



European Union



Mid-term Review

of the Integrated Care and Prevention
Project (ICP) Regarding People Living with
HIV (PLHIV) and
Orphans and Vulnerable Children (OVC)

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Disclaimer

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Table of Contents

EXECUTIVE SUMMARY	5
I. Introduction	7
1. Background	7
2. Rationale	7
II. Study objectives	8
III. Methods	9
1. Sites and target groups	9
2. Sample sizes and sampling approach	9
3. Questionnaire development.....	10
4. FGD and in-depth interviews (Qualitative component)	10
5. Training the data collection team	12
6. Data collection	12
7. Data entry and analysis.....	13
8. Ethical considerations.....	13
IV. Results	14
1. Qualitative results.....	14
1.1. Socio-demographic characteristics of OVC and PLHIV	14
1.2. Education and related support for OVC	15
1.3. Their living and family conditions	17
1.4. Health conditions and nutritional issues	18
1.5. Community and NGO support.....	19
1.6. Work and income of PLHIV	22
1.7. Health condition, HIV/AIDS status and the use of ART	24
1.8. The worrisome (Concerns of PLHIV) and community support.....	26
1.9. Satisfaction of HIV care services among PLHIV and OVC.....	28
2. Quantitative results.....	32
2.1. Program implementation	32
2.2. Level of satisfaction with the implemented programs.....	43
2.3. Impact on the quality of life of target groups.....	45
2.4. Lessons learned	46
V. Conclusions	48
VI. Recommendations	49
VII. References	51

List of Tables

Table 1 : Samples and groups collected in qualitative component.....	11
Table 2 : Samples collected from each province.....	14
Table 3 : Socio-demographic Characteristics of OVC and PLHIV.....	15
Table 4 : Schooling Conditions and Support for OVC.....	16
Table 5 : OVC Living and Family Conditions.....	18
Table 6 : Mental Health and Nutrition.....	19
Table 7 : Community and NGO Support.....	21
Table 8 : Work and income of PLHIV.....	23
Table 9 : HIV/AIDS status, health condition and the use of ART.....	25
Table 10 : The worrisome (The Concerns of PLHIV) and community support.....	27
Table 11 : Satisfaction with home-based care and self-support groups.....	29
Table 12 : Satisfaction with HIV/AIDS related health education.....	30
Table 13 : Satisfaction with HIV/AIDS related care and treatment services.....	31
Table 14 : Summary of FGD and IDI by province.....	32

List of Figures

Figure 1 : Organizations and People Supporting OVC and their Families.....	20
Figure 2 : Persons or NGOs supports PLHIV in the past 6 months.....	28
Figure 3 : Overall satisfaction scores with HIV-related care services.....	31
Figure 4 : Summary of comprehensive care for PLHIV/OVC.....	33
Figure 5 : Activities conducted by KHANA and partners to support PLHIV/ OVC*.....	34

EXECUTIVE SUMMARY

With funding support from the European Commission (EC), the ICP project has been implemented since 2007 in Prey Veng, Kampong Chhnang, and Kampong Speu provinces. The project consists of home-based care (HBC); facilitation of access to care and treatment; provision of socio-economic support to PLHIV, OVC and their families; and stigma and discrimination reduction faced by PLHIV and OVC. Reviewing and documenting the mid-term project, relating to all relevant information regarding project implementation, is crucial in order to monitor progress and provide feedback to the project planner and implementer, so that revised interventions and better project implementation can be made.

A quantitative method was used to identify and determine the magnitude of a number of main, project indicators, while a qualitative approach was used to explore and get a greater insight into issues and challenges faced over the course of the project's implementation. A total of 194 OVC and 193 PLHIV were randomly selected for face-to-face interviews in September 2009. Moreover, about 8 focus group discussions and 18 in-depth interviews with different key informants were conducted, ranging from PLHIV to OVC; foster families; as well as from health center staff to project staff.

Results from quantitative and qualitative methods are highly consistent and complementary with each other, indicating good achievements over the project implementation period to date. Some key findings are highlighted as follows:

Orphans and vulnerable Children

- About 84% of OVC are currently in schools. However, about 60% of those in school had reported suspending their study at some point in order to earn extra income for their family.
- 95% of OVC got support from KHANA and its partners, including: clothes, school materials and medical care.
- 36% of OVC lived with grandparents who were head of the household and the main caretakers.
- Close to 95% of them were visited by the home-based care team.
- The level of discrimination toward OVC had declined substantially over the past year.
- Overall satisfaction with the ICP services provided by the project was high. No negative feelings regarding OVC support were reported from the OVC, their families, and service providers.



People living with HIV/AIDS

- 70% of PLHIV were women. Close to 15% of them ever sold their farms rice-fields or houses in which their money from selling their properties were spent mostly on food, clothes, medical care and repayment of the debt. About 95% of PLHIV reported getting supports from KHANA and its partners.
- More than 95% of PLHIV disclosed their HIV status to their spouses.
- 83% of PLHIV were on ART. Some misunderstanding about taking ART still existed.
- Their main concern was the lack of money to spend on food (57.5%) and health care (53.4%).
- 75% of the PLHIV reported a decline in level of discrimination in their community.
- PLHIV reported high satisfaction with the overall ICP services. No negative feelings were reported regarding this service from the PLHIV.

Key Recommendations

- The project should work with OVC, their families, schools and communities to reduce school absenteeism. Additional support should be considered for some OVC and affected families who are in need of financial support for food and schooling.
- External, financial and HIV-related healthcare support from NGOs will still be needed in the long term. Therefore, other sources of support should be encouraged, particularly among charity groups and communities, to ensure long-term sustainability.
- A proper mechanism should be developed in order to take into account the issue of support distribution. Some families with many HIV infected members should be able to receive additional support, since most of their income generating power has been lost.
- There will be a greater need for income generating skills (IGS) for PLHIV or HIV/AIDS affected families, especially those who have no land; cannot perform heavy work; or have no education. Programs focusing on IGS allow PLHIV and their families the opportunity to generate income and improve their living conditions.
- Clearer messages should be addressed regarding correct information about OI and ART. Also, communication between the HBC team, ART staff and VCT staff should be improved. This may result in strengthening the existing referral systems. It has been suggested that having regular meetings among the teams may help improve coordination of services provided to OVC, PLHIV and their families.

1

INTRODUCTION

1. Background

The Khmer HIV/AIDS NGO Alliance (KHANA) is the largest national, non-governmental organization to provide HIV prevention, care and treatment services in Cambodia. KHANA works in 17 provinces through a network of over 60 community-based organizations and local NGOs. Its programs focus on HIV prevention, particularly among most-at-risk populations, including men who have sex with men (MSM); drug users (DU), including both injecting and non-injecting drug users; entertainment workers (EW), that broadly include: brothel-based sex workers, freelance sex workers, karaoke workers, beer promotion women and beer garden women. Also, married couples and youth are included in the prevention program. Furthermore, providing care and support to adults and children infected and affected by HIV/AIDS is an important component of KHANA's strategies. The Integrated Care and Prevention (ICP) program is one of the largest program areas. It began in the late 1990's as KHANA's home-based care project. Recently, the ICP approach has expanded beyond home-based care to include the engagement of PLHIV in positive prevention; the facilitation of access to treatment and care; the provision of socio-economic support to PLHIV, orphans and vulnerable children (OVC) and their families; as well as reduction of stigma and discrimination faced by PLHIV/OVC through community education [1].

Currently, KHANA receives financial and technical support from USAID, Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM). Round (GF) 5, GF 7. World Food Program (WFP) and European Commission (EC). KHANA is also a linking organization of the International HIV/AIDS Alliance. Therefore, it benefits from regular communication with, and technical and resource mobilization support from the Alliance.

2. Rationale

The ICP has been implemented since 2007 in Prey Veng, Kampong Chhnang, and Kampong Speu provinces with EC funding support. The ICP consists of home-based care, facilitation of access to care and treatment, provision of socio-economic support to PLHIV, OVC and their families, and stigma and discrimination reduction faced by PLHIV and OVC [1]. Reviewing and documenting the mid-term project, relating to all relevant information regarding project implementation, is crucial in order to monitor progress and provide feedback to the project planner and implementer, so that revised interventions and better project implementation can be made as part of the project cycle. In this mid-term review, our particular focus is on OVC and PLHIV.

2

STUDY OBJECTIVES

The overall objective of this mid term review is to review and document information relating to the implementation of the ICP, focusing on OVC and PLHIV.

The following are the specific objectives:

- 1.** To identify the level of care and support from the communities toward OVC and PLHIV.
- 2.** To determine the level of satisfaction related to the HIV care and support among OVC and PLHIV.
- 3.** To identify project implementation issues with regard to care, treatment and support among PLHIV and OVC, as well as community involvement.
- 4.** To make recommendations for further improvement of the implementation of the ICP.

3

METHODS

Two methods were used in this mid term review: quantitative and qualitative. A quantitative approach was used to identify and determine the magnitude of a number of main, project indicators, while a qualitative approach was used to explore and get a greater insight into issues and challenges faced over the course of the project's implementation.

1. Sites and target groups

The study was conducted in Kampong Chhnang, Kampong Speu and Prey Veng provinces, from July to September 2009. KHANA's NGO partners are running the project, which is funded by the EC, targeting PLHIV, OVC and their families as well as their communities.

2. Sample sizes and sampling approach

Single proportion with specified absolute precision was used to calculate the sample size for the quantitative component. A 5-7% margin of error and 95% confidence interval were taken into account when calculating the required sample size. A number of project indicators were used to calculate the sample size, including: psychological and schooling support for OVC/PLHIV, PLHIV's health status and access to Anti Retroviral Treatment (ART). These indicators were based on World Vision Cambodia's ICP project report in early 2009 and project document [2-5]. The sample size was calculated by using Epi Info software. As the result, total sample sizes required were 190 for the OVC group and 190 for PLHIV group.

Since there was a complete sampling frame for these two groups, a simple random sampling (SRS) was used to select PLHIV and OVC at their households. Coordination and administrative support was facilitated by the KHANA's partners at the provincial level to ensure the effectiveness of the data collection.

In order to be effective and feasible for the planning of data collection, the sample size in each group was proportionally allocated to the size of PLHIV and OVC in each province. Also, the list of PLHIV and OVC selected randomly from the sampling frame was sent to local NGO partners a few days prior to the field work. Then, interview arrangement at the nearby health centers or PLHIV's home where appropriate was scheduled accordingly. The transportation fee was reimbursed for PLHIV and OVC who came for the interview.



3. Questionnaire development

For the quantitative component, two sets of questionnaires were developed separately for PLHIV and OVC. They were developed based on existing questionnaires from a previous, similar study: indicators related to the project objectives such as satisfaction with care services and activities described in the project documents [6, 7].

The questionnaires were developed in Khmer, then pre-tested in the field to ensure that the wording and content were culturally suitable, acceptable and clearly understandable to the study participants. About 2-3 study participants in each group were interviewed face-to-face to assess the content, format, length, language, and appropriateness of the questionnaires. Then, wordings and suggestions from the pretest were revised and reformatted accordingly. The final version of the questionnaires was used for data collection.

Also, the questionnaires were pre-tested with the interviewers to ensure clear understanding and that there would be no confusion when using the questionnaires with participants. Clear instructions and explanations were added and revised.

4. FGD and in-depth interviews (Qualitative component)

In addition to questionnaires asking information about access to care and treatment, community support and satisfaction levels among OVC and PLHIV, the qualitative approach was conducted to gain optimal insights into the project from different angles: a more thorough assessment of the quality of life of PLHIV, OVC and their families, as well as the quality of care and support provided to the groups as experienced firsthand by the study population, stakeholders and health providers involved in the project.

The qualitative components included both in-depth interviews and focus group discussions (FGD). While FGD helped in exploring a variety of issues related to quality of life and care, satisfaction levels, and in-depth interviews; it also provided a good opportunity to investigate rigorously each issue of interest, while at the same time allowing the investigator to make sense of the complex behaviors, problems and challenges the groups faced.

To have a comprehensive picture of the project's implementation, eligible participants in this qualitative component included participants who had been with the project at least 2 years. FGD were conducted among PLHIV and foster families (for OVC) to assess the quality of life, care, support and community involvement relating to the implemented project.



In each FGD, 6 to 8 targeted people were invited to participate.

In-depth interviews were conducted among PLHIV, self-support groups, OVC and foster families to gather information related to the quality of care and support OVC and PLHIV have received. In addition, community people, health staff, project staff and staff at the Provincial AIDS Office (PAO) and Operational District (OD) were also invited for interview: with the main purpose of examining the characteristics of the project and collecting lessons learned from the process of implementation. In total, there were 8 FDG and 18 in-depth interviews conducted in Kampong Chnnang, Kampong Speu and Prey Veng. Table 1 summarizes the samples interviewed.

Different field guides were developed for OVC, PLHIV and other stakeholders involved. Each guided question included components such as demographic information of participants, awareness of HIV and AIDS information, experience of stigma and discrimination, types of services received, quality of service received, process of receiving services, impact of services on the quality of life of PLHIV and OVC, and how to improve the existing services. All focus group discussions and in-depth interviews were note-taken and backed up with taped records, with the consent from the study participants.

Table 1: Samples and groups collected in qualitative component

Target group	In-depth interview	FGD
PLHIV	3	4
Foster family (for OVC)	3	4
Health center staff	3	
Project staff	3	
Community people*	3	
PAO and OD staff	3	
TOTAL	18	8

* Village chief, village volunteers and others involved



5. Training the data collection team



The main objective of the training was to make sure that all interviewers and supervisors understood the same procedures and followed the same standard to ensure the quality of the data collected. Therefore, interviewers and supervisors were trained before the data collection. The training covered necessary skills including: interview techniques, confidentiality and privacy, as well as practice of the questionnaires. Study protocol was also addressed during the training session in order to familiarize the team members.

Since supervisors and interviewers were the key to the quality of the data in the survey, quality controls such as rechecking and reviewing the questionnaires after administration; as well as resolving issues that might arise during the fieldwork, were included. Regular review sessions with interviewers were conducted during the survey period to review progress and communicate any problems or issues during the data collection.

6. Data collection

Quantitative data was mainly collected by trained interviewers and supervisors, who had previous experience with data collection. Informed consent, confidentiality, as well as privacy of the subjects, was strictly ensured. Refusal rates were counted and recorded every day by the interviewers and supervisors. Coordination and administration was arranged and collaborated by the KHANA network. **Mr. Tuot Sovannary**, Research and Documentation Coordinator, was the main person who coordinated the study. Subjects were interviewed face-to-face after informed consent had been obtained. The estimated time for each interview was about 20-30 minutes, including informed consent.

Qualitative data collection was conducted by both the consulting team and the trained, experienced KHANA team. The consulting team was responsible for the in-depth interviews, while the KHANA team was in charge of the FGD. Field guides were used to ensure the flow and completeness of information from both FGD and in-depth interviews. All FGD and in-depth interviews were tape recorded, with consent from study participants.



7. Data entry and analysis

Quantitative data were coded and entered into a computerized database using Epi Data version 3 (Odense, Denmark). Double data entry was performed to minimize entry errors. The data entry was performed by KHANA staff under a consultant's supervision. Then, the data were analyzed using STATA 10. Descriptive statistics were performed for all variables to determine mean, median, range and frequency. Three dimensions of different sets of satisfaction variables (home-based care, HIV care and treatment, care and services provided by KHANA) were generated based on the summation of different sets of satisfaction variables. Each dimension comprised of about 7-10 questions relating to level of satisfaction, with the score ranging from 1 (unsatisfied) to 10 (highly satisfied). Qualitative data were first transcribed in Khmer. Then, content analysis was performed by the consulting team to identify meaning units, categories and themes related to the objectives of the review. The final results were translated into English.



8. Ethical considerations

The study protocol was approved by the National Ethics Committee for Health Research at the Ministry of Health. Anonymity of all study participants was guaranteed. There was no record of the names of study participants. All collected questionnaires and field notes were kept at the **Strategic Information Department (SID)** under the responsibility of the Research and Documentation Coordinator.

Privacy and confidentiality were protected during the interview sessions. The participation in this study was voluntary: the PLHIV and OVC (foster families) had the right to refuse to participate in the study and they were able to stop at any time during the interview.

4 RESULTS

The ICP mid-term project review was conducted from July to September 2009. Both quantitative and qualitative approaches were used to collect the data. Samples collected from the quantitative survey are summarized in **Table 2**. The results from the quantitative approach are described first, followed by the qualitative findings.

Table 2: Samples collected from each province

Province	OVC	PLHIV
Kampong Chhnang	34	43
Kampong Speu	86	85
Prey Veng	74	65
TOTAL	194	193

1. Quantitative results

First, socio-demographic characteristics of both OVC and PLHIV were presented together. Then, findings for OVC and PLHIV were presented separately: specifically schooling conditions and support; health and living conditions for OVC; HIV/AIDS status; use of services; and understanding about antiretroviral therapy (ART) for PLHIV.

1.1 Socio-demographic characteristics of OVC and PLHIV



Table 3 showed that mean age for OVC and PLHIV was about 12 and 38 years old respectively. The youngest age for OVC was 7 and the oldest was 16 years, while the range age for PLHIV was between 24 to 65 years old. Close to 53% of PLHIV were in their productive age (<40 years old). For OVC, nearly 60% of the samples collected were boys, while for PLHIV, about 70% were women. Most of the PLHIV were married, while about 40% of them reported being divorced or widowed. Overall, the education level was low for both groups (about

3.5 years in school) and most of the OVC (83.3%) were at primary school (less than or equal to grade 6).



Table 3: Socio-demographic Characteristics of OVC and PLHIV

Variables	OVC (n=194)		PLHIV (n=193)	
	Freq	%	Freq	%
Age of the participants, mean (median), years	11.9 (13)		38.6 (38)	
Sex of the participants:				
Male	112	58.0	59	30.7
Female	81	42.0	133	69.3
Marital status:				
Married and live together			98	50.8
Divorced, widowed			77	39.9
Married but not living together			12	6.2
Education level, mean (median)	3.5 (3)		3.5 (3)	
Grade in school:				
Primary (1-6 years)	135	83.3		
Secondary (≥ 7 years)	27	16.7		

1.2. Education and related support for OVC

Access to basic primary education for all children is critically important, as indicated in the Millennium Development Goals (MDG) in 2000 and was clearly addressed in the national strategic plan for OVC and other vulnerable children [8]. In this survey, the average number of years of schooling for OVC was 3.5. Most of them were in primary school and about 17% were in secondary school. The highest school level was grade 9. Almost 84% were currently in school. This finding was comparable to the OVC study in Preah Vihear by World



Vision Cambodia [9], but higher than a report in a study conducted in Phnom Penh, Battambang and Takeo that showed the enrolment rate for those affected by HIV was less than 70% [10]. Among those who reportedly had no schooling, there were a number of reasons: ill-health, lack of money and obligation to help family with housework. Furthermore, more than 60% of OVC had temporarily



stopped attending school at some point in order to earn extra income for the family in the past 6 months. About one third of OVC reported having enough school materials, and close to 80% received external support relating to their schooling of which more than 65% of the support was from KHANA, while less than 3% was from school (**Table 4**). An encouraging finding was that although they were either HIV-infected or affected children, close to 98% had friends either in schools or villages, indicating a positive, supportive social and schooling environment for the OVC.

Table 4: Schooling Conditions and Support for OVC

Variables	OVC (n=194)	
	Freq	%
Enough stationary for schooling (n = 163)	53	32.5
Currently attending school	162	83.5
Reason for not attending school:		
Lack of money	16	8.2
Doing housework/working to help the family	11	5.6
Still under age for school	10	5.1
Have temporarily stopped school to earn money in the past 6 months for family (n = 164)	104	63.4
Received external support for schooling in the past 6 months (n = 162)	127	78.4
Sources of external support for schooling:		
KHANA	129	66.5
Charity	8	4.1
Other NGOs	16	8.2
Experienced difficulties in school because teacher did not pay attention due to parents/siblings who had died/were sick from AIDS (n = 163)	47	28.8
Have friends in school/village	190	97.9



1.3 Their living and family conditions



Details of OVC living conditions are shown in **Table 5**. About 45% of these children live with their parents, while another 36% lived with grandparents - who were head of the household and the main caretakers of the children. This finding was consistent with the additional data analysis of the national population based survey, Cambodia Demographic Health Survey 2005,[10]. The findings addressed a concern that soon after the parents had died of AIDS-related illness, all the burden would go to their closest relative

first and extended families; mainly grandparents, who consequently would not be able to earn an adequate income to support the children; either for schooling or food, not to mention long term. In South Africa, where the HIV prevalence is close to 20% among the adult population [11], caring for a large number of OVC has been a big concern for both the government and civil society. It was found that more than 60% of people over 60 years old took care of OVC [12]. Therefore, without additional support there will be a significant strain and extreme difficulty in caring for these children.

Family conditions can have a great impact on children over the course of their lives: some situations can make OVC living conditions worse. These might include: caretakers who are not willing to take care of children, very sick parents, alcohol- related behavior of the caretaker, lack of financial resources and other skills necessary. Fortunately, in our study it was found that many OVC were in a better situation. For example, more than 50% of the OVC were reported to be happy living with their families or extended family members. With regard to the caretakers' attitudes towards them, most OVC (67%) reported being paid more attention than other children. Less than 3% reported being physical abused by their caretakers.



Table 5: OVC Living and Family Conditions

Variables	OVC (n=194)	
	Freq	%
OVC living with:		
Parents	89	46.1
Aunts and uncles	27	12
Grandparents	69	35.8
Sibling or by themselves	5	2.6
Foster families	3	1.6
Feelings living within this household or family:		
Happy	66	52.8
Normal	36	28.8
Not happy	18	14.4
Ability to discuss with caretakers when having trouble (n = 125)	94	75.2
Caretakers' general attitude toward OVC: (n = 125)		
Blame or scold	18	14.4
Unequal treatment compared to children in the family	11	8.8
Paid more attention than other children	84	67.2

1.4. Health conditions and nutritional issues

Health support and psycho-social support were part of 5 standard minimum packages of support for OVC recommended by the Cambodia's National OVC Task Force (NOVCTF) [8]. Therefore, assessment of these indicators was explored in this survey. **Table 6** illustrates a number of variables related to the health and nutritional status of OVC. From the findings, close to 60% of OVC reported having been sick in the past 6 months, of which 70% were very sick; leading to limited performance of daily work or study. Only 13.4% reported feelings of despair or depression in the past month. Regarding nutritional issues, more than 75% reported having enough food to eat in the past 6 months. However, the quality of the food with sufficient micronutrient for a child's development might be questionable, particularly for smaller children. Also, it was found that in the past 12 months, some OVC families had reduced the number of daily meals due to lack of/or insufficient food.



Table 6: Mental Health and Nutrition

Variables	OVC (n=194)	
	Freq	%
Ever got sick in the past 6 months	110	56.7
Ever got very sick which can not perform daily work or study, (n = 110)	77	70
Number of days getting sick, mean (median)	5.7 (3.0)	
Feeling of dispair, depressed in the past month		
Never	125	64.4
Rarely	35	18
Frequently	26	13.4
Have enough food to eat in the past 6 months	150	77.3
Time of meal per day for OVC		
2 times per day	75	38.7
3 times per day	119	61.3
Reducing time of daily meal due to lack of food in past 12 months	103	53.1
Ever had meal interuption in the past 12 months	70	36.1
Think about availability of food comparing with other children in villages		
The same	88	45.4
Less than others	101	52.1

1.5 Community and NGO Support

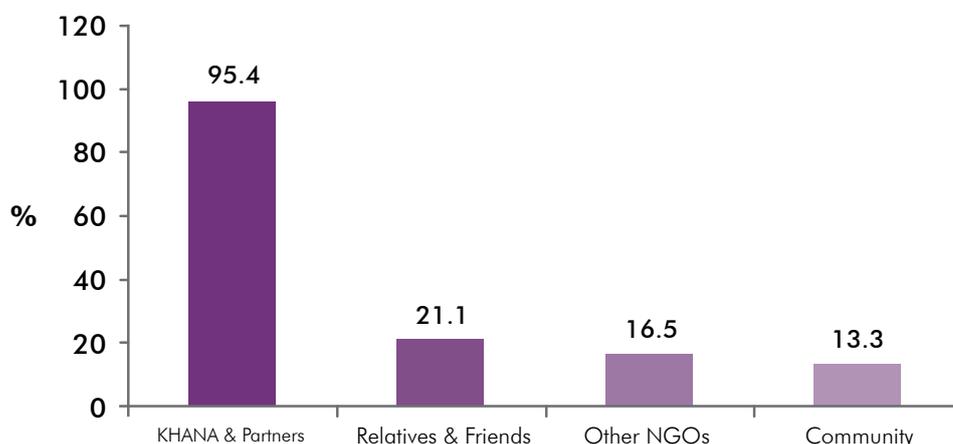


The community which included: neighbors, self-support groups, villagers, village leaders and other members, played an important role in providing the first line support for affected families and children. However, as illustrated in **Figure I**, while about 13% of the support came from those mentioned above, 95% received support from KHANA and its implementing partners. It should be noted that multiple answers were structured to get this information. The high support from KHANA and its partners indicated intensive assistance and intervention to help



the families and children in need of support from civil society. However, in the long run the community should be more active and less dependable on NGOs. One mechanism was to mobilize resources in the community such as the “Assistance Fund for Community”; or involving people, both infected and affected families, to form the “Friend help Friend” group for income saving or income generation activities and incorporate it into the HIV continuum of care to further support the OVC and their families in a sustainable way.

Figure 1: Organizations and People Supporting OVC and their Families



Furthermore, different types of external support were identified. They included: financial support, support for school/school materials, psychological support, and support for clothes and other materials. Noticeably, more than 85% of OVC received food support such as rice, noodles, canned fish, cooking oil and salt. When OVC were asked what they considered to be the most useful support for themselves and their families, food, clothing and other materials came first followed by financial support (**Table 7**). However, when asked a question regarding their personal needs, the two main things that OVC urgently needed were food (69.6%) and school uniforms and materials (57.2%).

The findings also showed that most of the OVC received home-based care (HBC) visits in the past 6 months (95%), which was useful to both the affected families and children in terms of basic care and treatment for minor pain and fever, counseling and referral for further health care. A topic frequently discussed during HBC visits was health and hygiene. Also about 30% of the OVC reported that the HBC team brought some medicine and food to them. Another finding was that about 88% of OVC reported that the level of discrimination toward OVC and their families had decreased significantly compared to a year ago. This could indicate a wider acceptance and understanding of HIV/AIDS related issues and their impact on the community. Furthermore, it was encouraging for both HIV infected and affected children and their families to be more open in the community by sharing their experiences in coping with psycho-social issues and illness with other members of the community.



Table 7: Community and NGO Support

Variables	OVC (n= 194)	
	Freq	%
Types of support from NGOs and other people since your parents died:		
Psychological support (visits, encouragement)	91	46.9
Financial support	97	50
Food (rice, noodles, canned fish)	170	87.6
Schooling	61	31.4
Clothes and other materials	143	73.7
Help taking care of small children	20	10
Other support	57	29.4
Support which you think helpful and useful for you and family:		
Psychological support (visits, encouragement)	13	6.7
Financial support	94	48.5
Food (rice, noodles, canned fish)	155	79.9
Schooling	54	27.8
Clothing and other materials	116	59.8
Home-based care visits in the past 6 months	184	94.8
Topics that HBC team discussed with you and family:		
HIV/AIDS	98	50.5
Psychological support to overcome illness	55	28.4
Care services that available	17	8.7
Illicit drug issues their bad effects	14	7.2
Medicine and food (bought by the HBC team)	61	31.4
Health and hygiene	117	60.3
Others	43	22.2
Two main things urgently needed for you:		
Food	135	69.6
Clothing	49	25.3
School uniform and school materials	111	57.2
Medical care	53	27.3
Level of discrimination toward you and family compared to a year ago:		
Dramatically decreased	68	35.1
Decreased	102	52.6
Still the same	12	6.2
Increased	8	4.1



1.6 Work and income of PLHIV

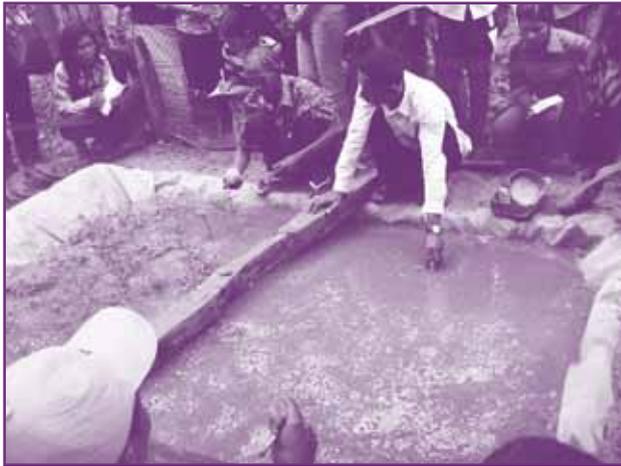


Table 8 describes the working conditions and sources of income for PLHIV. The main source of their income was farming (44.6%), followed by selling their labor, self-employed work, and employees. Nearly half of the patients were the bread-winners of the family, followed by their spouses (31%). The average family income per week was about \$12 and about 90% of reported that this was not enough for them; it was about two times lower than what should be enough for the actual needs. Furthermore, to some extent in the past 12 months, PLHIV had reported selling

their assets such as domestic animals; TVs and mobile phones. The findings also showed that 14.5% of the people had sold their farms, rice-fields or houses in order to pay for food, care and debt. A similar study in Preah Vihear province, supported by World Vision Cambodia, found that a greater number of patients (almost 40%) had sold their house, farms or rice-fields in the past 12 months [9]. This phenomenon will create a vicious cycle of poverty for PLHIV and their families in the long run. Also, the respondents reported that money (48.7%) and food (38.3%) were the first two items urgently needed.



Table 8: Work and income of PLHIV

Variables	PLHIV (n = 193)	
	Freq	%
Main income for the family:		
Monthly salary	20	10.4
Selling labor	55	28.5
Charity from NGOs or individuals	42	21.7
Farming	86	44.6
Self-employed	83	43
Main breadwinner in the family:		
Myself	92	47.8
Spouse	60	31.1
Sibling or relative	14	7.3
Children	21	10.9
Family income per week, mean (median), USD	11.7 (7.3)	
Family income per week that should be considered to be enough, mean (median), USD	23.0 (17.0)	
Different items sold in the past year:		
Buffalo/cow/pig	56	29
Chicken/duck	77	39.9
Motobike/ bicycle	12	6.2
TV/radio/mobile phone	17	8.8
Farm/rice field/house	28	14.5
Have borrowed money or rice from others	176	91.2
Money from what was sold last year spent on:		
Food and clothes	123	63.7
Medical care	68	35.2
Support for children to attend school	22	11.4
Transportation	23	11.9
Paying debts	33	17
Others	76	39.4
Urgent need for the family:		
Food	74	38.3
Money	94	48.7



1.7. Health condition, HIV/AIDS status and the use of ART



Health condition was one of the main factors contributing to the quality of life of PLHIV. Close to 40% reported being unhealthy or unwell 6 months prior to the survey. The average time of being aware about their HIV status was 3.3 years (range: 1-18 years). More than 95% of them disclosed their status to their spouses (**Table 9**). Referring to places where their HIV status was confirmed, public health facilities were the most frequently mentioned (59%). About 27% got their HIV status confirmed at the voluntary counseling and testing centers

(VCT). The low report of using VCTs might be due to a number of reasons, such as limited access to VCT services or being unable to distinguish between public health facilities and VCT sites. However the latter may be the main reason, since many VCTs have been integrated into the public health facilities.

Regarding antiretroviral treatment (ART), currently 83% of PLHIV have received ART. The mean duration of taking ART was 25 months, ranging from 1 month to 10 years. Of 160 PLHIV taking ART, 30.6% took for more than 1-2 years and 36.3% took for more than 2 years. Close to 60% of the patients reported that the HBC team and self-support groups referred them to the opportunistic infections (OI) and ART services, followed by friends and relatives. Furthermore, 85% of the participants reported themselves to be members of self support groups in their communities. All this suggests the important role of NGOs, relatives and self support groups that have built a good, supportive environment and referral system for PLHIV. The knowledge related to ART was high in general, but some misconceptions still remained with regards to HIV prevention and condom use: about 7% of them believed that they did not need to use condoms when taking ART. Therefore, health workers and prevention and care program staff should be aware about this and take action to address this. It was also interesting to find that the level of discrimination against PLHIV had declined over the past 12 months (**Table 9**): a finding that was highly consistent with the OVC report.



Table 9: HIV/AIDS status, health condition and the use of ART

Variables	PLHIV (n = 193)	
	Freq	%
Patient's health status compared to 6 months ago:		
Better	7	3.6
Good	111	57.5
Not as good as compared to others	71	36.8
Not well	4	2.1
Duration knowing HIV/AIDS status, mean (median), years	3.3 (3.0)	
Spouses or partners knowledge of HIV/AIDS status	188	97.4
Places where HIV status was confirmed:		
Public hospital	114	59.1
Voluntary counselling and testing center	52	26.9
Last time HIV tested got counselling	189	97.9
Currently taking antiretroviral drugs (ARV)	161	83.4
Duration taking ARV, mean (median), months (n = 161)	24.8 (20.0)	
Person or services who referred you to the OI/ART services:		
Home-based care and self-support groups	111	57.5
Relatives and friends	32	16.6
Health staff	16	8.3
Other	19	9.8
Currently a member of a self-support group	164	85
Understanding about antiretroviral treatment (ART)		
Prevents you from additional infection	143	74.1
Makes you as healthy as before infected	157	81.4
No need to use condoms when having sex	14	7.3
Prevents you from sexually transmitted infections	86	44.6
Discrimination level against your family compared to 12 months a go:		
Dramatically decreased	89	46.1
Decreased	90	46.6
No decreased	9	4.7
Increased	4	2.1



1.8 The worrisome (Concerns of PLHIV) and community support

PLHIV worried about a number of issues, ranging from the support of their children's schooling and housing, but their primary concern was the financial issue of food (57.5%) and medical care (53.4%) (**Table 10**). KHANA and its partners were their primary support in areas related to HIV/AIDS integrated care and prevention. When asked what kind of support they needed from KHANA, most participants mentioned financial support (72.5%); followed by other supports (66%); income generation support (49.7%); and assistance for the establishment of self-support groups (less than 3%). Actual support received in the past 6 months by PLHIV was: food, including rice, salt, canned fish (92.7%); financial support (73.1%); and psychological support (22.8%). Other support included counseling, clothes, and school uniforms for children. The duration of support from KHANA was 22 months (median = 21 months), which was consistent with the formation of the ICP project since early 2007. However, we should be careful about long-term sustainable support. The project should consider designing a community-centered approach to mobilize resources within the community or other "mutual support funds", so that the level of dependency on NGOs is minimal.

Similar to the OVC findings, the level of discrimination had declined over time: due to either: ICP interventions, other programs, or the greater level of awareness and understanding of HIV in the community. It was reported that more than 75% of PLHIV thought that the level of discrimination had decreased compared to a year ago and this was reflected in the finding that there had been an increase in the number of visits from friends and neighbors in the past 6 months (93%).

Some misunderstandings about ART were observed. When asked whether PLHIV "agree" or "do not agree" with statements linking ART to the prevention of further infection, including STI and condom use, more than 40% of PLHIV believed that taking ART could prevent them from further STI; more than 7% said that when taking ART, it was not necessary to use condoms during sex.



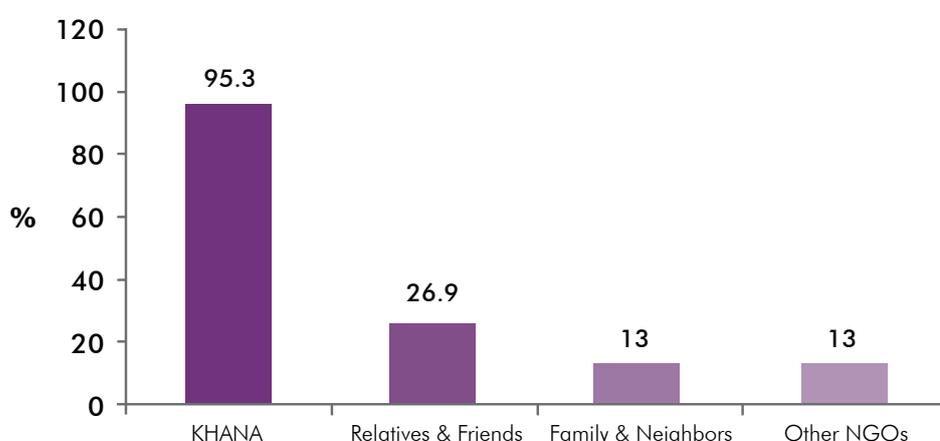
Table 10: The worrisome (The Concerns of PLHIV) and community support

Variables	PLHIV (n = 193)	
	Freq	%
The greatest concern about your illness:		
Money supporting children to attend school	56	29
Money for food	111	57.5
Money for health care	103	53.4
Taking care of sick children	17	8.8
Support needed from KHANA and partners:		
Financial support	140	72.5
Psychological support	23	11.9
Income generation support	96	49.7
Support for children's education	21	10.9
Other support	128	66.3
Support received in the past 6 months;		
Psychological support	44	22.8
Financial support	141	73.1
Food support (rice, noodle, salt, canned fish)	179	92.7
Clothing and provisions	25	12.9
Counselling support	35	18.1
No. of months received support from KHANA, mean (median)	22.0 (21.0)	
Useful support that helps PLHIV's families living:		
Psychological support	33	17
Financial support	155	80.3
Food support	178	92.2
Friends and neighbors have shared a meal with you	172	89.1
Friends and neighbors have visited in the past 6 months	179	92.8
Thought about level of discrimination compared to a year ago:		
Increased	23	11.9
Decreased	150	77.7
The same	19	9.8



Figure 2 : Indicates the assistance for PLHIV families in the past 6 months. As shown, KHANA and its partners played a major role in providing assistance to the needs of the patients. Also, their relatives were another source of support for the families, followed by the support from other NGOs and villagers.

Figure 2 : Persons or NGOs supports PLHIV in the past 6 months



1.9 Satisfaction of HIV care services among PLHIV and OVC

In the past, a client satisfaction survey relating to HIV prevention and care services has never been conducted in Cambodia. As part of this mid-term review, the satisfaction level of PLHIV and OVC was measured on different dimensions related to the care services. Three main dimensions were included: home-based care and self-support groups, HIV related information and education provided by KHANA, and the HIV/AIDS care and treatment services.

Overall, the satisfaction level related to the home-based care services and self-support groups was high. Mean scores ranged between 9.2 and 9.7 for PLHIV and between 8.9 and 9.4 for OVC, out of a maximum score of 10: 1 being the minimum score (**Table 11**). They included: information provided by the home based care team, referral services, counseling and psychological support, to name a few. In terms of self-support groups, the variables measured were the importance of the self-support group; satisfaction with experience sharing; psychological coping strategies; and others. Then, all the variables were combined together to generate the overall score to reflect the overall satisfaction about the home based care and self support groups. After this, the score was categorized into 3 levels: low, medium and high. Overall, 90% of PLHIV and 70% of OVC were satisfied with the services respectively. It should be noted that the lower satisfaction level reported by OVC might be due to in part by the delayed availability of services for the OVC compared to PLHIV. Another reason was that OVC or foster families that answered the questionnaire on behalf of the OVC may not have clearly understood about the HBC services. KHANA's project staff reported a delay in making this kind of service available to OVC.



Table 11: Satisfaction with home-based care and self-support groups

Variables	PLHIV (n=193)	OVC (n=194)
	Mean (Median)	Mean (Median)
Satisfaction with home-based care services	9.5 (10)	9.4 (10)
Information and education related to home-based care services	9.5 (10)	9.0 (10)
OI treatment and care related to home-based care	9.2 (10)	8.9 (10)
Referral services, including OI and HIV testing	9.5 (10)	9.4 (10)
Counseling and psychological support	9.5 (10)	9.1 (10)
Competency of the home-based care team	9.5 (10)	9.3 (10)
Friendliness and good relationship of the team	9.7 (10)	9.4 (10)
HIV/AIDS self-support group	9.6 (10)	9.0 (10)
Importance of the self-support groups in sharing experiences and psychological coping strategies	9.5 (10)	8.9 (10)
Importance of the self-support groups in helping each other	9.6 (10)	9.1 (10)
Receiving regular services and drug compliance	9.7 (10)	9.0 (10)
Ease in getting the services when needed	9.3 (10)	9.1 (10)
Overall satisfaction with the home-based care and self support groups	83.0 (87)	74.8 (79)
Categories of the overall satisfaction level		
Low (score < 40)	1 (0.5%)	4 (2.1%)
Medium (score 40-69)	18 (9.4)	52 (27.8%)
High (score ≥ 70)	173 (90.1%)	131 (70.1)

The measures of satisfaction with regards to the provision of information, education and KHANA support included: vocational training for income generation, financial support and transportation, and OVC arrangement. The details of the variables and scores are presented in **Table 12**. All scores ranged between 9.3 and 9.8 for PLHIV and between 9.1 and 9.7 for OVC. When all scores were combined, more than 85% of PLHIV and almost 71% of OVC were satisfied with the information, education and support provided.



Table 12: Satisfaction with HIV/AIDS related health education

Variables	PLHIV (n=193)	OVC (n=194)
	Mean (Median)	Mean (Median)
HIV related education sessions organized by KHANA	9.6 (10)	9.3 (10)
Vocational training skills for income generation for family	9.3 (10)	9.2 (10)
Financial support for transportation to the services and testing	9.6 (10)	9.3 (10)
Commodity support (rice,cooking oil,salt) for patients and families	9.8 (10)	9.7 (10)
OVC arrangement for care and support from the foster families	9.5 (10)	9.1 (10)
OVC arrangement for schooling and school materials	9.7 (10)	49.1 (53)
Overall satisfaction with health education provided by KHANA	55.5 (59)	9.4 (10)
Categories of the overall satisfaction scores		
Low (score <25)	6 (3.1%)	12 (6.2%)
Medium (score 25-44)	19 (9.8%)	45 (23.3%)
High (score ≥ 45)	168 (87.1)	136 (70.5%)

HIV/AIDS related care and treatment domain was measured based on a number of variables included the competency of the health personnel, staff’s friendliness, waiting time, confidentiality and others. In general, mean scores ranged between 8.7 and 9.8 for PLHIV and between 8.4 and 9.4 for OVC. After combining and categorizing overall scores, close to 80% of PLHIV and more than 65% of OVC were satisfied with the HIV/AIDS care and treatment services provided (**Table 13**).



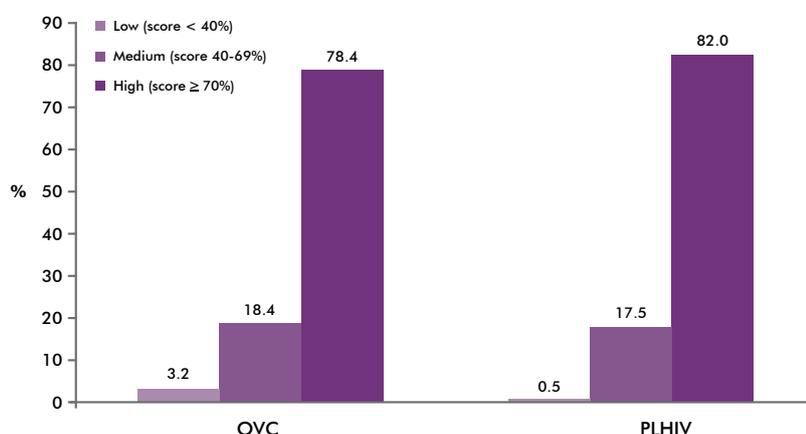
Table 13: Satisfaction with HIV/AIDS related care and treatment services

Variables	PLHIV (n=193)	OVC (n=194)
	Mean (Median)	Mean (Median)
Current treatment and care service you are using	9.5 (10)	9.4 (10)
Competency of medical professionals in the health facilities	9.8 (10)	9.0 (10)
Friendliness and attention from health professionals and staff	9.5 (10)	8.6 (10)
Proper location and cleanliness of the health facilities	9.3 (10)	8.6 (10)
Proper working hours of the health facilities	9.2 (10)	
Waiting time for services at the health facilities	8.7 (10)	8.4 (10)
Confidence in the confidentiality of your HIV/AIDS status	9.2 (10)	8.7 (10)
Ease in getting necessary information when needed	9.4 (10)	8.9 (10)
Overall satisfaction with HIV/AIDS care and treatment services*	72.8 (85)	69.5 (76)
Categories of the overall satisfaction scores		
Low (score <40)	30 (15.5%)	1 (4.4%)
Medium (score 40- 69)	10 (5.2%)	7 (30.4%)
High (score ≥70)	153 (79.3%)	15 (65.2%)

*For OVC only, 23 reported using OI/ART care and treatment

Lastly, the combined scores from the 3 dimensions of satisfaction were calculated and categorized to reflect the overall scores related to the overall satisfaction with the HIV services for both PLHIV and OVC. As shown in **Figure 3**, more than 80% of the PLHIV and slightly close to 80% of OVC were satisfied with the service. Only less than 1% and about 3% for PLHIV and OVC reported being dissatisfied with HIV-related care services.

Figure 3: overall satisfaction scores with HIV-related care services



*For OVC, satisfaction scores with treatment and care services were excluded when generating the overall score for satisfaction for OVC, because many OVC were not HIV-infected and received care and treatment services.



2. Qualitative results

In total, there were 8 FGD and 18 in-depth interviews (IDI) conducted in the 3 provinces: Kampong Chhnang, Kampong Speu and Prey Veng.

Table 14: Summary of FGD and IDI by province

	Kampong Chhnang	Prey Veng	Kampong Speu	Total
FGD	Care givers (2) PLHIV (1)	Care givers (2) PLHIV (1)	Care giver (1) PLHIV (2)	8
IDI	Key informants (4) PLHIV (1), OVC (1)	Key informants (4) PLHIV (1), OVC (1)	Key informants (4) PLHIV (1), OVC (1)	18

One of the main objectives of this mid-term evaluation is to assess the implementation and the level of satisfaction of the programs. In addition, mid-term impacts of the program have also been measured whenever feasible. Therefore, this qualitative result section was divided into 4 parts: the implementation of the programs, satisfaction with the programs, the impact on the quality of life of the target groups, and lessons learned.

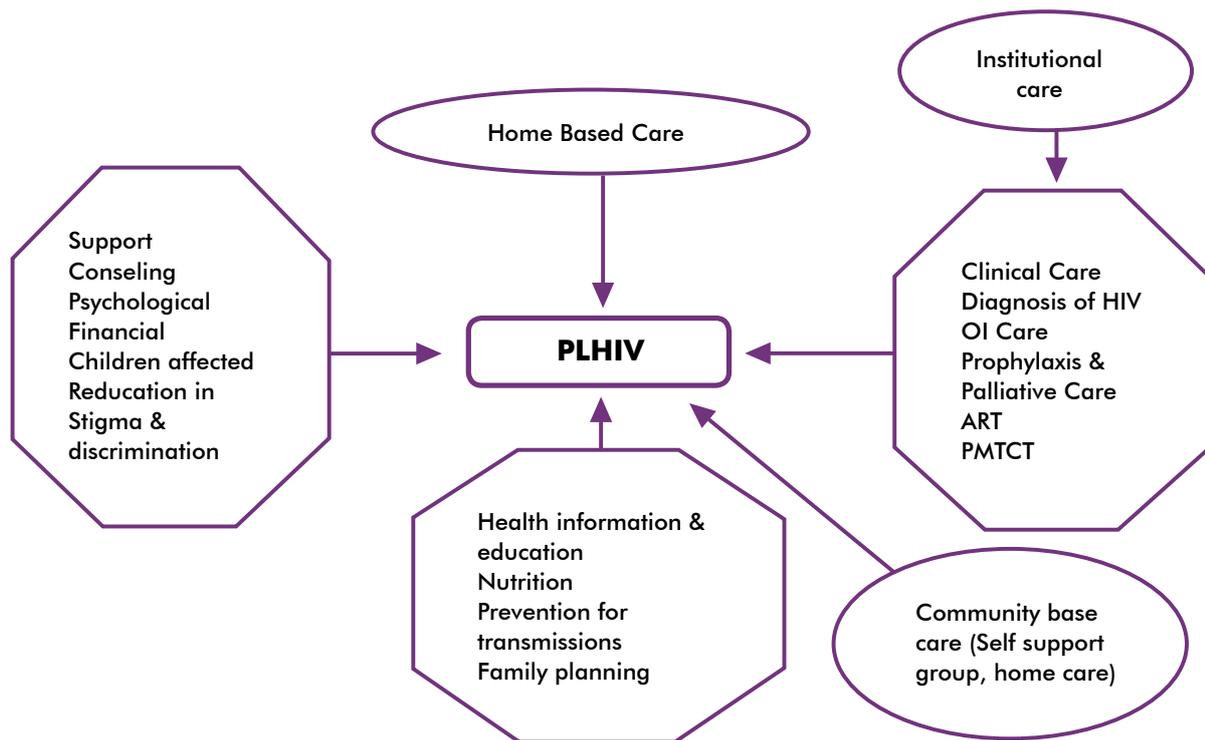
2.1. Program implementation

PLHIV have been facing a number of consequences in addition to physical and mental health. PLHIV have also faced economic difficulties and often social and legal consequences [13]. Therefore, the care for PLHIV may have to include, not only healthcare components, but other components such as psychological; social; as well as legal support.

Continuum of Care (CoC) framework of the National Center for HIV/AIDS, Dermatology and STI (NCHADS) identified three main areas to ensure comprehensive care for PLHIV: clinical care, support and health promotion, and education [13]. **Figure 4** illustrates all the activities offered in the CoC framework.



Figure 4: Summary of comprehensive care for PLHIV/OVC

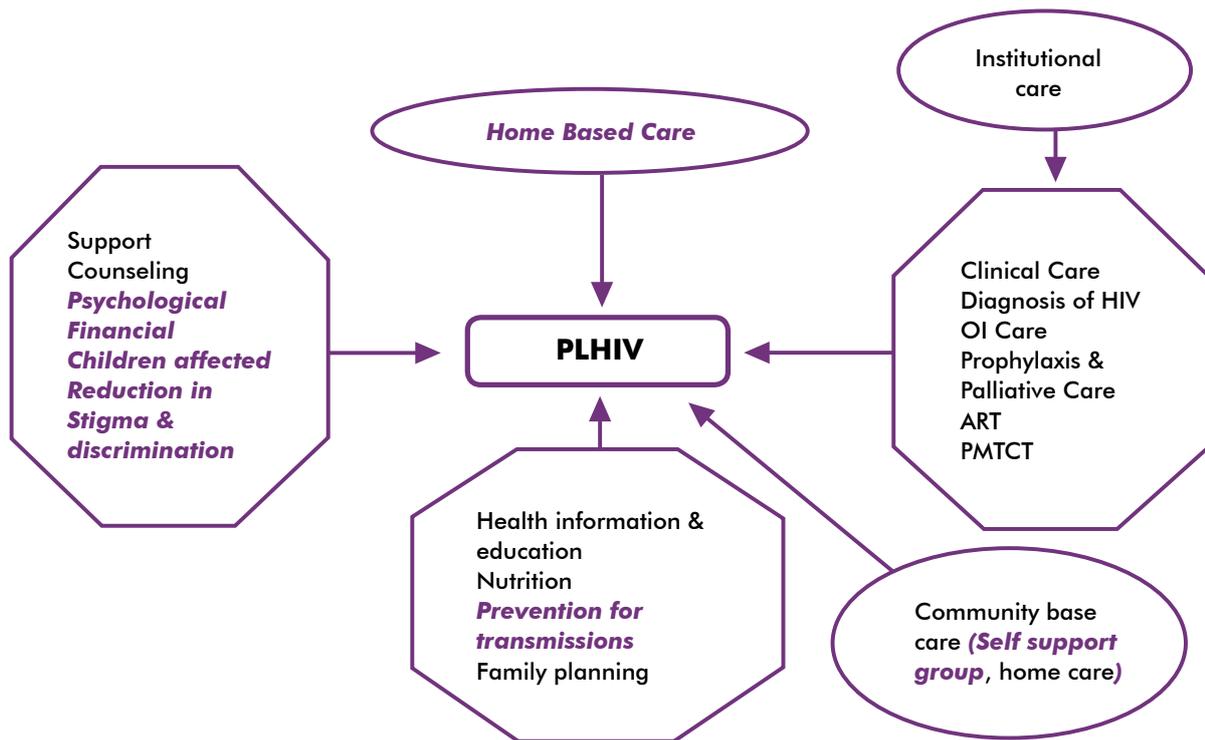


Following the national guidelines on care and treatment for PLHIV and OVC, KHANA has collaborated with their implementing partner (IP) NGOs to undertake some selective activities. The main activities conducted are: referring PLHIV to health services, conducting training for the HBC team, volunteers and peer educators, providing basic medical care and treatment to PLHIV and OVC, and support for OVC. In short, these activities are routine activities included in the HBC, community based care and health information and education components of the comprehensive care for PLHIV as developed by NCHADS.

In this report, the analysis concentrates on the implementation of HBC teams, self-support groups, OVC support, other support; and the collaboration with other institutions, since these are the main activities that KHANA and their IP NGOs are involved in.



Figure 5: Activities conducted by KHANA and partners to support PLHIV/ OVC*



*All activities written in italics with red highlight were conducted by KHANA and partners

2.1.1 Home-based care program

Four aspects of the HBC program were examined. They included: the appropriateness of the program, the structure of the implemented HBC, the sustainability of the program, as well as suggestions on how to improve the HBC program.

Appropriateness of the HBC program

The appropriateness of HBC was assessed by looking at AIDS patients’ responses to the services provided by HBC program. HBC visits were considered as a ‘one stop’ support where the provider approached their clients at home and delivered most of services in response to the needs of AIDS patients.

“...In addition to opportunistic infection drugs, we gave them some Para [Paracetamol] and Vitamin...”
(a project staff, PVG)



“HBC program provides food. Each month, [we receive] 30kg of rice, 1 kg of cooking oil, 0.5kg of salt and a budget of 30\$ to start an income-generating activity. HBC also provides education and counseling about HIV/AIDS, unwanted pregnancies and stigma and discrimination.” (a PLHIV in KCN)

“There are a lot of benefits from HBC. They encourage us and also improve our living conditions” (a PLHIV, KPN)

“In fact, the function of home-based care is the most important: if we did not pay attention to our patients, they may have problem with drug resistance...” (a PLHIV in KCN)

Structure of the home-based care team

The structure of the HBC team varied, especially in terms of the number of team members from one province to another and over time. For example, numbers were reduced if the team faced financial difficulties. Despite this, the main activities have been maintained through the collaboration between implemented NGOs and health centers.

“Now the contract [for having one health center staff in the HBC team] is over, however we still provide services if we are asked for help.” (a health center manager, PVG)

There was no significant variation in the implemented HBC from the original protocol. Some of HBC structure and services have been modified to fit with existing structure of the IP NGOs and situation of the communities they served. Having flexibility on the formation of the HBC to fit the actual situation of the community was considered to be one of the good practices in HIV/AIDS care and treatment.

Sustainability of the program

The sustainability of any program remained one of commonly asked questions in the evaluation of public health programs and there was no exception for HBC program. Since the HBC program was financially supported by external budget NGOs, the sustainability of this program also relied heavily on funding availability.

There are no indicators to ensure that the HBC team could survive without external funding or resources from the central level. Furthermore, there are no strategies in place aiming for long-term sustainability of the program: although strategies for working towards self-sufficiency among PLHIV were integrated into the activities of self-support groups.



"The financial support from NGOs has been cut for about 1 year. Now there is no longer activity [home-based care activities]. However, we [health center] still provide some help to AIDS patients when they [PLHIV] are not well." (a health center manager, PVG)

Improving HBC programs

Two points were raised regarding how to improve the HBC team's performance; both from the service provider's perspective and the patient's perspective. From the service provider's point of view, there should be more support for HBC team members in terms of means of communication (phone card or gasoline), in order to maximize service coverage and communication among the teams. In addition, capacity building for all HBC teams was also needed, since HBC team members should know not only about health, but also about advocacy skills; some agriculture methods (i.e. gardening, animal raising); and other income generating activities.

"...asking for support for telephone so we [home-based care teams] can help each other...to save time and gasoline and budget is also needed." (a health center manager, PVG)

"Our staff is weak in advocacy skills and there is also a shortage of training materials. I would like to ask KHANA to provide more training materials, since the materials help communities to understand better than lessons and books." (a project staff, KPS).

"We don't have posters for teaching. Using posters may improve the outcome of the training..." (a project staff, PVG)

In addition, the duration of the contract for implementing HBC projects should be extended to 3-5 years instead of one year. Longer projects may result in better planning and management of the funds. It also can lead to stronger collaboration between KHANA, IP NGOs and other institutions. Again, having contracted activities on a yearly basis might affect the services provided to PLHIV, since there was always an interruption of services until the new contract was granted.

The communication between the HBC team, ART staff and VCT staff should be improved and strengthened. This may result in strengthening the existing referral systems. It has been suggested that having regular meetings among the teams (HBC team, ART and VCT staff) may help minimize the loss of information and contact with PLHIV.

"...To make programs better, there is a need to improve the communications via different means; such as telephone, face-to-face meetings... we should support each other if we find any weaknesses,



so we can cooperate for [the good of] the province.” (a provincial AIDS Office, KCN)

“...ART staff, VCT staff should have a meeting. Thus they should be updated. We should focus on the topic of information feedback to help all teams understand it and understand each other on how to operate it [feedback system].” (a health center staff, KPS)

From the client’s perspective, HBC was a good approach to reach the majority of PLHIV. Activities provided by HBC supported PLHIV in many areas. However, there was a suggestion to provide information on a wider variety of topics during HBC visits. For example, in addition to information about HIV testing, OI care and ART uses, PLHIV also need information about agriculture methods and other income generating activities.

“...I want NGO to develop more projects so that we [PLHIV] can have more ideas.” (a PLHIV, KCN)

“... I want IP NGO to create more jobs for PLHIV, because some jobs such as selling food or cakes may not good since some people are still afraid to buy...” (a PLHIV, KCN)

Support offered to HIV/AIDS affected families should depend on the number of family members who were infected with HIV/AIDS, not per household affected. Some families have lost all of their income generating power and they received the same amount of support as the families in which only one member was infected.

“Some families have more HIV-infected members: children, husband and wife. This family receives 30kg of rice support, whereas a family with only one HIV infected member also receives the same amount of rice.” (a caregiver, KCN)

2.1.2. Self support groups



Self-support groups were assessed on four different aspects: the appropriateness of the program, implementation, sustainability, and suggestions to improve self- support groups.



The appropriateness of self-support groups

Self-support groups gather all PLHIV in the same community to join together. The main purpose of self-support groups is to create an environment that PLHIV can help each other, such as in sharing experiences and psychosocial coping mechanisms, when formal support from institutions may not be readily available. The ultimate goal of self-support groups is to help PLHIV become self-sufficient and independent. Thus, this program is very appropriate for its target population.

"...It encourages PLHIV to go to [ART sites] by themselves. Now NGOs have budget for patient transportation...in the future that budget may not be available, so we have to educate them [communities] about the transmission of HIV/AIDS and encourage them to go testing [VCT] by themselves." (a provincial AIDS Office, PVG)

"...It [a self support group] allows those who have been on ART for a longer time to share their experience on how to take the drugs with those who are just on ART and also helps PLHIV to counsel each other." (a PLHIV, KCN)

PLHIV in self support groups were not only able to share their concerns, but they were also able to provide advice to other people in their own communities. Some sick people might avoid seeking care and treatment by staying home and using private health providers. In turn this might make their health worse and they could waste a lot of money. Therefore, self-support group members played a key role in referring suspected AIDS patients in their communities to appropriate treatment and care services.

"...I have observed that some patients refused to go to receive services in order to hide their HIV status until their illness advanced to the late stages. Later, NGOs counseled them until they decided to seek services and now they are in good health like others." (a health center staff, KCN).

"...I always encourage others [PLHIV] to go to collect their ARV medicine on the appointment date because, as I am a volunteer, I want all the members [in self-support group] to have good adherence to treatment to prevent [occurrence of HIV] drug resistance..." (a PLHIV, KCN)

In Cambodia, PLHIV often end up living in poverty due to loss of income generating capacity and considerable healthcare expenses. Therefore, the introduction of self-support groups is vital because PLHIV group members can come together to offer financial and/or physical support to each other whenever a group member is in a critical situation.

"Some families are desperately poor and when their house collapsed [due to natural disaster], the community provided food and some roofing materials." (a project staff, PVG)



“It [self-support group] helps me more than my children. My children were often not at home to take care of me when I felt sick, but homecare groups always came to visit when I was not well.” (a PLHIV, KPS)

The implementation of self support groups

Self-support groups, consisting of PLHIV that provide support to other PLHIV in their communities, are supposed to be owned and operated by PLHIV. However, it has been found that the group receives funding from IP NGOs and the meetings are being led by IP NGO staff.

“Regarding the ownership of the group [among PLHIV], it is about 50%, during a self-support group meeting there are some difficulties if we [NGOs staff] are not with them. We can inform them about the topic for the meeting; then he/she [self support group leader] can lead the meeting.” (a project staff, KPS)

The organizing of self-support group meetings is still coordinated by NGO staff. It has been reported that the self-support group meeting is conducted on an ad hoc basis. This may create difficulties for some members of the group to be in the meeting.

“[NGOs staff] did not tell [us] in advance when the next meeting will be, where to meet...” (a PLHIV, KPS)

Self-support groups agreed to also create a savings fund: the money coming from each members travel allowance, for the purpose of helping those in desperate need for support.

“We have a saving. Each month, the members contribute their share of 500 Riel from their transportation costs that was given by IP NGOs.” (a PLHIV, KCN)

The sustainability of self-support groups

Members of self-support groups are often PLHIV voluntarily working to help their peers. Therefore, with a little initiative and/or support, it may be possible that the sustainability of these groups can be ensured.

“Since we are also patients [PLHIV], we can share our experiences with those who were recently ill; about medication and income generating opportunities.” (a PLHIV, KPS)

At this stage of the evaluation, all self-support groups are run by IP NGOs under technical and financial support from KHANA. It is not clear whether KHANA currently has any policy in place to ensure the sustainability of the self-support groups they have established. However, it has been observed that some



IP NGOs already plan to tailor their programs so that the sustainability of their self-support groups can be ensured.

"...if there will be no more support, they [PLHIV] will still be able to work by themselves [self-sufficient] through self-support groups. They can gather to work together...for those who have large plot of land, they can team up with others to raise chickens, ducks, pigs and vegetables. This is our plan for the new year." (a project staff, KPS)

Another strategy for ensuring the sustainability of the whole program, particularly self-support groups, is the need for strong commitment from the government and local authorities:

"... without NGOs, local authorities could keep reminding PLHIV [to adhere to all positive behaviors]." (a project staff, PVG).

Improving self-support groups

Not only limited to HIV/AIDS, self-support groups can be used for other purposes, including as a resource center to provide information about legal issues and human rights for PLHIV and other people in the community. Thus far, self-support groups have been used as the meeting point where PLHIV could share and exchange their knowledge and thoughts with each others. With some modifications, the group may produce some strategies that may work well within their own community.

Participants also requested IP NGO to increase funding for income generating activities from \$40 to \$50, so that they could buy a pig. They also asked IP NGOs for assistance to help consumers buy their products: that is, finding a market for their products so that they could have a sustainable income for their families.

2.1.3 OVC support

In this review, OVC are defined as children (< 18 years old) who have either been infected or affected by HIV/AIDS. Therefore, support for OVC is designed to minimize the negative impact of HIV on the children of PLHIV. The objective is to maximize the chance for OVC to have normal schooling and to live in an environment where there is no stigma and discrimination against them. IP NGOs, close relatives, extended families, and particularly grandparents of OVC are the primary sources of physical and emotional support. The decision to foster OVC is mainly due to blood ties as well as sympathy and compassion by the family for OVC.



“It’s because of blood line [I] have to take care of them. Their mother is sick” (a caregiver, KPC)

Providing support to OVC may also put the foster family in a difficult position in terms of food security. Most of the foster families have their own children to take care of and their living standard is not high. Therefore, by having more dependents, all the children would face a potential food shortage. On top of this, the support for OVC increases when they come of school age, in particular for clothes, food, and school materials.

“My living standard is low; I have 3 children and now I have other 2 OVC; it is more difficult than before.” (a caregiver, KPC)

The activities for supporting OVC have been integrated into HBC activities and self-support groups. The concept of child protection has been introduced in the meetings of self-support groups. The support for OVC can be directly given to OVC or indirectly offered to OVC foster families.

“[NGOs] help me to be able to go to school, encourage me to go to school.” (an OVC, KCN)

“[Self-support group] discusses about children rights. Self-support group promotes peer relationship and to support each other.” (an OVC, KCN)

OVC need different kinds of support. Some OVC may need food support, while others may need schooling support or both. Therefore, a flexible guideline should be considered when reviewing the needs of OVC.

“[NGOs] provides clothes, mosquito nets, blankets, soap, toothpaste, toothbrushes, pens, books...to help kids to go school.” (a PLHIV, KPS)

“I want to have a bicycle for going to school” (an OVC, KCN)

Some foster families have problems with creating a bond with their foster children. OVC may not listen to the advice given by their foster families, since they are not their biological parents. Training and counseling to foster families on how to deal with the emotions and care-related issues of OVC have not been offered.

2.1.4 Other support

PLHIV also need mental health support, especially at the time when they learn their HIV status and/or the time that they disclose their HIV status to their spouses. Providing psychological support is included in the support package, however it appears that PLHIV did not clearly mention how this type of support helps them through their difficulties.



"[I] am very concerned. I am the only one breadwinner for the family. [I am] afraid of dying [since I don't want to] leave my children alone." (a PLHIV, PVG)

"[When my wife knows my status, she] wanted to divorce. [What will you do then?] I don't know what to say...I said if she wants a divorce, we will get divorced." (a PLHIV, PVG)

IP NGO is also working towards encouraging people to get tested and minimize stigma and discrimination against PLHIV and OVC. They provide training to communities on HIV/AIDS topics and the importance of using ART. Self-support groups have been used to reinforce this and to provide resources to individuals in communities, especially those who seek for information on HIV/AIDS.

"[We want]...someone to give advice, accompany us to testing centers and help reduce the level of stigma and discrimination against us." (a PLHIV, PVG)

Complaints have been raised in FGD regarding the lack of sufficient financial support for transportation in order for foster families to bring OVC to ART care. The shortage was due to the fact that the cost of transportation had increased over the past year. Sometimes the OVC or PLHIV had to travel to the ART site to collect their medicine more than 1 time per month.

"I have to take 3 types of tablet. I run out of 1 type of drug before the end of the month, so I have to go to pick up my drugs often." (a PLHIV, KPC)

NGOs do not provide loans to PLHIV. PLHIV have been refused loans for their business because of their HIV status. This practice should be eliminated by IP NGOs working with PLHIV.

"Some NGOs provide loans. When we are sick [HIV] they did not allow us to borrow money - even a small amount of money..." (a PLHIV, KPC)

2.1.5 Collaboration with other institutions

Collaboration with other NGOs or government institutions is considered to be a good practice. It is possible that through collaboration, more services could be provided with more or less the same effort to the infected and affected groups. IP NGOs have showed some collective efforts through collaboration with other NGOs or government institutions.

"World Vision trained communities on techniques





for raising animals. For this NGO [IP NGO] there is no such training, but I used my knowledge from other NGOs...” (a PLHIV, KCN)

“RHAC also help to pay for health services for poor people...” (a health center staff, KPS)

“I received instructions about raising chickens....I got a loan from CEDAC NGO...” (a PLHIV, KPS)

In order to increase cooperation between NGOs and government institutions, there is a need to improve the relationship between NGOs and local authorities. All local authorities or organizations have to be informed and kept up-to-date about NGO projects. Without involvement of all parties, the maximum effect of the program on the target population may not be achieved.

“I suggest [NGOs] inform the village chief and the commune leader [about their activities] - only this will ensure good cooperation.” (a HC staff, PVG)

“...When having training, they [NGOs] should invite teachers, police and local authorities to participate, then they are informed about what is going on [related to NGO work].” (HC staff, KPS)

“When IP NGO has not yet arrived in the area, there is little support from local authorities... now that IP NGO invites them to join, they offer more support.” (a caregiver KPC)

Again, the practice of offering support directly to individuals may have no effect on improving the capacity of existing healthcare systems. Once improved, it may result in higher quality services for whole communities.

“[NGOs] should provide support to [health] centers because a center has many program activities each year for school students, for example providing deworming medicine and vitamin A supplement. If [NGO] strongly supports the center, students will also receive support.” (a health center staff, KPS).

2.2 Level of satisfaction with the implemented programs

The level of satisfaction with the program was measured based on whether the implemented programs answered to the target population’s needs and whether the target population acknowledged the importance of the programs. Based on interviews, it seemed that the delivery of the program was viewed as being right on target, with those in need having received support from the programs.



"I observed that it is good that the [the program] provides materials to AIDS patients, not someone else. There is a clear list of really poor families and orphans living in villages: those are the ones who receive rice support." (a provincial AIDS office staff).

"I think that the goal of NAPA matches one of the needs of our people: a need that helps people to expand their knowledge." (a health center staff, KPS)

"[IP NGOs] help them with transportation fees to receive drug and food supplies: it is appropriate for them." (a project staff, PVG)

On the other hand, the level of satisfaction can be measured by using a proxy of the level of support for the program. It has been observed that there is a high level of participation from communities in program activities.

"...People strongly support (the programs). When we launched candle light, there were a lot of participants and there was collaboration with others." (a provincial office staff, PVG)

PLHIV are happy with the fact that they can get support from their networks. Through self-support groups and financial support from IP NGOs, PLHIV receive opportunities to get trained in raising animals; vegetable farming; and running small business. This may help them become financially independent.

"...I am pleased with the training sessions on raising animals. It helps us to have better living standards." (a PLHIV, PVG).

"It [self-support group] helps me more than my children. My children are often not at home to take care of me when I feel sick, but the homecare group always comes to visit when I am not well." (a PLHIV, KPS)

Also, the level of satisfaction of OVC support was very high. There are no negative feelings regarding OVC support from OVC or their foster families.

"I am satisfied with the support. [It] helps us not to worry and we feel happy." (an OVC, KPS)

"I like it [support] very much. They prevent us from dropping out of school, encourage us and give us clothes..." (an OVC, KCN)



2.3. Impact on the quality of life of target groups

2.3.1. Quality of life among OVC



OVC have been observed to lead a normal life like any other typical village child. This may be due to the support that OVC have received directly or indirectly from the program. OVC received enough food, schooling opportunities, and were able to perform some of the routine work that other children in the village did, such as cleaning or feeding their livestock.

"I cook rice; then I go to the field with my cow. I am now in year 3 at school. I go to school in the morning..." (an OVC, PVG)

Thanks to the implemented programs, knowledge of HIV/AIDS prevention and how to live with HIV infected family members among OVC has increased. Having better understanding about HIV/AIDS and other related information may help OVC in their day-to-day lives.

"Now I am healthy, I help do house work and vegetable farming to create income. Then we can eat good food to become healthier." (an OVC, KPS)

"The support may reduce 90% of the hardship. Now, it is better than before. Before, it was difficult to find food to eat..." (an OVC, KPS)

"I have good food to eat like others." (an OVC, KPS)

Stigma and discrimination, either at school or in their communities, was rarely reported by OVC, although they all acknowledged that it had been very common in the past. However, it is possible that the stigma and discrimination still exists among children affected by HIV/AIDS, but they are unaware of it.

2.3.2. Quality of life among PLHIV

One of the major indicators for quality of life is physical health. After receiving ART, the physical health of PLHIV is significantly improved. By having their health return close to normal, PLHIV are able to perform their routine activities.

"I have found that the support is very strong: some people [PLHIV] were almost dead, but now they are healthy, they have strength to work. I like this activity [support]..." (a staff from Health Center, KPS)



"Before I weighed 15 kg, now (I am) 59 Kg." (a PLHIV, KPS)

"I have seen a lot if we compare from 1993 to now. From 93 to 2002-2004-2005, patients [PLHIV] died within 1 or 2 years. Now with support from NGOs, in a period of 6-7 years there has been only 1-2 PLHIV who has died. It is better than before." (a health center staff, PVG)

Physical appearance, especially skin diseases, is one of the major factors leading to discrimination. After receiving opportunistic infection treatment or ART, the PLHIV may return to their normal look. This may help them to get along well with other people. However, some of the stigma and discrimination still exists, especially among who are very poor.

"In the past, we were sick, they discriminated against us because of our skin lesions... and now we no longer have skin lesions...then they stop discriminating against us." (a PLHIV, KPS)

"The quality of life of adults and children [PLHIV], after making available home based care, community based care plus the provision of ART, we observed that adults and children became healthier." (a provincial AIDS office, KCN)

Some programs provided by IP NGOs help their recipients become economically independent. That is, PLHIV were able to generate income to support their own family without any support from NGOs or other sources (i.e. relatives). In addition, there was significant change in the knowledge and understanding of HIV/AIDS and social issues among PLHIV.

"I have some chicken and bought some materials for motorcycles, bicycles... I make some profit." (a PLHIV, KPS)

"In terms of the wealth of the family, [NGOs] can help half [of the hardship]... not yet help them to be self-sufficient, but help them to become healthier..." (a project staff in PVG)

2.4 Lessons learned

- Providing for the costs of transportation once a month may be not enough, since some PLHIV or OVC are required to go to the ART site more than once a month and the cost for transportation also increases per year. Also, sometimes different members of the same family who have HIV may be asked to go to pick up their drug on a different date. For example, a HIV infected mother may have to go to pick up her drug on one day and her infected child on another.
- More varieties of IGA should be introduced to self-support groups to help PLHIV improve their living standard. However, some PLHIV are not able to initially start their work themselves. For example, some PLHIV do not have a plot of land so that they can grow vegetables or raise animals. Thus, members of the self-support groups should be encouraged to work collectively on income generating activities and then they can share their benefits based on their contribution. PLHIV working together with other non-HIV infected individuals should also be considered.



- IP NGOs should have an agenda to transfer the ownership of self-support groups to PLHIV. The sustainability of the self-support group will be maintained if PLHIV take complete ownership of the group.
- Some overlapping activities between home-based care, self support and other supports have been observed. This may result in the reduction of efficiency of the services. From the client perspective, there are signs of confusion between services provided by home-based care, self support groups and peer education. This confusion may be due to overlapping of services provided by the different teams, or project staff has been assigned to work in different teams.
- There is a shortage of materials for training in the community. IP NGO request a greater variety of training materials specifically related to HIV/AIDS transmission. It has been observed that having training materials such as leaflets, charts or posters may improve the learning among people in the community.
- Providing training in isolation is not a very effective strategy. ‘Self-support groups’ and ‘home-based care teams’ should be integrated with training sessions.
- A good relationship with local authorities is vital to ensure good participation from the community and other institutions. Local authorities, teachers and police should be involved in program activities so that they are aware of the introduction of new programs in their communities.
- Short-term contracts with IP NGOs to implement any program may result in some disruption of the services provided to PLHIV. That is, to have a one-year contract for implementing a program puts pressure on IP NGO and consequently the IP NGO cannot establish a proper plan of action or coordination.
- Living standards may play a role in the existence of stigma and discrimination among PLHIV. Thus, providing education only on stigma and discrimination may not able to eliminate this problem. Programmers should at the same time look at other alternatives, such as increasing self-esteem and the living standards of PLHIV.
- The same support is given to families affected by HIV/AIDS, regardless of the number of family members infected. Families with many HIV infected family members may in fact receive less support overall. Given this fact that, these families should receive more supports since they have lost more sources of incomes and their health expenses are higher
- Although PLHIV can produce products through income generating activities, there is a lack of support for finding a market for their products.
- There is a notable shortage of psychological support in dealing with the disclosure of a person’s HIV/AIDS status and also with foster families dealing with adopted children.
- Providing direct support to individuals does not have any positive effect on strengthening the health system, which could be beneficial to all people in the community, not only those who are HIV infected.

5 CONCLUSIONS

The results from the quantitative and qualitative approaches are highly consistent and complementary with each other, indicating good achievements over the project's implementation period. However, gaps and weaknesses have been also identified in this project. A number of key points to sum up are:

For orphans and vulnerable children

- About 84% of OVC are currently in school. However, about 60% of those in school have reported suspending their study in the past 6 months in order to earn extra income for their families.
- 95% of OVC got support from KHANA and its partners for food, clothes, school materials and medical care.
- 36% of OVC lived with grandparents, who were head of the household and the main caretakers.
- Close to 95% of them were visited by the home-based care team.
- The level of discrimination toward OVC had declined substantially over the past year.
- Overall satisfaction with ICP services provided by the project was high. No negative feelings were reported with regards to OVC support.

For people living with HIV/AIDS

- 70% of PLHIV were women. 14.5% of PLHIV had sold their farms, rice-fields or houses, to have money for food, clothes, medical care and outstanding debts. About 95% of PLHIV reported getting support from KHANA and its partners.
- About 40% of PLHIV had reported feeling unwell in the past 6 months. More than 95% had disclosed their HIV status to their spouses, and 83% of PLHIV were on ART. Some misunderstandings about taking ART still existed, such as "it is not necessary to use condoms when having sex."
- Their main concern was the lack of money to spend on food (57.5%) and health care (53.4%). The support from KHANA most needed was financial support (72.5%) and income generation support (49.7%).
- 85% are currently members of self support groups. 75% reported a decline in the level of discrimination in their community.
- PLHIV were highly satisfied overall with ICP services. No negative feelings were reported.

6 RECOMMENDATIONS

Overall, financial support for food schooling, and care issues are needed by PLHIV and OVC. KHANA and its partners have properly addressed these needs.

For OVC in particular, the project should work with both infected and affected children, their families, schools and communities to keep their school interruptions to the minimum, so that school attendances is more regular. Since the financial burden for foster families and close relatives (particularly grandparents) will grow, additional support should be considered for some OVC and poor families who are in need of extra food and support for school.

A children's club for OVC should be established with the purpose of raising awareness about HIV and health issues; drug issues and the consequences; the importance of school education; and to link OVC and their families with other organizations and charity groups for additional resource support.

Instead of a one year contract of the HBC implementation project, the contract should be extended to 3-5 years. Longer contracts might result in better planning and management of the funds. It can also lead to stronger collaboration between KHANA, IP NGOs and other institutions. Again, having yearly contracts can affect the services provided to PLHIV, since there are always interruptions of services until a new contract is granted.

The communication between the HBC team, ART staff and VCT staff should be improved and strengthened. This may result in strengthening the existing referral systems. It has been suggested that having regular meetings among these teams may help minimize the loss of information and contact with PLHIV.

It is expected that external financial and HIV-related healthcare support, particularly from NGOs, will still be needed in the long run, thus raising the question of sustainability. Therefore, other sources of support should be encouraged, particularly among charity groups and communities, to ensure long term sustainability and less dependence on KHANA.

Furthermore, it seems that there is a greater need for income generating skills for PLHIV and HIV/AIDS affected families, especially those who have no land; cannot perform heavy work; or have no education. Programs focusing on IGA enable PLHIV and their families the opportunity to generate income and improve their living conditions. Also, it can reduce stigma and discrimination towards PLHIV. This will be more robust if this hypothesis could be further investigated through sound quantitative research. Additionally, uninfected family members should be encouraged to invest with other members of self-support groups, so that more ideas and human resources can be brought to the group. Moreover, there should be activities advocating the sustainability of the programs through contribution from government institutions and local authorities. Mechanisms for providing loans for IGA should start from offering small loans to larger loans; if there is enough evidence for the business to improve on a small scale.



Since there is still some confusion or misunderstanding about the use of ART among PLHIV relating to STI and condom use, this should be addressed by project staff so that the correct messages can be clearly conveyed to PLHIV and their families.

Providing additional training for IP NGO staff, especially in other areas apart from HIV/AIDS, is needed including: income generating methods; psychological counseling and advocacy. Also, supplying more training materials for use in communities is needed.

A proper mechanism should be developed in order to take into account the issue of support distribution: Families with many HIV infected members should receive supports proportional to the number of infected members, since most of their income generating power has been lost.

It seems that providing direct support to individuals is appropriate only in the emergency stage. KHANA and its partners should develop and implement mechanisms that provide support to individuals in need, and at the same time contribute to strengthening the health care system in the long term; for example by working in collaboration with health facility staff.

Based on this midterm review, it is clear that the project has played a very important role in alleviating the burden of HIV/AIDS among PLHIV and OVC in the targeted provinces. Sustainability of the ICP is essential for the wellbeing of current ICP beneficiaries: both direct and indirect; infected and affected people; and OVC. This good achievement should be maintained with additional improvements to bridge the remaining gaps for the benefit of those infected and affected people.

7

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