Health-seeking behaviour among adults in the context of the epidemiological transition in Southeastern Tanzania
Metta, Emmy Onifasi

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2016

Link to publication in University of Groningen/UMCG research database

Citation for published version (APA):

Copyright
Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

The publication may also be distributed here under the terms of Article 25fa of the Dutch Copyright Act, indicated by the “Taverne” license. More information can be found on the University of Groningen website: https://www.rug.nl/library/open-access/self-archiving-pure/taverne-amendment.

Take-down policy
If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Downloaded from the University of Groningen/UMCG research database (Pure): http://www.rug.nl/research/portal. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.
Appendices

Appendix 1  Focus group discussion guide – Malaria
Appendix 2  Focus group discussion guide – Diabetes
Appendix 3  In-depth interview guide – Malaria patients
Appendix 4  In-depth interview guide – Diabetes patients
Appendix 5  In-depth interview guide – Diabetes family member
Appendix 1: Focus group discussion guide - Malaria

Introduce yourself to the group and explain again the following:

✓ **Explain the general purpose of the study:** To learn about cultural aspects in health seeking behavior for malaria in this village

✓ **Aim of the interview:** To learn about malaria and its treatment practices

✓ **Expected discussion time:** Approximately 1:30 hour

✓ **Why participant's cooperation is important:** Your participation and cooperation is very important for the success of this study as we would like to learn from you; your views, opinions and experiences with malaria and health seeking behavior in general

✓ **What if participants don’t want to be part of the study?** Being part of this study is important but it is up to you to decide. If you do not want to take part in this study, it will not affect any care or treatment you receive. It will not cost you or your family anything.

✓ **What will happen with the collected information and how the study participants will benefit:** The information collected will only be used for the intended purpose of meeting the requirements of the PhD candidate. This information will not help you directly, but it could benefit many other people in future because it will help the policy makers and implementers on how to improve malaria services provision and uptake in Tanzania

✓ **Use of tape recorder:** To be able to keep a more accurate record of our discussion I am proposing to use a tape recorder; if you don’t mind. Do you mind if I use a tape recorder? (observe whether people agrees)

✓ **Confidentiality:** The information that we will discuss here today will remain confidential and no one apart from the research team will have access to these data. Your names will be removed from the data and no one will be able to link your name with what is said. This data will be published and shared with the scientific community but your name will not appear in any of these publications

✓ **Ground rules:**
  * One person will speak at a time
  * It is important for us to hear opinions and views from every one. There is no right and wrong answer rather it is ideas, opinions, views and experiences, which are all important.
  * It is important for us to hear both sides of the topic, the positive and negative side
  * We silence our mobile phones
• We ensure you confidentiality; after these discussions today, everything we discuss should remain here, don’t share what we discuss here today with people outside this group.

✓ Do you have any question?
✓ Consent: Do you agree to take part in this discussion?
✓ The moderator turns on the digital recorder and start the discussion.

Note: Group discussants background characteristics fill appendix Ai – FGDs participants’ recruitment form. (Remember some of the aspects in this form are to be filled at the end of the discussion – example participants age and education level.)

1. Let us start our discussion by talking about febrile illnesses in this village. What are the common febrile illnesses found in this village? Probe:
   a. What are the febrile illnesses affecting adults in this village? (Probe for all febrile illnesses affecting adult people)

2. If malaria is not mentioned in question 1: Ask what do people in this community know about malaria? If it is mentioned on question one above continue with the following probes:
   a. How do they know about it (probe: where did you hear about malaria)?
   b. What do they think are the causes of malaria? How?
   c. What is the local name for malaria in this village?

3. What do people in this village do to prevent themselves from local name/malaria? (Probe: All local name/malaria preventive measures used in the community. What do most of the villagers use and why? What are the traditional ways/means for preventing malaria?)

4. How do people feel about the use of nets in the village? (probe: what is the feeling of adults for using nets? What are the beliefs associated with net usage? And whether people see any importance of using nets? How are the nets used over the year? Why?)

5. In recent years, there has been a universal coverage for nets in the country (free nets for every household), what do you think about it?

6. How can you describe the problem of local name/malaria to adults in this village? Is it an issue of concern? Why? Probe:
   a. Are there many adults who gets local name/malaria in this village? Why are you saying so?
   b. In which period of the year do many adults get local name/malaria in this village? Why? (probe for seasonality – rainy and dry season, environments)

7. How do people know when they have local name/malaria in this village? (Probe: symptoms that identify presence of local name/malaria and which ones are most common?)
8. What do people do when they think have local name/malaria in this village? Probe:
   a. For different actions that people take and why they do so? e.g self-treatment and why? going to health facility – of which type and why? drug shop and why? use of traditional/local medicines and why? When traditional healers are consulted for treating local name/malaria and when health facilities are consulted for the same? 
   b. How is it if people with local name/malaria will not take any action concerning their health? How is this happening in this village?
9. What comes up in your mind when you think of going to health facilities for malaria treatment? Probe for:
   a. Medication costs – consultation and medicine costs 
   b. Availability of medicines – anti malaria medicines 
   c. Waiting time before consultations 
   d. Operating hours 
   e. How about health care workers 
   f. What considerations people take before seeking treatments for malaria? Why?
10. What happens when you arrive at the health facility for malaria treatment?? Probe: why do they do that? Is that not enough? What are your expectations from them? How can you describe the whole process?
11. What medicines do you get when you go to the health facilities for malaria treatment? Probe:
   a. What do you think of those medicines? 
   b. We have heard people saying that ALu is best for treating malaria in children what do you think about this? Why do people think so?
12. Now, let us discuss on the use of anti-malaria medicines. Is there any need for adult people with local name/malaria to finish their prescribed dose? Why? What are the things that can make adult people not to finish their prescribed treatments? How?)
13. When people fall sick with local name/malaria who helps them in seeking treatment? (Probe: family, neighbour, friends and why do they have to help? What kind of help do they offer?
14. What are the challenges people with local name/malaria face in this village? (Probe: for social, economic and health challenges and how they occur)
15. What can be done for people with local name/malaria to seek treatments promptly? (Probe: who is to do it? What can people themselves do?)
16. Are there other issues about local name/malaria that we have forgotten and you would like to share with us? What are those?

THANK YOU FOR YOUR TIME AND COOPERATION
Appendix 2: Focus group discussion guide - Diabetes

Introduce yourself to the group and explain again the following:

✓ **Explain the general purpose of the study**: To learn about the cultural aspects influencing health seeking behavior for diabetes

✓ **Aim of the discussion**: To learn about diabetes and its treatment practices

✓ **Expected discussion time**: Approximately 1:30 hours

✓ **Why the participant’s cooperation is important**: Your participation and cooperation is very important for the success of this study as we would like to learn from you; your views, opinions and experiences with diabetes and health seeking behavior in general.

✓ **What if participants don’t want to be part of the study?**: Being part of this study is important but it is up to you to decide. If you do not want to take part in this study, it will not affect any care or treatment you receive. It will not cost you or your family anything.

✓ **What will happen with the collected information and how the study participants will benefit**: The information collected will be used only for the intended purpose of meeting the academic requirements of the PhD candidate. This information will not help you directly, but it could benefit many other people in future because it will help the program managers and policy makers on how to improve their diabetes service provision in the country.

✓ **Confidentiality**: The information that we will discuss here today will remain confidential and no one apart from the research team will have access to these data. Your names will be removed from the data and no one will be able to link your name with what is said. This data will be published and shared with the scientific community but your name will not appear in any of these publications.

✓ **Use of tape recorder**: To be able to keep a more accurate record of our discussion I am proposing to use a tape recorder if you don’t mind. Do you mind if I use a tape recorder? (observe whether people agrees)

✓ **Do you have any question?**

✓ **Consent**: Do you agree to take part in this discussion? (observe whether people agrees)

✓ The moderator turn on the digital recorder and start the discussion.

Note: Group discussants background characteristics fill appendix Ai – FGDs participants’ recruitment form. (*Remember some of the aspects in this form are to be filled at the end of discussion – example participants age and education level.*)
1. Let us start our discussion by talking about illnesses in this /your village. What are the illnesses found in this /your village? Probe:
   a. What are the illnesses affecting adult people more? Probe for all illness affecting adults in the community.

2. **If not mentioned:** Ask if have ever heard of diabetes? Probe:
   1. What do they know about it?
   2. Where have they heard about it?
   3. What do they hear about it?
      a. What is the cause of diabetes? (Probe: all possible causes? can one get diabetes from another person?)
      b. How is diabetes treated?
      c. How can people prevent themselves from getting diabetes? (Probe: for all possible measures that people can take)

3. How is diabetes known in this /your village? Probe:
   a. What is the local name for diabetes?
   b. How is diabetes associated with other diseases in the village? (Probe: what are those diseases? And what are the reasons for such association?)

4. How can you describe the issue of diabetes in this /your village? Is it an issue of concern? Why? Probe:
   a. Are there many people with *local name if available* (diabetes) in the village
   b. Who gets *local name if available* (diabetes) in the village? Probe also in terms of gender and age?
   c. Why is it that those people (mentioned) are getting *local name if available* (diabetes) and not others?
   d. Is it possible for anyone to get *local name if available* (diabetes)? Why?

5. How do people know when they have local name if available/diabetes? Probe: symptoms that identify presence of diabetes and which ones are most common?)

6. What do people do when they think they have *local name if available* (diabetes) in this / your village? Probe:
   a. For different actions that people take and why they do so? e.g self treatment and why? going to health facility – of which type and why? drug shop and why? use of traditional/local medicines and why? How is it if diabetic people will not take any action concerning their health? How is this happening in the village?

7. What comes up to your mind when you think of going for diabetes treatments in the health facilities? Probe for:
   a. Medication costs – consultation and medicine costs
   b. Availability of medicines
c. What about health care workers  
d. Waiting time before consultations  
e. What can you say of the whole process of seeking diabetes care at the health facility?  

8. Where else can people get treatments for diabetes in this/your village? What type of treatment is obtained there? Probe: use of traditional healers; when traditional healers are consulted; when health facility is consulted and why?  

9. How is the life of diabetes people in this/your village? Probe:  
   a. Their participation in social gatherings?  
   b. Their workings in the farms/or other activities?  
   c. What about foods? Why?  
   d. What about life style change prescriptions? Why?  
   e. In continuing with their medications? Why?  

10. What are your opinions concerning the use of diabetes treatments prescriptions? (Probe:  
   Is there a need for people with diabetes to continue with their medical prescriptions? Why? Probe for both continuing medicine use and practicing life style prescriptions)  

11. Who are involved in helping local name if available (diabetes) people in seeking treatment in this/your village? (Probe: relatives of the sick person, family members, friends or any villager/neighbours etc) Why are those people involved?  

12. What support do people with local name if available (diabetes) need from their family and friends in taking care of their illnesses properly?  

13. What are the challenges faced by families as a result of having local name if available (diabetes) people? Why? Probe for social, economic and health challenges  

14. What do you think needs to be done for people with local name if available (diabetes) to seek diabetes treatments promptly and to continue with their medical prescriptions? (probe for both continue with treatments and practice life style changes. Who is to do it? What can people themselves do?)  

15. What can be done for family members or caregivers to be able to help people with local name if available (diabetes) to continue well with their medical prescriptions? Probe: treatment use continuity and life style prescriptions?  

16. Are there other issues about local name if available (diabetes) that we have forgotten and you would like to share with us? What are they?  

THANK YOU FOR YOUR TIME AND COOPERATION
Appendix 3: In-depth interview guide - Malaria patients

Introduce yourself to the study participant

✓ *Explain the general purpose of the study:* To learn about cultural aspects in health seeking behavior for malaria in this village

✓ *Aim of the interview:* To learn about malaria and its treatment practices

✓ *Expected discussion time:* Approximately 1 hour

✓ *Why participant’s cooperation is important:* Your participation and cooperation is very important for the success of this study as we would like to learn from you; your opinions, perceptions and experiences with malaria and health seeking behavior in general

✓ *What if you don’t want to be part of the study?* Being part of this study is important but it is up to you to decide. If you do not want to take part in this study, it will not affect any care or treatment you receive. It will not cost you or your family anything.

✓ *What will happen with the collected information and how the study participants will benefit:* The information collected will be used only for the intended purpose of meeting the requirements of the PhD candidate and for advising program implementers on how to improve malaria services provision and uptake in Tanzania

✓ *Use of tape recorder:* To be able to keep a more accurate record of our discussion I am proposing to use a tape recorder; if you don’t mind. Do you mind if I use a tape recorder? *(observe whether agrees)*

✓ *Confidentiality:* The information that we will discuss here today will remain confidential, no one apart from the research team who will know what you said and it can’t be directly linked with you. This data will be published and shared with the scientific community but your name will not appear in any of these publications

✓ *Do you have any question?*

✓ *Consent:* Do you agree to take part in this discussion?

✓ The moderator turns on the digital recorder and start the discussion

Section A: Background characteristics

1. I would like to know more about you and your family:
   a. What is your age?
   b. What is your tribe?
   c. What is your religion?
   d. Have you been to school? If yes, up to which level?
   e. What is your source of income?
f. Are you married?
g. What is your spouse’s education level?
h. What is your spouse’s source of income?
i. How many children do you have?
j. Perhaps, you could now tell me a little bit about your family members. Who do you live with here? And how do you relate with them? (For recorder: Names are not important but give number and fill in the table below):

<table>
<thead>
<tr>
<th>S/N</th>
<th>Relationship</th>
<th>Age</th>
<th>Gender</th>
<th>Religion</th>
<th>Education level</th>
<th>Source of income</th>
</tr>
</thead>
<tbody>
<tr>
<td>eg</td>
<td>Aunt</td>
<td>20yrs</td>
<td>Female</td>
<td>Christian</td>
<td>Std 7</td>
<td>Petty trader</td>
</tr>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. **Recorder observe:** Housing condition e.g house made of mad, trees, mad bricks, thatched grass, cemented bricks, cemented floor, sand floor etc.

Section B: Health seeking behavior practices

1. As you already told me that you had malaria within the last two weeks, could you please tell me a little bit more about this malaria illness?
   a. How it started? What were the initial symptom
   b. What was the first thing you did after noticing the symptoms? Why? (probe for each action taken and the reasons behind)
   c. Who was with you or helped you decide on the actions you took? Why did you involve this person? [broaden to include gender depending with responses given]
   d. Who else was around or you talked with about you illness symptoms when you got sick? What did this person do concerning your illness?[broaden to include gender depending with responses given]
e. What do you think was the cause of the malaria fever you had? Why do you think so? Is there any other causes? What about degege for example? What about evil spirits

2. In your opinion how can one prevent himself from getting malaria (Probe: Is there any one in your family who is using malaria preventive measures? Who is that person and what is he using? What about you? Which one do you use?) Probe also about traditional means, sprays, leaves, cow dams etc.

3. Who else had malaria in your family in recent days (if there were no one continue with probe D below)
   a. How do you relate with him/her?
   b. What symptoms did this person experienced? (Did he/she experience the same symptoms you had?)
   c. Tell me a little bit about what that person did after noticing malaria symptoms (Probe for each action taken and the reasons for doing it)
   d. How frequently are you or your family members are affected with malaria fever? (Probe for adult members of the family and children?) Can you explain a little bit more why this is happening or not happening?
   e. Do you think its many people who get malaria in this community? Why?

4. In your last malaria episode, did you know that you had malaria before you went to the health facility? how did you know that? What made you to go to the health facility?

5. How long did it take between the time you noted the signs or symptoms of malaria and the time you decided to seek care at the health facility? Why

6. Before you went to the hospital, what other treatments did you use? (Probe according to the type of treatment used)
   a. Self-medication – what type of medicine was used? What was the source of that medicine? Why self-treated first?
   b. Bought medicine from drug shop – what type of medicine, who advised that medicine? Why buying drugs from the shop before hospital consultation?
   c. Use of traditional herbs – which ones were used? What was the source? Who advised their use?

7. **If went to the health facility after using treatment Qn 6 above:** How was it then after using the treatments you just mentioned you still went to the health facility? (probe for reasons that prompted his/her visit to health facility)

8. Who did you involve in making decisions before seeking care for the malaria fever? Why?

9. What support did you needed from your family or friends to be able to seek care for your last malaria fever episode? (Probe: what support was needed and who gave it)

10. **[Start like a story – Vignette]** What preparations were you to make before deciding to seek malaria fever treatments? Probe: for medical costs (consultation and treatment
Appendix 3  In-depth interview guide – Malaria

costs); distance/transportation costs) other responsibilities that had to be met first (e.g. looking after the family etc) and how they affected his/her decision to seek care?

11. Tell me a little bit about the process that you had to follow while looking for your malaria treatments last time? Probe for:
   a. What do you think of the time you had to wait before consultation? How long did you have to wait?
   b. How was the consultation –
      i. What questions did the doctor/prescriber asked you?
      ii) How were you tested?? What type of test was used? RDT or BS?
      iii) What did the doctor/prescriber told you about your illness?
   c. What did the doctor/prescriber explained to you on the use of the treatments suggested?
   d. What opinions do you have concerning the whole consultation process? How else would you want it to be?

12. What medicines were you prescribed to use? Probe: where did you get those medicines? How is it normally? How much did you pay for medicines? What do you think about those costs?

13. How long did you use the treatments? Why? (Probe according to response given: What made him/her to stop before finishing the dose? Or why he/she had to finish the dose?)

14. How are you feeling now after using the treatments you just described? Probe: what other medicines have you used after the ones you just told me? Where did you get them? Why?

15. What do you think of the treatments that you were prescribed for your last malaria episode? (Probe: about timing of the dosage, duration of the dose and number of tablets? Perceptions of the effectiveness, side effects etc)

16. Where will you seek treatment if you get malaria fever again? Probe: What medicine would you prefer using in treating malaria fever next if you get sick? Why?

17. How does the cost of care and treatment for your last malaria episode affected the welfare of your family? (Probe: How did you cope with this problem?)

18. What consequences one can get as results of having malaria? Why? Probe for: Social, economic and health consequences

19. [Start like a story – Vignette] What do you think can be done for people with malaria to seek care promptly?

20. Is there anything concerning malaria that we have left /missed and you would like to share with me?.

THANK YOU FOR YOUR TIME AND COOPERATION
Appendix 4: In-depth interview guide - Diabetes patients

Introduce yourself to the participant and explain again the following:

☑ Explain the general purpose of the study: To learn about the cultural aspects influencing health seeking behavior for diabetes

☑ Aim of the interview: To learn about diabetes and its treatment practices

☑ Expected interview time: Approximately 1 hour

☑ Why the participant’s cooperation is important: Your participation and cooperation is very important for the success of this study as I would like to learn from you; your views, opinions and experiences with diabetes and health seeking behavior in general.

☑ What if a participant doesn’t want to be part of the study? Being part of this study is important but it is up to you to decide. If you do not want to take part in this study, it will not affect any care or treatment you receive. It will not cost you or your family anything.

☑ What will happen with the collected information and how the study participants will benefit: The information collected will be used only for the intended purpose of meeting the academic requirements of the PhD candidate. This information will not help you directly, but it could benefit many other people in future because it will help the program managers and policy makers to improve their diabetic control programs.

☑ Confidentiality: The information that we will discuss here today will remain confidential and no one apart from the research team will have access to these data. Your names will be removed from the data and no one will be able to link your name with what is said. This data will be published and shared with the scientific community but your name will not appear in any of these publications.

☑ Use of tape recorder: To be able to keep a more accurate record of our discussion I am proposing to use a tape recorder if you don’t mind. Do you mind if I use a tape recorder? (observe whether people agrees)

☑ Do you have any question?

☑ Consent: Do you agree to take part in this discussion? (observe whether people agrees)

☑ The moderator turn on the digital recorder and start the discussion

Section A: Background characteristics

1. I would like to know more about you and your family:
   a. What is your age?
   b. What is your tribe?
   c. What is your religion?
d. Have you been to school? If yes, up to which level?
e. What is your source of income?
f. Are you married?
g. What is your spouse’s education level?
h. What is your spouse’s source of income?
i. How many children do you have?
j. How long since you have been diagnosed with diabetes?
k. Perhaps, you could now tell me a little bit about your family members, who do you live with? And how do you relate with them? (For recorder: Names are not important but give number and fill in the table below):

<table>
<thead>
<tr>
<th>S/N</th>
<th>Relationship</th>
<th>Age</th>
<th>Gender</th>
<th>Religion</th>
<th>Education level</th>
<th>Source of income</th>
</tr>
</thead>
<tbody>
<tr>
<td>eg</td>
<td>Aunt</td>
<td>20yrs</td>
<td>Female</td>
<td>Christian</td>
<td>Std 7</td>
<td>Petty trader</td>
</tr>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Section B: Health seeking behavior practices

1. As you already told me that you are having diabetes could you please tell me a little more about this illness?
   a. How it started?
   b. What were the initial symptoms you had? Probe: Are you still experiencing the same symptom?
   c. What was the first thing you did after noticing the symptoms? Why? (Probe: for each action taken and reasons for doing so)
   d. Who was with you or helped you decide on the actions you took? Why did you involve this person?
2. What do you think is the cause of the diabetes you are suffering from? Probe:
   a. All possible causes and why?
   b. Do you think one can get diabetes from another person?
   c. How can one protect or prevent him/herself from getting diabetes?
   d. How is diabetes cured? Probe: is it a curable disease? Why?
2. Before you were diagnosed with diabetes, did you know that you might have been suffering from it? (Probe: If yes, how did you know? If no, what prompted you to seek care?)
3. How did you feel when you were first diagnosed with diabetes? Probe:
   a. Was this the first time to hear about diabetes or you already heard about it?
   b. Where did you hear about it? And what information did you have?
   c. What did you do when you were first diagnosed with diabetes? Probe: did you tell your family/friends and other people about it? Why?
   d. In your opinion, what do other people in the family think about you because of having diabetes? Why?
4. How long did it take between the time you noted the diabetes signs or symptoms and the time you decided to seek care at the health facility? Why?
5. What treatments did you use before you went to the health facility? (Probe according to the type of treatment used):
   a. Self medication – what type of medicines were used? How did you get them? Why self treated first? Who gave the advice?
   b. Bought medicine from drug shop – what type of medicine, who advised that medicine? Why buying drugs from the shop before hospital consultation?
   c. Use of traditional herbs – which ones were used? How did you get them? Who advised their use?
6. How was it then you went to the health facility after using medicines you just mentioned? Probe:
   a. What prompted his/her use of the health facility services
   b. Who was involved in making decisions for seeking diabetes treatments
7. What support do you need from your family or friends to be able to seek treatment for your diabetes? (Probe: the type of support and who is giving it)
8. What preparations do you have to make before going to seek care from the health facility?
   Probe: for medical costs (consultation and treatment costs); distance/transportation costs; and how they affect his/her decision to seek care?
9. Tell me a little more on the processes of seeking diabetes care at the health facility?
   a. How long do you have to wait before seeing the specialist?
b. What about medical costs – consultation and treatment costs?

c. How long did you go with the same symptoms before being diagnosed with diabetes?

d. What instructions did the health care worker gave you on using medications? Do you understand well? How can you describe your relationship with the health care worker?

e. What is your opinion concerning the way consultations are made? How would you like it to be

10. Tell me a little more about diabetes self-treatments at home? What challenges are you facing? (Probe: How does cost of care and treatments affect your continuity with the use of the recommended treatment?)

11. Can you please explain again a little more on how you feel about the life style changes prescriptions? Probe: How are you managing with the life style changes prescriptions? What are the challenges faced and how do you cope with them?

12. How does the cost of care and treatment for diabetes affect the welfare of your family? (Probe: How do you cope with this problem?)

13. How do you feel about the diabetes treatments that you are using? (Probe: for personal experiences and feelings on the medicines used and lifestyle change practices; How is it helping you? Do you think there is need to continue using as was advised?)

14. Now let us talk a little more about the use of traditional healer’s services for diabetes treatments, what is your experience on this? (Probe: have you ever sought traditional services for your diabetes? What made you to do so? What kind of services did you get?)

15. Where is the other place that you went to seek care after initiating treatment from the health facility/diabetes clinic? What type of service did you get? And what are the reasons for doing that? – Probe for any type of care eg prayers etc

16. What consequences one can get as results of having diabetes? Probe for: social, economic and health consequences

17. What do you think need to be done to help people with diabetes attend their diabetes clinic as required? Probe:

   a. What can health care workers do to help people with diabetes to comply better with their medical regimen? – probe for both continuity with treatments and life style changes

18. What support do you get from your family and friends in taking care of your diabetes? (Probe: Who is providing most of your care/support and what are the tasks that this caregiver carries out for you?)

19. What do you think needs to be done for patient caregivers/family members to provide care to people with diabetes?
Appendices

20. Is there anything concerning diabetes that we have left /missed and you would like to share with me? What is it?

THANK YOU FOR YOUR TIME AND COOPERATION
Appendix 5: In-depth interview guide - Diabetes family member

Introduce yourselves to the study participant

✓ Explain the general purpose of the study: To learn about cultural aspects in health seeking behaviors for diabetes

✓ Aim of the interview: To learn from the experiences of diabetic caretakers/family members on diabetes and its treatment practices

✓ Expected discussion time: Approximately 1

✓ Why the participant’s cooperation is important: Your participation and cooperation is very important for the success of this study as we would like to learn from you; your opinions, perceptions and experiences with living/taking care of people with diabetes and its health seeking behavior

✓ What if a participant doesn’t want to be part of the study? Being part of this study is important but it is up to you to decide. If you do not want to take part in this study, it will not affect any care or treatment your patient receives. It will not cost you or your family anything.

✓ What will happen with the collected information and how the participant will benefit: The information collected will be confidential and is going to be used only for the intended purpose of meeting the requirements of the PhD candidate and for advising program implementers on how to improve diabetic services provision and uptake in Tanzania

✓ Use of tape recorder: To be able to keep a more accurate record of our discussion I am proposing to use a tape recorder if you don’t mind. Do you mind if I use a tape recorder? (observe whether agrees)

✓ Confidentiality: The information that we will discuss here today will remain confidential, no one apart from the research team who will know what you said and it can’t be directly linked with you. This data will be published and shared with the scientific community but your name will not appear in any of these publications

✓ Do you have any question?

✓ Consent: Do you agree to take part in this discussion?

✓ The moderator turns on the digital recorder and start the discussion

Demographic characteristics

1. I would like to know more about you and your family:
   a. What is your age?
   b. What is your religion?
c. What is your tribe?
d. Have you been to school? If yes, up to which level?
e. What is your main economic activity?
f. Are you married?
g. What is your spouse’s education level?
h. What is your spouse’s main economic activity?
i. How many children do you have?
j. Are you living with ________(diabetic person). If yes; ask QN K: If not ask QN L and observe 2.
k. How long have you being living with ________(diabetic person) here?
l. Perhaps you could now tell me a little bit about your family members. Who do you live with? And how do you relate with them? (For recorder: Names are not important but give number and fill in the table below):

<table>
<thead>
<tr>
<th>S/N</th>
<th>Relationship</th>
<th>Age</th>
<th>Gender</th>
<th>Religion</th>
<th>Education level</th>
<th>Source of income</th>
</tr>
</thead>
<tbody>
<tr>
<td>eg</td>
<td>Aunt</td>
<td>20yrs</td>
<td>Female</td>
<td>Christian</td>
<td>Std 7</td>
<td>Petty trader</td>
</tr>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. Observe: Housing condition e.g house made of mad, trees, mad bricks, thatched grass, cemented bricks, cemented floor, sand floor etc

B: Health seeking behavior practices and assistance to diabetic patient

1. ________ informed me that you are one of the important people who are taking him/her care. Tell me a bit more about your relationship with ________ and for how long have you been helping him/her?

2. Please tell me a little bit more about your experiences in providing care to ________ concerning his/her illness. Probe: Is there any person who is helping you with taking
Appendix 5  In-depth interview guide – Diabetes family members

_______(diabetic person) care? Who is that person and where does he/she stay? What kind of help he/she is offering? Are there social groups? Church groups, neighbours or friends helping? What type of assistance are they offering?

3. How did you know about diabetes before _________ was diagnosed with it? Before X’s diagnosis have ever heard about diabetes? Probe:
   a. You heard it from where?
   b. What did you hear about it?
   c. How can one prevent from getting diabetes? Have you ever asked?
   d. How can diabetes be cured? Haven’t ever heard people saying?
   e. How did you feel when _________(diabetic person) told you he/she is being diagnosed with diabetes? Why?

4. What do you think is the cause of X (diabetic person) diabetes? (Probe: all possible causes, can one get diabetes from another person? How?)

5. What diabetes symptoms do you know? (Probe for as many symptoms as possible. Did X (diabetic person) experience these symptoms before being diagnosed with it?)

6. What do you think of X before being diagnosed with diabetes? Do you think s/he knew he has it? Why? What prompted her/him to seek health care?

7. How long did it take from when _________(diabetic person) noted the signs or symptoms of diabetes and the time he/she decided to seek care at the health facility? Why?

8. Where did X seek treatment before initiating treatments from the health facility? Why? was there anyone who have looked for him/her or brought him/her some medications? Where did that person find the medicines/which medicines were bought?

9. What are the things that X have to consider before seeking care from the health facilities? (Probe: for medical costs (consultation and treatment costs) distance – transport costs)

10. What are the processes that X has to follow at the health facility when looking for diabetes treatments? Probe:
   a. How long he/she has to wait after getting to the facility before seen a specialist? Why?
   b. What about medical costs – consultation and treatment costs?
   c. What about advices he is given concerning his/her diabetic treatments?
   d. How can you describe X’s relationship with health care workers?

11. How long did it take for _________(diabetic person) visiting health care facility with the same complaints or symptoms before they tested him/her diabetes?

12. What is the experience of X in accessing his diabetes medicines from the health facility? How frequently does X get or miss his diabetic treatments from the facility? Why? (Probe: When it happens what do you do?)

13. What can you say of the diabetic treatments that _____ is using? Probe:
a. Do you think the treatments are helping him/her and why?
b. Is there a need for him/her to continue with the prescribed treatments? Why?
c. Is there a need for him/her to follow the prescribed life style changes? Why?

14. What are the challenges that X (diabetic person) is facing in his/her diabetic self care at home? (Probe: for both treatment continuity and life style change prescriptions; probe also for social and health challenges that the patient is facing)

15. How does the cost of care and treatments of ________ (diabetic person) diabetes affect the welfare of his/her family? (Probe: How is the family coping with problem?)

16. What challenges are you facing in helping X managing his/her disease? (Probe: How do you cope with such challenges? Who do you share with those challenges? what is their response?) Probe about time, economic, social and health consequences

17. If not leaving with X (diabetic person) ask: How does it affect your family/your welfare because of your involvement in taking care of X? (Probe: How do you cope with this problem?)

18. Now let us discuss a bit about the use of traditional healer services for diabetes, what is your experience on this? (Probe: have you ever sought traditional services for X? What made you to do so? What kind of services did you find for him/her?)

19. What kind of support does X mostly need from you in respect to his/her diabetes? (Probe: What kind of support are you mostly providing? What can be done to enable you provide that kind of support better?)

20. In your opinion what can be done to help diabetic people attend diabetic clinic as required? Probe:
   a. What can health care workers do to help people with diabetes comply better with their medications? (probe for both treatment continuity and life style changes)

21. What do you suggest to be done for the diabetes people to be able to practice their diabetic self care at home well? Also probe: How patient caregivers can be empowered to take care of the diabetic people better?

22. Is there anything concerning living/taking care of diabetes people that we have left / missed and you would like to share with me?

THANK YOU FOR YOUR TIME AND COOPERATION
Public policy, health system and community actions against illness as platforms for response to NCDs in Tanzania: a narrative review

Summary / Samenvatting