Understanding Health Discourses from a livelihoods perspective; Family and Community Management in the Malaria Control Programme in Sierra Leone.

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Abstract

Malaria is a global health problem. Despite the national malaria control programmes, it continues to be a major cause of death and disease in many sub-Saharan countries. The current study draws on data collected in 2016-2017 in Moyamba district Southern Sierra Leone, to explore the role of family and community management in dealing with health problems like malaria. The research question was: '*How are family and community management perspectives reflected in discourses concerning incidents of malaria in Sierra Leone?* 'The study used a multi-qualitative methodological design and a discourse analysis of texts and transcripts to examine how knowledge about family and community management in relation to malaria was generated. The study's conceptual framework was drawn from the Sustainable Livelihoods Framework which views capacities as determined by assets and resources that influence household and community responses to malaria. In-depth individual interviews (n=54), focus groups discussions (n=3) and a policy documents review (n=6) were conducted with a snowball sample from a cross–section of rural and Moyamba town communities. Key discourses found to characterise family and community management were Social capital, Volunteering, Coping strategies. and Leadership. Social capital was seen to create relations of trust that facilitated collective action. Volunteering was seen to provide human resources to complement the health workforce and improve access to services and health information. Coping was seen as enabling families and communities to undertake preventive actions, diversify livelihoods, adopt treatment pluralism and religion to withstand malaria threats. Leadership discourses highlighted strong leaders influencing uptake of services. Policy makers and stakeholders in malaria control should therefore work towards establishing cross-level learning communities that can accommodate competing discourses to provide more understanding of family and community management approaches that can contribute to reducing the mortality and morbidity from malaria and improving health outcomes.

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Abbreviations and Acronyms

ACT	Artemisinin-based Combination Therapy
ANC	Antenatal Care
BCC	Behaviour Change Communication
CHC	Community Health Centre
CHP	Community Health Post
CHW	Community Health Worker
CLTS	Community led total sanitation
CRS	Catholic Relief Services
DFID	UK Department for International Department
DHMT	District Health Management Team
FAO	Food and Agricultural Organization
FMC	Facility Management Committee
FGD	Focus Group Discussion
FHCI	Free Heath Care Initiative
GDP	Gross Domestic Product
GFATM	Global Fund for Aids, tuberculosis and malaria
IPTp	Intermittent preventive treatment of malaria in pregnancy
ITN	Insecticide-Treated Bed net
IVM	Integrated vector management
MoHS	Ministry of Health and Sanitation
MSG	Mother Support Groups
MCHP	Maternal and Child Health Posts
MODCAR	Moyamba District Children's Awareness Radio
MOHS	Ministry of Health and Sanitation
NACSA	National Committee for Social Action

NGO	Non-governmental organisation
NHSSP	National Health Sector Strategic Plan
PBF	Performance-Based Financing
PHU	Peripheral Health Unit
RDT	Rapid diagnostic test
SDG	Sustainable Development Goals
TBA	Traditional Birth Attendant
UNICEF	United Nations Children's Fund
UNDP	United Nations Development Programme
WHO	World Health Organisation

CHAPTER 1: Introduction

This PhD focuses on the contribution of family and community management to the success of health programmes in sub-Saharan Africa, using the case study of the malaria control programme in Sierra Leone and the discourses of people and communities with which this programme works. The first part of this chapter sets out the justification for a study of family and community management, and its relevance and importance to health management in these circumstances. The second part introduces the specific aim and purpose of the study. The chapter concludes with an overview of the study structure and includes a summary of each chapter.

1.1 Why a study of Family and Community Management?

Poor health continues to afflict large parts of the developing world where high rates of preventable illness affect the lives of hundreds of millions mostly in sub-Saharan Africa. Sub-Saharan African countries continue to suffer from diseases that have proved to be too difficult to combat, causing millions of deaths. Individuals and communities are all subject to adversities and to threats of disease in their environments. Ending the epidemics of HIV/AIDS, Tubercolusis and Malaria is the focus of Sustainable Development Goal 3.3 (UNDP 2017). WHO (2020) noted that malaria is a global public health problem and the leading cause of death in many developing countries where pregnant women and children are groups mostly affected.

Approaches to overcoming diseases in sub-Saharan Africa such as malaria have focused on biomedical interventions and paid less attention to how it might have relevance in specific contexts for people and communities in withstanding the threats from the disease. Questions about the viability, effectiveness and sustainability of interventions remain. The case for examining family and community management is that biomedical interventions on their own may not explain the variable success rates of programmes in malaria control globally. Malaria control programmes provide a good case for studying family and community management for an understanding of how this concept could be applied in searching for alternative approaches to overcome the threats and address actual incidents of the disease. The drive for a family and community management approach stems from the need to address gaps in health science and practice, where scientific theory and knowledge and biomedical approaches do not provide understanding of human behaviour and do not give adequate means of integrating social and cultural factors in withstanding epidemics (Mwenesi 2005:291). Analysing family and community management may therefore help in providing understanding on sustainable approaches to withstanding malaria threats. In this way,

this research seeks to understand family and community management not only as a response to adversity but also as a strategy for building peoples' capacity to shape and deal with adversity such as malaria.

1.2 Research Aim and Purpose

The research aimed to examine factors from a livelihoods perspective that enable people to withstand the threats of diseases specifically malaria, in the context of a resource constrained sub-Saharan country as typified by rural and Moyamba town communities in Moyamba district, Southern Sierra Leone. The purpose was theory building, to build understanding from discourses of better addressing community health needs through more local community processes that contributed to sustainable and effective response strategies for withstanding the threats from malaria. This may provide insights and add to current knowledge in the field of family and community management for health, and providing more understanding of alternative approaches that may inform policy makers in designing and implementing interventions. The focus was on discourses using qualitative multiple data collection methods. The study needed therefore to access discursive data from a cross-section of types of communities using qualitative interviews, focus groups and policy documents as they can present analysis of peoples' perceptions and narratives of withstanding the threats of malaria in poorer and marginalised communities. The thesis structure outlined here reflects the stages in the study.

1.3 Thesis Structure

This thesis structure provides a concise outline and summary of the research as a whole indicating to the reader relevant chapters where key elements of my arguments may be found. This structure situates the reader in the research, capturing what has been discovered and why it is important and original, both at the beginning and at the end of the study.

Following this introductory chapter, Chapter 2 critically reviews the relevant published literature. The review engages with extant literature providing the background to the topic, draws on and identifies concepts pertinent to the study of family and community management, the conceptual framework and research question. From the search, review and critique, and on the basis of the understanding of family and community management developing from this chapter, the literature was organised and discussed around themes and sub-themes leading to the conceptual framework to guide the work, setting down the research question, identifying gaps in the published literature to justify

the focus of the research question. The chapter concludes by indicating how the research design will seek to answer the research question that emerged from the review.

Chapter 3 sets out and justifies the research design, which underpins the measures to be taken to explore the research question identified in Chapter 2. This chapter then provides the study context and gives an overview of the study setting that situates it within the national context. It describes how the study locations and participants were selected. It then details and justifies the methods of data collection and data analysis using discourse analysis. It presents my reflexive account acknowledging my own perspectives on the study, and reflecting on these throughout the analytic process. The chapter then considers the main limitations of the study including the appropriateness of the design and methods, and concludes with the ethical considerations that I encountered.

Chapters 4, 5, 6 and 7 present the findings chapters, addressing the research question set out in chapter 2 and ordered by themes from the conceptual framework and the literature review. These chapters are structured much like academic papers in that they combine presenting the theme at the beginning of each chapter, a focused review of relevant academic literature, presentation of research findings, and discussion of each finding as presented. Four main discourses emerged from the empirical study: Chapter 4 on 'social capital'; Chapter 5 on 'volunteering' including women's voluntary role; Chapter 6 on 'coping strategies'; and Chapter 7 on 'leadership'. The findings from the documents review are incorporated into the four results chapters. Each chapter ends with a summary of the key points from that chapter. These four results chapters therefore present analysis of peoples' perspectives on the socially differentiated nature of family and community management in responses to malaria when they articulate their experiences and their capacities, and the effects of policies and interventions on their responses.

The discussion Chapter 8 provides an overview of the findings in each results chapter and the contribution of the chapter to knowledge of family and community management in relation to malaria identified in the discourses. This chapter argues and explains how family and community management can help in providing understanding of poorer peoples' capacities to withstand the threats of the epidemic using the Sustainable Livelihoods conceptual framework. It evaluates the usefulness of the framework in underpinning family and community management approaches in relation to malaria. Further it presents a model of family and community management , involving stages that communities in epidemics such as malaria are likely to move through in relation to

vulnerability, forms of capitals and indicators, and health outcomes. The chapter provides an evaluation of the theoretical and methodological contributions of the study, and then makes suggestions for further theoretical development through research, and the implications for policy. The final Chapter 9 sets out the thesis conclusions summing up the contribution of family and community management to withstanding the threats of malaria and contributing to reducing the mortality and morbidity from malaria. In the next chapter, I undertake a critical review and synthesis of existing literature leading to the conceptual framework in order to share with the reader the results of other studies that are closely related to the current study.

Chapter 2: Literature Review: Building the Conceptual Framework

2.1 Introduction

In chapter 1, I presented family and community management as an approach in helping people deal with adversity such as ill health. I also presented the research aim and purpose and the structure of the overall thesis. Chapter 2 critically reviews the literature that provides the background to the topic and informs the choice of the conceptual framework used throughout this thesis. In the conceptual framework, it is proposed that poorer and marginalised communities have capacities determined by assets and resources that will influence how families and communities respond to the threats of malaria. The framework established the importance of the study as well as providing a benchmark for comparing the results with other findings. In addition, different family and management criteria were extracted from the literature and categorised into six themes: poverty, vulnerability, social capital, volunteering, coping strategies and leadership. Examining the relationship between these criteria and the underlying components of the conceptual framework, highlighted the multi-faceted nature of family and community management. Exploring the contribution of the identified themes to health outcomes can provide understanding alternative pathways in malaria control. Next, I discuss the literature review process.

2.2 The literature review process

The literature review process highlights the aspects of the literature that informed the study design. The review focuses on published literature globally, but in particular includes a review of relevant literature from sub-Saharan Africa more broadly as a source of experience, evidence and comparison. I undertook a critical review of the published literature on studies relating to family and community management to identify which of the core ideas and concepts are especially relevant in poorer and marginalised communities. My data sources included Google Scholar, Web of Science and Scopus. In addition, particular attention was paid to selected key journals such as Lancet, African Health Sciences, Bulletin of the World Health Organisation, Social Science and Medicine, Malaria Journal and to articles through email alerts from Research Gate, WHO Bulletin and Mendeley. A sample of Sierra Leone Ministry of Health and Sanitation (MoHS) policy documents relevant to family and community management were also reviewed. Given the multitude of articles relating to the topic of family and community management, it was not only necessary to review the relevant literature on this topic but to also make a decision on inclusion criteria. The main inclusion criteria considered empirical studies relating to infectious diseases in particular malaria and were written in

English, as I am English speaking and due to resources available. The selected articles represented original scholarship and documents published in the last 30 years (1990-2020) to capture 30 years of primary research (JBI 2014). It is assumed that the articles published within this period will provide the current trend on the theories relating to family and community management. Other relevant literature, such as books and book chapters were also included.

The literature search was an iterative process, continuing throughout the research, helping to develop ideas and strategies, ultimately aimed at answering the research question. Furthermore the literature provided a summary that highlighted the most important studies, captured major themes, suggested why more research is needed on the topic and advanced how the propose study will fill this need. The reviewed studies are presented in Appendix 5. Also, the literature review informed the research design. I worked back from the findings to identify concepts and selected studies which supported and contrasted findings. Research gaps were also identified in the literature relating to the study topic. This gap analysis supported the rationale for undertaking this important study. In the next section I present the literature review findings starting with the background to family and community management (section 2.3) followed by the six themes (2.4, 2.5, 2.6, 2.7, 2.8, 2.9).

2.3 Background to Family and Community Management

The literature on the background starts with a brief presentation on malaria as a global problem and continues with highlighting several topics in the literature relating to family and community management including: supply and demand barriers to care; gender inequality; a 'people focus'; and community actions in seeking care. Globally malaria deaths and cases have been common among populations. WHO (2020) reports an estimated 229 million cases of malaria worldwide in 2019 when the estimated number of deaths stood at 409,000 deaths. An estimated 94% of deaths in 2019 were in the WHO African Region (ibid.).

Evidence suggests that most health systems in sub-Saharan Africa struggle to provide quality primary health care to their populations (WHO 2014; Soors et al 2013; WHO 2001). WHO (2014) noted that despite increases in malaria intervention coverage, millions of people still do not receive the services they need. Gaps in service coverage are evident in all countries that have national malaria control programmes (ibid.). Many supply and demand side barriers exist, particularly among vulnerable groups, which limit the uptake of care (Bedford & Sharkey 2014; Rickie 2012; WHO 2006; Ensor & Cooper 2004). For example, Bedford and Sharkey (2014) in Rwanda noted that too few children

receive appropriate and timely care, particularly in high burden countries and in the most deprived settings due to a range of inter-related supply and demand factors. Supply-side factors included lack of access to care, inadequate health information systems, poor geographic access to services, poor quality of care, cost of access to care for example transportation and treatment costs, lack of trained health workers, shortages of staff, attitudes of staff (Johansson et al 2000). Unreliable supplies of medicines are persisting challenges that further deepen inequities in the quality of care provided to countries (WHO 2006). Geographic access refers to physical access to facilities applying to communities in remote rural locations. It included factors such as inadequate road infrastructure and availability of transport that limit the availability of health promotion and preventative and curative services (Atkinson et al 2011). Bates et al (2004:368) found that the incidence of the disease is higher in remote rural locations than in urban areas because of the difficulties in accessing prompt diagnosis and treatment. Lack of care can refer to lack of financial resources or health information creating barriers to accessing services and acceptability of services relating to how responsive health service providers are to the social and cultural expectations of individual users and communities (Peters et al 2008). Johansson et al (2000) in their study in Vietnam found that unhelpful staff attitudes and poor-quality services were the main factors that contribute to delays in accessing treatment. Demand-side barriers are locally specific, operating at the family and community level and include cultural beliefs, social norms around household decision-making, gender inequality, perceptions of and previous experiences with health services and illiteracy (Scott et al 2014; Colvin et al 2013).

Wong & Guggenheim (2018) noted that linking supply and demand is a problem common to community interventions. For example, whilst health programmes provided facilities, it was beyond the programmes ability to mandate that health practitioners go into the facilities or to ensure there were enough trained health practitioners to staff the facilities. In many cases the supply side did not deliver (ibid.). These views are echoed in Mason (2002) on knowing the boundaries of research, for example where a programme begins and ends, suggesting other approaches to complement the programme. The impacts of supply and demand side barriers have been documented in several WHO publications (WHO 2017; 2016; 2015; 2008; 2006; 2001; 2000). For example, WHO (2001) noted that in many countries, preventive interventions are centralised limiting access to care with many in poorer and marginalised communities seeking treatment at home, from traditional healers or private practitioners such as drug dealers. WHO (2006) highlighted a shortage of health workers in poor rural areas in Africa. The implications are that the health service on its own does not have the required workforce to take services to poorer people, particularly in the hard-to-reach areas.

Rickie (2012) noted that communities also face economic barriers. When health services are available, the costs associated with preventive and curative treatment of malaria might deter or prevent the poorer from seeking care. Costs of seeking care can be divided into direct costs such as fees for services at the facility including registration and cost of drugs, indirect costs such as the cost of transportation where available, and opportunity costs of lost livelihoods from farming or fishing. Communities also face socio-cultural barriers. In Nigeria, Diala et al (2013) noted the importance of community factors relating to the culture and norms of the community. For example pregnant women may be expected to seek care in health facilities, or with traditional providers, or a combination of both. Issues of spirituality and witchcraft may therefore play important roles alongside medical treatments in women's beliefs and uptake of care.

Expanding on the work of Rickie (2012), Soors et al (2013) explored the lack of access to health care in African countries, from a social exclusion perspective. Social exclusion refers to structural inequalities such as health inequalities. It is manifest in top-down approaches (Atkinson et al 2011) within African societies including within programmes and projects aimed at benefiting the excluded. Soors et al (2013) found that the uptake of a social exclusion perspective in Africa has been limited, despite social exclusion is a driver of poverty and inequity in care, particularly in hard-to-reach communities (Langford & Panter-Brick 2013). These studies might help understanding my data on the experiences of the socially excluded.

In Kenya, Chuma et al (2010) noted multiple barriers relating to affordability, acceptability and availability interacting and influencing access to prompt and effective treatment. Regarding affordability, the authors reported many patients not having enough money to pay for transport or treatment. Regarding acceptability, the major inter-related factors identified were the provider-patient relationship, perceived effectiveness of treatment, mistrust in the quality of care and in antimalarial tablets. Identified availability barriers included long waiting times and drug and staff shortages (ibid.).

WHO (2008) reported that a significant demand-side factor was gender inequality, putting women often at a severe social disadvantage and influencing responses to malaria. WHO (2008) noted that although women have less land, yet they have higher level of burdens and caring responsibilities, including family care, caring for patients in community and reproduction. Within the health sector, gender and power relations translate into differential access to and control over health resources. Both within and outside the health sector, gender inequity means reduced voice and decision-making power (ibid.). WHO (2008:69) noted that for most poorer people in low and middle-

income countries, land is the primary means of generating a livelihood, particularly for marginalised and landless groups such as women. This is the case for example in Sierra Leone where land tenure and land rights are given to men by customary law. GIESCR (2014) noted that the majority of women in Sierra Leone live in rural areas and deliver 60-80% of the agricultural output of the country. However, whilst women constitute the majority of the agricultural workforce, they have less access or control of land or property in Sierra Leone. In their final report of the Women and Gender Equity Knowledge Network of the WHO Commission on Social Determinants of Health, WGEKN (2007:145) noted that gender inequities in communities and organisations are pervasive including gender biases in power, resources, entitlements, norms, and values. They influence health through lack of access to resources and opportunities, and lack of decision-making power over peoples' own health.

WHO (2008) however argues counterintuitively that the struggles by the most disadvantaged in society, builds local peoples' leadership, is empowering and gives people a greater sense of control over their lives. As one example, women with sick children can seek care and take early action such as immunising the child to prevent illness, highlighting an example of women's role in family and community management of malaria. These studies can help learning and understanding my data on gender inequality in the study communities.

The supply and demand barriers are interacting. For example, they can apply in the context of antimalarial drugs where drugs can be effective, but supply-side factors such as the proximity of the facility or availability of diagnostics may lead to low drug effectiveness and uptake (Rao et al 2013). Similarly, bed nets if used properly can be effective but using them for other purposes such as fishing (Trisos et al 2019) may increase mortality and morbidity from malaria. Separately and together, these barriers can delay or prevent poorer people from accessing health care services (Rickie 2012). They are likely to be more important particularly for the poorer and vulnerable groups such as pregnant women and breast feeding mothers, where the costs of access, lack of information and cultural barriers impede them from access (Diala et al 2013; Ensor & Cooper 2004). Thus the threats of diseases such as malaria persist and yet relatively little attention is given, either by policy makers or researchers, to ways of minimising the effects of barriers. While many barriers remain, there is little evidence about the most effective ways for communities to reduce them and what people themselves do and think to take action (WHO 2017; WHO 2014; Bedford & Sharkey 2014; Rao et al 2013).

The literature review on this background emphasised paying attention to a 'people-centered' approach to care, focusing on communities and their capacities, and on the 'people' component of health systems (WHO 2015; Health Systems Global 2014; Rickie 2012; Mwenesi 2005; Seeley & Pringle 2001). WHO (2015) for example argued that the approach adopts the perspectives of individuals, families and communities. In this sense, mapping the family and community management perspectives in discourses of communities in health programmes can be a recommended strategy. The 2014 Cape Town Statement in the Third Global Symposium on health systems research called attention to the need for ''people-centered health systems'' (Health Systems Global 2014). Mwenesi (2005:296) noted gaps in health science and practice, where scientific theory and knowledge and biomedical approaches do not provide understanding of human behaviour and so do not give adequate means of integrating social and cultural factors in withstanding epidemics. In a HIV/AIDS context, Seeley and Pringle (2001) argued adopting a people-centred approach to the threat of the HIV/AIDS epidemic, drawing attention to the role of families and communities in managing HIV/AIDS. A family and community management with a focus on people rather than on the disease is proposed as an approach that can provide understanding of alternative pathways for individuals and communities in withstanding the threats of malaria.

Direct community management has been recognised in several African countries including Sierra Leone (Witter et al 2016; Scott et al 2014), Tanzania (Obrist et al 2010), in Ethiopia (Kidane & Morrow 2000) and in evaluation of health committees in low-income settings (Gilmore et al 2016). Kidane and Morrow (2000) noted that attention be given to what family and community-based efforts can achieve when properly designed and applied in a receptive setting. This study adopted an approach based on the selection and training of mother coordinators to teach all mothers to recognise possible malaria and give chloroquine to their young children. Obrist et al (2010) examined the ways in which social actors mobilise, combine and transform capitals on the household and community levels to obtain malaria treatment. Scott et al (2014) noted families and communities seeking care from multiple sources including home treatment, herbalists, drug peddlers and facility-based providers. Witter et al (2016) in their review of the 'free health care initiative Sierra Leone' noted community health volunteers taking on wider roles such as directly administering malaria medication and traditional birth attendants supporting women coming into facilities for antenatal care and delivery care. Gilmore et al (2016) in their evaluation of community health committees in low-income settings noted that many governments have introduced community groups. These included facility health committees, comprising community members and health practitioners working together to achieve a specific health goal such as malaria control,

and promoting community participation for health, advocacy and raising awareness, reflecting community management. These authors noted that though frequently used within health programmes, little research is carried out on such committee's contribution to capacity building. Similarly Underwood et al (2013) noted there is a dearth of evidence on how exactly such committees work and what features contribute to community capacity building.

Underscoring family and community management of diseases, Perry et al (2015) and Rao et al (2013) noted that many causes and treatments of ill health in poorer and marginalised communities particularly among children can be effectively addressed at the household and community level. These include home-based neonatal care, integrated community case management of childhood illness, and promotion of health improving household behaviours and appropriate utilisation of health facilities. These authors argue that it is the caregivers, families, and communities that are the key producers of health through the health-related decisions they make at the household level (ibid.). Highlighting the role of mother groups, Sacks et al (2017:5) noted that care groups in Mozambique and women's anticipatory learning and action groups in Malawi demonstrated how groups can identify health priorities and work with facilitators and programme planners in designing effective interventions, and acting as mentors to other women in their communities, increasing the dissemination of information and health impact. In contrast, previous research has noted that gender inequalities including women lacking power and control over resources and decision-making, may not give women capacity to provide such care (Mearns & Norton 2009; Jenkins 2009; Bates et al 2004). These studies can help understanding my data on women care giving, despite the inequalities they faced.

Additionally, interest from government and donors in family and community involvement in malaria control grows ever stronger. As one example, MoHS (2015)-Sierra Leone Malaria Control Strategic Plan 2016-2020 documents several community perspectives of interest to the study such as reaching the hard-to-reach, enhancing the role of community health volunteers and the facility management committee. The Plan envisages that communities take ownership of and be accountable for their health. In their three-country comparative case study, Bedford and Sharkey (2014) identified demand-related barriers and solutions to care-seeking and treatment uptake for pneumonia, diarrhoea and malaria among children under five years of age in low-resource settings in Kenya, Nigeria and Niger, focusing on community involvement. These authors noted that in Kenya, the Kenya Health Policy 2012–2017 includes a central goal to attain 'the highest possible health standards in a manner responsive to

the population needs' (KHSSP 2012). In Nigeria, 'community ownership' is a priority area of the National Strategic Health Development Plan 2011–2015 and 'increasing access to' and 'demand for health services' are key objectives (NSHDP 2010). In Niger, the Plan de Development Sanitaire 2011–2015 includes enhancing community participation in the development and monitoring of health programmes and strategies as a key objective (PDS 2011). The Global Fund (2016) in their 'challenging operating environments' position paper, aim to build stronger community and health systems.

Despite the widespread promotion of the idea of enabling communities to thrive in adversity, demonstrated benefits that this idea has achieved to date are modest, and less is known about what may be communities' collective strengths to deal with significant adversity and risk. This omission includes the strengths of communities involved in health programmes (Poortinga 2011). This is partly because there is little research on demand-side factors such as the cultural, values, beliefs and practices, experiences, and interactions of poorer rural communities with organisations in health programmes. What this means in practice is undertaking studies that can provide more understanding of demand-side factors exploring the capabilities in communities can be useful.

In summary, this background highlights family and community management for health can link supply and demand. For example, families may provide home-based care, and women and men groups may undertake activities to improve health outcomes. Family and community management can also contribute in providing health information. It further highlights a people-centered approach to care, enabling families and communities to take and make decisions about their health. It is building on the care seeking literature in showing how families and communities navigate plural health systems in seeking care. It can also contribute to developing understanding on families and communities using assets and resources, despite social exclusion in withstanding malaria threat. Family and community management can contribute to building capacity for health in community health volunteers complementing the health workforce and in expanding the reach of services to poorer and marginalised communities, and in community health committees mediating between the community and the facility.

It is beyond the scope of this study to provide an in-depth description of all potential themes which might relate to the study. I therefore reviewed six themes for which more evidence and information were seen to be available in the literature. Although most of these studies could be seen to have relevance to my topic, none of these studies focused exclusively on exploring family and community management discourses in relation to

malaria. In the sections that follow, I present these six themes of poverty, vulnerability, social capital, volunteering, coping strategies and leadership in turn.

2.4 Literature review theme 1-Poverty

This section extends the analysis of how family and community management, in addition to providing insights into the interaction of multiple stressors, might provide insights into understanding poverty and health, and further suggest how poorer people can build and sustain secure livelihoods in the midst of adverse health conditions such as malaria. I start by looking at how analyses have integrated family and community management concepts into understanding poverty, which give traction and add to existing knowledge of poverty.

Poverty can be understood as the lack of or inability to achieve an acceptable standard of living, or the possession of insufficient resources to meet basic needs (ESPA 2012). Conventional approaches to define poorer population groups distinguished between absolute and relative poverty, where absolute poverty is the inability to meet absolute minimum requirements for human survival, and the poverty of an individual or a household is considered independent from others. It defines poverty in terms of a given level of income or consumption by defining a 'poverty line' as the lowest amount of money needed to purchase the minimum amount of food for a household (WHO 2000:6). Absolute poverty also encompasses forms of deprivation and lack of access to basic needs such as safe water, education and health services, poor housing and environmental conditions (Brown 2016; Rickie 2012). Relative poverty is more country specific and defines poverty in terms of relevance to a specific society or country such as Serra Leone (Brown 2016; WHO 2000).

The understanding of poverty has broadened beyond a focus on income and consumption (Addison et al 2009; WHO 2008; WHO 2006) as defined in absolute poverty to a multidimensional poverty encompassing other forms of deprivation such as access to resources and skills, voicelesnness, vulnerability and powerlessness to influence decisions that affect peoples' lives (Rickie 2012: WHO 2011; Peters et al 2008: WHO 2006; Sachs 2001). It suggests a more dynamic perspective on poverty is required and a move away from an economics dominated understanding and focus on income and consumption to a multidimensional understanding. The Human Development Report (2019:320) highlights poverty levels in sub-Saharan Africa. *Table 2.1* shows some poverty levels from a selected number of countries, reflecting the proportion of the population in poverty.

Table 2. 1: Selection of countries in sub-Saharan Africa in multidimensional poverty

Country	Population in multidimensional poverty-%
Burkina Faso	83.8
Burundi	74.3
Cameroon	45.3
Chad	85.7
Côte d'Ivoire	46.1
Ethiopia	83.5
Guinea	61.9
Kenya	38.7
Liberia	62.9
Malawi	52.6
Nigeria	51.4
Rwanda	54.4
Senegal	53.2
Sierra Leone	57.9
Tanzania	55.4
Uganda	55.1

Source: Human Development Report (2019:320)

The empirical evidence suggests that most rural communities in developing countries such as Sierra Leone experience chronic poverty (Rickie 2012; Green 2009; Peters et al 2008). Green (2009) argues that durable poverty and destitution highlight social relations in poorer and marginalised communities that ensure certain people are likely to experience poverty over an extended period and suggests that the longer you are poor, the more likely you are to remain poor. Green (2009) further argued that the durable poor are often the most severely poor, and caught in transgenerational poverty traps across generations. Poverty traps cause poverty to persist where people fall into a vicious cycle of poverty. It is about staying poor, not just being poor at one moment in time (Barrett et al 2011; Woolcock 2009). Woolcock (2009) noted that the concept of poverty traps explains the persistence of poverty at different scales and calls for analysis to include consideration of social exclusion and cultural explanations. The literature on poverty recognises the necessity to overturn chronic poverty and to enable people to

escape poverty traps. The Chronic Poverty report (CPRC 2008) argues for strategies to escape poverty traps including gender empowerment, building individual and collective assets, social protection and services for the hard-to-reach. CPRC (2008) suggest that without these measures the poorest will remain in persistent poverty.

A collection of papers emphasised the bi-directional relationship between malaria and poverty: poverty causes malaria and malaria causes poverty (Rickie 2012; Peters et al 2008; Wagstaff 2002; Sachs & Malaney 2002). Peters et al (2008) and Wagstaff (2002) noted a causal relationship between poverty and access to health care where poverty leads to ill health and ill health leads to poverty. Similarly, Sachs and Malaney (2002) noted that malaria and poverty are intimately related, and the relation could be bi-directional. Poverty may promote malaria transmission whilst malaria may cause poverty for example by impeding economic growth and the educational achievement of children or causality may run in both directions (ibid.). These authors found that malaria endemic countries are not only poorer than non-malarious countries, but they also have lower rates of economic growth. Malaria might further impoverish poorer households through the costs of preventive and curative measures as well as the inability to work while ill (Rickie 2012). MoHS (2015)-Sierra Leone Malaria Control Strategic Plan 2016-2020 identified the dual nature of causality between poverty and malaria. Similarly, Brown (2016) noted that the interactions of poverty and ill health can impact peoples' welfare, with ill health in particular eroding peoples' wealth and their opportunities to seek livelihoods.

A focus on poverty is reflected in Sustainable Development Goal 1 (UNDP 2016)-Human Development Report, which aims at ending poverty in all its forms everywhere and includes specific targets on access to basic services, which are critical to reducing poverty and improving health, reflecting the multidimensional nature of poverty. The review highlighted that diversification of income (Ellis 2000), can move people out of poverty. In another study Diala et al (2013) pointed out that caught between hunger and illness, some people will choose food over antimalarial drugs. These studies can help learning and understanding my data on the persistent poverty in the study communities.

Overall, the reviewed articles provide understanding on what family and community management can contribute toward knowledge on poverty and its persistence. Further research is needed on multidimensional poverty and its relation to malaria. More research is needed on the poverty-environment relationship including the collaboration in communities between the health sector and others sectors in communities. Next, I review the literature on Vulnerability.

2.5 Literature Review theme 2-Vulnerability

Vulnerability has been defined as the likelihood of injury, disruption of livelihoods or harm resulting from adverse climatic or social conditions (Eriksen & O'Brien 2007:338). In the field of health, these factors can range from individual and community (e.g. poverty related, culture) to institutional factors (e.g. inadequate health services). The literature on vulnerability suggests distinguishing between vulnerability as the *outcome* of situational factors interacting to adversely affect the health of persons and communities, or vulnerability as *context* (Bizimana et al 2015; O'Brien et al 2005; Bates et al 2004).

Vulnerability as *an outcome* is portrayed in the factors that lead to diseases and their impacts between different individuals and communities (UNIFEM 2002*)*. In the case of malaria such factors of vulnerability included inadequate health services, lack of access to care, poor environmental sanitation, and social conditions such as poor nutrition, poor housing conditions, overcrowding, and gender discrepancies (Bizimana et al 2015: Rickie 2012; Bates et al 2004). Inadequate health services such as low coverage of facilities, distance to facilities, poor infrastructure, staff shortages, staff attitudes, stock-outs, long delays, cost of care, mistrust in modern medicines can increase vulnerability to malaria. Eriksen and O'Brien (2007) and Bates et al (2004) argued that these are reasons why people, particularly those with limited resources, prefer to self-treat or consult traditional healers. As was seen in the background to family and community management section, lack of access to health care for example can make people vulnerable and is affected by both demand-side and supply-side factors. The United Nations has highlighted the lack of access to care and adopted universal health coverage as one of the newly adopted Sustainable Development Goals of the United Nations (UNDP 2017-SDGs 3.7, 3.8), reinforcing the principles of the Alma-Ata Declaration (WHO 1978), which called for universal access to care, equity, decentralisation of services as close to the home as possible, echoing Sachs (2001:7) notion of a close-to-client system.

Poor environmental habits can increase vulnerability to diseases (Bates et al 2004). Similarly World Bank (2000:124) noted that in the control of communicable diseases such as malaria, it is almost impossible for any group to avoid these diseases unless the sources of contagion are eradicated. Poorer people, undernourished and living in environments with greater exposure to disease are especially vulnerable to infection (ibid.). Bartram et al (2005) and Bates et al (2004) emphasised that efforts at environmental sanitation need to be complemented by other non-health sectors such as water and sanitation as interactions between these factors are complicated and may

require multisectoral collaboration and communities for appropriate targeting of interventions (ibid.). These views are echoed in Watermen and Caincross (2005:1959) who noted sanitation coverage in sub-Saharan Africa has not kept pace with population increase, but has dropped from 60% in 1990, to 47% in 2000. The importance of adopting proper hygiene and environmental sanitation habits is also recognised in Sustainable Development Goal 6 (UNDP 2017), to ensure the availability and sustainable management of clean water and sanitation for all.

A number of studies highlighted proper environmental sanitation as a strategy that can prevent malaria (Norris et al 2008; Rose 2001). Rose (2001) in exploring sick individuals and sick populations noted that once environmental sanitation became accepted as a social norm of behaviour in those communities and people adapted themselves to the pattern, then the maintenance of that situation may no longer require particular efforts. The strategy seemed to have advantages: it was radical as it attempted to remove the underlying causes in the environment that make the disease common; it was also behaviourally appropriate (ibid.). Similarly in Tanzania, Castro et al (2009) highlighted that environmental management has brought important achievements in malaria control and overall improvements of health conditions. In another study, Paina and Peters (2012:369) highlighted the notion of 'neighbourhood effects 'which capture how an individual's community and environment can affect that individual's health. These authors noted that peoples' environmental conditions are characterised by cycles of mutual influence in which settings directly influence peoples' health and concurrently people in settings modify the healthfulness of their surroundings through individual and collective action (ibid.).

Poor housing conditions reflected the predisposition of certain communities to malaria infection and their reduced ability to mitigate the risk of malaria. Poor quality housing increases exposure to malaria infection as mosquitoes can easily enter through unprotected opening. Overcrowding in homes which is common in poorer communities can also increase vulnerability to malaria infection due to the chances of mosquitoes infecting more than one person on the same night. These social conditions can result in greater morbidity and mortality from malaria. Conversely, malaria might further impoverish poorer households through the costs of preventive and curative measures as well as the inability to work while ill (Rickie 2012). In contrast O'Brien et al (2005) argue there is evidence from sub-Saharan Africa suggesting that communities and countries themselves have significant capacity in coping with vulnerability (Eriksen et al 2005), reflecting a relationship between vulnerability and coping.

The review highlighted *contextual vulnerability* including the agricultural and coastal communities context. While agriculture can provide livelihoods for many communities, manual methods of cultivation with cutlasses and hoes meant lands can create stagnant basins in which mosquito larvae grow in large numbers. Further, the more poorer people relied on physical work in farmlands, the higher the potential for disease with exposure to mosquito bites in the farms (Packard 2007; Helman 2007). Packard (2007) in his research in East Africa and South East Asia observed that patterns of agricultural production were undercapitalised, used few technical inputs and relied on the extensive use of human labour involving little in the way of mechanization. Forms of production placed human population at the risk of infection and allowed malaria to maintain its hold in communities. Additionally, subsistence only provided food for the home and not at scale, thus was inadequate to cater for all family needs, making them undernourished and susceptible to malaria. Jirstrom et al (2011:74) noted that in sub-Saharan African countries, agriculture as the primary source of income has not secured adequate livelihoods for most farming households because the agricultural sector is characterised by small sized farmlands, low production per crop, high subsistence farming and vulnerable to a range of stresses.

The coastal community context can put populations at risk of malaria. A number of studies highlight that coastal communities bordering different populations, where temporary migrations with a significant heterogeneity in populations can occur, can be a likely source for malaria transmission (Bunce et al 2010a; Helman 2007; Berkes & Jolly 2001). Bunce et al (2010a) suggest that many coastal inhabitants consider themselves vulnerable, facing multiple stressors such as rising illness, population density, little access to land and influx of migrants. Often it is the interaction of multiple stressors that cause the greatest impacts, for example migration, combining with population density and rising illness (ibid.).

A distinction is drawn between risk, susceptibility and vulnerability. Risk is the odds and possibility of disease and refers to the social and economic environment that can facilitate rapid infections (Barnett & Whiteside 2000). A risk environment is one in which the chances of disease transmission are increased as a result of social, economic and cultural factors. Such an environment can be seen in poorer communities as in this study. Susceptibility is the predisposition of a population to disease. Vulnerability is those features of a social or economic entity making it more or less likely that excess morbidity and mortality associated with the disease will have impacts upon that entity (Barnett & Whiteside 2000:7). This study can help in understanding my data on the differentiated nature of vulnerability in the study communities.

Further, the review highlighted linkages between poverty and vulnerability. Adger (2006) and World Bank (2000) highlighted pre-existing poverty has portrayed many developing countries such as Sierra Leone are at risk and 'more vulnerable'. World Bank (2000) noted that poorer people are particularly vulnerable to adverse events outside their control such as hunger, and ill health, and often excluded from voice and power (World Bank 2000:32). However Adger (2006) highlights a 'vulnerability paradox' that while developing countries are portrayed as 'most vulnerable' there is evidence suggesting that communities and countries themselves have significant capacity in local knowledge and experience of coping with climatic variability (e.g. Berkes & Jolly 2001). In support of this view, World Bank (2000:124) provides an example in Guinea in West Africa where despite their vulnerability, a pilot project showed that communities were involved in designing and managing projects such as building and maintaining new infrastructure. Communities mobilised local resources, used grant funds equitably and efficiently, and targeted funds to help vulnerable women and children, demonstrating their capability for financial capital and direct community management. This study can help learning and understanding my data on activities of community groups.

Coetzee (2002:5) noted that poverty and vulnerability do not coincide in the same way in all cases. People experiencing vulnerability are not necessarily poor; and amongst the poor, there may be varying levels and patterns of vulnerability, depending on the multitude of dynamic processes through which individuals and households respond to changes in the environment, adopt and adjust strategies and reconfigure their relative wellbeing. These literature can help illuminate my findings by providing more understanding on the relationships between vulnerability and poverty and the strategies of individuals and different social groups in responding to malaria.

The purpose of this section was to review the extant research in order to evaluate and potentially enhance the current understanding of vulnerability to malaria, as well as to provide direction for further study in this area. The review showed communities used local resources in activities aimed at making their conditions better. Overall, this review provides research support to a number of overlapping concerns that should be addressed in future research regarding vulnerability: 1) Research is needed on how vulnerability to malaria and family and community management can play out for different individuals and communities; 2) Further research is needed on contextual vulnerability as distinct from vulnerability as an outcome; 3) Research is needed into the links between vulnerability and malaria. The relevance of the vulnerability theme is an indication of its significance for family and community management. Therefore attention

is required to understanding poorer and marginalised peoples' vulnerability to malaria. Next, I review the literature on Social Capital.

2.6 Literature Review theme 3-Social Capital

Over the few last decades, the concept of social capital has attracted widespread attention in the public health literature and a growing number of researchers have used this concept to explain individual and community health (Sacks et al 2017; Poortinga 2011; Thomas-Slayter & Fisher 2011; Adger 2003; Macinko & Starfield 2001; Carroll 2001; Putnam 1993). Early conceptualisations were offered by the theoretical fathers (Putnam 1993; Coleman 1990; Bourdieu 1986). For example Putnam (1993:167) defined social capital as the 'features of social organisation, such as networks, norms and trust that facilitate action and cooperation in communities for mutual benefit'. Bourdieu focused on individuals or small groups as the units of analysis with the benefits of social capital accruing to individuals or families through their connections with others (Portes 2000). By contrast, Putnam extends the concept of social capital to communities. According to Putnam (1993) framework, social capital is seen as a collective attribute where the amount of social capital in a community has the potential to benefit the community as a whole. Social capital is relational, and exists in the interaction between families, individuals and communities (Stone & Hughes 2002).

Recent scholarship building on Putnam's theory of social capital, expanded on the meaning of social capital and provided another distinction as to whether the social ties represented bonding, bridging, or linking capital (Szreter & Woolcock 2004; Edwards 2004: Adger 2003; Stone & Hughes 2002). These terms describe the respective forms of social capital that tie people to close networks such as in family, diverse networks in communities, and institutions of power (Stone & Hughes 2002). *Figure 2.1* illustrates these dimensions of social capital.

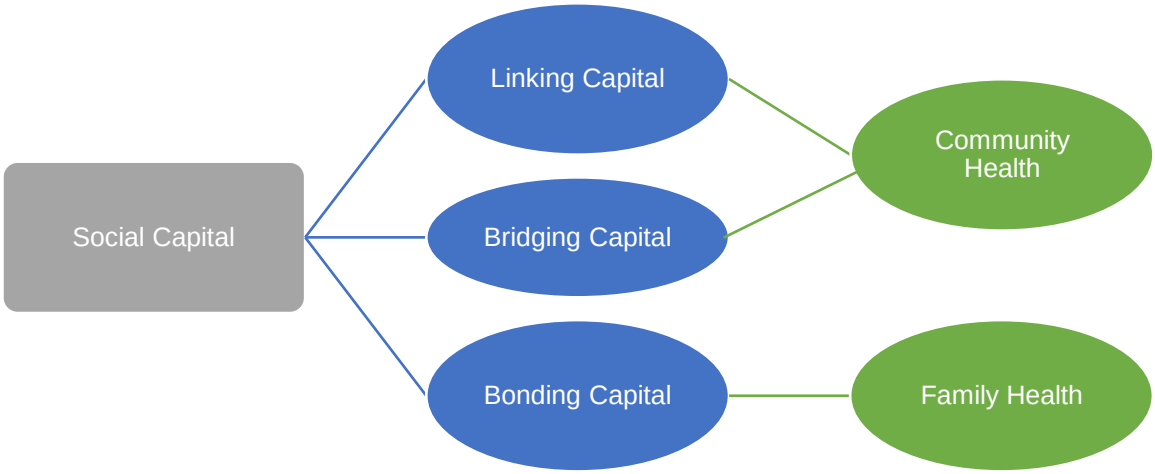

Figure 2. 1: Dimensions of Social Capital

Szreter and Woolcock (2004) make a useful distinction between bonding, bridging, and linking social capital. Bonding social capital refers to 'inward looking' social networks such as in families, close friends and neighbours and generally people from the same homogeneous groups. Bridging social capital refers to outward looking' social networks, horizontal trust and reciprocal connections between heterogeneous groups. Linking social capital refers to relationships with institutions that have power or authority such as health organisations which gave access to donor resources (Putnam 2000; Woolcock & Narayan 2000). Linking social capital ties have a vertical dimension that works across power structures. According to Szreter and Woolcock (2004), all three forms are important for peoples' health and well-being. However Edwards (2004) noted that bridging social capital is more valuable and effective than bonding social capital. These views are echoed by Putnam (2000) who noted that the bonding type of social capital reinforced homogeneous groups and social exclusion whereas bridging social capital fostered social inclusion as in voluntary associations. These studies can help understanding my data on the different forms of social capital in the study communities.

Thomas-Slayter and Fisher (2011:5) noted that knowledge of the interplay of bonding, bridging and linking social capital alerts the need to pay attention to different dimensions of social capital and to recognise that communities in specific times, places and political contexts have access to more or less of them. Poorer people may have a strong supply of 'bonding' social capital that they employ to survive while at the same time they lack 'bridging' social capital. Different combinations of these aspects of social capital can lead to varying outcomes, and these combinations can vary dynamically over time (ibid.). Story (2013) noted that social capital is of particular importance to physical health in developing countries because of their lack of human and financial capital. These views are echoed by United Nations (2011) that the least developed countries have great

potential to benefit from the various forms of social capital due to their low income, weak human resources, and high economic vulnerability.

Caroll (2001:2) and Ostrom (2000:172) noted that social capital is a complement to the other “capitals” (physical, financial, and human) to produce better outcomes and suggest that while all forms of capital are essential for development, none of them is sufficient as an end of itself. This idea is largely consistent with the work of Bourdieu, Coleman and Putnam, each of whom is concerned with how social capital translates into other “outcomes” or resources ((Stone & Hughes 2002:64). Similarly Cavaye (2001:7) argued that social capital increases the efficiency of other forms of capital and describes how the various “capitals” might operate to enhance one another within community. For example a group or community with high levels of trust is able generate community funds, reflecting financial capital than a group with low social capital.

The literature however offers several criticisms of social capital. One criticism is social capital’s ‘dark side’. This is the idea that strong ties that bring benefits to members of a group can also exclude others from those benefits. Social capital is not always health producing; closely knit, homogenous, communities can foster stigma or other tensions against individuals who do not or cannot conform to group norms (Hegney et al 2008; Stone & Hughes 2002).

Another criticism is related to power. Popay (2000) and Baum (2000) claimed that current approaches to studying social capital and health are limited, in that they neglect questions of power. Baum (2000) commented on the role of power in producing and continuing economic, social and health inequities. This can happen in gender inequities for example with men having more control over resources and decision making than women. These views are echoed by Molyneux (2002) on the gender dimensions of social capital that women are often central to the forms of social capital that development agencies are keen to mobilise in poverty relief programmes, but the terms of women's insertion into these programmes is rarely problematised. Women volunteers for example as local experts who are serving their communities are given a set of tasks that have been framed by the designers and are involved in implementing predesigned programmes and may have a role in programme planning (Banerjea 2011). Edwards (2004) discusses the issue of power in the context of social capital, noting that despite women had the great burden of care for children and in community, they were marginalised in the public sphere and did not benefit from family as a social capital resource in the same way as men, for example in the path to financial power (Sapiro 2003). Their involvement in informal networks were also not recognised as the

dominant social capital focus was on formal organisations. This author argued that unless the activities of mothers are conducted in the recognised public sphere, they remain absent, despite their significance to social capital building (Edwards 2004:15). These studies can help in understanding my data on power differentials between men and women and how power operates in poorer and marginalised communities.

Sheilla et al (2018) found that since social capital is rooted in social relations, social capital cannot be understood without reference to the specific social contexts in which it is created and mobilised. These authors emphasised the role context plays in the approach to public health intervention such as malaria including using ideas from social capital to help improve health in context-aware and context-tailored ways. Nevertheless, most scholarship finds social capital to be a source of positive effects in times of adversity (Sacks et al 2017; Thomas-Slayter & Fisher 2011; Carroll 2001; Putnam 2000). Sacks et al (2017:8) noted that communities with high social capital and strong personal networks may better contribute to improving health within the community, can support more effective utilisation of health services and participate in the monitoring of the quality of health services (ibid.), a testament to family and community management.

Despite continued attention, there are knowledge gaps in the field of social capital and health, relating to the importance of the forms of social capital for community health. Based on the review presented above, I propose several elements of a research agenda to explore links between social capital and health including: increase understanding of relationships between social capital and different aspects of health in different communities such as rural and Moyamba town; analyse the characteristics on the relationship between social capital and health by gender; explore the underlying social, cultural, economic and material resources that social capital can produce in different communities; analyse the different forms of social capital and their effects on community health. Most research thus far focused on bonding capital at the expense of bridging and linking capital. Although a number of studies have found evidence that bridging social capital (Mitchel & Lagory 2002) and linking social capital (Sundquist & Yang 2007; Sundquist et al 2006) are important for community health, it is crucial to include the three forms of social capital, which so far have been relatively little explored, to fully understand the impact of different forms of social on health outcomes (Poortinga 2011; Ferlander 2007). Therefore undertaking a further study of the processes generating social capital and of the components of social capital within communities may be an essential tool of public health (Macinko & Starfield 2001; Hawe & Shiell 2000). Next, I review Volunteering.

2.7 Literature review theme 4-Volunteering

My objective for including volunteering in the review was two-fold. Firstly, to provide contextual, academic and conceptual background information around volunteering and development. Secondly, as a resource that could become useful for future research into the contribution of local volunteering in health programmes in low-income settings. Although much research has been conducted in the North about volunteering, less attention has been paid to volunteering in developing countries (Franco & Sharokh 2015; Uny 2008). Within the volunteering for development literature, recent research has mostly focused on international volunteering and organisational forms of volunteering from a western perspective (Perold et al 2011) rather than on community-led volunteering, mutual aid and self-help (IDS 2015; Kondal 2014; Bhattacharyya 2004). This sub-section critiques some of the key ideas emerging from the volunteering literature that can help learning and understanding my data.

Volunteering can be defined as unpaid work that the person doing it intends to generate value for both the individual volunteer themselves and community (UNV 2018; Smith et al 2016; IDS 2015; Uny 2008). Uny (2008) noted that the main characteristics of volunteers worldwide are that they take part in an activity of their own free will and for no remuneration.

Filling the gap in the health workforce in low-income countries is a major reason for the health sector in the use of volunteers (Perry & Gigler 2014; Rao et al 2013; Sudhinaraset et al 2013; Takasugi & Lee 2012; WHO 2006). WHO (2006) noted that the crisis in human resources for health with a dire shortage of health care workers globally, particularly in low and middle-income countries, and the lack of health providers especially in poor rural areas in Africa has highlighted the need for volunteers. Similarly, Perry and Gigler (2014) noted that the critical shortages within the essential health workforce in low and middle-income countries pose a serious obstacle in attaining health goals. To address the shortfall task shifting to community health volunteers has been used (Natalie et al 2015; Rao et al 2013; Takasugi & Lee 2012). Natalie et al (2015) noted the shift in sub-Saharan countries towards using community health volunteers to increase access to treatment. These authors highlighted community health volunteer roles including identifying sick and malnourished children, and encourage patients to seek early referrals in health facilities, and providing community based oral rehydration therapy and nutritional support. Similarly Sudhinaraset et al (2013) highlighted the role of volunteers in poor and marginalised communities, commenting that in the developing

world, volunteers represent a significant portion of the health care system, particularly among poorer populations.

The characteristics of local volunteerism most valued by communities are the ability to self-organise and to form connections with others (UNV 2018: ix). The self-organisation reflects autonomy and ownership and was particularly important for isolated and marginalised communities (ibid.). UNV (2018) noted that self-organised actions can help marginalised groups meet their own needs in the absence of wider provisions and services such as health services. Self-organisation volunteering sustains community autonomy by avoiding dependence on outside actors and is a key strategy for marginalised groups whose needs are not adequately addressed by formal institutions. However, the authors acknowledge that local volunteerism, particularly when volunteer participation is informal, to be most effective, often require support from more formalised structures. It is rooted in community power dynamics and may exclude some vulnerable groups such as poorer women. Further spontaneous volunteers who are not well integrated can hamper effective responses. These views are echoed by Davidson (2013) who argues that self-organisation by definition cannot be ‘‘planned’’ for. It is an emergent phenomenon that spontaneously arises and due to other interacting factors, for example the inadequacy of health infrastructure. Similarly, Paina and Peters (2012) noted that humans self-organise in many ways, particularly in decentralised systems such as health systems in communities as a way of establishing social norms, though not always with the most optimal results (ibid).

Paine et al (2012) and Banerjea (2011) noted that programmatic approaches planned by international and local NGOs designed to deliver services to meet a specific need such as health can generate a sense of disconnect with the purpose of the volunteering endeavour. These studies reflect the fact that the sense of volunteering is lost, as the approach of the NGOs has brought about the unintended consequence of having not recognised equally those non-programmatic volunteering endeavours such as self-help initiatives, cooperatives, and support groups in communities (ibid.). In contrast, Uny (2008) in a school feeding programme study in Malawi noted that NGOs and development projects including school feeding programmes are partly relying on volunteers and are eager to foster participation and empowerment. This practice creates a ‘triple burden’ (Jenkins 2009) in volunteering as women volunteers from impoverished communities shouldering responsibilities in programmes on top of their reproductive and productive responsibilities. This combination of factors tends to make women more vulnerable than men to the consequences of diseases such as malaria.

Uny (2008) noted several intrinsic and extrinsic motivations and factors for women in volunteering with orphan children in Malawi including compassion, social networks, personal satisfaction, a deep concern for orphans and vulnerable children, a moral obligation to help, and also to external factors such as spirituality, links of reciprocity, and the building of social capital with volunteers invoking notions of reciprocity that they were helping because one day they or their family might need the same help. This helps understanding the motivation of women in Malawi to volunteer and exemplifies how, despite their own burdens and difficulties, these women continued to make considerable contributions to the community in terms of their time and labour. The findings are similar in MKandawire and Muula (2005) in their Malawi study on motivational factors of community care givers. These authors noted extrinsic factors of motivation including recognition by the community and eventual employment. Similarly Uny (2008:437) study of community volunteers' participation in a nursery feeding project in Malawi noted several intrinsic motivations, namely a deep concern for orphans and vulnerable children, a moral obligation to help, and a declared love of the work undertaken, and also to external factors such as spirituality, links of reciprocity, and the building of social capital rather than monetary incentives. Other studies illustrate how volunteers are driven by goals that can be both self-centred including a desire to show community concern, seek knowledge, and develop skills (Snyder & Omoto 2000). Snyder and Omoto (2000) argue matching individuals willingness to volunteer by the benefits they receive. For example, volunteers who are motivated by a desire to learn will be more likely to stay if they receive regular training. This study highlighted multifaceted reasons for volunteering including deep passion for the work, feeling of making a difference and own personal benefit. In the next section, I expand on the gender dimension in volunteering.

Gender dimensions in Volunteering: Women's Voluntary work

Several recent articles have brought the debate over volunteering in low-income countries to a focus on women's role in volunteering (UNV 2018; Banerjea 2011; Jenkins 2009; Bates et al 2004; Cornwall 2003: Neysmith & Reitsma-Street 2000). For example, Neysmith & Reitsma-Street (2000) found that the volunteering literature has observed that in the global north, community improvement initiatives are relying more and more on the unpaid labour of women. UNV (2018) highlighted several examples of how the presence of formal organisations influenced decisions around the inclusion of women and other marginalised groups in health programmes. However, others have argued that women face forms of exclusion in the implementation of programmes. As one example, Cornwall (2003) noted that women's involvement is often limited to implementation and caring roles. These views are echoed by Bates et al (2004) who noted that the burden

of caring at home and community for people with malaria with the associated emotional stresses is increasingly falling on women.

The articles reviewed highlighted women involved in self-help programmes. Bhattacharyya (2004) argued that self-help by women builds and utilises agency, mobilises peoples' cultural and material assets including, indigenous technical knowledge, tools, and labour, and most importantly in the context of volunteering avoids dependency. The principle of self-help corresponds to empowerment in raising the consciousness of women to take action on their impoverished lives in transforming their circumstances themselves through action and change of power. Victoria (2013) and WHO (2008) for example argue that having increased access to economic resources and information, increased uptake of preventive and curative services and undertaking activities can have a positive impact on women health and the health of their children (Undlien et al 2016; Perry al 2015). In contrast, Fernando (2006) commented that whilst NGO led programmes can be empowering, the empowering effects of these interventions are complex, consolidating existing power hierarchies as top-down approaches and increasing women's workloads. This author further noted that traditional beliefs about gender roles, giving power to men over resources and decision-making, often accompanied by cultural norms and inherent power structures might not be empowering, whilst current inequalities or power structures within the community remain unaddressed. Access to microcredit, for example, may not lead to an improvement in the quality of women's lives if they are unable to make loan repayments (ibid.).

Expanding on the work of Fernando (2006), Batliwala (2007) argued that empowerment is not achieved by providing women with access to credit, enhanced incomes, or land titles. Empowerment was about shifts in social and economic power between and across marginalised groups such as women and stressed that the institutional change dimensions were critical to sustaining empowerment and real social transformation. Similarly, Jenkins (2009) noted the quandary of self-help projects and the inappropriateness when applied to local level development that such grassroots projects cannot easily be economically viable as they cannot generate enough income for poorer peoples' needs (ibid.). More recently, Rigaud (2020) review of empowerment theory noted the paradox in which the implementation of an empowerment intervention for example microcredit leads to the opposite outcome: the disempowerment of the targeted study participants.

Emphasis on the marginalisation of women in development has largely been formulated within three frameworks elaborated in the literature. These are Women in Development

(WID), Women and Development (WAD), and Gender and Development (GAD) (Banerjea 2011; Batliwala 2007; Cornwall 2003). In turn, each approach has been shaped by different understandings of both feminism and development that have conceptualised the feminist aspect of this response (McIlwaine & Datta 2003; Banerjea 2011). Whilst the WID proponents have concentrated on the equal recognition and access of women for example to resources, WAD advocates have highlighted class issues. GAD practitioners, on the other hand, emphasised the need to address gender relations in society and communities as a whole (ibid.).

Two malaria studies (Stromberg et al 2011; Nonaka et al 2008) and one water, sanitation, and hygiene study (Thevos et al 2000) each relied heavily on local volunteers. Stromberg and colleagues (2011) made use of the local health system to distribute bed nets, and then implemented a community mobilisation strategy through which to deliver malaria health education. Nonaka and colleagues (2008) implemented a health education program extending outward from schools into the community, and organised a one-day antimalarial campaign. Thevos and colleagues (2000) distributed a safe water system technology and then followed up to provide health education at the household level. These studies can help learning and understanding of my data on families and communities providing health information to withstand the threats from malaria.

While volunteers are seen to be integral to the health service and community health and continue to play a vital role, there are specific challenges in volunteering in poor rural communities, which raises questions about the sustainability of such programmes. For example, Victoria (2013) discusses in the International Journal of Epidemiology, the challenge of questions around sustainability and ultimately community ownership. This author argues that women's groups are not aimed at specific changes in health status but rather at raising the awareness about factors in their daily struggles about access to resources and lack of power so that communities can be empowered to take control over resources and decision making. Similar to the Gender and Development practitioners (Banerjea 2011), this view may require understanding the persistent socio-economic inequalities in maternal and child mortality, which are likely to be affected not only by access to economic resources and health care, but also by issues related to empowerment and ability to control one's life conditions (ibid.). These literature may provide critical insights for examining my data on women's caring role and volunteering in poorer communities.

The literature reviewed revealed diverse examples of local people voluntarily coming together to overcome adversity. For example, it explored the role of volunteer's

involvement in service delivery as community health workers (Takasugi & Lee 2012), as women in formal and informal organisations (Banerjea 2011). UNV (2018) found a major characteristic of volunteering is in human resources contributions to programmes in increasing access to care particularly in hard-to-reach communities and in strengthening community capacities to withstand the threats of malaria. A perspective that is often lacking in the existing literature but which I can explore later is whether unpaid volunteers can contribute to improving health outcomes to enhance community management in relation to malaria.

In palliative care, Dein and Abbas (2005) examined the stresses associated with hospice volunteering. The authors found that volunteers are an integral part of the palliative care team, responsible for bridging the gulf between the health care programme and the community, similar to community volunteers in this research, taking services to the community. The study also found that volunteers derive satisfaction when working in the hospice setting.

Offering a global perspective, WHO (2017) noted that including community health volunteers in facility heath committees can facilitate the flow of information and communication from household to community. This can help strengthen linkages between community and health facility, thereby providing people-centered health care services. Such committees can create more harmonisation of health initiatives with communities identifying their needs and organisations including them in programme plans, thus adopting a bottom-up approach (Atkinson et al 2011). Bottom-up approaches refer to grassroots community members identifying and prioritising their health concerns in order to make decisions regarding programmes and projects, which government and non-governmental organisations support. Facility health committees can also be involved in mediating between the community and practitioners on health matters affecting the community. In this sense, the committees can increase the potential for community empowerment and facilitate the participation of community members in health initiatives with a view to increasing programme ownership and sustainability (Butterfoss & Kegler 2002). Sacks et al (2017) noted that programmes guided by locally identified priorities are much more likely to have high uptake and can be sustained over time as community people are more likely to accept interventions when they participated in planning and implementing.

Based on this literature search, it appears that volunteering has been applied in three ways in the volunteering literature: 1) a catalyst for improving access to care and

inclusion of marginalised societies; 2) factor in the study of women volunteering and care giving roles; 3) human resource contributions to the health sector.

The purpose of this section was to review the extant research on volunteering to assess how these ideas might be relevant for understanding my data. The current literature reveals a lack of studies on local volunteering in rural communities in self-help initiatives, mother support groups and youth in communities in relation to withstanding the threats of malaria. Overall, this review provides research support to address aspects of volunteering at the community level that may enhance community management in marginalised communities. Most research has focused on volunteering in organisations. Based on the review presented above, I propose the scope of research in the future should include empirical research on communities in self-help initiatives of informal women, mother support groups and youths about how their roles contribute to malaria control, and to improving health outcomes. Next, I review Coping strategies.

2.8 Literature review theme 5-Coping Strategies

Coping strategies can be understood as actions aimed at short-term survival and adaptations to adverse conditions (Fabricius et al 2007; Smit & Wandel 2006; Blaikie et al 2001). The coping strategy literature has focused on livelihoods and income diversification (Bird & Prowse 2009; Ellis 2000). Bird and Prowse (2009) noted that the term coping strategy emphasises the ability of households to decide and select appropriate activities in light of their resources whereas Blaikie et al (2001) defined coping as the manner in which people act within the limits of existing resources.

Folkman (2010) distinguishes two major theory-based functions of coping, namely problem-focused coping which involves addressing the problem causing distress such as malaria, and emotion-focused coping which is aimed at ameliorating the negative emotions associated with the problem. Examples of emotion-focused coping are seeking emotional support. Dercon (2002) resonates with Folkman (2010) on problem-focused coping in the sense of problem appraisal and action. Dercon (2002:5) argued that coping is more difficult if ill health persists. Coping strategies will then require actions such as forming informal networks.

The review identified different coping strategies including: preventive strategies using bed nets (Trisos et al 2019; Bizimana et al 2015; Lengeler et al 2007; Panter-Brick et al 2006;); using songs (Panter-Brick et al 2006), the practice of hand-washing (Langford et al 2011); social support (Seeley et al 2009; Norris et al 2008); livelihood diversification (Blaikie et al 2001; Ellis 2000); medical pluralism (Scott et 2014; Sudhinaraset et al 2013;

Helman 2007: Marks 2006). The reviewed studies noted that the use of bed nets has benefits for both individuals and the community, a reflection of family and community management. However Trisos et al (2019) noted the use of bed nets for other purposes such as fishing. Panter-Brick et al (2006) noted that songs can put across locally relevant messages and draw many issues into one compelling format to influence health seeking behaviours. Hand-washing as a preventive strategy can help to reduce infections. The hand is used many times in the day on other parts of the body e.g. putting in mouth, putting on the face, putting on the eyes. It is used to shake other hands and to carry other things that could be dirty. So if the hand is unclean, it can infect other parts of the body. However Langford et al (2011) noted that campaigns that aim to improve hand-washing behaviours, but make no changes to environmental sanitation, can have only limited impact on children's growth (ibid.).

The review identified livelihoods diversification as a coping strategy. Livelihoods can be defined as comprising 'the assets (natural, physical, human, financial and social), the activities, and the access to these (mediated by institutions and social relations) that together determine the living gained by the individual or household' (Ellis 2000 10). The analysis of livelihood focuses on marginalised peoples' capacities and builds upon their initiatives. It therefore seeks to identify poorer peoples' asset bases, livelihood strategy and desired objectives in order to create an atmosphere that can sustain them (Kim 2011). Livelihood diversification is the process through which families and communities built a diverse portfolio of activities for their survival and improving their health conditions (ibid.).

In Ethiopia, Ayana et al (2021) used the Sustainable Livelihoods Approach as an empirical tool to examine the determinants of diversification of livelihoods. Ayana et al (2021:2) noted that for diversification of livelihoods resources are very crucial encompassing financial, human, social, physical, and natural capital. These capitals are correlated to the sustainable livelihoods approach and can be further divided into sub-components: human (skills, knowledge, health), social networks (membership of formalised groups and trust relationships that facilitate cooperation and economic opportunities), natural (land, soil, water, forests, and fisheries), physical (roads, water and sanitation, schools}, and financial (savings, credit, trade) (Rakodi 2002; Ellis 2000; DFID 1999). Rakodi (2002) also noted that livelihood assets such as natural capital, social capital, human capital, physical capital and financial capital are useful for local communities' livelihoods. Anaya et al (2021) highlighted that social or economic vulnerability faced by individuals or communities in adversity determines the types of livelihoods they seek (Scoones 2005; DFID 1999), linking coping with vulnerability. This

study can help understanding my data on livelihoods diversification in study communities that had a high proportion of non-literate people.

Medical pluralism encompassed how patients were seeking care from both the biomedical and traditional systems of care. Scott et al (2014) in their study exploring plural health care seeking for sick children in Sierra Leone noted that patients often combine types of treatment and seek care from a wide range of sources including home treatment, herbalists, religious healers, drug peddlers and facility based providers. Medical pluralism in this sense is part of coping with patients navigating a landscape of options in seeking care. Scott et al (2014) noted that while most frameworks distinguish demand from supply-side barriers to care seeking (Peters et al 2008; Ensor & Cooper 2004; Standing 2004), the reality is often more interactive, as care seeking particular in developing countries is a socially negotiated process where factors such as cultural norms and beliefs about causes of disease, the acceptability of interventions, perceptions about the quality of care provided in facilities, household power relations with men having control over resources and decision making and social networks interact to inform household care seeking pathways (ibid).

The review identified the role of traditional healers in influencing coping with illness. Sudhinaraset et al (2013) in their systematic review commented that more rural populations are more likely to use traditional practitioners than their urban counterparts. Higginbotham et al (2001) observed that traditional healers still play a role in helping people cope with the disease in rural communities despite western medicine. The author argued that this is because the illness is usually linked to practices such as witchcraft, and were interpreted as having spiritual causes that would only benefit from the intervention of traditional healers (Covin et al 2013). They are popular in communities because compared with health practitioners they are greater in number, are more accessible to the population, work in underserved rural and urban areas and have lower service charges. Furthermore, people in such communities feel more at home' with traditional healers than with practitioners as they reside in the same communities (Higginbotham et al 2001). Another reason is they have a shared concept of disease which is rooted in their culture and therefore have more confidence in these healers and their medicines (ibid).

Family and community management in coping with malaria featured in the review. Béné et al (2012:48) argued that the ability of a community to cope is whether community management can be maintained. Due consideration was given to all the different agents of the community through the complementariness of their coping capacities (ibid.).

Similarly, Folkman and Moskowitz (2004:759) identified a communal perspective and referred to coping responses that were influenced by and in reaction to the social context. In contrast, Norris et al (2008:135) observed that community's abilities to cope with a threat such as malaria can themselves be harmed by the threat, which will require robustness of activities undertaken (ibid.). Applying this view to my study, malaria could lead to loss of productivity in farms, loss of livelihoods and absenteeism in schools, which may undermine family and community management.

In the context of HIV/AIDS, Seeley et al (1995:80) observed different coping strategies for individuals and households. These authors noted the differential vulnerability to illness in households and communities. This can be understood as the differential capacities of men and women in the same households or community and in communities in their geographic location, with those in hard-to-reach areas seen to be more vulnerable. In order to 'cope' the individual members of a household may adopt different coping strategies, which may provide benefits to the whole household or particular individuals, for example strategies provided by women providing care at home and in community.

Religion featured as a coping strategy, both in terms of volunteering capacities and with many initiatives coming from faith based organisations (Nwokoro 2017; Tchombe et al 2015; Dein & Abbas 2005; Christoplos et al 2001). Nwokoro (2017) in her study on faith based organisations in Nigeria noted that in cases where the state was weak, faith based organisations provided basic social benefits such as economic empowerment in form of skills acquisition, providing shelter, clean water supply, health, and educational services to marginalised communities. The author found that in the health sector, church organisations tend to provide services to improve the health of people, such as building community or rural health centers for managing peoples' health and family planning; offering HIV screening, counselling and treatment services. In Palliative care, Dein and Abbas (2005) argue that religion was a coping strategy, helping patients coping with cancer manage the progression of their illness and even prepare for death.

Christoplos et al (2001) noted that some NGOs and religious institutions have a presence at the grassroots level, and are ideally placed to develop an understanding and knowledge of local capacities and coping strategies. However, these authors noted that there is insufficient attention paid to how such strategies may or may not be relevant in light of existing coping strategies. Tchombe et al (2015) found that peoples' religious beliefs offered a coping strategy that they used to overcome adversity. These studies

will help understanding my data on how outside agencies and religious beliefs influenced health seeking behaviours in my study communities.

The review highlighted rural-urban differences in coping strategies. Heggenhougen et al (2003) noted rural communities may consist of relatively homogenous populations belonging to the same tribe, cultural group, while other communities may be quite heterogeneous belonging to different tribes and cultures and adopting different strategies. For example in rural communities, culture is often more pervasive and dominant and such communities can have more social cohesion. Survival strategies and health seeking behaviours tend to be heavily influenced by local culture (ibid.). In Ghana, Agyepong & Manderson (1999) found a higher rate of insecticide impregnated bed net acceptance and usage in rural compared to urban areas. People in such communities will for example use traditional medicine which may not require transport costs and in situations where the husband has dominant control over the use of resources. Other culturally appropriate provisioning activities include gardening, and fishing is often supplemented by trade in rural communities such as weekly markets. Some families also cut back on what they consume, for example in the rainy season when food is scarce (Struthers & Bokemeier 2000). These studies can help understanding of the contrasts in coping strategies in the study settings.

Patterson (2002) in their research on children with chronic health conditions, noted a risk perspective when studying populations at significant risk as in the current study was articulated by practitioners interested in a new approach focusing on individual and family strengths rather than deficits (Paterson 2002:238). This author noted that many families faced real limits in getting the services they needed, and belief in their inherent ability to discover solutions and new resources to manage challenges may enable withstanding adversity, a testament be the cornerstone of building family and community management. This author further noted that for any given situation families implicitly appraise its difficulty, akin to Folkman (2010) notion of coping. Thus many families coped by changing the way they thought of their circumstances. Through meaning making process they increased their capabilities and reduced their demands (ibid.).

Coping strategies were related to the volunteering theme in the form of emotion-focused coping and problem-focused coping. In palliative care, volunteers adopted a range of strategies including keeping an emotional distance from patients, religious beliefs and perceiving death as a merciful release and a necessary process, meaning making through appraisal, seeking advice from members of the hospice interdisciplinary team

(Dein & Abbas 2005), or talking with other volunteers (Claxton-Oldfield & Claxton-Oldfield 2007: Dein & Abbas 2005).

Based on this literature search, it appears that coping strategies have been applied in four ways in the literature: 1) by adopting emotional and problem focused coping; 2) as a strategy in accessing care by people taking preventive measures: 3) people using existing resources in family and community to cope with malaria; 4) the influence of culture in coping. The purpose of this section was to review the extant research on coping in family and community management to assess how these ideas might be relevant for understanding my data. The current literature reveals a lack of studies on supporting poorer communities in coping with illness. Overall, this review provides research support to address coping at the community level that enhances community management in marginalised communities. Most research has focused on coping at the individual level. Based on the review presented above, I propose the scope of research in the future should include empirical research on coping communities, particularly hard-to-reach communities. Such research can explore why some communities are not adopting preventive strategies and why pluralistic approaches are often the practice in some communities. It can further explore the application of emotion and problem-focused coping in poorer communities facing malaria. Next, I discuss Leadership.

2.9 Literature Review theme 6- Leadership

Leadership can be seen as the process of influencing peoples' behaviours, attitudes and activities to facilitate achieving goals (Hegney et al 2008; Folke et al 2005b; Hogan & Kaiser 2005). Different individuals or groups of individuals can offer leadership. Leadership can be formal as in local authority or informal as in individuals or group action (Hegney et al 2008). The empirical review by Hogan and Kaiser (2005:169) concluded there was substantial evidence that leadership had a profound influence on communities. Strong leadership enhanced the health and wellbeing of those being led by promoting effective performance whilst weak leadership led to low quality of life for everyone associated with it' (ibid.). Similarly Fabricius et al (2007) observed that community management becomes possible through leadership and vision. Visionaries and champions build trust between different actors and organise them towards a common goal or vision (Folke et al 2005b; Hogan & Kaiser 2005). These studies might be relevant in understanding the role of local leaders in the dissemination of health information to poorer and marginalised populations.

Information from leaders can be seen as from trusted sources often the case in communities with strong leadership. Longstaff (2005) noted that trusted sources are those that are closer and local as sources of information more likely to be relied upon (ibid.). Essien et al (1997) noted that leaders are selected by their people and are custodians of community culture, norms and social values, coupled with their ability to influence peoples' activities (Hegney et al 2008) such as facilitating the decision to seek care by women with obstetric complications. Leaders are able to influence and encourage changes in behaviours and attitudes by disseminating health information such as properly using bed nets (ibid.).

Sacks et al (2017) noted that community members and actors possess unique knowledge in understanding local perspectives and the ability to identify and access local resources. Including leaders and other community members such as village and household heads at the outset of community interventions fosters a sense of ownership that can help promote sustainability. Similarly, Thomas-Slayter & Fisher (2011:S330) argued that in many parts of Africa, it would not be possible to engage in programmes in a local community without the approval and blessings of the local chief (Tchombe et al 2012). In another study, Ambasa-Shisanya (2009) noted how the various ways to engage community leaders may facilitate the adoption of safe practices and would be one way to acknowledge and involve the local community. Working with local leaders is acknowledging their role as custodians of community culture, norms and social values, having knowledge of their local environments and are able to influence uptake of care.

The leadership roles of women featured in the review. UNV (2018) noted that women can benefit from taking on more leadership and decision making roles in their voluntary work. Promoting women's participation in community action committees and engaging with community leaders can advance more equitable representation of women. Also valuable are policies and frameworks that emphasise women's leadership and meaningful participation; training and resources for women's groups (ibid.). UNV (2018) noted that external agencies could also model the value of leadership positions for women by explicitly creating leadership opportunities for women in their programmes which can alter perceptions of women's roles and challenge men's dominant role in decision making.

The review highlighted fostering capacity for sustained leadership at the local level (Campbell et al 2002) by recognising existing leadership when organisations seek to implement community programmes. Thomas-Slayter and Fisher (2011:S325) noted that such recognition entails participatory approaches to community involvement in

monitoring and accountability that enabled local ownership. This literature can help understanding my data on approaches to implementing health programmes in communities and the role of community leaders.

Leadership is related to other concepts including human capital, social capital, financial capital and natural capital. Human capital is utilised in developing and accessing resources to develop the community (Chaskin et al 2008; Flora & Flora 2004). Gram (2019) noted bottom-up leadership through which local groups and leaders collaborated with external agents identifying and tackling the causes of ill health. Regarding financial capital, Fofana et al (1997) noted that major obstetric complications included haemorrhage, obstructed labour, septic abortion and ectopic which required funds to access care in a referral hospital. The establishment of funds for this purpose has been documented and have been associated with community mobilisation efforts which are more likely in communities with strong leadership (Borgi et al 2005; Essien et al 1997; Kandeh et al 1997, Fofana et al 1997). Such relation between concepts was recognised by Bebbington (1999) who found that at the local level, networks of trust and mutual accountability in collective action are also required in providing access to financial capital. However, Fernando (2006) argued that access to financial capital for example microcredit may not lead to an improvement in the quality of women's lives, if for example their circumstances make them unable to make loan repayments (ibid.).

Based on the review presented above, I propose several elements of a research agenda on leadership and health. The review of the literature revealed four overlapping concerns that should be addressed in future research on leadership in rural communities facing disease epidemics including: 1) involving local leaders in the planning and implementation of health programmes; 2) the need for strong leadership; 3) the need for human resources and capacity building for implementation of by-laws; 4) the current literature reveals a lack of studies on community leaders as in the facility management committee. Indeed, there is a lack of research specifically, in examining the role of local leaders in the implementation of programmes.

2.10 Overall Summary

In summary the literature leading to the conceptual framework was developed from the review, starting with the background, which highlighted influencing access to care and family and community responses using local assets and resources in withstanding the threats of malaria. The literature on vulnerability gives insights into how and why different social groups are affected differently by diseases such as malaria and have different

capacities to respond. The literature also revealed vulnerability as depending on both context and outcomes of supply and demand-side factors contributing to malaria, reflecting the value of social and constructive approaches to vulnerability to explain why families and communities were at risk of malaria. The reviewed literature yields mixed evidence regarding the relationship between vulnerability and poverty (Coetzee 2002:5). People experiencing vulnerability are not necessarily poor and amongst poorer people, there may be varying levels and patterns of vulnerability. This literature presented an integrative understanding, which allows for a multifactor analysis of vulnerability that can inform family and community management approaches to withstanding the threats of malaria. Further the literature (Panter-Brick 2014; Almedom & Tumwine 2008) view a shift from an emphasis on vulnerability to ideas of assets and strengths or capacities in communities.

The literature on poverty highlights the multidimensional nature of poverty and .how families and communities remain in poverty. The review highlighted pathways to escaping poverty for example through management of natural resources such as lands and medicinal plants as kinds of natural capital. The review highlighted a shortage of health workers in malaria control programmes in sub-Saharan Africa (Takasugi & Lee 2012; WHO 2006). Thus many programmes have used community health volunteers in improving access to care and inclusion of marginalised societies, highlighting the human resource contributions of volunteering to the health sector, as a manifestation of human capital. The review highlighted coping as a strategy in accessing care by people taking preventive measures and using existing resources in family and community to cope with malaria. The literature on social capital highlighted there are knowledge gaps in the field of social capital and health, relating to the importance of the forms of social capital for community health. The review highlighted that both human and social capital contribute to health of populations (Rose 2001). The review further identified that current approaches to studying social capital and health are limited, in that they neglect questions of power (Popay 2000; Baum 2000). The review further identified the need to explore potential explanations for mechanisms through which social capital might influence health for example through individual social networks and social support, requiring understand better the pathways through which social capital may work. The literature on leadership identified relationships to human capital, social capital, financial capital and natural capital (Chaskin et al 2008; Flora & Flora 2004).The review identified leadership roles of women. UNV (2018) noted that women can benefit from taking on more leadership and decision-making roles in their voluntary work.

Based on the literature discussed above, the different themes on poverty, vulnerability, social capital, volunteering, coping and leadership highlight how the Sustainable Livelihoods Framework (DFID 1999) can be a useful analytical tool within this research. Overall, these themes are highly important for understanding the abilities of communities to withstand the threats of malaria. These initial themes resulted in the framework noted in *Figure 2.2* which I present in the following section.

2.11 Conceptual Framework: Sustainable Livelihoods and Health

Based on the findings of this review, it can be argued that a livelihoods framework is needed to understand the value and challenges such as poverty and vulnerability of family and community management to improved health outcomes. Many of the reviews have identified health improvements as a result of family and community action. In this quest for defining what contributions of family and community management to health, a framework that takes into account the specific context of communities and drawing on assets and resources to withstand the threats of malaria can be useful. It directs attention to the analysis of five livelihood assets and resources which can be social, human, natural, economic and physical. In the DFID (1999) view, these assets and resources will influence how a household or community responds to a particular disturbance such as malaria. Poorer and marginalised communities are reliant upon these assets and resources to maintain good health (Brown 2016; Poortinga 2011; Manzi et al 2010). They are the assets that give people and communities capability, and the outputs that contribute to improved health outcomes. This conceptualisation suggests elements of a framework linking levels of analysis in research and practice, addressing the relationship between vulnerability, access to resources and health outcomes. The suggestion is that the framework would conceive of livelihoods and the enhancement of health in terms of different types of capitals that are the resources that make livelihood strategies possible. The framework is predicated on strengths rather than on vulnerabilities, capabilities rather than deficits, resources rather than exposures (Panter-Brick 2014; Almedom & Tumwine 2008). Almedom and Tumwine (2008) noted a shift from deficit models of vulnerability to ideas about assets and strengths. Rather than designating those who face adversity as passive victims, they can instead be recognised as resourceful and view them with an enhanced agency (Eriksen et al 2005:302). It integrates vulnerability and capacities which enable people to deal with disturbances such as illness, through livelihood assets and institutions. It provides a firmer understanding of how the presence of five capitals can contribute to family and community management. I present the framework in *Figure 2.2* below.

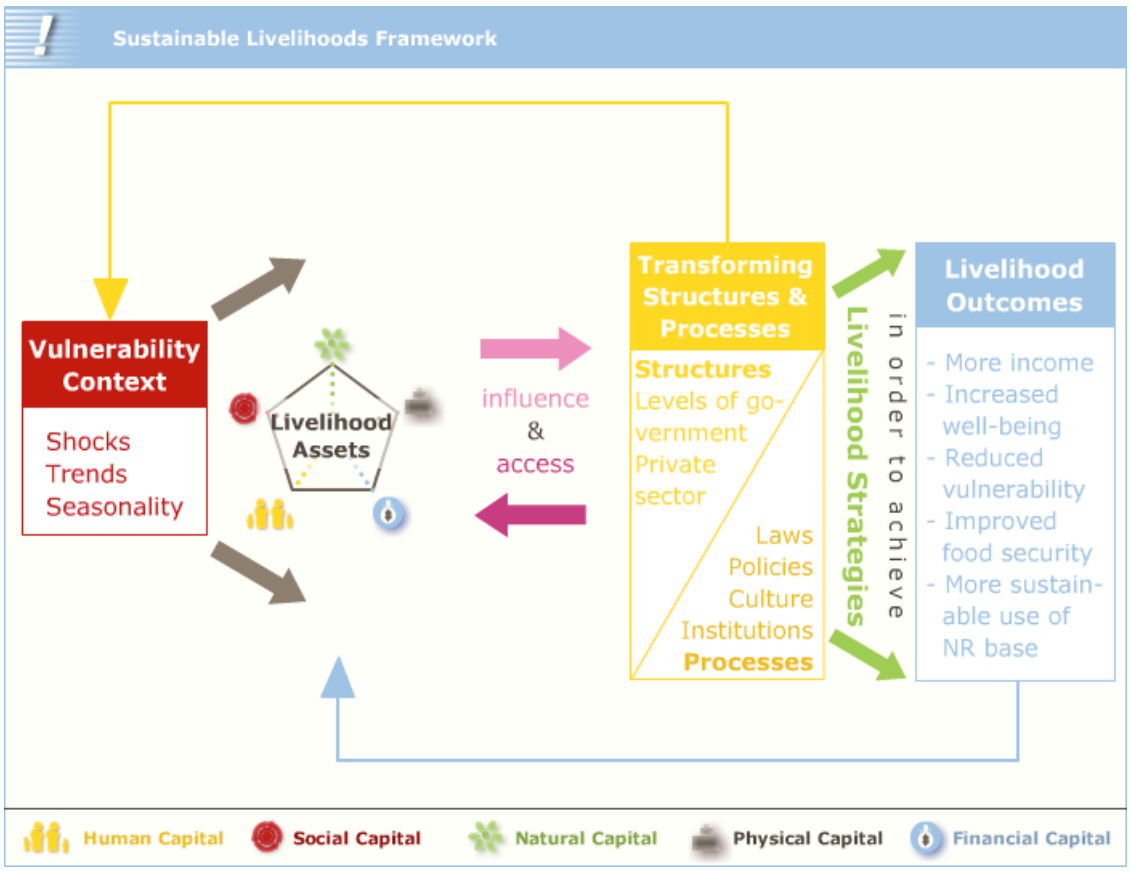

Figure 2.2: Sustainable Livelihoods Framework (DFID 1999:2)

This framework starts out from the perspective of vulnerability and concludes with livelihood outcomes. It is composed of five key components. These are: (1) the vulnerability context which in the current study emerged when people faced malaria threat with inadequate capacity to respond effectively; (2) the assets or capitals providing buffers for poorer people which influenced how a household or community responds to a particular disturbance; (3) the policies, institutions and processes in communities that govern how assets are used; (4) the livelihood strategies (e.g. by-laws, culture) through which community action was taken; (5) the outcomes such as health outcomes that people strive for. There are subcomponents also to every major component of the framework. Each component has backward or forward ties to one or more other components of the framework. For example lack of access to physical capital such as hospitals can make communities more vulnerable to malaria.

Rakodi (2002) noted that a livelihoods approach require a clear understanding of the assets in order to identify the opportunities they offer and the constraints to livelihoods. The current study would draw on the Sustainable Livelihoods Framework for understanding community responses to malaria from a livelihoods perspective and to show how this framework can contribute to the knowledge building process

(Joseph & Macgowan 2018) in relation to malaria. It takes a slightly different position than previous studies. Rather than focusing on the disease, it explores the ways in which people combine what assets, capitals or capacities they do have and put to use in creative ways to overcome the threat of malaria. This conceptual framework aimed to answer the research question resulting from the literature review. Using this analytical lens can extend conventional approaches and insights, and to develop a more socially nuanced understanding of human capacities and opportunities in the face of malaria. The Sustainable Livelihoods approach shifts from a disease focus, which emphasises risk, ill health and disease. Its primary goal is to answer the question of what creates health by focusing on peoples' resources rather than what causes disease (WHO 2017; WHO 2015; Panter-Brick 2014). It places emphasis on the generation of health and the actions that families and communities take towards improving their health.

The Sustainable Livelihoods Approach has mostly been used in disasters, climate change but less in health. According to my knowledge, few studies have used this approach in sub-Saharan Africa. By focusing on peoples' discourses of malaria from a livelihoods perspective, this thesis aims to reveal a series of new insights and challenges about new ways of withstanding the threats of the disease.

2.12 Gaps in the literature

There are several gaps that can be identified when reviewing the literature on family and community management. Firstly, there is little research investigating gender inequality in poorer and marginalised communities, where women despite having more burdens of care at home, community and reproduction, lack power and control over resources and decision-making. Such research can inform understanding of the importance of power asymmetries that influence women's capacity to respond to malaria. Secondly, complex adversities and interacting stressors occurring simultaneously e.g. poverty, poor housing and environmental conditions, ill health are rarely analysed together. This complexity places limit on extant research. Thirdly understanding what motivates volunteers to take part in volunteering in resource-poor settings is crucial to recognising, facilitating, and sustaining the work that they do. Further research into volunteering in the South is crucially needed. Fourthly, there is little research using a livelihoods framework in malaria control programmes in sub-Saharan Africa. Using a livelihoods framework can help gather insights from the field that describe how the components of this framework are interacting with lived experiences of poorer and marginalised communities in working to overcome the threats of malaria. Such insights can add to the usefulness of attending to different types of assets and resources by enabling analysis of the capacities in families

and communities to withstand the threats of malaria. Fifthly further research is needed on the full effect and sustainability of family and community management for health as an approach in reducing the mortality and morbidly from malaria. All these perspectives present important areas for further research to better understand family and community management in relation to malaria. The next section summarises the resulting research question.

2.13 Research question

This review has identified, several issues for family and community management for health. Identifying family and community management as an issue builds on the health care seeking literature depicting families and communities navigating plural health systems in seeking care. This review also highlights a people-focus in bottom–up approaches enabling for example families and communities taking and making decisions about their health as in home-based care and facility management committees. Their relevance to the current study is in providing understanding of alternative pathways and possible futures in withstanding the threats of malaria and malaria control.

This study, undertaken in poorer and marginalised communities, sought to map the stakeholders and identify the discourses that contributed to family and community management in relation to malaria. The current study builds on the current literature and attempts to improve understanding by examining through empirical research how knowledge about family and community management in relation to malaria was generated in poorer and marginalised communities in Sierra Leone. The research question was: '*How are family and community management perspectives reflected in discourses concerning incidents of malaria in Sierra Leone?* The Methodology Chapter follows.

Chapter 3: Methodology

3. 1 Introduction

In the last Chapter 2, I reviewed the literature on family and community management in relation to malaria. The review led to the conceptual framework guiding the research design and data collection methods. This chapter describes the methodology and methods that were employed to conduct this research. It consists of seven main sections. Following this introductory section, I provide in section 3.2 my overall philosophical assumptions that guided the research and informed the rationale for the research design and methods. I present the theoretical background of a discursive approach to understanding family and community management in relation to malaria. Section 3.3 provides the study design. It describes the case study (section 3.3.1) and study setting (section 3.3.2). Section 3.3.3 presents the methodological approach to adopting discourse analysis. Section 3.4 presents the data collection methods including policy documents, interviews, focus groups and field notes, ethical considerations and data analysis. Section 3.5 focuses on 'Reflexivity' whilst Section 3.6 provides the study limitations. The final section 3.7 summarises the arguments for matching my methodology and methods to my research problem and application of the study framework in data collection and analysis. In the next section, I present the philosophical assumptions in the study.

3. 2 Philosophical Assumptions

Despite significant research and investment in public health programmes to combat epidemics such as malaria, high mortality rates continue to affect many families and communities in sub-Saharan Africa countries such as Sierra Leone and their sustainability is contested. The nature of the approaches to withstanding the disease has focused on biomedical interventions and paid less attention to how family and community management might have relevance in specific contexts for people, communities and health programmes to prevent, manage and control the disease. My philosophical assumptions were therefore influenced and informed by 'discourse theory' that helps to explain how language and texts constitute social practices and contributing in terms of providing understanding of what needs to be done at the level of families and communities to withstand the threats of malaria (Greenhalgh et al 2012; Shaw & Bailey 2009; Hodges 2008; Mason 2002).

I therefore defined my research in terms of two distinctive philosophical assumptions. Firstly, that the reality about malaria existed in social constructions at the family and

community levels that were meaningful (Mason 2002:128**).** This ontology has implications in turn for epistemology. I proposed that such reality can be apprehended by capturing discourses which can directly represent lived experiences in language. My epistemological position, therefore, was that subjectivity in individual's perspectives and experience and texts were constructed by language, were discursively constituted and explored in my research setting. According to Joseph and Macgowan (2018:8), "a theory should embrace its philosophical integrity by clearly explaining its ontological and epistemological connections". In the next section, I present the study design.

3. 3 Study Design

A qualitative multiple methods design was employed in a case study of the malaria control programme in Sierra Leone. The case study enabled an in-depth enquiry of family and community discourses that occupied the space between the government's national programme and the responses of people in communities. This study used a qualitative case study approach to gain a deeper understanding of the issues related to malaria control. This methodology was used to gain a deeper understanding of family and community management in these communities and to explore community processes and perceptions surrounding the epidemic.

A reason for a qualitative design was that different stakeholders in the malaria control programme held different assumptions, values and worldviews. Values produced peoples' views about the environments they lived in and explained differences in responses across communities to malaria. They were the established ways of life or cultures that influenced the choices people made in their ordinary life. In the community, values influenced daily activities including health-seeking behaviour. Worldviews were the society or community knowledge and points of view. In the context of this study values interacted with worldviews as together, they influenced peoples' interpretation and respond to malaria risk. In a social system such as communities, they explained why different actors make different choices even in similar situations such as the malaria epidemic. Use of a qualitative design that looks at the policies of the government malaria control programme, as well as the discourses occurring at family and community levels enabled exploration of the dimensions referred to by Mason (2002:1).

Another reason for a qualitative design was to capture the interaction between the natural and physical worlds or between people and their environments. Discourses varied across individuals and groups. One person's reality may shift and alter when exposed to that of another. A qualitative design was particularly suited to accommodate the varied and

competing discourses. Ungar (2003:2) noted that qualitative methods are well suited to:1) discover unnamed processes; 2) attend to the contextual specificity of health phenomena; 3) increase the volume of marginalised voices; 4) produce thick enough descriptions of lives lived to allow for the transfer of findings between contexts (ibid.). The different stakeholders meant multiple realities including the reality of government policy and the reality of family and community-based services. Another kind of reality was the interpretation and responses of families and communities to interventions. The relevance for my study is that diverse and alternative worldviews as reflected in discourses opened up spaces for innovation and possibilities to reassess human and environmental relationships (Kuecker & Hall 2011) and other approaches to malaria control.

Multiple data collection methods were employed to support the trustworthiness of the data and reduce the impact of biases in a single method. Alexander et al (2008) observed that multiple data collection methods in qualitative research were seen as the most appropriate way to gain insights into the social processes which were the relations between individual interactions and community level behaviours. It indicated that the more sources of data generation employed to explore the research question, the richer the data and the more believable the findings. In the next section, I describe the case study in detail.

3.3.1 Case Study

I selected the Malaria Control Programme in Moyamba, Southern Sierra Leone for the case study because it focused on an issue of intrinsic value and of high relevance to the population. Malaria was considered to be a useful case study in Sierra Leone where infant and under-five mortality rates are high at 78.5/ 1000 live births and 105.1/ 1000 live births respectively (UNDP 2020). It is the major cause for morbidity and mortality and a major impediment to socio-economic development leading to poverty (MoHS 2015)-Sierra Leone Malaria Control Strategic Plan 2016-2020. The boundary of the case was the national malaria control programme in Moyamba district, a defined health system that included families, communities and organisations in health programmes.

Although no single initiative can be seen as representative of the field as a whole, the programme in Moyamba district was appropriately illustrative. It presented a case where a government public health programme incorporated family and community management as a major component as reflected in policy documents e.g.

(MoHS 2015)-Sierra Leone Basic Package for Essential Health Services 2015--2020; (MoHS 2015)- Sierra Leone Malaria Control Strategic Plan 2016-2020). The programme was characterised by three basic components: 1) the identification of a geographically defined target area, in this case, Moyamba district; 2) a recognition of family and community management in the governance of planning and implementing health activities at the local level; 3) a recognition of community assets and resources (in line with the study framework), as well as needs in the planning process (MoHS 2015)- Sierra Leone Basic Package of Essential Health Services 2015--2020.

Yin (2009:18) defines the scope of a case study as an empirical inquiry that 'investigates a contemporary phenomenon in depth and within its real-life context, especially when the boundaries between phenomenon and context are not evident.' In this view, the case study provided insights into the different contexts of the phenomena when communities responded in particular ways to the disease (Creswell 2007; Danemark et al 2002). According to Creswell (2007), a case study is appropriate as it intends to understand an issue or problem (family and community management in relation to malaria) using the case as a specific illustration. Danemark et al (2002) noted that the approach focuses on a particular case studied in the natural contexts where the case gets particular signification as part of the context. The inductive element of the case is the orientation towards understanding, 'thickness' and theory generating (ibid.), as reflected in the purpose of this study. As the approach allowed multiple sources of evidence to be triangulated, and the prior development of theoretical propositions in the literature including social capital, coping, empowerment, innovation and discourse theory, it was considered most relevant. In the next section, I present the study setting.

3.3.2 Study Setting

Sierra Leone is a West African nation with a population of 7,092,113[1]. The country has varied terrain, ranging from coastline swamps, through inland swamps and rain forest. The vegetation is mainly secondary palm-bush, interspersed with numerous swamps that are mostly cultivated for rice. These swamps provide ideal breeding places for mosquitoes. Moreover, the coastal line has several mangrove swamps, which also provide the breeding sites for mosquitoes. Despite substantial mineral and agricultural resources, Sierra Leone is classified as a low-income country: HDI rank- 182/189 countries; human development index- 0.452; population below income poverty line-

[1] Statistics Sierra Leone (2015). 2015 Population and Housing Census. Final Results

52.9 %; population in multidimensional poverty-57.9%; income per capita-$1,668 (UNDP 2020)[2] .

The study area are rural and Moyamba town communities in Moyamba district. The headquarter town is Moyamba about three hours' drive south of Freetown. The majority of the population are Mende living in dispersed settlements and small trading centres. The inhabitants are largely subsistence farmers who produce small amounts of cash crops such as bananas and coffee. The district is comprised of fourteen chiefdoms **n**amely Bagruwa, Bumpe, Dasse, Fakunya, Kagboro, Kaiyamba, Kamajei, Kongbora, Kori, Kowa, Ribbi, Lower Banta, Upper Banta and Timdale. The district has one of the highest incidences of malaria in Sierra Leone (Mara/Arma 1998). It is also the second poorest with a district level poverty rate of 70.8% (Statistics Sierra Leone & World Bank 2013). It borders several other districts including 'Port Loko' district and 'Tonkolili' district to the north, 'Bo' district to the east and 'Bonthe' district to the south. The capital and the largest city is Moyamba in the 'Kaiyamba' chiefdom.

Moyamba district is predominantly rural with an economy based around subsistence agriculture and fishing (OCHA 2015). The Ministry of Local Government and Rural Development (2014) summarises the environmental, social, health and water and sanitation problems facing the district. The environmental problems include lack of proper dumping sites in the chiefdoms, no appropriate hold dustbin, ineffective civil education on refuse disposal. The social problems include poor road conditions, inadequate market facilities, poor housing conditions and poor telecommunications network. The health problems include breeding habitat for mosquitoes and other pests, inadequate health facilities, inadequate health personnel, shortage of essential drugs at health facilities, inadequate beds and working tools at health facilities, untimely payment of personnel, poor water supply, and difficulty in accessing safe drinking water. The sanitation problems include inadequate sanitary inspectors in the district, poor drainage facilities and poor toilet facilities.

The research was located in the South of Sierra Leone in Moyamba district *(Figure 3.1),* one of sixteen districts in the country with a population of 318,064 - Female-164,710, Male-153,354 (Statistics Sierra Leone 2015).

[2] UNDP {2020) Human Development Report. The next frontier. Human Development and the Anthropocene. UNDP.

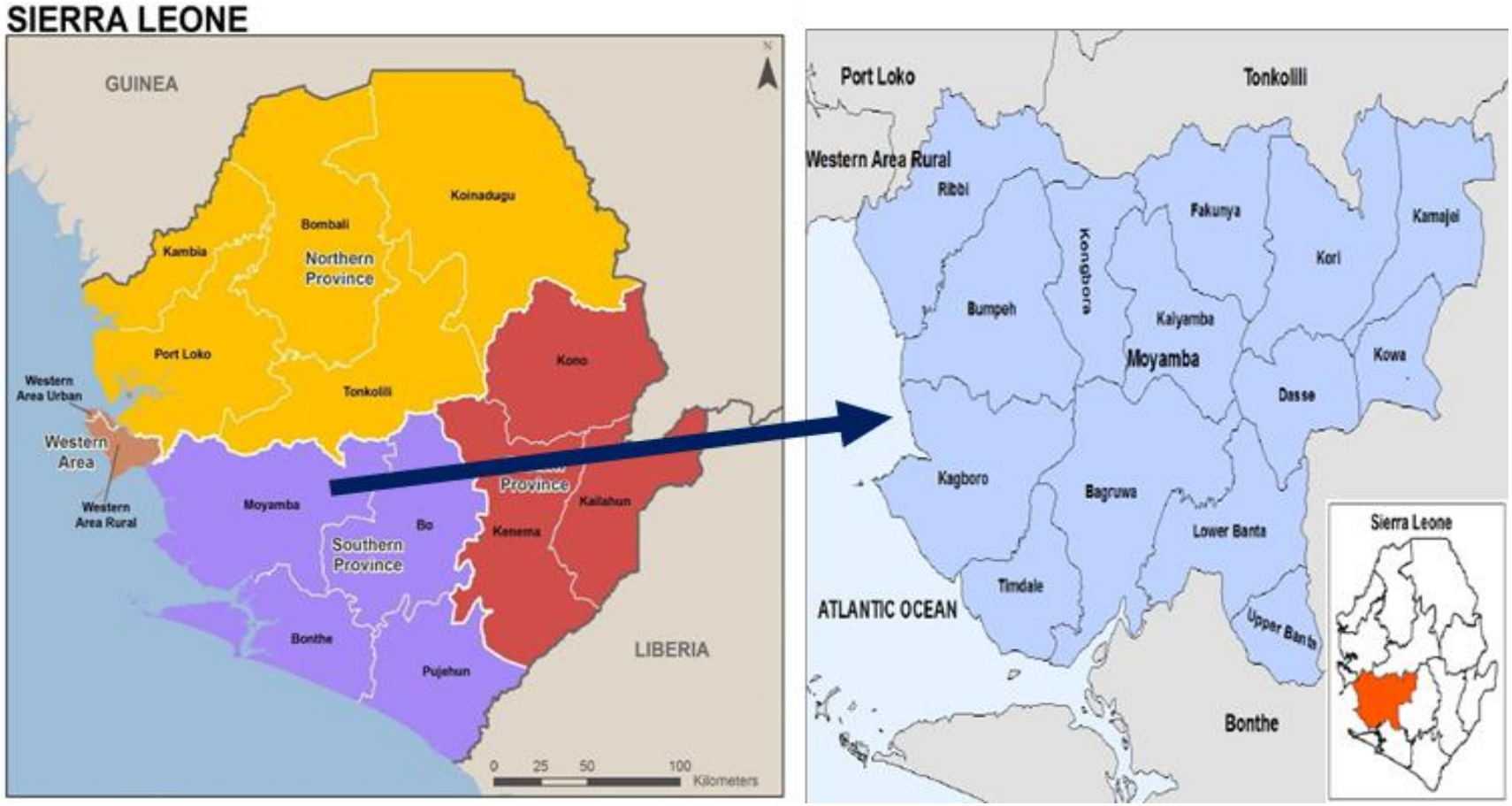

Figure 3.1: Map of Sierra Leone and study sites in Moyamba

The entire population in the district is at similar risk of malaria as is the whole country (MoHS 2015)-Sierra Leone Malaria Control Strategic Plan 2016-2020). The primary health care facilities in the district are peripheral health units (PHUs) which are sub-classified into three levels: Maternal and Child Health Posts (MCHPs); Community Health Posts (CHPs) and Community Health Centres (CHCs). According to the Sierra Leone Malaria Control Strategic Plan (MoHS 2015), the MCHPs are situated at village level covering populations of less than 5,000. The CHPs are at small town level covering populations of between 5,000 and 10,000. The CHCs are located at Chiefdom level, usually covering a population ranging from 10,000 to 20,000 (ibid.). This study was conducted across all three levels.

Sampling of Chiefdoms

Chiefdoms in Sierra Leone are a system of indirect rule which was established by the colonial government in 1896 (Reed & Robinson 2012). They are governed by locally elected paramount chiefs. The Paramount chiefs are the sole authority of local government. Only individuals from the designated ruling families of a chieftaincy are eligible to become Paramount Chiefs. A brief description of the chiefdoms follows. *Table 3.1* presents the community profiles of chiefdoms studied.

Table 3.1: Chiefdom Profiles

Name of Chiefdom	Population	Setting	Terrain	livelihoods	Ethnicity	Malaria intensity
Kagboro	34,863	Rural	Coastal	Sea fishing	Sherbro/ Temne	High
Lower Banta	37,317	Rural	Coastal	Agriculture/Sea fishing	Mende	High
Timdale	10,292	Rural	Coastal	Agriculture/Sea fishing	Mende	High
Bumpeh	37,445	Rural	Highland	Agriculture/Sea fishing	Sherbro/ Temne	Low
Dasse	13,217	Rural	Highland	Agriculture	Mende	Low
Fakunya	27,646	Rural	Highland	Agriculture	Mende	Low
Kongbora	10,328	Rural	Highland	Agriculture	Mende	Low
Bagruwa	27,623	Rural	Highland	Agriculture	Mende	Low
Kaiyamba	25,749	Moyamba town	highland	Agriculture	Mende	Low

Source: Adapted from Statistics Sierra Leone (2015)

I applied purposive sampling to select the chiefdoms, which supported the diversity of contexts. The study purposively targeted 10 of the 14 chiefdoms in Moyamba. The components of the purposive sampling strategy were: 1) capturing geographical diversity, including rural areas and in Moyamba town community; 2) representation of disease intensity including communities with high and low malaria prevalence); 3) representation of terrain (coastal/highland); 4) ethnic diversity; 5) reasonable accessibility to Moyamba[3]. The criteria for defining the purposive sample were practical and resource-based. The practical reasons were that some chiefdoms are in dispersed locations in mountainous riverain and hard-to-reach areas. Further given the study overall timeline, data collection was scheduled to occur over a six-month period, which did not allow the study of every chiefdom within this time with the resources available. Out of fourteen chiefdoms in the district, ten chiefdoms (Bagruwa, Bumpeh, Dasse, Fakunya, Kagboro, Kaiyamba, Kori, Kongbora, lower Banta and Timdale) were originally in the study sample plans. The main study included nine of the chiefdoms with only one chiefdom, namely 'Kori' subsequently withdrawn from the study because of lack of response to participant recruitment activities, i.e. failure to confirm dates and times for interviews. Several attempts by phone calls to confirm availability for the interviews were unsuccessful. As participation was voluntary, I did not consider it worth pressing them. In the next section, I present the methodological approach.

3.3.3 Methodological Approach

Because peoples' discourses concern what language they use and how they use it, the methodological approach of this research, therefore, needed a way to recognise how people talk or record views and account about managing family and community language. This approach meant collecting data in which people talk or record their views on these topics and then analysing the features of such discourses.

The focus is on analysis of how discourses which can be read in texts and talk constitute the social world. Thus the idea of a human actor or agent where human action, events or activities are subjects of analysis is absent (Mason 2002: 57). Rather what features in this approach is what people and texts say about those events and activities. At no point can discourse analysis tell us about the empirical reality of events, but it can tell us about

[3] Accessibility may not be acceptable as a site selection criteria as it may bias the results to some extent. However given the poor road conditions in the district and the existence of river rain communities, I considered this criteria to be relevant. Most of my selections are within distances of 50km to Moyamba apart from Gbangbatoke and Youndo which are 90km and 87km respectively

the empirical reality of what people are talking about and what they talk. Knowledge claims are not based on events or activities but on findings that relate to discourses about events or activities. Though no human action is involved, the orientation captures how people use discourse to do things, construct versions of events and show differences in their attitudes and accounts by the use of language. The main argument is that it is possible to undertake a critical analysis of family and community management in relation to malaria by paying attention to the detailed specifications of discursive interaction.

The present section constitutes both a presentation of `what happened' in this study and aims to highlight some of the central issues involved in adopting a discursive approach to the study of family and community management. It also shows how the methods are inherently bound up with theoretical assumptions. I present how discourse analysis conceptualises and uses sources and methods and how useful I found this approach for my research.

The method is summarised in Box 3.1. In this analysis, I was interested in the community discourses and malaria policy documentation that contribute to the vision of family and community management. To identify these, I followed the basic principles of discourse analysis of interviews and focus groups, supplemented by selected policy documents (Greenhalgh et al 2012).

Prior to the primary data collection in January 2017, a pilot study was undertaken in December 2016 in Moyamba. The pilot was intended to gain direct knowledge of the sites and experience of living conditions there. It was undertaken to try out sampling strategies for the selection of communities and participants, and data generation and analytical techniques. The rationale was to assess how the products from the pilot fed into my study as a whole to make advance decisions about the study.

Box 3. 1: Methodological approach

Box 1 Methodological Approach

Familiarisation Phase

1. Desk research. Reading articles on family and community management and on malaria interventions in Sub- Saharan Africa
2. Familiarisation visit to study site in Moyamba, contacted the malaria control programme and partners. Identified literature in the country
3. Pilot study

Main Phase

4. Data collection using interviews ,focus groups and policy documents
5. Data analysis
6. Interpretation: drawing the above together to drawing the above together to produce an account of different discourses, the communities where these are produced and from which participants, and the similarities and contrasts

Consolidation Phase

6. Member checking; interpretation is checked for resonance with a sample of participants including representatives of different stakeholder groups in second-round interviews

Source: Adapted from Greenhalgh et al (2012)

Table 3.2 provides a chart setting out how the research question linked with the methodology (Mason 2002: 27). It helped to work out in detail what might be evidence or knowledge relevant to the research question. It worked out which methods and sources were most appropriate for answering the research question and making choices of method and data source. It enabled to spot and eradicate inconsistencies between what a particular method can yield and what kinds of data were needed to generate to address the research question.

Table 3. 2: Chart linking research question with methodology

Research question	Methodology	Data sources and methods	Rationale	Relevant sample	Plans for analysis	Ethical issues
How are family and community management perspectives reflected in discourses concerning incidents of malaria in Sierra Leone?	Qualitative Research Strategy. Discourse analysis approach using a case study of the malaria control programme in Sierra Leone	Multiple methods including semi-structured interviews and focus groups. Also published and unpublished literature. Documentary analysis (Qualitative, desk based, textual analysis). Also field notes	To obtain data on everyday life experiences to discern the influences of family and community management perspectives on health outcomes	Snowball sampling; Individuals in rural and Moyamba communities including patients, pregnant women, community leaders; religious leaders, youth leaders, men and women, teachers, health practitioners Conducted 54 interviews and 3 focus groups, Reviewed 6 policy documents as data sources	Reading and re-reading the data, searching for linguistic evidence Discourse analysis	Informed participants about the study. Obtained freely given consent and signed consent forms. Ensured confidentiality by using pseudonyms to protect the identity of participants

The chart provided a check on the consistency of my thinking about the research process and helped to decide the methodological strategy that lied behind the design that I assembled. The multiple methods typology and types of data sources is illustrated in T*able 3.3* below:

Table 3. 3: Multiple methods typology

Policy Documents	Policy Documents from the Ministry of Health and Sanitation
Individual interviews	Included participants from a cross-section of communities in Moyamba district
Focus groups	3 focus groups: 1) rural communities across the district; 2) Moyamba town; 3) health practitioners across the district
Second round interviews	Follow up interviews
Field notes	Produced at the end of each field day to complement transcripts

3.3.4 Ethics Approval

The study was given ethical approval by the Sierra Leone Ethics and Scientific Review Committee on 1 August 2016, and the University of East Anglia Ethics Committee on 26 October 2016. Ethical issues relating to the interviews and anonymisation of the respondents in the study are discussed in section 3.4.9 'Ethical considerations'. I ensured that all required permissions were gained before making contact with the community, including applying for Ethics Approval. In the next section, I present the data collection methods.

3. 4 Data Collection

The data collection and analysis presented is based on five principal sources: (1) first-round in-depth interviews in rural and Moyamba town communities; (2) second-round interviews; (3) focus group discussions; (4) policy documents ;(5) field notes. Interviews and focus groups (1-3) explored perceptions of family and community management in relation to malaria. Policy documents (4) depicted involving communities and individuals in malaria control to contribute to improved health outcomes. Field notes (5) complemented transcripts. These data were used with the conceptual framework to advance understanding of existing theories and answer the research question.

The semi-structured interviews were conducted with individual people in the communities, with individuals as the unit of analysis. I also reviewed policy documents and in that review, the unit of analysis was the government malaria control programme. I therefore did not simply add the data sets together because their substance and form

was different and were organised around different analytical units, in this case individuals on the one hand, and the national malaria programme on the other (Mason 2002:34). I therefore needed to weave the argument and analysis derived from the different data sets together intellectually, both ontologically and epistemologically, at the level of explanation (Mason 2002:35).

A distinction is made between data sources and the methods used to generate data from those sources. In this research, I saw 'people' as data sources in the sense that they were repositories of knowledge and experiences that were relevant to the research. Methods were the techniques and strategies I used to generate data from people, in this case, interviews and focus groups. I also saw policy documents as data sources. I use the words 'generating data' to draw awareness to the wider range of relations between myself as a researcher and the social world I explored. As I sought to construct knowledge about that world using methods derived from my epistemological position, I was therefore not simply collecting data from these sources but was involved in activities that were intellectual, analytical and interpretive that helped to answer my research question (Mason 2002).

The overall data collection period was between July 2016 and June 2017. *Table 3.4* provides a summary of the field research activities. The research was based in Moyamba from where I made frequent travels to dispersed chiefdoms in the district.

Table 3. 4: Summary of research activities

Research Phase	Summary of Activities
July-August 2016	An exploratory visit to Sierra Leone. Consultations in Freetown with malaria control programme manager and partners- WHO, UNICEF, CRS Consultations in Moyamba with the malaria control programme and the district council staff Obtained policy documents Obtained the Sierra Leone Ethics and Scientific review committee approval
September-November 2016	At UEA. Obtained UEA Ethics approval Prepared for probationary review
December 2016	Returned to Sierra Leone for a pilot study. Tested sampling strategies and research tools. Conducted pilot interview with malaria focal point in Moyamba
Jan-June 2017	Primary research. Conducted first individual interviews. Conducted the three focus group discussions. Conducted second round individual interviews

The next section reports on each of the methods, the tools designed and used, the recruitment strategy to select participants, data collection procedures and data analysis.

3.4.1 In-depth semi-structured Interviews

Interviews were used as one of several methods to explore the study research question. At the inception of fieldwork, a participants mapping exercise was done to identify the institutions and individuals from whom data and information to answer the research question will be collected. Semi-structured interviews were carried out with individuals considered as capable of providing an expert and useful insight into processes being researched. The study took the perspective that knowledge is contextual and semi-structured interviews enabled that relevant contexts were brought into focus so that situated knowledge could be produced (Mason 2002:62). In this sense, the method contributed to the rigour of the study and enhanced validity. According to this perspective, meanings and understandings are created in a face-to-face interaction between researcher and interviewees which tend to be seen as involving the construction

or reconstruction of knowledge. Semi-structured interviews were appropriate as they supported a more fluid and flexible a conversation or discussion, rather than a formal question and answer format as in structured interviews (ibid).

Recruitment Strategy

Snowball sampling (Hancock et al 2007) was used to recruit participants. The approach relied on referrals from people who knew other people who met research interests. The aim was not to acquire a representative sample from Moyamba. In this study, no attempts were made to standardise or control the selection of participants as for example in experimental studies. This approach was appropriate as it facilitated a more relationship-based identification of participants for the study. It was a two-step sampling approach which located individuals and asked them to name other likely participants. Snowball sampling helped me to access participants in the range of communities that might otherwise be difficult to access. To recruit the communities sample and find suitable participants for the interviews, close collaboration with the malaria programme staff was particularly important. The study therefore, demanded 'gatekeepers' in the malaria programme who had knowledge and experience from working in the programme and were familiar with all the chiefdoms and the communities where the programme was implemented. I established these 'gate-keepers' during my exploratory visit in July 2016. They were informed about the aim of the study and they provided me with information and contact details of peripheral heath units in Moyamba district. Following the visit, I constructed a sampling grid for sites and participants. Whist the snowball approach was useful for finding participants, it was not a sufficient strategy in itself for participant selection due to potential bias. I recognised that the participants selected were not representative of the whole population, thus I did not make claims from what they said about the prevalence of any views in a community. However, the approach aimed to include a range of participants so that the research did not have obvious limitations, such as choosing just patients who went to the clinic, or community leaders familiar with the community and its issues.

Participants were selected using the following inclusion criteria: individuals who are resident in the identified settings; individuals who can and were willing to provide information by virtue of knowledge; elders with empirical knowledge who were willing to impart their knowledge and experiences with malaria over time; direct experience of the disease and disease management experience. This was used in the initial snowballing following my familiarisation visit. The participants for the individual interviews consisted of health practitioners, community leaders, pregnant women, religious leaders, youth

leaders, women's leader, men's leader, previous and current patients, and heads of households, teachers, a district council official and drug suppliers.

The main data collection took place between January 2017 and June 2017 when a total of 54 participants were interviewed. The present section will discuss the characteristics of participants, their selection and general issues relating to the presentation and engagement with participants in discourse analysis. *Table 3.5* provides a summary of the participant categories and the total number of interviews and gender distribution.

Table 3. 5: Summary of data gathering-Individual interviews

Category	Rural	Moyamba town	Total	Gender	
First round interviews				f	m
Health Practitioners	4	2	6	3	3
Community health worker	1		1	1	0
Pregnant women	1	2	3	3	0
Religious leader	1	1	2	0	2
Current patient		1	1	0	1
Previous patients	4	2	6	3	3
Community leaders	4	2	6	3	3
Teachers	2	2	4	2	2
International NGO		3	3	1	2
Local NGO		2	2	1	1
Youth leaders	1	2	3	1	2
Head of household	2	1	3	0	3
Drug distributor	2	1	3	0	3
District council official		1	1	1	0
Sub Total	**22**	**22**	**44**	**19**	**25**
Second round interviews					
Health practitioners	3		3	1	2
Religious leader	1	1	2	0	2
Teacher	1		1	0	1
Community leader		1	1	0	1
Head of household		1	1	0	1
Interviews with FGD participants					
District medical officer		1	1	0	1
CRS zonal coordinator		1	1	0	1
Sub Total	**5**	**5**	**10**	**1**	**9**
Grand Total	**27**	**27**	**54**	**20**	**34**

Female participants represented 43% (19/44) of first round interview participants which I considered appropriate as related to the wider universe I was interested in namely, discourses of people in communities, organisations, policies, and social practices (Mason 2002:122).

Individual Interviews Procedure

The participants were informed about this study orally through the malaria programme focal point and health practitioners a week before the study. I called the participants a day before interviews for confirmations. Prior to interviews, a one-page description of the study and its aims and intended use of the information was explained to participants using a prepared information sheet (see Appendix 2.1). Following that a written consent (see Appendix 2.2) was obtained from each participant). For participants who were unable to read, the researcher read the consent to each subject in their local language ('creole','mende') and those who agreed to participate in the study used a thumbprint to sign their consent.

In the rural sample, most interviews (n=20) were conducted in the peripheral health units and in quiet locations to avoid interruptions and in closed stores of the drug suppliers (n=2) in 'Bagruwa' and 'Lower Banta' chiefdoms. In the Moyamba town sample, interviews were conducted at facilities (n = 10), in offices (n=4), in schools or communal buildings (n= 4) and at homes (n = 4) for the pregnant woman, the breastfeeding female youth leader and female patients. At each interview, I encouraged participants to use the language they spoke most comfortably. Most interviews were conducted in 'creole' the common language in Sierra Leone with some in English. For non-English speaking participants in rural communities (n=2), interviews were conducted in their primary language (mende), the main local language in the district.

People took part on a completely voluntary basis and could choose not to answer any question or withdraw from the study at any time. Participant confidentiality was maintained throughout the study. In each chiefdom, I carried out the interviews and the focus groups whilst the research assistant conducting the interviews with female participants on matters sensitive to women such as: how they dealt with malaria during pregnancy; ante natal visits; how they responded to men household control of resources; access to facilities for women. Thus I could not claim a 'women's standpoint' epistemological position on women's issues based on insider understanding of women's' experiences (Mason 2002: 193) which would not have interpretive validity (Adkins 2002). I conducted individual interviews using a pre-prepared interview guide with open-ended questions *(*Appendix 3*).* I devised interview guides for the identified set of stakeholders from secondary literature analysis. The guide was also informed by the study research question. Interviews covered a range of topics related to family and community management in relation to malaria. I selected topics to explore in detail the participant's perceptions and accounts to gain an in-depth understanding of their beliefs, practices and experiences in order to establish forms of capacities at the community level. Overall

I sequenced the questions in chronological order thus: experiences of malaria; reasons for the spread of malaria; dealing with malaria; help for malaria; information and knowledge about malaria; organisations involved in health programmes; community action. In some interviews, I asked the questions iteratively, taking queues from participants. In particular, I looked for participants views about how family and community management can be demonstrated and assessed. On any one day, the number of interviews could range from 1-3 interviews especially in the rural communities which were long distances away. The interviews lasted from 40 to 90 minutes. In the next section, I present the second round interviews.

3.4.2 Second round Interviews of individual interview participants

Second round interviews were undertaken to respond to threats to the validity of interpretations of certain data (Seale 1999). It was a crucial technique for establishing credibility, where I referred to the interview transcripts of some participants so that they can indicate their agreement or disagreement with the way in which I represented them. It was done to make sure research participants and their ideas were represented accurately (Glesne & Peskin 2006:38). It assisted in clarifying the initial themes that were generated and any questions that had arisen.

What participants said did not represent one single factual reality of what happened in communities; this was a study of accounts not of actions. In order to establish the credibility of accounts, I undertook second round interviews to probe participants further. This method was also used to test research claims by gathering new evidence and to follow up on the findings by taking specific descriptions or themes back to participants and ascertaining whether these participants saw them as relevant and applicable.

However, the use of second round interviews has been criticised, because there could be many reasons for participants agreeing or disagreeing with an account that are unrelated to its credibility (Spencer et al 2003:77-78). Such reservations about second round interviews include: the idea that there is no one true reality or ultimate truth, so one cannot go back to seek such truth emanating from previous discourse; the possibility that participants may not be motivated; research subjects are unfamiliar with social science interpretation or knowledge about them (Mason 2002:193); or that there is no intrinsic reason for believing that participants interpretations were somehow superior to that of the researcher's (Spencer et al 2003; Mason 2002). Consequently, second round interviews may simply be better described as a courtesy or a way of gaining a more rounded picture (Silverman 2000; Angen 2000). However second round

interviews could be useful to check the reliability and accuracy of interview transcripts with interviewees, but not to expect this as a 'quick-fix' to the problem of interpretive validity (Mason 2002:192).

Recruitment Strategy

I purposively selected eight participants (rural, n=5; Moyamba town, n=3) from the first round interviews for the second round interviews as below:

Rural Participants: Head teacher rural, male; health practitioner rural, female; health practitioners rural, male (n=2); religious leader rural, male

Moyamba town Participants: community leader, male; religious leader, male; head of household, male.

These participants were selected as they provided data in the first round interviews of relevance to the research question that needed further exploration. They also demonstrated empirical knowledge and were willing to impart their knowledge and experiences with malaria. I took the data and interpretations back to the participants so that they can judge the accuracy and credibility of their account.

Despite mostly male participants, I had a sense of gender relations in discourses about structures of power with men and women differentiated for example in household decision making, helping with farming, and as distinctive male and female attributes e.g. women as providers of care, caring for people in the health system and caring at home, men as going out in seeking livelihoods for the family. These differentials will be taken up in discussion.

Second round interviews Procedures

These interviews were conducted between the 19-30 June 2017 towards the end of the field study. They could not be held earlier as all health practitioners were preoccupied until 10 June 2017 with the national bed nets distribution campaign which was ongoing at the same time. Further, I prioritised the remaining focus group discussion for health practitioners which was held on 17 June 2017. I was constrained in time and resources to undertake more second round visits in rural and Moyamba town communities within this period. Two of the second round Moyamba town interviews with the head of household and the community leader were held at my residence. The interview with the Moyamba male religious leader was held in the mission compound. The second round rural interviews with the health practitioners were conducted in the District Health Management Team offices when the health practitioners were in Moyamba for their monthly meeting. The second round interview with the rural religious leader was held in

Freetown as he had travelled there for meetings and I was scheduled to be there at the same time at the end of June for my return journey to the UK. These were shorter interviews lasting from 25 minutes –1 hour. The interview with the rural head teacher was conducted by telephone. The issues that were explored further in the second round rural interviews were*:*

Rural Participants

Male, head teacher, ’Taninihun Kapuima’:1) l**i**teracy of facility management committee members; 2) performance based financing related with the financial capital component of the study framework; 3) the role of women in health activities, related with human and social capital components of the study framework: 4) the natural leader, related with the natural and social capital components of the study framework.

Male, health practitioner, ‘Bagruwa’: 1) integrating with traditional healers, related with the natural capital component of the study framework; 2) mobilising community resources, related with the financial capital component of the study framework; 3) helping community health volunteers on their farms, related with the social and human capital components of the study framework.

Male, health practitioner, ‘Lower Banta’:1) low uptake of services, related with the social and natural capital components of the study framework; 2) traditional healers related with the natural capital component of the study framework; 3) helping community health volunteer on their farms, related with the social and human capital components of the study framework; 4) the role of youths, related with the human and social capital component of the study framework.

Female, health practitioner,’Fakunya’:1**)** home deliveries, related with the human and social capital components of the study framework; 2) access to care in hard-to-reach areas, related with the physical capital component of the study framework; 3) women support groups, related with the social capital component of the study framework; 4) trust, related with the social capital component of the study framework: 5) traditional leaders, related with the natural capital component of the study framework

Male, religious leader, ‘Lower Banta’: 1) **l**ack of trust in modern medicine in some communities, related with the social capital component of the study framework; 2) lack of knowledge, information or inability to assimilate and utilise the information on health care, related with the human capital component of the study framework; 3) access to care for hard-to-reach communities, related with the physical capital component of the study framework; 4) top-down approaches in health care organisations, related with the human and social capital component of the study framework.

Moyamba town Participants

Male, community leader:1**)** lack of sensitisation about malaria, related with the human capital component of the study framework; 2) sanitary inspection, related to the physical capital component of the study framework; 3) the challenges in the facility management committee, related to the human capital component of the study framework;

Male religious leader*;* 1) five minutes health talks to congregations, related to the human capital component of the study framework; 2) interreligious council, related with the social capital component of the study framework; 3) Joint visits to villages by Christian and Muslim congregations, related to the social capital component of the study framework:

Male, head of household: 1) community-based approaches, related with the social capital component of the study framework; 2) community led total sanitation, related to the physical capital component of the study framework); 3) partnerships with traditional healers and traditional birth attendants, related with the natural capital component of the study framework; 4) unimplemented policies, related with the social capital component of the study framework. In the next section, I present the focus groups interviews.

3.4.3 Focus group Interviews

The design utilised focus groups interviews with a wide range of people from rural and Moyamba town communities and with health practitioners from a variety of practice settings –the maternal and child health posts, the community health posts and the community health centres. Focus groups were organised to explore a specific set of issues through a group setting. Its purpose was to obtain information about how people in their social groups discussed their perceptions of the topic.

I adopted focus groups to explore peoples' knowledge and experiences and to examine not only what people think but how they think and why they think that way. The approach aimed to contribute to my investigation of discourses and was an ideal method for exploring peoples' own meanings and understandings of health and illness. The focus groups considered health interventions and explored service users' views, their current experiences and perceptions on malaria and strategies in families and communities in coping with the disease. This was useful for the discursive approach of the study (Bates et al 2019; Spencer et al 2003).

The focus groups further showed significant learning about meanings, preferences and knowledge can occur as a result of the interactions among group members and their evolving understanding of the consequences of proposed actions (Gregory et al 2012). Focus groups interviews were particularly useful where participants expressed multiple

perspectives on similar experiences such as the implementation of malaria control interventions, for example, experiences of the policy on bed net distribution. Focus groups interviews enabled a larger number of individuals to be interviewed in a shorter period of time than do individual interviews (Adato 2007). The focus groups did not only record the responses from the participants but also provided an opportunity to explore the social dynamism of the community. In the context of this study social dynamism was the existing networks that directed community members to interactions and group level behaviours that improved health outcomes. One may ask how such exploration was possible when participants were drawn from across the district and there was 'no one distinct community'. I provide in the study limitations (section 3.6) my arguments about the limitations of this exploration.

A possible disadvantage to focus groups was that some individuals for example the female 'community leader' from 'Bumpe' was less inclined to speak. Possible reasons were she had a minority opinion in an earlier discussion in the rural focus group on sanitary inspectors when she said they did not exist whilst all others reported differently. In another contribution on outreach to communities, she suggested only herself and her sister were doing outreach work in their communities when community health workers and nurses also went on outreach services.

Recruitment Strategy

The study conducted three focus groups, rural (n=9), Moyamba town (n=7) and health practitioners (n=10), with participants drawn from rural and Moyamba communities in Moyamba district to explore the knowledge, beliefs, attitudes and practices and the response of the community to health interventions. The participants were purposely selected to represent a cross-section of communities and included men and women in each group. Most participants had already taken part in the individual interviews. *Table 3.6* provides the distribution of the focus group by participant category and type of focus group

Table 3. 6: Summary of data gathering-Focus groups

Participants category	Rural	Moyamba town	Health Practitioner	Gender *f*	*m*
Health Practitioners			7	2	5
Community leaders	3	2		2	3
Teacher	1	1		0	2
Religious leader	1	1		0	2
International NGOs		2	1	0	3
Local NGOs			1	0	1
District Council			1	0	1
Pregnant woman		1		1	0
Community health volunteer	1			1	0
Pervious patient	1			1	0
Head of household	1			0	1
Drug Supplier	1			0	1
Total Participants	**9**	**7**	**10**	**7**	**19**

In total, 26 participants (f=7, m=19) accepted the invitation and were recruited to the study. The 7 female participants included 2 health practitioners, 2 community leaders and 3 pregnant women. As I mentioned in the section on sampling strategy, the study did not intend to comment on gender differences between participants. However, gender concerns were addressed and I drew for the focus groups a representative sample of men and women that related meaningfully and empirically to the gender relations that I was interested in (Mason 2002:123). For example as relations or interactions between men and women in use of household resources, in discourses on gender relations as structures of power within which women and men were differentially located, with men having more access to land and power in decision making. Thus I did not draw for the focus groups an equal number of men and women, but a proportion of people by gender in the context of the study.

The issue of power is discussed underscoring the ability of people and communities to respond to malaria. Power was manifested in the differential forms analysed in three dimensions, namely overt power, covert power and structural power (Peterson 2000). Overt power operates for brief periods in a specific location; covert power operates at larger institutional scales such as organisations in health programmes that control whether issues are discussed or addressed by institutions: and structural power operates

in cultural norms and values that influence community response and framing interventions by policy makers. The three dimensions of power can be thought of as operating at different scales in the current study, for example with overt power in punishing those who use bed nets for malaria prevention for other purposes, with covert power in facility management committees where health issues are addressed between communities and organisations in health programmes, and structural power in cultural adherence to local values and beliefs. I acknowledge dominant voices in the health practitioners focus group such as the district medical officer, however, other voices in the focus group were heard including: traditional birth attendants as the backbone of the health service (rural female health practitioner); health care seeking for children mediated by poverty; keeping sick children at home or going to an herbalist (rural female health practitioner); drama groups from school health clubs communicating health messages aimed at raising awareness of malaria and influencing uptake of care (international NGO participant); attaching traditional birth attendants to facilities due to limited staff in facilities (district medical officer).

Additionally the study benefited from policy perspectives, and the group discussions were interactive. Hornborg (2009) argues that policy makers fail to recognise power differentials between actors. Thus their policy prescriptions are not inclusive, will only support weak engagement in action, being aligned more to the status quo, rather than to communities seeking change. The relevance to my study is in exploring the power differentials in communities.

The rural focus group was held in ‘Taninihun Kapuima’, headquarter town of ‘Dasse Chiefdom’. The town was selected as it is more accessible by road to other participants and centrally located in the district and more easily accessible for most of the participants. The Moyamba town and health practitioner’s focus groups were held in Moyamba, the district capital. The Moyamba town focus group was held at the Moyamba District Awareness Radio (MODCAR), a public communal hall in the town were most meetings of organisations are held. The health practitioners focus group was held at the district health management team offices in Moyamba town.

Focus Group Procedures

Initially, I contacted the participants by phone. A formal letter of invitation to attend a focus group followed. A few days before the actual meeting, I made a second call to remind them. Participants for the rural focus group travelled from long distances from various chiefdoms on the day of the focus group. Most participants travelled by ‘Okada’ (commercial motorbike taxi). I refunded the travel costs of participants. As is customary,

permission was obtained from the town chief before the commencement of the rural focus group. Each focus group started with opening prayers followed by welcoming participants, and the icebreaker. Pre-prepared topic guides (rural/Moyamba town-Appendix 4.1*,* Health practitioners-Appendix 4.2*)* were used to facilitate the discussions. I used topic guides, which informed the questions in the rural and Moyamba town focus groups and the different questions in the health practitioners group. I assumed the role of the moderator and the facilitator for the group discussions which were conducted in a mixture of English and 'Creole'. No translations were required as participants spoke the creole language.

Participants were asked 6-7 questions (Glesne & Peskin 2006:103). The topics for the rural and Moyamba town focus groups were: 1) opening question; 2) experiences of malaria; 3) reasons for the spread of malaria; 4) seeking help for malaria; 5) information on malaria; 6) organisations involved with health programmes; 7) community action. I combined two topics that were in the individual interviews topic guides, namely 'dealing with malaria' and 'help for malaria' into one overarching topic for the focus group guide i.e. 'seeking help for malaria' as answers to these questions in the interviews were overlapping. The topics in the health practitioners focus group were: 1) opening question; 2) health care services: 3) dealing with malaria: 4) reasons for the spread of malaria: 5) malaria control interventions: 6) organisations involved with health programmes. The focus group guides were developed based on a critical review of the published literature relating to family and community management in relation to malaria. The guides were also informed by the study research question and conceptual framework. The topics were selected to explore in detail the respondents perceptions and accounts to gain an in-depth understanding of their beliefs, practices and experiences in order to establish forms of family and community management. Despite these guiding questions, the approach taken was more flexible allowing the participants to identify issues that were of importance to them in such a way that richer dialogue and deeper thinking was encouraged as participants reflected on their actions and experiences. This resulted in a set of transcripts which detailed the views, opinions and beliefs of these participants discussing their understanding of the disease, their responses and interventions in health programmes. Each focus group discussion lasted between 1-2 hours and was guided by a focus group discussion guide, a set of thematic and specific questions on issues under investigation. The focus group discussion guide is attached as Appendix 4 of this thesis. In the next section, I discuss the second round interviews.

3.4.4 Second round Interviews with health practitioners focus group participants

I conducted two second-round individual interviews with selected health practitioner's focus group participants to help the validity of interpretations of certain data. These were two additional follow up interviews undertaken at about the same time as the other follow up interviews towards the end of the fieldwork. The two interviews were conducted on 28 June 2017.

Recruitment strategy

Two participants namely the district medical officer and the Catholic Relief Services zonal coordinator were purposely selected. These participants were selected as they provided data in the health practitioner's focus group of relevance to the research question that needed further exploration. As they represented policy and management levels, the aim was to discern the 'higher level' discourses and broad overarching perspectives of policy makers and the relationships with 'lower level' discourses from interviews and focus groups, while recognising the reciprocal relationship between these two levels (Greenhalgh et al 2012:3). The two interviews were held at the district health management team offices in Moyamba. The interviews lasted for 45 minutes to one hour. Audio-recordings of the interviews were made and subsequently transcribed verbatim for analysis. The issues that were explored further in these second round rural interviews were:

Moyamba town male, district medical officer: 1) the 'triangle'-the host, the agent and environment in malaria control, related to the natural capital component of the study framework; 2) multisectoral approach, related to the social capital component (linking capital) of the study framework; 3) ownership of bed nets in households, related to the financial capital component of the study framework.

Moyamba town male, international NGO: 1) community health clubs, related to the social capital component of the study framework; 2) school health clubs, related to the social capital component of the study framework; 3) NGO coverage of communities related to the physical capital component of the study framework. In the next section, I present the policy documents review.

3.4.5 Policy documents review

This study opted for a qualitative document analysis method (Bowen 2009), which is a systematic procedure for reviewing and evaluating written texts to elicit meaning, gain understanding, and develop knowledge. Document analysis requires data to be explored and interpreted by researchers for identifying meanings relevant for the study aims and through systematic coding, developing understanding about the phenomena under interest (ibid.). A deductive content analysis was applied in the data analysis (Bowen 2009; Hsieh & Salman 2005).The documents review entailed policy documents from the Sierra Leone Ministry of Health and Sanitation. The study used documents alongside other methods for data generation. The purpose of the review was to establish a clear political backdrop to the study. The documents provided a context in terms of health policy and practice. Governments are often identified as the key agents for policy documents (Brown 2016:45). The review mapped the policies to what participants said in the interviews and focus groups to find out whether and how far the policies were away from them.

The rationale for document analysis lay in its role in providing an understanding of whether and how the promises and commitments made in the documents influenced the response of communities to the threats and actual incidents of malaria. Moreover, documents may be the most effective means of gathering data when events can no longer be observed or when participants have forgotten the details (Bowen 2009). Bowen (2009) observed that as a research method, document analysis is particularly applicable to qualitative case studies which are intensive studies producing rich descriptions of a single phenomenon. The relevance to the current study was in the review of the relevant texts in the documents pertaining to the phenomenon of family and community management in relation to malaria. Bates et al (2019:3) observed that policy discourses shaped communicative interactions among political actors as social problems were translated into policies. Next, I discuss the search strategy detailing the documentary review in terms of sampling.

Search strategy and documents retrieved

The review focused mainly on government documentation, the majority obtained through internet searches. Some hard copies were delivered by hand from officials but were also available electronically. The search focused on documents in English which is the official language of Sierra Leone**.** From approximately 15 candidate documents (all of which were published since 2009, but mostly since 2015), I considered a final sample of 6

relevant for inclusion in the review using the following inclusion criteria:1) a policy document relevant to the study in Sierra Leone and makes reference to family and community management in relation to malaria; 2) it discusses family and community management outlining contextual issues; 3) keyword searches that includes the following terms-policy, plan, strategy, agenda, service, frameworks, organisations, programme, management, enabling environment, capacity, development, accountability and implementation in the front cover of the title of the document or title of a subsection**;** 4) it is from home country Sierra Leone, whether in hard or soft copy; 5) it should be the most recent policy document focusing on Sierra Leone. I was interested mainly in the prevailing policy environment and to that end, prioritised material produced in the last 5 years prior to the study that is 2011–2016. But in order to couch current discourses appropriately in historical context, policy documents published before that date and still being used as 'current' were included, for example, the MoHS (2009)-National Health Sector Strategic Plan 2010-2015.

Six policy documents that met the inclusion criteria were reviewed including:1) MoHS (2015)-Sierra Leone National Malaria Strategic Plan 2016-2020; 2) MoHS (2015)- Sierra Leone Basic Package of Essential services 2015- 2020; 3) MoHS (2016)-National Community Health Worker Policy 2016-2020; 4) MoHS (2015)- Health Sector Recovery Plan 2015-2020; 5) MoHS (2009)-National Health Sector Strategic Plan 2010-2015; 6) MoHS (2012)-Integrated Vector Management Strategic Plan. I excluded 9 documents using the following criteria:

a) limited in discussions of family and community management
b) Focused on discussions of specialised areas that merit separate investigation.

Table 3.7 as described by (Bowen 2009:36) provides the type and characteristics of the documents included in the sample, giving the data analysed and targeted audience.

Table 3. 7: Summarising Policy discourses in relation to malaria

Document selected	Prescription/ Focus	Target audience
1. MoHS (2015)- Sierra Leone Basic Package of Essential services 2015- 2020	Aim to make services and inputs that can withstand future epidemics and provide quality health care services to all communities that they can access and afford (pg6). Emphasises community ownership, encouraging communities and individuals to take ownership of their own health and of their responsibilities in supporting a functioning health system. Recognising community leadership, sensitising community leaders on their roles and responsibilities, and strengthening community groups such as community health clubs, mother support groups, and engagement of youth and men in women's and children's health issues (pg20). Communities can be involved in the health system through management structures such as facility management committee, agree on the use of performance based funds, and may contribute community materials and labor to infrastructure improvements at facilities such as construction of wells and latrines (pg27). Community health volunteers provide a direct link between the health system and communities, and can play a significant role in ensuring community ownership and accountability of the health system to the communities it serves (pg28).	Health practitioners, community leaders, facility management committee, mother groups, men and women youth groups, community health volunteers
2. MoHS (2016)-National Community Health Worker Policy 2016-2020	Makes the case for community health volunteers bridging the gap between the health facilities by bringing the clinic to communities and communities to the clinic (pg7)	Traditional leaders ,community health workers

	Chiefs and other traditional leaders help community health workers to promote healthy and health-seeking behaviours in their communities (pg15)	
3. MoHS (2015)-Health Sector Recovery Plan 2015-2020	Focuses on building trust, community engagement and ownership. Supports local partner organisations to strengthen community abilities to take ownership of programmes. Envisages working through community networks such as religious groups, women's groups and youth groups and enhanced effective messaging and mobilisation (pgs.28, 48).	Community leaders, community groups local and international NGOs
4. MoHS (2009)-National Health Sector Strategic Plan (NHSSP) 2010-2015	Emphasises decentralisation and active participation of key stakeholders. Scaling up priority interventions in an integrated manner to produce targeted outputs and outcomes. Supports strengthened multistakeholder responses and better-targeted, low-cost prevention strategies. Recognised the need for an Intersectoral approach. Promises to develop a communication strategy for the health sector. Includes a traditional medicine policy. Promises to have a focus on disadvantaged groups. Aims to build a resilient health system (pgs. 8, 26, 27, 50).	Policy makers, donors, technical and specialised agencies, local and international NGOs
5. MoHS (2012)-Integrated Vector Management Strategic Plan	Importance of equitable community participation in health programmes. Aims to ensure full involvement of communities in decision-making processes and planning and implementation of Integrated vector management activities within the context of malaria control. Aims to improve the health quality of rural poor people, eliminate the risk of vector and nuisance insect biting (pgs15,34)	Practitioners, community leaders
6. MoHS 2015-Sierra Leone Malaria Control Strategic Plan 2016-2020	Several community perspectives are documented in the Plan which focus on the demand-side: behaviour change communication; equity in care by reaching the hard-to-reach; community empowerment; bottom-up approaches; enhancing the role of existing community structures such as community health workers and the facility management committee. The linkages between poverty and malaria (pgs.21,58-59,60)	Policy makers, community leaders, community health workers, NGOs in health programmes

All of these documents provided background information on the health system in the study setting and on policy-making processes.

In addition to the documents review, semi-structured interviews, focus groups and second-round interviews were the main methods used. *Table 3.8* summarises these methods, the issues explored, timings and quantitative density.

Table 3. 8: Synthesis of methods and quantitative density

Method	Topics covered	Data acquisition time	Quantitative density
First round interviews	Experiences of malaria; help with malaria; Information on malaria; relations with health organisation; community action	January 2017- May 2017	44 interviews with rural and Moyamba town participants
Focus groups	Rural/Moyamba town: seeking help for malaria; experiences of malaria; information on malaria; health organisations; community action: Health Practitioners; health care service; reasons for the spread of malaria; dealing with malaria	Rural-May 2017 Moyamba-June 2017 Health practitioners-June 2017	3 focus groups conducted- 1 rural, 1 Moyamba and 1 health practitioners
Second round interviews	'Natural leader'; facility management committee; mistrust in modern medicine	June 2017	10 second round interviews- (8 first round individual participants), (2 with focus group participants

In the next section, I discuss field notes taken during interviews and focus groups.

3.4.6 Field Notes

Field notes were taken by the research assistant in addition to audio recordings of interview and focus groups. The notes were recorded in a book and included descriptions of all that happened in the interviews and focus groups. I trained the research assistant to prepare a report each day on the outcomes from interviews and focus groups, focusing on the experiences with participants. The field notes recorded observations and interpretations in a more relaxed manner and enabled reflexive (Mason 2002:97). They evoked memories of things that were not in the audio recordings. I incorporated perceptions and everyday interpretations into my field notes and a discussion of my feelings and impressions, and analytical ideas.

In conclusion, the reason for using different methods was to corroborate each other for some form of methodological triangulation. By comparing data from these multiple sources, verification of responses was possible, and further probing questions were identified. Mason (2002:59) observed that multiple methods enable the research question to be approached from a variety of angles or conceptualised in a variety of ways. Additionally, they enable methodological triangulation where different methods or sources corroborate each other. The next section provides an analysis of the data from the multiple sources.

3.4.7 Data Analysis

I made audio-recordings of data using a Sony ICD- PX 240 digital recorder. All interviews were recorded and fully transcribed for analysis. After each conducted interview and focus group, I transcribed the recorded material verbatim. Spencer et al (2003) observed that quality requires detailed verbatim transcription. No translations were required as I am fluent in both creole and mende and provided simultaneous translation. The main benefit of using digital as opposed to analogue recordings of interviews is that audio was of a much higher quality than that from say an ordinary analogue cassette tape. Good sound quality was important for the present research as the interest was not only with what the participants said but also with how they said it. The process of transcription was speeded up using the digitally recorder because of the instant and reliable access which digital recording equipment affords. Textual transcripts could be produced relatively quickly compared to transcribing from a cassette tape with moving parts. I prepared reports of both interviews and focus groups which were discussed during supervision sessions.

To make sure that the transcription was correct, I listened to the recording again and again in multiple readings of the data without fear of wear and tear of the disc itself. I imported the transcribed data into NVivo 11, a computerised system for organising data for qualitative research. I then defined the first generation of nodes. I remembered that for coding I needed the sources as well as the nodes and created nodes to hold that coding. I coded at nodes at the top level i.e. directly into nodes and in folders or tree nodes.

Qualitative document analysis as described by Bowen (2009), was used to study the inclusion of family and community management in the six Sierra Leone health policy documents that were analysed. Each of the documents were investigated for whether the policy specifically mentions the term family and community management and, whether the policy proposes the approaches to family and community management in

relation to malaria. I highlighted lines in the documents as I went through each document in detail. I imported the documents into NVivo 11 and created categories which reflected the issues in the documents that were of relevance in the study and coded the slices of data to the study nodes and child nodes. A content analysis of the Sierra Leone Ministry of Health and Sanitation policy documents was undertaken. I used a selective coding system. The reason for the selective coding was to analyse the contents of the policy documents narratively synthesising data contained in the included documents and integrate what seemed to be relevant for understanding and explaining study themes. During the coding process, the texts were first read several times before words or sentences were identified and highlighted to be included in the predetermined codes. The aim was to create concepts which give meaning to data and categories which brought together different concepts at a higher level of abstraction.

For all data sources, I developed a coding framework, guided by the conceptual framework described previously in Chapter 2 as well as collected data. All data were organised into themes and sub-themes. I illustrate below in *Table 3.9* the coding framework and general description of the coding process that was used to develop the themes during the analysis.

Table 3. 9: Coding framework

Method/Data source	Sample guiding question	Codes from responses to questions	Sub-theme	Main theme
Rural focus group	What kinds of actions are taken in communities to control malaria?	Youths in environmental cleaning of 'dirty' and bushy environments; formal women groups involved in child nutrition and disseminating health information; Informal women groups involved in constructing toilet facilities and fences for facility, community health volunteers involved in linking communities with facilities, early referrals and increasing uptake of care, youths taking the ill in hammocks to the health facility. Negative instances include; Distance from facilities Mistrust in modern medicine	Environmental sanitation, Health information; community social capital.	Social capital, Volunteering
Moyamba town focus group	What kinds of actions are taken in communities to control malaria?	Youths in environmental cleaning of 'dirty' and bushy environments. Negative instances include: 'Salina' community not cooperating to repair broken hand-washing machine	Cultural beliefs Religion, Inadequacy of the health system	Coping strategies
Health Practitioners focus group	What are reasons for the spread of malaria in communities?	Poor environmental habits Communities do not take malaria seriously weak leadership knowledge, attitudes and practices, lack of multisectoral collaboration-beyond the scope of the MoHS alone to overcome the threats of malaria	Environmental sanitation Cultural beliefs .	Volunteering, Leadership
Individual interviews	What kind of help do you get for malaria?	Traditional medicine. Awareness raising Community health volunteers. Religious faith. Negative instances include: lack of support from men to women in farm	Cultural beliefs Health information	Coping strategies, Volunteering, Low social capital

		work, men control over household resources and decision making, by-laws	Power differentials	
Second round interviews	What women activities were undertaken in your community?	Mother groups selected by community, involved in child nutrition, sensitising of other women, early referrals to clinics, income generation activities, informal women groups	Ownership, children's health, health information, complementing health service, self-help,	Community social capital, volunteering

The initial coding scheme was based on a literature review (Lough 2017), and the theory and conceptual framework established a basic hierarchy in the standardised codes. Each statement was coded to facilitate easier data interpretation and disaggregation. When a statement warranted more than one code, I copied that statement into a separate row on the recording file and assigned it an additional code. Initial coding involved extracting all data relevant to understanding family and community management discourses and analysed for common themes. To support the developing themes, quotes were extracted from the data throughout the review process. Analysing the data was an iterative process of identifying themes and rereading transcripts to ensure clarity and consistency of themes or quotes identified. Discrepant findings or disconfirming evidence were discussed with supervisors to avoid confirmatory bias and simplistic interpretations. Contact was maintained with supervisors throughout the research to discuss themes.

Data analysis was undertaken using discourse analysis. Discourse analysis is a well-established technique in qualitative research (Greenhalgh et al 2012; Shaw & Bailey 2009: Hodges et al 2008). Discourse refers to both spoken such as interviews and focus groups and written forms of communication such as policy documents. Discourse was revealed by studying both policy documents and transcribed interviews and focus group data (Greenhalgh et al 2012:3). Discourse analysis attempts to deconstruct text and talk to tease out of the subtle and various meanings of particular words that are otherwise fragmented. The study considered such communications to be broadly equivalent to one definition of discourses: 'ensemble[s] of ideas, concepts and categories through which meaning is given to social and physical phenomena, and produced and reproduced through an identifiable set of practices' (Hajer 2006:67). In the interpretation and synthesis phase, I drew together findings from this analysis and themes generated from the combination of different sources informed data interpretation.

One main criticism of discourse analysis is it does not have human agency and there is rarely a sense of human actor or agent. It does not reflect the social reality. Mason (2002:57) pointed out that it stands in marked contrast to humanist approaches. Human action does not figure in this approach but rather discursive practices and analysis of the ways in which discourses, read as texts or talk, constitute the social world. The approach therefore uses interviews and focus group transcripts for data analysis, and documentary sources such an s policy documents (ibid.). In the current study, I explore what social discourses to gain understanding about the empirical reality of what different groups talk about and how. In this sense knowledge claims are not based on events or activities but on findings that relate to discourses about events or activities. The thinking is that it is possible to undertake a critical analysis of family and community

management by paying attention to the detailed specific of discursive interaction. In the next section, I outline integrating the different data methods and sources.

3.4.8 Integrating different methods and sources

In order to integrate methods and sources, I considered how whether the effective generation of data using for example interviews was contingent upon prior analysis of data from policy documents that relate with the narratives have been analysed together with the narratives. The key to integrating methods was to establish what will be achieved in so doing and to understand the implications of combining approaches which may have different underpinning logics, and which may suggest different forms of analysis and different ways of constructing social explanations and arguments.

The different types of data were integrated to provide coherence in answering the research question at three levels: 1) Technical integration; 2) Integration at the level of knowledge and evidence; 3) Triangulation of methods. Technical integration was possible by organising findings in NVivo using NVivo11 to build hyperlinks between different forms and types of data, including forms of textual data. By examining information collected through different methods, I corroborated findings across data sets including policy documents and thus reduce the impact of potential biases that can exist in a single study. Integration at the second level of knowledge and evidence asked whether the different sources emanate from the same epistemology, whether for example documentary and textual data from policy documents compared with empirical data from the interviews and focus groups. The study compared empirical data from interviews with the scrutiny of documentary data as partial forms of evidence. At the third level of triangulation of methods, triangulation moved me beyond a position of receiving the deceptive assurance that can result from obtaining data using one method only. It was based on the idea of taking a number of different 'readings' of data through different methods and data sources (Spencer et al 2003). However there is much debate in the literature about the value of triangulation and the extent to which it is possible to arrive at a single definitive account (Mason 2002; Silverman 2000). These authors argue that its use lies more in providing a broader, richer account, or even in generating alternative accounts (ibid.). This research conducted primarily through narratives was not looking for simple, coherent synthesis of data or methods. Once the interviews were completed, triangulation surfaced as a critical element that added one layer of data to another to build a confirmatory edifice. With a firm reliance on multiple methods, I sought to cross over, converse with, and tap into the different kinds of data. I searched for contradictions between methods that would most powerfully inform policy (Fine et al 2003).

Mason (2002:190) pointed out that one method of data collection will not straightforwardly corroborate with the other and careful thought will be given about how the sets of data from documents, interviews and focus groups corroborate each other. I gave careful thought about corroboration by comparing, for example, the experiences and accounts from actors in interviews with discussions of similar events in the focus groups. Triangulation should therefore not be expected to be a way of increasing the validity of my findings as people talk about things very differently in different contexts (ibid.). In this research, there were several instances where interviews data did not straightforwardly corroborate focus groups data e.g.: on sanitary inspectors where the Moyamba town youth leader said they did inspections, though infrequently, whilst the rural female community leader in' Bumpe' said they did not visit her community; on community health volunteers work where the previous female patient in 'Gbangbatoke' said they were not working well in her community whilst the female community health volunteer said she was working hard in her community; in cultural adherence where the female community leader in 'Timdale said she was using traditional and modern medicines whilst one Moyamba town focus group participant said rural communities adhered to their cultural practices, values and beliefs in seeking care. In the next section, I discuss the ethical considerations.

3.4.9 Ethical Considerations

Ethical issues are important to consider in any empirical social study which involves human or animal participants (BPS 2000:10). Ethical guidelines provide codes of conduct with regards to how researchers should relate with their participants. Although ethical guidelines are often written with the protection of participants in mind, ethical codes also work to protect researchers. Briefly, in this section, I will consider attempts to protect the participants in the present study.

The main ethical consideration of relevance to the present study was confidentiality. ' In research reports, it is customary to anonymise one's participants by giving them pseudonyms and disguising their personal details so that they cannot be identified by readers or reviewers' (BPS 2000:10). Confidentiality was important in the present study as participants voluntarily offered to participate and did not of necessity want to be identified. In the present study, efforts were made to ensure the anonymity of all study participants. The next ethical issue was the protection of the participants. `Investigators have a primary responsibility to protect participants from harm during the investigation' (BPS 2000:10). In the present study, attempts were made to ensure no harm to participants. For example, interviewees were never asked to directly to talk about the loss of their loved ones to malaria, which might have caused some discomfort to speak

about. However, some participants spoke about it. All of the participants were informed that they could withdraw from the study at any time. If, as the interview progressed, the participant was uncomfortable with what had been asked or the direction in which the interview was going, then they could just say so and withdraw. 'At the onset of the investigation, investigators should make plain to participants their right to withdraw from the research at any time, irrespective of whether or not a payment or other inducement has been offered' (BPS 2000:10). Other ethical issues in the interviews were:

Low literacy

The pregnant woman in the rural interview was non-literate**.** This risk was addressed by interpreting both the information sheet and the informed consent form to the participant in her local language. No translator was required as I and the female research assistant speak the same language of the participant.

Venue

Individual interviews were conducted in peripheral health units, community office space, and occasionally in residences (e.g. outdoors in my residence and head of household's residence in the Moyamba town interviews). The drug suppliers could not leave their stores on busy business days. This was addressed by closing the stores for business for the period of the interviews to minimise disruptions.

Time in Interviews

The rural head of household in 'Timdale' chiefdom arrived ahead of me for the interview as I was travelling from Moyamba and had delays in travel arrangements by 'Okada'. This was addressed by calling the facility to inform the participant of the delayed arrival.

Data access

I securely stored data from the field research (digital recordings of interviews and records of participant demographic data) in the field and subsequently in UEA. A copy of the thesis will be held at the University of East Anglia library.

Payment for participation

I made clear that there were no direct benefits for participating in the study and as such no promises of 'benefit' were made. I refunded the transport costs that were incurred.

Ethical issues in focus group discussions

Participants were asked to say what rules they would like to observe. They mentioned timekeeping, respect for each other views, one person speaks at a time. These were written on a flip chart by the research assistant and combined with the study ground

rules. Appendix 4 provides the ground rules. All participants indicated their agreement to the rules. The ethical issues raised in the focus group discussion were:

Tensions and disagreements in focus groups

The female community leader in the rural focus group said that there was no sanitary officer in her chiefdom which was challenged by other participants, mostly male. One may argue that these were examples of voices of women often left unheard, highlighting gender inequality, men dominance and voicelessness of women. I worked to reduce the power differentials and to give all voices equal weight within my research process. In another example, the previous female patient said that community health workers were not effective in her chiefdom which was challenged by the female community health worker participant in the rural focus group. I resolved these tensions by reminding participants of the ground rule to respect each other's views.

Confidentiality

As part of the ground rules, members of the focus group may not speak openly unless they are comfortable that others present will treat their contributions as confidential. It was expected that the content of the discussion which is about to take place will only be known by those present.

Recording the focus group

Verbal permission was obtained from participants at the commencement of each focus group for audio- recordings.

Payment for participation

I made clear that there were no direct benefits for participating in the study and as such no promises of 'benefit' were made. I refunded the transport costs were incurred. In the next section, I discuss reflexivity in the study.

3. 5 Reflexivity

An important aspect of the current study is the incorporation of reflexivity about my role researcher in the research process. The aim was to reflect critically on my role in the research, which entailed self-awareness (Lambert et al 2010) of my active involvement in the research process and self-inquiry and awareness. It was also a recognition of how values and assumptions impacted on the data (Spencer et al 2003:71).

I raise reflectivity at this point to enable the reader to have an understanding of my personal and professional experiences and to acknowledge my interests in the research. I share various reflexivities to ensure the trustworthiness of the research. Palaganas et al (2017) observed that reflexivity in research constitutes part of the research findings. Reflexivity located me in the data generated and my role in the process of generating and interpreting of the data, and my reading which captured my relationships with the data (Mason 2002). In this research, I developed several types of reflexivity: personal including personal connections to sites and people, professional, gender', epistemological, and a focus on participant's meanings of discourses.

Personal reflexivity reflects how my values, beliefs and personal positionality shaped the research. In this research, there was relatively limited personal reflexivity. Hardly any discourses related to my interpretations of what was going on in interviews or focus groups. However, there may have been instances of my empathy or agreement with what was said e.g. in narratives of experiences of participants of malaria and the consequences on their families. Many times during the data collection I felt I could do nothing except to empathise with the plight of the participant's discourses for example about poverty or bereavement. Some participants spoke of a vaccine for malaria, that the researcher should communicate this to policy makers. Others suggested I should get the authorities to come and talk to the community, about, for example, the allocation of bed nets where nurses prioritise pregnant women when they made antenatal visits to the clinic and children and make no provision for husbands. My thoughts are as many homes were overcrowded more bed nets should be made available. Giving a few bed nets leaves many others in the home exposed to mosquito bites. Husbands for example as the 'breadwinner 'go out of the home seeking livelihoods for the family in the farms where they are exposed to mosquito bites. I listened to the participants' stories and views and made them aware that the research aimed to inform policy makers on alternative approaches to interventions in their communities and will not result in a 'vaccine'.

Personal reflexivity made my relationship and influence and the participants explicit (Jootun et al 2009). At the initial phase of deciding to undertake this thesis, I pondered over the challenges and complexity of undertaking a qualitative research study with participants from my district most of whom share the same culture and language with me (mende*)*. I was also familiar with a few of the communities where I conducted the research such as Moyamba township. It was evident that my previous acquaintance affected the research process, although not in a straightforward way. Like them, I have lost relatives to malaria including my two years old son who passed in 1994. These lived experiences meant I had some closeness with the research participants and the

closeness had implications for the worth of assumptions made. A few questions therefore arose. Would I be seen by participants as an insider who would be expected to have an insight into issues that affect them as Moyamba community and to take on responsibilities to promote their cause? Or would I be considered as an outsider who is primarily interested in their stories in order to acquire a PhD in England?

My personal reflections also helped me to consider whether research participants could potentially identify me as either an insider or an outsider. As a potential insider, I was privileged in conducting interviews in shared language '*mende'*. However, my access to participants' narratives or my interpretation of them might not be any different from those an 'outsider'. Furthermore, I also encouraged participants to express their views freely in interviews and were promised anonymity. I also determined the approximate length of the interviews. Pursuing reflexivity might not guarantee that these issues and the research process are no longer problematic. However, the process of reflexivity provided relational avenues to understand the implications of these issues for the interpretations and understanding of the data.

Professionally I have an interest in approaches to community development and my perspective on family and community management were informed through work in development programmes and projects in Sierra Leone and internationally. I worked in Sierra Leone as a young project accountant in the 'Seed Multiplication Project', an agriculture project with operations in rural communities in several districts. I also have several years of international work experience in the United Nations Development Programme as a UN Volunteer (South Africa, Nigeria and Albania) as UNDP head of operations (Albania, Romania. North Korea and South Africa) where UNDP is implementing several programmes in health and development, sustainable development, poverty reduction and governance. Thus my perspective of rural communities was informed by various social phenomena and issues such as poverty and ill-health through familiarity. I hold two masters degrees, one from the Institute of Development Policy and Management in The University of Manchester in Management and Implementation of Development Projects, and the other from the School of International Development, UEA in Impact Evaluation for International Development. One of my key modules in the UEA masters was the 'health in development' module. My UEA master's thesis assessed the impact of the Oxfam-funded 'Health for All Ghana' (Stedman-Bryce 2013) intervention, using an alternative to the process tracing approach applied of a combined contribution analysis and realist evaluation approach. These experiences undoubtedly contributed to the data quality and the interpretation process.

Reflecting on the gendered nature of my research ensured I looked at more specific household processes and relations. Being involved in the process of gathering the data, I saw the complexity of household relations, embedded in the culture of the people where men had dominance over household resources and decision making at the household level. The implications of this were there were socially differentiated impacts where unequal access to resources and decision making and greater burdens of labour and caring meant women were less able to cope with malaria. There was also the consideration of myself as a male needing to interview females about their experiences with malaria which had implications of sensitivity and facilitating interviews as sensitively as possible.

My epistemological reflections on the data included undertaking semi -structured interviews and focus groups that allowed themes to emerge from the data collected in an inductive way with the reflexivity that a structured approach could not support (Parahoo 1997). Reflexive activity with the data also informed my undertaking second round interviews of some participants to probe further into relevant issues to ensure the accuracy of transcriptions, and to give participants an opportunity to clarify or add to any of their responses. I also tasked my research assistant to keep notes during all interviews and focus groups to aid my self-reflection of the transcripts during analysis (Rubin & Rubin 2011). Further, I discussed developing themes throughout the analytic process with the research assistant and used self-reflection to challenge initial analytic assumptions (Hollway & Jefferson 2013).

Another epistemological reflection was in coding. The process of coding demanded tedious work which involved undertaking multiple readings of transcripts and coded some narratives to several nodes when a narrative warranted more than one code. I nonetheless needed to remain concise and accurate in identifying categories and data by doing selective coding. I selected data that was more core and fundamental rather than non-essential to give due importance to the information provided by the participants (Palaganas et al 2017). I did this by slicing data sets (Mason 2002:151) and using only relevant data. I ensured reflection of codes and themes were used to challenge analytic assumptions and ensure consistency. An example of interview discourses with the female community leader in ‘Timdale’ and ‘Bumpe’ which involved discourses that included bushy environments, lack of support from men to women in farm work only utilised data on the differential in men being more capable to have access to natural resources such as lands.

I employed reflexivity to establish the trustworthiness of my collected data and data analysis. I was aware that my interpretation of the collected data was influenced by my values, beliefs and experiences. As I was working with the discursive type of data about family and community management in relation to malaria, this meant I needed to undertake qualitative data collection. This would require multiple methods of data collection and discourse methods of data analysis. To collect trustworthy data through multiple methods I needed to attend particularly to; describe how individual interview and focus group questions were derived; include the actual interview and focus group protocol in my research; explain in detail how each type of data was collected, using subheadings. To ensure my data analysis would be trustworthy I needed to attend particularly to analytical processes through which my discursive data might be turned into evidence and used to assemble arguments and explanations of participants and used my multi-methods approach to integrate data analytically. I made no claims to social reality but of what participants said about social reality. I also needed to attend to describe data management procedures, how data sources were integrated. Furthermore, I described my immersion in the data and involved with multiple readings of the data to the point that I can move immediately to various locations in the data to compare and contrast one part of the data with others. The analysis included immersion of the data by transcribing, proof-reading and rereading the transcripts. I also needed to always remain mindful of detaching my interpretation at this stage of data processing. This involved me constructing a version of what I thought the data meant or represented or what I thought I can infer from them. For example, if I read a section of interview transcript on discourses of by-laws and how they were influenced, I may place more emphasis on my interpretations and in this way, I was involved in reading beyond the data (Mason 2002: 149).

However, reflexivity must be demonstrated not claimed (Camfield et al 2014). It ensured quality in research (Spencer et al 2003). Throughout the research a reflexive approach ensured I focused on learning the meanings that participants held about the problem from discourses and not my meanings or what others have said in the literature (Creswell 2009). Next, I turn to the study limitations.

3. 6 Study limitations

The main limitation was perhaps, that the discourse analysis approach (Greenhalgh et al 2012; Shaw & Bailey 2009; Hodges 2008) applied by the design is necessarily subjective and hence is likely to have limited credibility. It was based on what people said, which may not be objectively verified in reality outside of the

interview and focus group interactions. But the approach challenges the traditional, rationalist view of an objectively discoverable social world, instead acknowledging that social worlds are subjectively understood and experienced. The study's interpretive inductive methodology, where the claim to rigour lies in narratives of people in rural communities and close reading of texts, and reflexivity is likely to be questioned by those who value experimental study designs and 'objective' tools and techniques (Greenhalgh et al 2012:13). Given the exploratory and largely qualitative nature of the research, discourse analysis was thought to be an appropriate strategy for analysis that would lend rigor while respecting the exploratory nature of the research.

One limitation was that participants in the rural focus group were quite heterogeneous, belonging to different tribes, cultures and different geographic and ecological locations such as coastal and landlocked communities. Thus the rural focus group of nine participants did not represent 'one distinct community. 'In exploring the social dynamism in such communities, I recognised that the dynamics within and between such communities was situated within local contexts that affected health-related behaviours. I reflected on the different voices from rural communities. In contrast participants in the Moyamba focus group were drawn from the one community, namely the Moyamba township. They were from relatively homogenous populations and belonging to the same tribe, cultural group and geographic location, having similar practices and health seeking behaviours. Thus it was possible to explore social dynamism as they were seen as 'one community'. 'However as in the rural focus group the dynamics and relationships in the Moyamba community was situated within local contexts that affected health-related behaviours. The Moyamba focus group reported similar and sometimes contrasting views from rural focus group participants which I reflected.

A specific limitation to the study was in the health practitioner focus group and the rural focus group where dominant voices were more likely to be heard. Despite the group dynamics being amiable and lively, I felt some questions brought up strong opinions from certain members and others faced a kind of peer pressure as the rural female community leader on the question of sanitation to agree with the dominant voices. Hence, the data gathered is understood to be with some 'bias' of the participants.

A possible limitation was the constitution of focus groups in which fewer women were in attendance. This may have limited understanding of for example women's health seeking behaviours and factors that influenced their response to malaria. I was therefore alert to the effect of gender and ensured that women's voices were heard in all the group discussions.

A potential flaw in the study was in the documents analysis. It seems the included documents were produced for some purpose other than research (Kaarlson et al 2020); consequently, they did not provide sufficient detail to answer the research question as sometimes, the information was lacking from the documents. Further the term family and community management was not explicitly defined in any of the policy documents (ibid.).

Another limitation in the study is that participants for interviews were selected using the snowballing approach, on the basis of referrals from the malaria control programme focal point. The approach meant that the research missed out on other potentially relevant players: e.g. policy makers, paramount chiefs, medical supply companies and media (Waweru et al 2019).

A final limitation was the single case study (Makinen et al 2000), thus not generalisable. Generalisability was a particular problem in this qualitative work. The research cannot apply the findings to other settings and it could be argued that this could affect the generalisability of the results both nationally and regionally. However the single case study allowed for in-depth examination of community discourses at the levels of family and formal and informal groups of men and women at community level. Story (2013:8) noted that qualitative methods provide in-depth insights into potential mechanisms of action and improve internal validity for a particular context, at the expense of limited external validity to other contexts. Whilst the results cannot be said to be representative of other malarial regions in low-income settings in sub-Saharan Africa, they provide useful insights into the family and community processes. Thus they provide detailed illustrations of community members and actors seen as having the ability to identify and access local resources and to possess unique knowledge in understanding local perspectives in withstanding the threats of malaria, which may resonate in other similar settings. These results may not necessarily be transferable across communities in Sierra Leone or other endemic settings, however the exercise of comparing experiences and insights across men and women is generalisable, and this study suggests that it is a valuable activity that can yield useful information for policy makers (Geyer et al 2000).

3. 7 Summary

Since the methodological framework is largely qualitative, the design used a case study as the most effective way of empirically analysing the detail of discourses related to contexts at the family and community levels in relation to malaria. The focus in this design was on theory building through understanding the discourses.

In this chapter, I have described and justified the range of data collections methods spanning interviews, focus groups, field notes and policy documents. I used purposing sampling in selecting sites in the setting and snowball sampling in selecting participants. To maximise variation, I made an effort to interview not only participants according to categories listed in the sampling grid but also actors from government and NGOs. For example, as initial interviews were analysed, it became necessary to collect other types of data from actors I had not anticipated as it became apparent that they had relevant roles and information and knowledge they could contribute on family and community management of malaria. These included a community health worker, the district medical officer and key international NGOs in health programmes partnering with the malaria control programme such as Catholic Relief Services and Cause Canada.

The Sustainable livelihoods approach (DFID 1999) with a particular focus on the five capitals was used as a framework for data collection and analysis. The components of the framework were for example reflected in the topics in interviews and focus groups, such as 'help for malaria'- social capital, natural capital and financial capital, and 'community action'-human capital.

Using discourses to study peoples' accounts and experiences may provide understanding how family and community management may influence health outcomes in relation to malaria. The discourses bring the concept to people who are poorer and who are living in marginalised groups and circumstances to ask how family and community management perspectives are reflected in their lives and experiences with malaria. I describe these contrasting discourses *(Figure 3.2)* in more detail in the next four chapters starting with chapter 4 which focuses on discourses associated with social capital. Chapter 5 then describes the discourses of volunteering. Chapter 6 focuses on coping strategies whilst the final results Chapter 7 presents the discourses on leadership. Each theme incorporated several sub-themes that are explored in depth. Findings from policy documents are also presented. These results chapters examine some of the key issues people highlight when explaining their vulnerability and the capabilities and strategies they employed using local resources in response to their adversity. The chapters are structured much like academic papers in that they combine some of the academic literature, a presentation of research findings including the findings from the documents review, with accompanying discussion of each point as presented. The central research question was: *'How are family and community management perspectives reflected in discourses concerning the malaria incidence in Sierra Leone?'*

Figure 3. 2: Family and Community Management in relation to Malaria

Results Chapter 4: Social Capital

4.1 Introduction

So far in this thesis, I have looked at different scientific perspectives of family and community management and highlighted how the concept is undertheorized in communities facing disease epidemics. The Social Capital discourse depicted social support in the form of tangible and emotional support from relatives, friends and neighbours to individuals in illness. It recognised social cohesion, trust and reciprocity that enabled people to work together for common benefit. In this results chapter 4, I explore some of the social capital literature (section 4.1.1) relevant to the findings (section 4.2) and then present and discuss the social capital findings (section 4.2.4). I conclude the chapter (section 4.2.5) by considering the potential benefits for families and communities in low-income countries from efforts to improve social capital.

4.1.1 Brief Literature Review

This section highlights some of the literature relevant to the findings. Social capital has been conceptualised at the individual and collective levels. At the individual level social capital positively influences health by reducing stress for those who access forms of social support including emotional, instrumental and informational support (Eriksson 2011). Further at the individual level, the social capital literature has examined the role of social networks. By belonging to social networks, individuals can secure certain benefits and resources that would not be possible in the absence of these networks. According to Bourdieu the resources are not intrapersonal residing within the individual but in the structure of the social networks. At the collective level, trust and collective action are defined as outcomes of social capital (Woolcock 2001). The dissemination of health information can also be more effective in an environment characterised by trust which can have a positive effect on health. Community members can also improve their health by undertaking collective action such as environmental sanitation, which may increase the capability of communities to change health-related behaviours. Collective social capital can have indirect positive effects on health by facilitating the ability of communities to work together to solve collective health problems (Kim et al 2008). Whether social capital is an individual or a collective feature is still debated (Poortinga et al 2006a; Kawachi et al 2004).

Family and community social capital featured in the review. Fergusson (2006) review highlights the importance of both family and community social capital in the context of young people. In applying bonding and bridging forms of capital this author

acknowledged the importance of bonding relationships that exist within families, and relationships that bond and bridge families to local communities. The elements of family social capital included family support. The elements of community social capital included social support networks e.g. peer support in school health clubs, community engagement in local institutions e.g. in volunteering, religiosity e.g. attendance at religious services.

Carroll (2001) noted the capacity of social capital to be used by poorer people as a primary means of protection against risk and vulnerability. This author found that communities endowed with a rich stock of social networks will be in a stronger position to confront poverty and vulnerability. These insights have two key implications for rural communities. First, they highlight the endowment of social connections of poorer people as a potential asset, such as for managing risk and vulnerability. Second, these insights turn attention to societies with weak, infrastructure and inadequate services. Together, these processes highlight the need to strengthen communities capabilities in managing diseases.

Putnam (2000) noted that organised groups had the capacity to derive required human, financial, material and organisational sources from established networks, manifesting the relationship between social capital and other components of the study framework. Similarly Littlefield (2007) and Portes (1998) argued that peoples' social networks or relationships enable them to gain access to cultural, social and economic resources.

However, social capital may not always produce beneficial outcomes as in closely knit communities excluding migrants (Hegney et al 2008). Some communities for example 'close out' others such as migrants, withdrawing from maintaining associations with the wider society and turning to close-nit groups (Hegney et al 2008; Pelling & High 2005). Carroll (2001:xii) observed the effects of social capital, especially of the bonding type, can be positive or negative for communities at large as what binds can also exclude and sometimes groups constrain their own members. Bridging, i.e. "cross-cutting ties," can counteract the adverse effects of certain bonding relationships (ibid.). In the next section, I present the results.

4.2 Results

The analysis identified two overarching discourses: family social capital, and community social capital. Family social capital presented the social capital that can be drawn from the immediate and extended family in forms of social support. It examined the role of family social capital on health risk behaviours including how they access, generate and

mobilise ‘social capital’. Community social capital recognised community actions, networks and activities of local institutions that contributed to improved health outcomes. Relations of trust emphasised social trust that facilitated cooperation and coordination in activities that brought health benefits to family and community. Each overarching theme incorporated several sub-themes that are explored. The discussion also covers the forms of social capital – bonding, bridging and linking and how they were reported to improve access to care, and the relationships of social capital with other concepts in the study framework. The findings from the policy discourses are presented. *Figure 4.1* provides the schematic diagram of the organising discourse of social capital and its domains and sub-domains.

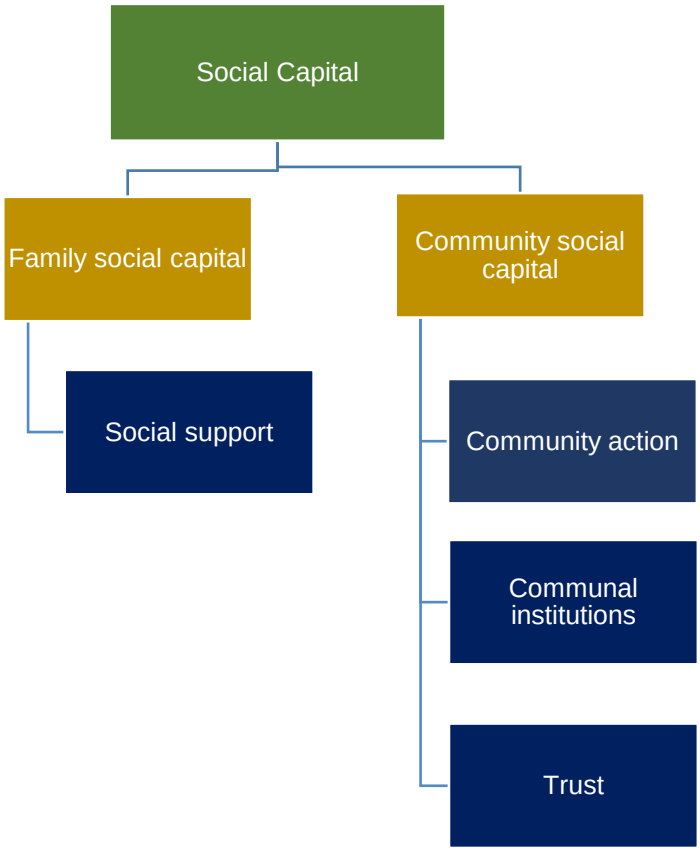

Figure 4. 1: Schematic diagram of Social Capital

Next, I present the findings on family social capital.

4.2.1 Family Social Capital

Participants reported receiving support and encouragement from some family members in seeking care. The analysis distinguished sources of social support and types of social support and is divided into three subtypes; emotional, instrumental or economic support

and informational support. Emotional support was related to love, caring relationships, sympathy and understanding from family, friends and the community:

> *'When one is sick they 'bayo bayo' (encourage) him to drink medicine, and to eat. Mum, my brother and sister, they take over the work I do, they get water, and they do the work I do' (*Male, previous patient in Moyamba*).*

This quote reflected that the consequences of illness were spread more widely throughout the household which had to manage not only the patient but also his share of tasks at home. The reallocation of tasks ensured a degree of continuity that kept the disruption from ill health at a minimum. It reflected a relationship between social capital in the family and the human capital component of the study framework described in chapter 2 (DFID 1999). Families depended on such support as strong bonding forms of social capital which showed caring relationships.

Social support in the form of instrumental or economic support referred to practical help given with tangibles such as labour or money or medicines from family:

> *'Well our big sister 'Mafoe' takes care of us, she bought the medicine'* (Female, pregnant woman in Moyamba).

Support from elderly family members with resources is common in African families especially in times of illness. The financial capital component of the study framework could be applicable here as such support in the form of economic support helped family members who lacked resources secure access to care.

Social support in the form of informational support referred to health information received from neighbours about malaria risks. The quest for livelihoods meant that many were away in their farms during the day and missed visits by health workers and relied on the radio. This had implications for health information, especially making information about malaria exposure accessible to local populations. Communities therefore relied on their neighbours with feedbacks between themselves on health information from the radio:

> *'Me and some of my neighbours, we pray to God to have a radio. Through MODCAR (Moyamba District Council Awareness Radio) they advise us about the cleanliness, to keep our environment clean*. *We who listen radio also pass the information to our brothers to use tent' (*Rural male, head of household).

This quote reflected that the radio was used as a vehicle for education on malaria at the community level. It helped increase the uptake of services by broadcasting health messages. Local networks with neighbours who had radio passed on information on

malaria. Such a network may have helped individuals to be more aware of health messages and was important for the health of the community.

Furthermore, the information from neighbours was reported to be more trusted than from the health worker. Trusted sources were those people could rely on. Being of the place with a common identity and place attachment, neighbours were seen as more trustworthy, unlike health workers.

> *'Well, first of all for the community the ultimate goal is to spread out the news to those who do not get it, then to tell them because when their companion tell them what is happening they believe them more than the health worker. Sometimes they have more trust in themselves more than the health worker'* (Male, health practitioner in Moyamba).

Neighbours were more trusted as they were in the immediate circles and people with shared interests and goals relied on each other. Closer and local sources of information were more likely to be relied upon than unfamiliar, distant sources such as health workers who visited periodically.

Community members outside the family also provided social support. The following quote illustrates how this male health practitioner felt and described this kind of support:

> *'Others are put in a hammock, the youths put them in a hammock if they can't afford bike'* (Male, health practitioner in Moyamba).

Social capital in this discourse reflected that support was also found outside in the community where youths from the same community undertook collective action in taking the sick to hospital. The response showed that outside the family there was a social network which was supportive to the community in helping people who lacked transport or the means to pay transport costs to the facility. The human capital component could be applicable here as youths provided an alternative to transportation by utilising their labour in taking patients to the facility.

In summary, participants described social support from family and community as an important factor which buffered their illness. The narrative that emerged is one of the vulnerable people impacted upon by the epidemic who needed to support each other and not totally rely on the health service. Where the service failed to provide transportation, they used local resources to do so. Where the service failed to provide medicines, they used family resources to buy medicines. Family members helped and supported each other because of shared responsibility for their people. People derived social capital from membership of the family. Instrumental support in money to buy medicines or in food were forms of gift-giving that established social relationships. Family

members who had provided small acts of kindness and support in the past may themselves be recipients in the future. Of relevance to family and community management is that social relationships in family and community gave meaning and shape to collective and individual action inside communities. It reflected their ability to cope with the threats of malaria by the means of the resources that were directly available to familial and community relationships. The specific ways of influence were in enhancing a positive mood in the patients that they were cared for in their illness. Next, I discuss community social capital.

4.2.2 Community Social Capital

Sub-themes for community social capital included, community action, communal institutions and relations of trust. I discuss these in turn.

Community action

Participants in interviews and focus group discussions referred to the collective action capacity of formal and informal groups at the community level. Such actions brought together local resources of men and women. Examples of collective action were many*:* communal labour- weekly and monthly cleaning, grass brushing, mobilising funds for obstetric care, digging toilets, collective enforcement of rules relating to ante natal visits, immunisation campaigns, organising security against theft in hospital, membership of revolving savings and credit associations in mother support groups, leadership and environmental cleaning:

> *'Well Friday to Friday we do town work, the law is there long ago. We met it with our people and we are developing it. It is compulsory to do cleanliness every Friday'* (Rural male, head of household).

The above illustrates collective action in environmental cleaning. However, it also provides an example of 'compulsory volunteering'. 'Compulsory volunteering' refers to youth volunteers involved in cleaning the environments as fines were imposed in communities for non- compliance.

Communities took collective action and contributed subsidised labour to support community health volunteers who would otherwise be working on their farms. Time for farming activities competed with time for health work. Thus in some communities volunteers got support from family and the community:

> *'So but in some communities the members of their family or some communities volunteer to work for them in their farms and their gardens so that they will not be discouraged to do the work' (*Rural male, health practitioner).

The labour of such voluntary groups can be seen as manifesting social capital. It motivated volunteers as it ensured disruption of work on their farms was kept at a minimum, whilst they provided services to the community. Similarly, collective action was demonstrated when youths reciprocally shared farm labour:

> *'Well really in this area most of the youths do not have government work. .What they do mostly is farming. Some time they make a company say 2 or 3 or 10 people, they say let us work for this person this time and next time other person and when there is community work they come there' (*Rural male, previous patient).

A norm of reciprocity prevailed in the Moyamba town community where youths demonstrated their expectations of reciprocity. It implied that a significant proportion of youths in the community were seen as trustworthy. Reciprocity was affirmed between individuals who exchanged their labour resource. In applying the study framework, youths were reported as drawing on human capital in the form of knowledge and skills in farming, despite they did not have wage labour from the government that will increase financial capital.

Another form of collective action was seen in 'Youndo' community where this female health practitioner reported mobilising funds for obstetric care:

> *'We formed groups for home deliveries. You born outside we hold you and pay a fine of Le 100,000 (£8). That is put in a fund for future emergencies - say deliveries and you need blood which you need to go to Moyamba to get'* (Rural female, health practitioner).

This quote reflected that home delivery was considered illegal and there were financial penalties for non-compliance. In 'applying the financial capital component of the study framework, the communities demonstrated their capacity to mobilise financial resources to be available to transport pregnant women to the referral hospital for deliveries. Ensuring funds were available for transportation of pregnant women for obstetric care at the referral hospital in Moyamba was crucial to deal with the emergencies and complications that may arise on delivery such as blood transfusions requiring blood donations. It demonstrated financial management at the community level.

Community action was manifested in accounts of knowledge sharing between traditional healers and the health facility. This rural health practitioner reported that the collaboration included the healers as colleagues and experts in their particular field working with the practitioner:

> *'Like my own chiefdom I work to team up with them. Like if I see one that can attend to bones I try to work with him. If you combine the herbal with the chemotherapy it works*. *They appreciate it. When you go to their catchment area you share ideas with them. In my own area, I have a text book on herbal. We sit together to identify drugs and the herbal name'* (Rural male, health practitioner).

The approach offered a 'window of opportunity' for a perceptive understanding of health problems. In applying the study framework, it harnessed the material and human resources of both biomedical and traditional medicines for the overall health of the community. This close cooperation between modern and traditional healers led to establishing a mutual referral system, whereby healers referred patients to the modern practitioners and the practitioner referred certain patients to the healer, an arrangement that may have led to an overall improvement in health in rural communities:

> *'So now they are open to me. If they have a case they send them to me first. They say go and see the CHO (chief health officer) whatever he says then come to me. When the patient comes with kinds of complaints more we treat them and they do not even go back to the herbal'* (Rural male, health practitioner).

Despite their polarised approaches to treatment, the healer and the practitioner were cooperating more closely. Such cooperation was evidenced in this specific community. However other data as by the rural health practitioner in 'Gbangbatoke' suggests that traditional healing was relied on by many in rural communities. There may be evidence of greater confidence of people in rural communities in the services offered by traditional healers.

Community action was manifested by school children and community members in disseminating health information through community and school health clubs. The community health clubs were selected by the chiefs and consisted of volunteers based in the community. The school health clubs comprised twelve children from mid primary class 3-5. Those in upper primary class 6 were not included as they were leaving whilst those in junior primary classes 1 and 2 had little knowledge. This rural female head teacher described the role of the children in promoting healthy habits to their peers:

> *'Because children listen more to themselves. So FAWE (Forum for African Women Educationists) trains them on this. So the children help to clean the compound. I believe the children hear their companions more. So these children go for training in Moyamba to come and train their companions. There are 15 of these children'* (Rural female, head teacher).

This quote reflected that children may have created a demand for services and passed the knowledge they acquired to their peers to adopt healthy behaviour. In this sense the school health clubs helped to increase the children's self-esteem and made them realise

that they were an important part of the community, playing a role and contributing to improving health outcomes in their communities. Competitions were organised as an extended educational activity to increase children's knowledge about malaria:

> *'They have knowledge, evidence of that is there. The other time they went for competition with other schools. They took them to MODCAR to compete with other schools they came first. The 'pikin to pikin' people came to congratulate us. So by that now the awareness is there. And they share knowledge with each other, they talk with their companions'* (Female, school teacher in Moyamba).

Notable in the above comment is the awareness about malaria in school children and there was knowledge sharing with the peers, reflecting the human capital component of the study framework.

Within communities, performing arts seemed to have been adopted by the school health clubs as a means of communicating health messages aimed at raising awareness of malaria. The following quote describes the impressions from stakeholders on performance by the drama group:

> *'Some clubs even have drama groups now, all the messages are disseminated through drama on all the topic and this resonates more with the people. The children so performed that the chief and stakeholders stood up and said they never took the malaria medicine but from what the children have done I will now'* (Health practitioners focus group*).*

This quote reflected that the format and content of health messages affected uptake of services. In this sense using entertainment as a vehicle for education about malaria raised awareness and brought the importance of taking antimalarial medicine into the forefront of peoples' minds. It reflected the skills of the children, linking with the human capital component of the study framework. Next, I discuss communal institutions as a component of community social capital.

Communal Institutions

Social capital was built through communal institutions. The discourses identified such institutions in five key ways. Firstly, it focused on hospitals and schools that provided health and educational services. Secondly, it focused on women organisations in health promotion activities. Thirdly, it emphasised women organisations and youth groups involved in environmental sanitation. Fourthly, it presented actions by formal and informal leadership in influencing peoples' activities in preventing and controlling malaria. Local leaders were members of structures such as facility management committee and set up processes to allow individuals, groups and communities to play meaningful roles to

achieve health goals. Finally, it alluded to the interconnections and relationships with organisations in health programmes.

To illustrate the dimensions of social capital seen at multiple levels, social capital entities (institutions and groups) are paired with the types of interventions (programmes and activities) that were the sources of social capital (*Figure 4.2).* For example, women in formal organisations were in mothers groups involved with child nutrition (Undlien et al 2016), whilst women in informal organisations were involved with facilities constructions for a hospital. Youth groups were involved in providing environmental sanitation. School and community health clubs were involved in educational programmes and disseminating health information. Religious organisations provided bed nets to be distributed in several communities in Sierra Leone.

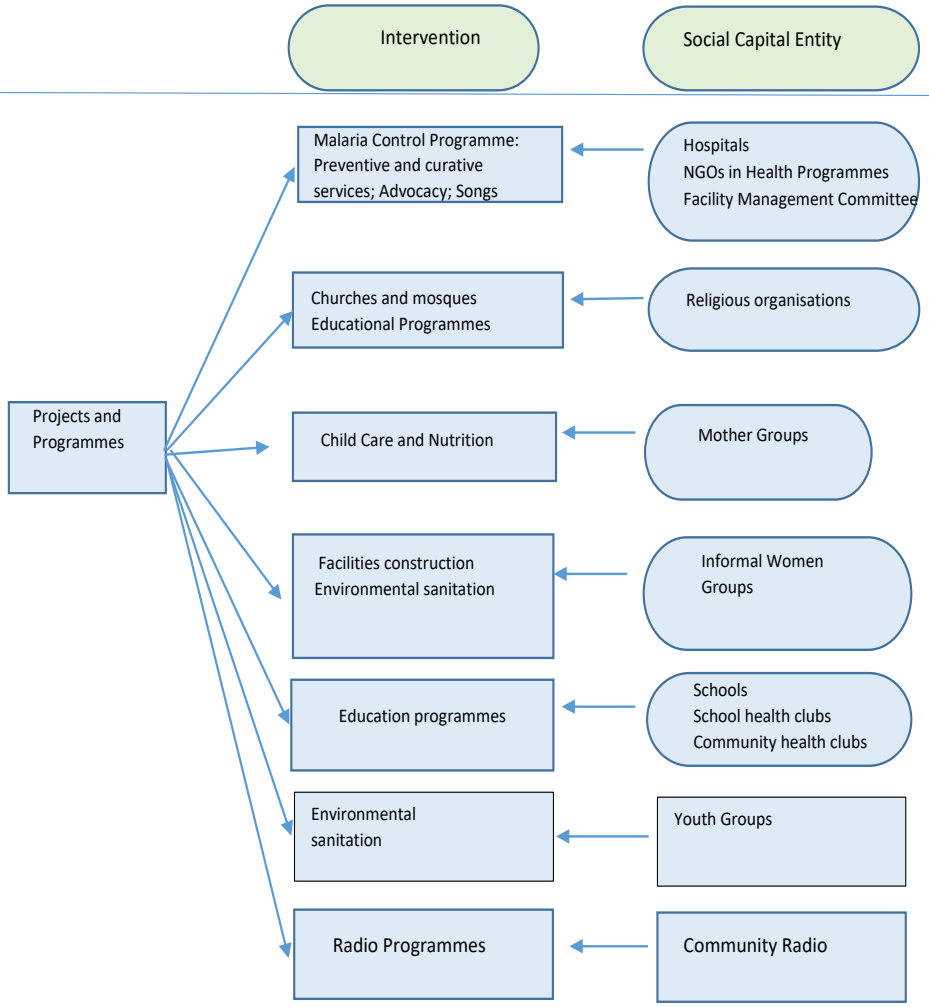

Figure 4. 2: Institutional manifestations of Social Capital

Hospitals were facilities that provided health care services to patients. Hospital-based treatment was considered by many to be key to remedies against the all-pervasive malaria disease. Hospitals provided preventive services such as bed nets, intermittent preventive treatment for pregnant women and infants and curative services such as antimalarial tablets. Nurses also provided health talks to patients when they visited the facility. Many participants reported using them as sources of care, often as the first choice for treatment. The value of attending a medical facility was clearly expressed, even in the circumstance of the end of a busy and tiring day's work:

> *'The earlier you do it the better. Perhaps someone worked the whole day in his farm, he gets back he is tired and says he has malaria. But once you go to the clinic they examine your blood to see if you have malaria content. And so once you have the malaria content in your blood you take treatment'* (Rural male, religious leader).

This quote reflected that participants seeking facility-based care perceived the effectiveness of the treatment and saw it as superior to other forms such as from informal providers. Hospitals in this sense provided treatment to those who visited the facility. However, there were much larger populations who may have had increased risk or illness from malaria but whom services did not reach. Geographic location was reported as a factor influencing access to services:

> *'Yes most of them live in hard-to-reach area. As I said earlier cross using local canoes, river rain or walks in mountainous areas, distance are as rocky areas, very challenging. For them most times they prefer to stay'* (Rural male, health practitioner).

This quote reflected that geographic location was a major obstacle in the decision to seek care. People is some communities however used local resources such as canoes, reflecting the physical capital component of the study framework.

Distance to facility was both a supply-side factor in the lack of facilities in some communities which required patients to travel long distances and a demand-side factor where for example there was a lack of community based schemes to meet costs of travel to the facility and travel time from home to a facility. Distance was often seen to negatively impact on the demand for services and was cited by many participants as a reason why people choose to use herbal medicines rather than a health facility as illustrated in this example:

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> *'True if someone is 14 miles away to the facility, then the access is limiting him. So he says I met my people boiling leaf, or covering in smoke, so based on that they continue'* (Moyamba focus group).

This quote reflected that distance to facilities in poorer communities was a factor limiting the uptake of services. Distance interacted with other factors such as transportation to the facility, opportunity costs in missed livelihoods for the day and delays in the facility. Therefore, people resorted to local solutions they are more familiar with that has been passed on to them from one generation to the next.

Thus whilst hospitals provided preventive and curative measures other factors may operate to explain why risks varied between communities. Health care services provided inputs into maintaining individual health, but it remains to be explained by why, despite hospitals existing, some communities had more malaria than others. Those going to the hospital may receive specialist advice but there were still much larger numbers not able to go to their base hospital who remained untreated.

Yet another explanation is that in Moyamba, there existed a wide spectrum of disease settings that can be divided into stable with high disease intensity and unstable transmission areas with low intensity. Under both conditions, whilst it was recognised that hospitals provided treatment, malaria was reported or observed to be present in most communities, across the changes in season:

> *'Here is a stable region for malaria, all the year round even in the rainy season you can't stand here, we do not even kill mosquitoes one by one as they are so many'* (Rural female, health practitioner).

This quote reflected that communities in a stable malaria zone are susceptible to malaria particularly in the rainy season when malaria infections increase owing to more water for breeding sites for mosquitoes. It corroborates the data from the rural youth leader in the same community in 'Youndo' in the preventive strategies section in the coping strategies chapter of his inability to stand in his farm in one year due to the prevalence of mosquitoes.

Some participants expressed their reluctance to go to the hospital to receive malaria treatment. Several factors emerged from the interviews as to why people suffering from malaria would be reluctant to go to the hospital, which highlighted issues on the supply and demand side of treatment. As described in Chapters 1 and 2 the reasons why poorer people make less use of health services were driven by both supply and demand factors. Participants reported the larger part of the population as actually staying away from the hospital, also attributing it to people using other kinds of healing:

> *'Like how I said in terms of the clarification I made.eg in 'Gbangbatoke', we have a population of over 11,000 .I expect to have 200 patients every day. But most of them they do not come the reason being they decide to go to herbal (traditional healing).or 'pepper Dr - drug peddlar'* (Rural male, health practitioner).

This quote reflected that patients seemed to have more confidence in using herbal medicine or drugs from peddlars. These sources of healing were seen as easily available and affordable, and provided an immediate type of action to combat the effects of malaria which is low cost, home administered and easily accessed, relating to family and community management.

Another reason for peoples' reluctance to go to the hospital was mistrust in modern medicine. The following quote illustrates dislike for tablets and why people avoided the hospital:

> *'The other woman said, tablet does not even go through my throat. Even to the centre, people do not go there' (*Moyamba focus group).

This quite reflected that some women would even not take tablets and might seek an alternative remedy to replace the treatment received from the health facility due to mistrust in modern medicine. People often did not trust modern medicine and set awareness about the quality of the treatment received at the clinics against local perceptions, and so weighed their options before turning to the clinic. Not less important were the other factors associated with modem medicine such as cost and availability in some cases. Thus local people had no motivation to take modern medicines. Participants also cited unhelpful staff attitudes such as negative behaviours and attitudes of some health care practitioners as contributing to their reluctance to go to hospital:

> *'Secondly, we have health practitioners who when they are in communities they forget they are giving a service to humanity, they think they are rather lords. This is more associated with women practitioners. Instead of befriending the people, they scare them away. There are cases when a nurse in a hospital stood on top of the head of the traditional birth attendant. So the people who were coming, when the birth attendant avoided the hospital they too avoided the hospitals'* (Male, head of household in Moyamba).

The above statement reflects a strongly perceived 'us' and 'them' attitude held and expressed by some practitioners towards patients in need of care in certain rural communities. It can also reflect hostility towards traditional birth attendants who attempted to maintain the traditional culture and practices of certain communities.

Another factor for not going to the hospital was a shortage of doctors. For example, the referral hospital in Moyamba had only one doctor. At the time of this research, Sierra Leone had a low doctor-to-patient ratio of 1:40,000 patients (Witter et al 2016:227). Participants expressed their frustration in the difficulty of seeing a doctor:

> *'There is another factor, the approach our practitioners take people to herbal. An ordinary man like me to see the doctor who I believe is the solution to my problem, one Dr who even only sees patients on serious cases'* (Male, youth leader in Moyamba).

The above comment is a reflection of the inaccessibility of doctors to patients who may want to see them and in this case, had a belief he could be cured. It seems patients had a preference for modern treatment, however the scarcity of doctors made it difficult for patients to see practitioners in the facility. They therefore turned to herbal treatment rather than traveling to the facility.

In summary, accessing hospitals was a key element of the discourse by some participants. In particular, it was recognised by health practitioners as an effective way of dealing with malaria. However, this was not recognised by all participants. Supply

side factors such as access to facilities limited uptake but so did demand-side factors such as the dominance by men in decisions on the use of household resources. Furthermore going to the hospital was temporary and not radical as it did not seek to alter the underlying causes of diseases in communities but mainly to cure patients. Presumably, sick people will always be there in every generation and if prevention and control were confined to those individuals, that control needs to be sustained year after year and generation after generation. This aspect will be also be taken up in the discussion chapter.

Another community institution was Schools. Schools were recognised as places of learning and knowledge acquisition for young children living in marginalised communities. Opportunities for life-long learning happened through formal education. Schools provided opportunities for children of furthering their education and increasing their knowledge of epidemics such as malaria:

> *'Malaria is a topic in all classes because we know how stubborn malaria is. Even in devotions and in the health education classes they teach them. They have some knowledge from the health education classes'* (Female, head teacher in Moyamba).

This quote reflected that opportunities for health learning about malaria and control management were available through schools in devotions at the start of the day and in pre-arranged classes. Further, the messages around malaria featured at different life course stages of children through their life in school. The life course view emphasises how children will become more knowledgeable about how the malaria epidemic has affected their lives over time. Pupils with formal education over the years in school gained knowledge and were likely to adopt healthier habits and have better health. For some participants, the ability in school children to learn and have a focus in a school environment was important, as education has the potential to enhance health outcomes, through enabling the children to cope more effectively with threats of diseases. It enhanced the capacity in the children who may have become more knowledgeable about malaria:

> *'Yes, so even in the malaria programme we ensure it is factored in schools. Children in schools are easy as they are in a learning environment and can recall what you told them. Children listen to you as you talk with them'* (Male, head of household in Moyamba).

The above quote reinforces the potential influence of schools as they provided a conducive environment for learning about malaria. Furthermore, children were seen as having good listening skills and may have understood what was taught to them. There was an expression in the potential of children from looking inwards to looking outwards,

which may have had positive effects on health in the school environment. It related to the human capital component of the study framework, contributing to the educational achievement of children.

A further manifestation of social capital was in religious organisations. Religious affiliation was seen to influence peoples' responses to health interventions so that religion was seen to inform a major part of peoples' socio-cultural identity. Congregations were seen as a key vehicle through which followers responded to health messages as they listened and often adhered to health messages through religious leaders, forming a rallying point for disseminating health messages. Such religious networks were also often found in the most inaccessible areas where government services do not reach, were more established than local or national governments, and provided channels of information that people relied on:

> *'We go around together, we go to the villages we tell them to use the bed nets. Yes they are aware of it' (*Male, religious leader in Moyamba).

Religion offered means to reach poorer people at the grassroots, connecting people to health care services. Because connecting to their health needs was an integral part of the poorer peoples' lives, hence their respect for religious organisations that could sustain their social values while delivering necessary messages to them. As religious organisations were perceived by the community peoples' representing their cultural and traditional values, they were more accepted, respected, and trusted than the health service:

> *'And what we say to our congregation, they have respect for us they take it in good faith. Pastor says when we do this this will happen'* (Male, religious leader in Moyamba).

This quote reflected that religion played a distinct role in creating trust among people and as providing a moral justification for shared responsibilities such as taking antimalarial drugs collected from facilities. Trust was necessary for building loyalty and confidence for collective actions in participating in the use of services.

NGOs undertook outreach in communities where the government services did not go. They supported government efforts in providing basic health services to communities in rural areas. For example, local NGO 'p*ikin to pikin'* was seen as playing an active role in communities to support government efforts in withstanding the threats of malaria:

"I have 10 people in 'pikin-to-pikin' group here concerning malaria. They go to the communities to meet the people, they tell them once you have the symptoms go the hospital, sensitising people about malaria, telling them to go to the clinic' (Rural female, health practitioner).

The narrative demonstrates that the NGO focused on awareness raising to ensure people referred malaria cases for treatment early. Early referral is likely to reduce morbidity and mortality from malaria. It is also likely to increase the uptake of health interventions.

Another communal institution was the community radio, the 'Moyamba District Children's Awareness Radio' (MODCAR). People listened to health programmes over the radio from local authorities and organisations in health programmes. Whilst radio was a means of mass communication, participants in both rural and Moyamba town communities mentioned that its effectiveness was limited due to several factors including lack of radio and batteries, poverty, willingness to listen, and inability to listen to the radio, due to farm work demands:

'This is the question I always ask. I may be fortunate to have radio and listen, I listen, and I love. But my uncle at 'Rogoya' in 'Fakunya' does not listen, does not have radio. In the morning he goes to the farm and comes at night at 8.00 o clock. By the time he comes the programme is even past' (Male, youth leader in Moyamba).

Thus the interactions of poverty, technology, perceptions, and preferences had severe impacts on peoples' ability to access health information. Poorer people did not have money to buy radios whilst those who had radios did not listen to them whilst in their farms seeking livelihoods. The reason was because they prioritised farming which was their source of livelihoods in communities.

Social capital can have positive and negative effects and does not always produce beneficial outcomes. For example, closely connected groups where the members have something in common such as livelihood can serve to isolate persons where the difference is perceived. Some communities can 'close out' for example temporary migrant populations from different cultures or hold them in disfavour, or let them go unheard in the community:

'And here on Saturday the town is full, from 'Kailahun' district, 'Bo' district for the 'doweh' (weekly market). When people come for the 'doweh', they do what they want. The 'doweh' is fine because people come with food etc., but the way they leave our community is not fine' (Rural female, head teacher).

The weekly market provided opportunities for trade to buy cheap food. The financial capital component of the study framework can be applied here as the buying and selling of goods and services can generate income for communities. However, the temporary migrants were seen to have brought unhealthy habits which may have put the health of people in the communities at risk. Thus the traders were stigmatised for leaving the communities in unhealthy conditions and not conforming to the standard they met. Next, I present relations of trust as a component of community social capital in the analysis.

Relations of Trust

The various forms of social capital contribute to collective action by enhancing trust among actors. Trust was the linkage between forms of social capital and collective action Trust was enhanced when individuals were trustworthy and networked with one another. The social capital input highlights the relevance of trust which is essential for bonding members of the community. Trust was necessary for building confidence and loyalty toward collective actions which could be accessed through associational life. Trust was important for associational life and has properties of public good when utilised appropriately for positive benefits in society. The following quote illustrates trust in community leaders:

> *'This is an opinion leader, a town chief trusted by his people. We try to incorporate him into community health club as he is the town chief''*
> (Health practitioners focus group).

This quote reflected that involving local leaders in implementation of community-based health programmes such as community health clubs is more likely to increase the uptake of such services. With trust, communities are more often collectively likely to adhere to health information disseminated from the community health clubs. Next, I present policy discourses on social capital.

4.2.3 Policy discourses on Social Capital

Three discourses were identified by this analysis from the policy documents that are linked with the social and human capital components of the study framework: 1) community action; 2) communal institutions; 3) Trust. I discuss these in turn.

Community action

The Health Sector Recovery Plan identified key players who undertook collective action related to community management of malaria:

> *'Working through community networks such as religious groups (churches and mosques), women's groups and youth groups enhanced effective messaging and mobilization-including the safety of routine health services and when to use them' (*MoHS 2015:48)-Health Sector Recovery Plan 2015-2020.

This quote reflected that the policy recognised involving community groups in complementing the work of the health service in delivering health information. The human capital component of the study framework is applicable here as it relied on skills and labour of groups of local people The majority of the participants in interviews and focus groups expressed the role religious groups played in influencing health seeking behaviours in malaria control, collaborating the discourse in this document.

Communal Institutions

The Malaria Control Strategic Plan envisaged involving community-based organisations in malaria control:

> *'Civil Society Organizations (CSOs) and Community Based Organizations (CBOs) will to empower and encourage communities to demand for services, know their health rights, and accountability from duty bearers therefore increasing utilization and value for money'* (MoHS 2015:16)-Malaria Control Strategic Plan 2016-2020.

The Strategic Plan supports local organisations to strengthen communities' abilities to manage malaria risk. It makes the case for involving communities in malaria control'. . However, some participants, such as the previous male patient in 'Timdale 'reported that youth groups, were very unhappy with their exclusion and lack of employment. Thus whilst the policy sought to involve communities, it was less likely to succeed as people participated as 'passive' beneficiaries, particularly in some communities where malaria was accorded a low priority in the eyes of the community.

Relations of Trust

The documents highlight trust as essential to build confidence for the uptake of services:

> '*There has long been a strained relationship and tenuous level of trust in the health system among communities in Sierra Leone. With recent improvements in policy and implementation of health services, trust had been improving, with corresponding increases in health facility utilization' (*MoHS 2015:20)-Sierra Leone Basic Package of Essential Health Services 2015-2020.

The document envisioned that social capital in the form of trust can lead to an improvement in health outcomes. Communities in which there was extensive trust can accomplish much more than a comparable community without trust.

In summary, the value participants gave to social capital was in recognising it as contributing to family and community management of the threat of malaria. The examples presented provide useful examples and insights into people using social capital and collective action to adapt to malaria risks. Through mobilising their assets and resources they demonstrated the abilities to deal with their adversity. The social interactions that resulted in social capital were reciprocal and regularised in norms of behaviour. Social capital accumulated in communities as a result of groups and organisations cooperating in health programmes. Some NGOs were also able to assist in capacity building among poorer people, not only enhancing human capital in terms of personal skills but also in empowering marginalised groups.

4.2.4 Discussion

The present chapter reported the discourses on social capital as a component in family and community management of malaria in Moyamba, Southern Sierra Leone. I identified two main overarching themes to social capital '; 'family social capital' and 'community social capital'. I discuss these in turn.

Family social capital is referred to here as the social capital that can be drawn from the family environment. The 'family social capital' theme illustrates social support from family, neighbours and friends**.** Social support was a "naturally–occurring" type of support that was seen as helping here to ensure that families and communities retained the capacity to exchange emotional and tangible support (Norris et al 2008; Landau & Saul 2004). In contrast, Kaniasty and Norris (2004) noted that although helping behaviour and cohesion are abundant initially, they do not last. This can be seen in poorer communities where the very family members offering help are themselves from poorer backgrounds.

Social support here was manifested in three forms: emotional, instrumental support and informational support. Emotional support was related to love and caring relationships and sympathy and understanding from family, relatives and friends (Ferlander 2007). It influenced health-seeking behaviours as people looked to similar others to help them make decisions about appropriate behaviours. Social support in the form of emotional support contributed to family social capital in ensuring medication adherence as relatives encouraged patients to drink medicines. Emotional support allowed family members that

had malaria to believe that they were cared for, loved and valued especially in times of need (Aldrich & Meyer 2015). The male youth patient narrated how his brothers and sisters encouraged him to take medicines. The findings in this study are consistent with previous research that highlighted the significance of support from relatives, friends and neighbours as an important asset that can be called upon in a period of need. Such support also influenced coping capacity (Seeley et al 2009; Carroll 2001; Berkman et al 2000). The implications are that they highlight such social connections as a potential resource for managing ill health. Family social capital entailed not only the physical presence of adults in a household but also the presence of supportive interactions.

Discourses on instrumental support referred to practical help for example in relation to money or labour in kind. People ill of malaria received help or assistance with tangible needs (Berkman et al 2000; Berkman & Glass 2000). However instrumental support can also be associated with the inability of poorer people to provide such kinds of support.

Discourses on informational support (Alvarez et al 2017; Norris et al 2008) presented neighbours disseminating health information from health workers or radios to others in the community. It related to the provision of advice or information on malaria interventions.

This study found that health information from sources such as community health volunteers and community leaders was relied on, confirming the finding in Longstaff (2005) that closer, local sources of information are more likely to be relied upon than unfamiliar, distant sources. Jordan et al (2010) argued that health literacy encompassing a person's ability to seek, understand and utilise health information is important in being able to access and benefit from health care services. In support of this view, a report by the United States Institute of Medicine identified health literacy to be one of the most important opportunities to improve population health (Carmona 2006). However Jordan et al (2010) noted that for health information to be utilised, it had to resonate with patient health beliefs and attitudes, supporting the finding in this study that despite health practitioners giving anti-malaria tablets to cure malaria, participants as reported by the rural religious leader refused to take them, due to the mistrust in modern medicine. The rural religious leader and the pregnant woman in the Moyamba town focus group reported patient's previous experiences with tablets which deterred them from utilising health information. The utility of health information was also limited by the medium of delivery. Previous research has emphasised the need for health professionals to tailor information to patient needs and using appropriate formats assisted understanding (Panter-Brick et al 2016; Jordan et al 2010; Longstaff 2005).

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Another example of family social capital was from the narrative about the work of women in informal groups who constructed toilets and security fences. Consistent with research presented by Coleman (1988) the findings of the present study explained that parents 'invested' in the health of their children, as the next generation of the family who will in turn, support them in later life. The informal activities of women provided opportunities for communication with other women. Participating in water collecting, stone breaking and fencing ensured that much valuable information was passed on. Communicating and mutual support within their informal network (Rifkin 1990) supplemented the work of the health facility. It generated and strengthened reciprocal relationships and manifested social capital where people came together voluntarily to contribute their labour in return for future services for their family and current services from the facility such as antenatal care.

As discussed above, the focus on family can provide an approach to understanding how this institution and its links with other community resources and organisations can influence health (Alvarez et al 2017). Alvarez et al (2017) noted that family social capital is multidimensional and that its components most likely have distinct effects on health.
In this sense, it can be argued that social capital acquired in the context of relatives and friends was an asset that can help people in illness from malaria. I identified and highlighted the elements of social capital that presented as supportive health assets in the family.

The findings also reflected family social capital when children in school health clubs adopted healthier habits at home that was acknowledged by their parents. Lifelong healthy behaviours benefitted not only the children but also their parents and others in the wider community. The children created a demand for services as they passed on what they learned from the health clubs to their parents, thereby increasing their parents' awareness as well.

In summary, the value of family social capital lay in strong and bonding ties in families and in often providing emotional and instrumental support. However other forms of social capital were reported as bringing more benefits to the community. These are discussed further in the following section on community social capital.

Community Social Capital

Community social capital encompassed *community action, communal institutions and relations of trust. Community action* discourses recognised the collective role played by men and women which included; women in formal and informal groups; communal labour -weekly and monthly environmental cleaning, labour sharing; mobilising funds for obstetric care; leadership in collective enforcement of rules relating to antenatal visit, immunisation campaigns, and transportation of the sick to hospital.

Women in mother support groups added to community social capital through being involved in preventive actions to improve health and nutrition among children. This finds resonance in Undlien et al (2016) who in their work in Kenya, found mother support groups complementing the health services by improving mothering capabilities and providing nutritional assistance for improved nutrition status of children.

The study findings revealed that through their gendered social positioning as family and community carers and networkers, as nurses, chairlady in the facility management committee, community health volunteers, and the majority of teachers in schools, women were central producers of social capital. The findings show that women were often those: with the stronger community ties; they networked and engaged in reciprocal supportive relations; they were often those who supported church activities most; and they attended meetings mostly than men. They were also found to be at the heart of voluntary self-help schemes in health programmes. However, this social positioning as some feminists (Leal 2007: Sapiro 2003; Molyneux et al 2002), and consequent social capital generation was problematic in communities where there were clear issues of gendered inequality and power imbalances in communities and families. For example the paths of women to financial capital in the study framework (DFID 1999) were limited as men had control and mothers were not 'free' to take independent decisions, for example about seeking care in facilities.

Community action was reflected in the mutual referral system as reported by one heath practitioner. Consistent with research conducted by Marks (2006:477) the findings in the current study explain that traditional healers mirrored the methods and practices of the biomedical system and their collaboration included the indigenous healers as colleagues and as experts in their own field (ibid.). In applying the human capital component of the study framework, the finding showed that the mutual acknowledgement will benefit the wider community by pooling the knowledge of practitioners and herbalists.

Community action was manifested in religious networks. Religious organisations through their networks had capacity to reach the poorest and provide services to the marginalised

and deprived communities (Lipsky 2011). Participants narrated that both Christians and Muslims were working together in the interreligious council. These religious networks were often found in the most inaccessible areas where health services do not reach. Applying the human capital (pastors and imams) and physical capital (churches and mosques) components of the conceptual framework, the rural religious leader narrated their presence in communities and provided health information for example to people who refused to take medicines until they were urged to do by the religious leader (ibid.). Their closeness to poorer people in remote communities, and identification with the needs of the poor, made religious leaders highly reliable partners of organisations for disseminating health messages. They were identified as sources of health information as with trust, they had the capacity and were able to gain local peoples' cooperation. In this way, religious organisations can achieve more impact in the communities and enable community people to gain access to resources–social and physical resources such as bed net for preventing malaria, applying the social and physical capital components in this study. Religious organisations tend to impact more on communities that are affiliated to their faith, hence enabling a distinct form of social capital which facilitated health information. The findings are similar in Nwokoro (2017) who argued that religion provides such opportunity because it constitutes associational life by virtue of its congregational status in the community. Religion also has the potential to bring people together under one family or group with a common and accepted method of worship, values and belief.

Community action was reflected in mobilising resources for emergencies such as obstetric care. Where they are available financial management can be more cost-efficient at the community level (Sacks et al 2017). These were vital resources as a lack of such resources can lead to fatal consequences in deliveries, due to lack of money for families and communities to transport pregnant women to the referral hospital. The findings of the current study appear to be in line with previous studies showing the need for preparedness and transportation of pregnant women for emergency obstetric care (Campbell & Graham 2006) that was only available at the referral hospital in Moyamba. It targeted women who may have complications. Such emergency care was seen as an essential requirement for reduction of a substantial proportion of maternal mortality, contributing to community management. Where community loan funds are established, utilisation of emergency obstetric care may increase (Borji et al 2005). However, Borji et al (2005) noted that such funds suffer from several constraints including: financial sustainability; limited capacity to generate funds; limited management capacity and difficulty to ensure the cash is used for the intended purpose.

People had the confidence to invest in collective activities, knowing that others will do so (Pretty & Ward 2001), in applying the human capital component of the study framework. People worked together in constructing security fences, in cleaning the environment and in constructing toilets facilities. Community action also lowered the costs of working together in the application of the financial capital component of the framework. For example, when youths reciprocally shared labour, they reduced the costs of farming.

In light of the conceptual framework (DFID 1999) described in chapter 2 and the findings on Communal institutions presented in figure 4.2, a communal institution can be considered as an important dimension of social capital. Communal institutions included the community radio, schools, hospitals, and the facility management committee. These institutions and structures contributed to social capital in providing educational and cultural programmes, health and sanitation, health information and mediation with the facility. Since people in poorer communities have few assets and little access to services, they can gain from membership in communal institutions (Carroll 2001). Working together meant greater efficiency of their human resource uses, in applying the human capital component of the study framework. They also had a voice in community structures such as the facility management committee to make it more responsive to their health needs. Gilmore et al (2016) conceptualised committee health committees such as the facility management committee as having a more sustainable influence on community health and well-being, partly due to the collaboration between professionals and community members such as community leaders in this study. Together they were involved in identifying health problems by drawing on local and biomedical knowledge. Such committees were seeing as creating harmonisation of health initiatives, increasing potential for community empowerment and facilitating the participation of community members in health initiatives. Such committees were also seen as increasing programme ownership and sustainability of programmes.

Opportunities for life-long learning happened through formal education. Brooker et al (2000) noted that significant numbers of school children in Kenya are at risk from malaria-specific mortality and morbidity, thus health education in schools may be an effective way to promote recognition of disease symptoms for prompt treatment by family. For example the rural school head teacher in ‘Taninihun Kapuima’ commented on the provision of supplementary readers by UNICEF which they then used to teach children about the hygiene practices including, personal hygiene, food hygiene, and environmental hygiene. Similarly the rural female school head teacher narrated children in school health clubs created demand for services by disseminating heath information

to their peers. School health clubs built the capacity to cope with malaria as they were seen by participants as increasing awareness in the children by equipping them with knowledge about malaria. Children passed on knowledge from their training to other children in the schools. Lifelong healthy behaviours were adopted by the children which were seen as of benefit not only to the individual children, but also to their parents and others in the wider community, contributing to family and community management. Learning in school health clubs increased knowledge and awareness of diseases in school-going children.

Children added to community social capital in school health clubs. School health clubs and networks discourses added to social capital as they increased awareness in the children by equipping them with health knowledge which they passed to their peers (Alvarez et al 2017). Disseminating health information through school health clubs showed the central importance of implementing programmes though school children who may have created a demand for services to prevent malaria as they passed on information to their peers and parents (Alvarez et al 2017). Training of teachers as facilitators in the school health clubs who needed to be able to identify such vulnerabilities and risk of malaria was also seen as important. School health clubs increased awareness in the children by equipping them with the knowledge that can support behavioural change and influenced health-related behaviours through peer influence. Similarly community health clubs involved in disseminating health information may have increased awareness of malaria risks and preventive measures by creating demand for sanitation and hygiene (Watermen & Caincross 2005). School and community health clubs may have influenced community members to change their health behaviour and to use services. School health clubs may have created demand and increased services take-up by peers and parents. Similarly, community health clubs may have influenced early referrals as was revealed from the drama performance.

Hospitals were seen to be of benefit to individuals in providing cure for patients who visited. However as narrated by the male health practitioner in ‘Gbangbatoke’ most people in his community do not come to the hospital, deciding to rather go for traditional healing. Hospitals however do not seek to identify why patients were not coming to the facility, rather prevention and control efforts in the biomedical paradigm were seen as targeting and treating people who have the disease. Thus the approach would need to be sustained year after year as there will always be sick people in the population. Rose (2001) noted that the approach is temporary, not radical. It does not seek to identify the root of the problem but rather seeks to protect those who are vulnerable and who will

always be around. Thus the potential in the approach in improving health outcomes for the population is limited (ibid.).

Another community institution was the community radio which was established as a children community-based radio station to foster peace and reconciliation in the region following years of conflict. Its programmes expanded to providing health information for communities. The station was accessed by people with radios. The study identified the radio as a social capital input as it provided health information that had the potential in reaching a large number of households with education and health information on malaria (Galavotti et al 2001). The radio was also fora where children from different schools competed with each other on knowledge about malaria. In this sense, the children gained knowledge about health and learned how to take care of others.

The 1997 Human Development Report of the United Nations stresses the importance of mobilising poor people for building communal institutions such as formal and informal women groups. Having their organisations, this report concludes, improves their life opportunities. Moreover, empowering the marginalised such as women who are unlikely to have the collective action capacity to achieve adequate power, can also combat "social exclusion' (ibid.). Women were marginalised in access to farmlands and household resources (Brown 2016:118).

Trust in relationships was important in building social capital. Families and community actions based on trust and reciprocity were also seen as helping to improve health outcomes. Trust linked forms of social capital and collective action. It was trust that led to peoples' collective efforts to overcome threats of malaria. Consistent with the review on social capital and the environment (Pretty & Ward 2001), these findings show people as having trust in members of their family whom they knew and others in the community who they did not know but trusted because of wider confidence in the local social structure and culture. Valuing trust was necessary for building confidence and loyalty to act collectively (ibid.). Where such trust was seen, it was reported as leading to voluntary collaboration (Carroll 2001) of varying types among poor communities, as in voluntary group labour (Krishna 2001).

Stone (2001) categorises trust in three ways:1) trust in familiar individuals; 2) trust in formal institutions and: 3) generalised trust. In this study familiar trust pertained to people who were part of the immediate family network and knew each other. Institutional trust

related to formal organisations in health programmes such as NGOs and the malaria control programme. The data showed that there was a lack of trust in different stakeholders in formal institutions for example in hospital staff and mistrust in modern medicine which had implications for uptake of services. Consistent with research conducted by Akbar and Aldrich (2018) and Parker and Allen (2011), the findings in the current study explain that poorer people have shown non- compliance with mass drug administration programs, because drug treatment makes undernourished people sick in ways that interfere with daily livelihoods, an example of lack of institutional trust. Generalised trust refers to trust held by people in the society as a whole. Generalised trust was not limited to trust in a particular entity such as the malaria control programme, but to the trust held by the community as a whole. Disease epidemics such as malaria affected the generalised trust of communities.

Policy discourses on Social Capital

The documents make little mention of family social capital. Rather there is a focus on community social capital including working through community networks and community-based organisations (MoHS 2015:16) - Sierra Leone Malaria Control Strategic Plan 2016-2020, in applying the social and human capital component of the study framework (see DFID 1999). Where communities are involved in the formulation and implementation, they are more likely to use the services. The findings are similar in Rifkin (1990).

The documents allude to the lack of trust in the health system and efforts at improving trust (MOHS 2015:20) - Sierra Leone Basic Package of Essential Health Services 2015-2020. Trust from communities was envisioned as increasing uptake of care. There were conflicting discourses around the policy in the interviews and focus groups. Some participants reported community volunteers as contributing to an increase in levels of trust and uptake of services.

Levels of trust in this study were in a limited way as relating to the perceptions of fairness of health policies by the target groups and wider community. Participants lost trust in the services as they reported that they were very unhappy with how they were treated by health workers at some health facilities as reported in the health practitioners focus group. Most of them complained about the inability to travel to the facility, long waiting time to access the services at the facility, the difficulty to see the doctor at the facility. Some participants as the Moyamba town female teacher were particularly dissatisfied

with payment of fees such as registration and for medicines in pharmacies when the facility was out of stock.

Scaling up services to increase uptake of care featured in the documents. This corroborates the narratives from the rural community leader about the low coverage of facilities. Many communities for example were underserved, with many sections lacking facilities which limited their access to care. Despite the MOHS (2015)-Sierra Leone Basic Package of Essential Health Services 2015-2020 promise to provide services to all people including the most isolated communities, discourses revealed that many particularly in the hard-to-reach communities lacked access to care due to supply factors for example distance to facility and demand factors such as culture (Ensor & Cooper 2004; Sachs 2001; Thaddeus & Maine 1994). In summary, the policy documents were sometimes inconsistent with the reality that many participants narrated they faced in their health needs.

Relationship to the Conceptual framework

Social capital potentially interacted with other forms of capital. The DFID (1999) framework puts emphasis on assets (capitals) which can be social, human, physical, economic, financial, and natural as providing the base for family and community management and the means of sustaining family and community health. These assets are presented by DFID as capacities to influence how families and communities respond to a disturbance such as malaria (DFID 1999). Social capital related to these other concepts in that they interacted with each other and enabled family and community management, as discussed below.

Social Capital and Human Capital

Examples of human capital were the community health volunteers, volunteers in formal and informal groups and the facility management committee. Social capital enabled groups to derive required human capital in reciprocal labour sharing arrangements. It was also manifested in knowledge sharing in collaborations between traditional healers and health practitioners combining traditional knowledge of plants used by herbalists with scientific knowledge. In all cases, social capital interacted with human capital so that people could develop and access resources for community health (Flora & Flora 2004; Chaskin et al 2001). In families, parental interest in and support for their children enabled those children to increase their human capital in learning (Edwards 2004) about malaria in school health clubs, creating demand for services from their peers.

Social Capital and Natural Capital

Natural capital referred to farmlands and rivers when applying the natural capital component of the study framework here. Social capital interacted with natural capital when communities undertook farming and fishing activities. Natural capital was influenced by human activities through individual and collective human action. In this sense, social capital played an important role in people obtaining and providing access to natural capital. The findings of the current study appear to echo previous studies showing the inherent capability that social capital brings to help gain access to resources, reduce risks and hence to enhance health (Adger 2003: Pretty & Ward 2001; Carroll 2001).

Social Capital and Financial Capital

Social capital related with financial capital as trust enabled communities mobilising community funds for obstetric care (Gram et al 2019; Witter et al 2016) and women involvement in income-generating activities in mother groups, relating with the financial capital component of the study framework. Communities also could seek outside financial assistance (Kulig 2000), reflecting the linking capital type of social capital. The contribution of financial capital was to increase the capacity of families and communities to withstand impacts and vulnerability to malaria.

Social Capital and Physical Capital

Social capital enabled informal women groups and youths constructing physical structures such as fences and toilets for the facility. Youths made hammocks local materials for transporting ill people to the facility. Taking together these resources provided the means of sustaining families and communities. The assets and resources-social, human, physical, financial and natural interacted with one another and influenced collective action in the response to malaria.

The study communities, whilst very poor, were often well-endowed with forms of social capital including bonding, bridging and linking capital (Aldrich & Meyer 2015; Magis 2010; Ostrom & Ahn 2007; Putnam 2000. Carroll 2001). The prevalence of different types of capital was important for different groups. Their contribution to improving access to care is discussed.

In the current study, bonding capital was evident in forms of family support in ill health. The value of networks of strong and bonding ties lies in their tendency to provide emotional and instrumental support in times of illness. They were the immediate sources

of care available to the family. Bonding capital related to the study framework in forms of social support. Social capital as bridging capital represented the inter-community networks that gave individuals better access to resources and information, as well as more opportunities to negotiate support (Harpham et al 2002; Carroll 2001). Bridging capital was evident in community-based structures such as the facility management committee and religious organisations. Such bridging ties enabled the involvement of communities in implementing the malaria control programme. Religious organisations provided health information that complemented malaria prevention efforts. Communities with greater access to bridging relationships were more likely to have the necessary knowledge and resources to practice healthy behaviours (Story 2013). It was critical to community management as it enabled for example the facility management committee to mediate with the health facility in all activities to improve health outcomes. Although bonding social capital was important for immediate health needs more commonly available resource in families, bridging social capital as in the facility management committee and with religious organisations provided opportunities for mediation and health information.

The findings in the present study are similar to previous studies showing that linking capital is particularly important for communities poor in resources (Rocco et al 2014; Szreter & Woolcock 2004; Ahmed et al 2004). Participants spoke of the community involvement with health promotion programmes including the malaria control programme, international NGOs (Cause Canada for mother groups, ACF for infection programmes, CRS for health information), local NGOs ('Pikin to Pikin', NACSA), UN Agencies (UNICEF, WHO, FAO) and Religious organisations. Youths had links with government agencies who provided them tools for environmental cleaning activities. Linking brought together organisations in the search for solutions to health problems in the same community. For example whilst Cause Canada focused on malnutrition in women's' support groups, ACF focused on infection prevention in providing hand-washing machines. UNICEF focused on education materials on malaria for children. The malaria control programme focused on supply including the provision of hospitals, and provision of preventive tools such as bed nets, curative services such as antimalarial tablets and on other supply factors such as health information. Previous research has argued that by combining different resources and different kinds of knowledge, linkages generated complementarity in the form of mutually supportive relations between actors (Carroll 2001). It was also evident in the provision of health information in communities through health talks in hospitals and community health workers. However, this dimension of social capital is related to power due to the top-down nature of interventions (Ferlander 2007; Kunitz 2001). This is applied in my study for example where participants

narrated the failure of organisations in health programmes to involve communities in the formulation of programmes and have not adequately considered whose needs are being met (Burns et al 2013)*.* Linking ties also brought in external resources in bed nets from religious organisations to further complement prevention efforts (Nwokoro 2017). The findings in this study revealed ways in which the three types of capital discussed-bonding, bridging, and linking social capital, would contribute to family and community management in relation to malaria.

4.2.5 Summary

In chapter 4, I explored the contribution of social capital discourses to family and community management. The contribution of social capital was in how individuals provided social support in family and participated collectively in community action to improve community health. Social capital acquired in the context of family and community was an asset that was seen as helping in minimising malaria risks. Family social capital was reported as having a direct effect allowing family members believe they were cared for. Community social capital reflected activities undertaken by community groups to improve health outcomes for the community as a whole. Community social capital was also revealed in communal institutions. Next I present the discourses on Volunteering.

Results Chapter 5: Volunteering

5.1 Introduction

Volunteering can be defined as unpaid work that intends to generate value for both the individual volunteer and community (Smith et al 2016:10). The discourse recognised benefits to both volunteers and the community by making their health conditions better. Sierra Leone like other low-income countries has a dire shortage of health care workers. To address this health workers were selected as volunteers by the chiefs in communities from people who were respected and trusted, to complement the work of formal health workers (Takasugi & Lee 2012). The research found that men and women from within communities volunteered in various roles in the malaria control programme, in applying the human capital component of the conceptual framework for this study. In the context of this study, participants referred to the volunteers as community health workers, who operated at the community level and provided a range of services. *Figure 5.1* illustrates activities and roles performed by volunteers which included: providing malaria treatment within the communities; facility management committee members; volunteering mediation services; mother support groups volunteering child nutrition services and health and malaria education; women in informal groups volunteering constructing toilet facilities; and youths in environmental sanitation. All categories were involved in advocacy and awareness raising in communities. This is an important finding because inclusiveness and the participation of diverse groups in decision-making and in community structures are key characteristics of family and community management.

Figure 5. 1: Activities of Volunteers in Health Programmes

In this Chapter, I explore some of the volunteering literature (section 5.1.1) relevant to the findings (section 5.2) and then present and discuss the volunteering findings (section 5.2.6). I conclude the chapter (section 5.2.7) by considering that volunteering contributed to improving health outcomes and family and community management and interacted with services provision in several ways including: inclusion, ownership, participation and as hubs of volunteers who were present in all communities, responding to emergencies and working in challenging environments.

5.1.1 Brief Literature Review

This section highlights some of the literature relevant to the findings. The volunteering literature (UNV 2018; Cornwall 2003) has documented the role of community health workers as volunteers. UNV (2018) highlighted several examples of how the presence of formal organisations influenced decisions around the inclusion of women and other marginalised groups in health programmes. Cornwall (2003) noted that women's involvement is often limited to implementation and caring roles. These literature can help understanding local volunteering as in this research.

The review highlighted community self-help initiatives undertaken by women.
Bhattacharyya (2004) noted that self-help builds and utilises agency, mobilises peoples' cultural and material assets including, indigenous technical knowledge, tools, labour, and most importantly in the context of volunteering avoids dependency. Volunteering is linked to community management as a resource and social capital (Smith et al 2016). As a resource volunteers freely gave their time to make a difference on the issues that affected them and their communities, often in the most difficult of circumstances. As social capital volunteerism connected people, enabling them to work together to tackle adverse conditions in their environments.

The review highlighted multifaceted reasons for volunteering including deep passion for the work, own troubled past, feeling of making a difference and own personal benefit (Hardill & Baines 2007; Snyder & Omoto 2000). Next I present the results on Volunteering.

5.2 Results

The analysis identified four main sub-themes relating to the volunteering component of family and community management: inclusion; ownership; environmental sanitation; women volunteering. These are described in detail in the following sections.

5.2.1 Inclusion

Inclusion referred to the role of volunteering in taking services to the poorest and most marginalised communities. In this study, marginalised communities were those that lived in hard-to-reach areas where location and distance costs were reported to impact negatively on service utilisation. Throughout the research, I found examples of how community volunteers were helping to extend the reach to communities with services such as antimalarial drugs, health information and early referrals.

To realise their tasks, community health volunteers attended training sessions organised by the health service. They were given basic training on major health programmes which included: dissemination of information on public health issues; mobilisation of communities to participate in health sector planning; malaria education; community-based malaria diagnosis and basic treatments using rapid diagnostic tests; and provision of malaria treatment within the communities:

> *'These ones are people that have been trained for various community interventions'* (Rural male, health practitioner).

The training helped to mobilise and sensitise communities to actively participate in utilising the available health services, provide health education and treatment of uncomplicated diseases. Given the nature of duties carried out by community volunteers, the training may have helped them to increase their capacity to undertake such tasks.

The following quotations illustrates how these participants felt about the difficulties nurses face in taking care to the hard-to-reach and the ability in community health volunteers to find people with illnesses even in remote locations:

> *'So physically the nurses have a challenge to reach the people who they cannot reach because of mobility and distance to the facility and the people also have a challenge because of distance to access'*
> (Male, local NGO manager in Moyamba*)*
> *'*
> *We have community health volunteers who go in and out to the interior. But these volunteers go and 'fish' sick people. Even when the people cannot move to the facility, the volunteers take supplies of medicines to them'*
> (Male, health practitioner in Moyamba).

The first quote reflected a supply-side barrier of lack of transport and long distances faced by nurses in taking services to communities. Distance was a much greater barrier for communities to access services. It also reflected less access by women to household resources to pay for transport or cultural influences to use traditional medicines rather than going to a facility. The second quote reflected volunteers involving in taking services

to remote communities not reached by nurses from the facility and in identifying patients in those facilities who would otherwise remain hidden. The volunteers thus provided care and included the sick in service provision. In this sense, the role of the volunteers was seen by the practitioner to increase community participation in the malaria control programme. The volunteers also complemented existing services and contributed to bridging the gap in lack of access to services. The two quotes are representative of a general understanding of barriers communities face in accessing services.

An understanding may be required on why despite hospitals existed some communities as in this narrative did not visit them. Health care services provided inputs to maintaining individual health. Those going to the hospital may receive treatment, but at the same time, there were much larger numbers who were not able to go to the base hospital who remained untreated but faced barriers to care. Additionally, the hospital treatment it seemed was temporary, not radical. It did not seek to alter the underlying causes to deal with the root of the problem of malaria but to identify, treat and advice individuals who were susceptible to those causes. It may underscore the need to take services to locations particularly for poorer and hard-to-reach populations rather than them coming to the facility. Next is the discourse on Ownership.

5.2.2 Ownership

Volunteers were immersed within the communities they served as they lived in and were selected by local leaders, which strengthened local ownership. It was an allusion to the participation and representation of local people in health programmes. This was important as it empowered local communities which can be an important element for the success and sustainability of programmes. Volunteers were also more likely to be listened to as communities were reported to have more trust in them. The fact that community health volunteers were known to and had the trust of community members was cited in the research as one of the reasons why they were able to be effective in reaching out to communities and getting them to trust in and adhere to what the volunteers told them:

> *'Most time the communities adhere more to them than to us. They live with them in the communities, they respect them and with them serving them in that capacity they appreciate them and most time they adhere to them they trust them more'*(Rural male, health practitioner).

The above reflected there was respect and trust between community health volunteers and communities and connectedness with the community as one of their own, which were important requisites for the effectiveness of for example health information

disseminated by volunteers and for monitoring compliance with by-laws. People were more likely to have more understanding and make the connection to the causes of malaria thereby enhancing their mitigative capacity. Community ownership and management were demonstrated by the communities as people placed more reliance on volunteer's delivery of health services and information. However, health information from volunteers may not necessarily lead to a change in health seeking behaviours due to other demand-side factors in accessing care.

Community ownership was demonstrated in the involvement of local leaders who volunteered to serve in the facility management committee. The committee was a community structure consisting of five members and led by a chairlady. It was created jointly by the district heath medical team and the community leadership to facilitate links between the communities and the health system at the community level. In essence, they were organised gatherings of volunteers through which individuals, community leaders and health professionals engaged in health problems in the community:

> *'Every month we meet and deliberate on certain issues on the progress of the health facility, peripheral health unit'* (Rural male, school head teacher).

The above quote reflected that decentralisation of the decision-making process to the local level was found to include communities in monitoring health services provision. This head teacher saw shared leadership or a sense of ownership to be of importance to the communities. There was a merging of practitioners and local knowledge to help generate solutions to existing problems that were seen to be locally appropriate and sustainable. Facility management committees enabled local leaders to take more active and meaningful participation in influencing health outcomes in their communities.

Volunteering can incur significant opportunity costs, and a person's ability or willingness to place community needs before their own may be weakened by poverty. Often volunteers were themselves from poor and marginalised communities. For example the facility management committee was not always fully functional in certain communities. Some members lacked interest and motivation because the work was unpaid. They did not participate regularly in meetings and rather preferred to go to their gardens:

> *'Since this is a sacrificial job they are not paid, the members do not participate fully as they do not get stipend. When it is time to meet we call them some do not comply they say I have domestic problems or am going to my garden'* (Rural male, head teacher).

> *'It is the farm work. Where they get is where they are, it is the poverty (*Rural male, previous patient).

The quotes reflected that there were structural and professional personal challenges facing committee members which were seen to have negative effects on their performance. In the first quote the structural challenges were that volunteering was an unpaid activity and a commitment to poor rural communities. It often had an opportunity cost as time spent in meetings was at the cost of foregone livelihoods from their gardens. The professional challenge was the lack of full participation as they were selected by their communities to serve and were letting their communities down from that perspective. The structural challenge in the second quote was poverty. In the second quote attending committee meetings had implications for their livelihoods as it limited opportunities to engage in economic activities such as farm work. Like the first quote, it provides an example of what things the volunteers might lose by volunteering for other activities.

A frustration expressed by local actors was that external organisations adopted top-bottom approaches and did not support ownership as they failed to engage with local leaders in the community. Top-down approaches entailed policy makers formulating action plans that lacked consultation with those parties likely to be affected and endeavouring to convince communities to actively participate in their implementation. This youth leader described how he felt about this approach:

> *'Then the organisations working in the interest of health. I feel some time the bottom-top approach should be paramount. As they say' he who feels it knows it'. If we make the people part of the fight, we can eradicate the animals in our community. When people take ownership of any development, it is sustainable. If people do not take ownership it is not sustainable. If we talk to the communities they can tell us how the malaria spreads. Let the people tell us how malaria spreads*' (Male, youth leader in Moyamba).

This quote reflected including people in the fight to overcome malaria as a more viable approach to the eradication of the disease. Local people who lived with the disease were more aware of their environment and can develop locally appropriate solutions. Top-down approaches had disadvantages as they lacked ownership and were less likely to be sustainable. In contrast, a bottom-up approach which seeks to engage communities in identifying and prioritising their health needs may create sustainable health behaviours. When peoples' knowledge is sought, incorporated and built upon during planning and implementation, then they are more likely to sustain activities after project completion.

These statements reflect the preferred position that dominates the health promotion literature of programme 'ownership' by communities. Empowering the community in this

way may make it more likely that a sense of 'ownership' will develop, thereby increasing the prospect of long-term success. If people do not feel vested in a programme they will not take it on when the funding runs out, or even work towards new funding When people are involved in the planning and implementation of programmes as active beneficiaries, they reported being more likely to use the services. This shows how volunteering may open the space for grassroots knowledge, learning and action that relies on locally derived strategies for community participation that may lead to improved health outcomes in malaria control. Next is the discourse on Environmental Sanitation.

5.2.3 Environmental Sanitation

Environmental sanitation referred to approaches in adopting healthier habits in regard to sanitation and environmental hygiene. It was organised by youth leaders. Youth leaders did this for two main reasons. Firstly, there were by-laws in communities for monthly cleaning which needed to be organised. Second, some communities such as 'Youndo' were in large townships which required dividing communities into zones for the cleaning activity to be more manageable. When undertaken, it may potentially mitigate the conditions in the environment such as unsightly refuse dumping sites and breeding habitat for mosquitoes that caused malaria. This discourse drew attention to the capacity to develop preventive strategies. More frequently participants linked malaria to the presence of mosquitoes in unclean or dirty environments:

> *'One is lack of environmental sanitation, making gardens, planting corn around our dwellings, we do not brush, and we should clean around our dwelling places, discard empty cans '*(Rural female, health practitioner*)*.

> *'I think of environmental sanitation is one of the key factors of malaria in my community. And I can say also in other surroundings, these are also as a result of the same environmental factor' (M*ale, youth leader in Moyamba*).*

In the first quote, the health practitioner reported the relevance at the individual level where people had poor environmental habits that involved not only cleaning and brushing but also removing debris from their households. In the second quote, the youth leader reported the relevance of moving towards community involvement in environmental sanitation and. adopting a 'population approach' that seeks to control the spread of malaria. The recurring focus of participants on the need for environmental sanitation demonstrates they saw it as a major reason for the spread of malaria, reflecting the predisposition of individuals and community to malaria infection and their ability to mitigate its risk.

Community involvement in environmental sanitation was seen across generations, although particularly undertaken by youths. Moyamba district has a youthful population with sixty per cent of its population under 25 years old (Statistics Sierra Leone 2015:25). In spite of adversity, many youths were able to voluntarily offer their services to collectively involve in cleaning the environment and offer advice on avoiding malaria.

Environmental sanitation undertaken by youths was frequently mentioned by participants. The youths offered their services as volunteers and mobilised resources in their labor to provide services in the community. Examples of their responses included:

> *'The youths clean last Saturday in the month. They clean all public places, the streets, the hospital quarters and they advise people to clean their surroundings and they do cleaning to help the malaria out of the community'* (Rural female, previous patient).
>
> *'We have youth groups that volunteer to clean areas, we are here to support them. Some time we give them tools, given by government. We give it to them and they return it after cleaning- we say 'use the available tools to get the needed tools'* (Male, youth leader in Moyamba)'.

The first quote is another example of a bottom-up enterprise. The youths freely gave their time to make a difference in their communities, often in highly difficult circumstances. It demonstrates youths being involved in awareness raising and environmental cleaning activities to reduce the morbidity and mortality from malaria. The second quote demonstrates reciprocity which can be considered as a social capital input. Reciprocity was from government sources as well as from the community. Using tools given by the government and support from the community demonstrated the vertical and horizontal linkages to make existing situations better. The narratives and perspectives here demonstrate a strongly articulated sense of place, community and health that contributed to peoples' perceptions and experience of family and community management in relation to malaria. *Figure 5.2* shows the collective action of youths, men and women in environmental cleaning in Moyamba township.

Figure 5. 2: Youths in environmental cleaning in Moyamba

There were challenges in environmental sanitation. As in the case of women groups that were not organised and lacked leadership in the 'Gbangbatoke' community, this school teacher expressed lack of unity even in the Moyamba town community where actions in some sections resulted in socially negative outcomes in their defiance to clean their environments:

> *'Salina' community is difficult. The chiefs are doing their best but the community find it difficult to clean the environments. Especially the 'Salina' community. They say they have been paying local tax and the authorities are not doing anything so they won't do any community work to clean the environment'* (Male, school teacher in Moyamba).

The example illustrates that volunteering was not always straightforward and not all youths were involved in environmental sanitation as in the 'Salina' community. In the face of the risks of malaria from unclean environments, other factors such as the basic services that people pay taxes for and leadership in the community that influences communal work were important.

Additionally, environmental sanitation was also undermined by the lack of waste disposal facilities and dumping sites:

> *'The action is to identify one place to throw dirty. Here we throw dirty in the water from which people drink. There is no dumping ground here. Except some people dig hole where they throw dirty. We do not have dumping ground for the community'* (Rural female, head teacher).

> *'Basically it is untidiness when people refuse to keep their community clean. If you go round we do not have a garbage facility where people gather garbage and someone come to collect it to a center. But come rainy season it gets worse and worse, more harsh on people. You have these potholes and some of these people do not know the danger of maintaining those pot holes. They do not know that where water settle it is the breeding ground for the mosquitoes. So at night the mosquitoes bite people. So it is not only the treatment it is the public awareness'* (Rural male, religious leader).

These participants saw efforts at the community level in environmental sanitation as needing support. Poor sanitation and environmental habits in communities, the lack of health education and awareness of danger signs in the public, and government failure to provide dumping facilities undermined community efforts. In all cases, the implication for family and community management was that the capacity for collective action in environmental sanitation was likely to be weak.

Finding one uniform explanation for unclean environments was difficult. While there was cooperation on environmental sanitation in some communities, this NGO participant gave context-specific illustrations that undermined environmental sanitation.

> *'Some communities have communal labour like cleaning. But in most communities that habit is not part of their culture. But some communities do it. Cleaning is a major component from the Ministry. You can teach them but you cannot force them. In some communities they have a law for this but in others they do not' (*International NGO participant in Moyamba).

As noted in this quote the cultural context in certain communities was fundamentally at odds with efforts at environmental sanitation by volunteer and the government policies in some communities. Peoples' perceptions about malaria, and its treatment were influenced by their culture and top-down approaches on environmental sanitation were likely to have meaning for them in certain communities.

Some participants emphasised 'neighbourhood effects'. These were conditions in the neighbourhood surrounding homes that can have major health effects. This female youth leader and the health practitioners focus group reported that attitudes of neighbours such as poor healthy habits of neighbours with unclean environments influenced households and communities overall level of health:

> *'My house is an example. My area is clean but my neighbours. My own compound all to the boundary is clean but watch my neighbours, the dirty, the grass'* (Female, youth leader in Moyamba).

> *'The environment is key, you can clean your compound but your neighbour will not'* (Health practitioners focus group).

These quotes reflected peoples' concern about unhealthy environments and the differences between individuals in their approaches to keeping their environments healthy. The narratives reflected that people saw environmental habits of their neighbours and community as affecting the individual and community's health. Generally, people viewed a sanitary environment was crucial to malaria control, so seeing examples of poor sanitation as problematic.

Community health volunteers may have improved health outcomes by providing health information and outreach services to communities who needed it, however, they were beset with several challenges including working in difficult terrains, lack of rain gear in the rainy season, lack of positive responding from members of the community, and lack of motivation due to nature of volunteering as unpaid work:

> *'The challenge now is they are expecting money more than doing the work. They have put finances before work'* (Moyamba focus group).

> *'A lot of challenges, thinking of the work as you start the work you are a volunteer that is one challenge. We tell them you are working for your community, you are a volunteer, and one day you will be paid. They are volunteers that is one challenge as some people work for money. Even to get the reports from them is a problem. But we tell them they are working for their communities, one day they will benefit'* (Rural female, health practitioner).

The first quote from the Moyamba town focus group participant reported that lack of pay threatened the motivation of volunteers. It reflected that non-financial incentives may not be sufficient to ensure good work performance and can lead to low work morale. The second quote reflected responsibility within the community as a reward for voluntary service. In this sense, the volunteers did work that was value--driven, and generated something of value for both volunteers and their community and benefits in the future. It manifested the utility of volunteering.

5.2.4 Women Volunteering

Women volunteered their services as community health workers, membership of child care groups, as chairlady's of facility management committees. Women performed caring roles for the family at home and patients in health-based caring. A key finding in this study is that women volunteers played a vital role and were more active than men in participating in meetings to improve health outcomes:

> *'Yah the role of the women in the community is very vital. In the first place when it comes to meeting a good number of them participate. I also remember at the time of Ebola women came together to help the health workers'*
> (Rural male, head teacher*).*

This quote reflected that women tended to be the ones responsible for representing their households during community meetings and that men were less likely to fulfil this role. They carried out similar roles in the Ebola epidemic where they were actively involved in the Ebola response.

Woman participated in community actions in formal and informal organisations. The formal organisations were the mother support groups, consisting of up to twenty women headed by one of them. The groups were community based and members were selected from women resident in the community. The informal groups were independent groups of women that came together in health promotion activities. The mother support groups were established by the international NGO Cause Canada:

> *So we have the mother to a mother support group. We have trained them with a lot of refresher training. So those groups do home visits, they do health talks for malaria and other health conditions'* (Male, International NGO in Moyamba).

This quote reflected the mother support groups were involved in health promotion activities that can have a beneficial effect on health outcomes in their communities.

Mother support groups focused on improving infant and young child nutrition. Malnutrition can be an underlying cause contributing to child morbidity and mortality. The relation between malaria and malnutrition and the resulting mortality was highlighted:

> *'But at time where we have high rate of malnutrition, we put our strength there. We never know the children we are saving from malaria or malnutrition what they would be'* (Male, International NGO in Moyamba).

The quote reflected the importance this NGO gave to sufficient nutrition for the growth of children and making them less susceptible to mortality from malaria.

Although initially concerned about child nutritional activities, the groups expanded to include income generation projects. The women described being engaged in self-help to become more self-sufficient in food products and be able to earn money for other needs in their families:

> *'At the same time they mobilise themselves for 'garri' (maize) processing, for cassava peeling, they do rotational work between households. They do weeding and at the same time they harvest together. At time we get them involved like in planting groundnut. From this activity they can support themselves'* (Male, international NGO in Moyamba).

This quote reflected the programme as affecting women's empowerment, providing them with opportunities to meet collectively for various income generation and farming activities. The cash they realised supported themselves and their families and enabled them to respond to threats such as malaria. In this sense with this income, they prepared themselves for emergencies like children's illnesses with financial and economic means, for instance by saving cash to pay for such emergencies, relating to the financial capital component of the study framework. They were also spending money independently and experienced this as a source of power. The time the women spent together increased their awareness of women's issues in their daily struggle to assure the nutrition, health and education of their children. Their collective action in harvesting together showed the women supported each other and added to social capital, demonstrating a relationship between volunteering and social capital.

Women volunteers were also participants in informal groups and were reported as involved in constructing toilets and security fences for the health facility. These women supplemented the work of formal health providers by contributing their labour and local materials for the construction. When asked how they got materials for the construction of toilets, participants reported from their own sources:

> ***'**They came with all their resources. The community only volunteers at least to give them stones, the women break stones and bring water'. They also bail stones'* (Rural female, health practitioner).

> *'No out of their willingness, as their own support in terms of development to the community' (*Rural female, health practitioner).

These examples refer to the capacity in women to use self-sourced local resources voluntarily in providing material and labour inputs for constructing toilets for the facility. It seemed to reflect their satisfaction with being able to make a contribution in their community to improving health outcomes. By volunteering to become active in other areas of community life, they provided continuity that is essential in health programmes. The activities of the women implied forms of reciprocity between their group and the community. They gave back to the community and were seen in the community as capable of providing something of value to others and for future generations:

> *'From my own experience it is good, like for this work going on, for example, every morning they come to draw water from the well, we try to stop them, they say the hospital is for them and their children'* (Rural female, health practitioner)

This quote reflected how the health practitioner saw health provision as a community activity rather than solely a task for health services. This shaped health outcomes in several ways. When women strove for basic levels of sanitation in toilet construction, they saw themselves as having a positive influence on health status in the community. The women set an agenda that reflected their priorities for their children and community by investing their labour to achieve their children's health.

Communities through voluntary work undertook activities for local security and protection for women nurses in the health facility:

> *'Like here there are only women, this is why we want them to have a fence. We are working as a community to give them a fence so that they are not attacked at night and medicines taking away' (*Rural male, community leader).

Despite providing security for hospital staff and medicines would normally be the responsibility of the health services, this community leader reported they saw security for women and medicines stocks as a priority in the community. What is not said in such statements is as important as what is said. The narrative both reveals and hides the dependence of organisations in health programmes in low-income settings, on the contributions of volunteer work in this case in constructing a fence for the security of the health facility. *Figure 5.3* shows a fence construction for the health facility in 'Taninihun Kapuima 'by volunteers. Both men and women were involved in the construction.

Figure 5. 3: Fence Construction in Taninihun Kapuima

In contrast, there were other communities where women in informal groups were not able to make positive contributions to health outcomes due to the lack of organisation and leadership:

> *'But at the moment the women are also not organised. Because there is no authority, everyone fears, if authority is not there even the woman, will have fear. It is difficult for us to take the initiative, out of fear'* (Rural female, head teacher).

The quote reflected the importance of local authority and stability in some communities for women to participate in health activities. In this case, volunteering was context-specific and dependent on the leadership context. The contrasting results suggest that

women activities were more likely to be successful in communities that were organised with strong leadership and less likely in communities that lacked leadership. Thus, different types of contexts provided different opportunities. It was an invitation to consider the role context played in shaping the effectiveness of women volunteering.

Further success in women volunteers influencing health seeking behaviours may have been limited by power differentials in communities. Access to care for women was limited by cultural practices which gave men control over household resources. As a result, men decided on financial priorities for the family. Men were the sole determinants of family's economic situation, further disempowering women. This female district officer strongly expressed the view that health care seeking decisions were mostly done by men, the head of the family:

> *'Well as long as the money is from the man, it is difficult for the woman to have a say. The man decides which needs to prioritise'*
> (Female, district officer in Moyamba).

This quote reflected how in the context of power imbalance in health seeking decisions this frames men as decision makers. Men played an important economic role, including paying for transportation to and from health facilities and hospital services. This participant recognised women to have less agency than the men and a woman's degree of influence within the household on health related decisions was limited when men prioritised other needs. The culture was suppressing to women who needed care and it appeared to remain a cause of delays in seeking care. The findings reveal some of the ways in which power dynamics played out in struggles about access to resources between men and women sometimes in the same household.

A related discourse was from men who thought that, like women, they too should benefit from services in the facility:

> *'One time I said to myself: why the government, the NGOs focus on under 5s, lactating and pregnant women? But Mr Brewah you have protected them, they sleep under tent but me I go and 'charge', I feel fine, I go out and the mosquitoes bite me. Why don't you care for the entire family, make provision for all the people not just the children ad mothers? So this has been on my mind I want the government and the NGOs to know that they so care for the mothers, the under 5 and the lactating but not for the father, maybe this is why the malaria is there'*
> (Rural male, head of household Fakunya).

The policy of providing bed nets to protect only women and children is questioned by this participant who called for services to be extended to include men. The context in this

discourse is the vulnerability of the whole household to malaria, not only women and children.

Despite the challenges, some volunteers commented that volunteering gave them the opportunity to take on new roles and responsibilities. An example was provided by the female community health volunteer:

> *'Nurse made me become a community health volunteer. My people do not have the upper hand so I told her I want to work under you. So nurse made me become community health volunteer. I am not doing it for money'*
> (Rural female, community health volunteer).

In this sense, the motivation of this female volunteer seemed intrinsic as she received no apparent rewards except the role as a volunteer and the feeling that the work was worthwhile. Other factors include her desire for knowledge and the empowerment that knowledge could bring. She also saw the opportunity to contribute to improving the health of her community.

In summary, women volunteered their services to help build health resources in facility infrastructure and sanitation facilities. Women in mother support groups and informal groups were involved in collective action to improve health outcomes. The threat of disease had a positive effect on stimulating collective action among the women who drew on their resources and looked upon malaria as an opportunity and not a threat. Women contributed to building capacity and promoted self-activation and self-empowerment. More specifically women in mother support groups were seen as privileged as local experts by experience who were serving their communities. With the support of the International NGO Cause Canada, they acquired more knowledge to train other mothers and as they engaged in income-generating activities, linking with the financial capital component of the study framework. The mother groups also were seen as a source not only of greater self-confidence and esteem but a real and present source of social empowerment linking with the social capital component of the study framework. Next follows the Policy discourses.

5.2.5 Policy discourses on Volunteering

The documents do offer mentions of the contribution of volunteering to community management in relation to malaria. The findings on the inclusion and ownership sub-themes are presented in the following sections.

Inclusion

The policy documents acknowledged the role of volunteers in providing services to all communities including the hard-to-reach:

> *'Community health volunteers bridge the gap between the health facilities by bringing the clinic to communities and communities to the clinic'*
> (MoHS 2016:7) - National Community Health Worker Policy 2016-2020.

In many settings where access to health services was limited, especially in isolated rural areas, community health volunteers gave advise or care or early referrals to patients and their families. The policy documents corroborate findings in the interviews and focus groups on the role of volunteers in extending the reach of services to the poorest and most marginalised, and their ability to use their networks within communities to link individuals to health services.

Ownership

According to the National Malaria Control Strategic Plan, volunteering was identified as one of the components needed for the involvement of communities in facing the threats of malaria:

> *'Community involvement in malaria control is mainly through the participation of individual members of the communities, such as community health workers'. Their roles include dissemination of information on public health issues, and mobilization of communities to participate in health sector planning, monitoring, distribution of long lasting insecticidal nets and Sulphadoxine- Pyrimithamine for Intermittent preventive treatment for pregnant women, serve as spray operators for Indoor residual sprays, health/malaria education, malaria diagnosis using rapid diagnostic tests, and provision of malaria treatment within the communities' (*MoHS 2015:83)-Sierra Leone Malaria Control Strategic Plan 2016-2020.

Referring to volunteers selected from communities being involved in the implementation of the malaria programme seems to map this policy to the reality in communities. Similarly, the role of volunteers in fostering community ownership is emphasised in the Basic Package of Essential services document:

> *'Community health workers can play a significant role in ensuring community ownership and accountability of the health system to the communities it serves'* (MoHS 2015:28)-Sierra Leone Basic Package of Essential Health Services 2015-2020.

The above provided an expanded role of community health volunteers that linked the service to communities and held the health system accountable for providing the

promised services. This policy document also envisioned ownership through community structures such as the facility management committee:

> '*Communities can be involved in the health system through management structures such as Facility Management Committees'* (MoHS 2015:27)-Sierra Leone Basic Package of Essential Health Services 2015-2020.

The above envisaged community leaders and practitioners coming together in the facility management committee to make joint efforts in improving health outcomes.

In summary, local volunteering both formal and informal and compulsory encompassed a broad array of activities to support family and community management in relation to malaria. It was manifested as voluntary cooperation, adaptation and agency and self-organisation amidst challenges of malaria. Volunteering as manifested by women and youths interacted with the health service in providing care at the community level. Women and youths were involved in different categories of volunteering. *Figure 5.4* illustrates the configuration of volunteers, describing three types including formal, informal and compulsory volunteering. The 'formal' category refers to the volunteers in facilities such as the female volunteer, women in formal organisations such as mother support groups, and women in community structures such as the facility management committee. The 'informal' category refers to the volunteers involved in fence and toilet construction. 'Compulsory volunteering' refers to youth volunteers involved in cleaning the environments as fines were imposed in communities for non- compliance. 'Formal volunteering' such as in mother groups was reported in all communities whereas 'informal volunteering' in women groups constructing fences and toilets was reported in 'Mokorewa' and 'Taninihun Kapuima' communities. 'Compulsory volunteering' such as youths involved in environmental sanitation was reported in communities with strong leadership.

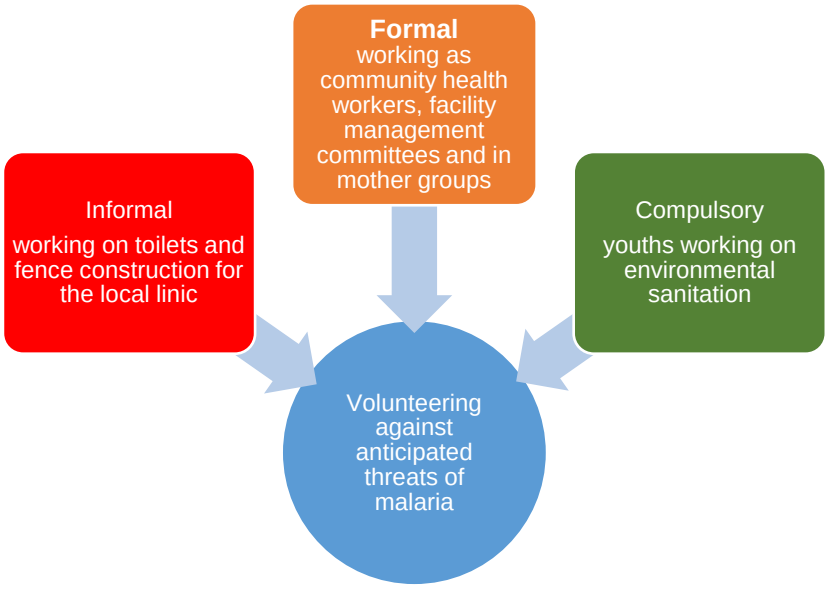

Figure 5. 4: Different types of Volunteering in communities

Volunteering discourse referred to many social actors (community health workers, community leaders, facility management committee members were volunteers. The idea that responding to disease may provide a 'window of opportunity' was strongly articulated by participants. For example, it provided opportunities for volunteering and opportunities for community participation in consultations on health promotion activities in the facility management committee. The discourses also illuminated collective action. The organisations in health programmes acted as a catalyst and assisted in providing support in activities undertaken by adult men and women in formal and informal groups, youths and school children. By addressing gaps in the health service provision that disproportionately affected the poorest and marginalised, community health volunteers were seen to provide critical and valuable support in malaria control.

5.2.6 Discussion

The present chapter reported the discourses on volunteering as a component of family and community management of malaria in Moyamba, Southern Sierra Leone. Four main discourses were identified namely inclusion, ownership, environmental sanitation and women volunteering. Firstly inclusion discourses reflected the ability in volunteers to take services to poorer and marginalised people including the hard-to-reach. Secondly, ownership discourses reflected the embeddedness of volunteers in communities. Thirdly environmental sanitation discourses reflected youths, both men and women involved in cleaning their environment. Finally, women in volunteering discourses reflected the role played by women as key providers of care in homes and to patients in communities. It

recognised community-based structures where women came together for livelihood activities.

Inclusion discourses emphasised improving health access to communities. Malaria is endemic in Sierra Leone and is the leading cause of morbidity and mortality (MoHS 2015:21)-Malaria control Strategic Plan 2016-2020. Shortages in the health workforce (Perry & Crigler 2014; Takasugi & Lee 2012) pose a serious obstacle particularly in the most remote areas where many in the population were not reached with services. Consistent with research conducted by UNV (2018), IDS (2015) and World Health Report (2000), the findings of the present study explain that community health volunteers can deliver basic cost-effective services to populations that have little access and would not otherwise get services.

Several examples from the field research highlighted how some communities lacked access to services, by either not having facilities in their localities or had distance barriers (Sacks et al 2017; Atkinson et al 2011; Ensor & Cooper 2004; Sachs 2001). They were seen to be excluded, actively disadvantaged and more at risk from malaria because of their marginalisation, exclusion and exposure (Brown 2016; Soors et al 2013; Atkinson et al 2011; Green 2009). The participant's narratives provided evidence of the exclusion from the decision making of the marginalised and vulnerable as reported for example by the Moyamba youth leader and the previous female patient. In this study, marginalised communities were those that were peripheral to the mainstream geographically, living in hard-to-reach areas and often economically and socially excluded. In contrast, other studies point to the marginalised as highly adaptive, are more emergent have greater flexibility (Perry & Crigler 2017; Kuecker & Hall 2011; Koblinsky et al 2010). Perry & Crigler (2017) and Koblinsky et al (2010) for example show that mothers and lay health workers can improve health indicators among very poor and geographically isolated families.

Ownership discourses reported volunteers playing various roles as community health volunteers, mother groups, as facility management community members and in youth groups. They were all selected by and based in their communities which strengthened local ownership of health programmes. The findings are similar in IDS (2015) who argued that the visibility of volunteers living in the community helped to build a sense of ownership and provided volunteers with direct experience of living in communities and understanding their needs such a health needs. This links with social capital as embeddedness opens up space for trust and reciprocity in relationships (IDS 2015:24). For example whilst volunteers attended facility committee management meetings, community members worked on their farms. Through participation in facility

management committees, women volunteers helped to ensure that services were relevant and responsive to communities' health needs. Previous research by Farnsworth et al (2014) found that decentralising the decision-making process, as including local leaders in the facility management committee, ensured that the community influenced implementing and effectiveness of health interventions. The findings are similar in Gilmore et al (2016) who argued that strengthening community actions by enhancing and working towards the empowerment of communities to improve ownership of their health actions is essential for promoting health outcomes. Pretty and Ward (2001) also argued that when peoples' knowledge is sought and incorporated during planning and implementation, they are more likely to sustain activities after completion of the intervention.

The *environmental sanitation discourse* drew attention to the capacity for preventive strategies undertaken by youth volunteers in cleaning their environments in some communities. Participants identified factors favouring mosquitoes included the bushes, garbage heaps, swamps and stagnant pools of water that surround many houses, led to poor environmental quality that made them more vulnerable to mortality from malaria. Previous research has noted that poor environmental sanitation was a key factor in malaria transmission (Bizimana et al 2015; Bates et al 2004; WHO 2000). WHO (2000) noted that children die from diseases largely due to poor water, sanitation and hygiene and poorly kept environments. When environmental sanitation is undertaken, it potentially reduces the conditions in the environment that caused diseases such as unsightly refuse dumping sites and breeding habitat for mosquitoes. It seemed to be a strategy that had a large potential for the population as it attempted to remove the underlying causes of the disease. It was also behaviourally appropriate. Once it became accepted and people adapted in certain communities it was no longer necessary to persuade people to clean their environments. The preventive measure brought many benefits to the population as a whole as it may have led to less malaria in those communities that embraced environmental sanitation (Norris et al 2008; Rose 2001). A finding in this research was one such measure was taken in the 'Youndo' community where participants described an innovative approach with zonal arrangements for environmental cleaning in certain communities with very large bushy environments. The zones had separate youth leaders. The novel element is that zonal arrangements facilitated collective action that made cleaning activities more manageable within their capacities. The relation to community management is that environmental sanitation was undertaken by communities themselves in an attempt to control the causes of malaria.
The lack of success in withstanding the threats of malaria in certain communities is attributed to what can be termed the' prevention paradox' (Rose 2001). A key finding in

this study is “the paradox of community health volunteering”. It is the problem of youth volunteers trying to undertake environmental sanitation for the whole community to build healthy environments in the face of the powerlessness to withstand the pressures towards poor environmental sanitation by the community themselves. Preventive measures which bring benefits for the population as a whole may offer little to each individual. It seemed there was a lack of motivation of people to clean their environments in some communities such as ‘Gbangbatoke’ that were seen to have weak leadership and were disorganised, undermining community management.

Youths invested their time and energies to improve the quality of sanitation in pursuit of containing the spread of malaria. In contrast to other actors, youths volunteers were involved in compulsory communal and environmental cleaning in certain communities where by-laws were enforced. In this view, such compulsory actions may fall outside the definition of volunteerism as there were fines for non-compliance (UNV 2018). Participants narrated that people often participated in compulsory collective action out of fear of community censure or other penalties. Despite this qualification, these expressions of “volunteering” were mentioned so frequently in the field research that they warrant attention.

There were variations in environmental sanitation. It depended on leadership and enforcement of by-laws. Communities which had effective leadership were seen to have had a profound influence on sanitation activities. Communities with weak leadership and disunity were seen to be unable to mobilise youths to undertake cleaning activities which undermined community management in such communities.

Women volunteering discourses involved women in both rural and Moyamba town communities who took part in the various activities in the malaria programme. Women undertook most caring for the family at home and patients in community. The finding is consistent with previous research which found that women were prepared to contribute time and energy to improve the health of their families and communities (Banerjea 2011; Cornwall 2007a, 2007b; Neysmith & Reitsma-Street 2000). However, in contrast to research conducted by Banerjea (2011) that men have little free time to volunteer as compared to women, the findings in the current study explain that men were also involved in volunteering as community health volunteers, community leaders in both rural and Moyamba town communities and as facility management committee members.

Women often emphasised opportunities to contribute to ownership of community-wide malaria activities, as the female community health volunteer. In applying the human

capital component in the conceptual framework (DFID1999), promoting women's involvement in the malaria program contributed to increasing gender parity more generally throughout the community. However in volunteering women in some communities felt they were disempowered as for example, they lacked control over household resources for ante natal care visits and did not get help from men in farming. Lack of access to household resources by women was a frequent discourse in interviews. Women in Sierra Leone face discrimination in virtually every aspect of their lives with unequal access to education, economic opportunities and health care (GIESCR 2014). Given their low status and lack of economic independence, women were rarely able for example to decide for themselves to go to a health care facility whether for visits, deliveries or emergency services as such a decision was normally in the hands of men (Witter et al 2006:10). A focus on gender equality is reflected in Sustainable Development Goal 5 (UNDP 2017) which aims at freeing women and school-age girls from the burden of caring for family members when they fall sick with malaria to increase their likelihood of completing school, entering and remaining in the workforce, and participating in public decision-making. The findings are similar in Heggenhougen et al (2003) who noted the evidence in sub-Saharan Africa that points to gender disparities in access to and control of assets including human capital assets (health and education), directly productive assets (labour, land, and financial services) and social capital (social participation at various levels).

Women volunteering discourses revealed how organised approaches such as mother support groups showed how women voluntarily participated in cooperative groups and the facility management committees to increase information dissemination and health impact.. Mother support groups focused on improving infant and young child nutrition and targeted malnourished children The women received training, focusing mainly on child nutrition as well as on disseminating health messages on malaria. They, in turn, trained other women, transferring the knowledge they had acquired. The roles the women played demonstrated family and community management as the mother support groups contributed to improving health and nutrition among children. The findings are similar in Undlien et al (2016).

In the case of women in informal groups, they had the confidence that the facilities can be improved through their contributions and that they were also setting an agenda that reflected their priorities for their children and community. It shaped health outcomes as mothers perceived the benefits and positive effect on children of investing their labour in hospital facilities in order to achieve their children's health. They were not connected to

the health system and provided their labour and material from their resources. Through their actions, the women volunteers saw the provision of health as a community activity rather than solely a task for the health services. These findings are consistent with previous research that the women were seen to place importance on using their labour to support future generations (Rotaranji & Russell 2009).

The women also engaged in self-help to become more self-sufficient and be able to earn money for other needs in their families. This took the form of self-help in income generating activities and small-scale commerce such as garden produce. The cash realised was used to buy food, medicine, education, and seeds for their gardens (Nelsen & Reenberg 2010**)**. Similarly, Obrist et al (2010) noted that this income prepared the women for emergencies like children's illnesses with financial and economic means by saving cash to pay for such emergencies. The financial capital component of the study framework could be applicable here in women generating capital to withstand the threats of malaria. Self-help is part of volunteering as their collective actions helped marginalised groups meet their own needs in the absence of wider provisions and services. Their self-help was also empowering to the women and gave them a form of independence. Self-help built and utilised their agency and avoided dependency (Bhattacharyya 2004). The findings are consistent with previous research that community and women's empowerment programmes can have a strong positive impact on the health of mothers and children (Sacks et al 2017).

The self-empowerment view can be challenged. An alternative view is where women in the mother groups were being involved in or 'co-opted into' initiatives that were run top-down (Banerjea 2011). Previous research has noted that despite such women playing an active role as local experts serving their communities, the tasks were framed by the designers of the programme. It seemed they were in effect the lowest functionaries of the mother support group programmes provided with specific skills to implement the pre-designed goals. To the extent that these groups were not involved in the planning of programmes, they may not have been self-empowering (Banerjea 2011; Jenkins 2009 Cornwall 2003). The findings are similar in Gram et al (2019) who found in their systematic review on promoting women and children's health groups and community members engaging in collective financial schemes mobilising resources as enablers to health, but were insufficient evidence for health promotion. This resonates reported findings in previous studies that such schemes were not empowering, as they do not generate enough income for poorer women's needs (Rigaud 2020; Jenkins 2009; Batliwala 2007; Fernando 2006).

Male volunteers as the head of household in 'Fakunya' also perceived themselves to be at high risk of malaria as women, thus the need for preventive tools such as bed nets .was perceived as similar amongst men as for women. This finding is in contrast with other studies in which men identified themselves as being less susceptible to diseases such as malaria, in comparison to women (Woldu & Haile 2015).

Discourses around '*Policies'* emphasised inclusion and equity in care by reaching the hard-to-reach (MoHS 2015:14-Sierra Leone Basic Package of Essential Health Services 2015-2020)*;* MoHS 2016:13-National Community Health Worker Policy 2016-2020); community empowerment, ownership and bottom-up approaches (MoHS 2015:61-Sierra Leone Malaria Control Strategic Plan 2016-2020). Women volunteers working in some of the poorest and remote areas were often themselves from poorer and marginalised communities. The implications were that many of those volunteers who are helping to extend the reach of services to the most marginalised were often the same individuals who are living in poverty. The findings are similar in IDS (2015) who pointed out the need for volunteers to be provided with resources and support to do their work such as training, supervision, stipends and allowances. Geographic access was a key factor for limited health-seeking behaviour and poor health outcomes in the policy documents (MoHS 2015)-Sierra Leone Malaria Control Strategic Plan 2016-2020; MoHS (2016)-National Community Health Worker Policy 2016-2020.

There was a strong focus by participants on the need to develop policies from the bottom up, and involving communities in the planning of programmes (Rifkin 1990) and to enable access to care. The Moyamba youth leader narrated that programmes were not involving communities in planning and that they were adopting a top-bottom approach rather than a bottom-up one. This finding is consistent with previous research which suggests that stakeholder engagement and community participation in the design and implementation of policies are important for trust, acceptability and uptake of services (Molyneux et al 2012). Despite community ownership was espoused in the policy documents, there was dependence on external partners mainly the Global fund for funding for malaria control as reported by the International NGO Catholic Relief Services participant. With limited access to resources, the dependence on aid was likely to affect the extent to which policy makers had a say in how money was invested. For example, malaria control Interventions and their timings were determined by the Global Fund and the communities had little say, as was reported by the Moyamba female community leader who expressed dissatisfaction on the timing of the 2017 bed net distribution in June 2017 after the rains had begun.

However, the findings showed how in poor marginalised communities, relying on volunteers may not be sustainable. Reported pressures on the personal resources of volunteers including their time and their emotional and financial resources may limit their ability to sustain their volunteer efforts despite their good intentions. Some participants narrated cases of volunteers whose performance was below required standards. This study found that greater recognition of volunteers and the risks associated with volunteering may be required for this approach to address the motivation of volunteers to make volunteering more sustainable.

5.2.7 Summary

The results in volunteering encompassed sub-themes including Inclusion, Ownership, Environmental sanitation and Women Volunteering. Volunteering contributed to improving health outcomes and family and community management and interacted with services provision in several ways including; *Inclusion*- community health volunteers increased utilisation of services by extending the reach of health services to the poorest and marginalised; *Ownership*- it strengthened local ownership of health promotion as community health volunteers selected and based in community, in mother groups, and in facility management committees; *Participation*- it created pathways to participation and active citizenship; *Self*-organisation- reflected autonomy and ownership; *Networks*- access to community networks, have capacities for human connections; *Hubs of Volunteers*- volunteers were present in all communities; responding to emergencies and working in challenging environments; as a resource in complementing the human resources for the health service and as social capital in the form of bonding capital that created trust and led to collective action, and bridging capital that provided a bridge between the health service and the community. Next I present the results on Coping Strategies.

Results Chapter 6: Coping Strategies

6.1 Introduction

Coping strategies discourse emphasised culture and the capacities in communities to seek alternative forms of treatment such as self-treatment and use of traditional medicine, their capacity to undertake collective action and to thrive in adversity using existing resources to cope with the ravages of malaria. Communities can adapt to illness by using coping strategies. In times of epidemics such as malaria, rural people use a combination of strategies to cope with their adverse circumstances. Such strategies remain unnoticed and understudied. The purpose of this chapter is to focus on these strategies. I explore some of the coping strategies literature (section 6.1.1) relevant to the findings (section 6.2) and then present and discuss the coping strategies findings (section 6.2.6).

6.1.1. Brief literature review

This brief review presents some of the literature relevant to the findings on coping strategies including preventive strategies, livelihoods diversification, medical pluralism and religion. The literature revealed that coping strategies can contribute to family and community management. Preventive strategies depicted practices and actions undertaken by the individual and community related to malaria prevention. They encompassed health interventions such as bed nets, using songs and the practice of hand-washing (Trisos et al 2017; Bizimana et al 2015; Lanford et al 2011; Lengeler et al 2007; Panter Brick et al 2006). Preventive strategies such as bed nets protected from the disease. Livelihood strategies (Ellis 2000) encompassed production and income diversification strategies that provided resources for people to cope with malaria. Medical pluralism discourses depicted the multiple treatments seeking behaviours adopted in communities to manage episodes of malaria (Scott et al 2014). Religion discourses focused on the hope and courage it brought to people in illness (Dein & Abbas 2005). It depicted the role of religious organisations in malaria prevention, and how religious leaders were able to mobilise the crowd of believers to listen to health messages (Nwokoro 2017). Folkman (2010) conceptualisation distinguished two major theory-based functions of coping, namely problem-focused coping. Folkman & Moskowitz (2004:759) identified a communal perspective and referred to coping responses that were influenced by and in reaction to the social context. Next I present the results on Coping Strategies.

6.2 Results

The analysis identified four overarching discourses around coping strategies centred on prevention; livelihoods diversification, medical pluralism; and religion. Each theme incorporated a number of sub-themes that are explored. I describe these contrasting discourses in more detail below. The findings from the policy discourses are presented.

6.2.1 Preventive Strategies

Three sub-themes were explored under preventions strategies*: Bed nets; Songs; Hand-washing.* These are discussed in turn.

Bed Nets

Malaria is endemic in Sierra Leone with the entire population at risk of malaria. It is presently the leading cause of morbidity and mortality. It remains a serious public health challenge causing immense morbidity and mortality (MoHS 2015:21)-Malaria Control Strategic Plan 2016-2020. To control the disease and protect people from mosquitos, the government of Sierra Leone carried out national campaigns to distribute Insecticide-treated bed nets throughout the country with the aim of ensuring that people have access to treated bed nets for their households. One such campaign for national distribution of bed nets was launched on 10 June 2017, during the period of my field research. The Ministry of Health and Sanitation in collaboration with local authorities in this case paramount chiefs, conducted the campaign. Prior to the campaign, the Ministry held a meeting of all paramount chiefs in Moyamba to sensitise them about the campaign to popularise the use of bed nets form the campaign. This was a focal point for many of my participants, and examples of their responses included:

> *'Yes when they supplied the bed nets, the chiefs and community leader put hand to make sure people do not sell the bed nets, they do not turn the nets for fishing, not to make a fence with it, they try their best'* (Female, school teacher in Moyamba).
>
> *'Well even the councillor was with us. Today on the bed net issue he was with us throughout, attending all meetings'* (Rural female, health practitioner*)*.

The recurring focus by participants on the efforts by of community leaders in ensuring people adopted properly using bed nets in preventing mosquito infections demonstrates family and community management. When local leaders are involved in the implementation of services they are more likely to be used. This was especially important in communities using bed nets for purposes other than malaria prevention such as fishing. Fish provides essential nutrients for people and harvests of small fish from rivers

and lakes in communities were important to nutritionally vulnerable populations, and also a source of income when sold. The small fish caught with mosquito nets tend to be especially rich sources of dietary micronutrients that can improve health and nutrition. Bed nets were used for fishing in some communities. Thus the community leaders in both quotes were reported as actively involved in implementing the proper use of bed nets.

Although relatively simple, lack of knowledge of bed net usage was documented. This female health practitioner reported that nurses provided outreach services to the communities to train people on the proper use of bed nets:

> *'We do house-to-house search for tents, some keep tents, collect bed nets and do not know how they should use it. By so doing if you do not know how to hang the tent, we will mobilise to go and hang it for you. We go into groups, we go around to hang the tents for them. If you do not know how to put the mattress under your tent, we can hang it for you'* (Rural female, health practitioner).

Nurses recognised the constraints on human behaviour and engaged local communities actively on correctly using bed nets for their intended purposes and knowing how to use them. *Figure 6.1* illustrates the hanging of a bed net in a household in Moyamba.

Figure 6. 1: Bed net in a household in Moyamba

However across all participants, there were concerns about the misuse of bed nets. Other uses described included fishing, goal posts, garden fencing and sale in markets.

> *'The other one is the effective use of mosquito nets. Government is doing everything possible to provide these nets we give them these bed nets for the under 5 children, the pregnant women in the first ANC visit get it. But the problem is the way they are using is incorrect. Many of them are not using it correctly'* (Rural male, health practitioner*)*.

This study found that people in communities responded in various ways to bed net interventions such as using them for mosquito net fishing and fencing. My attention was drawn to such misuse of bed nets for constructing fences around gardens after the interview with the Moyamba town male community leader. As regards fishing, coastal and riverain communities in particular 'Timdale', and 'Youndo' had high fish harvests. Several participants reported using mosquito net for fishing in order to have money to feed themselves. Examples of their responses included:

'We find out when government shares bed net, people plant onions, cover it with bed nets; some people use it for fishing, sell the fish to come and feed the child already sick because anaemia is quick to kill' (Male, head of household in Moyamba).

'Sometime they just think the bed is not as important as their livelihood' (Female, health practitioner in Moyamba).

The two responses above provide insights into the competing uses of bed nets in certain communities namely, fishing for livelihoods and the prevention of malaria. The financial capital component of the study framework can be applied here as bed nets were sold as a means of livelihoods for families. One focus group participant expressed dissatisfaction with the misuse of bed nets for fishing purposes in the viewing of the malaria programme donor official:

'With the GFATM (Global Fund for Aids, Tubercolusis and Malaria) official we travelled with, the woman was jerking her head because the misuse is too much. We met people standing holding going to the river, I was sitting with GFATM, and the woman started a video. The people were stretching the nets to pose for photo. It took time to convince the GFATM woman that these were old nets' (Health Practitioners focus group).

This quote reflected that the efficacy of bed nets as a viable prevention tool may be questionable. A tension appeared to exist between officially recommended use and informal local use of bed nets such as for fishing in this community.

The 2017 national bed nets campaign was launched during the fieldwork. Despite the campaigns, participants identified barriers to use and expressed reasons for their non-use of bed nets, including their knowledge about the causes of malaria, type and condition of nets, socio-economic factors and perceptions of heat and discomfort under a net:

'When they tell us to sleep under net, we ignore- the place is hot, we feel uncomfortable and we do not listen to the medical advice. They tell us to sleep under net, we look at the disadvantages of net, we feel uncomfortable, and we prefer the mosquito to bite us. But when I take the advice it can take 6 months I do not get malaria. But when I travel to the villages to do community work and expose to mosquitoes, I get malaria shortly' (Male, youth leader in Moyamba).

This quote reflected that some people viewed bed nets as intrusive and isolating, and exposure to the bites of infected mosquitoes led to malaria. Bed nets campaigns may have had some measure of success and potentially provided wider audiences with information on proper use, but it seemed there were still many in the communities who

did not make proper use of nets. Barriers in the adoption of bed nets were explained in terms of resistance, which encompasses peoples' active refusal to use bed nets. The interplay of culture (lack of belief in bed nets) and social factors such as discomfort influenced the lower uptake of bed nets.

The viability of bed nets as a prevention strategy in comparison to a vaccine for malaria was questioned by one rural focus group participant:

> *'So I say again, our solution is vaccination. The money they spend on the bed net is too much, the more people are dying of malaria'* (Rural focus group).

This quote reflected doubts in the efficacy of bed nets, and despite huge investments they have not contributed to decreasing mortality from malaria. The call for a vaccine is the more viable solution for the participant expressing his frustrations as not much progress it seems has been made in the development of a vaccine for malaria.

Songs

Songs were seen as contributing to local coping strategies in relation to preventing malaria. They were symbolic expressions of culture by a human voice that importantly included songs intended for pregnant women and breastfeeding mothers. They were a creative, catching and dynamic medium, seen to be part of local culture. Songs were particularly appropriate for health interventions in non-literate communities such as Moyamba. They were created specifically to communicate health messages and were composed in local languages for pregnant women and breastfeeding mothers who visited the hospital. They delivered messages that already prioritised, valued and resonated with the local culture, such as health behaviours that would save the lives of women and children. Songs promoted the importance of coming to the hospital and adopting healthy habits to minimise the spread of malaria. They included messages emphasising the importance of putting children to bed early, tucking the bed net under the mattress to avoid mosquitoes:

> *'When they come to the hospital, cleanliness, sweep every day, lock all potholes, at night do not sit with the child to be bitten by mosquitoes. We sing when your child is sleeping do not keep him outside to keep time. When you keep time wear long clothes, wear your cap, do not just sit down and forget the child. Take the child to the tent, drive the mosquitoes out and put the child in. These are what we put in the songs'* (Rural female, health practitioner).

This quote reflected that songs were being transposed into the context of household chores. They appealed to women to adopt proper health and sanitation habits in their

homes and in social interactions. When probed further about whose voice this was and reasons for the songs, this female health practitioner confirmed that it was her voice, to pass on health messages to women in the community:

> *'My voice, I just put the words in a song so that when they remember my voice when they listen they listen and say this is what nurse said. Singing for them as they like hearing songs. They liked the voice in the song'* (Rural female, health practitioner).

The use of words such as, '*child to the tent* ', '*wear long clothes'* and 'wear your cap' reinforced preventive measures to avoid malaria for the child and self and generated a sense of awareness. Despite the potential to capture the attention of the women the use of entertainment may not be enough as a stand-alone recipe for behaviour change as there were other social and cultural factors that influenced health seeking behaviours in communities.

Hand-washing

Another preventive strategy reported to cope with malaria was hand-washing. Hand-washing with soap was seen as preventing sickness and protecting people from infections. It emphasised the personal benefits of making people feel fresh, clean and healthy and community benefits by minimising the spread of diseases. The international NGO 'Action Against Hunger' (ACF) provided 'tap" stations for hand-washing, with independent pedals attached to jerry cans of clean water and jugs of soapy water. I observed that the hand-washing machines were in use in most health facilities and most schools visited for interviews. The NGO also delivered messages to communities about hand-washing in meetings:

> *'Mostly thanks to ACF because they supplied buckets to wash hands. Most time they call meetings for wash hand'* (Moyamba town focus group).

The above quote reflected that communities relied on outside assistance for equipment and health information on the importance of hand-washing with soap. This female NGO participant mentioned the passing of knowledge even to non-literate people and the adoption of the practice by most people in communities:

> *'So people know, I know, I believe and I am sure people have changed their mentality. Even the non-literate people 80-90% are now complying with the hand-washing'* (Female, international NGO in Moyamba).

This quote reflected that despite low literacy levels and norms and beliefs, communities' were changing hygiene behaviour in adopting hand-washing.

Children in school health clubs were involved in health promotion activities which included hand-washing:

> *'Yes like in hand-washing, even before we come in the morning they put the hand-washing soap ready. It is functional. Any NGO coming here can testify. The children run it, it is their club'* (Rural female, school head teacher).

In this sense, the children in school health clubs promoted the adoption of healthy habits in schools. They expressed agency by taking action in running the school health clubs that can influence health behaviours of their peers.

NGO programmes such as hand-washing may have promoted hygiene behaviours in communities. However, some schools had facilities that were shared with the community. There were problems when the system broke down due to lack of maintenance, with this Moyamba town community not cooperating with the school in undertaking repairs to the broken tap:

> *'Rather, unfortunately, we do not have drinking water now because the tap is not in good condition. The community people spoilt them they say it is a community school. And no one does anything about it. No one comes around to repair the tap*' (Female, community leader in Moyamba).

This quote reflected that the community lacked a sense of ownership and responsibility in dealing with common property. Linkages between the school, the community and the NGO who constructed the facility were weak and did not produce socially desirable benefits of accessible water. Lack of water in schools may have meant poor sanitation and undermined the children's efforts at having a healthy environment. The narrative also suggests a lack of monitoring on the part of NGOs of facilities they provided for the schools. .

6.2.2 Livelihoods Diversification

Livelihoods diversification encompassed diversification of production and income sources. Agriculture remained the mainstay of community residents, providing livelihoods for most of the population. It was the largest sector of the economy with communities having an abundance of land resources for farming. In the agriculture-based livelihood systems that characterise the study areas, land was a key resource for ensuring food and income security. The abundance of lands meant people were able to diversify their sources of livelihoods, especially by shifting from cash crops to food crops. Crops grown in the farms included mainly rice, yam, cassava, groundnut, ginger and pineapples. Farming was the predominant occupation in most communities and was prioritised in peoples' lives.

However, farming as the main occupation was typically conducted on a small scale with smallholdings of 0.5 to 2 cropped hectares (OCHA 2015), and the majority of farmers operated as basic subsistence food production units. This resulted in low production and consequently low farm incomes and poverty. Not surprisingly, low socio-economic circumstances were evident in the homes of people living in rural areas. Additionally, small farmers may not have adopted improved production techniques. This may have community scale implications for example in failures to coordinate weed, water or pest control. Due to manual methods of cultivation with cutlasses and hoes, lands that were cultivated were left untended and lacked adequate protection, allowing for mosquitoes to breed in the collections of water that formed and also created breeding conditions for malaria vectors. Furthermore, poorer people recognised that the more they relied on physical work in farmlands, the higher the potential for disease with exposure to mosquito bites in the farms:

> *'One year I made a small farm. I cannot stand there alone. I hired people, as we brushed the mosquitoes come'* (Rural male, youth leader).

While men and women farmed for their livelihoods, it seemed this exposed them to malaria. Thus, whilst production and income diversification strategies can be effective as coping mechanisms, they can undermine the basis of livelihoods.

Furthermore response capacity was different between men and women. Men were able to diversify their sources of livelihoods in response to epidemics by shifting from cash crops to food crops. This was in response to malaria as they produced food quantities for their families for their nutrition. In contrast, women were unable to call on additional income sources from farming. Women were disadvantaged in farming activities which usually included brushing farmlands, planting rise, weeding and harvesting. Whilst farming provided livelihoods, the activities were labour intensive and were mostly done by men who were seen as not providing help to women:

> *'Here men do not help women in work. And if you are 5 women and do not have a man, how can you work? If the place is bushy, it has to be brushed and burned before it can be turned into swamp. So we want to farm but they do not cooperate with* us' (Rural female, community leader)

The quote reflected that there were gender differences as different individuals had different capacities to seek livelihoods. Farming was perceived to have been particularly difficult for women. Lack of cooperation from men undermined collective action and marginalised women in farming activities associated with the labour required in farms. Consequently, there were differentiated impacts of land assets on people-men and women. Whilst men exploited resources such as farmlands to earn cash, unequal access

meant women coped in different ways. The case shows the differentiated impacts even on people (men and women) in the same communities.

In summary, farming, particularly in rural communities was relevant because it provided livelihoods. However, it was a possible factor in malaria outbreaks associated with manual methods of farming. This commentary is provided with caution as a causal relationship has not been established in the research. Next, I present the discourses around medical pluralism.

6.2.3 Medical Pluralism

Medical pluralism encompassing alternative health seeking behaviours to modern medicine was seen as a coping strategy. As shown in *Figure 6.2* this involved four dimensions: Traditional healers; self-treatment; combination treatment; and hospital treatment. These are discussed in turn.

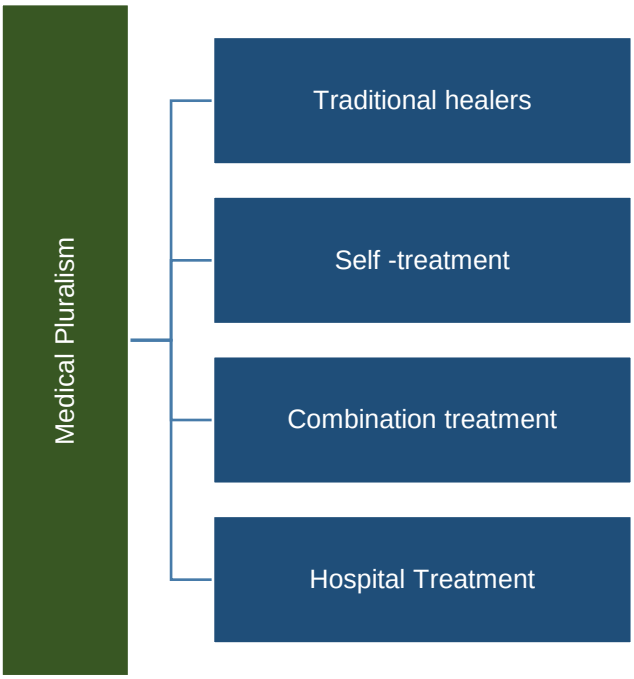

Figure 6. 2: Schematic diagram of medical pluralism

Traditional healers also known as *Herbalists* provided a form of treatment rooted in cultural beliefs. Several factors characterised the use of traditional healing including; more accessibility to the population in underserved rural areas than practitioners; belief in traditional healing; local knowledge; poverty and illiteracy. It seemed there was a communitarian spirit which prompted some to reject modern treatment and underpinned the prevalence of grassroots practices services such as herbalists used by all when

necessary including malaria victims. An advantage that participants cited was that herbalists had a grassroots presence and still hold sway over rural communities:

> *'Yah we have herbalists, herbalist in almost every community. And we all do know we are country people they are there'*
> (Rural male, health practitioner).

This quote reflected that a large percentage of people in rural communities may have availed themselves of traditional healing. In this sense, traditional healers were more accessible to the population than biomedical practitioners. This, in turn, accounted for the confidence of the population in traditional healers.

Another factor that influenced traditional healing was poverty. Participants in the health practitioners focus group and the rural religious leader reported that poverty was a major barrier to seeking care at health facilities. Poverty which they all shared may be the most important factor responsible for people continuing to support traditional healing. It was embedded in accounts of the daily lives of people. High levels of poverty which characterised the study setting (Statistics Sierra Leone & World Bank 2013) meant high levels of continuing use of traditional healing. Examples of responses included:

> '*In the case of our communities, one of the major reasons. At times a child is sick like high fever sometime a child has high fever, they need referral. But because they are poor, they stay at home, go to a herbalist with the child and lose the child'* (Health practitioners focus group).

> *'Then they have abject poverty. I have seen homes where you give them your last Le1, 000 (£1), they will appreciate it'* (Rural focus group).

This quote reflected that poverty restricted the ability of people to pay transportation to the clinic and afford clinic fees. In these circumstances, they used traditional healers which often resulted in fatal consequences. The second quote emphasises the depths of poverty faced by many in this area implying that people had little resources for their survival. It may explain their vulnerability to malaria as they often lacked the money to buy medicines and food.

Traditional healing also involved the use of traditional birth attendants. Participants expressed that this sub-group of healers were common in many communities in the past:

> *'If you go to a village you see children there, you should know that before modern medicine, TBAs (traditional birth attendants) were there thus they should not be alienated*' (Rural female, health practitioner).

This quote reflected that the health practitioner in this community was very passionate about birth attendants and formed a partnership with them. She called a meeting with the attendants and urged them to stop home deliveries. The attendants adhered to the call and they started working with her in the clinic daily, bringing all cases they previously handled at home to the clinic. On the day for the individual interviews, the researcher was delayed as the participant had two deliveries to perform together with the birth attendants in the clinic. Health practitioners focus group participants described similar efforts to integrate traditional birth attendants in the health facilities:

> *'So in as much as we are pulling them away from the old, they are attached to the health facility so the 'in-charge' can monitor their progress. They are very important because we have limited* staff' (Health practitioners focus group).

Participants in this focus group expressed confidence in the skills of traditional birth attendants. They recognised that these attendants played an important role in the health systems and that they supplemented the formal health workers who were in short supply.

Another part of coping was *Self-treatment*. In the face of perceived inadequacies of the health system and affordability of treatment, a discourse around self-treatment was observed. Self-treatment was care found closer to home, like herbal and home remedies or locally available drugs. It referred to using substances to self-treat self-diagnosed conditions which usually occurred when illness severity was perceived as low. There were several factors encouraging self-treatment: illiteracy; poverty; severity of symptoms, clarity of diagnosis; distance to the facility; cultural norms and control over resources. Self-medication was reported as the first response to malaria in certain communities, even with available free health care services. One focus group participant linked mortality rates attributed to malaria with self-treatment:

> *'We so much believe in treating ourselves, the native man believes in treating ourselves. And because of that the malaria is so fast to kill the immune system by the time you really know it is sickness. That is what causes this massive death'* (Moyamba town focus group).

This quote reflected widespread self-treatment, particularly in rural communities. In this sense, self-treatment appeared to be part of their everyday life and a coping strategy. However, there was tension as coping with malaria using self- treatment exposed people to malaria risk than can lead to mortality from malaria.

Self-treatment it seemed was often the rule rather than the exception. Regardless of the availability of a facility, some participants reported that they will self-treat with herbal

medicine and only go to the hospital if it did not work. This local NGO participant reported the outcome of their survey on malaria prevalence and treatment:

> *'The other day we said let us do a survey a short internal finding on malaria prevalence. Before and after our intervention the number of cases reported. In some communities, the case number was down. During the intervention, the cases numbers went up. And vice versa. When we asked why the case has increased they said initially people take herbs and do not self-report their malaria'* (Male, local NGO in Moyamba).

This quote reflected that people stayed away from facilities in some communities and used self-treatment. It was their initial primary form of treatment. They did not come to facilities to report their malaria and it was widespread in communities.

Many participants also reported that they used drugs for self-treatment. Drugs came from a variety of sources, including drug shops in the community and drug peddlers or 'quack doctors'. Several factors were associated with the use of this source of care; greater ease of access; longer and more flexible operating hours of stores; availability at the community level: in some instances, perceived cheaper costs. Drug sellers also responded to community pressure and were perceived as friendly, and as negotiating charges. I witnessed such negotiations in the field. These private practitioners were the closest semblance of western medicines available to communities particularly in hard-to-reach areas. They were an alternative to formal health care providers. Participants reported they used 'quack doctors' because of proximity and trust:

> *'Because we the health workers because of the distance we cannot and most time they are mobile they can go anywhere. And you the health workers only goes there on monthly basis the quack is there in river rain areas, he resides in the community, he resides there and is most* trusted'
> (Rural male, health practitioner).

Many communities did not receive full coverage of services from health workers, particularly in the hard-to-reach areas. Thus people relied on what drug shops and peddlers had to offer in their remote rural locations. In contrast to the narratives on mistrust in modern medicine, this discourse reflected that people had trust in 'quack doctors' and their medicines as they resided in the same communities as themselves.

Combination treatment was the use of multiple treatment options including biomedical treatments, drugs as well as herbal remedies and other forms of traditional treatment. It was often the case that participants talked of treatment options in combination and aligned one approach with another, sometimes sequentially but also oscillating between

the various options in seeking care. Most illnesses fell somewhere in the middle, with uncertainty around the diagnosis and often partial courses of treatment. In the process, people made use of a relatively wide range of options. There was a tendency to delay seeking medical help, with people trying self-medication and traditional healing until the illness was perceived as severe. Combination treatment occurred even in areas where biomedical services were accessible:

> *'When it happens I go to the hospital. But still, I will use herbal to make go to the toilet free. I prepare the 'mende' medicine, cook it and drink it in the evening'* (Rural female, community leader).

This community leader was comfortable with the parallel consultation of formal and traditional medicine. She did not see the two forms of care incompatible; on the contrary, she saw them as offering some complementarity.

Patients shifted from one system to the other with some portion of the population seeking the help of a traditional healer or herbs at the onset of illness before seeking care in the health facility. It seemed people were alerted that lives may be saved by prompt medical treatment of malaria and there was no dissonance between acting on this advice and maintenance of local beliefs in herbs:

> *'Some will say boldly I have the herbs at home and this is how our ancestors this is the way they survived, so we tried to use them at home but since we cannot get cured, that is why we decided to came to the hospital'*
> *(*Rural male, head teacher).

People employed multiple strategies to cope with illness. Herbal preparations were frequently used and if further treatment was needed people will go to the hospital. It seemed the hospital was the ultimate source of care for many community members. Examples of their responses included:

> *'As I said earlier, in those days we use our means, but these days we go to the hospital where they treat us'* (Rural male, previous patient).
>
> *'Before now, it was strained because there were few people not coping, there were problems. But now there are more of them the relationship is Ok. There were complaints that people are not coming quickly to the clinic days, some say I had to eat something before coming or I was seeing about my child. But now the practitioners tell them even at night, come.'* (Rural male, community leader*).*

The first quote reflected that some communities evolved from traditional to modern systems and took on health ideologies (espoused by health practitioners) to go to the hospital at once when they had the symptoms of malaria. The second quote reflected that people adduced reasons of hunger and child caring as constraints to going to a facility. However, with better relationships with practitioners, they were encouraged to take advantage of services at the facility.

The discourse on medical pluralism identified there being options for initial treatment for patients. The logic of multiple treatments appeared to involve both a desire for the combined effect of several treatments as well as a response to uncertainty around the diagnosis and any attempt to cover several possibilities at once, thus seeking alternatives to reduce the time between steps in the treatment process. People particularly in hard-to-reach communities tried to use more than one type of treatment whether traditional or medical as they saw them as complementing one another. Community members reported trying to minimise the inherent dangers of malaria by applying a combination of western and local treatments in cases that do not immediately respond to the initial treatment. This may have contributed to family and community management as combination treatments might be more accessible to the local population when adopting alternative strategies for treatment. Next, I present the discourses around Religion.

6.2.4 Religion

A belief in God was highlighted as a major coping resource for participants. Believing that God was in control gave respondents the feeling that the illness they faced were manageable. Their presence in remote communities, and identification with the needs of poorer people, made religious leaders highly reliable partners of organisations for disseminating health messages. This Moyamba town male religious leader expressed the reliance people had in the health messages from religious organisations:

> *'People listen to us, cleanliness leads to godliness. As we tell them people understand it'* (Male, religious leader in Moyamba).

This quote reflected that people had trust in messages from religious organisations and understood the need to adopt health and sanitation habits as believers.

Participants expressed taking advantage of the large numbers of people that went for prayers to mosques on Fridays and churches on Sunday. This provided the opportunity of delivering health messages to wider audiences:

> *'Sometimes when we go to the mosque we ask permission because that is when they come in large numbers, that is where you get them or in church every Friday when they come to mosques or church after, we put them together to talk to* them' (Rural female, community leader).

This approach may be useful as many in rural communities did not go to the health facility and may not have benefited from health messages. Additionally, it offered counselling and follow up to those that visited who may have been able to then receive advice.

Religious organisations provided services that contributed to prevention against malaria. This rural religious leader reported they provided bed nets to populations:

> *'UMC (United Methodist Church) gave up to 4 million treated bed nets. And it was our Bishop who went overseas and got the donation'* (Male, religious leader in Moyamba).

This quote reflected that religious organisations mobilised the necessary resources from external sources to complement health services by providing bed nets to most of the populations. The social capital component of the study framework can be applied here in the bridging form of social capital. They were also united in their approach of delivering health messages in churches and mosques in towns and villages:

> *'We have the interreligious council here, in fact, their meetings are held here. Even within ourselves, we give this health talks. Muslims and Christians. The Muslims go to villages we also in our different churches in our different churches'* (Male, religious leader in Moyamba*).*

By going to the villages to disseminate health information, religious organisations offered opportunities for reaching poorer people in grassroots by virtue of their being morally accepted and having legitimacy in communities.

The organisations also promoted the practice of hand-washing. The hand-washing machines were installed at the doors of churches and mosques where people used them to wash their hands when they attended services:

> *'We make sure hand-washing continues. Every Sunday all our doors are there with water and soap'* (Male, religious leader in Moyamba).

The practice complemented the work of the health care system in infection prevention. In the next section, I present the policy discourses on coping strategies.

6.2.5 Policy Discourses on Coping Strategies

Coping strategies identified by this analysis from the policy documents focused on two key discourses: 1) Preventive strategies; 2) Coping. I discuss these in turn.

Preventive strategies

The malaria control plan documents the provision of bed nets to population nationally for the prevention of malaria:

> '*This strategic plan proposes to use three vector control strategies; long lasting insecticide treated Nets (LLINs), indoor residual spraying (IRS) and larval source management (LSM) will be deployed according to the current risk stratification context. For LLINs, universal coverage for LLINs mass campaign is planned for by June 2017. Mass distribution campaigns will be repeated every three years'* (MoHS 2015:66-67)-Sierra Leone Malaria Control Strategic Plan 2016-2020.

The document recognised the importance of bed nets in malaria control and aimed to make them available to the population throughout the country through campaigns. The document corroborates the interview data on the priority given to bed nets. Other tools in malaria prevention such as larvicides and indoor residual spraying were also employed.

Coping

The national health sector strategic plan documents the need for shifting towards coping:

> *'As the health system in Sierra Leone remains comparatively weak, there is a need to exploit the current opinion that health is a contributor to national development and shift towards innovative evidence-based ways of coping' (*MoHS 2009:9)- National Health Sector Strategic Plan 2010-2015.

This quote reflected the official view that health services, particularly in weak health systems, may not overcome the challenges in malaria control and need to be complemented by other approaches such as enhancing coping.

6.2.6 Discussion

The present chapter reported the discourses on coping strategies as a component in family and community management of malaria in Moyamba district, Southern Sierra Leone. I identified four main overarching themes: preventive strategies; livelihoods diversification; medical pluralism; religion and policy discourses on coping strategies.

Preventive strategies discourses in coping with malaria included; using insecticide-treated bed nets, using songs and hand-washing with soap. The malaria control programmes are based largely around the prompt treatment of clinical cases and the promotion of insecticide-treated nets as a means of reducing exposure to the bites of mosquitoes. The government launched campaigns periodically to provide communities

with bed nets as a barrier against mosquitoes. The last campaign was launched in June 2017, during the current study period. Insecticide treated bed nets is an effort to reduce the significant morbidity and mortality burden of malaria in the country (Lengeler et al 2007). The use of bed nets has benefits for both individuals and the community, a reflection of family and community management. It protects the individual who sleeps under the bed net and in some cases when used by an entire community, can result in a 'mass killing effect' which reduced the density of the local mosquito population. Previous research has noted that when bed nets are used by many members of the community, it can confer partial protection for people without nets (Bizimana et al 2015:5; Magbity et al 1997:79). Bizimana et al (2015:5) noted that for bed nets to be effective, coverage must be high. In another study, Panter-Brick et al (2006) noted that bed nets could be useful in the fight against malaria in benefiting largely poorer people in rural and Moyamba town communities. Yet although usage of bed nets was popularised in national campaigns, participants reported multiple uses for purposes other than malaria. People used bed nets in other ways for their livelihoods such as ' garri' (maize) making, soap making and mosquito net fishing particularly in coastal and riverain communities ('Kongbora', 'Sembehun, 'Timdale'). The findings are similar to those in Trisos et al (2019) in their multidisciplinary research on the sustainable development goals (SDGs) conflicts in two global goals, namely SDG3 (bed nets for malaria prevention) and SDG 2 (bed nets for food security).

Sense-making (Greenhalgh et al 2012; Folkman 2010; Weick 1990) can be seen as people in certain communities giving a meaning to their collective experiences that enabled them to rationalise, understand and explain their health seeking behaviour in ways aligned to their worldviews of the disease. Thus these groups of people did not connect mosquito bites with malaria and therefore preventive strategies such as bed nets or antimalarials were not seen as their local solutions. People had a different understanding and frequently relied on their experiential knowledge, the shared knowledge of their culture which informed responses to prevention technologies such as bed nets. Consistent with research conducted by Folkman (2010) the findings in the current study explain that people were involved in problem appraisal of malaria as a burden in their communities and seeking ways to cope with the disease. The current study found many examples of peoples' health-seeking behaviour that resulted from sense-making in the adversity of malaria. People framed technology differently, for example, they typically used bed nets for their livelihoods such as fishing and 'garri' making. In this view, sense-making may provide new perspectives for understanding family and community management in the context of malaria. Previous research has found that at the community level, modern methods of prevention such as bed nets,

indoor residual sprays, do not 'make sense' in terms of indigenous beliefs (Helman 2007).

In some communities coping involved people combining efforts in innovative actions (Armitage 2005). Examples of innovation were the use of *songs* in delivering health messages to women for behavioural change. The novel element was they that served simply to remind women of their everyday health activities. Locally composed songs articulated pre-existing social priorities for protecting the health of women and children through adopting health and sanitation habits. There was community ownership of the songs as they were an expression of culture and were delivered in languages the women can understand. Consistent with the research conducted by Panter-Brick et al (2006), the findings in the present study explain that songs were a culturally compelling medium with which to inspire and motivate health seeking behaviours. Even when spontaneously created as was the case in this study, songs can put across locally relevant messages and drew many issues into one compelling format. Such messages were valued and resonant with the local women as they were transposed to the context of household chores that pertained to women and their family health (ibid.). The current study has shown that using songs as a vehicle for community management is a promising approach. The findings in the current study appear to be in line with previous studies showing that to deliver health messages that seem relevant and culturally compelling to the target audience, they must be sensitive to the form as well as to the content of health messages targeted to a given audience (Panter-Brick et al 2006; Willms et al 2001). Further the medium by which the message is delivered is as important as the message itself (Johnson et al 2001). In the current study, the female health practitioner targeted the messages to pregnant women in their local languages. The content of the messages included health seeking behaviours that the women should adopt in preventing and coping with malaria.

Discourses around *hand-washing with soap* as a preventive strategy revealed that they were direct hygiene prevention programmes reinforced by school health clubs to encourage school children to wash their hands with soap every day they are at school. Hand-washing machines were also installed in health facilities. Hand-washing was aimed at controlling infections from malaria and other diseases. Previous research found that hand-washing machines were less effective in infection control in poor rural communities (Panter-Brick 2014; Langford et al 2011). Panter-Brick (2014) and Langford et al (2011) suggested that campaigns that aim to improve hand-washing behaviours but make no changes to environmental sanitation, can have only limited impact on health. Panter-Brick (2014) argued that these issues engender much

discussion in global health on moving from approaches focusing on individual health toward a more people-centred and deeply accountable approach to foster health equity and lifelong wellbeing (ibid.). Rifkin (1990) highlighted that developing countries should have more focus on adopting healthier habits in regard to sanitation and environmental hygiene in the wider community for rapid improvements in health. The findings highlight that efforts are required both at the individual and community levels in approaches to disease eradication.

Livelihoods diversification discourses (Ellis 2000) recognised that agriculture was the main source of livelihoods in most study communities. The study findings revealed communities as having an abundance of land resources. The abundance of lands meant people were able to draw on diverse crops and varieties, especially by shifting from food crops mainly rice, yam and cassava, to cash crops such as groundnut, ginger and pineapples. Previous research found that communities with resource diversity had capacity for livelihoods diversification because they were able to cope if any one resource became depleted and with environmental variations (Adger 2000). Diversification in agriculture was therefore linked to supporting better health and therefore offered better human conditions for withstanding malaria risk, a testament to family and community management. The strategy often resulted in meeting subsistence needs even in bad years. In this sense planting a greater variety of crops represented a precautionary strategy for coping with food shortages that might increase vulnerability to malaria. Ellis (2000) noted mixed cropping which refers to growing two or more crops on the same piece of land to take advantage of complementarities between crops. Food shortages can lead to hunger and malnutrition, undermining peoples' resistance to malaria and contributing to mortality (Adeyeye et al 2017; Undlien et al 2016). This finds resonance in Blaikie et al (2001) who noted that diversification of crops enabled people to respond effectively to food shortages by switching from one to the other, and can be effective as a coping mechanism in adversity.

Livelihoods diversification discourses affected family and community management in both positive and negative ways. The positive response was made possible by such factors as diverse land resources. Previous research has shown that community management depended not only on the volume of economic resources but also on their diversity (Norris et al 2008; Adger 2000). Negatively subsistence agriculture undermined family and community management as it partly led to the spread of disease. Manual methods of cultivation with cutlasses and hoes meant lands that were cultivated were left untended, allowing standing water to collect and increasing breeding of malaria vectors. They created stagnant basins in which mosquito larvae grow in large numbers.

Furthermore, the poorer people relied on physical work in farmlands, the higher the potential for disease with exposure to mosquito bites in the farms (Packard 2007; Helman 2007). Packard (2007) in his research in East Africa and South-East Asia observed that patterns of agricultural production were undercapitalised, used few technical inputs and relied on the extensive use of human labour involving little in the way of mechanization. Manual methods of production placed the human population at the risk of infection and allowed malaria to maintain its hold in communities. Additionally, subsistence only provided food for the home and not at scale, thus was inadequate to cater for all family needs.

Discourses around *medical pluralism* revealed that the worldviews of people were characterised by a certain degree of pluralism in the pursuit of a cure. The term 'pluralism' referred to approaches to several sources of treatment that included formal health provision, self-treatment and traditional healing (Scott et al 2014; Sudhinaraset et al 2013; Marks 2006). Traditional healing consisted of treatments received from local herbalists and midwives. Self-treatment either used traditional home remedies or pharmaceutical drugs bought from a retail outlet.

Even though western medicines were used, traditional medicines were also used in various combinations. The rural female community leader in 'Timdale' narrated using both traditional healing and modern medicines for herself and her family. This shows that traditional beliefs and values still strongly influenced malaria management behaviour in communities even though other factors were also present. Previous research found that there was a large range of variation in treatment-seeking patterns. Individuals often use a combination of self-treatment, traditional medicines, and more than one clinic or health care provider (Scott et al 2014: Kamat 2008; Higginbotham et al 2001). Several factors explained why communities adopted medical pluralism including, easier accessibility to the population of traditional healers, herbal medicines and drug peddlers, distance and cost to health facilities, delays in facilities, and mistrust in modern medicine resulting in greater trust in healers and peddlers.

Discourses revealed the healing and curative powers attributed to traditional healers. In pursuing healing, peoples' actions varied and oscillated between traditional and conventional treatment options simultaneously or sequentially. They were simultaneous when as some previous patients reported they consulted different domains at the same time. They were sequential when the patients exhausted the resource of one domain, say the traditional, before moving to another, say the hospital. This means visiting the

traditional healer and taking herbal medicines, and going to the hospital at the same time as was narrated by the female community leader in 'Timdale'. When the traditional treatment was not seen as able to help, people would frequently resort to what the hospital next in the sequence could offer (Higginbotham et al 2001). In other cases, the order was reversed when self-treatment strategies sometimes replaced medical care, especially if the drugs failed to work and the patient deteriorated.

The view of traditional healers was reinforced by the fact that people were aware of their presence in every community, and of their belief in their ability to heal. This was also based on narratives from participants that traditional healers were greater in number than health care workers, were more accessible to the population than biomedical practitioners (Higginbothan et al 2001). The female rural patient in 'Youndo' narrated that the community had a traditional healer in their community who helped patients. The rural male health practitioner in 'Bagruwa' alluded to peoples' awareness of the presence of traditional healers in every community. Participants narrated that people had greater confidence in traditional healers and mistrust in modern medicines in some communities. People also had doubts about the quality of health services and difficulties in accessing facilities which increased reliance on traditional healers, particularly among the poorest individuals (Bates et al 2004:371). Moreover, it seemed many of the herbal medicines were available in the nearby bushes. It seemed the traditional healer's strength was in healing patients rather than curing them. Healing referred to services to local people or their immediate circle which made them comfortable and reduced their malaria. The process of healing was predicated on the perception and expectations of sick people and their culture. People in some rural communities promoted and had greater confidence in traditional medicines. They were deeply rooted in culture and the practices passed on to them from generation to generation (Oberlander & Elverdan 2000).

These standpoints have led to contrasting perspectives in the malaria response. In contrast, practitioners dismiss traditional medicine as not having curative power, primitive, lacked scientific efficacy and inimical to people health and well-being (Higginbothan et al 2001). Curing referred to practices viewed by practitioners as efficient, and either limited, reversed or prevented malaria. These views were corroborated in the interviews with rural and Moyamba religious leaders and the health practitioners focus group. The contrasting views have led to the recognition of the importance of accommodating both biomedical and traditional medicine and the need to develop interventions that accommodate socio-cultural dimensions (Witter at al 2016; Marks 2006; Higginbothan et al 2001). This is because socio-cultural considerations offer a 'window of opportunity' for: 1) an understanding of health problems that recognises

local perceptions; 2) developing appropriate interventions; 3) harnessing the natural and human resources of both biomedical and traditional medicines for the overall health of populations (ibid.). These authors recognise the utility of this integrated approach in coping with malaria, in applying the natural, human and social capital dimensions of the study framework.

Participants in both individual interviews and focus groups reported midwives or traditional birth attendants providing curative services and reflected on the indispensable need for their services in communities before modern medicine, serving at-risk and underserved segments of their populations, i.e. infants and pregnant women. The rural female health practitioner in 'Youndo' said that any health practitioner in a rural community will understand that in past times, before the health services, the children who are the adults of today were delivered by traditional birth attendants. Thus, traditional birth attendants should not be antagonised but partnered with and motivated within the community health system. In unpacking the discourse it appeared that there was recognition of the need for curative services from midwives at vulnerable times such as pregnancy. In those communities, pregnant women did not go to a health facility for antenatal care visits even when they have malaria symptoms. Reasons for some women not attending antenatal appointments included beliefs that only the seriously ill go to a health facility, the services were inadequate, hospital staff had poor attitudes, women in some cases lacked knowledge and information about ante natal care visits and mistrust in modern medicine. Previous research has noted that women act as traditional birth attendants in many developing countries, and still carry out the majority of deliveries in communities recognising the value of traditional approaches and actively supported their integration into the health service (Bashki et al 2013; Covin et al 2013; Diala et al 2013). Traditional birth attendants helped bringing deliveries even from the hard-to-reach areas to facilities. The study interviews were delayed in 'Youndo'' with the health practitioner as she had two deliveries brought in by birth attendants on the day of the interviews At the time of the research, efforts were made to integrate them into the official sector as narrated by the male health practitioner in 'Bagruwa' and the health practitioners focus group. The health practitioner's focus group spoke of traditional birth attendants or midwives as the 'backbone' behind the health service. Many lived in the communities where they helped pregnant women to seek early intervention before they had complications. A contribution to community management is that the institution of traditional birth attendants was vital in influencing demand for services at the community level. It demonstrated flexibility in the malaria response as communities sought alternative means for healing. The level of flexibility possible within the community had

a bearing on the response capacity, and by implication community management outcomes.

Discourses identified two potential links of traditional healers that focused on coping as an important part of community management: 1) local knowledge of medications; 2) the collaboration between traditional and institutional medicine. First, participants described elderly people as having developed local knowledge of medications to identify plants that healed malaria, in applying the natural capital component of the study framework. Thus natural resources in the community fed into community management, manifested in traditional practices such as using herbs that had antimalarial properties (Packard 2007). It seemed such knowledge persisted with herbalists in many communities. In this view, communities retained the ability to generate and apply local knowledge and pass it on, relating to the human capital components of the study framework. Thus the system of knowledge endured which recognises the dynamic and adaptive nature of local knowledge. In other words, the community retained the ability to generate, transmit and apply local knowledge. The relation to family and community management is that community members and actors can possess unique knowledge in understanding local perspectives and having the ability to identify and access local resources for withstanding the threats of malaria. Local knowledge was acknowledged as a source of community management in communities retaining valuable biological and cultural information of their environment that influenced coping capacity. Traditional healers also seemed to be knowledgeable about the plants used in the treatment of malaria, relating to the natural capital component of the study framework. The male patient and the female district officer narrated how the ‘granny’ in the village could easily find the medicines. Communities from their cultural beliefs and within their social context found them reflected as communities referred patients to specific local practitioners as the ‘healer’ or the ‘granny’. Collectively, therefore, the communities recognised the value of local practitioner’s medicines and continued to use them. The contribution to community management is that communities recognised these knowledge systems and the practices they encompassed as contributing to sustaining health. The findings are similar to Brown (2016:12) that such knowledge systems have evolved from experimentation and learning, representing sources of knowledge for communities.

Second, discourses on local knowledge provided insights into appropriate collaboration between traditional healers and institutionalised medicine. Whilst these roles performed by traditional healers may be ancillary, meaning providing healing services to support the primary activity from the health service, there were instances where practitioners in the service attempted on a very limited scale to integrate traditional healers into clinical

settings, which can be seen as a coping strategy in integrating practices. Findings of the present study suggest that collaboration between traditional healing and the biomedical model may address the challenges in the health system as treatments were sought from traditional healers in many communities (Marks 2006; Hill et al 2003; Ahorlu et al 1997). A contribution to family and community management is that traditional healers complemented the curative service provided by the health service. Consistent with research conducted by Satterfield et al (2013) the findings in the present study explain how negotiations played out where practitioners sought to integrate traditional knowledge and values into community health provision. Satterfield et al (2013:103) noted that communities and the indigenous and cultural knowledge they hold were key to good environmental management.

Findings revealed resistance in communities was influenced by culture (Brown 2016). For example, there was resistance in the use of modern medicine and the use of bed nets. This was particularly the case if we view resistance as the means through which people built strategies for treating malaria such as herbal treatment or a traditional healer (Helman 2007). Resistance shifted the emphasis towards socio-cultural factors and about the coping capacity where people in some rural communities were seen as lacking access to modern medicine. In this view family and community management encompassed the power in communities to resist modern medicines determined by outsiders and shape alternative futures in dealing with adversity (Brown 2016). The ability to resist and question modern approaches based on locally upheld traditions and culture had the effect of .contributing to family and community management by enabling people to shape their strategies by building alternatives and using pluralistic approaches in their health seeking behaviours.

Health practitioner commentators in this discourse continued to view modern medicine as the only approach to overcome the threats of malaria. But in an explicit departure from the technological stance (Greenhalgh et al 2012) as in the health practitioners and the Moyamba town focus groups, they sought to emphasise that it will require a great deal of transformation to alter the health-seeking behaviours of poorer people. Panter-Brick (2014) and Helman (2007) observed that cultural narratives of risk can be given priority over epidemiological and medical evidence, with cultural narratives having more explanatory power with people relying more on their culture in explaining their life circumstances and predicting misfortune such as ill health. In summary despite poverty, people talked of alternative health seeking behaviours that were evidence of a more local form of coping that contributed to family and community management.

Religion was seen as enhancing coping with illness. Congregations were perceived as the vehicle by which followers responded to health messages by listening to and adhering to health messages through religious leaders. Congregations enabled informing a rallying point for the dissemination of health messages. Such religious networks often found in the most inaccessible areas where government services do not reach, were more established in communities and provided channels of information that people relied on. Consistent with research conducted by Gessler et al (1995) the findings in the current study explain that communities combined religion and health into a unified system of belief and practice which influenced their health seeking behaviours as they listened to religious leaders. Religious networks were often found in the most inaccessible areas where government services did not reach. These networks can achieve successful grass-root operation in delivery of health information because the physical infrastructure in the poorest communities were probably churches and mosques which informed the focal point and assembly of the communities they served (Nwokoro 2017). Health talks to congregations by religious leaders can be seen as supporting efforts to cope with malaria, urging communities to practice healthier habits and avoid antimalarial behaviours.

Policy discourses on coping strategies emphasised preventive strategies such as the use of bed nets in malaria control (MoHS 2015:16) - Malaria Control Strategic Plan 2016-2020. However little is said about the improper uses of bed nets, which was a dominant discourse in interviews. This finding is similar to previous research which suggests that health policy intervention focus on delivering services such as bed nets and pay less attention to many of the demand-side barriers faced by communities (Ensor & Copper 2004; Sachs 2001).

Recognising the weak health system in Sierra Leone, MoHS (2015)-National Health Sector Strategic Plan pays attention to coping strategies that may complement health services. The effects of interacting stressors including poverty, poor environmental sanitation, illiteracy, and poor agricultural methods were presented as combining to increase vulnerability to malaria, thus coping strategies.

Relation of coping strategies with other themes and the Conceptual framework

Coping strategies were related to other themes and reflected applying components of the study framework including natural, human and financial capital. In coping with malaria people harnessed natural capital in medicinal plants and human capital of both health practitioners and traditional healers for overall health. Livelihood diversification strategies galvanised financial capital gained from cash crops. Coping strategies were also related

with financial capital in the form of community funds for obstetric care. Coping strategies were related with social capital in the form of community support for example in transporting the sick to hospital.

6.2.7 Summary

Chapter 6 explored a range of coping strategies in communities including preventive strategies, livelihoods diversification, medical pluralism and religion. All helped people and communities to withstand the threats of malaria. In the next and final results chapter, I present the discourses and discussion around Leadership.

Results Chapter 7: Leadership

7.1 Introduction

The leadership discourse depicted the local authority and ability in local leaders to set up processes and structures for influencing community activities that facilitated achieving health outcomes. In this study, local leaders included paramount chiefs and their section chiefs, and community leaders in the facility management committee. In this final results chapter, I present leadership as a component of family and community management. I start by exploring some of the leadership literature (section 7.1.1) relevant to the findings (section 7.2) and then present and discuss the leadership findings (section 7.2.5).

7.1.1 Brief literature review

The purpose of this section is to provide a brief review of the research on leadership Leadership can be considered as the process of influencing peoples' behaviours, attitudes and activities to facilitate achieving goals (Hegney et al 2008; Folke et al 2005; Hogan & Kaiser 2005). Hogan and Kaiser (2005:169) noted the leadership literature concluded there was substantial evidence that leadership had a profound influence on communities and that strong leadership enhanced the health and wellbeing of those being led by promoting effective performance whilst weak leadership led to poor quality of life for everyone associated with it (ibid.).

People needed information about the risks of diseases such as malaria communicated effectively and from trusted sources. The relation with leadership is that information from leaders can be seen as from trusted sources. Longstaff (2005) noted that trusted sources are those that are closer and local sources of information that are more likely to be relied upon (ibid.).

Thomas-Slayter and Fisher (2011:S330) argued that in many parts of Africa, it would not be possible to engage in programmes in a local community without the approval and blessings of the local chief (Tchombe et al 2012). Next I present the results on Leadership.

7.2 Results

The analysis identified one main overarching discourse: 'community leadership'' and two sub-themes; by-laws and health information. *Figure 7.1* provides a schematic diagram

of leadership in my data. Community leadership depicted leaders influencing people in striving to achieve health outcomes. By-laws recognised the unwritten and informal health laws made by the paramount chiefs in complementing the formal health laws from the government on malaria control. Health information focused on malaria risk reduction messages that can make it possible for community members to access basic health services. The main theme and sub-themes identified are described in detail in the following sections. The findings from the policy discourses are presented.

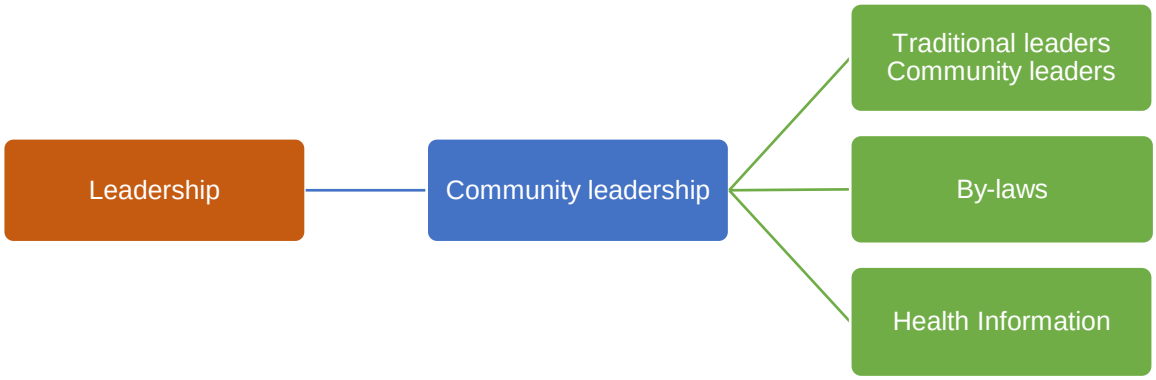

Figure 7. 1: Schematic diagram of leadership discourses

7.2.1 Community leadership

Community leadership consisted of paramount chiefs who were the traditional leaders. Such leadership was institutionalised and embedded in a local tradition of chieftaincy that empowered paramount chiefs (the locally elected head of the chiefdom) as the sole authority of local government elected by the community was acknowledged by younger groups such as this youth leader:

> *'You see the paramount chiefs they are the custodians of the lands, they have their section chief'* (Male, youth leader in Moyamba).

This quote reflected the value people placed on the authority of traditional leaders over their territories. Such authority was borne out of their role as custodians and transmitters of community culture, norms and social values in their communities. They were therefore able to influence and encourage changes in behaviours and attitudes.

Traditional leaders were key actors across communities and were viewed by participants as relevant in implementing malaria control programmes. They, in turn, appointed the chiefdom committee to assist in running the affairs of the chiefdom including health matters:

> *'The chiefdom committee sent a representative from 'Mano', the headquarters to elect a leader to help the women who were careless, leave stools outside and flies go on it. So this 'natural leader' goes out every Friday more especially for the lactating mothers to make sure they comply. So the chiefdom committee activated that one in all the communities'* (Rural male, head-teacher).

This quote reflected that the 'natural leader' followed up on healthy and sanitation habits in homes and environmental sanitation. Applying the human capital component of the study framework helped identify ways people in this community could be galvanised to complement the work of the health service. It is also notable from this quote that the committee members saw it as part of their duties to keep women compliant. This provided an important dimension of community management that can be seen as a more viable approach in modifying health seeking behaviours as leaders were seen in communities with strong leadership as trusted sources of information.

Community leadership was also reflected in how the facility management committee acted. They initiated awareness-raising activities that the community health workers then carried out. The facility management committee represented how people came together into addressing health concerns for the benefit of the community. The malaria control programmes is based around the promotion of bed nets as a means of reducing exposure to the bites of mosquitoes. Thus the facility management committee supported individuals and communities to more actively and meaningfully take part in health promotion by playing a part in implementing and monitoring of the use of bed nets:

> *'There are five of us, we go house-to-house, we interview those not well, do they use tent we go to their room to confirm. If they do not have it, the nurse jots it down and when they go to hospital they give them net'*
> (Male, community leader in Moyamba).

This quote reflected community members and health workers as coming together following up on the uptake and usage of bed nets in households.

Participants referred to women's notable leadership of the facility management committee. This was important for maternal and child health programmes such as the malaria control programme as women's views, interests and needs were represented and are likely to be recognised more readily by other women. One male participant described women's majority composition of the facility management committee:

> *'Chairlady- woman, secretary a man, the chief and two other members, but most are women'* (Rural male, health practitioner).

This quote reflected that having more women in the committee can be seen as ensuring more involvement of women in community health activities and stability. This ensured stability as women frequently had traditional and natural roles as providers of care within the family and community. Men may have less time to volunteer as they are usually involved in other activities outside the home in search of livelihoods such as in farm work or may migrate in search of paid work. In volunteering to the committee, they provided a continuity that was essential for the functioning of the committee. As the Moyamba town community leader reported, there was poor attendance in committee meetings as men went in search of livelihoods.

Some communities were seen as having strong leadership:

> *'For 'Bagruwa' specifically, the kind of paramount chief I am having is well disciplined and very tough. He says things that he means'*
> (Rural male, health practitioner).

This quote reflected that some community settings were characterised by committed leadership that was seen to follow through on activities consistently aimed at achieving community goals. These included promoting community ownership of interventions and setting up structures and processes for encouraging compliance with by-laws and mobilising community resources:

> *'He calls chiefdom meetings. We involve the community so that they have the awareness that they own it. That government is giving them this net and they should have a monitoring system. The chief has opened a bank account where the fines are put'* (Rural male, health practitioner).

However, not all the responses regarding leadership were positive, with several participants from the 'Gbangbatoke 'rural community claiming that there was a lack of good leadership particularly in the area of implementation of by-laws on bed net misuse. Examples of responses from interviews and the Moyamba town focus group included:

> *'The chiefdom people have a problem. They are not able to control their people. As a health practitioner, the last time I saw people with nets fishing. So I used that opportunity to see the chief and reported to the chief. The matter just died down. We are not governed by chiefdom people here'*
> (Rural male, health practitioner).

> *'Like the Paramount chiefs are just coming from 'Bo'. They were told to go back to their town chiefs, to their section chiefs, but they have come and sat down'*
> (Moyamba town focus group).

The first quote reflected a lack of effective leadership and the chief's attention to ensuring communities complied with health by-laws. Bed nets meant for prevention of malaria were used for fishing. However, it can be argued that factors other than ineffective

leadership, such as poverty, malnutrition and the need to pursue livelihoods can explain such bed net misuse. In the second quote, this Moyamba town focus group participant reported that despite the engagement of paramount chiefs for their support in the bed nets campaign, in certain communities they failed to pass messages to their section chiefs.

Lack of effective community leadership was also reported in Moyamba:

> *'I do not see community leaders doing anything. From the time I am here, any action is from the medical wing'* (Female youth leader in Moyamba).

This quote reflected there was less involvement of community leaders in health activities with practitioners seen as the ones undertaking health promotion activities. This discourse was supported by a similar discourse in the Moyamba town focus group that by-laws were more effective in rural communities. It illustrates the difficulties involved in efforts to influence health behaviours through decentralisation to local leaders in some communities such as this Moyamba town community, where monitoring for compliance was rather left in the hands of practitioners.

There were also conflicts in some communities which affected leadership and led to disorder. Lack of maintaining proper sanitation habits and cooperation with the chief in the rural 'Gbangbatoke' community was reflected in the following quote from the rural religious leader:

> *'The chief told me once he counted the households here without toilets. He went around counting. The next thing the people said this man should be removed'* (Rural male, religious leader).

This quote reflected that conflict management was seen as an ability that effective leaders should demonstrate to gain support from their subjects. The extent to which local leaders were able to manage conflict can avoid breakdown of leadership. People seek in their leaders evidence of encouraging their participation in matters pertaining to their lives and listening to their inputs if they are to continue leading them.

7.2.2 By-laws

Health laws and policies were aimed at improving access to basic services such as providing health care for pregnant women during their pregnancy, during and after delivery and proper use of bed nets (MoHS 2015:53)-Malaria Control Strategic Plan 2016-2020. However such national laws were seen as not always complied with in certain communities. Thus paramount chiefs passed by-laws accompanying national health laws. Such laws included proper uses of bed nets in households, environmental cleaning and antenatal visits. Strong leadership was seen in those communities that

enforced compliance with by-laws. The need for strong leadership was often mentioned relating to enforcement and compliance with by-laws on health promotion. Examples of rural community responses included:

> *'It is the laws we follow them up to the letter. If you make a law, follow it otherwise it will not hold and it is working. In anything no law it will not work. And it is also the commitment. Also if there is no commitment nothing will move forward only backward' (*Rural male, community leader)

> *'So if we can involve our elders also paramount chiefs and community leaders in this same practice to have by-laws in place to make sure measures and laws are put in place to make sure those misusing the nets are punished'* (Rural male, health practitioner).

The first quote emphasised the need for strong leadership and commitment to enforcing by-laws. The second quote agreed with this and specifically that bed nets interventions should promote proper usage of the nets and also incorporate periodic monitoring for compliance or punishment of offenders. The narratives demonstrate the value placed by these community leaders in ensuring compliance with by-laws. Community management in communities with strong leadership was reflected in community leaders creating by-laws making misuse of bed nets a finable offence:

> *'A point in time, I was told anyone caught using bed nets for other purposes will be fined'* (Female, international NGO in Moyamba)

This quote from the international NGO which implemented programmes (hand-washing) in rural communities reflected the consequences for improper of bed nets. Fear of punishment may have deterred people in poor rural communities who cannot afford fines from misuse.

There were variations in compliance with by-laws. One participant in the Moyamba focus group believed that rural communities, as opposed to Moyamba communities, were more likely to report the by-laws as being upheld through fear of paying fines:

> *'Also by-laws, but in big towns, it is not effective but in village communities, they fear by-laws'* (Moyamba town focus group).

This quote reflected that rural communities may have been more widely willing to undertake activities that will make their health conditions better. An alternative view is that people in rural areas may have more fear of the chief due to stronger community ties. By-laws also punished offenders for use of traditional medicines:

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> *'There is a law we should not give 'mende' medicine, we should bring them to the hospital. It is the hospital that knows the medicines. If the child body is warm we go to the hospital. If we catch any herbalist, in fact, you are fined Le500, 000 (£50)'* (Rural female, community leader).

This quote reflected the by-law against using traditional medicines. However this stands in contrast with discourses from other communities such as the 'Gbangbatoke' community where the health practitioner reported he expected to see 200 patients from a community of 11,000 everyday, but most in the community did not come to the facility, suggesting they may be using alternative sources of treatment. Patients shifted from one system to the other with the largely rural populations seeking help from herbalists at the onset of illness before going to the hospital. Such behaviours were also known to be punished by heavy fines in communities with strong leadership that enforced by-laws.

Other participants spoke about leadership in enforcing by-laws in a broader sense and the extent to which community leaders facilitated groups to collaborate in working on cleaning the whole community:

> *'Also our leaders have been promoting last Saturday every month we do cleaning until 10. You do not go out before 10, if you do you will be fined'* (Male, religious leader in Moyamba).

The quote reflected the importance of punishment in enforcing by-laws on environmental sanitation. Moyamba town community leaders were involved in enforcing the by-law on the monthly cleaning exercise in Moyamba township. Next, I discuss health information.

7.2.3 Health Information

Health information emerged from the data and was incorporated as a sub-theme of the leadership main theme. Leaders provided health Information on malaria risks that provided opportunities for preventing the disease and seeking care. It emerged from the data and was incorporated as a sub-theme of the leadership main theme. As described in Chapter 6 on coping strategies, people in most rural communities were reported adopting pluralistic health seeking behaviours such as using traditional healers, self-treatment, combination treatment and hospital medicines. Therefore through providing them with information on malaria risks, traditional leaders were seen as supporting the communities in making them more aware of risks such as the improper use of bed nets:

'Because the Paramount chief was clear, all other uses should be avoided and the nets used judiciously' (Rural female, health practitioner).

'We were using local drama in our local languages to tell people, now the hospital is safe, the schools are safe. It is high time to get our pregnant women and lactating mothers now go to the health centre. And we were using our traditional leaders. The traditional leader is powerful in the communities'
(Male, head of household in Moyamba).

The first quote emphasised the importance of local leadership in popularising issues at stake, in this case, the proper use of bed nets. The second quote reflected an attempt to integrate the content of the messages with local knowledge or concepts by using local culture, drama, and local languages. It involved using traditional leaders who had local authority over their people and were, therefore, local sources of information who were especially likely to be relied upon. This female practitioner reported the role of traditional leaders in bringing health messages mobilising support for the uptake of services:

'Well in the villages, they can appoint their people to help with malaria. The chief can appoint people to do this work in telling people to take their children to the hospital' (Rural female, community leader).

This quote reflected that traditional leaders through their assistants provided health information to the grassroots where people were less likely to use services. The aspect of the availability of human resources in the human capital component of the study framework may be applicable here as community leaders were seen as complementing the health workforce, implementing by-laws that promoted the uptake of services.

In summary interviews and focus groups discourses on leadership referred to ways in which community leaders were seen to influence peoples' behaviours in health promotion activities. Health programmes in which community leaders were committed were seen to gain influential support. Leader's roles were seen to include instituting and enforcing by-laws, supporting health campaigns, selecting community health workers and disseminating health information to their communities. Leaders in some study communities were reported as ensuring compliance with health by-laws and disseminating health information. Specifically, leaders supported community structures such as the facility management committee that mediated between the community and the health service. In some communities that lacked leadership, such outcomes were not seen to be revealed. Communities, where leaders did not support health promotion activities, were less successful in implementing by-laws and influencing the uptake of services. This was seen in communities such as the rural 'Gbangbatoke' community which at the time of this research was reported as disunited resulting in the chief

relocating from the headquarter town of his chiefdom. This was also seen in Moyamba where the facility management committee was seen engaging in livelihood activities rather than attending committee meetings. Problems of the link between committees and community members were also reflected with the Moyamba female youth leader reporting that community leaders were not doing anything. In contrast, rural communities with strong leaders such as the 'Bagruwa' and 'Bauya' communities were more successful in implementing by-laws and influencing the uptake of services.

7.2.4 Policy Discourses on Leadership

In general, the policy documents reviewed emphasised and helped explain the need for governments involving community leaders in implementing programmes aimed at improving access to care and influencing uptake of services was. Four policy documents referring to leadership were reviewed: 1) MoHS 2015-Health Sector Recovery Plan 2015-2020); 2) MoHS 2012-Integrated Vector Management Strategic Plan; 3) MoHS 2015-Sierra Leone Malaria Control Strategic Plan 2016-2020; 4) MoHS 2015-Sierra Leone Basic Package of Essential Health Services 2015-2020. This analysis identified three discourses from the policy documents:1) community leadership; 2) by-laws; 3) health information. I discuss these in turn.

Community leadership

In these documents, the need for involving community leaders was emphasised
The MoHS (2015)-Health Sector Recovery Plan 2015-2020 document emphasised leadership through the facility management committees as one of the components needed to improve the quality of health care and uptake of services:

> '*These facility management committees are the primary mechanism through which community leaders and members will be informed, educated and empowered to understand their role in improving health services and the importance of utilising the systems in plac*e' (MoHS 2015:51)-Health Sector Recovery Plan 2015-2020..

This text envisaged building the capacity of the facility management committee in their mediation role for working with the facility on improving health outcomes. The committee was involved in other roles beyond focusing on by-laws, for example, engaging facilities on the quality of services provided to communities and providing feedback to facilities from the communities, a testament to community management of malaria in monitoring service provision with the support of the local leaders.

The MoHS (2012)-Integrated Vector Management Strategic Plan explicitly directs the involvement of community leaders in planning and implementing programmes:

> *'Chiefdoms and local community leaders and community-based organisations shall be engaged by the health education programme to ensure full involvement of communities in decision making processes and planning and implementation of Integrated vector management activities within the context of malaria control'* (MoHS 2012:38)-Integrated Vector Management Strategic Plan.

This discourse contrasts with the dominant discourse in the development literature arguing for top-down approaches, which are associated with a lack of involvement of community leaders in planning and implementing programmes. Ensuring full involvement of communities as in this discourse may provide planners with more understanding of local perspectives that may help in the control of malaria. Local leaders were seen as having more knowledge of their environments, more aware of the resources including human and natural resources, were trusted sources of health information and able to influence and encourage changes in behaviours and attitudes. By including them and other community members in planning and implementation, the interventions were more likely to be successful and viable. In the next section, I discuss by-laws.

By-laws

Leadership in some communities with strong leadership implemented by-laws that accompanied national laws on home deliveries. Home deliveries assisted by traditional birth attendants were often a common practice in many rural communities. Pregnant women who lived in remote locations did not go to facilities even when they had malaria symptoms and often delivered at home. The Malaria Control Strategic Plan provided for the involvement of local leaders in implementation of by-laws:

> *'Involvement of local authorities in the formation of by-laws on pregnancy related issues and clinic attendance' (*MoHS 2015:103) - Sierra Leone Malaria Control Strategic Plan 2016-2020.

In the context of Ebola-related actions, the health sector recovery plan acknowledged the importance of implementing by-laws through traditional leaders:

> '*The passage and enforcement of local by-laws and decrees by traditional leaders provided visible political commitment to address the epidemic'* (MoHS 2015:48)-Health Sector Recovery Plan 2015-2020.

Health Information

Leaders were involved with the dissemination of health information to communities. The documents offer suggestions on ways to involve communities in the provision of health information and the dissemination of health messages through community leaders. Examples of discourses from the documents include:

> '*Community leaders can mobilize their communities for participation in mass campaigns and for seeking care at the nearest facility'* (MoHS 2015:28)-Sierra Basic Package of Essential Health services 2015-2020.
>
> *'Chiefs and other traditional leaders help community health volunteers to promote healthy and health-seeking behaviours in their communities'* (MoHS 2016:17)-National Community Health Worker Policy 2016-2020.

The first quote reflected the importance of the role of community leaders in supporting mass campaigns such as immunisation campaigns and bed nets campaigns. Specifically, the leaders were involved in calling community meetings on campaigns, and also using the media in providing campaign related messages on the uptake of such services. For example, I observed the government convening meetings with paramount chiefs on their involvement in the 2017 bed nets campaign which was launched during my fieldwork. Similarly, the second quote depicts the involvement of traditional leaders as mobilising support for example with early referrals in getting people to go to the hospitals as nurses were not able to go to all communities, especially in the hard-to-reach areas.

In summary, traditional leaders exercised local level authority as elected leadership by the people and their involvement in the enforcement of by-laws and the provision of health information created a sense of ownership of programmes which may allow interventions becoming more viable, a testament to community management. However, some communities such as the 'Gbangbatoke' community were reported as lacking such leadership. The implications will be explored in the discussion.

7.2.5 Discussion

The present chapter reported the discourses on leadership as an important component of family and community management in relation to malaria in this area of Sierra Leone. It identified one main theme, *community leadership* and two sub-themes namely *by-laws* and *health information'*. Community leadership discourses emphasised the need to include leaders in the planning and implementation of health interventions. By-laws focused on the implementation of laws accompanying national laws (Tolhurst et al 2004) on the uptake of services and maintaining proper sanitation and environmental habits. Health information discourses recognised the role of leaders in providing messages on

malaria risks that were trusted. The discourses contributed to family and community management by advancing understanding of the role of leaders in influencing behaviours and attitudes that can improve health outcomes.

Community leadership involved local leaders seen as mobilising people and undertaking activities for improving health outcomes. The current study findings indicate that leaders were involved in linking actors and setting up community structures such as the facility management committee, supporting community health volunteers and building trust in the health service. Structures such as facility management committee and processes were seen as allowing individuals, groups and communities to play meaningful roles in achieving health goals. The committee also stimulated motivation where stakeholders shared common interests in membership of the health committee (Barthel et al 2005). Gilmore et al (2016:2) conceptualised committee health committees as 'community coalitions often considered to have a more sustainable influence on community health and well-being, partly due to the collaboration between professionals and community (grassroots) members such as traditional healers as in this study. Together they responded to identified health problems by drawing on traditional and biomedical knowledge. Such coalitions created harmonisation of health initiatives, increased the potential for community empowerment and facilitated the participation of community members in health initiatives. Such coalitions also increased programme ownership and sustainability of programmes. The findings in the present study explain that involving leaders in planning and implementing interventions fosters ownership. In this sense, leadership was important in coordinating health activities in communities and was an important attribute for community management.

The study conceptualisation of leadership is that it influenced and enhanced the ability of people and communities in dealing with adversity. In communities that had strong leadership, they developed strategies in making things better (Kulig 2000). Geographic isolation in remote rural areas of which the participants spoke may have enhanced community management because local leadership and infrastructure had to be developed for coping with situations that arose. For example, some community leaders were able to mobilise youths for environmental sanitation, and constructing security fences as in rural 'Taninihun Kapuima' and 'Bauya' communities.

Thomas-Slayter and Fisher (2011) found that understanding the roles of local authorities could illuminate specific ways in which local context might contribute to improving health outcomes. The findings in this study are similar in Chaskin (2001) who noted that leadership applies particular aspects of human capital such that leaders act

as agents to mobilise others. The human capital component of the study framework could be applicable here as local leaders such as paramount chiefs, their section chiefs and appointees such as the 'natural leader' were reported to influence health care utilisation.

By-laws were the unwritten rules passed by traditional leaders who were the elected leaders of the people to ensure compliance with health laws on uptake of interventions such as proper use of bed nets, antenatal visits, immunisation and environmental sanitation. Despite these laws, the study findings point to lack of compliance in some communities, for example, the 'Gbangbatoke' community where participants reported a lack of leadership and disunity. Lack of leadership and unity seemed to increase the threats associated with malaria as people failed in complying with by-laws pertaining malaria control. Terry (2011) highlighted how social conflicts in the form of tensions as in the 'Gbangbatoke' community.

Health Information reflected leaders providing Information about risks of diseases such as malaria. Such information needed to be communicated effectively from trusted sources. Trusted sources were seen as those closer to communities and were local sources of information that were more likely to be relied upon (Norris et al 2008; Longstaff 2005).

The study found that some communities mistrusted modern medicines as highlighted by one participant in the Moyamba town focus group and by the rural religious leader. The pregnant woman in the Moyamba town focus group reported that the medicines cannot easily be swallowed in some cases. The religious leader spoke of people keeping medicines because they heard that other patients experienced side effects after taking those medicines. It can be argued that there were other reasons such as the influence of culture and reliance on traditional medicine. Culture interacted with leadership as traditional leaders were also the custodians and transmitters of community culture, norms and social values in the communities. The Moyamba town youth leader narrated that paramount chiefs own their lands. This underscores the role of traditional leaders as despite some communities were rooted in culture, strong leaders were seen as able to influence health seeking behaviours in such communities.

Policy discourses on leadership are discussed. MoHS (2015)-The Health Sector Recovery Plan 2015-2020 documented the role of community leaders in the facility management committee, highlighting these committees as the mechanisms through which leaders' capacities could be enhanced in supporting service uptake and

neutralising potential non-compliance with by-laws on uptake of interventions. This document corroborated the interviews and focus group findings on the facility management committees bringing local leaders and health workers together in managing activities contributing to health outcomes. The committee was seen as involved in other roles apart from focusing on by-laws, such as monitoring service provision and disseminating health policies to communities and strengthening links between community and facility (MoHS 2015:81)-Sierra Leone Malaria Control Strategic Plan 2016-2020. MoHS (2016)-The National Community Health Worker Policy 2016-2020 documented the role of traditional leaders in helping community health volunteers in promoting the uptake of services. As community health volunteers provided basic services such as antimalarial treatment and early referrals of patients to the referral hospital in Moyamba, such support from leaders for acceptance of services was required. In summary, the policy documents envisaged the importance of the role of community leaders in service provision, a testament to their contribution to community management.

The participants acknowledged variations in leadership qualities where some communities had strong leadership whilst others had weak leadership. Weak leadership in some chiefdoms that were less organised such as 'Gbangbatoke' was reported as resulting in less effort in health promotion activities. The findings in this study are similar in Goodman et al (1998) who argued that communities with weak leadership were disorganised and lacked the capacity for encouraging participation from community groups, for facilitating provision and sharing of health information and lacked the ability to identify health risks such as malaria. Similarly Hosan and Kaiser (2005) noted that breakdown and loss of trusted influence can contribute to weak leadership. For some communities such as rural 'Gbangbatoke' that lacked leadership, there was less community involvement in health promotion activities.

Relationship of Leadership to the Conceptual framework

Leadership was related to concepts in the study framework including human capital, social capital, financial capital and natural capital. Community leaders galvanised human capital including appointing section chiefs to assist in running the affairs of the chiefdom including health matters, the 'natural leader', and community members in the facility management committee. Members of the committee were volunteers motivated by their desire for improving health conditions. They also supported volunteer youth leaders to be involved with activities that promoted health outcomes. Human capital was therefore utilised in developing and accessing resources to develop the community (Flora & Flora 2004; Chaskin et al 2001).

The findings emphasised that leadership was operationalised through recognised roles mobilising social capital, focused on networks and trust (Folke et al 2005b). The findings revealed that leaders were seen as contributing to managing malaria risks through utilising strategic and local networks and interactions for example in supporting women and youth groups in health promotion activities. Positive networks which motivated youths sprang up in conjunction with the government in some communities in environmental cleaning in Moyamba with the government giving tools, and in zonal arrangements in 'Youndo' community. Leaders contributed time and resources in building trust and cooperation by engaging in shared commitments and responsibilities between the health service and community in the facility management committee which, promoted the legitimacy and sustainability of health promotion strategies. As described in the social capital chapter 4, health interventions that were built from the bottom-up and included leaders in planning and implementing drew on bridging social capital that can alter the perceptions of malaria in communities from a problem for policy makers or a global problem to a local problem (Adger 2003). Adger (2003) argued that when people perceive the risk of malaria as within their powers to alter, they can make connections to the causes of malaria thereby enhancing their mitigative capacity. Similarly (Woolcock 2000) argued that these ties connected people that may otherwise not interact, enhancing their ability to work with each other and expanding the resources available to them. Bridging structures such as the facility management committee set up by leaders contributed to social capital as they mediated between communities and the health service. They can be seen as vital in monitoring health programmes.

Leadership related with financial capital by supporting community initiatives in mobilising resources for obstetric care as reported by the rural female health practitioner in 'Youndo'. Borgi et al (2005) noted that the success of financial schemes for obstetric care is dependent on community mobilisation, which is more likely in communities with strong leadership. Leadership related with natural capital as local leaders were seen as having more knowledge of their environments. Leaders were custodians of natural resources including lands that provided livelihoods that helped in withstanding the threats of malaria.

7.2.6 Summary

This chapter explored the role of community leaders in contributing to family and community management. Leaders were involved in influencing and mobilising the uptake of services in communities, through implementing by-laws, providing health information through local media and in supporting campaigns to increase the uptake of services. In

the next chapter, I present the overview of the findings in this study and the contribution of the findings from the chapters.

Chapter 8: Discussion-Overview of Findings

8.1 Introduction

The present study investigated the contribution of family and community management to withstanding the threats of malaria. Its findings identified four main overlapping discourses: social capital; volunteering for development, including gender dimensions of care giving and women's voluntary work; coping strategies; and leadership, which interacted with one another. Social capital discourse depicted social support in the form of tangible and emotional support from relatives, friends and neighbours to individuals in illness. It recognised social cohesion, trust and reciprocity that enabled people to work together for common benefit. Volunteering discourses recognised the role of volunteers including men and women in extending the reach of services to marginalised communities. It reflected women volunteers membership in formal and informal groups and in community structures such as facility management committee. Coping strategies discourses emphasised culture and the capacities in communities to seek alternative forms of treatment such as self-treatment and use of traditional medicine, their capacity to undertake collective action and to thrive in adversity, using existing resources to cope with the ravages of malaria. Leadership discourses depicted the local authority and ability of local leaders to set up processes that influenced community activities to facilitate achieving health outcomes.

I present below an overview of the findings (sections 8.1.1- 8.1.5) and how they interacted with one another (section 8.1.6), a model for family and community management, using the sustainable livelihoods framework proposed in this research (section 8.1.7), and the implications of the model (section 8.1.8). The chapter then considers the theoretical and methodological contributions (section 8.1.8). The chapter concludes with the Policy implications.

8.1.1 Social Capital

The findings in Chapter 4 suggest that family and community health in low-income countries has the potential to benefit from efforts to improve social capital. The findings in the current study have contributed to the social capital literature by showing that the health benefits of social capital apply to all types and aspects of social capital including social support, trust, and community action, communal institutions, suggesting that bonding, bridging, and linking social capital were seen to contribute to better community health. The findings should be considered as exploring the social capital component in

the DFID (1999) framework and its role in family and community management and health.

Another insight from the findings in Chapter 4 is that the social capital discourse incorporated analysis of power of men over women in control over household resources and access to lands to understandings and applications of family and community management in relation to malaria. Power imbalances discourses were related to social capital as social stressors in intra-household power disparities between people in the same households (Brown 2016) manifested in the differential capacities and forms of social capital women can draw on in responding to malaria that emphasised the power of men. The husband, as in the current study was often seen as being in control of required resources and as making decisions on the timing and type of treatment (ibid.). In turn this can limit the uptake of formal care with families particular in hard-to-reach communities with women resorting to traditional forms of care. There were complex interactions between gender inequality and other forms of exclusion based on for example exclusion of women with limited access to lands and culture (Mearns & Norton 2009). Mearns and Norton (2009) commented that a better gender analysis and intersectional analysis of differentiation is required alongside gender inequality.

Another contributing element of Chapter 4 in social capital discourse was gender inequality. Social capital discourse reflected the gender division of labour and the gender distribution of resources, responsibilities, agency and power. Women lacked power to influence resource allocation and investment decisions in the home and community (Zuckerman 2002). 'Empowerment' was equated in this discourse with giving women access to land and participation in decision making on use of household resources. Additionally, women felt that men were not willing to help them in farm work. These findings are consistent with evidence from other settings and health foci. Several studies have identified associations between female empowerment and improved health outcomes (Alaofe et al 2017; WHO 2008: Batliwala 2007; Laverack 2006). A desire for more control over resources and land was the predominant sentiment in the female community leader and female district official interviews, which reflected social and cultural challenges above and beyond the delivery of malaria control programs. Intersecting axes of inequity between factors such as geographic location within a community, education, poverty and income generating opportunities and culture can exacerbate gendered inequities to access services and respond to malaria.

The findings in Chapter 4 showed that men as well as women also reported feeling vulnerable and exposed to malaria. Their accounts included often going out to the coastal communities where they were more likely to be infected by mosquitoes, as reported by the community leader in 'Timdale'. Similarly the rural head of household in 'Fakunya' expressed the view that the father should also be included in the designated vulnerable group and was concerned over bed nets not given to men as well as to women, when men always went out in search of livelihoods and could equally be infected. As malaria is endemic and affected all households, both men and women were susceptible to the disease. Consistent with previous research, men identified themselves on a par with women as being vulnerable to diseases such as malaria (Woldu et al 2015). The different responses from men and women highlighted inequitable gender roles that policy makers may need to address for the communities in the malaria programme in order to achieve high coverage and uptake of services.

Social capital is of particular importance to physical health in developing countries because of their lack of human and financial capital. While social capital is not a tangible resource, it is thought to supplement the other types of capitals to produce better outcomes. Least developed countries have great potential to benefit from the various forms of social capital due to their low income, weak human resources, and high economic vulnerability (Story 2013; United Nations 2011).

Chapter 4 also highlighted that social capital is not always health producing.
Consideration is given to the 'dark side' of social capital'. Not all forms of social capital were always beneficial for all individuals and communities. It is the different combinations of bonding, bridging and linking capital that allow communities to confront risks of diseases.

These insights have two key implications for better health in poorer and marginalised communities. First, they highlight that the social connections of poorer people was a potential asset such as for managing malaria risk. Peoples' lives were embedded in social connections with families, friends and neighbours and were an important asset that can be called upon in times of illness (Seeley et al 2009; Caroll 2001). Second, these insights direct attention to health services such as in this study that were seen as inadequate and as having weaker capacity to respond effectively to disease epidemics. Together, these processes undermined health provision, hence social capital is valuable. Next I overview Volunteering.

8.1.2 Volunteering

Chapter 5 explored the contribution of volunteering to family and community management. This chapter makes several points about what volunteering brings to health and the importance of volunteering in family and community management in relation to malaria. The chapter explored the role of a volunteer in extending the reach of services in three contexts-as volunteers recruited through government and community-led volunteer schemes, as volunteers in NGO led groups and as volunteers in self-help groups. In the context of government and community led schemes, these were manifested in the community health volunteers and volunteers in the facility management committee. In the NGO led groups this was reflected in the mother support groups. In the self- help groups these were seen in the men and women groups involved in environmental cleaning, constructing security fences for the facility and in the informal women's groups involved in constructing toilet facilities. In all cases, the forms of volunteering contributed to improving health outcomes at the community level, a testament to community management in relation to malaria.

The research showed that volunteering contributed by improving access to health services in isolated and marginalised communities. Volunteers were seen to provide the alternative manpower in the health service in taking services to poorer communities, linking individuals and communities to services and information outside of the community that they would not otherwise have. They were seen not only as promoting better access to services but saving lives with early referrals, thereby contributing to reducing mortality from malaria, a testament to family and community management. Next I overview Coping strategies.

8.1.3 Coping Strategies

Chapter 6 explored the contribution of coping strategies to family and community management. The current study participants identified a range of coping mechanisms that they employed. Mechanisms put in place by the study participants included developing preventive strategies, livelihoods diversification strategies, medical pluralism and combining religion and health. The coping perspective developed here means that people were seen as active agents in their communities. Vulnerable people were actively engaged in diverse and dynamic strategies to reduce malaria risk.

Chapter 6 explored livelihoods diversification strategies including women income generating activities which helped to generate money to withstand the threats of malaria activities.

Communities were seen using multiple sources of treatment. This response to malaria is an insight that may indicate why malaria persists because many in communities are relying on using traditional medicines which may provide healing temporarily but not cure. Therefore, it is important to include this finding in highlighting the role of traditional medicines in a constructive way with policy in the control of malaria, rather than merely dismissing such forms of care as ineffective.

The chapter revealed that religion as a coping strategy featured in these discourses. Religious affiliation was seen to influence peoples' response to interventions. In this sense, religion informed the major part of peoples' socio-cultural identity. Religious congregations were often found in the most inaccessible areas where government services do not reach, were more established than local or national governments, and provided channels of information that people relied on.

Chapter 6 illustrated that whilst some conditions causing malaria were context specific such as geographical context in the 'Youndo' coastal community, others such as gender inequalities and poor environmental conditions were common in both rural and Moyamba town communities. However the presence of these factors did not prevent participants from striving to cope with the disease. Next I overview leadership.

8.1.4 Leadership

Chapter 7 explored the contribution of leadership to family and community management. This Chapter makes three major points about the importance of leadership. First, leaders were seen to matter in family and community management in relation to malaria. Leaders were reported as mobilising support for the uptake of interventions by families and communities. In this sense, it was consequential for the success of interventions. The second is when conceptualised in the context of communities, leaders were seen to have traditional authority to contribute to building trustful relationships between communities and the health service. Finally, because traditional leaders were the elected local authority of the people, they were seen as having the capacity for persuading people to pool community resources in undertaking activities that influenced health outcomes. This aligned with previous research which noted that programmes that had the support of local leadership and involved leaders in planning and implementing were more likely to succeed (Thomas-Slayter & Fisher 2011; Hosan & Kaiser 2005).

Strong leaders could influence health seeking behaviours even in those communities that tended to adopt pluralistic approaches, by implementing by-laws that increased uptake of services. This was seen as contributing to the overall health in such

communities. In contrast, weak leaders were less successful in influencing uptake of services which was seen as leading to degraded health conditions in such communities. Leadership was important in coordinating health activities in communities and was an important attribute for community management. However, its features depended on the conditions present in each specific community and on the relationships between them. Next, I overview the Policy discourses.

8.1.5 Policy discourses

The term 'family and community management' was not explicitly defined in any of the policy documents. In this study, the family and community management approach did not come explicitly across when synthesising the included documents. The documents had mainly adopted the rhetoric connected to the ideology of family and community management, but none of the documents detailed the processes or strategies to tackle issues of family and community management.

The prescriptions offered in these documents are quite diverse but they do have important features in common. These include the concepts of scaling up (MoHS 2015 – Sierra Leone Basic Package of Essential Health Services 2015-2020; MoHS 2015-Sierra Leone Malaria Control Strategic Plan 2016-2020), capacity building (MoHS 2015-Sierra Leone Malaria Control Strategic Plan 2016-2020; MoHS 2012-Integrated Vector Management Strategic Plan) and community ownership (MoHS 2015–Sierra Leone Basic Package of Essential Health Services 2015-2020; MoHS 2015-Sierra Leone Malaria Control Strategic Plan 2016-2020).

It is important to recognise that each policy document does not itself represent a single discrete discourse, the discourse might be shared by a number of different documents. For example the MoHS (2015)-Sierra Leone Malaria Control Strategic Plan 2016-2020, MoHS (2009) -National Health Sector Strategic Plan and MoHS (2016)-National CHW Policy 2016-2020, all mention community health workers linking communities with the facility. Likewise MoHS (2015)-Sierra Leone Malaria Control Strategic Plan 2016-2020 aims at strengthening the role of communities in malaria prevention and control mainly through the participation of individual members of the communities, such as community health volunteers and in community structures such as the facility management committee, facilitating linkages between the communities and the health system at the community level, disseminating information on public health issues, and mobilising communities to participate in health sector planning, monitoring and distribution of bed nets.

Although measures to improve the health and economic conditions of women were emphasised in some policy documents (MoHS 2015:51)-Health Sector Recovery Plan 2015-2020; MOHS (2015)-Sierra Leone Basic Package of Essential Health Services 2015-2020, gender equity was not a health policy priority, and women's health issues were overlooked in most of the policy documents. As a result, the problem of gender inequality in health and health care access remains. Whilst some of the policy documents of the present study emphasised that special attention should be paid to vulnerable groups such as women, there were women groups that may not have access to the health services.

However improving the health of women as explicitly suggested by the data, would require deepening the orientation of the policy measures toward women empowerment. The study reinforces the view of earlier studies (e.g. Whitehead & Popay 2010) that analysing existing policies for their impacts on different groups in the population would be crucial for addressing health and health equity. Similarly Whitehead and Dahlgren (2006) suggested that social inequities in health should be described and analysed separately for men and women and this difference should be taken into consideration while developing strategies to combat health inequities.

The scaling up of community action is most successful when it is supported by state policies and when it finds well placed allies in state bureaucracies (Carroll 2001). For example, the policy document (MoHS 2015:16)-Sierra Leone Malaria Control Strategic Plan 2016-2020) supports local organisations for strengthening communities abilities to manage malaria risk, and makes the case for involving communities in malaria control. Such bottom-up approach that seeks to engage and support communities in identifying and prioritising their health concerns can lead to developing individual and community empowerment and bring sustainability. However, some participants, such as the previous male patient in 'Timdale', reported that youth groups were very unhappy with their exclusion and lack of employment. The Moyamba town youth leader also reported the top-down approach taken by programmes in failing to involve local leaders in planning and implementing programmes and in excluding sections of chiefdoms. In the 'top-down' approach, policy makers developed objectives and action plans for community participation and then endeavoured to convince communities to actively participate in their implementation. Previous research has noted that whilst such policy sought to involve communities, it was less likely to succeed as people participated as 'passive' beneficiaries, particularly in some communities where malaria was accorded a low priority in the eyes of the community (IDS 2015; Ferlander 2007; Kunitz 2001). In contrast, Wong and Guggenheim (2018) noted that often it is top-down interventions that

drive reform in areas such as women's participation and social mobility, as was seen in this study with mother groups and informal women groups taking up roles that are normally the responsibility of the health service.

Health legislation can shape the way in which health policy is translated into health programmes and services. For example the policy document MoHS (2009:3)-National Health Sector Strategic Plan 2010-2015, in complementing the discourses noted that the greatest burden of disease is on rural populations, and on women within the rural population. The document further noted targeting men to make them aware of the importance of women seeking health care, while also targeting women to raise awareness about the importance of them seeking health care for themselves and their children (NHSSP 2009:39)-National Health Sector Strategic Plan.

Although some of the policy documents of the present study emphasised that attention should be paid to vulnerable groups such as women, it seems women were involved in struggles about access to land and resources as was reported by the female community leaders in 'Timdale' and 'Bumpe' and by the district council official in Moyamba. Women rights to resources were seen to be eroded through competition with men, thus further constraining their capacity to diversify their livelihoods to be able to improve their health and the health of their children. Alyaemni et al (2013) suggested that improving women's health would require improving gender equity in society across both the private (including family and cultural norms) and public (including access to resources and decision-making) (Karlsson et al 2020:8). Next, I discuss how the discourses interacted with each other.

8.1.6 How discourses interacted with each other

Social capital discourses (Chapter 4),volunteering discourses (Chapter 5), the mechanisms they have developed to cope (Chapter 6) and the perspectives on leadership (chapter 7) presented a picture of people reporting perceptions of the challenges they faced and their capacities to draw on assets and develop strategies to deal with malaria. Social capital was seen to be related to other discourses including leadership, volunteering and coping strategies. The relationship of social capital to leadership was seen with leaders setting up structures such as facility management committee (Barthel et al 2005) and processes to allow individuals, groups and communities to play meaningful roles to achieve health goals. The relationship with volunteering was for example that committee members were seen as volunteers contributing to social capital by mediating between communities and organisations in health programmes and monitoring health programmes, connecting people, enabling them to work together to tackle adverse conditions in their environments. Previous

research has noted that volunteers acted as catalysts and moved others, thereby generating collective action (Smith et al 2016; IDS 2015). The relationship of social capital with coping was seen in how coping strategies were enacted for families and communities including emotion–focused coping manifested in household coping strategies such as social support, and problem-focused coping (Folkman 2010; Seeley 1993a), livelihoods diversification and in networks of reciprocity. But although being seen as important for coping, social capital does not necessarily or directly enhance well-being (Dasgupta 2003).

The discourses reflected contrasting perspectives of the participants in this research. The four discourses–social capital, volunteering, coping strategies, and leadership were readily discernible and distinguishable from one another. However, some discourses reflected one (most commonly, social capital) discourse but to a greater or lesser extent, acknowledged elements of the other two. For example, social capital encompassed leadership and volunteering, with leadership based on trust and volunteering linked to community management (Smith et al 2016). As social capital, volunteerism connects people, enabling them to work together to tackle adverse conditions in their environments. While the different participants and groups were not entirely homogeneous, it was broadly the case that the four discourses described above reflected the position of one or more participants (Greenhalgh et al 2012). For example, in the volunteering discourse, whereas volunteering discourse engaged superficially with the issue of trust in volunteers presenting it as a straightforward and community presence, leadership discourses analysed it further in terms of trusted sources of health information. While the former viewed trust of the community in volunteers selected from the community by local leaders and residing in their communities, the latter similarly viewed trust of the community in their local leaders as trusted sources of information they could rely on.

The empirical investigation discussed emphasises the peoples' concerns about family and community management. Different discourses tended to 'talk past one another' on patterns of health-seeking behaviour with practitioners advocating visits to the hospital and the uptake of interventions, whilst people in certain communities spoke of poverty and their inability to afford modern care, thus their adherence to cultural practices. Women in volunteering emphasised the power differentials that denied them access to lands and resources.

The findings show a close connection between how people and communities perceived challenges and the way people responded to these challenges. An important element in

characterising this connection was the finding that despite malaria risks, certain communities saw themselves as able to mobilise resources at family level in the form of social support and community level in collective action to enable them to cope with the disease. A major challenge for people was how supply and demand factors combined to affect their capacities to withstand malaria. Next, I present a model of family and community management in relation to malaria.

8.1.7 Towards a model of family and community management in relation to malaria

The study considered the initial conceptual framework (DFID 1999) in Chapter 2 to be a work in progress and the final framework was refined upon considering results from the field work and findings. Following the fieldwork, I modified the framework by adding the vulnerability context in relation to malaria, cultural capital (Kulig 2000; Bebbington1999) as a sixth form of capital, and health related outcomes as informed by the data from the field study. Cultural capital though not included in the DFID (1999) framework was added due to its relevance to the findings. The current study found that cultural factors relate to malaria and there were interactions between local culture and malaria (Heggenhougen et al 2003). Participants in the Moyamba town focus group spoke of the influence of culture in peoples' health seeking behaviours which were based on practices passed on to them by their foreparents (Oberlander & Elverdan 2000; Muela et al 1998). The female community leader in 'Timdale' and the female district council official reported people adopted plural health systems, based on their culture in seeking care (Scott et al 2014). The female district council official reported men had dominant control over household resources and decision-making (Mearns & Norton 2009; Bates et al 2004). Culture created gender inequities in access to lands. Culture encompassed the contested nature of peoples' struggle to respond to, negotiate and mobilise for withstanding the threats of malaria.

Chapter 2 presented the relevant literature including the vulnerability context and the barriers to access to services that families and communities faced and how previous research had addressed the topic. Chapter 3 presented the study design and the philosophical assumptions in the study. The results Chapters 4, 5, 6 and 7 identified the key issues which people highlight when explaining their vulnerability and the assets and resources that communities drew on to manage the threats of malaria. The move to health outcomes was an important shift showing how families and communities were able to mage the threats of malaria. *Figure 8.1* depicts the proposed model for family and community management, reflecting how the six major forms of capital can contribute

to reducing vulnerability to malaria and contribute to improving health outcomes. The description follows the model.

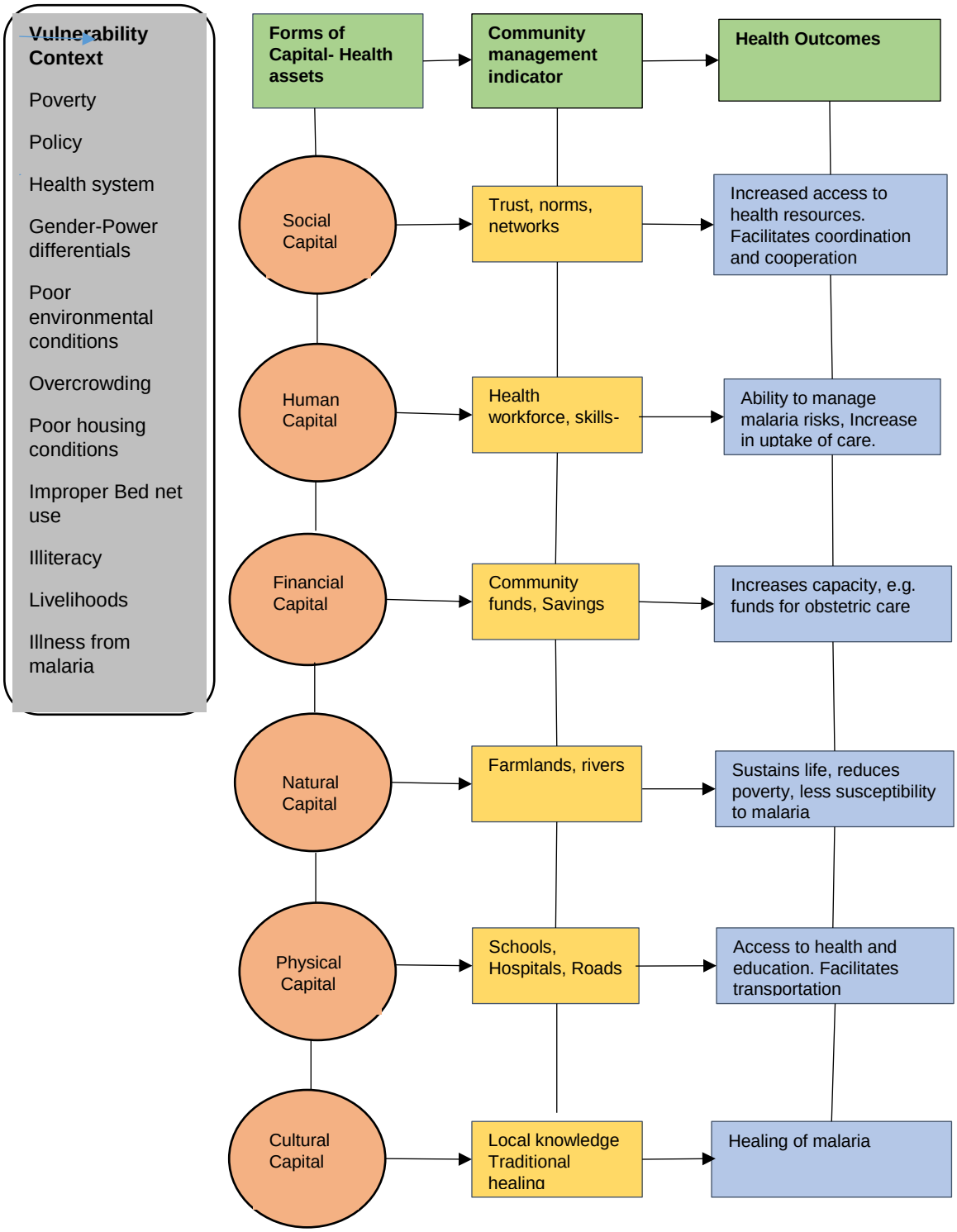

Figure 8. 1: Model of family and community management in relation to malaria

The model recognises multiple stressors and the need for integrated solutions which recognises underlying drivers of poverty and vulnerability, power imbalances and how a

livelihoods approach enabled people to draw on resources, anticipate, organise for in collective action for withstanding malaria threats. Using this model, it is possible to identify stages experienced by communities at risk of malaria. Men and women found themselves more or less vulnerable at each stage depending on their contexts. Vulnerability to malaria was often a result of circumstances and situations generated by influences as identified in the model including poverty, inadequate health system, power differentials, poor environmental conditions, low literacy, improper use bed nets use, and seeking livelihoods. As circumstances changed due to agency and factors such as the inadequacy of services more choices become available to families and communities, and people were more able to undertake activities moving between stages and ultimately towards achieving health outcomes. However achieving health outcomes can be a long and complex process. It is non-linear, and it required the appropriate range of capitals to be drawn on by communities, also necessitating health organisations support and building on peoples' coping strategies. It is acknowledged in the current study that this framework did not predict a linear progression from one stage to the next or that families and communities may not move back and forth between stages (Seeley et al 2010: 2) for example from drawing on the forms of capitals and back to vulnerability. Yet the discourses suggested that the forms of capitals and the community management indicators could provide a way of identifying ranges of strategies of families and communities affected by malaria. It is important to be aware of this non-linear pattern when planning and implementing interventions. Below I briefly outline the different stages identified by the model as they specifically relate to family and community management of malaria.

Vulnerability

The vulnerability context depicted in the model included poverty, policy, the health system, gender differences, poor environmental sanitation, poor housing conditions, overcrowding, illiteracy, improper use of bed nets, and livelihood factors causing malaria. Specifying vulnerability here the risk factors associated with malaria and the contexts in which these occur are found in peoples' narratives.

The study identified contextual vulnerability and vulnerability as an outcome *(*Bizimana et al 2015: Rickie et al 2012; Eriksson & O'Brien 2007; Adger 2006; O'Brien et al 2005; Bates et al 2004). As context, participants reported the agricultural context and coastal community's context. Vulnerability as outcome was manifested in poverty. Poverty and its correlates, including poor housing conditions, low literacy, population density and bed net misuse were dominant in these discourses.

Inadequacies in the health system was seen as increasing peoples' vulnerability. Such inadequacies included lack of access to care and perceptions of the quality of care offered. Access to care was affected by both and supply and demand side factors (Ensor & Copper 2004). Supply-side factors included the geographic distribution of facilities and lack of facilities in sections in some communities, as was reported by the rural community leader in 'Timdale' and the Moyamba town youth leader, and the burden of payments for health services as was reported by the Moyamba town school teacher. Other supply side factors included poor transport systems as narrated by the rural health practitioners in 'Bagruwa'. Unhelpful staff attitudes and poor quality services (Bates et al 2004) were also cited in the health practitioner's focus groups as one of the main supply side factors contributing to delays in accessing treatment, and increasing peoples' vulnerability. Additional factors included long waiting times in the facility and stock-outs as reported by the Moyamba town school teacher. The study participants such as the rural religious leader and participants in the Moyamba town focus group also reported women refusing to take modern medicines due to mistrust. Demand-side factors included illiteracy and knowledge about malaria, culture and lack of resources for women to pay for costs of access where men had control over resources and household decision making (Ensor & Copper 2004). Previous research has noted that women had limited power and ability to seek malaria prevention or care for themselves and their children and this combination of factors tends to make women more vulnerable than men to the consequences of malaria (Molyneux 2002).

Gender differentials were seen as increasing vulnerability to malaria. Women and men were seen as having different vulnerabilities influenced by a complex interaction of social, economic and cultural factors. Despite women having more caring roles at home and in community, the study participants reported women having more limited access to lands and farming opportunities and less control over household resources and decision making at the household level (Bates et al 2004:7). In another study, Lampietti et al (2000) noted that women may be more willing than men to invest in malaria prevention measures such as insecticide-treated bed nets but many lack the financial and decision making power to act on this desire thus increasing their vulnerability to malaria.

Illiteracy and low educational attainment were also seen as increasing women's vulnerability to malaria. The findings are similar in Bates et al (2004:8) that the provision of information on appropriate use of antimalarial drugs can influence treatment seeking behaviour and in Filmer (2001) that educated parents are more likely to seek formal treatment when their child gets malaria symptoms. This stands in contrast to

Aikman et al (2016:314) that applying such deficit terms is disregarding the skills and knowledge that participants already have and practise in their everyday lives such as seeking alternative treatment for their sick children (Scott et al 2014).

Another factor for vulnerability found in many participants accounts was that people were using bed nets for purposes other than protection against malaria, such as for fishing (Trisos et al 2018) as reported for example by the Moyamba town community leader who drew my attention to the nets in a garden in Moyamba, and by the international NGO CRS participant who reported seeing women fishing with the net on a trip with an official from the donor, the Global fund. Additionally by not deploying bed nets properly, their vulnerability to malaria was increased as reported by the female practitioner in 'Youndo', making visits to households to ensure proper hanging of nets. The findings concur with Bizimana et al (2015:6) in their study in Rwanda who noted that for bed nets to be effective, individuals should properly deploy their bed nets each night.

The current study found there was overcrowding in households as reported by the head of household in Moyamba in having eleven people in his family whilst only three bed nets were allocated to his family. This finding concurs with Bizimana et al (2015) and Lindsay (2003) conceptualisation that high population density might further increase vulnerability to malaria infection, and increasing the chances of mosquitoes infecting more than one person on the same night are higher. Vulnerability to malaria was also attributed in participant's accounts to poor housing conditions which provided less protection against mosquitoes (Bizimana et al 2015; Mwangangi et al 2012). The rural head of household in 'Fakunya' narrated sleeping in poor housing. Many houses in such communities were likely to have mud walls and open ceilings allowing mosquitoes entering houses and increasing peoples' exposure to mosquito bites. Consistent with research conducted by Bates et al (2004), the findings in this current study explain that poor quality housing increases exposure to malaria infection because mosquitoes can easily enter through unprotected openings.

The vulnerability context frames the external environment in which people exist. Critical trends as well as shocks and stressors, such as weather events, ill health, and seasonality of crops that people depended on for their livelihoods, were seen as impacting on peoples' health and nutrition over which people have limited or no control. Malaria was seen as harsher in the rainy season, leaving grassy lands and pools of water that provided breeding grounds for mosquitoes, as reported by the rural head of household in 'Fakunya'. The male community leader in 'Timdale' also reported that malaria is greater during the rainy season because people did not weed and cut grasses

in their compounds. A further effect reported of the rainy season was a period of high vulnerability for the farming populations as it was the 'hungry season' that left empty stocks of food before the next harvest. Many households were reported as experiencing food insecurity involving reducing portions of sizes or skipping meals to cope with the five months of the rainy season. Previous research has noted that the rainy season was also the hungry season before crops matured for consumption, and when food reserves were lowest with people having less to eat, leading to poor nutrition and increasing their vulnerability to malaria (Brown 2016; Lewnard et al 2014; Blaikie et al 2001).

An important dimension of vulnerability was seen as the physical risks that result from malaria stresses. Risk is defined as the likelihood of occurrence of (external) shocks and stresses plus their potential severity, whereas vulnerability is the degree of exposure to risk (hazard, shock) and uncertainty and the capacity of households or individuals to prevent, mitigate or cope with risk. These stresses included loss of livelihoods, absenteeism in schools and morbidity and mortality from malaria. They represented risks to poorer people that can contribute to a threat to their lives. The findings are similar in (Erikssen & O'Brien 2007).

There were variations in vulnerability across communities where some reported better performance in the malaria response. An example was the narrative from the male community leader in 'Bauya' who commended compliance with by-laws in the community and in the health practitioner's focus group where participants reported some communities performing better than others in the malaria response. The findings resonates with reported findings in Seeley et al (2009:2) who noted the differential vulnerability to illness or other suffering within the household, are complex issues which vary from community to community, and household to household.

The current study utilises the Sustainable Livelihoods Approach (DFID 1999) that recognises the interconnected influences of social, human, economic, physical, natural and cultural capital on families and communities in health seeking behaviours and the response to malaria towards family and community management. As the livelihoods approach is concerned first and foremost with the resources available impacting on peoples' lives (Seeley & Pringle 2001), its focus is on gaining an accurate and realistic understanding of peoples' strengths here called "assets" or "capitals". It is crucial to analyse ways in which people endeavour to convert these strengths into positive livelihood outcomes. The approach is founded on a belief that people require a range of assets to achieve positive livelihood outcomes such as health outcomes. Therefore the framework identifies six types of assets or capitals upon which livelihoods are built,

namely *social capital, human capital, financial capital, natural capital, physical capital* and *cultural capital.* This sub-section critiques some of the key ideas emerging from the literature on asset-based approaches to community management. It highlights some of the indicators of community management and signposts areas that require further enquiry. The six assets identified in the framework are discussed.

Social capital can be seen as the trust, norms, and social networks that facilitated collective action and status. Access to trustful relationships can help people to act together to overcome adverse conditions. In the context of community management, community ties and networks can be beneficial in allowing individuals to draw on the social resources in their communities and increasing the likelihood that such communities will be able to adequately address their collective concerns. The concept of social capital is important here because it can provide understanding how to resolve collective problems such as health challenges more easily (Mayunga 2007). Social capital illuminated the study findings as communities endowed with relations of trust and social networks were in a stronger position to overcome vulnerability to malaria. The study findings revealed links between social capital and health at both the family and community levels. At the family level, the support of friends and relatives was seen as being of benefit to individuals in ill health. It seemed the more people were involved in continuous social interaction, the easier their access to resources for medicines and health information. In this sense, bonding social capital within families and households can be an important asset for coping with the impacts of adverse conditions (Adger 2003). As regards community social capital, it was linked with the community level in membership of formal and informal organisations. The contribution of social capital to community health was in how individuals participated collectively in community action to improve community health.

Human capital encompassed the health workforce including health practitioners and local actors including community health volunteers, community leaders, women in formal and informal groups, facility management committee members and youths. From a livelihoods perspective, human capital is defined as representing the skills, knowledge, and labour that together enabled people to pursue different strategies and achieve their livelihood objectives" (DFID 1999:7). It also applied to traditional knowledge in healing which was reported here as giving people the ability to cope with malaria. Knowledge of plants used by traditional healers to treat malaria in their local community was seen as an important resource in building community management. Human capital was valuable not only for its own reasons, but also for its contribution to mobilising other assets in order to achieve positive health outcomes. Human capital illuminated the study findings

in local people voluntarily providing services as, in contributing their skills and services to activities aimed at withstanding the threats of malaria.

Financial capital referred to financial resources that people used to achieve their livelihoods; such as community funds for obstetric care, trading incomes from the weekly market in 'Gbangbatoke' and income generating activities undertaken by women. The contribution of financial capital in building family and community management is relevant here in the sense.

Natural capital referred to stocks of natural resources, such as rivers, minerals, land which provided livelihoods, and the ecosystems that maintain clean water and air (Adger 2003). Natural capital is essential in sustaining all forms of life including human life. In the context of malaria, natural capital such as lands was seen as playing an important role in agriculture for planting a variety of crops and in providing foods and incomes for withstanding the threats of malaria. Natural capital was influenced by individual and collective action (Magis 2010) for example in people undertaking farming for livelihoods. Rakodi (2002) noted that households can depend directly or indirectly on the urban and rural natural resources. Natural capital illuminated the study findings in providing local resources for poorer and marginalised communities to help withstand the threats of malaria, and that it increased the ability and capacity of individuals, groups, and communities to absorb the impacts of malaria. It was seen to be used directly to reduce vulnerability, such as through buying medicines or food to avoid malnutrition.

Physical capital comprised the physical infrastructure such as roads, community centres, hospitals and schools that were essential for the proper functioning of the community. Lack of physical capital is associated with poverty and related characteristics such as ill health and reduced access to education and health facilities. Consequently, this can be seen as reducing the productivity of available human capital (DFID 1999). Physical capital was generated through application of financial and human capital (Flora & Flora 2004; Goodwin 2003). Physical capital illuminated the study findings as an important resource in building the capacity of the community to cope with malaria. Physical capital such as schools illuminated the community findings in providing places for learning. Schools were recognised as places of learning and knowledge acquisition for young children living in marginalised communities. Physical capital such as hospitals illuminated the study findings as they were seen by participants as providing preventive services such as bed nets, intermittent preventive treatment for pregnant women and infants and curative services such as antimalarial tablets. This resonates findings in one study in an area of unstable transmission (Lindblade et al 2000) where health facilities

were used initially in preference to home treatment. This study in Uganda found that hospital care was favoured as provision of care was perceived to be of good quality, drugs were available on site, services were provided at very low cost, and the facility could treat severe cases of malaria. The rural religious leader reported urging his congregation to go to hospital once they feel symptoms of malaria. Health practitioners also reported providing health talks to pregnant women visiting the facility for ante natal care, thus building capacity to cope with malaria. This stands in contrast with several studies reporting simultaneous use of several alternative strategies in addition to biomedicine with people seeking local solutions to problems and using familiar sources of treatment such as herbs and traditional healers (Scott et al 2014; Bakshi et al 2013; Marks 2006). Scott et al (2014) in their study in Sierra Leone found people combined types of treatment in seeking care from a wide range of sources.

Cultural capital referred to people in social groups, for example, communities. It reflected communities' ways of knowing the world, their values, and their assumptions about how things fit together. It was represented by symbols in language, art, customs, and cultural worldviews (Satterfield et al 2013). Culture created the perspective from which people perceived life events, and sets in motion social rules related to power and influence in community (Flora & Flora 2004). Such observations imply that the notion of cultural capital (Bebbington 1999) might usefully add to the Sustainable Livelihoods framework. What this added to the study findings was that whist local people were more at risk from disease and mortality due to marginalisation and exposure for example from poor housing conditions, however shared identity and culture (McCubbin & McCubbin 2005) were seen as playing an important role in withstanding the epidemic, drawing from their community group efforts and local solutions.

Facets of culture important to community management included community members' belief in their ability to survive and thrive through ill health and to develop the necessary capacity for community management (Magis 2010) as manifested in collective actions. Local peoples' cultural worldviews and knowledge may be at odds with scientific knowledge but was seen as demonstrating their capacity to build community management in relation to malaria in their local environments (Rival 2009).

There were variations between accounts where some study participants in, for example, communities with good leadership such as 'Bauya' and 'Bagruwa' communities reported depending on collective action and the availability of local actors such as leaders, women and youth volunteers who were drawn upon for cleaning the environments, constructing facilities and in delivering health messages. Community management was achieved

through collective actions of the community as a whole and not on the similar activities of individuals in the community (Brown & Kulig 1996/97). Communities manifested community management in one set of circumstances at one point in time yet not another. For example, the study findings presented leadership as an important ingredient of community management. The model can be used by practitioners and community leaders as one mechanism for assessing capacities in communities. Collecting information through the model will help to more systematically analyse what level of community action may be occurring and ways in which this could be strengthened. It can therefore provide guidelines for the creation of relevant health programmes that will maintain and enhance community management within the community. This will in turn potentially improve the health status of the community.

8.1.8 The Implications of the Model: the added value of my Study

To understand the relationship between family and community management and improved health outcomes, a model that theorises the links between resources and health promoting activities undertaken by families and communities can be useful. The model showed how knowledge about family and community management was generated through empirical research. Furthermore, it manifested the complexities and non-linear processes that family and community management entails, where individuals and communities moved between the stages from vulnerability to forms of capital through community management indicators towards health outcomes. People undertook action to make their health conditions better and improve health outcomes in certain communities depending on context and socio-cultural factors and the degree of support available. It shows the key importance of individuals and collective actions people took to shift to stability from adversity.

With regards to the overall thesis the model illustrates ways in which the discourses on vulnerability, resources including social, human, natural, financial, physical and cultural can contribute to family and community management in achieving to health outcomes. The model takes into account the findings and conclusions of this thesis based on analysis of empirical evidence from fieldwork in two ways. The first is the thinking that led to the model derives from the forms of family and community management as reflected in the discourses. The second was in helping explain community adoption of strategies to manage the impact of the disease. However different communities had different capacities and constraints to achieving community management, thus raising the question of whether a ‘one size fits all” approach may effectively deliver family and community management. The forms of community management were not seen as

exclusive. It needs to be emphasised that people could manifest some types of community management in specific locations at one time point but not another. Not all communities responded to the malaria epidemic in the same way and some were seen as being successful in one aspect of community management without successfully drawing on another. Also community management was seen to shift dynamically according to local circumstances and this study identified discourses including social capital, volunteering for health, coping strategies and leadership as specific ingredients being seen as important and to be used in social settings associated with the range of different responses in different communities. These were often determined by the strength of specific characteristics in the model including the vulnerability context, the sources and effects of capitals by community as ingredients of community management that were seen to emerge in the study settings.

Predominantly, malaria control has been disease-focused and has lacked an integrated perspective, including ignoring family and community management aspects relative to withstanding the threats from malaria. These included family and community social capital, human capital manifested in volunteering, leadership and traditional knowledge, natural capital such as lands that provided livelihoods, financial capital manifested in income generating activities and community funds and physical capital manifested in schools and health care facilities. The Sustainable livelihoods framework enabled understanding of how people drew on local assets and resources reflected in the framework to withstand the threats from malaria. Instead of focusing only on the causes of diseases, the model shifts the focus towards peoples' agency and capabilities in dealing with health challenges present in their daily lives. The model enabled the elaboration of the different assets and resources and experiences that participants identify and use to deal with malaria. In other words, by using the model of family and community management of health, the current study has been able to develop a model on alternative approaches to withstanding malaria. These findings are important for informing alternative approaches in malaria control.

The integrated framework views vulnerability as depending on both outcomes and context to explain why families and communities are at risk of malaria. This presents an integrated understanding, allowing for a multi-scale analysis of vulnerability of poorer communities to malaria. The integrated findings indicate that people are active participants in taking responsibility for their health, drawing on local resources and employing livelihood strategies to withstanding the threats of malaria. This can be seen in the findings Chapter 4, 5, 6 and 7. This was also seen when participants recognised that diseases are present because of the poor environmental conditions and took

preventive measures like youths in environmental cleaning to ensure a better sanitary environment. Such collective actions as reported by people towards improving their environmental conditions were essential, but needed to be supported by health organisations.

8.1.9 Theoretical and Methodological Contributions

At the start of this thesis, I aimed to examine family and community management in relation to malaria, using an exploratory case study and empirical analysis to address the research question. A Sustainable Livelihoods framework revealed ways in which people and communities presented their capacities and abilities and their views on their experience of family and community management. As seen in Chapter 2, this research adopted the Sustainable Livelihoods framework based on (DFID 1999) conceptualisation. The findings revealed that communities drew on the forms of capital-human (volunteers), social (trust, norms, networks), economic (income generating activities, savings, community funds) physical (schools, hospitals) and natural (land and water resources) to help with thinking on the Sustainable Livelihoods approach and the malaria epidemic. The essence of using the livelihoods approach was highlighting the importance of assets and resources that families and communities can draw on in withstanding the threats of malaria. The findings revealed the capacities and abilities in some communities with these capitals, testifying contributing to family and community management in relation to malaria. The thesis has made significant theoretical and methodological contributions to which I now turn.

Theoretical Contribution

I undertook a literature review to investigate what is known about the concept, associated factors and application of family and community management in communities facing disease epidemics. I conducted a literature review to understand the conceptual and empirical development of family and community management and how it has been applied in the health context. The literature review addressed a gap in existing literature reviews of family and community management. Few studies have focused on family and community management in relation to malaria from a livelihoods perspective. This thesis has contributed to the family and community management literature and to a range of audiences including academics; practitioners and policy makers. The audience is intended to be academics interested in the study of family and community management. A comprehensive literature review of family and community management is lacking in the literature. This review addresses that gap through the critical assessment of emerging themes, gaps and areas for future research. The usefulness of this review is in helping with understanding the malaria epidemic not just as a ‘health’ issue but also a

'livelihoods' issue impacting on many different aspects of peoples' lives. This has the potential to inform policy makers on alternative approaches to withstanding the threats of malaria.

The thesis applied the Sustainable Livelihoods Framework in generating knowledge about family and community management in relation to malaria through empirical research. The Sustainable Livelihoods approach was suitable for shifting from the disease focus which emphasises risk, ill health and disease instead to place emphasis on how families and communities acted to generate and improve their health. By focusing on peoples' discourses of malaria from a livelihoods perspective, this thesis revealed a series of new insights on approaches to addressing the challenges of the mortality and morbidity from malaria and in new ways of withstanding the threats of the disease.

Another key contribution was to make a modest theoretical contribution by adding to the five components of the Sustainable Livelihoods framework-social, human, financial, physical, and natural, a sixth component of culture. The current study modified the dominant conceptualisation of the model in the literature on sustainable livelihoods approaches five components going on to incorporate characteristics of culture which included community members' belief in their ability to survive and thrive through ill health and develop the necessary capacity for community management.

The study contributed to innovation theory in the mutual referral system and in using songs to increase the uptake of services. The study contributed to empowerment theory in women performing roles as chairlady of the facility management committee and in women volunteering in many kinds of collective action to improve health outcomes for themselves and their children.

This study has contributed to the social capital literature by showing how peoples' accounts of the health benefits can be related to most types and aspects of social capital, including social support, trust, community action and communal institutions

Developing a model here is innovative for several reasons. It reflects a multidisciplinary theoretical perspective, focusing on social capital theory, coping theory, volunteering in development and gender dimensions in volunteering. Further the model identified stages experienced by families and communities at risk of malaria, moving from vulnerability through forms of capital, community management indicators to health outcomes, reflecting a shift from a disease focus towards family and community management in withstanding malaria threats. Further research in this area might involve comparative studies to further refine the model, develop the links to health outcomes and to develop

our understanding of the process of family and community mmagqemet of disease epidemics. The strengths of this model from an academic perspective are that it incorporates multidisciplinary theoretical perspectives. From a practitioner and policy perspective, it provides a mechanism to review approaches to malaria control which can inform strategies for health improvements. Further development of this research will involve the refinement of the model .Whilst this model is currently contextualised as a community's response to malaria, future research might consider the potential for creating a model that can be applied to other diseases.

The theoretical utility of the Sustainable Livelihoods Framework to the study of community management was to provide new insights about capacities of people living in poorer and marginalised communities for withstanding the threats of malaria. The framework has often been applied in climate change and disasters but hardly in health research. It was practically useful as it provided an analytical framework to assess findings from the empirical data and enabled an in-depth understanding of the study in terms of discourses. DFIDs Sustainable Livelihoods Framework with its focus on capitals, enabled the dynamics of individual and community interaction to be analysed in a complex health setting.

An important theoretical contribution of this research related to advancing theory relating to family and community management and exploring its implications. By furthering knowledge on factors that contribute to the capacity in families and communities to withstand the threats of malaria, this research contributes to knowledge on how people can learn to live sustainably within their environments and manage their health in relation to those environments.

Another theoretical contribution can be seen in providing the foundation for an understanding of the way that power operates in poorer communities that is more sophisticated than the understanding that informs the mainstream approach to power.

This study identified four constructs relevant to understanding accounts of community management in an epidemic; social capital; volunteering; coping strategies and leadership. These constructs broadly reflect theoretically derived constructs from the literature but which have not previously been explored in the discourses of rural communities facing disease epidemics such as malaria. To achieve such theoretical integration required a multidisciplinary perspective utilising different theoretical perspectives to develop a more comprehensive and cohesive picture of family and community management in relation to malaria. Reflecting on the different approaches

and theories used in this study such as coping theory (Folkman 2010), theory of social capital (Putnam 1995; Bourdieu 1986) indicates how these were instrumental in highlighting how people identified relevant strengths and capacities.

Methodological Contribution

My primary methodological contribution was to adopt a discursive approach to the study of community responses to health programmes, and so enabling the plurality of perceptions at play here to be more rigorously and richly explored through discourse analysis. Discursive approaches have been significant in presenting critical studies of science and examining how particular knowledges are privileged and becoming institutionalised (Brown 2016:17). For example traditional healers as reported by the rural male health practitioner in 'Bagruwa' belonged to the traditional healers association with the government formulating regulations institutionalising traditional healing approaches. Previous studies have identified possible adaptations in indigenous knowledge including traditional ecological knowledge (Salick & Ross 2009; Rival 2009; Berkes 2007).

One of the strengths of this study is that it included a cross-section of rural and Moyamba town communities living with malaria. By including these two groups, the study findings show diversity as well as similarities in stressors experienced, assets and resources they employed and coping mechanisms they put in place. By employing the same research question and methods across communities both rural and Moyamba town, the study explored similar issues across communities and can therefore reflect comparatively on rural and Moyamba town differences and on the similarities and differences in perceptions to highlight the contrasting discourses.

By using both interviews and focus groups, it was possible to get a wider and deeper perspective of peoples' perceptions and responses to malaria, in terms of what they mean to different communities. This fuller picture includes taking into account and interrelating aspects of the disease, and the context of living conditions helping contextualise peoples' responses to the threats of malaria. The multiple qualitative methods increased the validity of the research findings by corroborating discursive evidence and enabling a broader and more holistic view of responses to malaria programmes and actions than would have been possible with either only one-to-one qualitative interviews or only the discussions generated in focus groups.

The Sustainable Livelihoods Approach is oriented towards life and therefore leads to asking questions that will elucidate answers that can relate to people actively making gains in health. In conditions of poverty in particular, it is easy for policy makers to focus

on the biomedical approaches to diseases rather than on health-related or socio-cultural aspects as in a people-centred focus. By starting with a focus on how peoples' accounts may help identify what enables health even when this is not obvious from any one standpoint, this study revealed discourses of capacities that would not have been found without the framework. Also, using the framework was instrumental in understanding peoples' perceptions about malaria and how they acted based on those perceptions. The framework goes beyond the individual to include social dynamics to achieve improved health outcomes.

8.2 Policy Implications

Attending to family and community management may offer a way to link grassroots initiatives to policy in providing pathways for sharing local experiences and practical livelihood innovations that emerged in the accounts in this study, to tackle the impacts of malaria. To link supply and demand here would require involving community groups in coordinating with the health services in planning and service delivery and require policy makers to recognise that malaria is a livelihoods as well as a health issue. This may help recognise the need to adopt livelihood approaches as part of contributing to communities withstanding the threats of malaria in a sustainable manner. The next chapter sets out the study conclusions.

CHAPTER 9: Study Conclusion

While extensive research lays down the domain of technological solutions to malaria control, the current study found bringing family and community management to research on how discourses of poorer people may provide understanding of alternative pathways in malaria control as the research problem. In this concluding chapter, I argue that family and community management can be an alternative approach in withstanding the threats of malaria in poorer and marginalised communities in sub-Saharan Africa. The research question addressed in this thesis was: '*How are family and community management perspectives reflected in discourses concerning incidents of malaria in Sierra Leone?* This question aimed to capture the perspectives of individuals at family and community levels, to explore their narratives and to understand how people have responded to the threats of malaria using a discursive approach in diverse contexts and in rural and Moyamba town communities in the malaria control programme in Sierra Leone.

This research has made five key arguments. The first argument is that families and communities reported the capacity to mobilise and draw on the six capitals including social, human, financial, physical, natural and cultural capital to withstand the threats of malaria. However, these capacities were seen in communities with strong leadership, whilst those with weak leadership were seen as less organised and appeared to lack such capacities. The second is that the empirical evidence from this study confirms family and community management was recognised as providing poorer people, especially the disadvantaged such as women, with a voice to highlight their daily struggles over resources and how they were nonetheless undertaking activities which could improve health outcomes. The third argument is that despite the potential for withstanding the threats of malaria in family and community management, this study revealed the problem of community heterogeneity resulting in problems of marginalising some groups or communities and limiting collaborative actions. The fourth argument is that family and community management in poorer and marginalised communities can work better and be more likely to achieve the best results when it is supported by organisations in health programmes and policy, integrating efforts to improve the quality of public service delivery. Such integration was seen to require making linkages and promoting collaboration across different actors and scales as a way to make policy more responsive to the needs of diverse stakeholders, particularly of local community groups who were seen as relatively marginal to those decision-making processes impacting on their lives. Poorer communities as seen in this study were unlikely to overcome the threats of malaria on their own. Nonetheless, the findings identified ways in which communities had the capacity, through their uses of social capital in the form of linking capital, and

human capital in volunteering such as in the mother support groups in organisations which had skills, resources and experience in implementing health programmes which they themselves might lack. However there was little evidence of community involvement in planning and implementing programmes and or taking part in decision-making processes beyond being members of facility management committees in the malaria control programme. The fifth argument is bringing together stakeholders, both "traditional" and "scientific", and mobilising their knowledge as in the mutual referral system reported here, where traditional healers and practitioners were seen to combine their services, in sharing their knowledge and skills. Future research could be undertaken to identify key elements of the system that can be harmonised, given the plural health-seeking behaviours of poorer people, to inform policy makers of alternative pathways to malaria control.

The current study has approached malaria from a hitherto unexplored angle. Most research on malaria has been disease-focused and has lacked an integrated perspective, including ignoring social and cultural considerations. Instead of a disease focus, the Sustainable Livelihoods framework shifts the focus towards peoples' agency and capabilities such as the youths in environmental cleaning in dealing with malaria. Livelihoods approaches that are seen to move people towards achieving health outcomes as revealed in this thesis, are starting points for the rethinking by practitioners and policy makers of alternative approaches to withstanding the threats of malaria.

This research has examined how knowledge about family and community management was generated through empirical research eliciting peoples' discursive accounts. Highlighting family and community management deals with community health problems like malaria by moving beyond supply and demand paradigms to incorporate the multitude of perspectives and towards more nuanced understanding with people navigating alternative forms of treatment. The contribution of family and community management is in shifting the focus from a disease paradigm to people and communities taking control of their own health needs, resulting in the uptake of healthier behaviours and improving peoples' ability to manage their own illnesses. However there was no single unified vision of withstanding malarial threats as practitioners advocated biomedical solutions, whilst rural participants mostly and including rural health practitioners participants, reported people in rural communities using traditional healing.

The timeliness of this study is evident from further but important considerations. First is an increasingly urgent need to complement biomedical interventions, which in the present epidemiological context, can risk being undervalued and therefore not taken

seriously. There are also some who think that the centrality of epidemiology rightly stressed in treatment approaches must entail giving lesser importance to family and community management. Yet as this research in poorer communities has shown, family and community management does not necessarily conflict with peoples' engagement with treatment but may sustain it since it serves as an excellent avenue for prevention by mobilising the six capitals in supporting health. If properly embraced, family and community management is therefore an aid and not a hindrance to biomedical interventions.

Analysis of the themes identified in the findings chapter-–social capital, volunteering, coping strategies, leadership indicate that the volunteering theme was the most prevalent element related to family and community management, followed by social capital, leadership and coping strategies. Volunteering contributed to family and community management by improving access to health services in isolated and marginalised communities. Volunteers were seen to provide the alternative manpower in the health service in taking services to poorer communities, linking individuals and communities to services and information outside of the community that they would not otherwise have. They were seen not only as promoting better access to services but saving lives with early referrals of patients to facilities, thereby contributing to reducing mortality from malaria, a testament to family and community management. Social capital contributed to family and community management in creating relations of trust with facilitated collective action. Communities adopted coping strategies including undertaking preventive actions, livelihoods diversification, adopting medical pluralism, and combining their religious beliefs with health that promoted family and community management in relation to malaria. Leadership contributed to family and community management in highlighting the need for strong leadership in influencing peoples' behaviours, attitudes and in mobilising families and communities in increasing the uptake of services.

This case study could also be regarded as offering a learning process showing how stakeholders in the malaria control programme can learn from each other. This research therefore concludes that moving from a disease focus towards family and community management is a more widely accessible but complex process. There is therefore a related need for stakeholders in malaria control programmes to establish cross-level learning communities that will better accommodate competing discourses, if they are to move beyond a supply and demand approach to incorporate learning which will inclusively enhance the capacity in families and communities to contribute to reducing mortality and morbidity from malaria and improving health outcomes.

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Appendix 1 Ethics Approval

1.1 Sierra Leone Ethics Committee Approval

GOVERNMENT OF SIERRA LEONE
Ministry of Health and Sanitation
Office of the Sierra Leone Ethics and Scientific Review Committee
Directorate of Policy Planning and Information, 5th Floor, Youyi Building

3rd August, 2016

TO: **Paul Brewah (Ph.D Candidate)** **Principal Investigator**
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Study Title: **Resilience in Malaria Control Programme in Sub-Sahara Africa: A Case Study of the Sierra Leone National Malaria Control Programme**

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Submission Type: First version of protocol submitted for review

Approval Date: 01 August, 2016

The Sierra Leone Ethics and Scientific Review Committee (SLESRC) having conducted an expedited review of the above study protocol and determined that it presents minimal risk to subjects, **hereby grants ethical and scientific approval for it to be conducted in Sierra Leone.** The approval is valid for the period, **01 August, 2016 – 31 July, 2017.** It is your responsibility to obtain re- approval for any on-going research prior to its expiration date. The request for re-approval must be supported by a progress report.

Review Comments;

- **Amendments;** Intended changes to the approved protocol such as the informed consent documents, study design, recruitment of participants and key study personnel, must be submitted for approval by the SLESRC prior to implementation.

For further enquiries please contact: efoday@health.gov.sl

- **Termination of the study:** When study procedures and data analyses are fully complete, please inform the SLESRC that you are terminating the study and submit a brief report covering the protocol activities. Individual identifying information should be destroyed unless there is sufficient justification to retain, approved by the SLESRC. All findings should be based on de-identified aggregate data and all published results in aggregate or group form.

Professor Hector G. Morgan
Chair

1.2 UEA Ethics Committee Approval

APPLICANT INFORMATION

To be completed by the applicant

Forename	Paul
Surname	Brewah
Student ID number *(if applicable)*	100109291
UG, PGT or PGR *(if applicable)*	PGR
Supervisor *(if applicable)*	Dr Karen Bunning
Project Title	***Resilience in Health Programmes:The case of the Malaria Control Programme in Sierra Leone***

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Project Title	***Resilience in Health Programmes:The case of the Malaria Control Programme in Sierra Leone***

RESUBMISSIONS – IF YOU ARE ASKED TO RESUBMIT YOUR APPLICATION FOLLOWING REVIEW BY THE COMMITTEE PLEASE ALSO ATTACH **A LETTER** WITH YOUR REVISED APPLICATION DETAILING HOW YOU HAVE RESPONDED TO THE COMMITTEE'S COMMENTS. Students please ensure your supervisor has approved your revisions before resubmission.

REVIEWERS' RECOMMENDATION (✓)

To be completed by the Ethics Committee

NS – IF YOU ARE ASKED TO RESUBMIT YOUR APPLICATION FOLLOWING REVIEW BY THE COMMITTEE PLEASE ALSO ATTACH **A LETTER** WITH YOUR REVISED APPLICATION DETAILING HOW YOU HAVE RESPONDED TO THE COMMITTEE'S COMMENTS. Students please ensure your supervisor has approved your revisions before resubmission.

REVIEWERS' RECOMMENDATION (✓)

To be completed by the Ethics Committee

APPLICANT INFORMATION

Accept	✓
Request modifications	
Reject	

Risks and inconvenience to participants are minimised and not unreasonable given the research question/ project purpose.	✓	
All relevant ethical issues are acknowledged and understood by the researcher.	✓	
Procedures for informed consent are sufficient and appropriate	✓	

REVIEWERS' COMMENTS

General:

Section 1 Overview of the Study

i) if the researcher is using the conventional categories of 'livelihood capitals', then he should not forget 'financial/economic' (paras 1 and 4);

ii) Stakeholders – the researcher mentions 'health practitioners' – but not specifically district or national government health officials who may have valuable insights. In addition, pharmaceutical suppliers and distributors may also offer useful views on community resilience.

Ethical:

Section 3 Risks or costs to participants

Under 'distress', the researcher should consider being able to offer participants 'links to local support groups', who may be better placed to offer counselling and support.

Section 8 Consent

The researcher should perhaps advise participants that they will be able to withdraw their 'response data' at any time up to a specified deadline – e.g. as the first report draft is finalised.

Section 9 Cultural, social, gender-based characteristics

Participants of both sexes should perhaps be given the option of inviting a trusted friend/colleague to attend the one-to-one interviews.

Appendix 2 Informed consent for interviews

Bullet point 13 states *'free to withdraw at any time'* – this should be qualified in line with advice under Section 8 Consent (above).

Letter from Sierra Leone Chair of Ethics Committee

The Chair's last sentence reads *'All findings should be based on de-identified aggregate data and all published results in aggregate or group form'* If the researcher wishes to refer to individual findings or testimonials, he will need to seek specific permissions from this Committee.

COMMITTEE'S RECOMMENDATION

The International Development Ethics Committee has reviewed your application for ethical approval to conduct research on resilience to malaria in Sierra Leone. The Committee agreed that you had covered most of ethical issues, and can approve your application.

COMMITTEE'S RECOMMENDATION

Please take note of the comments made by the reviewer above.

Furthermore, and by an email to me (Chair of Int Dev Ethics Committee, s.russell@uea.ac.uk), this Committee would like to hear what you propose to do regarding the statement from the Chair of the Sierra Leone Ethics Committee, namely:

> **Letter from Sierra Leone Chair of Ethics Committee**
>
> The Chair's last sentence reads *'All findings should be based on de-identified aggregate data and all published results in aggregate or group form'*

Please clarify: Because if the researcher wishes to refer to individual findings or testimonials (such as quotes?), he will need to seek specific permissions from this Committee?

SIGNATURE (CHAIR OF THE INTERNATIONAL DEVELOPMENT ETHICS COMMITTEE)

Signature	Date
Steve Russell	24th October 2016

Appendix 2 Information Sheet and Consent Forms

2.1 Public Information Sheet

Title of Study: Understanding health discourses from a livelihoods perspective: Family and community management in the Malaria Control Programme in Sierra Leone

(An interpreter will be chosen to read **the contents of this form to all participants who are not literate)**

You are being asked to take part in a study that explores factors that influence the uptake and response of communities to health interventions and enable them to withstand the threats and actual incidents of diseases in their community such as malaria. Your views are very important and would help inform the study. This information sheet explains what the study is about and how I would like you to take part in it. You will be free to decide if you want to take part and you are free to say that you wish or do not wish to take part. If you decide not to take part this will not lead to you losing any services you may currently receive.

The purpose of the study is to find out why some malaria control programmes in Sierra Leone may work better with some communities. To gain your views I would like to interview you. If you agree to this, the interview will be audio-recorded and may last up to one hour. The information provided by you in the interview will be only used for this research. It will not be shared with other people who take part in any way that will allow you to be identified. Your participation is voluntary and you may withdraw at any time or terminate the interview.

The results from this interview will be used to write up the study findings. These will be reported in my thesis. Articles will be prepared and published in a Journal. I aim to provide you with summary findings before I finish this part of the study.

The study has been approved by both the Sierra Leone Ethics and Scientific Review Committee and by the University of East Anglia, UK Ethics Committee.

Once again, I would like to thank you for agreeing to take part in this study. If you have any questions about the research at any stage, please do not hesitate to contact me

(**Paul Brewah, email- p.brewah@uea.ac.uk: cell- +232 33998680**.

2.2 Informed Consent Form for Individual Interviews

Title of Study: Understanding health discourses from a livelihoods perspective: Family and community management in the Malaria Control Programme in Sierra Leone

(An interpreter will be chosen to read the contents of this form to all participants who are not literate)

- I have read (or been informed) and understand the study information sheet ☐
- I have been given the opportunity to consider the information and have my questions about the study answered satisfactorily. ☐

- I have been informed that the information I will provide in the interview will be used only for research purposes. ☐
- The information I provide will not be used in a way which will allow me to be identified ☐
- I understand that taking part in the Study will include taking part in interviews or focus groups ☐
- I understand that my views will be audio-recorded ☐
- I have been informed that I can stop the interview at any time for any reason☐
- I understand that the researcher may visit me one or more times ☐
- I understand that no payments will be made to me for taking part in the Study ☐
- I understand that data collected during the Study may be looked at by responsible individuals from the University of East Anglia, Norwich, UK or certain regulatory authorities, where it is relevant to my taking part in the research. I give permission for these individuals to have access to my records ☐
- I understand that summary findings from the study will be shared with all research participants before the end of the study ☐
- I agree that my contact details will be stored for the purpose of contacting me to provide feedback on the findings of the research ☐
- I understand that my participation is voluntary and that I am free to withdraw at any time, up to the time the first draft of the report is finalised, without any reason, and without my legal rights being affected ☐
- I have been informed that the name of the principal investigator of the study is Mr. Paul Brewah, a researcher from the University of East Anglia in UK. ☐
- I have been informed that the study has been approved by the Sierra Leone Ethics and Scientific Review Committee and the University of East Anglia Ethics Committee ☐

I hereby consent to my personal information being stored and used for the purposes of this study only

Name of Participant----------

Signature(or thumbprint)……..Date

Researcher……Date

2.3 Consent to participate in focus group

Title of Study: Understanding health discourses from a livelihoods perspective: Family and community management in the Malaria Control Programme in Sierra Leone

(An interpreter will be chosen to read the contents of this form to all participants who are not literate)

(To be signed by all participants before the start of discussions)

You have been asked to participate in a focus group organised by Mr Paul Brewah, a researcher from the University of East Anglia, UK. The purpose of the group is to find out why some malaria control programmes in Sierra Leone may work better with some communities. The data generated from the focus groups may be used in informing development of interventions to make communities more capable and able to withstand the threats and actual incidents of malaria.

Although the focus group will be tape-recorded, your responses will remain anonymous and no names will be mentioned in the report. You can choose whether or not to participate in the focus group and stop at any time.

There are no right and wrong answers to the focus group questions. We want to hear many different viewpoints and would like to hear from everyone. We hope you can be honest even when your responses may not be in agreement with the rest of the group. In respect for each other, we ask that only one individual speaks at a time in the group and that responses made by all participants be kept confidential. You agree not to share information disclosed in the group with people outside that group and not to disclose names of participants to others.

I understand this information and agree to participate fully under the condition stated above

Signed _____
Date_____

Appendix 3 Semi-structured Interview Guide

Title of Study: *Understanding health discourses from a livelihoods perspective: Family and community management in the Malaria Control Programme in Sierra Leone*

Presentation of ourselves*;* *introductory explanation: introduce myself as researcher and my research assistant;*

Confidentialit*y; describe the purpose of the research; affirm that questions asked will be confidential; that the opinions of the interviewee are very important and will greatly assist my study.*

Start recording

I request your permission to record the interview.

Experiences of malaria

1 Tell me about your experiences of malaria in your life?

Probe: *work-particular difficulties for you in your role: how have malaria experiences affected your working activities; family*

Reasons for the spread of malaria

2 What things cause malaria in your community?

Probe; biological causes; community causes

Dealing with malaria

3 How do you deal with malaria?

Probe: controlling: treating. How easy or difficult do you and your family finds to control malaria. How easy or difficult do your colleagues-in charge, health practitioners find to promote control measures?

Help for malaria

4 Where do you go for help for malaria?

Probe: Any forms of help: Traditional approaches: What are your reasons? Health facilities, what is in offer in these facilities specifically? Why do you think these are so important – and how easy are they to access? What are the day-to-day community-shared reasons for using herbal medicines – who provides and promotes them?

5 What information do you have about malaria? What information is provided to communities about malaria?

Probe: How and what ways sensitisation is carried out? How is it provided, what means are used? How is surveillance/monitoring done?

Organisations involved with Health Programmes

6 What health programmes are available in your community?

Community Action

7 What actions do you think your community can take to help with malaria?

Probe: bye-laws – how are they implemented? What is the impact of the by-law? E.g. on compliance with bed net use? Who manages the levying of fines? Probe: community health workers: - what effect on actions relating to malaria that you see from having these people embedded with communities? How were they drawn from the community? How does the institution of community health workers influence the perception of people on health issues? How does it influence the framing of community health interventions?

3.1 Individual Interview participant demographics

Date of Interview:		**Gender:** □ Male □ Female			
Interviewee ID		**Chiefdom:**			
Age:		**Town/Village:**			
Number in household:					
Marital status	□ Married	□ Single	□ Divorced	□ Widowed	□ Other
No of children	□1-5	□ 6-10	□ over 10		
Ages of children	< 1 yr.	1-5 yrs.	6-10yrs	> 10yrs	
Education	□ Primary	□ Secondary	□ Diploma/vocational	□ Bachelors	□ Higher
Religion	□ Christian	□ Muslim	□ Other		
Ethnicity	□ Mende	□ Sherbro	□ Temne	□ Loko	□ Other
Type of House	□ Straw	□ Straw with metal sheet	□ Cement		
Annual income	□ Le 1-Le2m	□ Le 2m-Le5m	□ Le 5m-Le10m	□ Over Le10m	

Appendix 4-Focus Group Guide

4.1 Focus group discussion guide

Date

Moderator initials

Co Moderator initials

Venue

Start time

End Time

Number of participants

Serving refreshments- to allow participants to meet each other before the focus group starts

Opening Prayers *(Christian and Muslim)*

WELCOME

Good morning/afternoon/evening. Thank you for agreeing to be part of the focus group. We appreciate your willingness to participate.

INTRODUCTION

My name is Paul Brewah. I am a researcher from the University of East Anglia in UK. Ms…. my co-facilitator is with us and will be assisting with our discussion today.

PURPOSE OF THE FOCUS GROUP

As we all know, public health interventions in epidemics such as malaria mainly take the form of biomedical interventions. Questions of viability, effectiveness and sustainability of interventions remain; malaria persists. The reason we are having this focus group is to have your views on why some malaria control programmes in Sierra Leone may work better with some communities.

GROUND RULES

1 **YOU DO THE TALKING**

I would like everyone to participate. I may call on you if I have not heard from you for a while

2 **THERE ARE NO RIGHT OR NO ANSWERS**

Everybody's experiences and opinions are important. You can agree or disagree, please say so at any time. You agree to respect each other's views. We want to hear a wide range of opinions.

3 **CONFIDENTIALITY**

What is said in this room stays here. We want everyone to feel comfortable sharing their experiences.

4 **ANONYMITY**

We will not identify anyone by name in our findings. You will remain anonymous.

5 **AUDIO RECORDING**

We will be tape-recording the group to capture everything you say.

6. **ONE PERSON SPEAKS AT A TIME**

<u>TOPICS AND QUESTIONS</u>

Start recording

I request your permission to record the interview.

We are bringing together community members in this focus group to share your experiences of the following issues**:** 1) Opening Question**;** 2) Experiences of malaria: 3) Reasons for the spread of malaria: 4) Seeking help for malaria: 5) Information on malaria; 6) Organisations involved with health programmes: 7) Community Action

The icebreaker

Please can you tell us something about yourself (including the name we should call you today) and your life in this community?

1 **Opening question**

Bed nets are given out to control malaria. Please tell us what you think about this.

Experiences of malaria

2 Please tell us about your experiences of malaria in your life? *Probe: work: family*

Reasons for the spread of malaria

3 What do you think causes malaria in your community?

Help for malaria

4 What help is available for dealing with malaria in your community*? Probe: health service: traditional healing: NGOs; Any other form of help.*

Information on malaria

5 What do you do when malaria affects you or members of your family? *Probe: controlling: treating, managing*

Organisations involved with health programmes

6 What health programmes are available in your community? *Probe: Types of programme actions*

Community action

7 How does your community respond to malaria? How can your community better withstand malaria? *Probe : Type of programme actions experienced*

Use card sort task- write participant's main ideas from discussions

Summary and Conclusions

Summarise ideas. Now that you have discussed these issues with other people, do you have any final point you would like to share. This brings us to the end of our discussions. I would like to thank all participants for taking part. I appreciate your time and cooperation.

4.2 Focus group discussion guide for health practitioners

Date

Moderator initials

Co Moderator initials

Venue

Start time

End Time

Number of participants

Serving refreshments- to allow participants to meet each other before the focus group starts
Opening prayers *(Christian and Muslim)*
WELCOME

Good morning/afternoon/evening. Thank you for agreeing to be part of the focus group. We appreciate your willingness to participate

INTRODUCTION

My name is Paul Brewah. I am a researcher from the University of East Anglia in UK. Ms…. my co-facilitator is with us and will be assisting with our discussion today.

PURPOSE OF THE FOCUS GROUP

The reason we are having this focus group is to have your views on why some malaria control programmes in Sierra Leone may work better with some communities

GROUND RULES

1 **YOU DO THE TALKING**

I would like everyone to participate. I may call on you if I have not heard from you for a while

2 **THERE ARE NO RIGHT OR NO ANSWERS**

Everybody's experiences and opinions are important. You can agree or disagree, please say so at any time. You agree to respect each other's views. We want to hear a wide range of opinions

3 **CONFIDENTIALITY**

What is said in this room stays here.We want everyone to feel comfortable sharing their experiences when sensitive issues come up

4 **ANONYMITY**

We will not identify anyone by name in our findings. You will remain anonymous

5 **AUDIO RECORDING**

We will be tape recording the group to capture everything you say

6. **ONE PERSON SPEAKS AT A TIME**

TOPICS AND QUESTIONS

We are bringing together health practitioners in this focus group to share experiences of the following issues**:** The topics for the health practitioners FGD were: 1) Opening question; 2) Health care services: 3) Dealing with malaria: 4) Reasons for the spread of malaria: 5) Malaria control interventions: 6) Organisations involved with health programmes.

The icebreaker

Can each person give a brief self-introduction (including the name we should call you today) and say something about things in our lives that can make it easier for us to be healthy?

Opening Question:

Can you tell the group why you decided to take part in this research?

Health care services

1 Tell me about the health service where you work

Dealing with malaria

2 What do you do when malaria affects you or members of your family? *Probe: controlling: treating*

Reasons for the spread of malaria

3 What are the reasons for the spread of malaria in your communities?

Malaria control interventions

4 What interventions do you offer? How do people in the community respond to the interventions on offer?

5 What can health programmes do to control the spread of malaria? *Probe*: *Type of programme actions*; *experiences with programme actions*

Organisations involved with health programmes

6 Tell me about organisations involved with health programmes in your communities?

Use card sort task- write participant's main ideas from discussions

Summary and Conclusions

Summarise ideas .Now that you have discussed these issues with other people, do you have any final point you would like to share. This brings us to the end of our discussions. I would like to thank all participants for taking part. I appreciate your time and cooperation.

4.3 Focus Group participant demographics

Date of Focus group:	**Gender:** □ Male □ Female	
ID:	**Chiefdom:**	
Age:	**Town/Village:**	
Number in household:		

Marital status	□ Married	□ Single	□ Divorced	□ Widowed	□ Other
No of children	□1-5	□ 6-10	□ over 10		
Ages of children	< 1 yr.	1-5 yrs.	6-10yrs	> 10yrs	
Education	□ Primary	□ Secondary	□ Diploma/vocational	□ Bachelors	□ Higher
Religion	□ Christian	□ Muslim	□ Other		
Ethnicity	□ Mende	□ Sherbro	□ Temne	□ Loko	□ Other
Type of House	□ Straw	□ Straw with metal sheet	□ Cement		
Annual income	□ Le 1-Le2m	□ Le 2m-Le5m	□ Le 5m-Le10m	□ Over Le10m	

Appendix 5-Selected studies related to family and community management in the literature and links with the conceptual framework

Author	Characteristics relevant to family and community management examined	Link with Conceptual framework
Health systems global 2014	Called attention to people -centered health systems. Community empowerment	Human capital; Social capital
WHO 2006	Highlighted crisis in human resources for health and the dismal lack of health providers especially in poor rural areas in Africa due to the HIV/AIDs epidemic resulted in the expansion of CHW programmes–	Human capital
Soors et al 2013	Social exclusion uptake limited in Africa and results in inclusion/exclusion characterised by unequal access to resources, capabilities and rights which leads to health inequalities .	All five capitals- social, human capital, financial natural and physical
Bedford and Sharkey 2014	Comparative case study on barriers to access treatment for childhood illness in Kenya, Nigeria and Niger. Provides important insights relating to demand-side barriers and locally proposed solutions e.g. communities participating in both problem identification and resolution	Social capital, human capital
Rickie 2012	Poorer and marginalised populations might not benefiting from investments in malaria control due to e.g.: poverty, malnutrition lack of access to care and. socio-cultural barriers.	Social capital, financial capital
Ensor & Cooper 2004	Supply and demand side factors in care. At the community level traditional birth attendants in Influencing demand	Social capital, natural capital
Bates et al (2004)	Summarises a wide range of evidence about Environmental and institutional factors that influence vulnerability to malaria, tuberculosis, and HIV infection.	Social capital, financial capital, human capital

Scott et al 2014	Health care seeking for children in Sierra Leones from sources including home treatment, herbalists, religious healers, drug peddlers and facility-based providers.	Social capital, natural capital, financial capital
Colvin et al 2013).	This systematic review on factors influencing families seeking access to care. Decisions determined largely by social, cultural and religious norms, beliefs about disease aetiology, acceptability of interventions and local decision-making practices	Social capital, natural capital, cultural capital
Diala et al (2013)	Factors influencing uptake and adherence of intermittent preventive treatment for pregnant women in Nigeria.	Social capital, financial capital, cultural
(Atkinson et al 2011)	Investment in people component of programmes. Bottom-up' approach to community participation.	Social capital, human capital
Chuma et al (2010)	Found treatment-seeking behaviour itself was often a coping strategy: households often opted for cheaper alternatives in order to manage potential cost burdens.	Financial capital
WHO 2008	Bottom-up approaches to health equity Empowerment	Social capital
WHO 2014	Social support; community "empowerment" ;Involving communities in planning and implementing programmes	Social capital, human capital
GIESCR (2014)	Gender imbalances; land rights and human rights	Social capital; human capital
WGEKN (2007)	Gender imbalances; land rights and human rights	Social capital; human capital
Rao et al (2013).	Task-shifting to community health workers valuable for communities that are traditionally hard-to-reach.	Human capital
Rosado et al 2012	Group members engaged in informal acts of financial, emotional or practical support for community members. These included helping others access health services	Social capital, financial capital