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).

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.

Download date: 14-09-2019
Chapter 3

Methodology, research area and study population
3.1 Introduction
This chapter provides a description of the research area, the study population, the study design, the pilot study, and the data collection methods. This is followed by a description of participant recruitment, the research team, the data analysis, and the ethical issues that were considered in the study. The chapter concludes by providing a reflection on the field work and the researchers’ positionality.

3.2 Research area and study population
This study was conducted in Kilombero (see Figure 3.1), one of the six districts of the Morogoro region, located in the southeastern part of Tanzania. Kilombero district has a total area of 14,018sq kms and a population of 407,880 (202,789 men and 205,091 women), representing 0.9 per cent of the total population in the mainland of Tanzania. The average household size in the district is 4.3. The district comprises 400,000 hectares of plain land suitable for agricultural activities such as farming, fishing and animal husbandry. Kilombero extends from the middle to the far southwest of Morogoro region. It is bordered by rural Morogoro to the east and Kilosa to the northeast. The north and west borders are shared by Mufindi and Nyombe districts of the Iringa region, while at its south and southeast it shares the boarders with rural Songea (Ruvuma region) and Ulanga districts respectively. Most of the district lies along the Kilombero Valley, a part of Rufiji Basin which extends below the Udzugwa Mountains from its east towards the southwest. There are major

Figure 3.1 Map of Kilombero district
plantations of teak wood in Kilombero and the neighbouring Ulanga district. The low-lying area in the northwest of the district is occupied mostly by the Illovo sugar company's sugar-cane plantations. The district has four climatic conditions: a hot, wet season from December to March; a cool, wet season from April to June; a cool, dry season from July to August; and a hot, dry season from September to November. The rainfall patterns in the district are bimodal, between 1,200 mm and 1,600 mm per annum, accompanied by seasonal flooding that makes physical accessibility to most parts of the district critical.

Kilombero is a low-lying district with 38 permanent rivers that are equivalent to 60 per cent of Morogoro Regions' total water bodies. This condition makes Kilombero an ideal area for paddy production, with 63 per cent of agricultural households cultivating paddy, the main staple food and cash crop in the area. The valleys climatic and ecological features are favourable for high and perennial transmission of malaria, making the Kilombero district one of the most malaria-prone areas in Tanzania.

Ifakara, a small town, is the headquarters and as such, the administrative centre of the district. There are four major health institutions in the district, all concentrated in this small town. Those include the Ifakara Health Institute – IHI (http://www.ihi.or.tz/); the St. Francis referral hospital (http://www.ifakara.org/en/st-francis-hospital/hospital.php), the Tanzania Training Center for International Health - TTCIH (http://www.healthtrainingifakara.org/); and the St. Francis Univeristy College of Health and Allied Sciences – SFUCHAS (http://www.sfuchas.ac.tz/ifakara/). Being a small rural town, Ifakara is in rapid transition, attracting people from different corners of the country either for business, cultivation or professional development. Also the ongoing building of a bridge over the Kilombero River between Ulanga district and Ifakara town is expected to bring rapid changes in terms of social, economic and the accompanied health changes. There is also a railway line in the area that goes from Dar es Salaam to Zambia through Kilombero district with railway stations along the way in Msolwa, Mang’ula, Kibelege, Ifakara, and Ruipa within the district. Most of the roads from Ifakara town to the villages and hamlets are difficult to pass, especially during the rainy season. The distance from Morogoro region to Kilombero district is 230 kms. Although this may not seem very remote to Western standards, Kilombero is actually quite a rural district due to the quality of the roads. Of the 230 kms that lie between Morogoro town and Kilombero district, 120 kms are on tarmac road from Morogoro region to Mikumi junction, (about one and a half hours drive), the highway to the southern parts of Tanzania. Of the remaining 110 kms (Mikumi to Ifakara), 85 kms are bumpy, dirty narrow road that make the trip to Ifakara a drive of about two and a half to 4 hours depending on the season.
There are 54 health facilities in the district, including two hospitals (the St. Francis referral hospital and another private hospital owned by the Kilombero Sugar Company), four government health centres and 48 dispensaries, some of which are owned by the government, and some of which are privately owned. Additionally, there is one diabetes clinic in the district and it is located within the premises of St. Francis referral hospital. Traditional healers of various types such as divine healers, herbalists and spiritual healers are also found almost everywhere in the district. Seeking health care services from outside the district such as travelling to Morogoro region could mean not only additional costs to the patients in terms of return bus fair, travel time and accommodation in Morogoro, but also the additional complication of the lack of reliable and suitable transport for the sick due to road conditions. Malaria is an important cause of ill health in the district and it affects people of all age groups. Together with other infectious diseases such as HIV and AIDS and tuberculosis, diabetes is one of the emerging concerns among other NCDs. This context of higher prevalence’s of acute infectious diseases such as malaria amidst a socio-economic development that is rapidly taking place provided the study with a unique opportunity to understand people’s health-seeking behaviour and their illness experiences of a newly emerging condition.

Two villages with a total population of 21,270, Viwanjasitini and Namwawala (see Figure 3.1), were purposively selected for the study with the help of District Council Health Management team members. The criteria for the selection of the villages were based on their proximity to St. Francis referral hospital. This hospital, where the diabetes clinic is situated, provides various health services, including those for malaria. To allow the study to capture a wider range of community perspectives on malaria and diabetes, the study villages had both semi-urban and rural characteristics. The semi-urban village (Viwanjasitini village) was located less than 5 km from Ifakara town, while the distance between the rural village (Namwawala village) and the town was 43 kms. The majority of the villagers in both places had no more than a primary school level of education, and were small-scale farmers who grew mainly rice and maize.

The main sources of health services for the residents of Viwanjasitini, the semi-urban village, are a laboratory facility and four dispensaries, all of which are privately owned, and which diagnose and treat malaria, along with other infectious diseases. There are also 14 drug shops located in the village, which sell a variety of medicines including anti-malarial drugs. The village has no government-run health facilities. As they live close to Ifakara, the residents of this village can also access a number of drug shops, laboratory facilities and dispensaries located there and have easy access to diabetes services through pharmacies or the diabetes clinic at St. Francis referral hospital. By contrast the rural village of Namwawala had one
private laboratory facility that provides diagnostic services only, and a government-run village dispensary. This dispensary provides both diagnostic tests and treatments for malaria and other infectious conditions. The inhabitants of this village can obtain anti-malarial medicines, among others, from the four drug shops located in their village or from several other shops in the adjacent villages. They also have the option of travelling to Ifakara to access treatments or purchase medicines, but the drive to Ifakara takes about one hour or more depending on the season. Diabetes services could also be accessed from Ifakara through pharmacies or the diabetes clinic at St. Francis referral hospital, as these services are not available in their village. There is no privately-owned health facility in this rural village. It is important to emphasise that despite the categorization of the recruitment sites as semi-urban and rural villages, the research site as a whole should be considered as a rural area due to the remoteness of the district to surrounding bigger cities like Morogoro (4 hours drive) and Dar es Salaam (8 hours drive).

The diabetes clinic at St. Francis referral hospital in Ifakara, which is the only public health facility providing diabetes services in the district, provides the services to people both within and outside the district. This clinic was involved in the study to provide access to diabetes patients from the surrounding rural villages who were visiting the clinic for their monthly routine check-up.

### 3.3 Study design

This study was divided into two main parts, a narrative review and primary data collection. The narrative review aimed to review literature to provide a general perspective on the NCD situation in Tanzania and the responses engaged. This review was also the start of a larger project where four PhD candidates worked on different aspects of the epidemiological transition, including issues of policy formulation and epidemiology of the diseases, health system operations, and community perspectives on the transition. Due to the holistic nature of the review topic, which includes policy, epidemiology, health system and community perspectives, a narrative review approach was chosen rather than a systematic review, because such an approach is well suited to present the broader perspectives needed for a newly emerging topic [10, 11].

The primary data were collected to get in-depth understanding of the meanings associated with malaria and diabetes and the reasons attached to behaviour and or actions in response to these diseases. An interpretative approach was used to enable identification of the issues from the study participants’ own perspectives [12]. This study approach aimed at getting the
emic perspectives from the people themselves, to reveal their perceptions and opinions about malaria and diabetes, how they make sense of the emerging symptoms, and to hear about the typical behaviour associated with the diseases and the underlying reasons for such practices. Qualitative data collection methods such as focus group discussion (FGDs) (see section 3.6.2.1) and in-depth interviews (IDIs) (see section 3.6.2.2) were used in collecting the primary data.

3.4 Pilot study and implications of its findings for the study design

The focus group discussion guides (FGD) were piloted in August, 2012. The pilot study was conducted in two villages (a rural and a semi-urban village) that would not take part in the main study. The pilot activities aimed at observing the practical application of the FGD guides in the field and whether the proposed topic guides would yield the intended information. The exercise also aimed at orienting the research team into the guides and at getting practical experience in administering them. The results of the pilot study helped to refine the final FGD guides that were used in the actual data collection, and also shaped the focus of the study in terms of the study sites and the type of participants involved in the study.

Initially, the plan of the study was to involve the general community members from Viwanjasitini (semi-urban village) and Namwawala (rural village) to participate in the malaria and diabetes FGDs. However, the main finding of the pilot study suggested limited awareness and knowledge about diabetes signs and symptoms and experiences on the condition among the members of the general community. Although this was an important finding as such, it meant that including members of the general community in the FGDs would not reveal any relevant substantial information about health-seeking behaviour in relation to diabetes. Therefore, instead of involving the general community members in the diabetes FGDs, diabetes patients, their neighbours and/or relatives were involved. The diabetes clinic at Ifakara town was used as a site to recruit diabetes patients from different surrounding rural villages for the FGDs, replacing the rural village Namwawala for ease of accessibility of participants: many patients came to Ifakara from surrounding villages for their monthly check-ups. Viwanjasitini village remained as a site to recruit neighbours and or relatives of diabetes patients for the diabetes FGDs for the same reason: its semi-urban characteristic permitted easy recruitment of potential participants by walking around the village, identifying patients or relatives of patients. The plan regarding diabetes IDIs, of engaging diabetes patients and their family members, remained unchanged. However, the IDIs with diabetes family members engaged participants from Viwanjasitini, the semi-urban
village only because it was not easy to recruit diabetes patient family members from the diabetes clinic at St. Francis referral hospital in Ifakara town as during their visits to the clinic the diabetes patients were unaccompanied by their family members. The sites for malaria FGDs and IDIs remained as originally planned.

3.5 Recruitment of participants

The study participants for FGDs (section 3.6.2.1) and IDIs (section 3.6.2.2) were purposively recruited as follows:

3.5.1 Participants for Malaria FGDs and IDIs

Participants for malaria FGDs and IDIs (see table 3.1) were purposively recruited with the assistance of the village leaders. The general criteria for inclusion in both FGDs and IDIs were being an adult member of the community (above 18 years), and being a permanent resident of the study district. An additional criterion for inclusion in the malaria IDIs was having a recent experience of malaria (14 days before the date of the interview). Separate FGDs were conducted for men and women.

3.5.2 Participants for Diabetes FGDs and IDIs

Participants for diabetes FGDs and IDIs (see table 3.1) were purposively recruited with the assistance of the village leaders (Viwanjasitini) or the clinic nurse (diabetes clinic in Ifakara town). Recruitment of the relatives of diabetes patients for the IDIs from Viwanjasitini village was done purposively with the help of the patients. The general criteria for inclusion on either FGDs or IDIs were being an adult member of the community (above 18 years), and being a permanent resident of the study district. Patients recruited were included in the diabetes FGDs only if they had been diagnosed with diabetes and were included in the diabetes IDIs only if they had at least 6 months’ experience with diabetes diagnosis prior to the interview.

As described earlier (section 3.4) at Viwanjasitini village, diabetes FGDs were conducted with neighbours and relatives of diabetes patients; while the IDIs were conducted with diabetes patients and their relatives. At the diabetes clinic in St. Francis referral hospital at Ifakara town, FGDs and IDIs were conducted with diabetes patients living in the surrounding rural villages. As for the malaria FGDs, the diabetes FGDs were conducted separately for men and women.
Table 3.1  Focus group discussions and in-depth interview participant characteristics and study focus

<table>
<thead>
<tr>
<th>Health condition</th>
<th>Malaria</th>
<th></th>
<th>Diabetes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>General</td>
<td>Patients</td>
<td>Neighbours/relatives and family members</td>
</tr>
<tr>
<td>Participants</td>
<td>community members</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Method used</td>
<td>FGD</td>
<td>IDIs</td>
<td>FGD</td>
</tr>
<tr>
<td>Study site</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Viwanjasitini</td>
<td>4</td>
<td>8</td>
<td>n.a</td>
</tr>
<tr>
<td>Namwawala</td>
<td>4</td>
<td>7</td>
<td>n.a</td>
</tr>
<tr>
<td>Diabetes clinic at Ifakara town</td>
<td>n.a</td>
<td>n.a</td>
<td>4</td>
</tr>
</tbody>
</table>

n.a: Not applicable

3.6  Data collection methods

3.6.1  Narrative review

The documents on the narrative review were obtained through searches of English literature from electronic data bases such as PubMed and google scholar with full text retrievals from HINARI. The search was done using a set of comprehensive topic-related search terms. Inclusion criteria in the narrative review were English - written articles on original work conducted in Tanzania. To ensure that the retrieved articles reflected the current and most recent responses, the search period was restricted to the work conducted between 1 January 2000 and 31 December 2012. Exclusion criteria were systematic or narrative reviews, opinion papers, documents including expectant women as participants, and articles on drug evaluation and diagnostics. The reference lists of all retrieved articles were searched for additional relevant articles. In addition, grey literature from websites of organizations active in the field of NCD was searched, including the government of Tanzania and the WHO (for a detailed search strategy see chapter four).
3.6.2 Primary data

The primary data were collected using qualitative data collection methods such as focus group discussions (FGDs) and in-depth interviews (IDIs). The strength of the qualitative data collection methods is their ability to examine feelings and meanings that people attach to their experiences, the interaction between knowledge, experiences, motivations and actions and the social factors that shape these processes [12, 13]. Such methods generate rich, detailed and valid process data that leave the study participants’ perspectives intact. To allow a better exploration of ideas and issues coming out of the discussions, the data collection activities were organized in two rounds, building on the strengths of each of the data collection methods employed. The first round of data collection involved the use of FGDs to collect general opinions and views on malaria and diabetes. Results from these FGDs were used to fine-tune and sharpen the IDI data collection guides (see appendix 3, malaria patients IDI guide; appendix 4, diabetes patients IDI guide; and appendix 5, diabetes family member IDI guide). These IDI guides were used during the second round of data collection to guide in-depth interviews for in-depth understanding of the issues at the individual level. The combination of the FGDs and the IDIs in the study contributed into a more thorough exploration of the issues that emerged [14]. The use of multiple qualitative data collection methods have been advocated for enhanced analysis of the phenomenon and for its broadened conceptualization [14, 15].

3.6.2.1 Focus group discussions

The first round of data collection engaged participants in focus group discussions (FGDs). FGD is a qualitative data collection method well accredited for its strength and ability to provide a wealth of insights into collective views, attitudes, perceptions and group feelings about the phenomenon [12, 16, 17]. They are “naturalistic”, as they are capable of providing the social contexts of meaning making and the general contextual factors surrounding the phenomenon under study [18]. Building on their ability to capture nuances of cultural meanings and behaviour, FGDs were used in the study to gain a wide-range of views and opinions on how malaria and diabetes are perceived in the community; community opinions and beliefs on their causes; shared experiences with the conditions; to ascertain their health-seeking behaviour and the typical behaviours associated with both malaria and or diabetes (see chapter one, research questions 2; 3; 5). In total, 17 FGDs (8 FGDs focusing on malaria aspects with 59 participants and 9 FGDs focusing on diabetes aspects with 58 participants) were conducted separately for each specific disease. Participants in the malaria FGDs were people from the general community in Viwanjasitini and Namwawala villages, while participants in the diabetes FGDs were diabetes patients and neighbours or relatives of diabetes patients (see table 3.1) recruited at the diabetes clinic in Ifakara town and
Viwanjasitini village respectively. The discussions with participants recruited in the village were held under natural settings convenient to participants within the respective villages and the discussions with participants recruited through the diabetes clinic were held in a private area within a canteen nearby the St. Francis referral hospital. The number of the participants in the discussions ranged from 6 to 9. The FGDs lasted from one hour to one hour and a half. FGDs guides (appendices 1 and 2) were developed to guide the discussions. The researcher facilitated all FGDs in Swahili, the most familiar language to people in the study setting and to the researcher. One research assistant was engaged in each of the FGDs for taking notes and observing the non-verbal communications. These FGDs started with a brief introduction of all people present and a re-introduction of the study objectives. Then, followed by a general discussion of the perceived common diseases in the community, the cultural meanings associated with them, and the perceived adult susceptibility to the conditions. To get more insights into how the cultural context informs health-seeking behaviour practices at the community level, FGD participants were questioned on their opinions about malaria and diabetes, specifically regarding how they respond when they face such conditions, and the reasons for the responses they make. With the use of open-ended and non-leading probes in a group setting, group members engaged freely by discussing and sharing their opinions, ideas, and experiences of malaria and diabetes, and of their health-seeking behaviour in general. The use of probes provided the opportunity for a detailed exploration of the components in the conceptual framework (section 2.4). Furthermore, to capture the diversity of opinions, ideas, free expressiveness and gender dynamics in the community, these FGDs were held separately for men and women. Each day that we conducted FGDs was concluded with an evening debriefing session. In these debriefing sessions the digitally recorded FGD files were replayed and summary notes were written for reflections. Some of these reflections were useful in identifying issues that needed more information or further probing, and these were then considered during the next FGDs. When during these reflections we could not identify additional information on each of the specific diseases and among men and women, data saturation was confirmed \[19\] and this determined the number of the FGDs. All 17 FGDs were digitally recorded with the consent of the participants and transcribed verbatim into electronic versions within 48 hours of the time they were conducted. Ideas, opinions, and issues generated from the FGDs were used to fine-tune and sharpen the IDI guides that were used for in-depth exploration of the aspects at the individual level.

3.6.2.2 In-depth interviews

In-depth interview (IDI) is a qualitative data collection method that involves an interviewer and interviewee into discussing specific topics in depth \[12\]. This method was used to collect
primary data during the second round of the data collection. Different from FGDs, IDIs are acknowledged for their strength in providing a “deeper” understanding of the social phenomena that can rarely be achieved through the other data collection methods \cite{16}. The potential of IDIs lies in their great emphasis on discovering an individual’s own feelings and emotions, his/her beliefs and perceptions about diseases and illnesses, the practices and actions they account for in their illness experiences and what opportunities and obstacles they face \cite{12} in responding to their health conditions. In-depth information on more sensitive personal issues and feelings can also be revealed in an IDI \cite{12, 20}. The assumption with this method of data collection is that if the data collection guides are correctly designed, the participant’s expressions of their experiences will reflect their reality \cite{14, 21, 22}. The IDIs were used in the study to gain an in-depth understanding of the individual perceptions on malaria and/or diabetes, their illness experiences, and the decision making processes in seeking care for the conditions (see chapter one, research question 2; 3; 5). In addition, the IDIs also aimed at getting a “deeper” understanding from the diabetes individuals themselves; of the behavioural practices shaping their experiences with diabetes medication use and continuity of use (see chapter one, research question 4).

A total of 41 in-depth interviews were conducted with adult community members. IDI participants were either people who had a recent malaria episode – 14 days prior to the interview (15) – or had more than six months’ experience of living with diabetes (19), or were family member of diabetes patients (7) (see section 3.5). IDIs with participants recruited from the villages Viwanjasitini (malaria and diabetes) and Namwawala (malaria) were conducted at the participants’ household and those of the participants recruited through the diabetes clinic at Ifakara town were conducted at a private area within a canteen near to the St. Francis referral hospital. IDI topic guides (appendices 3 - 5) were developed to guide the interviews. As with the FGDs, the researcher conducted all the interviews in Swahili. An in-depth interview lasted between 45 minutes and 1 hour. All interviews were digitally recorded with the verbal consent of the participants, and a research assistant made a verbatim transcript of the interview within 48 hours of its completion. The interview process started with a general introduction of the researcher and the research. The actual interviewing started after the individuals had given consent. It first started with the participants’ background information and thereafter, with the participants narrating their stories on how the illness started, the meanings ascribed to their symptoms, followed by a description of their actual health care-seeking process, their medication use experiences, and their day-to-day life experiences with the illness. With the use of probes, the different components from the conceptual framework (section 2.4) were explored. This method of data collection gave participants ample time to answer specific questions by detailing the actual accounts of their
illness, the actions employed when responding to the symptoms and the reasons for taking those actions; their real life experiences with medication use and the daily experiences of living with an illness. During the IDIs the research process was highly flexible to allow continuous probing as matters arose in the discussions. Similar to the FGDs, each day that we conducted IDIs ended with a debriefing session in which the digital recorded IDI files were replayed and summary notes were written for reflections. Some of these reflections helped to identify aspects that needed further information or clarity and these issues were then considered during the IDIs that followed. When these reflections identified no new information from the IDIs on the specific disease and among men and women, data saturation was confirmed [19] and this determined the number of the IDIs.

3.7 Research team

The research team comprised the researcher and two research assistants who had a social science background at a post graduate level. The research assistants had a one-day intensive training on the study. The researcher provided an overview of the research and the overall aim of the study, followed by a description of the study design and an elaboration of the study objectives to the research assistants. Afterwards, the training concentrated on orienting assistants to the specific data collection guides rather than to the modalities and technicalities for conducting the actual field activities as they were all considered competent in that area. Both of the research assistants had more than five years’ experience in conducting qualitative data collection activities with community members in different areas within Tanzania as well as in the writing of transcriptions. The researcher facilitated all the FGDs and the IDIs while the assistants were responsible for note taking and transcribing the digitally recorded files.

3.8 Data analysis

The data analysis processes started with the researchers’ familiarization with the data. Although I facilitated all the FGDs and IDIs myself, I read through all the transcribed files to match them against an audio file to ensure the transcripts’ authenticity and quality before importation to NVivo 9 (QSR International Pty Ltd, Australia), that was used to facilitate the analysis. Through the processes of re-reading and listening to the audio files, I became familiar with the data in a more in-depth way. This was followed by the generation of the codes, and then the code book, i.e. a list of ideas about what was in the data and what was interesting about the data and its descriptions. The codes for each data set (FGDs or IDIs) were developed separately following the same principles. These codes included both inductive and deductive codes, all of which were then shared among the principal researcher and her
three supervisors, one from Tanzania, and two from the Netherlands. Discrepancies were minimal and were reconciled through discussions prior to the finalization of the codes and the code books and to the coding of the data and the analysis. This reconciliation led to shared understandings that were critical for the analysis, to minimize possibilities of systematic biases and distortions during data analysis[13]. The last task entailed integration of the two data sets and categorization of the codes into themes and family codes following principles of the grounded theory[12], a process that continued until no new themes or categories emerged. This was followed by the writing of the descriptive reports. Most of the themes represented new concepts that emerged inductively from the data (self-medication; access to health services; and illness experiences), while the family codes reflected the HBM components that informed the data collection topic guides (see example figure 3.2). Family codes are thus at a higher level of abstraction than the themes. The emergent concepts suggested a need for additional theoretical concepts to further conceptualise and aide explanations of the actions on self-medication and treatment; the context on access to health services; and the illness experiences that go beyond the individual beliefs and perceptions, as the later could be well explained by the former theoretical concepts. In the specific chapters, the additional theoretical concepts of self-care (chapter five), 5A’s access to care dimensions (chapter seven) and explanatory model of illness (chapter eight) were adapted to aid interpretation of the emergent concepts. Figure 3.2, gives an example of how the codes were categorized into themes, as well as how the family codes were linked to conceptual/theoretical concepts in different chapters.

3.9 Ethical issues
The study was approved by ethical committees of the Faculty of Spatial Sciences, University of Groningen in the Netherlands; the Ifakara Health Institute (IHI) in Tanzania; and the National Tanzanian Medical Research Co-coordinating Committee of the National Institute for Medical Research (NIMR) at Dar es Salaam. Getting entry into the community involved introducing the study and its objectives to the District administrative authorities for permission to conduct the study in the district. With the help of the District Council Health Management team, the study villages were chosen. The District Authority provided an introductory letter to the villages. The village leaders were informed about the study and its objectives by the research team upon their arrival in the village. The same procedure was followed to gain entry into the diabetes clinic. After the introduction to the director of St. Francis referral hospital and introducing the study and its objectives, the director introduced the team to the diabetes clinic authorities. All study participants were thoroughly informed about the study and the risks and benefits involved were elaborated. Participation was
voluntary and participants were informed of the right not to answer any question or withdraw their participation at any point in time without giving explanation. Each study participant provided verbal consent for their involvement in the study and the digital recording before participating in either FGDs or IDIs. Specific to the low literacy in the setting, verbal consent was the most suitable form of consent taking and this was recorded. To ensure confidentiality, participants in the FGDs were discouraged from discussing each other’s views outside the FGD settings. To maintain anonymity, all participant identifiers were removed from the data and only their opinions are presented. The audio files were anonymized and coded by the principal researcher to identify the area, the focus of the discussion/interview and not the individuals involved. All the transcribed data have been carefully kept under secured files and are used only for academic purposes.
Chapter 3

3.10 Fieldwork reflections and researchers positionality

The fieldwork activities started with the FGDs (see section 3.6.2.1) between October and November 2012, followed by the IDIs (see section 3.6.2.2) between February and March 2013. During the fieldwork, the research team position was both a challenge and a benefit to the study. Introducing ourselves as affiliated to Ifakara Health Institute (IHI), an institution that is well recognized in the study settings for its contributions to improving the health of the local community through interventions on prevention and control of infectious diseases was an advantage to the team, providing a smooth entry into the study settings. In both villages and at the diabetes clinic, study participants were eager to share their opinions and stories regarding malaria and diabetes. It seemed from their expressions that participants had a general trust and confidence in sharing their information with the research team due to the goodwill that has been created between IHI and the communities within the Kilombero district. IHI has worked intensively on interventions research for prevention and management of malaria as well as other infectious diseases in the district. Such a background shaped some of the study participants’ expectations from the research, a main challenge to the study. Participants frequently demanded the team to provide them with information regarding diabetes signs and symptoms, causes, preventive measures and how the condition is treated and or could be cured. The team had to explicitly re-explain to the study participants about the research objectives and the intended outcome of the study in terms of academic qualifications, and explain the fact that they had no medical background. In addition, at the end of the discussions, a list of resources on where participants could get professional information was provided. Participants were also recommended that they seek help from the medical professionals at the diabetes clinic. Another challenge was specific to the diabetes in-depth interviews. As the interviews advanced, I felt compassion towards some of the participants as they narrated the emotional struggles they encountered during the process of being diagnosed to have diabetes and the fear they expressed in facing the possible consequences of living with the condition. One female participant started crying when she shared with me the struggle she is experiencing due to the fact that she has to change her lifestyle and ensure continuous use of the diabetes medications despite the severe social and economic consequences experienced on her end. It was important for me to show sympathy and responsiveness and at the same time stay focused in the questions I was asking, and striking this balance proved challenging.

Being a Tanzanian, conducting this research in my own country was an advantage because of the shared insights with the participants’ perspectives and understanding of the verbal and non-verbal languages. The study participants appreciated me as an insider. This reduced tension and motivated them to talk freely and to share their opinions, views and experiences.
My sociological background enhanced my skills in engaging the participants about issues central to their well-being like diseases and the illness experiences; while at the same time keeping participants contented. I was keen to ensure that participants were comfortable airing their opinions and views about malaria and diabetes and in recounting their illness experiences. In the FGDs, I paid quite a bit of attention to how my appearance and vocabulary could influence participants’ responses and impact their comfort in expressing their views and opinions. Although I had to pay attention to the same factors during the IDIs, there I also become more sensitive to the participants’ illness status. In so doing, I was able to gain trust and form a good rapport among the participants and this proved to be a key to the deeper understanding of malaria and diabetes health-seeking behaviour that was achieved in the study.

References


