisfied with HIV services offered by the government.
- Infected children showed issues related to growth.
- Some care givers of infected children were concerned about stigma from health care workers.
- There is family support to look after the child.
- Many had difficulties in accepting the diagnosis of HIV of the child.

Recommendations

- The need to provide more psychosocial services to improve the quality of HIV care services. It is recommended to have a qualified dedicated nurse counsellors at service delivery sites.
- The training programmes for healthcare workers on comprehensive care services for PLHIV need to be continued on a regular basis as there is high turnover of staff.
- Most infected children showed issues related to growth and nutrition. It is recommended that HIV infected and affected children are assisted with food supply and services of a qualified nutritionist at the clinic.
- Among infected children the most difficult task is disclosing the HIV status to the growing child. A multidisciplinary team comprised of psychiatrists and paediatricians need to be identified to help in this process.
- Defaulter tracing is a requirement and an important component of comprehensive care services. Dedicated public health staff is needed for HIV services to assist in contact tracing and defaulter tracing.
- Regular availability of laboratory reagents and presence of back up machines will make sure continuity of services and reduce the burden to the patient.
- Antiretroviral procurement and supply mechanism should be strengthened to have an uninterrupted supply of ARVs to patients.
- It is recommended to improve infrastructure and human resources at service delivery points as the quality of services are affected by lack of space, lack of human resource.
- PLHIV support groups should be actively get involved to improve social and financial needs of PLHIVs.

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9. NSACP, The guidelines for use of ART in Sri Lanka; 2014
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Annexes

Annex 1: Questionnaire for Women infected and affected by HIV

NATIONAL STD/AIDS CONTROL PROGRAMME, MINISTRY OF HEALTH THE QUESTIONNAIRE ON WOMEN INFECTED AND AFFECTED BY HIV/AIDS IN SRI LANKA – 2014

001 QUESTIONNAIRE IDENTIFICATION NUMBER |___|___|___|

002 District _____ CODE |___|

003 Name of the HIV clinic _____ CODE |___|

Confidentiality and consent: "I'm going to ask you some personal questions.. Your answers are completely confidential. Your name will not be written on this form, and will never be used in connection with any of the information you tell me. You do not have to answer any questions that you do not want to answer, and you may end this interview at any time you want to. However, your honest answers to these questions will help us better understand what people think, say and do about certain kinds of behaviors. We would greatly appreciate your help in responding to this survey. The survey will take about 30 minutes to ask the questions. Would you be willing to participate?"

_____

(Signature of interviewer certifying that informed consent has been given verbally by respondent)

1. Date	
2. Name of Interviewer	
3. Type of Interviewee	1. Women infected with HIV 2. Women affected by HIV/AIDS
4. Result code	1. Completed 2. Partially completed 3. Other

CHECKED BY SUPERVISOR: Signature _____ Date _____

THE QUESTIONNAIRE ON WOMEN INFECTED AND AFFECTEDBY HIV/AIDS IN SRI LANKA - 2014

Section 1: – Socio-demographic data

No.	Questions and filters	CODING CATEGORIES	Skip to
Q101	**TYPE OF THE RESPONDENT**	**INFECETED 1** **AFFECTED 2**	
Q102	In what month and year were you born?	dd/mm/yyyy --/--/----	
Q103	How old were you at your last birthday?	AGE IN COMPLETED YEARS [__|__] DON'T KNOW 98 *NO RESPONSE 99*	
Q104	To which ethnic group do you belong?	SINHALA 1 TAMIL 2 MUSLIM 3 BURGHER 4 OTHERS 5 MIXED ETHNICITY 6 NO RESPONSE 99	
Q105	What religion are you?	BUDDHIST 1 HINDU 2 ISLAM 3 CHRISTIANISM 4 ROMAN CATHOLIC 5 OTHERS 6 NO RELIGION 7 DON'T KNOW 88 NO RESPONSE 99	
Q106	What is you civil status?	MARRIED 1 SINGLE 2 DIVORCED /SEPARATED 3 WIDOW 4 LIVING TOGETHER 5 OTHERS 6 NO RESPONSE 99	
Q107	With whom do you currently live with (for the past 6 months)?	PARTNER/SPOUSE 1 FAMILY OR RELATIVE 2 FRIENDS 3 ALONE 4 PLHIV SUPPORT GROUPS 5 ……OTHER 6 NO RESPONSE 99	

Q108	What is your district of permanent residence? ----------	DISTRICT CODE -----	
Q109	What is the district of your residence during last 1 year? ----------	DISTRICT CODE -----	

THE QUESTIONNAIRE ON WOMEN INFECTED AND AFFECTED BY HIV/AIDS IN SRI LANKA – 2014

Section 1: – Socio-demographic data *(continued)*

No.	Questions and filters	Coding categories	Skip to
Q110	What is the highest level of education you completed? ----------	Grade 1-5 1 Grade 6-9 2 GCE OL 3 GCE AL 4 DIPLOMA OR HIGHER 5 OTHER 6 NOT ATTENDED SCHOOL 7 NO RESPONSE 99	
Q111	Can you read or write?	YES 1 NO 2 NO RESPONSE 99	

THE QUESTIONNAIRE ON WOMEN INFECTED AND AFFECTEDBY HIV/AIDS IN SRI LANKA – 2014

Section 2: – Socio-economic data

No.	Questions and filters	CODING CATEGORIES	Skip to
Q201	What is your current employment status?	STUDENT 1 HOUSE WIFE 2 SELF-EMPLOYED 3 COMMERCIAL SEX 4 GOVERNMENT SECTOR 5 PRIVATE SECTOR 6 RETIRED 7 UNSKILLED LABOURER 8 UNEMPLOYED 9 ……OTHERS 10 NO RESPONSE 99	
Q202	What is your monthly average income in rupees? LKR ----------	<5,000 1 5-9,000 2 10-19,000 3 20-49,000 4 ≥50,0000 5 NO INCOME 6 NO RESPONSE 9	→**Q 204**
Q203	What is your main source of income ----------	EMPLOYMENT 1 ……OTHER 2	
Q204	What is your monthly average income of your family in rupees? LKR ----------	<5,000 1 5-9,000 2 10-19,000 3 20-49,000 4 ≥50,000 5 NO RESPONSE 99	
Q205	What is your main source of income of your family? ----------	EMPLOYMENT 1 Specify……OTHER 2	
Q206	Is there any reduction of income as a result of your HIV infection or being affected by HIV?	YES 1 NO 2 NO RESPONSE 99	
Q207	Do you have to spend more as a result of your HIV infection or being affected by HIV?	YES 1 NO 2 NO RESPONSE 99	
Q208	Are you getting any financial assistance for medicine or investigations related to HIV in last 6 months?	YES 1 NO 2 DO NOT KNOW 88 NO RESPONSE 99	
Q209	What is your monthly expenditure for healthcare services? LKR ----------	NONE 1 < 1000 2 ≥ 1 000 3 NO RESPONSE 99	

THE QUESTIONNAIRE ON WOMEN INFECTED AND AFFECTEDBY HIV/AIDS IN SRI LANKA – 2014

Section 2: – Socio-economic data (continuation)

No.	Questions and filters	Coding categories	Skip to
Q210	Were you compelled to take a loan for HIV related issue following the HIV diagnosis of you or your family member?	YES 1 NO 2 NO RESPONSE 99	
Q211	Did you have to sell your assets following your HIV diagnosis or being affected by HIV?	YES 1 NO 2 NO RESPONSE 99	
Q212	What is the monthly expenditure of your family for foods? LKR ----------	< 5,000 1 ≥ 5, 000 2	
Q213	What is the monthly expenditure for education? LKR ----------	NONE 1 < 5,000 2 ≥ 5, 000 3 NO RESPONSE 99	
Q214	What is the main mode of transport of your family?	PRIVATE 1 PUBLIC 2 OTHERS 3 NO RESPONSE 99	
Q215	Do you have to expend more for transportation as a result of your HIV infection or being affected by HIV? E.g.; For frequent visits to health centers?	YES 1 NO 2 NO RESPONSE 99	
Q216	What is your monthly expenditure for transportation for attending healthcare? LKR ----------	< 5,000 1 ≥ 5, 000 2 NO RESPONSE 99	
Q217	Do you get any financial assistance for transport to the Healthcare facility?	YES 1 NO 2 NO RESPONSE 99	

THE QUESTIONNAIRE ON WOMEN INFECTED AND AFFECTEDBY HIV/AIDS IN SRI LANKA – 2014

Section 3: – Accessibility to Healthcare services

No.	Questions and filters	CODING CATEGORIES	Skip to
Q301	Are you currently using a modern family planning method?	YES 1 NO 2 NO RESPONSE 99	→**Q 304**
Q302	What is the family planning method?	ORAL PILLS 1 CONDOMS 2 IUCD 3 IMPLANTS 4 LRT 5 ……OTHER 6 NO RESPONSE 99	
Q303	From where do you get family planning method?	MOH CLINIC 1 GOVERNMENT HOSPITALS 2 PRIVATE HOSPITALS 3 GENERAL PRACTITIONER 4 IDH 5 NSACP 6 PERIPHERAL STD CLINIC 7 NO RESPONSE 99	
Q304	Which health facility do you usually visit for medical illness? (only one response)	MOH CLINIC 1 GOVERNMENT HOSPITALS 2 PRIVATE HOSPITALS 3 GENERAL PRACTITIONER 4 IDH 5 NSACP 6 PERIPHERAL STD CLINIC 7 NO RESPONSE 99	
Q305	**INFECTED WOMEN OR AFFECTED WOMEN?**	**INFECTED 1** **AFFECTED 2**	**→ Q 317**
Q306	What is the distance to the clinic you usually visit? ----------km	< 25 KM 1 ≥ 25 KM 2	
Q307	Is the facility visited by you the nearest one?	YES 1 NO 2 NO RESPONSE 99	→**Q 309**
Q308	If not, Why do you avoid the nearest health care facility?	FEAR OF BEING IDENTIFIED 1 DUE TO FELT STIGMA 2 STAFF IS UNFRIENDLY 3 NOT SATISFIED WITH THE QUALITY OF SERVICES PROVIDED 4 CANNOT TRUST THE WORKING STAFF 5 OTHER REASON 6 ---------- NO RESPONSE 99	

THE QUESTIONNAIRE ON WOMEN INFECTED AND AFFECTEDBY HIV/AIDS IN SRI LANKA – 2014

Section 3: – Accessibility to Healthcare services (continue)

No.	Questions and filters	CODING CATEGORIES	Skip to
Q309	How long do you normally have to wait to see the doctor after reaching the HIV clinic?	< 30 MINUTES 1 30 MINUTES TO 1 HOUR 2 > I HOUR 3 NO RESPONSE 99	
Q310	Are you happy with the facilities available within the waiting area?	YES 1 NO 2 NO RESPONSE 99	
Q311	During last visit how much did you have to spend for health services? (Medicine, investigation and transport) for you of person you cared for? LKR ----------	< 5,000 1 ≥ 5, 000 2	
Q312	How did you manage the cost in the last time that you had to pay?	ON MY OWN 1 SOUGHT SUPPORT FROM NGO 2 DID NOT BUY MEDICINES AT ALL 3 BOUGHT ONLY A PART Of MEDICINESPRESCRIBED 4 NO RESPONSE 99	
Q313	Are you satisfied with the available services?	NOT AT ALL 1 UNSATISFIED 2 NEITHER SATISFIED NOR UNSATISFIED 3 SATISFIED 4 VERY SATISFIED 5 NO RESPONSE 99	
Q314	Do you get enough time to discuss your medical problems at the health care facility?	YES 1 NO 2 NO RESPONSE 99	
Q315	Do you get enough time to discuss your social problems at the health care facility?	YES 1 NO 2 NO RESPONSE 99	
Q316	**INFECTED WOMEN OR AFFECTED WOMEN?**	**INFECTED 1** **AFFECTED 2**	**→ Q401**
Q317	Have you ever done an HIV test?	YES 1 NO 2 NO RESPONSE 9	
Q318	From where did you do your last test? ----------	MOH CLINIC 1 GOVERNMENT HOSPITALS 2 PRIVATE HOSPITALS/LABORATPRY 3 GENERAL PRACTITIONER 4 IDH 5 STD CLINIC 6 Other 7 NO RESPONSE 99	
Q3016	**INFECTED WOMEN OR AFFECTED WOMEN?**	**INFECTED 1** **AFFECTED 2**	**→ Q 405**

THE QUESTIONNAIRE ON WOMEN INFECTED AND AFFECTEDBY HIV/AIDS IN SRI LANKA – 2014

Section 4. Nutrition related data

No.	Questions and filters	CODING CATEGORIES	Skip to
Q401	Height in centimeters ----------	<150 1 ≥ 150 2	
Q402	Weight in Kg ----------	<50 1 ≥50 2	
Q403	BMI ----------	< 18 1 18-25 2 > 25 3	
Q404	Hemoglobin level ----------	<8 1 8-10 2 > 10 3	
Q405	What is the daily eating pattern of last 1 month?	< 3 MEALS 1 ≥ 3 MEALS 2 NO RESPONSE 99	
Q406	What is the main source of cooked food in the last 6 months?	PURCHASED FROM OUTSIDE 1 HOME COOKED 2 OTHER 3 NO RESPONSE 99	
Q407	How often do you consume protein rich (meat/fish/egg) food? (for the past 7 days)	DAILY 1 MORE THAN 3 TIMES A WEEK 2 LESS THAN 3 TIMES A WEEK 3 NEVER 4 NO RESPONSE99	
Q408	How often do you consume fruits?	DAILY 1 MORE THAN 3 TIMES A WEEK 2 LESS THAN 3 TIMES A WEEK 3 NEVER 4 NO RESPONSE 99	
Q409	How often do you consume vegetables?	DAILY 1 MORE THAN 3 TIMES A WEEK 2 LESS THAN 3 TIMES A WEEK 3 NEVER 4 NO RESPONSE 99	
Q410	Do you consume additional vitamin supplements currently?	YES 1 NO 2 NO RESPONSE 99	→**Q 412**
Q411	How often do you consume additional vitamin supplements for the last 6/12	DAILY 1 MORE THAN 3 TIMES A WEEK 2 LESS THAN 3 TIMES A WEEK 3 NEVER 4 NO RESPONSE 99	

Q412	Do you get any assistance for food at the moment?	YES RELATED TO HIV 1 YES NOT RELATED TO HIV 2 NO 3 NO RESPONSE 99	
Q413	**INFECTED WOMEN OR AFFECTED WOMEN?**	**INFECTED 1** **AFFECTED 2**	**→Q501**
Q413	Do you have any eating difficulties?	YES 1 NO 2 NO RESPONSE 99	

THE QUESTIONNAIRE ON WOMEN INFECTED AND AFFECTEDBY HIV/AIDS IN SRI LANKA – 2014

Section 5: – Psychosocial data

No.	Questions and filters	Coding categories	Skip to
Q501	In the last 12 months, have you been fearful of any of the following things happening to you?	YES NO NR 1.BEING GOSSIPED ABOUT 1 2 3 2.BEING VERBALLY INSULTED 1 2 3 3.BEING PHYSICALLY HARASSED 1 2 3 4.BEING PHYSICALLY ASSAULTED 1 2 3	
Q502	In the last 12 months, have you experienced any of the following feelings because of the HIV status?	YES NO NR 1. I FEEL ASHAMED 1 2 3 2. I FEEL GUILTY 1 2 3 3. I BLAME MYSELF 1 2 3 4. I BLAME OTHERS 1 2 3 5. I HAVE LOW SELF-ESTEEM 1 2 3 6.I FEEL I SHOULD BE PUNISHED 1 2 3 7. I FEEL SUICIDAL 1 2 3	
Q503	In the last 12 months, have you been excluded from social gatherings or activities?	YES 1 NO 2 No I DIDN'T DISCLOSE HIV STATUS 3 NO RESPONSE 99	
Q504	Have you ever experienced discrimination or stigma from,	YES NO ND 1.NEIGBOURS 1 2 3 2. FRIENDS 1 2 3 3. FAMILY MEMBERS 1 2 3 4. FROM HEALTH STAFF 1 2 3 5. CO-WORKERS 1 2 3 6. ANY OTHER 1 2 3	
Q 505 **INFECTED WOMEN OR AFFECTED WOMEN?**		**INFECTED 1**	

		AFFECTED 2	→ Q 601
Q506	In the last 12 months, have you ever been denied health services, because of your HIV status?	YES 1 NO 2 NO RESPONSE 99	

THE QUESTIONNAIRE ON WOMEN INFECTED AND AFFECTEDBY HIV/AIDS IN SRI LANKA – 2014

Section 5: – Psychosocial data *(continuation)*

No.	Questions and filters	Coding categories				Skip to
Q507	Feeling about support	DEFINITELY FALSE	PROBABLY FALSE	PROBABLY TRUE	DEFINITELY TRUE	
	1. I feel that there is no one in my family that I can share my most private worries and fears with.	1	2	3	4	
	2. If I were sick, I could easily find someone to help me with my daily chores	1	2	3	4	
	3. When I need suggestions on how to deal with a personal problem, I know someone I can turn to	1	2	3	4	
	4. If a family crisis arose, it would be difficult to find someone who could give me good advice about how to handle it.	1	2	3	4	

THE QUESTIONNAIRE ON WOMEN INFECTED AND AFFECTEDBY HIV/AIDS IN SRI LANKA – 2014

Section 6. The caring experiences

No.	Questions and filters	CODING CATEGORIES	Skip to
Q601	Are you caring for a HIV infected person?	YES 1 NO 2 NO RESPONSE 99	→Q 701
Q602	What type of a HIV infected person are you caring for?	CHILD 1 ADULT 2	
Q603	Have you ever experienced any burnout by caring for a HIV infected?	YES 1 NO 2 NO RESPONSE 99	

Q604	Have you ever been appreciated by anybody for being a caregiver for HIV infected?	YES 1 NO 2 NO RESPONSE 99	
Q605	Has anybody ever supported when you need a help to care for the HIV infected?	YES 1 NO 2 NO RESPONSE 99	

THE QUESTIONNAIRE ON WOMEN INFECTED AND AFFECTEDBY HIV/AIDS IN SRI LANKA – 2014
Section 7. Coping strategies

No.	Questions and filters	CODING CATEGORIES	Skip to
Q700	**INFECTED WOMEN OR AFFECTED WOMEN?**	**INFECTED 1** **AFFECTED 2**	**→ Q 704**
Q701	Have you disclosed your HIV status to anybody?	YES 1 NO 2 NO RESPONSE 9	**→ Q 703**
Q702	To whom have you disclosed?	SPOUSE 1 PARTNER 2 CHILDREN 3 PARENTS 4 SIBLING 5 OTHER RELATIVE 6 FRIENDS 7 OTHER 8 NO RESPONSE 99	
Q703	What was your response following diagnosis of HIV sero-status of yours?	ACCEPTED 1 COULD NOT ACCEPT 2 THOUGHT IT WAS A WRONG REPORT 3 FELT LIFE IS WORTHLESS 4 FELT NEUTRAL 5 OTHER RESPONSE 6 NO RESPONSE 99	
Q704	Did you face any difficulties in coping with your HIV result or HIV result of person you care for?	YES 1 NO 2 NO RESPONSE 99	
Q705	Did you have to send your children away to live with your relatives following the diagnosis of HIV sero-status?	YES 1 NO 2 NO RESPONSE 99	
Q706	Did you have to withdraw children from school once diagnosis was made?	YES 1 NO 2 NO RESPONSE 99	
Q707	How your sexual life got affected once the diagnosis was made?	COMPLETELY AVOIDED SEXUAL ACTIVITIES 1 CONTINUED WITHOUT ANY CHANGE 2 CONTINUED BUT IN REDUCED FREQUENCY 3 CONTINUED WITH CONDOMS 4 NO RESPONSE 99	

THE QUESTIONNAIRE ON WOMEN INFECTED AND AFFECTEDBY HIV/AIDS IN SRI LANKA – 2014

Section 8. Newly added questions for affected women

No.	Questions and filters	CODING CATEGORIES	Skip to
Q 800 INFECTED WOMEN OR AFFECTED WOMEN?		**INFECTED 1 AFFECTED 2**	**→ end Q**
Q 801	What is the relationship to the HIV infected person who introduced you to the study?	Spouse/Partner 1 Mother 2 Sister3 Daughter4 Aunt/Relative 5 Friend 6 Other Specify ……7 NO RESPONSE 99	
Q802	Do you usually visit HIV clinic with the person infected with HIV during last 6 months	YES 1 NO 2 NO RESPONSE 99	
Q803	Have you ever had the feeling of fear of contracting HIV while caring for the HIV infected person	YES 1 NO 2 NO RESPONSE 99	

That is the end of our questionnaire. Thank you very much for taking time to answer these questions. We appreciate your help.

Annex II: THE OUESTIONNAIRE ON CHILDREN INFECTED AND AFFECTED HIV

FOR USE WITH CAREGIVER OF CHILDREN LIVING WITH HIV OR AFFECTED BY HIV

001 QUESTIONNAIRE IDENTIFICATION NUMBER |___|___|___|

002 District _____ CODE |___|

003 Name of the HIV clinic _____ CODE |___|

Confidentiality and consent: "I'm going to ask you some personal questions regarding the child. Your answers are completely confidential. Your name will not be written on this form, and will never be used in connection with any of the information you tell me. You do not have to answer any questions that you do not want to answer, and you may end this interview at any time you want to. However, your honest answers to these questions will help us better understand what people think, say and do about certain kinds of behaviors. We would greatly appreciate your help in responding to this survey. The survey will take about 30 minutes to ask the questions. Would you be willing to participate?"

_____

(Signature of interviewer certifying that informed consent has been given verbally by

respondent)

1. Date	
2. Name of Interviewer	
3. Type of Interviewee	1. Child infected by HIV/AIDS 2. Child affected with HIV
4. Result code	1. Completed 2. Partially completed 3. Other

CHECKED BY SUPERVISOR: Signature _____ Date _____

THE QUESTIONNAIRE ON CHILDREN INFECTED AND AFFECTEDBY HIV/AIDS IN SRI LANKA – 2014

Section 1: – Socio-demographic data

No.	Questions and filters	CODING CATEGORIES	Skip to
Q101	TYPE OF THE RESPONDENT	INFECTED 1 AFFECTED 2	
Q102	SEX OF THE CHILD	MALE 1 FEMALE 2	
Q103	In what month and year was the child born?	MONTH [__ | __] DON'T KNOW MONTH 98 NO RESPONSE 99 YEAR [__ | __] DON'T KNOW YEAR 98 NO RESPONSE 99	
Q104	How old was the child at the last birthday?	AGE IN COMPLETED YEARS [__ | __] DON'T KNOW 98 *NO RESPONSE* 99	
Q105	What is the ethnic group?	SINHALA 1 TAMIL 2 MUSLIM 3 BURGER 4 OTHERS 5 MIXED ETHNICITY 6 NO RESPONSE 99	
Q106	What is the religion of the child?	BUDHISM 1 HINDUISM 2 ISLAM 3 CHRISTIANISM 4 ROMAN CATHOLIC 5 OTHERS 6 NO RELIGION 7 DON'T KNOW 88 NO RESPONSE 99	
Q107	With whom does the child currently live with (for the past 6 months)?	PARENTS 1 RELATIVE 2 CHILDREN'S HOME 3 PLHIV SUPPORT GROUPS 4 OTHER 5 NO RESPONSE 99	
Q108	What is your district of permanent residence? ----------	DISTRICT CODE -----	
Q109	What is the district of your residence during last 1 year? ----------	DISTRICT CODE -----	

THE QUESTIONNAIRE ON CHILDREN INFECTED AND AFFECTEDBY HIV/AIDS IN SRI LANKA – 2014

Section 1: – Socio-demographic data (continued)

No.	Questions and filters	CODING CATEGORIES	Skip to
Q110	**IS THE CHILD OLDER THAN 5 YEAR?**	**YES 1** **NO 2**	**→Q116**
Q111	Has the child ever attended school?	YES 1 NO 2 NO RESPONSE 99	**→ Q124**
Q112	Is the child currently attending school?	YES 1 NO 2 NO RESPONSE 99	
Q113	How many total years of education has the child completed up to now?	# YEARS COMPLETED [__ | __] NO RESPONSE 99	
Q114	What is the highest level of school completed: primary, secondary or higher?	PRIMARY 1 SECONDARY 2 HIGHER 3 NO RESPONSE 99	
Q115	If not attending school what are the reasons for non-attendance?	DUE TO ILLNESS 1 DUE TO ATTACHED STIGMA 2 CHILD IS ORPHANED AND DOES NOT HAVE ANY SUPPORT 3 OTHER 4 NO RESPONSE 99	
Q116	Did your child ever needed to change his/her school due to HIV status?	YES 1 NO 2 NO RESPONSE 99	
Q117	Did your child attend school > 80% of the days over the last one month?	YES 1 NO 2 NO RESPONSE 99	**→ Q119**
Q118	If no, what is the reason for non-attendance to school?	DUE TO ILLNESS 1 DUE TO FREQUENT CLINIC VISITS OR HOSPITALIZATIONS 2 DUE TO STIGMA & DISCRIMINATION 3 DUE TO FINANCIAL CONSTRAINTS 4 ANY OTHER REASON 5 NO RESPONSE 99	
Q119	Is your child's school performance adversely affected by HIV diagnosis?	YES 1 NO 2 NO RESPONSE 99	**→ Q121**

THE QUESTIONNAIRE ON CHILDREN INFECTED AND AFFECTEDBY HIV/AIDS IN SRI LANKA – 2014

Section 1: – Socio-demographic data (continued)

No.	Questions and filters	CODING CATEGORIES	Skip to
Q120	If your child's school performance was affected by HIV diagnosis, what do you think as the most likely reason?	ILLNESS 1 PSYCHOLOGICAL REASONS 2 ABSENTEEISM 3 DUE TO PROBLEMS IN THE CARE GIVERS/PARENTS 4 DUE TO FREQUENT CLINIC VISITS OR HOSPITALIZATIONS 5 DUE TO STIGMA & DISCRIMINATION 6 ANY OTHER REASON 7 NO RESPONSE 99	
Q121	Is anyone in the school aware of child's HIV status?	YES 1 NO 2 NO RESPONSE 99	
Q122	Does your child get involved in extracurricular activities?	YES 1 NO 2 NO RESPONSE 99	→ **Q124**
Q123	If not what are the reasons?	DUE TO ILLNESS 1 DUE TO FREQUENT CLINIC VISITS OR HOSPITALIZATIONS 2 DUE TO STIGMA & DISCRIMINATION 3 DUE TO FINANCIAL CONSTRAINTS 4 ANY OTHER REASON 5 NO RESPONSE 99	
Q124	Can the child read or write?	YES 1 NO 2 NO RESPONSE 99	

THE QUESTIONNAIRE ON CHILDREN INFECTED AND AFFECTEDBY HIV/AIDS IN SRI LANKA – 2014

***Section 2:* – Socio-economic data**

No.	Questions and filters	CODING CATEGORIES	Skip to
Q201	Are you currently employed (Care giver /respondent)	YES 1 NO 2 NO RESPONSE 99	→ **Q203**
Q202	What is your current employment status (Care giver /respondent)	STUDENT 1 HOUSE WIFE 2 SELF-EMPLOYED 3 COMMERCIAL SEX 4 GOVERNMENT SECTOR 5 PRIVATE SECTOR 6 RETIRED 7 UNSKILLED LABOURER 8 UNEMPLOYED 9 OTHERS 10 NO RESPONSE 99	
Q203	What is your family monthly average income in rupees? LKR ----------	<5,000 1 5-10,000 2 10-20,000 3 20-50,000 4 >50,0000 5 NO RESPONSE 99	
Q204	Do you have to spend more as a result of child's HIV infection?	YES 1 NO 2 NO RESPONSE 99	
Q205	Are you getting any financial assistance for child's healthcare?	YES 1 NO 2 DO NOT KNOW 8 NO RESPONSE 99	
Q206	What is your monthly expenditure for getting child's healthcare services? LKR ----------	<5000 1 ≥ 5000 2	

THE QUESTIONNAIRE ON CHILDREN INFECTED AND AFFECTEDBY HIV/AIDS IN SRI LANKA – 2014

Section 2: – Socio-economic data (continuation)

No.	Questions and filters	Coding categories	Skip to
Q207	What is the monthly expenditure of your family for foods? LKR ----------	< 5,000 1 ≥ 5, 000 2	
Q208	What is the monthly expenditure for schooling? LKR ----------	< 5,000 1 ≥ 5, 000 2	
Q209	Do you have to expend more for transportation as a result of infection? E.g.; For frequent visits to health centers?	YES 1 NO 2 NO RESPONSE 99	
Q210	What is your monthly expenditure for transportation? LKR ----------	< 5,000 1 ≥ 5, 000 2	

THE QUESTIONNAIRE ON CHILDREN INFECTED AND AFFECTEDBY HIV/AIDS IN SRI LANKA – 2014

Section 3: – Accessibility to Healthcare services

No.	Questions and filters	CODING CATEGORIES	Skip to
Q301	Which health facility do you usually visit for medical illnesses of the child? (only one response)	MOH CLINIC 1 GOVERNMENT HOSPITALS 2 PRIVATE HOSPITALS 3 GENERAL PRACTITIONER 4 TRADITIONAL MEDICAL PRACTITIONER 5 IDH 6 NSACP 7 PERIPHERAL STD CLINIC 8 NO RESPONSE 99	
Q302	What is the distance to the clinic? ----------km	< 25 KM 1 ≥ 25 KM 2	
Q303	Is the facility visited by you the nearest one?	YES 1 NO 2 NO RESPONSE 99	→ **Q305**
Q304	If not, Why did you avoid the nearest health care facility?	FEAR OF BEING IDENTIFIED 1 DUE TO FELT STIGMA 2 STAFF IS UNFRIENDLY 3 NOT SATISFIED WITH THE QUALITY OF SERVICES PROVIDED 4 CANNOT TRUST THE WORKING STAFF 5 OTHER REASON 6 NO RESPONSE 99	
Q305	How long do you normally have to wait to see the doctor after reaching the HIV clinic?	< 30 MINUTES 1 30 MINUTES TO 1 HOUR 2 > I HOUR 3 NO RESPONSE 99	
Q306	Are you happy with the facilities available within the waiting area?	YES 1 NO 2 NO RESPONSE 99	
Q307	During last visit how much did you have to spend for health services? LKR----------	< 5,000 1 ≥ 5, 000 2 NO RESPONSE 99	
Q308	How did you manage the cost in the last time that you had to pay?	ON MY OWN 1 SOUGHT SUPPORT FROM NGO 2 DID NOT BUY MEDICINES AT ALL 3 BOUGHT ONLY A PART OF MEDICINES 4 PRESCRIBED 5 NO RESPONSE 99	

THE QUESTIONNAIRE ON CHILDREN INFECTED AND AFFECTEDBY HIV/AIDS IN SRI LANKA – 2014

Section 3: – Accessibility to Healthcare services (continue)

No.	Questions and filters	CODING CATEGORIES	**Skip to**
Q309	Are you satisfied with the available services?	NOT AT ALL 1 UNSATISFIED 2 NEITHER SATISFIED NOR UNSATISFIED 3 SATISFIED 4 VERY SATISFIED 5 NO RESPONSE 99	
Q310	Do you get enough time to discuss your child's medical problems at the health care facility?	YES 1 NO 2 NO RESPONSE 99	
Q311	Do you get enough time to discuss child's social problems at the health care facility?	YES 1 NO 2 NO RESPONSE 99	
Q311.1	**INFECTED CHILD OR AFFECTED CHILD?**	**INFECTED 1** **AFFECTED 2**	**→ Q401**
Q312	Has the child ever tested for HIV?	YES 1 NO 2 NO RESPONSE 99	**→ Q401**
Q313	From where was it done?	MOH CLINIC 1 GOVERNMENT HOSPITALS 2 PRIVATE HOSPITALS 3 GENERAL PRACTITIONER 4 TRADITIONAL MEDICAL PRACTITIONER 5 IDH 6 NSACP 7 PERIPHERAL STD CLINIC 8 NO RESPONSE 99	

THE QUESTIONNAIRE ON CHILDREN INFECTED AND AFFECTEDBY HIV/AIDS IN SRI LANKA – 2014

Section 4. Nutrition related data

No.	Questions and filters	CODING CATEGORIES	Skip to
Q401	Height in centimeters ----------	<150 1 ≥ 150 2	
Q402	Weight in Kg ----------	<50 1 ≥50 2	
Q403	BMI ----------	< 18 1 18-25 2 > 25 3	
Q404	Hemoglobin level ----------	<8 1 8-10 2 > 10 3	
Q405	What is the daily eating pattern of last 1 month?	< 3 MEALS 1 ≥ 3 MEALS 2	
Q406	What is the main source of cooked food in the last 6 months?	PURCHASED FROM OUTSIDE 1 HOME COOKED 2 OTHER 88	
Q407	How often does the child consume protein rich (meat/fish/egg) food? (for the past 7 days)	DAILY 1 MORE THAN 3 TIMES A WEEK 2 LESS THAN 3 TIMES A WEEK 3 NEVER 4	
Q408	How often does the child consume fruits?	DAILY 1 MORE THAN 3 TIMES A WEEK 2 LESS THAN 3 TIMES A WEEK 3 NEVER 4	
Q409	How often does the child consume vegetables?	DAILY 1 MORE THAN 3 TIMES A WEEK 2 LESS THAN 3 TIMES A WEEK 3 NEVER 4	
Q410	Does the child consume additional vitamin supplements currently?	YES 1 NO 2 NO RESPONSE 99	
Q411	How often does the child consume additional vitamin supplements for the last 3/12	DAILY 1 MORE THAN 3 TIMES A WEEK 2 LESS THAN 3 TIMES A WEEK 3 NEVER 4 NO RESPONSE 99	
Q412	Do you get any assistance for food at the moment?	YES 1 NO 2 NO RESPONSE 99	
Q412.1	**INFECTED OR AFFECTED CHILD?**	**INFECTED 1** **AFFECTED 2**	**→ Q501**
Q413	Does your child have any eating difficulties?	YES 1 NO 2 NO RESPONSE 99	

THE QUESTIONNAIRE ON CHILDREN INFECTED AND AFFECTEDBY HIV/AIDS IN SRI LANKA – 2014

Section 5: – Psychosocial data

No.	Questions and filters	Coding categories	Skip to
Q501	In the last 12 months, have you been fearful of any of the following things happening to your child due to HIV status	YES NO 1.BEING GOSSIPED ABOUT 1 2 2.BEING VERBALLY INSULTED 1 2 3.BEING PHYSICALLY HARASSED 1 2 4.BEING PHYSICALLY ASSAULTED 1 2	
Q502	In the last 12 months, have you experienced any of the following feelings because of the HIV status of your child?	YES NO 1. I FEEL ASHAMED 1 2 2. I FEEL GUILTY 1 2 3. I BLAME MYSELF 1 2 4. I BLAME OTHERS 1 2 5. I HAVE LOW SELF-ESTEEM 1 2 6. I FEEL I SHOULD BE PUNISHED 1 2 7. I FEEL SUICIDAL 1 2	
Q503	In the last 12 months, has your child been excluded from social gatherings or activities?	YES 1 NO 2 NO RESPONSE 9	
Q504	Has your child ever experienced discrimination or stigma from,	YES NO 1.Neigbours 1 2 2. Friends 1 2 3. Family members 1 2 4. From health staff 1 2 5. Any other 1 2	
INFECTED WOMEN OR AFFECTED WOMEN?		**INFECTED 1** **AFFECTED 2**	**→ End**
Q505	In the last 12 months, has your child ever been denied health services, because of your HIV status?	YES 1 NO 2 NO RESPONSE 99	

THE QUESTIONNAIRE ON CHILDREN INFECTED AND AFFECTEDBY HIV/AIDS IN SRI LANKA – 2014

Section 6. The caring experiences

No.	Questions and filters	Coding categories	Skip to
Q601	Have you ever experienced any burnout by caring for a HIV infected child?	YES 1 NO 2 NO RESPONSE 99	
Q602	Have you ever been appreciated by anybody for being a caregiver for HIV infected child?	YES 1 NO 2 NO RESPONSE 99	
Q603	Has anybody ever supported when you need a help to care for the HIV infected child?	YES 1 NO 2 NO RESPONSE 99	

Section 7. Coping strategies

No.	Questions and filters	CODING CATEGORIES	Skip to
Q701	Have you disclosed your child's HIV status to the child?	YES 1 NO 2 NO RESPONSE 99	
Q702	To whom you have disclosed child's HIV status? (More than one answer possible)	SPOUSE 1 PARTNER 2 CHILDREN 3 PARENTS 4 SIBLING 5 OTHER RELATIVE 6 FRIENDS 7 OTHER 88	
Q703	What was your response following diagnosis of HIV sero-status of your child?	ACCEPTED 1 COULD NOT ACCEPT 2 THOUGHT IT WAS A WRONG REPORT 3 FELT LIFE WORTHLESS 4 FELT NEUTRAL 5 OTHER 88	
Q704	Did you face any difficulties in coping with your child's HIV results?	YES 1 NO 2 NO RESPONSE 99	
Q705	Did you have to send your children away to live with your relatives following the diagnosis of child's HIV sero-status?	YES 1 NO 2 NO RESPONSE 99	
Q706	Did you have to withdraw children from school once diagnosis of the child was made?	YES 1 NO 2 NO RESPONSE 99	

That is the end of our questionnaire. Thank you very much for taking time to answer these questions. We appreciate your help.

Annex III: Clinical check list for Children infected with HIV

A	Data extracted by				
1	Name of the ART clinic	Clinic Code:			
2	Link number to the questionnaire				
3	Master number				
4	Date of Data collection (dd/mm/yyyy)				
5	Date of registration in the clinic (dd/mm/yyyy)				
6	Date of Birth (dd/mm/yyyy)				
7	Current age				
8	Sex ***(In cases of males, fill this checklist only for children less than 15 years old)*** *i. Male* *ii. Female* *iii. Other*				
9	WHO staging at first visit ***(Circle only one response)*** *i. WHO stage I* *ii. WHO stage II* *iii. WHO stage III* *iv. WHO stage IV* *v. Not known*				
10	Performance at first visit ***(Circle only one response)*** *i. Normal activity* *ii. Bed ridden < 50% of the day last month* *iii. Bed ridden ≥ 50% of the day last month* *iv. Other*				
11	Reason for attendance ***(Can circle more than one response)*** *i. Voluntary - STI screening* *ii. TB* *iii. Outpatient* *iv. Inpatient* *v. Paediatric* *vi. PMTCT* *vii. VCT - STI screening asymptomatic* *viii. Private* *ix. NGO* *x. Self-referred-with HIV + diagnosis* *xi. IDU outreach* *xii. CSW outreach* *xiii. Visa screening local* *xiv. HIV screening foreign* *xv. Contact* *xvi. Blood donor* *xvii. Others*				
12	Date of the HIV diagnosis made (dd/mm/yyyy)				

13	WHO staging at the last visit ***(Circle only one response)*** *i. WHO stage I* *ii. WHO stage II* *iii. WHO stage III* *iv. WHO stage IV* v. *Not known*	
14	Performance at the last visit ***(Circle only one response)*** *i. Normal activity* *ii. Bed ridden < 50% of the day last month* *iii. Bed ridden ≥ 50% of the day last month* iv. *Other*	
15	Outcome of the HIV care as at last visit ***(Circle only one response)*** *i. Improved quality of life* *ii. No improvement* *iii. Lost to follow up > 3 months* *iv. Transferred out* v. *Other*	
16	CD4 count /% at baseline i. _____ ii. __ % iii. Not available	
17	CD4 count /% at baseline last visit i. _____ ii. __ % iii. Not available	
18	Viral Load count at baseline i. _____ ii. Not available	
19	Viral Load at last visit i. _____ ii. Not available	
20	Currently on ART? *i. Yes* *ii. No* ***(If no, skip 21-28 questions)***	
21	Opportunistic infections before starting ART ***(Can circle more than one response)*** *i. TB* *ii. Candidiasis* *iii. Diarrhoea* *iv. Cryptococcal meningitis* *v. PCP* *vi. CMV* *vii. Herpes zoster* *viii. Genital herpes* *ix. Toxoplasmosis* *x. others*	

22	Eligibility criteria to start ART (details) ***(Can circle more than one response)***	
	i. WHO clinical stage *ii. CD4 count* iii. *Sero-discordant couple* *iv. TB* *v. MARP continuing risk behaviours* *v. Other*	
23	Date of ART initiation (dd/mm/yyyy)	
24	Current ART Regimen	Code:
25	Type of current ART Regimen ***(Circle only one response)***	
	i. First line ii. *Second line* *iii. Third line* *iv. Other*	
26	Performance when start ART ***(Circle only one response)***	
	i. Normal activity *ii. Bed ridden < 50% of the day last month* *iii. Bed ridden ≥ 50% of the day last month* iv. *Not known*	
27	Diagnosis of opportunistic infections during the one year period (After ART, exclude IRIS) ***(Can circle more than one response)***	
	i. TB *ii. Candidiasis* *iii. Diarrhoea* *iv. Cryptococcal meningitis* *v. PCP* *vi. CMV* *vii. Herpes zoster* *viii. Genital herpes* *ix. Toxoplsmosis* x. *Others* *xi. None*	
28	Adherence issues ***(Circle only one response)***	
	i. Satisfactory - missed < 3 doses last 30 days *ii. Unsatisfactory - missed > 3 -12 doses* *iii. Highly unsatisfactory - missed > 12 doses* iv. *Not known*	

Annex IV: In Depth Interview (IDI) Guide

Objectives	To assess the accessibility and availability of education and healthcare services to HIV affected children and women in Sri Lanka
Specific objectives	1. To assess the accessibility and availability of education for women and children affected by HIV/AIDS 2. To assess the accessibility and availability of healthcare services to women and children affected by HIV/AIDS (2.1. Morbidity and mortality related to HIV/AIDS, 2.2. Availability of VCT, STI, OI and ART services, 2.3. Knowledge and consumption of nutrients) 3. To assess the psycho-social problems and support services including coping strategies for affected families.
Study design	In Depth Interview
IDI participants need to be identified in different sectors	List of informants to be interviewed is annexed
Recruitment method of participants	Participatory consultative workshop will be held to identify IDI participants. These participants will be deliberately chosen as different as possible from each other.
Location	Convenient location to the participant and the interviewer
Interviewer	Person with good background knowledge on the subject being interviewed, will be selected
Recorder/Note taker/ Transcriber	One recorder/notes taker, backed up by audio recording
Materials	1. General interview guide (semi-structured) 2. Information sheet for participants 3. Audio recorder
Ethical considerations	Informed consent for the IDI will be taken verbally from the participants

formation sheet for participants

සහභාගී වන්නන් සඳහා තොරතුරු සැපයීම හා අනුමැතිය ලබාගැනීම

You are welcome to this in depth interview and thank you for the participation.

This Interview is conducted by the representative of the National STD/AIDS control programme in the Ministry of health. This activity is facilitated by the SAARC TB and HIV/AIDS centre, Nepal.

Main objective of today's meeting (Interview) is to assess the accessibility and availability of education and healthcare services to women and children affected by HIV/AIDS in Sri Lanka. In this interview you will be required to answer, discuss or give your opinions and perceptions in relation to certain questions upraised by the interviewer

Participation in this interview is voluntary. You can decline to participate or can refuse participating in a part of it. It is important for you to know that your participation or non-participation will not affect anything.

Information from this interview will be shared among stakeholders and scientific community but no names or identification of any person will be used in the report.

We hope that you will participate since your participation and views are highly valued and important for the planning services for HIV affected children and women in this country.

If you have any questions regarding this you can discuss with me before starting the interview.
At this time, do you want to ask me anything about the discussion?

If you agree; we can start the interview NOW

පළමුව ඔබ මෙම සාකච්ඡාවට සහභාගී වීම සම්බන්දයෙන් ස්තුති වන්ත වෙමි.

මෙම සාකච්ඡාව කරනු ලබන්නේ සෞඛ්‍ය අමාත්‍යාංශයේ ජාතික ලිංගාශ්‍රිත රෝග හා ඒඩ්ස් මර්දන වැඩසටහන මගිනි. මේ සඳහා පහසුකම් සපයනු ලබන්නේ නේපාලයේ පිහිටි සාක් කළාපයේ ක්ෂයරෝග හා එච්.අයි.වී./ඒඩ්ස් පිලිබඳ මධ්‍යස්ථානය මගිනි.

අද හමුවේ ප්‍රධාන අරමුණ වන්නේ ශ්‍රී ලංකාව තුල HIV/AIDS බලපෑමට ලක්වී ඇති ළමයින් හා කාන්තාවන් සඳහා ප්‍රමාණවත් අධ්‍යාපන හා සෞඛ්‍ය සේවා තිබේද යන්නත් ඒ සඳහා ඔවුනට ප්‍රවේශයක් තිබේද යන්නත් පිලිබඳ කරුණු සොයා බැලීමයි. මෙම සම්මුඛ සාකච්ඡාවේදී නගන ප්‍රශ්න පිලිබඳ සාකච්ඡා කිරීමට, පිළිතුරු සැපයීමට, හා අදහස් ඉදිරිපත් කිරීම ඔබගෙන් බලාපොරොත්තුවෙමි.

මෙය ස්වේච්ඡාවෙන් සහභාගී විය යුතු සාකච්ඡාවකි. මෙයට සහභාගී වීම නොවීම හෝ ප්‍රතික්ෂේප කිරීම හෝ මින් කොටසකට සහභාගී නොවී සිටීම හෝ ඔබට කළ හැක. මෙයට සහභාගී වීම හෝ නොවීම ඔබගේ කිසිදු කාර්යයකට බලපෑමක් ඇති නොකරයි.

මෙම සාකච්ඡාවේ තොරතුරු පාර්ශවකරුවන් හා විද්‍යාත්මක ප්‍රජාව හමුවේ බෙදා-හදා ගන්නා නමුත් එහිදී ඔබගේ කිසිදු හඳුනාගැනීමේ තොරතුරක් භාවිතා නොකෙරේ.

HIV/AIDS බලපෑමට ලක්වී ඇති ළමයින් හා කාන්තාවන් සඳහා සේවා සැලසුම් කිරීමේදී ඔබගේ අදහස් හා යෝජනා ඉතා වැදගත් වන බැවින්, ඔබ මේ සඳහා සහභාගී වේ යැයි අප බලාපොරොත්තු වෙමු.

ඔබට මේ සම්බන්දයෙන් කිසියම් දෙයක් සාකච්ඡා කිරීමට ඇත්නම් සම්මුඛ සාකච්ඡාව පටන්ගැනීමට ප්‍රථම අසා දැනගත හැකියි.

මේ සාකච්ඡාව ගැන කිසියම් දෙයක් ඔබට දැන් ඇසීමට ඇත්ද?

ඔබ මේ සඳහා අනුමැතිය ලබා දෙන්නේනම් අපට සාකච්ඡාව දැන් ආරම්භ කල හැකියි.

In depth interview guide
Situation assessment of women and children affected by HIV/AIDS

1. Assessment of accessibility and availability of education for women and children affected by HIV/AIDS

1.1 HIV බලපෑමට ලක්වූ දරුවන්ට/කාන්තාවන්ට පාසලක/වෙනත් ආයතනයක අධ්‍යාපනය ලැබීමට ඇති අවස්ථාව හෝ නැතහොත් ඉඩ-කඩ පිලිබඳ ඔබගේ අදහස කුමක්ද?
අධ්‍යාපනය සඳහා ඉඩ තිබේද? එසේම ඒවා සඳහා ප්‍රවේශ විය හැකිද?

1.2 HIV බලපෑමට ලක්වූ ළමයින්ට/කාන්තාවන්ට අධ්‍යාපනය ලබාදීමේදී අපේ රටේ ඇති හොඳ තත්වයන් හා දුරවල් තත්වයන් මොනවාද?

1.3 HIV බලපෑමට ලක්වූ ළමයින්ගේ/කාන්තාවන්ගේ සාමාන්‍ය අධ්‍යාපන මට්ටම පිලිබඳ ඔබගේ අදහස කුමක්ද?

2. Assessment of accessibility and availability of healthcare services to women and children affected by HIV/AIDS

A. Morbidity and mortality related to HIV/AIDS

2.1 ලංකාව තුල HIV අසාදිත දරුවන්ගේ හා කාන්තාවන්ගේ රෝගී තත්ත්වය හා ඔවුන් එයින් මියයාමේ තත්ත්වය පිලිබඳ ඔබේ අදහස කුමක්ද?

B. Availability and accessibility of HIV testing and counseling services (HTC)

2.2 ඔබට හිතෙන ආකාරයට HIV බලපෑමට ලක්වූ ළමයින්ට හා කාන්තාවන්ට, HIV පරීක්ෂණ හා උපදේශන සේවා තිබේද? එසේම ඒවා සඳහා ප්‍රවේශ විය හැකිද?
එම තිබෙන සේවාවන්හි ඇති හොඳ දේවල් හා දුර්වල තැන් මොනවාද?

C. Availability and accessibility of STI services

2.3 ඔබේ අදහසට අනුව HIV ආසාදනයට ලක්වූ ළමයින්ට හා කාන්තාවන්ට, ලිංගාශ්‍රිත රෝග සඳහා ප්‍රමාණවත් සේවා තිබේද? එසේම ඒවා සඳහා ප්‍රවේශ විය හැකිද?
එම සේවාවන්හි ඇති හොඳ දේවල් හා දුර්වල තැන් මොනවාද?

D. Availability and accessibility of ART services and management of opportunistic infections

2.4 ඔබේ අදහසට අනුව HIV ආසාදනයට ලක්වූ ළමයින්ට හා කාන්තාවන්ට, ART හා අවස්ථාවාදී අසාදන සඳහා ඇති ප්‍රතිකාර හා සේවා ප්‍රමාණවත් ලෙස තිබේද? එසේම ඒවා සඳහා ප්‍රවේශ විය හැකිද?
එම සේවාවන්හි ඇති හොඳ දේවල් හා නරක දේවල් නැතහොත් දුර්වල තැන් මොනවාද?

E. Knowledge and consumption of nutrients

2.5 ඔබේ අදහසට අනුව HIV බලපෑමට ලක්වූ ළමයින්ට හා කාන්තාවන්ට, පෝෂණය හා පෝෂණය ලබාගැනීම පිලිබඳ ඇති දැනුවත් භාවය මොන වගේද?

3. Assessment of psycho-social problems and support services including coping strategies for infected and affected families

3.1 HIV බලපෑමට ලක්වූ ළමයින්ට හා කාන්තාවන්ට මුහුණදීමට සිදුවන සාමාජීය හා මනෝ-සාමාජීය ගැටළු මොනවාද?
එම ගැටළු නිරාකරණය සඳහා ප්‍රමාණවත් සේවාවන් තිබේද? එසේම ඒ සඳහා ප්‍රවේශයන් තිමේද?

3.2 HIV බලපෑමට ලක්වූ ළමයින්ට හා කාන්තාවන් පවුල තුල, සමාජය තුල, හෝ සෞඛ්‍ය සේවා ආයතන වලදී කොන් කිරීමට හෝ වෙනස්කම් කිරීමට ලක්වීම පිලිබඳ ඔබගේ අදහස කුමක්ද?
දැනට මේ සම්බන්දව මොනවගේ තත්වයක් පවතීද?

In depth interview guide
Situation assessment of women and children affected by HIV/AIDS

1. Assessment of accessibility and availability of education for women and children affected by HIV/AIDS

1.1 What is your opinion about the education in school/institution for HIV affected children and women? Do you think that it is available and accessible to them?

1.2 What are the good things (strengths) and bad things (weaknesses) when providing education to HIV affected children and women?

1.3 What do you think about the level of education among HIV affected children and women?

2. Assessment of accessibility and availability of healthcare services to women and children affected by HIV/AIDS

A. Morbidity and mortality related to HIV/AIDS

2.1 According to your understanding, what is your opinion about the level of morbidity and mortality related to HIV/AIDS among HIV infected children and women?

B. Availability and accessibility of HIV testing and counseling services (HTC)

2.2 Do you think that the HIV testing and counseling services are available and accessible to HIV affected children and women?
What are the good things (strengths) and bad things (weaknesses) of HIV testing and counseling services available?

C. Availability and accessibility of STI services

2.3 In your opinion, do you think that the STI services are available and accessible to HIV infected children and women?
What are the strengths and weaknesses of the STI services available?

D. Availability and accessibility of ART services and management of opportunistic infections

2.4 According to your understanding, what do you think about the availability and accessibility of ART services and management of opportunistic infections for HIV infected women and children?
What are the strengths and weaknesses of treatments and services on ART and opportunistic infections

E. Knowledge and consumption of nutrients

2.5 Do you think that HIV affected children and women are well informed about the nutrition and consumption of nutrition?

3. Assessment of psycho-social problems and support services including coping strategies for infected and affected families

3.1 What are the social and psychological problems faced by HIV affected children and women?
Are the services available and accessible to solve their problems?

3.2 What do you think about stigma and discrimination in the family, community or in healthcare settings? What is the current situation?

Recording format – in depth interview
Situation assessment of women and children affected by HIV/AIDS

IDI title	Situation assessment of women and children affected by HIV/AIDS				
IDI identification					
General Description of the participant (context)					
Place/Site of IDI					
Date		**Start Time**		**End time**	
Interviewer					

Office use only

ආරම්භය:
මෙම හමුවේ දී අපි සාකච්ඡා කිරීමට බලාපොරොත්තු වන්නේ ශ්‍රී ලංකාවේ HIV/AIDS බලපෑමට ලක්වූ ළමුන් හා කාන්තාවන් පිළිබඳවයි.
මෙහිදී ඔවුන්ට අධ්‍යාපනය හා සෞඛ්‍ය සේවා නිසි අයුරින් තිබේද? එසේම ඒ සඳහා ඔවුන්ට ළඟාවිය හැකිද යන්න ගැන සාකච්ඡා කෙරේ.

(මෙහිදී HIV බලපෑමට ලක්වූ කාන්තාවන් හෝ ළමයින් යනු - HIV අසාදිත අය හා අසාදිත අය සමග එකම නිවසක වාසය කරන්නන් හෝ HIV අසාදිත අය රැකබලාගන්නා දෙමාපියන් හෝ භාරකරුවන් වේ)

1.1. What is your opinion about the education in school/institution for HIV affected children and women?
Do you think that it is available and accessible to them?

1.2. What are the good things (strengths) and bad things (weaknesses) when providing education to HIV affected children and women?

1.3. What do you think about the level of education among HIV affected children and women?

1.1. HIV බලපෑමට ලක්වූ දරුවන්ට/කාන්තාවන්ට පාසලක/වෙනත් ආයතනයක අධ්‍යාපනය ලැබීමට ඇති අවස්ථාව හෝ නැතහොත් ඉඩ-කඩ පිලිබඳ ඔබගේ අදහස කුමක්ද?
අධ්‍යාපනය සඳහා ඉඩ තිබේද? එසේම ඒවා සඳහා ප්‍රවේශ විය හැකිද?

1.2. HIV බලපෑමට ලක්වූ ළමයින්ට/කාන්තාවන්ට අධ්‍යාපනය ලබාදීමේදී අපේ රටේ ඇති හොඳ තත්වයන් හා දුරවල් තත්වයන් මොනවාද?

1.3. HIV බලපෑමට ලක්වූ ළමයින්ගේ/කාන්තාවන්ගේ සාමාන්‍ය අධ්‍යාපන මට්ටම පිලිබඳ ඔබගේ අදහස කුමක්ද?

Res ID		

General observation:

2.1. According to your understanding, what is your opinion about the level of morbidity and mortality related to HIV/AIDS among HIV infected children and women?

2.1. ලංකාව තුල HIV අසාදිත දරුවන්ගේ හා කාන්තාවන්ගේ රෝගී තත්ත්වය හා ඔවුන් එයින් මියයාමේ තත්ත්වය පිලිබඳ ඔබේ අදහස කුමක්ද?

Res ID	Response	

General observation:

2.2. Do you think that the HIV testing and counseling services are available and accessible to HIV affected Children and Women?
What are the good things (strengths) and bad things (weaknesses) of HIV testing and counseling services available?

2.2. ඔබට හිතෙන ආකාරයට HIV බලපෑමට ලක්වූ ළමයින්ට හා කාන්තාවන්ට, HIV පරීක්ෂණ හා උපදේශන සේවා තිබේද? එසේම ඒවා සඳහා ප්‍රවේශ විය හැකිද?

එම තිබෙන සේවාවන්හි ඇති හොඳ දේවල් හා දුර්වල කැන් මොනවාද?

Res ID	Response	

General observation:

2.3. In your opinion, do you think that the STI services are available and accessible to HIV infected children and women?
What are the strengths and weaknesses of the STI services available?

2.3. ඔබේ අදහසට අනුව HIV ආසාදනයට ලක්වූ ළමයින්ට හා කාන්තාවන්ට, ලිංගාශ්‍රිත රෝග සඳහා ප්‍රමාණවත් සේවා තිබේද? එසේම ඒවා සඳහා ප්‍රවේශ විය හැකිද?
එම සේවාවන්හි ඇති හොඳ දේවල් හා දුර්වල තැන් මොනවාද?

Res ID	Response	

General observation:

2.4. According to your understanding, what do you think about the availability and accessibility of ART services and management of opportunistic infections for HIV infected women and children?
What are the strengths and weaknesses of treatments and services on ART and opportunistic infections

2.4. ඔබේ අදහසට අනුව HIV ආසාදනයට ලක්වූ ළමයින්ට හා කාන්තාවන්ට, ART හා අවස්ථාවාදී අසාදන සඳහා ඇති ප්‍රතිකාර හා සේවා තිබේද? එසේම ඒවා සඳහා ප්‍රවේශ විය හැකිද?

එම සේවාවන්හි ඇති හොඳ දේවල් හා නරක දේවල් නැතහොත් දුර්වල තැන් මොනවාද?

Res ID	Response	

General observation

:

2.5. Do you think that HIV affected children and women are well informed about the nutrition and consumption of nutrition?
2.5. ඔබේ අදහසට අනුව HIV බලපෑමට ලක්වූ ළමයින්ට හා කාන්තාවන්ට, පෝෂණය හා පෝෂණය ලබාගැනීම පිලිබඳ ඇති දැනුවත් භාවය මොන වගේද?

Res ID	Response	

General observation:

3.1. What are the social and psychological problems faced by HIV affected children and women?
Are the services available and accessible to solve their problems?

3.1. HIV බලපෑමට ලක්වූ ළමයින්ට හා කාන්තාවන්ට මුහුණදීමට සිදුවන සාමාජිය හා මනෝ-සාමාජිය ගැටළු මොනවාද?

එම ගැටළු නිරාකරණය සඳහා ප්‍රමාණවත් සේවාවන් තිබේද? එසේම ඒ සඳහා ප්‍රවේශයන් තිබේද?

Res ID	Response	

General observation:

3.2. What do you think about stigma and discrimination in the family, community or in healthcare settings?

3.2. HIV බලපෑමට ලක්වූ ළමයින්ට හා කාන්තාවන්ට පවුල තුල, සමාජය තුල, හෝ සෞඛ්‍ය සේවා ආයතන වලදී කොන් කිරීමට හෝ වෙනස්කම් කිරීමට ලක්වීම පිලිබඳ ඔබගේ අදහස කුමක්ද?
දැනට මේ සම්බන්දව මොනවගේ තත්වයක් පවතීද?

Res ID	Response	

General observation:

Now I will read out the important facts you brought up in the discussion for your final approval.

This is the end of the discussion, on behalf of the national STD/AIDS control programme, ministry of health; we thank you for your valuable time and corporation given to this interview.

මම දැන් ඔබ විසින් මේ සාකච්ඡාවේදී ගෙනහැර දක්වන ලද වැදගත් කාරණා නැවත වරක් කියවන්නෙමි. ඒ සඳහා ඔබගේ එකඟත්වය හා අනුමැතිය බලාපොරොත්තු වෙමි.

සාකච්ඡාව මින් අවසන් වන අතර, ඔබ මේ වෙනුවෙන් වැය කළ කාලයට හා ඔබ දැක්වූ සහයෝගයට සෞඛ්‍ය අමාත්‍යාංශයේ, ජාතික ලිංගාශ්‍රිත රෝග හා ඒඩ්ස් මර්දන වැඩසටහන වෙනුවෙන්. අප ස්තුති වන්නෙමු.