Chapter 1

Introduction
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The epidemiological transition – the change in patterns and cause of diseases from acute infectious and deficiency diseases to chronic non-communicable diseases (NCDs) [1] – has brought about a double burden of disease in most of the Sub Saharan African (SSA) countries. Despite the decrease, infectious diseases continue to dominate in SSA [2]. With the epidemiological, nutritional and demographic transitions alongside the increasing life expectancy, poverty, urbanization and globalization, non-communicable diseases are posing yet another threat to these communities. Indeed, while in 2013, 128 million people were infected with malaria in the Africa region [3], the number of African residents with diabetes reached 19.8 million in the same year [4]. This number of diabetes patients is projected to rise to 41.4 million by 2035 if appropriate measures are not taken [4]. Type 2 diabetes accounts for the majority (90-95 per cent) of the diabetes cases [5], and is mostly affecting adults [6]. Diabetes is responsible for 8.6 per cent of all deaths among adults aged 20-79 years in the African region [4].

This picture of Africa also applies to Tanzania. Infectious and non-communicable diseases coexist. Malaria remains a threat to the health of the Tanzanians [7, 8], accounting for over 30 per cent of the national disease burden [9]. According to the Tanzania Health System Assessment report 2010, malaria was responsible for 34 per cent of all people aged 5 years and above attending consultations in public health facilities, and for 28 per cent of the top 10 causes of in-hospital deaths in the same age group [10]. While the Tanzanian communities are in the middle of grappling with the persisting infectious diseases such as malaria, diabetes is emerging as another health concern. Diabetes is evolving rapidly in the country [11] and seriously challenging not only the health system’s capacity to manage the condition [12] but also the communities and the individuals who face both the physiological, economic, social and the psychological sufferings of the chronic NCDs. Thus, the general burden of diabetes – on the health system [11], the communities, and families – is alarming [13]. Considering that most of the type 2 diabetes patients are asymptomatic during early stages of the condition [14], the actual number of people in the country unknowingly living with the condition is unclear. Because malaria and diabetes are causing so much misery and suffering to the Tanzanians and have such a widespread negative impact, it is important to understand the current policy environment, the health system and the community responses against these illnesses in order to shed light on how these health constituencies could be adapted in response to the rising NCDs, including diabetes.
1.1 Epidemiology of malaria in Tanzania

In Tanzania, almost everyone is at risk of contracting malaria \[^{[15]}\]. Tanzania is the country with the 3rd largest population at risk of malaria in Africa after Nigeria and the Democratic Republic of Congo \[^{[16]}\]. However, the country has great variation on malaria endemicity and transmission risks due to differing rainfall patterns, altitude, and temperature \[^{[17]}\]. This variation suggests that 75 per cent of the population is prone to stable perennial or stable seasonal malaria transmission; 8 per cent to unstable highly seasonal transmission and 17 per cent to no malaria transmission in the average year (but still at risk of epidemic malaria). However, the available national statistics indicate a dramatic decline of malaria incidences over the last decade as a result of the expansion and intensification of malaria control programmes \[^{[15]}\]. For example, the Tanzania Demographic and Health Surveys (TDHS) indicate a successive fall in the number of fevers, a common indicator of perceived malaria, from 35.1 per cent in 1999 to 24.4 per cent in 2004 to 22.9 per cent in 2010 \[^{[18-20]}\]. Similarly, the national representative survey on malaria indicators shows that malaria prevalence in children 6-59 months old halved (from 18.1 per cent to 9.5 per cent) between 2008 and 2012, with higher declines seen more in urban than in rural areas \[^{[21, 22]}\]. Across Tanzania, between 2000 and 2010, there has generally been a greater than 50 per cent reduction in predicted mean population-adjusted parasite prevalence in children aged 2–10 years (malaria strategic plan 2014 - 2020). Despite such observed trends, malaria is still an important cause of health facility utilization in both children and adults in the country \[^{[7, 8]}\]. As children aged under five years continue to be the most susceptible age group to malaria, the recent literature shows a shift in the level of malaria infection to the older age groups \[^{[23, 24]}\]. Additionally, the observed changes in mosquito biting behaviour from indoor to outdoor biting \[^{[25]}\] is also thought to have increased adults’ susceptibility to contracting malaria. With this in mind, sustaining the lifesaving gains achieved with malaria control efforts and to continue reducing the malaria risks in the community, prompt, effective and appropriate health care-seeking behaviour is required on the part of every patient. This is because delays in appropriate treatment for malaria have the potential of increasing malaria transmission, as the parasite infection pool is maintained longer than necessary. Additionally, delays in treatment and management can allow malaria to rapidly develop into severe and complicated forms of the disease with fatal consequences to the patients. Therefore, understanding the people's perspectives on malaria, their experiences with the condition, and their motives in terms of seeking treatments in the context of decreasing malaria trends is crucial not only for informing development of such disease control interventions, but also for enhancing health care-seeking behaviour practices in the community.
1.2 Epidemiology of diabetes in Tanzania

In recent years, diabetes has evolved to become one of the most serious public health concerns in Tanzania. Its prevalence has risen steadily in both urban and rural areas from 0.9 per cent and 0.8 per cent in the 1980’s to 4 per cent and 1.3 per cent in 2000 respectively [11]. In 2003 diabetes prevalence reached 5.4 per cent in urban and 1.7 per cent in rural areas [26]. Ten years later, a national population survey reported the prevalence of diabetes to have reached 9.1 per cent among adults aged 24-65 years and at roughly equal rates between men and women in urban and rural areas [27]. The recent International Diabetes Federation estimates indicated that by 2013, 1.7 million Tanzanians were living with diabetes and the number is projected to double by the year 2030 [4]. Although the reported statistics on diabetes in the country are alarming, a population-based survey in one urban district of Dar es Salaam city and one rural village in Kilimanjaro region indicated that more than 80 per cent of the people with diabetes were not aware of their diabetes status [28]. Most people with diabetes are unaware of the signs and symptoms of the condition, leading to late presentation at the health facilities and initiation of care and management [11]. Consequently, many diabetes patients remain unreported and die undiagnosed and prematurely because they cannot survive long without treatments [29]. It is therefore important to understand from the people themselves what underlies diabetes perspectives in the community – the meanings ascribed to the emerging symptoms and the intricate relationship it forms – in order to shape individuals’ health-seeking behaviour including medication use, as well as their day-to-day life with the illness. Such information could contribute to the formulation of context-adaptive interventions; to the improvement of the awareness and knowledge of the disease’s signs and symptoms; to the strengthening of prompt and appropriate health-seeking behaviour in the community; and to the provision of the necessary social and psychological support to the patients and their families.

1.3 Health-seeking behaviour for malaria and diabetes

Literature on malaria health-seeking behaviour in Tanzania suggests that peoples’ responses to malaria depend on the perceptions about the illness symptoms and their aetiologies [30-32]; perceived severity of the illness [33, 34]; perceptions on the quality and effectiveness of the treatments [35]; access to the health care services [36, 37]; and household socioeconomic characteristics [38-40]. It also recognizes that most people with malaria in the country practice self-medication and treatment with the use of medicines from the drug shops and or medicines remaining from their previous malaria treatments [33, 40-44], and that medical professionals are only consulted when the illness symptoms persist or worsen [32, 43], which results in delays in initiating prompt, appropriate and effective treatments [45]. Despite the
relevance of this literature in understanding malaria health-seeking behaviour, the literature
does not help our understanding about the underlying decision-making processes with
respect to malaria health-seeking behaviour. Of specific concern is the information on why
people choose self-medication for malaria – What are the motives for the use of the medicines
from the drug shops? These issues are crucial, especially nowadays, because despite the
reports on reduction of malaria transmission, morbidity and mortality, malaria is still an
important cause of ill-health and health facility utilization. Non malaria fevers such as
typhoid, urinary tract infection (UTI) and dengue fever are increasingly being reported in
Tanzania. Therefore, to reduce prolonged illness in patients and improve their treatment
outcomes, it is important to ensure that all febrile illnesses including malaria are promptly
and effectively treated. A deeper understanding about the motives underlying peoples’
decision-making process for malaria self-medication and the use of drug shop services has
the potential to contribute to the development of context-adaptive interventions for informed
decision-making processes on malaria treatments in the community.

Although malaria and diabetes have different aetiologies, manifest differently and require
different modes of treatment and management, the two diseases occur in the same
communities and may coexist within the same households and or individuals. The coexistence
of these conditions adds stress to the already stressed communities in terms of resource
allocations for their health care-seeking behaviour and management, and the increased
burden of care on the households and families. It also increases the emotional, psychological
and the physiological pain for the sick individuals and their family members. Yet insufficient
information is available on how health-seeking behaviour for diabetes is framed in the
context of malaria as a predominant illness in rural settings. To develop more context-
adaptive interventions for their prevention and control, it is important to gain a deeper
understanding of the communities’ own points of view – firstly on how these diseases are
perceived in the community and the experiences that are encountered, and secondly, on the
meanings ascribed to the emerging symptoms and the linkage they form to shape health-
seeking behaviour, as well as on the reasons for the responses that are made.

Because of their differential nature in acuteness and chronicity, the interplay formed by the
socio-cultural aspects on malaria health-seeking behaviour might not be the same as for
diabetes. Whereas prompt and effective health care-seeking behaviour for malaria could lead
to a cure, this is not the case with diabetes. After its clinical manifestation, diabetes requires
patients to continue with the use of the medications and management of the condition and or
lifestyle changes. This requires a change from curative health care-seeking behaviour to
prompt and appropriate management of the condition, including probable lifestyle change
practices and continuation of care. Thus, understanding of diabetes health-seeking behaviour is crucial for encouraging the continuity of care – including medication use continuity – and for strengthening care continuity in the communities in general.

Health-seeking behaviour studies on diabetes in Tanzania are uncommon. The existing studies have assessed self-care and educational needs among diabetes patients [48]; health-seeking behaviour and related behaviour for type 2 diabetes [49]; and diabetes health-seeking behaviour and medical pluralism [13]. While these studies provided us with the relevant information on diabetes treatments, they are all concentrated in urban areas, reflecting the popular belief that diabetes is a disease affecting those living in urban settings [28, 50]. Such a focus does not help our understanding of how it is to experience a chronic NCD such as diabetes in rural areas. Social science literature detailing how diabetes is conceived in the rural settings of Tanzania and the motivations for health-seeking behaviour among patients is scarce. This study generates knowledge that contributes to filling that research gap. Understanding what underlies diabetes patients’ decision making processes and the resultant health-seeking behaviour practices will contribute to developing context-adaptive interventions for disease control and strategies for strengthening community responses to diseases in the country.

1.4 Research objectives and questions

Human actions and practices are shaped by the cultural context in which they occur. Understanding individuals’ health-seeking behaviour thus requires an understanding of the cultural aspects that shape the practices. Cognitive and behavioural change theories such as the concept of Cultural Schemas [51] and the Health Belief Model – HBM [52] were applied in the study to allow a better understanding of the intricate relationship between the processes underlying individual behaviours when seeking health care. Using these theoretical underpinnings, the overall objective of the 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. Guided by the following research question, a narrative review was conducted in order to provide an inventory of how the existing policy environment, health system and community platforms are addressing the NCD situation in the country:
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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 community responses to illnesses such as malaria suggest that self-medication and treatment with medicines bought at a retail shop is a common initial action when individuals experience ill health. To gain deeper insight into why people choose self-care practices in 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 how do these meanings shape the individuals’ health seeking behaviour practices? (Chapter six)

4. To gain insight into behaviour 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 differential nature in aetiology and management, malaria and diabetes occur in the same communities and sometimes coexist in the same households and or individuals. To better understand the illness experiences of diabetes in a context where malaria is a predominant illness, the following research question was formulated:

How is diabetes experienced in a context where malaria is a predominant illness? (Chapter Eight)
To provide in-depth information on the study’s objectives and to answer the specific research questions, a narrative review was conducted to document the existing policies, health system practices, and community responses to NCD prevention and control. In addition, fieldwork was conducted with (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.

1.5 Outline of the thesis

The theoretical framework of the PhD project, presented in chapter two, is based on a behaviour change theory: the Health Belief Model (HBM) is used as a guide in understanding individuals’ decision-making processes involving their health, specifically their responses to malaria and diabetes. One of the critiques of the HBM is its simplistic or narrow focus on individuals and their tendency to act based on what they know; it thus fails to account for the social context in which the individual behaviour is embedded. In view of the criticism and to increase the likelihood of the model succeeding to illuminate how cultural aspects in the community shape health-seeking behaviour, the cognitive anthropological perspectives of the Cultural Schemas was integrated into the components from the HBM. This combined conceptual framework is presented towards the end of the chapter (section 2.4) followed by an account of the theories that aided data interpretation during the analysis.

Chapter three presents the research methodology. A detailed description of the study area and population is provided, followed by a description of the study design. The chapter also provides explanations of the data collection methods (section 3.6) that were applied in the study. Data analysis processes (section 3.8) and a reflection on the field work and the researchers’ positionality (section 3.10) is provided towards the end of the chapter.

The chapter on platforms for responses to NCDs in Tanzania (Research question 1, chapter four; article published in Global Health Actions) provides a detailed account of how the existing public policy, health system and community actions against illnesses can be used as platforms for responses to the emerging NCDs. A discussion on how NCD research and policy agenda can be moved forward is provided. Chapter five (Research question 2; article published in Malaria Journal) discusses the underlying motives for malaria self-care in the communities. Both individual and health facility characteristics are indicated as important aspects informing self-care practices for malaria in the study. Chapter six (Research question 3; article published in BMC Public Health) discusses how the communities use the prevailing cultural meaning systems on infectious diseases to inform the emerging diabetes symptoms,
which in turn influences their health care-seeking behaviour. Chapter seven (Research question 4; article published in BMC Health Services Research) discusses the lived experiences with respect to medication use and continuity among diabetes patients in settings of limited access to medicines. Bringing together the findings in the previous chapters and considering the different natures of the two illnesses in terms of acuteness versus chronicity, Chapter eight (Research question 5; article submitted to international peer-reviewed journal) discusses the illness experiences of diabetes in the context of malaria as a predominant condition. As the final chapter, chapter nine then ties the research together and sets forth the contribution it makes to understanding health-seeking behaviour in communities with the double burden of malaria and diabetes in Tanzania. Theoretical and methodological reflections, as well as implications of the study findings, recommendations for policy and public health, and suggestions for community initiatives and future research directions are also included in this conclusion to the research.

References

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Introduction


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