

Information behavior and social control: Towards an understanding of conflictual information behavior in families managing chronic illness – Appendix A (Study Instruments)

Time 1

Individual Interviews

(with patients and family members)

Note: family member interview protocol provided as example, patient protocol was similar but questions were phrased to ask for the patient's experiences with illness

Families, Illness and Information

Individual Interviews

Family Members of People with Diabetes [or HIV/AIDS]

[Note: in keeping with the principles of qualitative research, these questions may evolve through the course of this research. However, this interview guide shows the possible range of questions to be asked.]

1. Could you tell me about your personal experience with diabetes [or HIV/AIDS]?

Probes:

- What important events have happened during the time your family member has had diabetes [or HIV/AIDS]?
 - What made X event important to you?
- Have there been any significant *turning points* or *changes* throughout your experience with your family member's diabetes [or HIV/AIDS]?

2. What happens during a typical day of your life with your family member's diabetes [or HIV/AIDS]?

Probes:

- What happens in the morning? Afternoon? Evening? At night?
- What role does your family member with diabetes [or HIV/AIDS] play in this?
- Is there anyone else who plays a big part in your daily life with diabetes [or HIV/AIDS]?
 - What part do they play?

3. Have your relationships with any of your family members changed since your family member got diabetes [or HIV/AIDS]? If so, how?

Probes:

- How has your relationship with X changed?....How has your relationship with Y changed?
- Why has your relationship with X changed in this way?....Why has your relationship with Y changed in this way?

4. If you were feeling upset about something to do with diabetes [or HIV/AIDS], what would you do?

Probes:

- Would you talk to anyone else? If so, who? If not, why not?
 - Would you talk to any members of your family?
 - Is there anyone in your family that you would **not** want to talk to?
 - What makes you not want to talk to this person?
- Has this happened before? If so, when?
 - What did you do when you *last* felt upset about your diabetes [or HIV/AIDS]?
 - Did you turn to anyone? If so, who?
 - (If unclear) Was this a member of your family?
 - What happened?
 - Did this help you? If so, how?

5. If you needed help with caring for your diabetic family member, what would you do?

Examples: you need to go away for work or a holiday, you need to pick up medication or take him/her to an appointment, you need help with preparing meals

Probes:

- Would you ask anyone for help? If so, who? If not, why not?
 - Would you ask any members of your family?
 - Is there anyone in your family that you would **not** want to ask?
 - What makes you not want to ask this person?
- Has this ever happened before?
 - What did you need help with?
 - Did you turn to anyone for help? If so, who?
 - (If unclear) Was this a member of your family?
 - What happened?
 - Did this help you? If so, how?

6. If you had a question about something to do with diabetes [or HIV/AIDS], what would you do?

Probes

- Would you ask anyone for help? If so, who? If not, why not?

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- Would you ask any members of your family?
- Is there anyone in your family that you would **not** want to ask?
 - What makes you not want to ask this person?
- Has this ever happened before?
 - What did you want to know?
 - Did you turn to anyone for help? If so, who?
 - (If unclear) Was this a member of your family?
 - What happened?
 - Did this help you? If so, how?

7. (If applicable) On your survey, you said that a family member gave you diabetes [or HIV/AIDS] information without you asking for it.

- a) What happened? Who was it?
- b) What impact did it have on you?

<repeat for every question from 73-85 on the survey to which participants did not say that he/she had “never” done this in the past 4 months>

8. Have you ever helped a member of your family learn something about diabetes [or HIV/AIDS]?

Probes:

- What happened?
- Why did you try to inform him or her about diabetes [or HIV/AIDS]?
- What effect did you **hope** to have?
 - What effect **did** this have on him or her?
- How often do you help members of your family find something out about diabetes [or HIV/AIDS]?

9. Dealing with a disease like diabetes [or HIV/AIDS] can be complicated. How do you keep track of things in relation to your family member’s diabetes [or HIV/AIDS]?

Probes:

- How did you come to those things? Are they different from what you’ve done in the past?
- How much do other people help you remember things?
 - Who helps you?
 - How do they help you?
 - How do you decide who does what?
- Do you use any *things* – like notebooks or computer programs or schedules – to help you?
 - If yes, can you show them to me and explain how they work?

10. People with diabetes [or HIV/AIDS] usually need to go to see doctors or other caregivers on a regular basis. How much do you interact with your family member's health care or support providers?

Probes:

- Do you go to your family member's health care appointments?
- How would you describe your relationship with your family member's health care or support providers?

11. How do members of your family learn about how your family member is doing, health-wise?

Probes:

- Who tells you?
- Do you tell other people?
- Do other people ask you?
- Do other people in your family tell each other? How do you know that?

12. Do you and/or members of your family ever disagree or hold different ideas about diabetes [or HIV/AIDS]?

Probes:

- Please describe this disagreement.
- What happens when members of your family disagree about diabetes [or HIV/AIDS]?

13. Overall, how well do you think your family member deals with his or her diabetes [or HIV/AIDS]?

Probes:

- What do you think is good about the ways that they deal with it?
- What do you think is not so good about the ways that they deal with it?
- Do they work together to deal with your family member's diabetes [or HIV/AIDS]? If so, how?

14. Overall, how well do you think your family as a whole deals with diabetes [or HIV/AIDS]?

Probes:

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- What do you think is good about the ways that they deal with it?
- What do you think is not so good about the ways that they deal with it?
- Do they work together to deal with your family member's diabetes [or HIV/AIDS]?
If so, how?

15. Is there anything else you'd like to tell me about your experiences with diabetes [or HIV/AIDS] within your family?

FAMILY NETWORK INTERPRETER & VISUALIZATION

In the interview, you mentioned: _____ as members of your family who are involved in how you deal with diabetes [or HIV/AIDS].

16. Are there any other members of your family who are involved in your support or care for your family member with diabetes [or HIV/AIDS]?

17. Are there any other members of your family who help you cope with diabetes [or HIV/AIDS]? If so, who?

18. Are there any other members of your family with whom you share information about diabetes [or HIV/AIDS]?

For each person identified in the interviews, ask:

19. (If unclear) Is ___ male or female?

20. (If unclear) How old is ___? (If you don't know, please give your best guess)

21. What is your relationship to ___? (e.g., spouse, cousin, father, sister)

22. Does ___ have diabetes [or HIV/AIDS]?

23. Where does ___ live?

24. How often do you communicate with ___?

- Every day
- More than once a week, but not every day
- Once a week
- Once every second week
- Once a month
- Once every 2-3 months
- Once every 6 months
- Once a year
- Less than once a year

25. Please tell me all of the ways you normally communicate with ___?

- Face-to-face

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- Telephone
- Text Messaging
- E-mail
- Online chat (like MSN Messenger or Yahoo Messenger)
- Social networking Web site (like Facebook, MySpace or BlackPlanet)
- Other _____

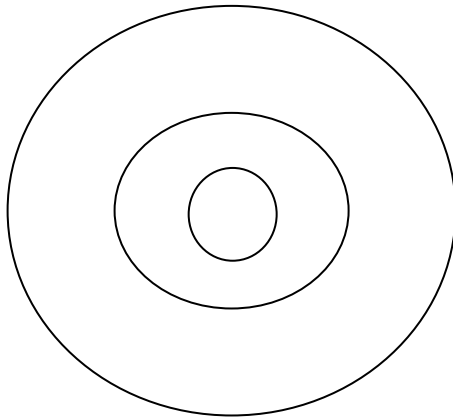
26. Just to confirm, would you say that _ gives you (check all that apply):

- Information related to diabetes [or HIV/AIDS]?
- Emotional support in relation to diabetes [or HIV/AIDS]?
- Help with caregiving, chores or other responsibilities in relation to your family member with diabetes [or HIV/AIDS]?

27. And would you say that you give ____ (check all that apply):

- Information related to diabetes [or HIV/AIDS]?
- Emotional support in relation to diabetes [or HIV/AIDS]?
- Help with caregiving, chores or other responsibilities in relation to your family member with diabetes [or HIV/AIDS]?

28. Now I'm going to ask you to make name tags for all of the people you have named, and put each tag on this diagram of your family network.



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When placing name tags on the diagram, follow these instructions:

1. Place tags on the lines, not between them.
2. The circles represent closeness, so place the closest people to you on the inner circle and work outward.
3. Place people who are close to each other close together.
4. Rearrange ties until you are satisfied.

(Note: a photograph will be taken of the completed network visualization diagram)

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Time 2

Family Group Interviews

Families, Illness and Information

Family Group Interviews

Discussion Guide

[Note: in keeping with the principles of qualitative research, these questions may evolve through the course of this research. However, this interview guide shows the possible range of questions to be asked.]

1. Can you please tell me about your experiences with diabetes as a family?

Probes:

- What important events have happened during the time your family has dealt with diabetes?
 - What made X event important to you?

2. Please tell me about your family life today. How is it the same or different from how your family lived before you were dealing with diabetes?

Probes:

- How much do you think this is because of diabetes?

3. What happens during a typical week of your family's life with diabetes?

Probes:

- What happens at different times of day? On different days of the week?

4. What important events have happened during the time your family has been dealing with diabetes?

Probes:

- What happened? Please tell me how it affected you as a family.
- Did this affect different people in your family differently?
- What made X event important to your family?

5. Please tell me about any significant *turning points* or *changes* throughout your family's experience of diabetes.

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Probes:

- What happened? How did it affect you as a family?
- Have there been any times where you have faced a health crisis as a family?
What happened then?
 - Who did what?
 - How did you decide who did what?
- Did this affect different people in your family differently?
- How are things different now than they were before X happened?

6. Could you tell me about what happened when you all found out that someone in your family had diabetes?

Probes:

- How did different family members find out?
- What conversations did people have?
- Did anybody decide on or agree to change anything?
- How did it affect you as a family?
- Were things different for some of you than for others?

7. Dealing with a disease like diabetes can be complicated. As a family, what do you do to keep up with it and deal with it?

Probes:

- How do you remember things?
 - Do people help each other remember things? How?
 - How do you decide who does what?
- Do you use any *things* – like notebooks or computer programs or schedules – to help you?
 - If yes, what are they, and how do they work?
- How does doing X help you?

8. How do members of this family learn about how X is doing, health-wise?

Probes:

- Do family members talk to health care providers?
- Who tells each other? Why does X tell Y?...Why does Y tell Z?
- How did you come to this way of keeping each other up to date?
 - Is it different than it was in the past? If so, how?

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9. Think about the last time people in this family learned something new about diabetes. What did you learn?

a) How did you learn about this?

Examples: from each other, from friends, from television, on a Web site, from a library book, from a doctor or nurse

b) What impact did learning this have on you?

Probes:

- Did anything change for you?
- Did you feel different?
- Did you do anything differently?

10. Does your family ever turn to a library for anything related to diabetes? If yes, which library(ies)? If not, why not?

For each library mentioned ask:

a) What type of help were you looking for?

b) In what ways has the library been helpful or not helpful to you?

c) Do you know any library staff by name? If so, who? What are your relationships to him or her?

11. How much do members of your family ever hold similar or different ideas about diabetes?

Probes:

- From your perspectives, what causes diabetes? Why does X member of your family have diabetes?
- From your perspective, what is the long-term health outlook for someone with diabetes?
- What do you all think of as important ways to manage or treat diabetes?

12. In some families, different people play different roles when something needs to be done. As your family deals with diabetes, how much do things happen like this?

Probes:

- In relation to diabetes, who does what in your family?
- How do you decide who does what?
- Has the part that different people play changed over time? If so, how?

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- 13. If President Obama wanted to make things better for families like yours who are dealing with diabetes, what kinds of things should he deal with, and what specifically would you like him to do about it?**

- 14. Is there anything else that I haven't asked you about that you want to tell me about your experience with diabetes?**

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Time 3

Family Group Interviews

Families, Illness and Information

Family Group Interviews

Discussion Guide

[Note: in keeping with the principles of qualitative research, these questions may evolve through the course of this research. However, this interview guide shows the possible range of questions to be asked.]

- 1. Can you please tell me about your family's experiences with diabetes in the past 4 months?**
- 2. Please tell me about your family life today. How is it the same or different from how your family lived before you were dealing with diabetes?**

Probes:

- How much do you think this is because of diabetes?
- 3. What happens during a typical week of your family's life with diabetes? Has anything changed about this in the past 4 months?**

Probes:

- What happens at different times of day? On different days of the week?
- 4. What important diabetes-related events have happened during past 4 months?**

Probes:

- What happened? Please tell me how it affected you as a family.
 - Did this affect different people in your family differently?
 - What made X event important to your family?
- 5. Please tell me about any significant *turning points* or *changes* throughout the last 4 months of your family's experience of diabetes.**

Probes:

- What happened? How did it affect you as a family?
- Have there been any times where you have faced a health crisis as a family? What happened then?

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- Who did what?
- How did you decide who did what?
- Did this affect different people in your family differently?
- How are things different now than they were before X happened?

6. Dealing with a disease like diabetes can be complicated. As a family, what do you do now to keep up with it and deal with it? Has anything about this changed in the past 4 months?

Probes:

- How do you remember things?
 - Do people help each other remember things? How?
 - How do you decide who does what?
- Do you use any *things* – like notebooks or computer programs or schedules – to help you?
 - If yes, what are they, and how do they work?
- How does doing X help you?

7. How do members of this family now learn about how X is doing, health-wise? Has anything about this changed in the past 4 months?

Probes:

- Do family members talk to health care providers?
- Who tells each other? Why does X tell Y?...Why does Y tell Z?
- How did you come to this way of keeping each other up to date?
 - Is it different than it was in the past? If so, how?

8. Think about a time people in this family learned something new about diabetes in the past 4 months. What did you learn?

b) How did you learn about this?

Examples: from each other, from friends, from television, on a Web site, from a library book, from a doctor or nurse

b) What impact did learning this have on you?

Probes:

- Did anything change for you?
- Did you feel different?
- Did you do anything differently?

9. In the past 4 months, has your family ever turn to a library for anything related to diabetes? If yes, which library(ies)? If not, why not?

For each library mentioned ask:

d) What type of help were you looking for?

e) In what ways has the library been helpful or not helpful to you?

10. In the past 4 months, how much have members of your family expressed similar or different ideas about diabetes?

Probes:

- From your perspectives, what causes diabetes? Why does X member of your family have diabetes? Has this changed in the past 4 months?
- From your perspective, what is the long-term health outlook for someone with diabetes? Has this changed in the past 4 months?
- What do you all think of as important ways to manage or treat diabetes? Has this changed in the past 4 months?

11. In some families, different people play different roles when something needs to be done. As your family deals with diabetes, how much have things happened like this in the past 4 months?

Probes:

- In relation to diabetes, who has done what in your family in the past 4 months?
- In the past 4 months, how have you decided who does what?
- Has the part that different people play changed in the past 4 months? If so, how?

12. Is there anything else that I haven't asked you about that you want to tell me about your recent experience with diabetes?

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Time 4

Family Group Interviews (w/home tours)

Families, Illness and Information

Family Group Interviews

Discussion Guide

[Note: in keeping with the principles of qualitative research, these questions may evolve through the course of this research. However, this interview guide shows the possible range of questions to be asked.]

- 1. Can you please tell me about your family's experiences with diabetes in the past 4 months?**
- 2. Please tell me about your family life today. How is it the same or different from how your family lived before you were dealing with diabetes?**

Probes:

- How much do you think this is because of diabetes?
- 3. What happens during a typical week of your family's life with diabetes? Has anything changed about this in the past 4 months?**

Probes:

- What happens at different times of day? On different days of the week?
- 4. What important diabetes-related events have happened during past 4 months?**

Probes:

- What happened? Please tell me how it affected you as a family.
 - Did this affect different people in your family differently?
 - What made X event important to your family?
- 5. Please tell me about any significant *turning points* or *changes* throughout the last 4 months of your family's experience of diabetes.**

Probes:

- What happened? How did it affect you as a family?
- Have there been any times where you have faced a health crisis as a family? What happened then?

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- Who did what?
- How did you decide who did what?
- Did this affect different people in your family differently?
- How are things different now than they were before X happened?

6. Dealing with a disease like diabetes can be complicated. As a family, what do you do now to keep up with it and deal with it? Has anything about this changed in the past 4 months?

Probes:

- How do you remember things?
 - Do people help each other remember things? How?
 - How do you decide who does what?
- Do you use any *things* – like notebooks or computer programs or schedules – to help you?
 - If yes, what are they, and how do they work?
- How does doing X help you?

7. How do members of this family now learn about how X is doing, health-wise? Has anything about this changed in the past 4 months?

Probes:

- Do family members talk to health care providers?
- Who tells each other? Why does X tell Y?...Why does Y tell Z?
- How did you come to this way of keeping each other up to date?
 - Is it different than it was in the past? If so, how?

8. Think about a time people in this family learned something new about diabetes in the past 4 months. What did you learn?

c) How did you learn about this?

Examples: from each other, from friends, from television, on a Web site, from a library book, from a doctor or nurse

b) What impact did learning this have on you?

Probes:

- Did anything change for you?
- Did you feel different?
- Did you do anything differently?

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9. In the past 4 months, has your family ever turn to a library for anything related to diabetes? If yes, which library(ies)? If not, why not?

For each library mentioned ask:

f) What type of help were you looking for?

g) In what ways has the library been helpful or not helpful to you?

10. In the past 4 months, how much have members of your family expressed similar or different ideas about diabetes?

Probes:

- From your perspectives, what causes diabetes? Why does X member of your family have diabetes? Has this changed in the past 4 months?
- From your perspective, what is the long-term health outlook for someone with diabetes? Has this changed in the past 4 months?
- What do you all think of as important ways to manage or treat diabetes? Has this changed in the past 4 months?

11. In some families, different people play different roles when something needs to be done. As your family deals with diabetes, how much have things happened like this in the past 4 months?

Probes:

- In relation to diabetes, who has done what in your family in the past 4 months?
- In the past 4 months, how have you decided who does what?
- Has the part that different people play changed in the past 4 months? If so, how?

12. Is there anything else that I haven't asked you about that you want to tell me about your recent experience with diabetes?

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Time 5

Individual Interviews

(with patients and family members)

Note: family member interview protocol provided as example, patient protocol was similar but questions were phrased to ask for the patient's experiences with illness

Families, Illness and Information

Individual Interviews

Family Members of People with Diabetes [OR HIV/AIDS]

[Note: in keeping with the principles of qualitative research, these questions may evolve through the course of this research. However, this interview guide shows the possible range of questions to be asked.]

1. Could you tell me about your personal experience with diabetes [OR HIV/AIDS] in the past 2 years?

Probes:

- What important events have happened during the time the past 2 years in which your family member has had diabetes [OR HIV/AIDS]?
 - What made X event important to you?
- Have there been any significant *turning points* or *changes* throughout your experience with your family member's diabetes [OR HIV/AIDS] in the past 2 years?

2. What happens now during a typical day of your life with your family member's diabetes [OR HIV/AIDS]? Has this changed in the past 2 years? If so, how?

Probes:

- What happens in the morning? Afternoon? Evening? At night?
- What role does your family member with diabetes [OR HIV/AIDS] play in this?
- Is there anyone else who plays a big part in your daily life with diabetes [OR HIV/AIDS]?
 - What part do they play?

3. Have your relationships with any of your family members changed in the past 2 years? If so, how?

Probes:

- How has your relationship with X changed?....How has your relationship with Y changed?

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- Why has your relationship with X changed in this way?....Why has your relationship with Y changed in this way?

4. If you were feeling upset about something to do with diabetes [OR HIV/AIDS] today, what would you do? Has this changed in the past 2 years? If so, how and why?

Probes:

- Would you talk to anyone else? If so, who? If not, why not?
 - Would you talk to any members of your family?
 - Is there anyone in your family that you would **not** want to talk to?
 - What makes you not want to talk to this person?
- Has this happened before? If so, when?
 - What did you do when you *last* felt upset about your diabetes [OR HIV/AIDS]?
 - Did you turn to anyone? If so, who?
 - (If unclear) Was this a member of your family?
 - What happened?
 - Did this help you? If so, how?

5. If you needed help with caring for your family member with diabetes [OR HIV/AIDS] today, what would you do? Has this changed in the past 2 years? If so, how and why?

Examples: you need to go away for work or a holiday, you need to pick up medication or take him/her to an appointment, you need help with preparing meals

Probes:

- Would you ask anyone for help? If so, who? If not, why not?
 - Would you ask any members of your family?
 - Is there anyone in your family that you would **not** want to ask?
 - What makes you not want to ask this person?
- Has this ever happened before?
 - What did you need help with?
 - Did you turn to anyone for help? If so, who?
 - (If unclear) Was this a member of your family?
 - What happened?
 - Did this help you? If so, how?

6. Right now, if you had a question about something to do with diabetes [OR HIV/AIDS], what would you do? Has this changed in the past 2 years? If so, how and why?

Probes

- Would you ask anyone for help? If so, who? If not, why not?
 - Would you ask any members of your family?
 - Is there anyone in your family that you would **not** want to ask?
 - What makes you not want to ask this person?
- Has this ever happened before?
 - What did you want to know?
 - Did you turn to anyone for help? If so, who?
 - (If unclear) Was this a member of your family?
 - What happened?
 - Did this help you? If so, how?

7. (If applicable) On your survey, you said that a family member gave you diabetes [OR HIV/AIDS] information without you asking for it in the past 4 months.

- c) What happened? Who was it?
- d) What impact did it have on you?

<repeat for every question on the survey to which participants did not say that he/she had “never” done this in the past 4 months>

8. In the past 2 years, have you ever helped a member of your family learn something about diabetes [OR HIV/AIDS]?

Probes:

- What happened?
- Why did you try to inform him or her about diabetes [OR HIV/AIDS]?
- What effect did you **hope** to have?
 - What effect **did** this have on him or her?
- How often do you help members of your family find something out about diabetes [OR HIV/AIDS]?

9. Dealing with a disease like diabetes [OR HIV/AIDS] can be complicated. How do you keep track of things in relation to your family member’s diabetes [OR HIV/AIDS]?

Has this changed in the past 2 years? If so, how and why?

Probes:

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- How did you come to those things? Are they different from what you've done in the past?
- How much do other people help you remember things?
 - Who helps you?
 - How do they help you?
 - How do you decide who does what?
- Do you use any *things* – like notebooks or computer programs or schedules – to help you?
 - If yes, can you show them to me and explain how they work?

10. People with diabetes [OR HIV/AIDS] usually need to go to see doctors or other caregivers on a regular basis. How much do you interact with your family member's health care or support providers?

Has this changed in the past 2 years? If so, how and why?

Probes:

- Do you go to your family member's health care appointments?
- How would you describe your relationship with your family member's health care or support providers?

11. Right now, how do members of your family learn about how your family member is doing, health-wise? Has this changed in the past 2 years? If so, how and why?

Probes:

- Who tells you?
- Do you tell other people?
- Do other people ask you?
- Do other people in your family tell each other? How do you know that?

12. In the past 2 years, how much have and/or members of your family disagreed or held different ideas about diabetes?

Probes:

- Please describe this disagreement.
- What happens when members of your family disagree about diabetes [OR HIV/AIDS]?

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13. Overall, how well do you think your family member has dealt with his or her diabetes [OR HIV/AIDS]?

Probes:

- What do you think is good about the ways that they have dealt with it?
- What do you think is not so good about the ways that they have dealt with it?
- Have they worked together to deal with your family member's diabetes [OR HIV/AIDS]? If so, how?
- Is there anything that you think that your family member has learned about dealing with diabetes in this time? If so, what?

14. Overall, how well do you think your family as a whole has dealt with diabetes [OR HIV/AIDS] in the past 2 years?

Probes:

- What do you think is good about the ways that they have deal with it?
- What do you think is not so good about the ways that they have dealt with it?
- Have they worked together to deal with your family member's diabetes [OR HIV/AIDS]? If so, how?
- Is there anything that you think that your family has learned about dealing with diabetes in this time? If so, what?

15. Is there anything else you'd like to tell me about your experiences with diabetes [OR HIV/AIDS] within your family?