Summary

Tanzania is experiencing the epidemiological transition and the resultant challenge of the double burden of disease. Whereas infectious conditions such as malaria remain major public health concerns, the incidences of non-communicable diseases such as diabetes are rising at an alarming pace. Malaria and diabetes have different aetiologies, manifesting differently and requiring different models for their treatment and management, but their coexistence in Tanzanian rural communities compounds the physiological, social and psychological suffering of the individuals and their families. Information on health-seeking behaviour in contexts where both infectious and non-communicable diseases are occurring in the context of an epidemiological transition is limited. Such information could be a useful contribution towards the efforts to support and encourage people to make informed decisions in seeking prompt, appropriate and effective care, and to determine the uptake of the disease control and management interventions that are already in place.

The overall objective of this study was to explore the cultural aspects shaping health-seeking behaviour for malaria and diabetes among adults in Tanzania, a country that is undergoing the epidemiological transition. Several specific objectives and research questions followed from this overall objective:

1. To provide an inventory of how the existing policy environment, health system and community platforms are addressing the NCDs situation in the country, a narrative review was conducted guided by the following research question:

   *How can the existing public policy environment, health system and community actions against illnesses be used as platforms for NCD responses in Tanzania?* (Chapter four)

2. Studies on communities’ responses to illnesses such as malaria suggest that self-medication and treatment with medicines bought at a drug shop is a common initial action when individuals experience ill-health. To gain deeper insight into why people choose self-care for malaria treatment and the motives for the choice of drug shop services, the following research question was developed:

   *How do the underlying cultural motives shape adults’ decision-making processes in their choice of malaria self-care practices?* (Chapter five)
3. The new challenges in public health have arisen with the emergence of chronic non-communicable diseases such as diabetes. The following research question was developed in order to grasp – via an emic perspective – how the communities assign meanings to the emerging symptoms, and the intricate relationship these meanings form to shape individuals’ health-seeking behaviour.

   How does the underlying cultural context inform the meaning given to the emerging diabetes symptoms and shape the individuals’ health-seeking behaviour practices? (Chapter six)

4. To gain insight into behavioural aspects shaping diabetes medication use experiences and continuity of use, the following research question was developed:

   How do the underlying cultural motives shape diabetes patients’ decision-making processes and their experiences regarding diabetes medication use and continuity of use? (Chapter seven)

5. Despite their differing nature in aetiology and management, malaria and diabetes occur in the same communities and sometimes coexist in the same households and or individuals – hence, the term, double burden of disease. To better understand the illness experiences of diabetes in a context of malaria as a predominant condition, the following question was formulated:

   How is diabetes experienced in the context of malaria as a predominant illness? (Chapter Eight)

The research objective described above and the research questions outlined formed the basis of this thesis.

Theoretical framework
The Health Belief Model (HBM) was applied in the study to guide the inquiry into individuals’ health-seeking behaviour for both malaria and diabetes. Originating in the 1950’s, this theory was constructed by the US Public Health Service Department to explain why public health preventive services were not successful. The theory was later expanded for insight into compliance with medical prescriptions. The HBM components are perceived susceptibility, perceived severity, perceived benefits and perceived barriers. To increase the
applicability of the HBM components in guiding the understanding of how cultural aspects shape individuals’ health-seeking behaviour, D’Andrade’s concept of Cultural Schemas was adopted in the study. These two theories, the concept of Cultural Schemas and the HBM, were used to construct the study’s conceptual framework. The conceptual framework formed the basis for designing the topic guides that were used to guide data collection activities and the subsequent analysis.

Study design, data collection and analysis

The study was divided into two main parts: secondary data analysis and primary data collection. Secondary data analysis involved conducting a narrative review of the published and grey literature on how the existing policy environment, health system and communities are addressing the NCD situation in Tanzania. Primary data were collected in Kilombero, a rural district in Tanzania involving: (i) people in the community (ii) malaria and/or diabetes patients, (iii) neighbours and/or people related to diabetes patients, and (iv) family members of diabetes patients. The data collection team comprised the researcher and two research assistants with social science background and experienced with qualitative data collection activities. The data collection activities were organized into two rounds: round one involved conducting FGDs between October and November 2012; round two involved conducting IDIs between February and March 2013. Data analysis followed grounded theory principles and was assisted by NVivo 9, qualitative data management software. During the data analysis, different theoretical concepts such as the concept of self-care, the 5A’s access to care dimensions and the explanatory models of illness were applied to aid data interpretation.

Key findings

This section summarizes the key findings of the study. These findings are presented following the sequence of the chapters in the thesis and follows the order of the research questions.

Chapter four present results of our narrative review on how the existing policy environment, health system and community actions against illness can be used as a platform for NCD responses in Tanzania (research question 1). The narrative review findings showed that the disease prevention and control efforts in Tanzania are focused more on infectious diseases such as malaria, tuberculosis and HIV/AIDS. This focus reflects the dominance of these conditions and their consequences in the community. The emergence of NCDs challenges the government, health system and communities that have to face both the infectious and the emerging non communicable conditions simultaneously. It was evident in the narrative
review that a lack of a national NCD policy in the country led to fragmented efforts in their prevention and control. This narrative review showed inadequate preparedness of the health system to accommodate the requirements of the emerging NCDs, especially in the primary level health facilities that are characterized by insufficient availability of trained personnel, diagnostic equipment and treatments. We found no evidence of community involvement in the prevention and control of NCDs, nor of community perceptions of NCDs, especially among the rural communities. This is the focus of the current study.

In chapter five, results of the primary data are presented, detailing how the underlying cultural motives shape adults’ choices regarding malaria self-care practices (Research question 2). The study findings indicate that the biomedical knowledge about malaria signs and symptoms have been acculturated into the community’s cultural meaning system and schemas about the condition. This cultural meaning system was seen to inform the individuals’ perceived susceptibility and perceived severity of malaria and their self-diagnosis, self-medication and treatment practices. The shared schemas on malaria in the community and the individual experiences of the condition triggered these self-care practices. The perceived benefits associated with specific antimalarial treatments informed the use of anti-malaria monotherapies and the preference for single doses in the study. Perceived barriers associated with the fears of side effects from the recommended first-line anti-malarial combination treatments hindered their use.

Chapter six provides an account of the findings on how the underlying cultural contexts inform the meanings given to the emerging diabetes symptoms and shape the individuals’ health-seeking behaviour (research question 3). The study findings show that diabetes is a relatively new condition in Tanzania and the knowledge and awareness about its signs and symptoms is limited among the communities in the study settings. People used the prevailing cultural meaning system and schemas on infectious diseases such as malaria, HIV and AIDS to inform their interpretation of the emerging chronic diabetes symptoms. Schemas for body image informed the meaning given to diabetes symptoms similar to those of HIV/AIDS because of the severe weight loss. The community’s cultural meaning system about malaria signs and symptoms such as headache, fever and tiredness informed individuals’ perceived susceptibility to malaria as well as their perceived severity, and consequently they usually chose to self-medicate with anti-malarial medicines. Misdiagnosis of diabetes symptoms was common, as not only the patients but also the health care professionals were unable to recognize the symptoms. When the cultural meaning system could not aid in assigning meaning to the emerging diabetes symptoms, it informed the decisions of some patients to consult traditional healers and/or associate the symptoms to witchcraft causes.
Chapter seven presents results on the lived experiences of diabetes medication use and continuity of use in a setting with limited access to diabetes services (Research question 4). In the study, the perceived benefits associated with the use of diabetes medications in reducing the perceived severity of the symptoms informed patients’ acceptability of the medicines. However, affordability, availability and the physical accessibility of the diabetes services, including the medicines, were the perceived barriers to their use and continuity of use among patients. These issues were more pronounced among rural diabetes patients because diabetes services were completely unavailable in the rural and remote areas. Because of the perceived severity of diabetes when patients are not using medicines, diabetes patients in the study reported engaging in several behaviour practices as coping mechanisms to offset the perceived barriers and ensure their use of the medications. Such practices included: dose omission, using less of the required dose and or sharing their medications among themselves.

Chapter eight provides findings on the illness experiences of diabetes in the context of malaria as a predominant condition (research question 5). The study findings demonstrate that the cultural meaning system and schemas about acute infectious illnesses such as malaria shaped the individuals’ perceived severity of malaria and diabetes. These perceptions in turn informed the individual accounts of the illness experiences on the severity and chronicity of the conditions. However, the illness experiences of malaria were indicated as being relatively bearable because of the acuteness and shorter duration compared to the experiences of diabetes. The accounts of diabetes illness experiences were characterized by serious, lifelong consequences such as unpredictable health conditions, loss of consciousness, memory, libido, functional incapability, limited social life, and increased stress and tension.

Conclusion

This study provides important findings for a greater understanding of the factors shaping health-seeking behaviour with respect to common infectious conditions such as malaria as well as the emerging chronic non-communicable diseases such as diabetes. This information is useful for policy makers and for public health practitioners and those concerned with improving the quality of life for all people and it can contribute to designing interventions for informed decisions regarding seeking treatment for the illnesses. In general, the findings of this study could contribute to the development of context-specific interventions for strengthening peoples’ decision-making processes in terms of malaria self-care practices; raising awareness on the emerging signs and symptoms of diabetes and NCDs in general; strengthening behavioural practices with respect to medication use; and improving illness experiences and day-to-day life for people with chronic NCDs such as diabetes. The study findings also make important contributions to future research and policy formulations.