

## of affected family members living with HIV in Bhutan



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## **Lhak-Sam(BNP+) – Bhutan Network of People Living with HIV/AIDS**

**Changjalu Lam, Olakha, Thimphu, Bhutan**

**P.O. Box:1358**

**Website: [www.lhaksam.org.bt](http://www.lhaksam.org.bt)**

**Email: [lhaksambhutan@gmail.com](mailto:lhaksambhutan@gmail.com)**

**Contact: +975 02337687**

## ACKNOWLEDGEMENTS

This study relied on input from affected family members living with HIV at all stages of the study process. We are grateful to all the respondents and mindful of the time and effort it takes for people to complete the survey questionnaire.

A range of stakeholders have been actively involved in this study process - starting from the development of consultation tools, administration of survey and Focused Group Discussion (FGD) , data entry, analysis, and report writing. We are thankful to all the individuals and member representation from organizations such as National Aids Control Program (NACP), Health Counselors, Voluntary Counseling and Testing (VCT) focal, Save the Children, World Health Organization (WHO) Bhutan, Care Support and Treatment Unit (CSTU) focal, Respect Educate, Nurture and Empower Women (RENEW) focal, Affected people, Lhak-sam members, Human of Thimphu, Queers Voice of Bhutan (QVoB), National Statistical Bureau (NSB), Bhutan Health Partners, and SDI Consultancy.

## ACRONYMS

PLHIV	People Living with HIV
AFM	Affected Family Member
NACP	National Aids Control Program
VCT	Voluntary Counseling and Testing
WHO	World Health Organization
CSTU	Care Support and Treatment Unit
HISC	Health Information Service Center
KAP	Key Affected Population
QoL	Quality of Life
HIV	Human Immunodeficiency Virus
AIDS	Acquired Immunodeficiency Syndrome
HH	Household
FGD	Focused Group Discussions

# EXECUTIVE SUMMARY

The needs of people living with HIV are more complex and sensitive as they must deal with varied issues such as stigma, discrimination, disclosure, safe sex, economic challenges, etc. Evidences regarding the nature, structure, movement, degree of fear, prejudice, and discrimination associated with AIDS and its effects on people living with HIV and their impacted family members is known to be lacking in Bhutan. Thus, this study attempts to provide evidences on areas like QoL of AFM through various determinants such as family interaction, parenting, emotional well-being, physical/material well-being, HIV related support, economic challenges and food sufficiency. Findings relating to prevalence of stigmatization and discrimination were also highlighted and discussed in this study.

A cross sectional design with mixed methods (qualitative and quantitative) was used for this study. Quantitative and qualitative data were collected between July and September 2022 from 82 AFM. 8 AFM consented to participate in FGD. For survey, respondents completed a questionnaire using online form or hardcopy form. The survey instrument comprised 84 items as per the identified objectives of this study. For the FGD, semi-structured interview guide (questionnaires) was used to extricate information relating to the quality of life and their well-being. The discussion revolved around their attitude, beliefs, physical health, mental health, independence, social relations, stigma and discrimination, environment,

health services, and economic challenges.

The study was conducted by Lhak-Sam, fielding in expertise from various stakeholders acknowledged in this study for their valuable inputs in refining the questionnaire, carrying out FGD and survey administration, data analysis and report writing. The study was funded by South Asia Small Grants Program (SASGP).

## Demographic Characteristics

Survey questionnaire were completed by 82 AFM. Of this 82 participants;

- ◆ 43.9 % (n=36) are male and 56.1 % (n=46) are female.
- ◆ Respondents age ranges from 18 to 72, with an average participants' age of 34.4 years.
- ◆ Majority 68.3% (n=56) are married
- ◆ 39.0% (n=34) are employed, 47.6% (n=39) unemployed and 13.4% (n=11) are self employed
- ◆ 34.1 % (n=28) completed higher secondary school, 17.1% (n=14) completed middle secondary school, 17.1% (n=14) have completed up to lower secondary, 11% (n=9) completed bachelors and above, 4.9% (n=4) attended monastic education and 15.9% (n=13) have not attended any formal education.
- ◆ Average monthly household income is Nu.30001.52 per month. Income ranges from lowest Nu.5000 to Nu.300000.
- ◆ 81.7% (n=67) participants live in a household where at least 1-2 people earn income.
- ◆ Most common income source are from salary and wages (70.7%, n=58)
- ◆ 26.8% (n=22) own houses and mostly (45.1%, n=37) live in private rental. While 38.3% (n=23) live in other arrangements like

government quarter, house provide by NGO, Employers, and live with immediate friends/relatives.

- ♦ Average household size is 4
- ♦ 72% (n=59) reported having children below 18 years in their HH.
- ♦ 93.9%(n=77) follow Buddhism and 6.1%(n=5) follow Hinduism.

### AFM's QoL findings

- ♦ 57.3% (n=47) reported good overall QoL. Only 3.7%(n=3) reported poor QoL.
- ♦ No significant association were observed between perception towards overall Family Quality of Life and socio-demographic characteristics of the participants like gender, age, education, income, occupation, marital status and employment status.
- ♦ Overall good QoL is associated with positive family interactions such as family members who spends time together, open communication , problem-solving, support to achieve/ accomplish family goals, and ability to handle life's challenges
- ♦ 75.6% (n=62) felt the importance and need for parenting training.
- ♦ Overall good QoL is associated with good parenting practices such as helping children to learn to be independent, make good decisions, and quality time and attention towards children's need.
- ♦ Overall good QoL is associated with AFMs having support from friends or others.
- ♦ It was evident that there are family members who perceived that they don't get outside help

to take care of their PLHIV.

- ♦ Overall good QoL is associated with AFMs who feels safe at home, work, school and in their neighborhood, and also with the AFMs who are able to manage family expenses.
- ♦ Evidently, there are cases where family members perceived that they don't get support to make progress at school or at the workplace.
- ♦ Overall good QoL is associated with family members having support to progress at their home.

### Household food sufficiency, poverty, financial challenges and happiness perception

- ♦ Only 7.4%(n=6) reported having experienced food insufficiency. Majority 87.7%(n=71) reported not having experienced food insufficiency.
- ♦ Further, it was found that 34.1%(n=28), reported that they couldn't afford to eat balanced meals.
- ♦ 6.1%(n=5) participants reported that their household is poor. This is lower compared to the general population perception, where 15.3% (BLSS 2017) believed that their household is poor.
- ♦ 73.1%(n=60) participants perceived themselves as happy. This is lower compared to the general population perception, where 75.5% (BLSS 2017) reported being happy<sup>9</sup>.
- ♦ 22%(n=18) participants reported that they have faced financial challenges like not being able to pay bills, not being able to pay rent or mortgage on time, going without meals, or needing to ask

friends, family or services for financial assistance. AFM shared that they were hit hard especially during the Covid-19 lockdowns.

#### Indicator 1: Number of AFM living in fear of public opinion

39.0% (n=32) participants reported living in fear of public opinion.

#### Indicator 2: Number of AFM living in fear of being perceived as having HIV too

19.5% (n=16) participants reported that they live in fear of being perceived as having HIV too.

#### Indicator 3: Number of AFM stigmatized and discriminated based on perceived living with HIV

18.3%(n=15) participants reported having experienced stigma and discrimination from community (12.2%,n=10), from friends (3.7%, n=3) and from family (2.4%, n=2).

#### Indicator 4: Number of AFM who's peaceful spiritual journey has been distracted

Majority 82.7%(n=67) participants reported that they get time to pursue spiritual activities, whereas only 8.6%(n=7) reported not getting time for spiritual activities.

#### Indicator 5. Number of AFM who believes that their family member living with HIV is due to previous karma.

58%(n=47) of the participants agree to the statement 'HIV is a result of previous karma. 23.5%

(n=19) participants disagree to the statement and 18.5% (n=15) have neutral opinion.

#### Indicator 6. Number of AFM who fear that their family member living with HIV will die from AIDS very soon

29.6%(n=24) participants fear that PLHIV in their family will die from AIDS soon.

#### Indicator 7. Number of AFM who fear that their family member living with HIV can't do any work

87.3% (n=69) participants believe that their family member living with HIV can live and work like any other normal people as oppose to 12.7% (n=10) participants , who believe that their family member living with HIV can't live and work like any other normal people.

#### Attitude towards PLHIV

- ♦ 98.7%(n=77) reported that they support PLHIV in their family.
- ♦ 93.9 %(n=77) participants reported that they feel comfortable living with HIV. 6.1 %(n=5) participants reported not feeling comfortable living with HIV.
- ♦ 90.1%(n=73) participants feel empathetic towards PLHIV in their family. However, there are cases 9.9%(n=9) participants who don't feel empathetic towards PLHIV.
- ♦ 81.7%(n=67) reported having access to quality health care and treatment services for PLHIV.
- ♦ Need for emotional support, timely treatment, self motivation and nutritional support were quite evident from the qualitative findings.

## Implication for practices—recommendations

Based on the above findings, following recommendations were suggested;

- ◆ *Prioritize investment in strengthening the QOL of the PLHIV and their affected families*
- ◆ *Prioritize investment towards more aggressive treatment literacy programs*
- ◆ *Promote Social connectedness for active engagement of PLHIV and their AFM*
- ◆ *Strengthen In-house data management*
- ◆ *Need for stronger research, policy and practice collaboration for similar studies in the future*



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# FOREWORD

The financing and techniques that are focused on making an HIV-positive individual noninfectious through treatment are a head-on response to the AIDS epidemic. The goal of identifying as many people living with HIV who are unaware of their status must come from their heart with the best intentions to save lives, mitigate the effects of the virus, and ensure a meaningful livelihood for those who have been diagnosed with HIV. Compassions is must when dealing with HIV and AIDS.

After 28 years of the HIV epidemic in Bhutan, this study is an attempt to conduct a mixed mode study to understand the health-related quality of life and psychological well-being of people living with HIV and their affected family members. The findings from this research are significant as the study approach embraced the WHO QoL instrument. In addition, the research team went a bit further to understand the nature, structure, and movement of fear of stigma, discrimination, and internal prejudice and its relationship to the quality of life and psychological well-being.

With the completion of this study, Lhak-Sam is now able to clearly see the difficulties faced by people living with HIV and their impacted family members. The research findings are authentic as the PLHIV organization took the lead in the research involving its key PLHIV, their affected family members, and KAPs. Invaluable inputs were sought from various organizations from the government, CSOs, KAPs, FBO, development partners, and the National Statistical Bureau (NSB) when designing the research protocol. We remain grateful for their contribution and solidarity.

The evidences gathered from the research will be fully utilized for advocacy for influencing social, economic, policy, and procedural improvement and change that are creating barriers and affecting achieving zero new HIV infections, zero discrimination, and zero AIDS-related death by 2030. The stigma and discrimination can be reduced, human rights and values can be promoted, and access to a meaningful livelihood could be assured through partnership and the effective use of this evidence.

Without the generous contribution of the Asia Foundation through its South Asia Small Grant Program (SASGP), this research wouldn't have materialized into a comprehensive, breathing document. We are grateful to the National HIV/Hepatitis & STIs Control Program for the collaboration and the WHO Country Office for assistance when developing the research methodology. Our sincere thanks also goes to SDI Consultancy Firm and Bhutan Health Partners for assisting and genuinely guiding us in achieving the goal and objectives of our research.

(Executive Director)

Lhak-Sam

# ABOUT THIS REPORT

This study titled “Quality of Life (QoL) of affected family members living with HIV attempts to understand the Quality of Life from various determinants like household income, living condition, food sufficiency and financial challenges. Besides these factors, the study also explores family’s QoL from different aspects such as; family interaction, parenting, emotional well-being, physical/material well-being and HIV related support based on literature reviews.

The study also attempts to answer indicators like; 1) Number of AFM living in fear of public opinion, 2) Number of AFM living in fear of being perceived as having HIV, too, 3) Number of AFM stigmatized and discriminated based on perceived living with HIV, 4) Number of AFM who’s peaceful spiritual journey has been distracted, 5) Number of AFM who fear that their family member living with HIV will die from AIDS very soon, 6) Number of AFM who fear that their family member living with HIV can’t do any work, and 7) Number of AFM who believes that their family member living with HIV is due to previous karma.

Data for this study were collected between July and September 2022. Questionnaires were administered by trained Lhak-Sam staffs and VCT/HIC focal person. Survey instrument comprised of 61 questions. Main study findings are divided into 5 sections; 1) Demographic profile of AFM, 2) Family QoL, 3) Indicator findings, 4) Family attitude towards HIV and 5) Study Discussions and recommendations. To further substantiate the quantitative data, FGD findings were collected and reported in this study. The report cannot and does not aim to express the full diversity of experience and complexities of the AFM living with HIV in Bhutan. Lhak-Sam nonetheless hope that it is useful for evidence based decision making by the policy implementers.

The study is prepared by Lhak-Sam in support of SDI consultancy and Bhutan Health Partner for data analysis. Since its inception, series of in-house and external consultations with relevant stakeholders were made to finalize the survey instruments. The study is funded by South Asia Small Grants Program (SASGP).

## PLHIV STUDY 1 sample

Survey questionnaire was completed by 82 AFM and 8 AFMs participated in the FGDs . Here the term ‘respondents/people/participants’ would mean those who participated in this survey. Reference to all literature review and sources were cited and linked with reference number. In some section, suggestions/comments shared by the respondents were quoted to support the findings.

# BACKGROUND AND RATIONALE

The first case of HIV was detected in Bhutan in 1993, now its 29 years of AIDS epidemic and its response in Bhutan. However, there has not been a single study that was carried out to understand the psychosocial health and wellbeing of the Bhutanese PLHIV, their affected family members, friends and the general population. The fear and negative perceptions of AIDS continue to prevail at the individual, family, community and society at large in Bhutan. The past global and national portrayal of AIDS as deadly, killer, immoral and sin has deeply imbed the fear and negative perceptions into people's mind to fear, to judge and distrust, to hate and divide and deny love and care for each other.

Today it was estimated that 628 <sup>1</sup> people are living with HIV and the trend is increasing. More infections of heterosexuals are appearing, and young people and women are becoming more vulnerable. Interventions were mainly focused on the individuals infected with HIV, especially on preventing HIV/AIDS and strategies to cope with the disease. Infection with HIV, however, also has an impact on the individual's family. HIV has a large psychological, physical and social impact on infected individuals and their families.

Stigmatization worsens this impact; it hinders the prevention and treatment of HIV and hampers social support and HIV disclosure<sup>2</sup>.

The typical Bhutanese family is large and our social structure and religion deem that we take care of each other as if we were all related<sup>3</sup>. Given the

family-oriented structure of Bhutanese society, HIV can have a devastating effect on Bhutanese families. Though the culture and religion aspects of kindness and care are deeply rooted in every Bhutanese, HIV being chronic, the psychological burden and stress overtime may impact the care givers or the families in general. The psychological burden and stress affect their overall mental health, and depression is common among parents and caregivers as they struggle with financial limitations. Many caregivers find that they can no longer work as the disease progresses and their health deteriorates, and unemployment leads to extreme economic hardships<sup>4</sup>. Worldwide, people living with HIV/AIDS have multiple sources of stress: the disease itself, financial burdens, stigma and discrimination, pressure from worrying about family, and so on<sup>5</sup>. HIV can also have an effect on relationships between family members. Chronic illness in the parent can change family roles causing anger or guilt. The ability of HIV-positive parents and caregivers to care for their children is also impaired<sup>4</sup>. HIV/AIDS leaves people both physically and emotionally vulnerable: physically, because their immune systems are fighting a difficult battle, and emotionally because of the threat of death, and the stigma and discrimination attached to a condition that is associated with sex, sex work, and injection drugs<sup>6</sup>. The study also confirms that as a result of these physical and emotional vulnerability, people living with HIV/AIDS are sometimes forced out of their homes and jobs. They can be rejected by families and friends. Often, they are accused of being personally responsible for their situation. The impact overall is stretch towards their family members too, with studies confirming that besides their family

priorities, families living with HIV have to go through various emotional stress resulting from stigma, fear of AIDS-related death of their loved ones and economic challenges<sup>4</sup>.

In view of considering HIV as a family illness not an individual illness, need for more family-based interventions are deemed important for any HIV related treatment, care, reduction and wellbeing policies/interventions. With lack of evidences or no research conducted so far with the AFM, the present study attempts to study family's QoL aspects, stigma and discrimination and their (AFM) attitude toward PLHIV in Bhutan. The report cannot and does not aim to express the full diversity of experience and complexities of the AFM living with HIV in Bhutan. Lhak-Sam nonetheless hope that it is useful for evidence based decision making by the policy implementers.

#### Study Objectives:

1. Assess QoL of AFM, and use the findings for evidence based planning for appropriate program interventions and policy advocacies and,
1. Pointer for any future community lead researches and maintain the knowledge gained as an in-house research capacity.

# STUDY METHODOLOGY

In carrying out the study following approaches were taken by Lhak-Sam;

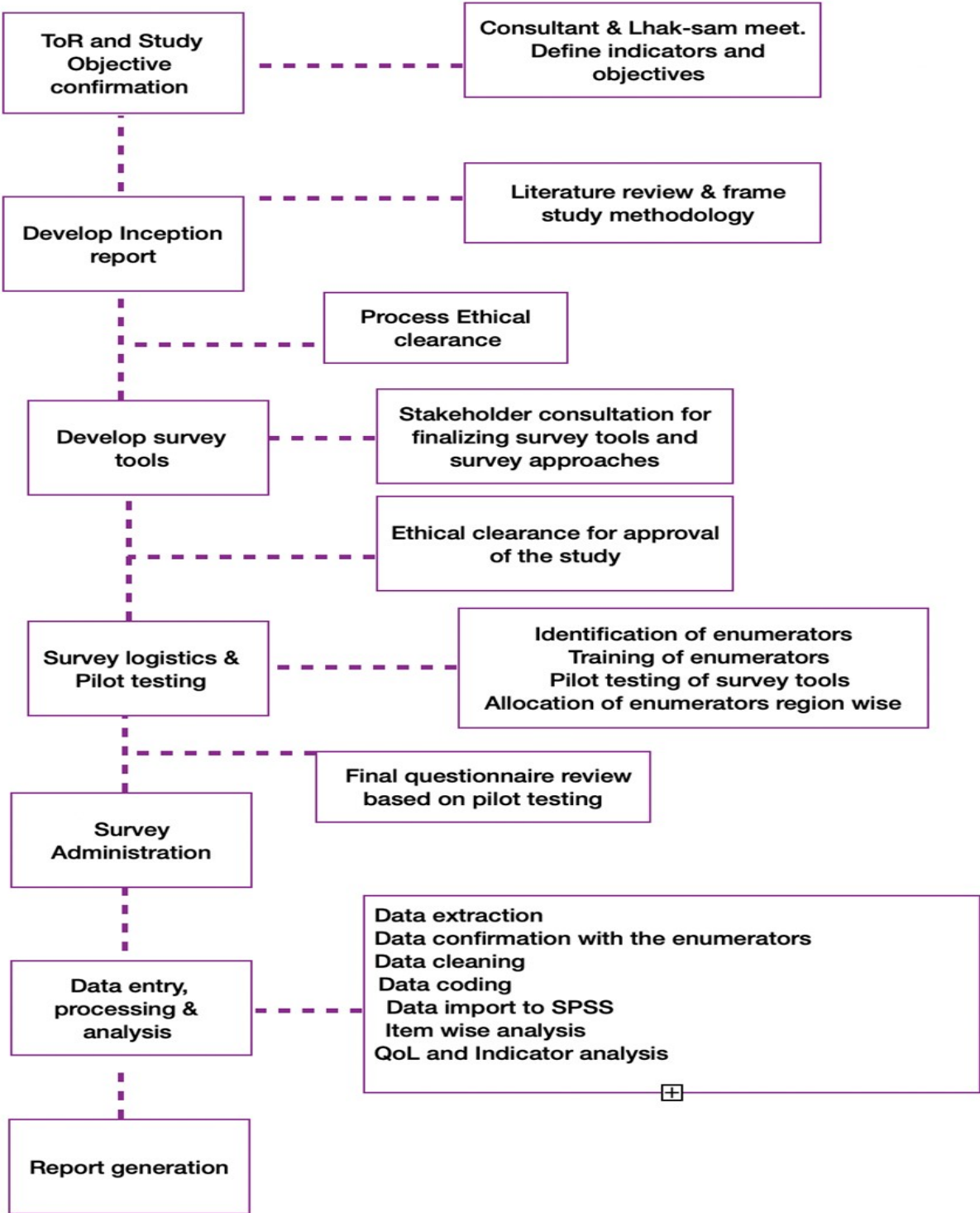


Figure 1: study design framework

## 1. Objective confirmation as per ToR

Lhak-Sam and team reviewed the study objectives, indicators and timeline of the study.

## 2. Inception report

Based on the finalized ToR, desk research was carried out by the team to frame study methodologies and consultation tools. The inception report outlined understanding of the study objectives, study areas, aligning indicators with consultation tools and analysis (outputs), work plan and reporting framework. Based on this inception report an application was processed for approval by Research Ethics Board of Health, MoH, Bhutan.

## 3. Development of survey tools

The survey framework was designed based on the review of research reports in line with the expected outputs and results of the study. A cross sectional design with mixed methods (qualitative and quantitative) was used for this study. After the design, questionnaire items went through series of refinement process such as;

### ◆ Development of Question bank

Based on the literature review a conceptual framework was drawn to develop consultation tools. Based on this theoretical framework, all relevant items were developed in the question bank. Question bank contained items, coding for researches and area of assessment/objectives/indicators. The question bank was discussed and deliberated in-house (Lhak-sam and SDI) for further fine-tuning and relevancy check.

### ◆ 1st Stakeholder Consultation for refinement of the question bank

First consultation was held in 29th October, 2021 with members from UNICEF Bhutan, WHO Bhutan, RENEW, CSTU, NACP, HISC Counselor, Human of Thimphu, QVoB, Affected People, Lhak-sam members and SDI Consultant. During the meeting, study objectives, methodologies and survey tools were presented to the participants. Recommendations/comments/suggestion from the meeting were compiled and amended in the survey tools.

### ◆ 2nd Consultation with NSB

Following up to the recommendations and comments from the 1st stakeholder consultation meet, questionnaire items and study methodologies were presented and discussed with the expertise from the National Statistical Bureau (NSB). Based on this deliberation items were modified and coded for analysis later.

### ◆ 3rd Consultation with NACP

3rd Consultation meeting with NACP was held in 7th January, 2022 for further discussion on the study methodologies and areas of collaboration for data collection.



- ◆ Online/printed copy design of questionnaire

After finalizing the items, questionnaires were in-built online using google form. Options were also made to do the survey using printed copies.

- ◆ Pre-testing of the questionnaire

Questionnaires were then pre-tested in Thimphu with few respondents as a part of the training for the enumerators and also to identify issues related to the survey tools. Cronbach's Alpha analysis was carried out to measure internal consistency of the items.

Final 84 items were classified in different sections as shown below;

Section of questionnaire	No
Enumerators tracking	4
Section A - Demographic Profile	25
Section B - Family attitude towards PLHIV	6
Section C - Quality of Life - Family	31
Section D - stigma and discrimination	5
Section E - Food sufficiency and financial aspects	8
Section F - Beliefs and purpose in life	5

Table 1: Questionnaire section and itmes

#### 4. Sample design

Convenience sampling method was used to collect data from a conveniently available pool of respondents. Sample were selected merely based

on proximity, availability and willingness to participate in the survey. Owing to the lack of

population data, the representation in this study doesn't consider whether they represent the entire population or not. Using this technique, the study observed opinions and viewpoints of the studied population.

The general inclusion criteria were; age 18 years or older, able to decide on family matters, affected family member living with HIV and be able to understand the questionnaires provided. Prior to filling the set of questionnaires, the participants were informed about the purpose of the study and provided with an informed consent form.

Based on this technique, 82 people consented to participate in the survey and 8 people in FGDs.

#### 5. Training of Supervisors and enumerators

Lhak-Sam deployed 16 enumerators for this survey. Enumerators were from Lhak-sam, CSTU, HIC focal and QVoB. Two-days training on sampling procedure and administering questionnaires was organized for the enumerators. Mock demonstrations and field test were also organized during the training.

## 6. Field survey

The enumerators were divided into 3 team - West, Central and East. Each team was led by a supervisor. The survey was carried out from 16th July to 8th August 2022. The data were collected both online using google form and printed booklet at the convenience of the respondents and network reach. Prior to the survey administration, respondents were thoroughly briefed on the objective of the study and consent were seeded from the respondents. Survey locations were identified based on the convenience of the respondents.

All focus group discussions and interviews were conducted by the researcher who maintained reflexivity throughout analysis and writing by recording, debating, discussing, and questioning presumptions. The researcher also kept reflective notebooks. To facilitate discussion and maintain consistency, a semi-structured interview guide (questionnaires) was used during the focus group discussion to extricate information relating to the quality of life and their well-being. The discussion revolved around their attitude, beliefs, physical health, mental health, independence, social relations, stigma and discrimination, environment, health services, and economic challenges. Further, the participants were also asked to describe their focused life history before getting infected with HIV and life thereafter reflecting on their experiences to elicit information on their behavioural risk factors. Often probing questions and trigger questions were employed to extract consistent information from among the participants.

Using a mobile audio recorder, the discussions were audio recorded which were then transcribed into texts.

## 7. Data entry, cleaning and processing

On a daily basis, the enumerated questionnaires were reviewed for its completeness. All the completed survey questionnaires were coded and stored for data entry. A team of data punchers transferred the data from the questionnaire to SPSS. Upon entry again on a daily basis, the entered data was cleaned for errors of omission. All the data was processed in SPSS software and relevant quantitative information was generated.

For FGD data, using the Tagut software, content analysis was done. The keywords from the transcripts were categorized into different themes, and concepts using different colour codes. Once the primary and secondary coding was completed, the coded file was exported for further analysis. The team used an analytic matrix to identify patterns and connections amongst the content domains.

## 8. Data analysis

Statistical analysis was performed using the Statistical package for Social Science (SPSS) software package, version 21.0. Data were presented using frequency and percentages, mean for descriptive variables, and testing between proportion using t-test to compare means, and

Chi-square and Fisher Exact tests to compare categorical differences. At all times,  $P < 0.05$  was considered as statistically significant.

## **9. Conceptual framework of the study**

The study cover 4 areas ;

1. Demographic profile: show findings related to gender, age, marital status, occupation, income, household members etc.
2. Family QoL: QoL is studied from various aspects of life like household income, housing type, food sufficiency and financial challenges. Adapted from a more validated instrument developed by Beach Centre Family QoL scale, the study also cover on areas like family interaction, parenting, emotional well-being, physical/material well-being and HIV-related support.
3. Indicators: findings related to 7 indicators were also presented in this study
4. Family attitude towards PLHIV– findings related to family support, empathetic feelings, satisfaction of the health care services, living with PLHIV were also presented. The conceptual framework is presented below;

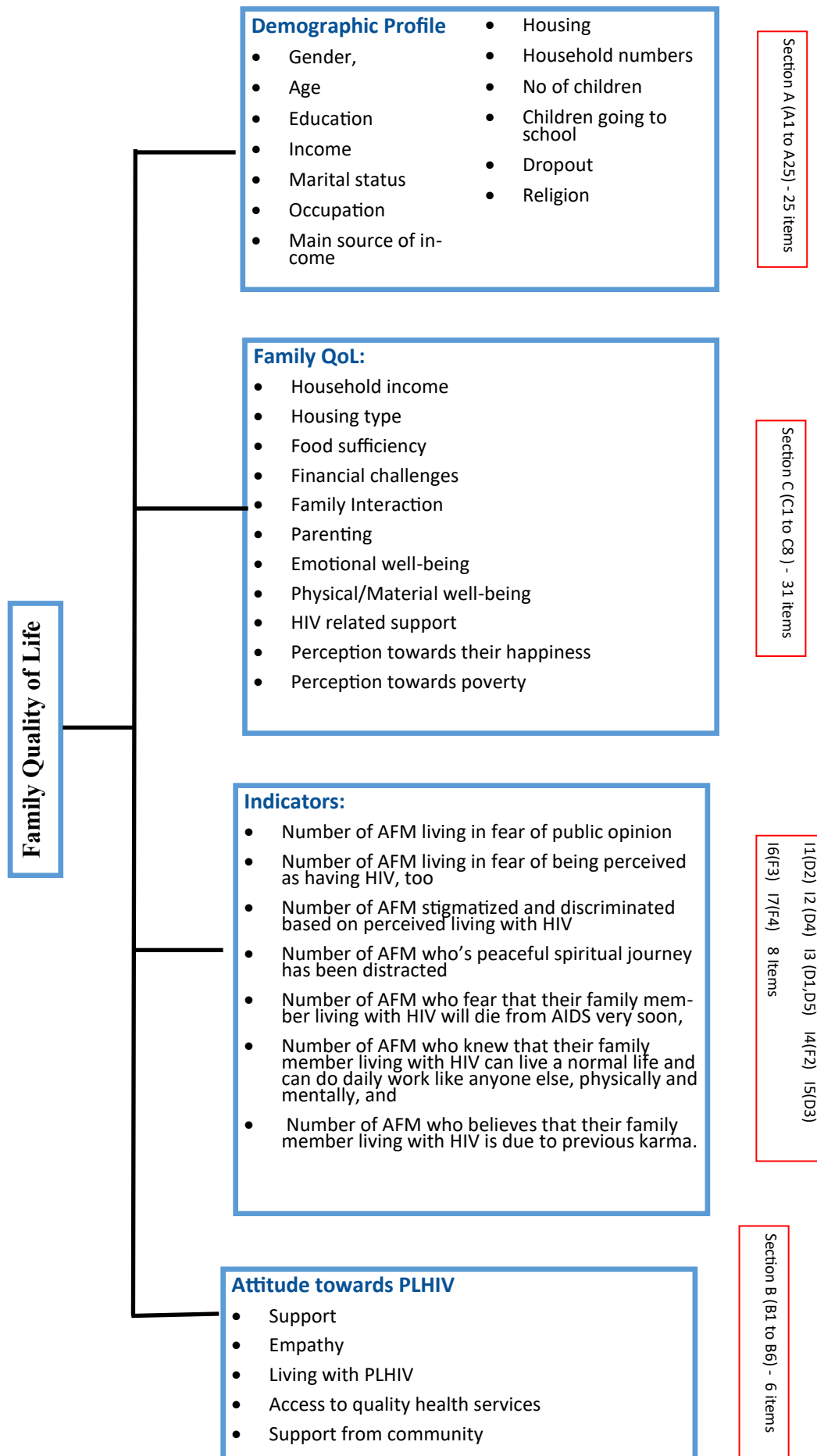


Figure 2: QoL Framework

# DEMOGRAPHIC CHARACTERISTICS

## Number of Respondents

There was a total of 82 valid responses to AFM survey. Not all participants responded to every question, and hence the n value differs for some questions. Throughout this report, we present the valid percentage of responses - that is the percentage of those who responded to a question.

## Gender

43.9 % (n=36) male and 56.1 %(n=46) female participated in this study (Table 1).

## Age

Respondents' ages ranged from 18 to 72, with an average age of 34.4 years. The average age of male is 37 years, which is higher than female average age of 32. Majority of the responses are from age range of 25-34 (35.4%) (Table 1).

## Marital status

Participants are mostly married (68.3%, n=56) (Table 1).

## Employment status

39.0% (n=34) are employed, 47.6%(n=39) unemployed and 13.4%(n=11) self employed participated in this study (Table 1).

## Occupation

Of the 39.0% employed, 14.6% (n=12) are working in private sector, civil servant (11%, n=9), 7.3% (n=6) in NGO, and 1.2%(n=1) in corporate. Those unemployed are from occupation categories like farmer (n=7), housewife (n=7), students (n=8), monk (n=2), unemployed youths (n=9), unemployed adults (n=4) and those who retired from services (n=2). (Table 1). Self-employed are the ones who run their own business (n=7) and work as a Taxi driver (n=4)

Demographic Profile	n	%	Demographic Profile	n	%	Demographic Profile	n	%
<b>Gender</b>			<b>Employment status</b>			<b>Education level</b>		
Male	36	43.9	Employed	32	39.0	Primary School	8	9.8
Female	46	56.1	Unemployed	39	47.6	Lower Secondary	6	7.3
Total	82	100.0	Self employed	11	13.4	Middle Secondary	14	17.1
<b>Age</b>			Total	82	100.0	Higher secondary	28	34.1
18-24	17	20.7	<b>Occupation</b>			Bachelor and above	9	11.0
25-34	29	35.4	Farmer	7	8.5	Monastic Education	4	4.9
35-44	22	26.8	Housewife	7	8.5	No schooling	13	15.9
45-54	9	11.0	Civil Servant	9	11.0	Total	82	100.0
55-64	2	2.4	Student	8	9.8			
65&above	3	3.7	Business	7	8.5			
Total	82	100.0	Private Sector	12	14.6			
<b>Marital status</b>			NGO	6	7.3			
Single	18	22.0	Armed Force	4	4.9			
Married	56	68.3	Corporate	1	1.2			
Living together	2	2.4	Unemployed	15	18.3			
Divorced	4	4.9	Monk	2	2.4			
Widowed	2	2.4	Driver	4	4.9			
Total	82	100.0	Total	82	100.0			

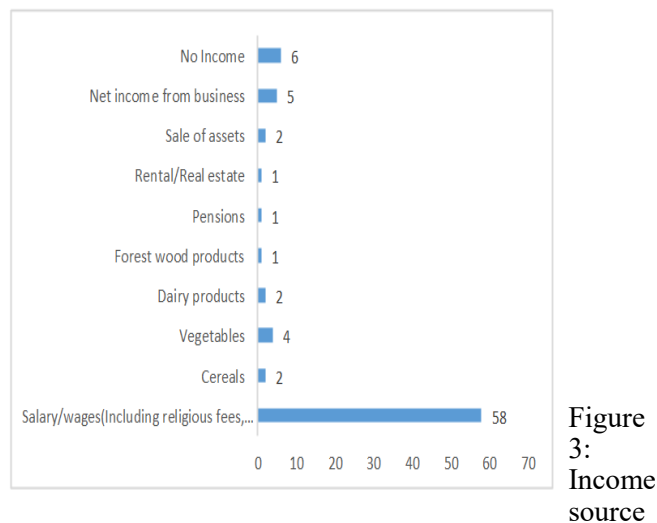
Table 1: Demographic profile of the participants

### Education

34.1% (n=28) of the respondents completed higher secondary. 17.1%(n=14) of them completed middle secondary level. 15.9% (n=13) of them did not attend any school. There were participants who have attended monastic education (n=4) as well.

### Income

The most common income source was salary and wages (70.7%, n=58) (Figure 3). Average monthly household income is Nu.30001.52 per month. Household Income ranges from lowest Nu.5000 to Nu.300000 per month. Majority of the respondents' live in a household, where at least 1-2 people earn income.



(n)

### Household information

Average household size is 4. With average number of male (1.7) and female (2.1) in the household. Majority of participants live in a household where there are at least 1 male (45.1%) and 2 female (31.7%).

### Housing arrangement

26.8%(n=22) participants live in their own house, without having to pay rent. 73.2%(n=60) participants do not own the house and majority of them live in private rental (45.1%) and government quarter (19%).

### Children

72%(n=59) participants reported having children below 18 years in their HH. Of this majority 39% (n=32) have 1 children below 18 years old. 15.9% (n=13) have 2 children, 12.2%(n=10) have 3 children, 1.2%(n=1) have 4 children and 3.7% (n=3) reported having 5 children below 18 years old. 53.7%(n=44) participants reported that their children attend school. Of this majority 24.4% (n=20), have at least 1 children going to school. 68.1%(n=32) of the children attend government day school, 21.3%(n=10) attend government boarding school. 6.1% (n=5) of them attend private schools. Convenience and affordability are the two main reasons for their choice of Government school over private school.

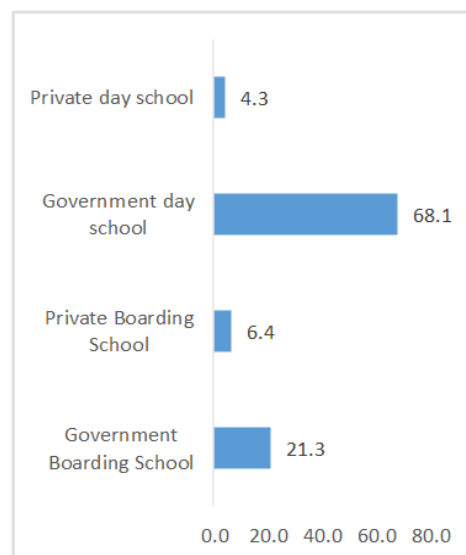


Figure 4: Choice of school

# QUALITY OF LIFE

Measuring QoL has become an important component in the evaluation of the wellbeing of people living with HIV/AIDs (PLHIV). Growing emphasis has now been given to a more family-centered approach towards HIV treatment and care. HIV has a significant and growing impact on families across the globe, especially in poorly resourced contexts, where already-struggling public health systems face an increasing burden of care<sup>6</sup>. Hence, understanding the families QOL is as important as the QoL of PLHIV.

As such there are no validated instrument for measuring the families QoL in the area of HIV. QoL aspects is measured though a more generic approach like using the question “how would you rate your quality of life.” and how are current family relations?<sup>4</sup>. For more in-depth understanding, the present study attempts to find out the family QoL using the general perception of their QoL, happiness rating using BLSS 2017, participants’ satisfaction level on four areas like family interaction, parenting, emotional well-being, physical well-being and HIV related supports<sup>7</sup>. Besides, the study will also present on important determinants of QoL like, income, housing type, food sufficiency and financial challenges.

Traditionally, families were thought of as being genetically related. Nowadays, families are defined more broadly<sup>2</sup>. In the present study, we understand

family as not just biologically related, it can be a friend/relative or anyone who provides care and support to the PHIV and impacts their daily living.

## Perception on the overall family QoL.

For this a question “overall how would you rate your QoL?” was used to measure the overall perception of the AFM’s QoL.

Ratings were from 1 to 5, where 1 would mean very poor to 5 very good. For the analysis and interpretation, we have categorized the rating into three scale Poor (clubbing very poor and poor), Neither poor nor good, and Good (clubbing good and very good).

Response shows that 57.3(n=47) reported good overall QoL. 3.7%(n=3) reported poor QoL

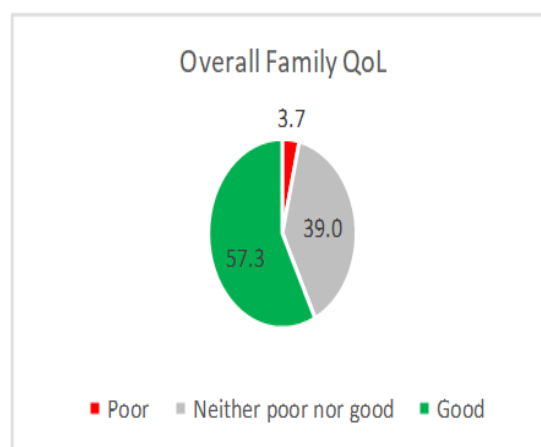


Figure 5: Overall QoL Rating

No significant relationship were observed between, perception towards overall Family Quality of Life and socio-demographic characteristics of the participants like gender, age, education, income, occupation, marital status and employment status (Annexure Table 1).



## Family interaction

Family interaction is understood as a process used to maintain relationships with siblings, parents, family, and other individuals and to reduce the sense of abandonment and loss that children experience at placement<sup>8</sup>. The present study aims at understanding family interaction among AFM living with HIV people. It is presented through 6 items (family time, open communication, problem solving, support to accomplish goals, love and care, ability to handle life's ups and downs).

Result shows overall mean of 4.08 indicating good family interaction. Highest mean (4.18) was observed in the item "My family members show that they love and care for each other", where 67 participants perceived that their family members show love and care for each other. Lowest mean (3.98) was observed in the item "My family talks openly with each other", where 61 participants are satisfied with this statement. 15 participants are neither satisfied nor dissatisfied with the statement and 6 participants dissatisfied with this statement (figure 6). *The indication is that, though majority of the families are satisfied with the level of openness, there are families who perceived that their family members do not talk openly with each other.*

Further it was observed that items like spending time together, open communication, problem solving, support to accomplish family goals, and ability to handle life's ups and downs are significantly associated with their perception toward overall QoL.

Result shows;

- *family members who spends time together*

*reported good overall QoL (p=0.000)*

- *Open communication within family members reported good overall QoL (p=0.000)*
- *Family members who solves problem together reported having good overall QoL (p=0.003)*
- *Having support to achieve/accomplish family goals reported good overall QoL (p=0.001)*
- *Family's ability to withstand life's ups and downs reported having good overall QoL (p=0.000)*

The results are shown in the annexure Table 2.

On family interaction, results from FGDs shows that the affected family members have the liberty and independence to do whatever they felt like doing. Any issue that requires family intervention is first discussed among the family members before finding an amicable solution.

## Parenting

Parenting is presented through 6 items (help children to be independent, help in school work and activities, teach how to socialize with others, make good decision, knowing about their child's friend & teachers, time for children). Result shows overall mean of 4.02 indicating good parenting practices at home. Highest mean (4.2) was observed in the item "Adults in the family teach children to make good decision", where, 62 of the respondents perceived that adults in their family teach children to make good decisions. Lowest mean (3.8) was observed in "Family members help children with schoolwork and activities". 49 participants feel that their family members help



children to do their school work and activities. 13 of them have neutral opinion and 11 participants perceived that they do not help children in doing their school works and activities (figure 7) .

From the FGD, It was found that the elderly members of the family guide their children and young ones as one child said during FGD, “My parents guide me to practice safe sex if we are in a relationship to prevent getting STIs and unwanted pregnancies”.

On the question of whether the participants or any family members attended any sort of parenting care training/workshop, majority 77.8% (n=63) reported that they have never attended such trainings. 8.6% (n=7) participants reported having attended few sessions organized at the school level only and 13.6% (n=11) participants don't know about such trainings/workshops. Further, FGD result substantiate that, none of the impacted family members interviewed is aware of any of their parents attending the training. 75.6% (n=62) felt the importance and need for parent trainings.

Further it was observed that items like family members help children learn to be independent, teach children to make good decisions, and give time to children's needs are significantly associated with the overall QoL (Annexure table 2).

It was observed that:

- *family member who help their children learn to be independent report overall good QoL (p=0.045)*
- *family member who teach children to make good decision reported overall good QoL*

(p=0.001)

- *family member who give time for their children's need reported overall good QoL (p=0.019)*

### Emotional well-being

This is represented through 4 items (support to relieve stress, have support from friend and others, time to pursue their own interests, and support from community to take care of PLHIV). Result shows overall mean of 3.64 indicating good emotional well-being. Highest mean (4.05) was observed in the item “My family has the support we need to relieve stress”, where 61 of the participants feel that their family have the support to relieve stress. Lowest mean was observed in the item “My family has outside help available to take care of PLHIV”. 49 participants reported having that support, 20 have neutral opinion and 23 participants perceived that they don't have the support from outsiders/communities to take care of PLHIV (figure 8). *It was evident that there are family members who perceived that they don't get outside help to take care of their PLHIV.*

Further it was observed that;

- *family members having support from friends or others reported good QoL (p=0.029)*

On asking about their emotional and mental health during FGD, all respondents reported being happy except for one case who reported suffering from depression. “Yes, my mother is depressed and is on medications. And she still does not agree to visit the hospital. She is completely silent and does not speak to us”.

When discussing their physical health, all respondents reported being physically fit, mentally strong, and sexually healthy. The leisure activities of the affected family members ranged from playing basketball, going for picnics, looking after their babies, etc.

### Physical/material well-being

This is presented through 4 items (mobility, access to health care services, handle expenses and safety). Result shows the overall mean of 3.98 indicating overall good physical/material well-being.

Highest mean (4.2) was observed in the statement “My family gets basic health care when needed”, where 68 participants reported that their family have access to basic health care services. Lowest mean was observed in the item “My family members have transportation to get to the places they need to be.” 49 participants reported having transportation facilities, and 19 participants reported not having this facility to get to the place they need to be (figure 9)

It was observed that;

- *Family who can manage/ take care of their family expenses reported having overall good QoL ( $p=0.002$ )*
- *Family who feels safe at home, work, school and in their neighborhood reported having overall good QoL ( $p=0.014$ )*

### HIV-related support

This is presented through 4 items (support to progress at school or workplace, support to make pro-

gress at home, support to make friends, and support for HIV –related care and treatment services). Result shows overall mean of 3.7 indicating good HIV-related support. Highest mean (4.1) was observed in the item “My family has a good support from the service providers who work with our family member with HIV”, where 66 participants reported having good support from the HIV service providers. Lowest mean (3.5) was observed in the item “My family member with PLHIV has support to make progress at school or workplace.” 44 participants reported that their family members with PLHIV has support to make progress at school or workplace. Whereas, 14 participants feel that they don’t have this support (Figure 10)

*Evidently, there are cases where family members perceived that they don’t get support to make progress at school or at the workplace.*

Further it was observed that;

- *Family member having support to progress at their home reported overall good QoL ( $p=0.012$ )*

While discussing HIV-related support for the infected family member, most of the affected family members in the group discussion reported that they received HIV medicines, counselling, and laboratory check-ups well on time either from HISCs or from the outreach workers as described by one of the participants, “We do get our ART medicines from the outreach worker while we get our blood check-up done in the hospital”.

On asking whether they have any suggestions to improve HIV-related health services, one participant said, *“When it comes to medical services, doctors need to be aware of all these things as there’s still stigma attached whenever the infected person visits them for medical check-ups. It mentally disturbs us, especially the weak ones like us”*.

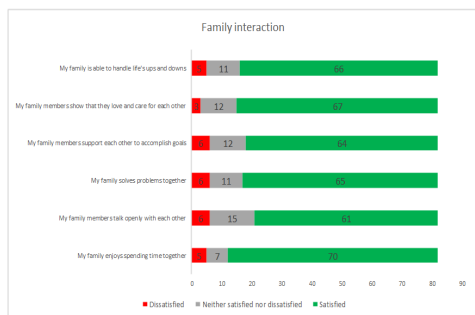


Figure 6: Family interaction

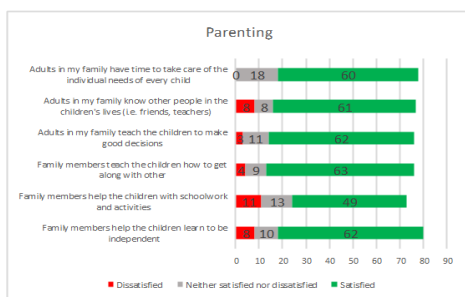


Figure 7: Parenting

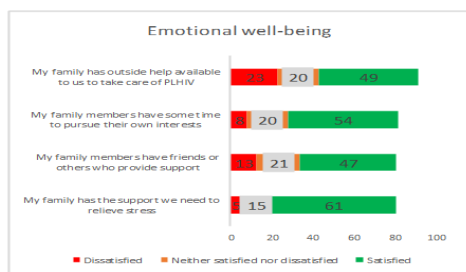


Figure 8: Emotional well-being

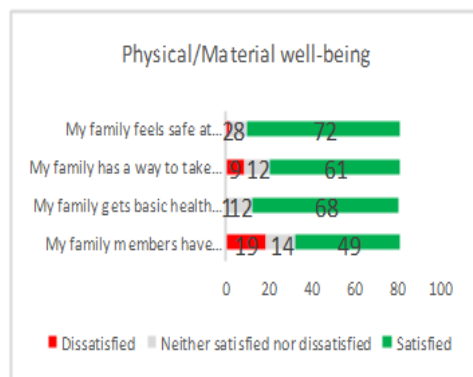


Figure 9: Physical/material well-being

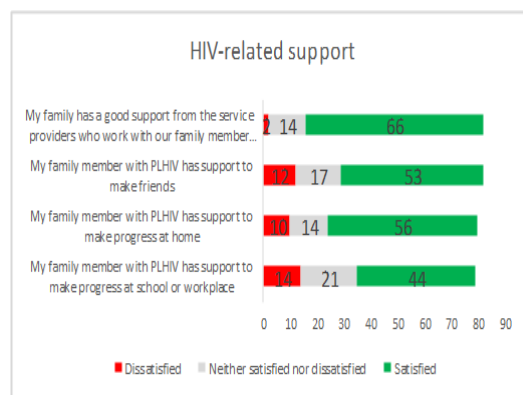


Figure 10: HIV-related support

# Household food sufficiency, poverty, financial challenges and happiness perception

Survey respondents were asked whether during the last 12 months the household has experienced food insufficiency (i.e not enough food to feed all household members). On this, only 7.4%(n=6) reported having experienced food insufficiency. Majority 87.7%(n=71) reported not having experienced food insufficiency. This is lower than the general population result, where 97% of the households in Bhutan reported sufficient food<sup>9</sup>. Further, it was found that 34.1%(n=28), reported that they couldn't afford to eat balanced meals (Table 3).

	Frequency	Percent
Yes	6	7.4
No	71	87.7
Not sure	4	4.9
<b>Total</b>	<b>81</b>	<b>100.0</b>

Table 2 : Cases of food insufficiency in the last 12 months.

	Frequency	Percent
Never true	47	57.3
Sometimes true	26	31.7
Often true	2	2.4
Don't know	7	8.5
<b>Total</b>	<b>82</b>	<b>100.0</b>

Table 3: In response to 'I/we couldn't afford to eat balanced meals'

On their perception towards poverty, 6.1%(n=5) participants reported that their household is poor. This is lower compared to the general population perception, where 15.3%<sup>9</sup> believed that their household is poor.

	Frequency	Percent
No	19	23.2
Neither poor nor unpoor	50	61.0
Poor	5	6.1
Don't know	8	9.8
<b>Total</b>	<b>82</b>	<b>100.0</b>

Table 4: In response to 'do you believe that your household is poor?'

On the general perception towards their happiness level, 73.1%(n=60) participants perceived themselves as happy. This is lower compared to the general population perception, where 75.5%<sup>9</sup> reported being happy<sup>9</sup>.

	Frequency	Percent
Very unhappy	2	2.4
Unhappy	2	2.4
Neither happy nor unhappy	18	22.0
Moderately happy	38	46.3
Very Happy	22	26.8
<b>Total</b>	<b>82</b>	<b>100.0</b>

Table 5 : In response to ' In general, how happy you consider yourself to be?'

Further it was found that, their perception towards happiness and QoL is significantly associated at p 0.000. *People who perceived themselves as happy, reported having good QoL.*

On the area of financial challenges, 22%(n=18) participants reported that they have faced financial challenges like not being able to pay bills, not

being able to pay rent or mortgage on time, going without meals, or needing to ask friends, family, relatives etc., for financial assistance. 73.2%(n=60) did not faced such financial issues, 4.9% (n=4) are unaware of such financial challenges. Further probing on this majority 48.1%(n=37) relied on their own savings and 44.2%(n=34) relied on borrowing from family/friends during emergencies.

When asked about the economic and financial hardships experienced by the family during FGD, most of them reported that it was painfully difficult during the Covid-19 lockdowns as one participant explained, *“At times we face some financial problems, but we were hit quite hard during the Covid-19 lockdowns”*.

# INDICATORS

## 1. Number of AFM living in fear of public opinion

39.0% (n=32) participants reported living in fear of public opinion (Table 6).

	Frequency	Percent
Yes	32	39
No	35	42.7
Not sure	15	18.3
<b>Total</b>	<b>82</b>	<b>100</b>

Table 6: No. of AFM living in Fear of Public opinion

## 2. Number of AFM living in fear of being perceived as having HIV too

19.5% (n=16) participants reported that they live in fear of being perceived as having HIV too.

	Frequency	Percent
Yes	16	19.5
No	66	80.5
<b>Total</b>	<b>82</b>	<b>100</b>

Table 7: No. of AFM living in fear of being perceived as having HIV

## 3. Number of AFM stigmatized and discriminated based on perceived living with HIV

9.7% (n=8) participants reported that their family member did experienced certain stigmatization and discrimination. Majority 90.2 % (n=74) reported not having experienced stigmatization and discrimination.

	Frequency	Percent
Never	74	90.2
Occasionally	2	2.4
Sometimes	5	6.1
Often	1	1.2
<b>Total</b>	<b>82</b>	<b>100.0</b>

Table8: Response to ‘in the last 12 months, did you experience any stigma and or discrimination due to PLHIV in your family?’

12.2%(n=10) participants reported that they have experienced stigma and discrimination from community. 3.7(n=3) from friends and 2.4%(n=2) from family. *It was observed that, when participants’ were asked on a general statement ‘In the last 12 months, did you experience any stigmatization and or discrimination due to PLHIV in your family, only 9.7%(n=8) reported having experienced stigmatization and or discrimination. However, upon probing questions, it was found that 18.3%(n=15) participants reported having experienced stigma and discrimination from community (12.2%,n=10), from friends (3.7%, n=3) and from family (2.4%, n=2). 81.7(n=67) have never experienced stigma and or discrimination.*

It is also evident from the FGD that stigma and discrimination is prevalent among the society. On enquiring about social stigma and discrimination that they face from their friends, neighbours, and relatives, many said that if they had not faced any stigma or discrimination, it was purely because they did not disclose the HIV status of the infected family member to others. Otherwise, once the HIV

status is known, there is widespread stigma and discrimination in society as one of the respondents said, *“On knowing that my parents were infected with HIV, I and my sister were expelled from the school. The landlord even evicted our family from the rented building on the same night of knowing the HIV status of my parents”*. Another retorted that they had to relocate to a different place because of severe discrimination from students and teachers in one of the schools where their children were studying. *“They’d badmouth saying that their parents take HIV medicines because they are HIV positive. And when we discussed it with school authorities, they never listened and never tried to help us. So, we decided to move here”*. However, at the present school where their children are admitted, the school teachers and students are understanding, helpful, and well-behaved with their children.

Another respondent said that because of severe discrimination at the workplace, her mother was expelled from the weaving training while her father had to quit going to the gym. Further, another participant added, *“Knowing that my mother is HIV positive, she would be deliberately kept in the last line and was treated differently whenever she visited the hospital with dental problems. It is quite appalling”*. In another incident, a friend accused the family saying that *“Your mother got HIV because she’s a prostitute.”*

#### 4. Number of AFM who’s peaceful spiritual journey has been distracted

Majority 82.7%(n=67) participants reported that they get time to pursue spiritual activities, whereas only 8.6%(n=7) reported not getting time for spir-

itual activities.

	Frequency	Percent
Yes	67	82.7
No	7	8.6
Don't know	7	8.6
<b>Total</b>	<b>81</b>	<b>100</b>

Table 9: Response to ‘do your family get time to pursue spiritual activities?’

#### 5. Number of AFM who believes that their family member living with HIV is due to previous karma.

On their believe towards karma, 58%(n=47) of the participants agree to the statement ‘HIV is a result of previous karma. 23.5% (n=19) participants disagree to the statement and 18.5% (n=15) have neutral opinion.

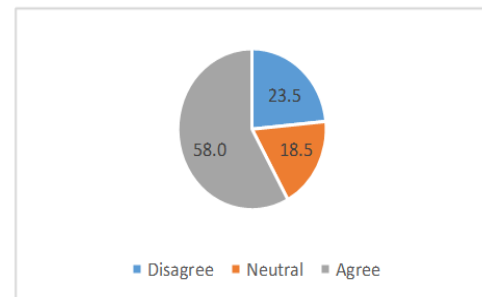


Figure 11: Response to ‘HIV is a result of previous karma.

Similar to the beliefs held by the people infected by HIV, the affected family members also gave a mixed response with regards to past life actions and present life sufferings. One of the participants said, *“I believe 50-50 because sometimes I do feel it’s because of their Karma but sometimes I believe it’s because of themselves - not taking proper care of themselves”*.

#### 6. Number of AFM who fear that their family member living with HIV will die from AIDS very soon

29.6%(n=24) participants fear that PLHIV in their family will die from AIDS soon.

	Frequency	Percent
Yes	24	29.6
No	32	39.5
Can't say	25	30.9
<b>Total</b>	<b>81</b>	<b>100</b>

Table 10 : Response to ‘ do you fear that your family member living with HIV will die from AIDS soon.

#### 7. Number of AFM who fear that their family member living with HIV can’t do any work

87.3% (n=69) participants believe that their family member living with HIV can live and work like any other normal people as oppose to 12.7% (n=10) participants , who believe that their family member living with HIV can’t live and work like any other normal people.

	Frequency	Percent
Strongly disagree	3	3.8
Neither agree nor disagree	7	8.9
Agree	23	29.1
Strongly agree	46	58.2
<b>Total</b>	<b>79</b>	<b>100.0</b>

Table 11: Response to ‘ i/we believe that my family member can live a normal life and can do daily work like anyone else, physically and mentally

One of the FGD respondent of the affected family member was more positive in her outlook when she said, *“I feel like it’s a blessing in disguise. Because of HIV, my sister got employed and we have friends and a community that supports us. If it weren’t for HIV then she would have been unemployed because she is uneducated and would have been struggling in life”*. Further, all the affected family members reported becoming more religious once one of their family members became infected with HIV and sought solace and fortitude in Him.



# Attitude towards PLHIV

Qualitative results shows mix- responses when queried about family support and connections. While some of the family members and relatives supported them, others did not help them. Even within the core circle of their friends, they were apprehensive at the beginning, which however became better later on as one respondent said, “*A friend of mine didn’t support me at first but I didn’t mind because she lived her whole life in the village and wasn’t exposed to such things. But later on, she accepted and supported me*”. From the quantitative data, majority 98.7%(n=77) reported that they support PLHIV in their family (Table).

	Frequency	Percent
Yes	77	98.7
No	1	1.3
<b>Total</b>	<b>78</b>	<b>100.0</b>

Table 12: In response to ‘do you support your family member living with HIV?’

93.9 %(n=77) participants reported that they feel comfortable living with HIV. 6.1 %(n=5) participants reported not feeling comfortable living with HIV (Table).

	Frequency	Percent
Yes	77	93.9
No	5	6.1
<b>Total</b>	<b>82</b>	<b>100.0</b>

Table 13: In response to ‘do you feel comfortable living with HIV in your family?’

90.1%(n=73) participants feel empathetic towards PLHIV in their family. However, there are cases 9.9%(n=9) participants who don’t feel empathetic towards PLHIV.

	Frequency	Percent
Yes	73	90.1
No	8	9.9
<b>Total</b>	<b>81</b>	<b>100.0</b>

Table 14: In response to ‘ do you feel empathetic towards PLHIV?’

On the question of whether their family member living with HIV have access to quality counseling and treatment services, 81.7%(n=67) reported having access that access, 1.2%(n=1) reported no access and 17.1%(n=14) are unsure about this.

	Frequency	Percent
Yes	67	81.7
No	1	1.2
Notsure	14	17.1
<b>Total</b>	<b>82</b>	<b>100.0</b>

Table 15: In response to ‘do you think your family member living with HIV have access to quality counseling and treatment services?’

Still majority (63.4%,n=52) of the respondents’ are unsure whether they get support from the community or not. Drawing evidences from the qualitative findings reasons could be non-disclosure of HIV status for fear of stigma and discrimination, thus not seeking support form the community.

	Frequency	Percent
Yes	25	30.5
No	5	6.1
Notsure	52	63.4
<b>Total</b>	<b>82</b>	<b>100.0</b>

Table: In response to In general do you get the kind of support from the community?

On the question of what they feel are the main support needed for PLHIV, most common responses are emotional support, timely treatment, care and counseling, self motivation and nutritional support.

## Implications for practices

Family support and care is identified as one of the most important factor for improving PLHIV's QoL as per the PLHIV STUDY 1. Study found that interventions and strategies are more focused towards PLHIV, especially on HIV treatment and care. Infection with HIV, however, also has an impact on the individual's family. It has large psychological, physical and social impact on infected individual and their families. Stigmatization worsen this impact, it hinders the prevention and treatment of HIV and hampers social and HIV disclosure<sup>2</sup>.

### Strengthening QoL

57.3%(n=47) participants reported having good QoL as per this study. 3.7%(n=3) reported poor QoL. Overall good QoL is observed with families having positive family interactions, good parenting, families who feel safe at home/workplace, and with those families who have outside support to progress on their family matters. Such practices need to be continued and inculcated among the families living with HIV.

While most participants reported having good QoL, there are also participants reporting challenges like experiencing financial stress (22%,n=18) and food insufficiency (7.4%,n=6) that hinders their daily living and QOL.

Advocacies can be done with Government and policy makers for support and program interventions. Lhak-Sam could also initiate a talk

with corporate and private industries as a more corporate social responsibility support to theses affected groups. Relevant poverty data can be provided to Royal Kidu for support and assistance too. Lhak-Sam could also initiate, client services to provide immediate emergency crisis intervention to such AFM experiencing distress.

### Aggressive advocacy programs

39% (n=32) AFM fear public opinion, 19.5% (n=16) AFM perceived themselves as having HIV after living with HIV member, 18.3% (n=15) experienced stigma and discrimination. The prevalence of stigmatization and discrimination is still a concern for PLHIV and AFM. Investments need to be diverted for aggressive advocacy programs influencing social, economic, policy, and procedural improvement and change that are creating barriers and affecting achieving zero new HIV infections, zero discrimination, and zero AIDS-related death by 2030.

### Social connectedness

PLHIV STUDY 1 Found that participants feel comfortable sharing their HIV status to health officials (84.1%,n=201) and then to the family (46.9%,n=112). Only 5.4% (n=13) feel comfortable sharing their HIV status to public, and most fear stigma and discrimination for HIV disclosure. This is where the community sector support play a major role in improving QoL.

Social support groups can be formed to promote active engagement among AFM through activities like group meetings, discussions, social and

educational events. Such activities have positive impact on reducing stress, isolation reduction and in promoting culture of help.

There are avenues for HIV communications - Speak out Newsletter, PLHIV Talk, PLHIV Blog. These avenues provides opportunities to reflect the voice of AFM, their thoughts, feelings and aspirations over the course of their life journey.

### Strengthen In-house data management

Strengthening present data management practice at Lhak-Sam is also an important step towards planning any future advocacy programs and researches. AFMs profile like ( Age, Gender, Address, Education, Occupation, Contact, have/have not attended treatment literacy or advocacy before, beneficiaries or not, etc). Such data will have reach inputs in defining target participants for any future advocacy programs/events/activities, define success indicators/level of reach, fine tuning the advocacy program contents that is gender sensitive, age inclusive and at par with participants' literacy level.

### Spiritual and wellbeing sessions

When discussing their belief of present life suffering due to their past actions, there were mixed responses, many believed that it was due to the retributions of their Karma, while some of them reported that it was their own doing. Many also affirmed that they became more religious once one of their family members became infected with HIV and they sought solace and fortitude in God.

The study suggest organizing spiritual talks and sessions focusing on areas like training mind, stress relief, generating positive vibes, self-motivation, leadership in self, empathy, and kindness, etc.

### HIV Futures

With lack of AFM data, 82 AFM participation in this study is not representative of the actual number of AFM in Bhutan. They study also revealed the perceptions and experiences of PLHIV and affected family members rather than their actual behavior. Observations of the PLHIV and affected family members day to day interactions may have illuminated a better understanding of the QoL. Such inputs or researches need to be promoted at the HISC, VCT, CSTU for more in-depth understanding and because of their access to information and closeness to PLHIV. There is an ongoing need for stronger research, policy and practice collaborations for such studies in the near future..

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# ANNEXURE

Table 1: Demographic profiles and perception towards QoL

Overall how would you rate your quality of life?							
Factors	Very Poor	poor	Neither poor nor good	Good	Very good	Total	p value
Gender							
Male	0	2	12	16	6	36	0.324
Female	0	1	20	13	12	46	
Age Range							
18-24	0	0	7	5	5	17	0.330
25-34	0	0	11	12	6	29	
35-44	0	2	9	6	5	22	
45-54	0	0	4	3	2	9	
55-64	0	0	0	2	0	2	
65&above	0	1	1	1	0	3	
Marital status							
Single	0	1	6	6	5	18	0.998
Married	0	2	22	20	12	56	
Living together	0	0	1	1	0	2	
Divorced	0	0	2	1	1	4	
Widowed	0	0	1	1	0	2	
Education level							
Primary School	0	1	2	4	1	8	0.382
Lower Secondary	0	1	1	1	3	6	
Middle Secondary	0	0	6	8	0	14	
Higher secondary	0	1	11	8	8	28	
Bachelor and above	0	0	4	2	3	9	
Monastic Education	0	0	1	2	1	4	
No schooling	0	0	7	4	2	13	
Employment status							
Employed	0	1	12	13	8	34	0.725
Unemployed	0	2	15	10	9	36	
Self employed	0	0	5	6	1	12	
Occupation							
Farmer	0	0	4	3	0	7	0.804
Housewife	0	0	3	2	2	7	
Civil Servant	0	1	4	2	2	9	
Student	0	0	2	2	4	8	
Business	0	0	3	4	0	7	
Private Sector	0	0	3	5	4	12	
NGO	0	0	2	4	0	6	
Armed Force	0	0	1	2	1	4	
Corporate	0	0	1	0	0	1	
Unemployed	0	2	7	3	3	15	
Monk	0	0	0	1	1	2	
Driver	0	0	2	1	1	4	

Income						
5000	0	0	1	0	0	1 0.921
6000	0	0	1	0	0	1
8000	0	0	0	2	0	2
9000	0	0	0	1	0	1
10000	0	0	4	1	1	6
10400	0	0	0	0	1	1
10500	0	0	0	0	1	1
15000	0	0	3	0	1	4
16000	0	0	2	0	0	2
17000	0	0	1	0	0	1
18000	0	1	1	1	1	4
20000	0	0	3	6	3	12
21000	0	0	1	0	1	2
25000	0	0	0	1	1	2
27000	0	0	0	1	0	1
30000	0	0	3	2	1	6
31700	0	0	0	0	1	1
32500	0	0	0	1	0	1
33000	0	0	0	1	0	1
35000	0	0	1	1	1	3
36000	0	0	1	1	0	2
40000	0	0	0	1	0	1
41000	0	0	0	1	1	2
48000	0	0	1	0	0	1
50000	0	0	1	0	0	1
55000	0	0	0	0	1	1
56000	0	0	1	0	0	1
58000	0	0	0	1	0	1
60000	0	0	0	1	0	1
120000	0	0	1	0	0	1
300000	0	0	1	0	0	1

Table 2: Factors association with QoL

Family Interaction	Very Poor	Poor	Neither poor nor good	Good	Very good	Total	P value
My family enjoys spending time together							
Dissatisfied	0	1	4	0	0	5	0.000
Neither satisfied nor dissatisfied	0	0	5	1	1	7	
Satisfied	0	2	16	22	4	44	
Very satisfied	0	0	7	6	13	26	
My family members talk openly with each other							
Very dissatisfied	0	1	0	0	1	2	0.000
Dissatisfied	0	1	1	2	0	4	
Neither satisfied nor dissatisfied	0	0	9	6	0	15	
Satisfied	0	0	11	17	6	34	
Very satisfied	0	1	11	4	11	27	
My family solves problems together							
Very dissatisfied	0	0	0	0	1	1	0.003
Dissatisfied	0	1	3	1	0	5	
Neither satisfied nor dissatisfied	0	0	8	2	1	11	
Satisfied	0	2	10	20	4	36	
Very satisfied	0	0	11	6	12	29	
My family members support each other to accomplish goals							
Very dissatisfied	0	0	0	0	1	1	0.001
Dissatisfied	0	1	4	0	0	5	
Neither satisfied nor dissatisfied	0	0	8	4	0	12	
Satisfied	0	1	9	18	3	31	
Very satisfied	0	1	11	7	14	33	
My family members show that they love and care for each other							
Dissatisfied	0	1	1	1	0	3	0.092
Neither satisfied nor dissatisfied	0	0	7	3	2	12	
Satisfied	0	1	12	16	5	34	
Very satisfied	0	1	12	9	11	33	
My family is able to handle life's ups and downs							
Very dissatisfied	0	1	1	0	0	2	0.000
Dissatisfied	0	1	2	0	0	3	
Neither satisfied nor dissatisfied	0	0	8	2	1	11	
Satisfied	0	0	11	21	5	37	
Very satisfied	0	1	10	6	12	29	

Parenting	Very Poor	Poor	Neither poor nor good	Good	Very good	Total	P value
Family members help the children learn to be independent							
Very dissatisfied	0	1	0	1	0	2	0.045
Dissatisfied	0	1	4	1	0	6	
Neither satisfied nor dissatisfied	0	0	4	4	2	10	
Satisfied	0	0	14	16	5	35	
Very satisfied	0	1	10	6	10	27	
Family members help the children with schoolwork and activities							
Very dissatisfied	0	0	0	1	0	1	0.656
Dissatisfied	0	1	5	3	1	10	
Neither satisfied nor dissatisfied	0	1	5	4	3	13	
Satisfied	0	0	10	12	5	27	
Very satisfied	0	0	9	6	7	22	
Family members teach the children how to get along with others							
Dissatisfied	0	0	2	2	0	4	0.29
Neither satisfied nor dissatisfied	0	1	6	1	1	9	
Satisfied	0	1	13	15	6	35	
Very satisfied	0	0	11	8	9	28	
Adults in my family teach the children to make good decisions							
Very dissatisfied	0	0	0	1	0	1	0.001
Dissatisfied	0	1	0	1	0	2	
Neither satisfied nor dissatisfied	0	0	9	1	1	11	
Satisfied	0	1	8	13	5	27	
Very satisfied	0	0	15	9	11	35	
Adults in my family know other people in the children's lives (i.e. friends, teachers)							
Very dissatisfied	0	0	1	0	0	1	0.180
Dissatisfied	0	1	5	1	0	7	
Neither satisfied nor dissatisfied	0	0	5	2	1	8	
Satisfied	0	1	14	19	9	43	
Very satisfied	0	0	7	4	7	18	
Adults in my family have time to take care of the individual needs of every child							
Neither satisfied nor dissatisfied	0	0	13	4	1	18	0.019
Satisfied	0	2	10	16	7	35	
Very satisfied	0	0	9	7	9	25	



Emotional well-being	Very Poor	Poor	Neither poor nor good	Good	Very good	Total	P value
My family has the support we need to relieve stress							
Very dissatisfied	0	0	1	1	0	2	0.658
Dissatisfied	0	0	2	1	0	3	
Neither satisfied nor dissatisfied	0	1	7	5	2	15	
Satisfied	0	0	11	14	5	30	
Very satisfied	0	1	11	8	11	31	
My family members have friends or others who provide support							
Very dissatisfied	0	0	0	2	2	4	0.029
Dissatisfied	0	1	5	3	0	9	
Neither satisfied nor dissatisfied	0	1	8	9	3	21	
Satisfied	0	0	14	13	5	32	
Very satisfied	0	1	4	2	8	15	
My family members have some time to pursue their own interests							
Very dissatisfied	0	0	0	1	0	1	0.337
Dissatisfied	0	1	4	1	1	7	
Neither satisfied nor dissatisfied	0	1	11	5	3	20	
Satisfied	0	1	12	18	8	39	
Very satisfied	0	0	5	4	6	15	
My family has outside help available to us to take care of PLHIV							
Very dissatisfied	0	1	4	3	1	9	0.296
Dissatisfied	0	0	8	4	2	14	
Neither satisfied nor dissatisfied	0	1	6	11	2	20	
Satisfied	0	0	10	9	8	27	
Very satisfied	0	1	4	2	5	12	
Physical	Very Poor	Poor	Neither poor nor good	Good	Very good	Total	P value
My family members have transportation to get to the places they need to be							
Very dissatisfied	0	1	4	3	2	10	0.495
Dissatisfied	0	1	4	3	1	9	
Neither satisfied nor dissatisfied	0	1	8	2	3	14	
Satisfied	0	0	6	12	7	25	
Very satisfied	0	0	10	9	5	24	
My family gets basic health care when needed							
Very dissatisfied	0	0	0	0	1	1	0.518
Neither satisfied nor dissatisfied	0	1	7	3	1	12	
Satisfied	0	1	11	11	9	32	
Very satisfied	0	1	13	15	7	36	

<b>My family has a way to take care of our expenses</b>						
Very dissatisfied	0	0	1	0	1	2
Dissatisfied	0	1	5	1	0	7
Neither satisfied nor dissatisfied	0	1	8	3	0	12
Satisfied	0	0	13	17	4	34
Very satisfied	0	1	5	8	13	27
<b>My family feels safe at home, work, school, and in our neighborhood</b>						
Very dissatisfied	0	0	0	1	0	1
Dissatisfied	0	0	0	0	1	1
Neither satisfied nor dissatisfied	0	1	6	1	0	8
Satisfied	0	2	15	21	5	43
Very satisfied	0	0	11	6	12	29

HIV Related Support	Very Poor	Poor	Neither poor nor good	Good	Very good	Total	P value
My family member with PLHIV has support to make progress at school or workplace							
Very dissatisfied	0	0	0	2	2	4	0.391
Dissatisfied	0	1	5	3	1	10	
Neither satisfied nor dis-satisfied	0	1	10	6	4	21	
Satisfied	0	0	9	15	6	30	
Very satisfied	0	0	7	3	4	14	
My family member with PLHIV has support to make progress at home							
Very dissatisfied	0	0	1	1	2	4	0.012
Dissatisfied	0	0	4	1	1	6	
Neither satisfied nor dis-satisfied	0	1	10	1	2	14	
Satisfied	0	0	9	20	4	33	
Very satisfied	0	1	7	6	9	23	
My family member with PLHIV has support to make friends							
Very dissatisfied	0	0	1	0	1	2	0.454
Dissatisfied	0	0	4	4	2	10	
Neither satisfied nor dis-satisfied	0	2	8	5	2	17	
Satisfied	0	1	12	16	6	35	
Very satisfied	0	0	7	4	7	18	
My family has a good support from the service providers who work with our family member with HIV.							
Very dissatisfied	0	0	0	0	1	1	0.273
Dissatisfied	0	0	1	0	0	1	
Neither satisfied nor dis-satisfied	0	1	7	3	3	14	
Satisfied	0	0	14	17	4	35	
Very satisfied	0	2	10	9	10	31	

# SURVEY QUESTIONNAIRE

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Affected Family Member Questionnaire

## Affected Family Member Questionnaire

Kuzuzangpo la!

You are invited to participate in a research study titled "Understanding the nature, structure, movement and severity of fear, prejudice and discrimination of AIDS and its impact on PLHIV and their dear and near ones." The study is conducted by Lhak-sam in collaboration with SDI consultancy with following objectives;

- 1.Assess health related quality of life of PLHIV through different domains using WHOQOL- HIV-BREF instrument and also to measure differences/impact based on their socio-demographic characteristics.
2. Use the findings to educate and sensitize relevant government agencies, policy makers, development partners and social welfare sectors to make inclusive and evidence based decision while planning and budgeting national social welfare and development programmes relating to PLHIV.
3. Use as a baseline study for future researches.

This questionnaire is for affected family members and your response represents your perception of the family relating to family quality of life aspects. You will be asked to complete an electronic survey using google form. Your participation in this study is voluntary and you are free to withdraw your participation from this study at any time. The survey should take only 30 minutes to complete.

This survey has been approved by Research Ethics Board of Health (REBH), Ministry of Health. There are no risks associated with participating in this study. The survey collects no identifying information of any respondent. All of the response in the survey will be recorded anonymously.

By completing and submitting this survey, you are indicating your consent to participate in the study. Your participation is appreciated.

Thank you!

Survey Records

This section is to be filled by enumerators only.

1. Questionnaire code

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Affected Family Member Questionnaire

2. 2. Name of the Enumerators

3. 3. Survey Date

Example: January 7, 2019

4. 4.Place of survey (mention Village, Gewog and Dzongkhag e.g Motithang, Thimthrom, Thimphu)

SECTION A:  
SOCIO-  
DEMOGRAPHIC  
CHARACTERISTICS

This section identifies respondents socio-demographic characteristics. Please select or indicate only one appropriate response for each area.

5. A.1 Village (Mention your current living address)

6. A.2 Gewog (Mention your current living gewog)

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Affected Family Member Questionnaire

7. A.3 Dzongkhag (Mention your current living Dzongkhag)

Mark only one oval.

☐ Bumthang

☐ Chhukha

☐ Dagana

☐ Gasa

☐ Haa

☐ Lhuentse

☐ Mongar

☐ Paro

☐ Pema gatshel

☐ Punakha

☐ Samtse

☐ Samdrup Jongkhar

☐ Sarbang

☐ Thimphu

☐ Trashigang

☐ Trashy Yangtse

☐ Trongsa

☐ Tsirang

☐ Wangduephodrang

☐ Zhemgang

8. A.4 Gender

Mark only one oval.

☐ Male

☐ Female

☐ Other:

9. A.5 Your age in completed years

10. A.6 Marital status

Mark only one oval.

☐ Single

☐ Married

☐ Living together

☐ Separated

☐ Divorced

☐ Widowed

11. A.7 Your highest education attainment

Mark only one oval.

☐ Primary school

☐ Lower Secondary

☐ Middle Secondary

☐ Higher secondary

☐ Certificate/Diploma

☐ Bachelors and above

☐ Monastic Education

☐ No schooling

12. A.8 I am currently

Mark only one oval.

- ☐ Employed
- ☐ Unemployed
- ☐ Self employed

13. A.9 Your occupation

\_\_\_\_\_

14. A.10 Number of income earning household member(s)

Mark only one oval.

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6 & above

<https://docs.google.com/forms/d/11GeVJfPuTCUx1YBgQTWJX6UkvsNhAjXz8SMvTR3xEU/edit>

5/23

15. A.11 In the last 12 months, what is the main source of income in your household?

Mark only one oval.

- ☐ Salary/wages (including religious fees, TA/DA)
- ☐ Cereals
- ☐ Fruits
- ☐ Vegetables
- ☐ Meat
- ☐ Dairy Products
- ☐ Eggs
- ☐ Forest wood products
- ☐ Forest non-wood products
- ☐ Potting
- ☐ Weaving
- ☐ Remittance received
- ☐ Pensions
- ☐ Rental/Real estate
- ☐ Inheritance
- ☐ Donations received
- ☐ Scholarships
- ☐ Sale of assets
- ☐ Net income from business

16. A.12 Any other income source, please specify?

\_\_\_\_\_

17. A.13 Average monthly household income in the year 2021

\_\_\_\_\_

<https://docs.google.com/forms/d/11GeVJfPuTCUx1YBgQTWJX6UkvsNhAjXz8SMvTR3xEU/edit>

6/23

18. A.14 Does the household own the dwelling?

Mark only one oval.

- ☐ Yes
- ☐ No

19. A.15 If no, from whom do you rent/obtain the dwelling?

Mark only one oval.

- ☐ Government quarter
- ☐ Public corporation
- ☐ Employer
- ☐ Private person
- ☐ Boarding house, crisis accommodation
- ☐ Other: \_\_\_\_\_

20. A.16 Total number of male in the household

Mark only one oval.

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6 & above

<https://docs.google.com/forms/d/11GeVJfPuTCUx1YBgQTWJX6UkvsNhAjXz8SMvTR3xEU/edit>

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21. A.17 Total number of female in the household

Mark only one oval.

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6 & above

22. A.18 Total number household members

Mark only one oval.

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6 & above

23. A.19 Total number of children below 18 years

Mark only one oval.

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6 & above

<https://docs.google.com/forms/d/11GeVJfPuTCUx1YBgQTWJX6UkvsNhAjXz8SMvTR3xEU/edit>

8/23

24. A.20 Total number of children attending school?

Mark only one oval.

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6 & above

25. A.21 Type of school your child is attending

Mark only one oval.

- ☐ Government boarding school
- ☐ Private boarding school
- ☐ Government day school
- ☐ Private day school
- ☐ school abroad (outside bhutan)

26. A.22 Any reasons for your choice of school?

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27. A.23 Any drop-out from school. How many?

---

<https://docs.google.com/forms/d/11GeVJIPuTCLUx1YBgQTWJX8UkvsNHjXz8SMvTR3xEU/edit>

28. A.24 What is your religion?

Mark only one oval.

- ☐ Buddhism
- ☐ Hinduism
- ☐ Christain
- ☐ Atheist
- ☐ Don't know
- ☐ No answer

29. A25.1 Other religion, please specify

---

Section B: Family attitude towards PLHIV

Select one appropriate response

30. B.1 Do you feel comfortable living with PLHIV in your family?

Mark only one oval.

- ☐ Yes
- ☐ No
- ☐ Maybe

31. B.2 Do you support your family member living with HIV?

Mark only one oval.

- ☐ Yes
- ☐ No

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<https://docs.google.com/forms/d/11GeVJIPuTCLUx1YBgQTWJX8UkvsNHjXz8SMvTR3xEU/edit>

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Affected Family Member Questionnaire

10/23

36. C.1 Overall how would you rate your quality of life? Rate from 1 to 5, 1 would mean very poor, 2 would mean poor, 3 would mean neither poor nor good, 4 would mean good and 5 would mean very good.

Mark only one oval.

	1	2	3	4	5	
Very poor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Very good

32. B.3 Do you feel empathetic towards people living with HIV?

Mark only one oval.

- ☐ Yes
- ☐ No

33. B.4 Do you think that your family member living with HIV have access to quality counseling and treatment services?

Mark only one oval.

- ☐ Yes
- ☐ No
- ☐ Not sure

34. B.5 In general, do you get the kind of support from the community ?

Mark only one oval.

- ☐ Yes
- ☐ No
- ☐ Not sure

35. B.6 What do you feel is the main support needed for PLHIV?

---

Section C: Overall Family's Quality of Life, parenting, family connection, emotional well-being and Physical/material well-being

Please respond to all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

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11/23

<https://docs.google.com/forms/d/11GeVJIPuTCLUx1YBgQTWJX8UkvsNHjXz8SMvTR3xEU/edit>

12/23

37. C.2 Following statements ask about your level of satisfaction towards factors like family interaction, parenting, emotional well-being, physical/material well-being and HIV related support which describes things that were "important for families to have a good life together." Please rate from 1 to 5, 1- very dissatisfied, 2-dissatisfied, 3- neither satisfied nor dissatisfied, 4-satisfied and 5-very satisfied.

Mark only one oval per row.

	1	2	3	4	5
C2.1 My family enjoys spending time together	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C2.2 My family members talk openly with each other.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C2.3 My family solves problems together.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C2.4 My family members support each other to accomplish goals.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C2.5 My family members show that they love and care for each other.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C2.6 My family is able to handle life's ups and downs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C2.7 Family members help the children learn to be independent.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C2.8 Family members help the children with schoolwork and activities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C2.9 Family members teach the children how to get along with others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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C2.10 Adults in my family teach the children to make good decisions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C2.11 Adults in my family know other people in the children's lives (i.e. friends, teachers).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C2.12 Adults in my family have time to take care of the individual needs of every child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C2.13 My family has the support we need to relieve stress.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C2.14 My family members have friends or others who provide support.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C2.15 My family members have some time to pursue their own interests.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C2.16 My family has outside help available to us to take care of PLHIV.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C2.17 My family members have transportation to get to the places they need to be.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C2.18 My family gets basic health care when needed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C2.19 My family has a	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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way to take care of our expenses.

C2.20 My family feels safe at home, work, school, and in our neighborhood.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C2.21 My family member with PLHIV has support to make progress at school or workplace.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C2.22 My family member with PLHIV has support to make progress at home.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C2.23 My family member with PLHIV has support to make progress at home.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C2.24 My family member with PLHIV has support to make friends.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C2.25 My family has a good support from the service providers who work with our family member with HIV..	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

38. C.3 Who makes the major decision for child in your family?

\_\_\_\_\_

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39. C.4 Did anyone in your family attended any parental care workshop?

Mark only one oval.

- ☐ Yes  
☐ No  
☐ Don't know

40. C.5 If yes, where did he/she attend the meeting, duration of training and training funded by? (e.g Skills Development Institute, 7 days, RGOB)

\_\_\_\_\_

41. C.6 If no, do you feel the need for such training in the near future?

Mark only one oval.

- ☐ Yes  
☐ No  
☐ Don't know

42. C.7 In general, how happy you consider yourself to be? 1-Very unhappy, 2-Moderately unhappy, 3-Neither happy nor unhappy, 4-Moderately happy and 5-Very happy

Mark only one oval.

	1	2	3	4	5
Very Unhappy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Very happy					

<https://docs.google.com/forms/d/11GeVJPuTCUx1YBgQTWjX6UkvsNHjXz8SMvTR3dEU/edit>

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43. C.8 Do you believe that your household is poor?

Mark only one oval.

- ☐ No  
☐ Neither poor nor unpoor  
☐ Poor  
☐ Very poor  
☐ Don't know

Section D: Experience of stigma and discrimination, fear of public opinion and death

Select one appropriate responses.

44. D.1 In the last 12 months, did you experience any stigma and or discrimination due to PLHIV in your family?

Mark only one oval.

- ☐ Never  
☐ Occasionally  
☐ Sometimes  
☐ Often  
☐ Always

45. D.2 Do you fear of public opinion of having PLHIV in your family?

Mark only one oval.

- ☐ Yes  
☐ No  
☐ Not sure

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46. D.3 Do you fear that your family member living with HIV will die from AIDs soon?

Mark only one oval.

- ☐ Yes  
☐ No  
☐ Can't say

47. D.4 Do you fear of being perceived as HIV positive when you live with HIV person in your family?

Mark only one oval.

- ☐ Yes  
☐ No

48. D.5 I/We have experienced stigma and/or discrimination mainly from. Select one appropriate response from the following.

Mark only one oval.

- ☐ Community  
☐ Friends  
☐ Family  
☐ Employer

Section E: Food sufficiency and financial aspects

Please choose one appropriate response

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49. E.1 In the last 12 months, has a situation been faced when there was not enough food to feed all members of the household?

Mark only one oval.

- ☐ Yes  
☐ No  
☐ Not sure

50. E.2 I/we couldn't afford to eat balanced meals

Mark only one oval.

- ☐ Never true  
☐ Sometimes true  
☐ Often true  
☐ Don't know

51. E.3 In the last 12 months, did you face any financial challenges (including not being able to pay bills, not being able to pay rent or mortgage on time, going without meals, or needing to ask friends, family or services for financial assistance)?

Mark only one oval.

- ☐ Yes  
☐ No  
☐ Don't know

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52. E.4 What is the main option for the household during emergencies?

Mark only one oval.

- ☐ Use own savings  
☐ Borrow from family/friends  
☐ Borrow from money lender  
☐ Borrow from savings committee  
☐ Liquidate assets (e.g sale of livestock)  
☐ Other: \_\_\_\_\_

53. E.5 Do you or anyone in your household have saving/deposit account?

Mark only one oval.

- ☐ Yes  
☐ No  
☐ Don't know

54. E.6 Does any member of your household have loan?

Mark only one oval.

- ☐ Yes  
☐ No  
☐ Don't Know

55. E.7 Type of loan availed?

\_\_\_\_\_

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56. E.8 Have you availed any insurance services? What insurance products/schemes have you availed? (Mark all that apply)

Check all that apply.

- ☐ None  
☐ Life insurance  
☐ Health insurance  
☐ Crop insurance  
☐ Property insurance (assets, livestock, housing)  
☐ Other: \_\_\_\_\_

#### Section F: Beliefs and purpose in life

57. F.1 HIV is a result of previous karma

Mark only one oval.

- ☐ Strongly disagree  
☐ Disagree  
☐ Neither agree nor disagree  
☐ Agree  
☐ Strongly agree

58. F.2 Do your family get time to pursue spiritual activities?

Mark only one oval.

- ☐ Yes  
☐ No  
☐ Don't know

59. F.3 I believe that my family member who is living with HIV is dependent and can not do any work?

Mark only one oval.

- ☐ Strongly disagree  
☐ Disagree  
☐ Neutral  
☐ Agree  
☐ Strongly agree

60. F.4 I believe that my family member who is living with HIV can live a normal life and can do daily work like anyone else, physically and mentally?

Mark only one oval.

- ☐ Strongly disagree  
☐ Disagree  
☐ Neutral  
☐ Agree  
☐ Strongly agree

61. F.5 Please feel free to share any other comments or suggestion if you have?

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