

## Interview Guidelines with Parents of Adult Children Living with or Who Died of AIDS

### 1. Introduction

- a. Describe the purpose of the project and the visit. (Including- ask when child died.)
- b. Confirm that interview is voluntary.
- c. Request permission to tape interview.
- d. Stress that the interviewee is free not to talk about any particular issue and/or terminate interview at any time.

## **BACKGROUND**

### 2. Background Characteristics of Respondents

*Note to Interviewer- Ask both parents if they are present. If only one parent is present, also ask these things about the spouse who is not there.*

- a. Ask about background of Respondent.

*Note to Interviewer-*

*Where from*

*How long lived here*

*Age*

*Education*

*Work*

*Spouse- still married? Where spouse lives. Spouse's background.*

- b. Ask about other people in the household.

*Note to Interviewer-*

*Who*

*Age*

*Education*

*School*

- c. Ask about children of the Respondent.

*Note to Interviewer-*

*Where are they now*

*Have any other children died, besides (name)*

### 3. Characteristics of the Person who died of AIDS

*Note for Interviewer- Ask about most recent case if there is more than one AIDS death*

- a. How about (name)? Please tell us a little about him/her before the sickness.

*Note for Interviewer-*

*What kind of person was (name)? (Well liked, well behaved, troublemaker...)*

*Where was (name) living before s/he got sick?*

*Did (name) move in with you at any time?*

*Why did (name) move in with you?*

*Had (name) ever gone to school?*

*What kind of work was (name) doing?*

*Did (name) work for the family business, on the farm, or do household duties?*

*Did (name) give money to your household or send remittances (if s/he lived away)?*

- b. Did (name) have a family/children?

*Note to Interviewer-*

*Please tell me more about (name)'s family.*

*What happened to the family?*

#### **CAREGIVING AND SUPPORT FOR CAREGIVING**

##### **4. Caregiving to PWA**

a. Did you care for (name) while s/he was sick?

b. (If yes)- What did you do to care for (name)?

*Note to Interviewer-*

*Did this change in the course of (name)'s illness?*

*How so?*

*Were there any special things you did to care for (name)?*

c. (If no)- Why not? Who cared for (name)?

d. (If bandages and blood not mentioned) Did you have to change bandages or handle any blood from (name)?

*Note to Interviewer-*

*(If yes): Could you describe what you do with the bandages and/or blood?*

e. Did you get any advice or training from anyone on how to care for (name)?

*Note to Interviewer-*

*Please tell me more about this.*

*Who gave you the advice?*

*What did they tell you?*

*Was the advice/training helpful?*

##### **5. Knowledge and Beliefs about HIV/AIDS and caregiving**

a. What is the best way to help keep a person with HIV/AIDS healthy?

*Note to Interviewer-*

*What are the best treatments for their illness?*

*What sort of things do they need to eat and do?*

*What sort of things do they need to avoid eating and doing?*

b. Did you have any concerns about giving care to (name)?

*Note to Interviewer-*

*Did you ever worry about becoming infected? From living in the same house, eating together, touching (name), touching (name)'s blood?*

c. Where did you learn how to care for (name)?

*Note to Interviewer-*

*Health clinic or hospital, home-based care team, NGO, radio, TV, ...*

##### **6. ART and medications**

(If Respondent hasn't mentioned ART or medications)

a. Have you heard of any modern medications that can help HIV/AIDS?

*Note to Interviewer- Have you heard of ART?*

b. Did (name) receive ART?

*Note to Interviewer-*

*From where, from who?*

*Who gave the medications (ART) to (name) every day?*

*(If respondent did)- Did someone tell you how to properly give the medications?*

*How did you feel about giving the medications? Was it easy/hard?*

- c. Do you think the medications helped? How so?
- d. Did (name) take any other modern medications?

*Note to Interviewer-*

*What kind of medications? For what?*

*From where/whom did (name) receive them?*

*Did someone tell you how to properly give the medications?*

*Do you think the medications helped? How so?*

7. Home-base care assistance

- a. Did anyone come to (name)'s home and help give care?

*Note to Interviewer-*

*Who came?*

*Did you ask them to come or did they offer help?*

*What did they do?*

*How often did they come?*

*Was it helpful?*

8. Support groups

- a. Did (name) ever go to any group meetings for people living with HIV/AIDS?

*Note to Interviewer-*

*Why or why not?*

*How often did s/he go to these meetings? Regularly or not regularly?*

*Did you or anyone else go with (name)? Were you invited to go?*

*Were the meetings helpful for (name)? How so?*

*Were the meetings helpful for you? How so?*

9. Treatment for PWA

- a. Please tell me about any places (name) went for treatment?

*Note to Interviewer-*

*Please tell me more about this.*

*Where did (name) go?*

*Why did (name) go to this place for treatment?*

*What kind of treatment did s/he receive?*

*How much did it cost? How did you pay for it?*

- b. Did (name) go anywhere else for treatment?

*Note to Interviewer- Keep asking this question until all treatments have been discussed.*

- c. (If never went to government clinic or hospital)- Why didn't (name) go to a government clinic or hospital?

*Note to Interviewer-*

*Financial, transport, attitude of staff, ...*

10. Other assistance for PWA

- a. Did any other family members, friends, or neighbors give any help to (name) during his/her illness or afterwards?

*Note to Interviewer-*

*Please tell me more about this.*

*Who helped?*

*How did they help? For example: health care, financial support, transport, help around the house/garden/other family care, funeral... anything else.*

- b. Did (name) receive any other kind of help or care from the government or any organization or group?  
*Note to Interviewer- For example- NGO, other formal program, wat/monks, community group, village health volunteer*
- c. (If yes)
  - i. Please tell me more about this.  
*Note to Interviewer-  
Who helped (name)?  
What kind of help did they give? (For example- care in the home, medications, emotional support, visiting, financial support, babysitting grandchildren, funeral ...)*
  - ii. Did you have to pay for this?
- d. Did anyone else give any help or care for (name)?  
*Note to Interviewer- Keep asking this question until all help and care has been discussed.*
- e. Were there any organizations in your community that provide help or care for PWA, but did not help (name)?
- f. (If yes)-  
*Note to Interviewer-  
Please tell me more about this.  
Why did they not help? Probe: financial, transport, refused to help...*

## **IMPACTS**

- 11. Financial impact related to illness and/or death of the PWA
  - a. Did you have many expenses associated with the care of (name)?  
*Note to Interviewer-  
What sorts of things did you have to pay for?  
How about medicines, travel expenses, doctor fees, ... ?)*
  - b. What about a funeral and other ceremonies after (name) died?  
*Note to Interviewer-  
What ceremonies did you have?  
How much were the funeral expenses?  
How did you pay for the funeral?  
Did community members come to the ceremonies? Did they give contributions?*
  - c. How much do you think you spent for (name)?
  - d. Did these expenses cause hardship for you and your family?  
*Note to Interviewer- Can you explain?  
Did you have to take extra work?  
Did caring interfere with working?*
  - e. Where did you get the money to pay for this?  
*Note to Interviewer-  
From savings, selling assets (land, animals...), sell gold, borrow money*
  - f. Did any other family members help pay for this?

## 12. Community reaction

- a. How did your neighbors react to (name)'s illness?  
*Note to Interviewer-*  
*Did they help you, avoid you, gossip... ?*  
*Have your relationships with your neighbors changed since (name) became ill?*  
*How were things with the community while (name) was still alive?*  
*How about after (name) died?*
- b. What was the response of community leaders (e.g., headman, health officials) during the time that (name) was sick?
- c. How about after (name) died?

13. Physical health of caregiver(s) related to PWA.

- a. How is your health these days?
- b. Was caring for the patient difficult for your health? How so?
- c. Are you still having these health problems?

14. Emotional issues related to PWA.

- a. Did you feel stressed or depressed when you were caring for (name)?
- b. Could confide in someone about the difficulties of caring for (name)?

*Note to Interviewer-*

*(If yes)- With whom could you talk?*

*What issues did you usually discuss?*

*Did discussing this help you feel better?*

- c. Did you do anything else to help your stress or depression?
- d. How are you coping with things since (name) died?

15. PWA's family

*Note to Interviewer- Ask these questions only if (name) had family.*

- a. What happened to (name)'s spouse?

*Note to Interviewer-*

*Is s/he still alive and healthy?*

*Where does s/he live?*

*Are you still in contact?*

- b. (If PWA had children): Who takes care of (name)'s children?
- c. (If interviewee does):

- i. What type of care do you provide?

*Note to Interviewer-*

*Do you provide housing, food, school, emotional support, spiritual guidance...*

*What type of expenses are involved in caring for the grandchildren?*

*How much do you spend on this per month?*

- ii. Does anyone help you with caring for the grandchildren?

*Note to Interviewer-*

*What do they do?*

*Help in caring/babysitting, financial help... anything else?*

- iii. How do you feel about caring for and living with the grandchildren?

*Note to Interviewer- Please tell me more.*

*Does having them around make things easier or harder for you?*

*How so?*

- d. How did the community feel or act towards the grandchildren when (name) was sick?
- e. How about after (name) died?
- f. Do the children go to school?

*Note to Interviewer- (If no)- Why not?*

- g. (If someone else is the primary grandchild caregiver): Are you involved in raising the grandchildren?

*Note to Interviewer- (If yes)- What do you do?*

## **ENDING**

### 16. Special needs of the interviewee

- a. What was most difficult for you in dealing with (name)'s illness?
- b. What would have helped you the most in your care-giving?

### 17. End of the interview

- a. Is there anything else you would like to tell me about this?
- b. Thank Respondent for interview
- c. Tell Respondent how to contact the project if they have any questions.
- d. Give Respondent gift.
- e. Thank Respondent again.