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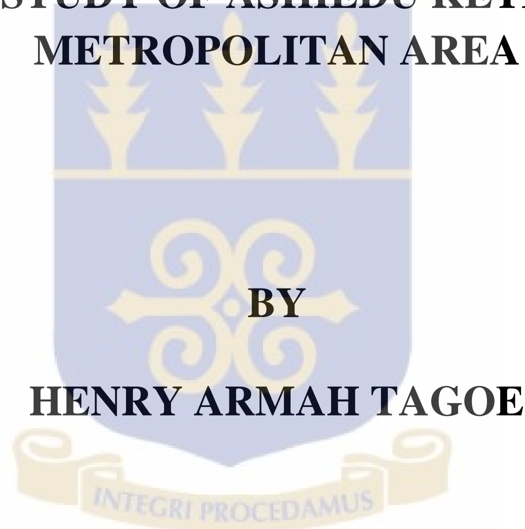
REGIONAL INSTITUTE FOR POPULATION STUDIES
AT THE
UNIVERSITY OF GHANA

URBAN POVERTY AND HOUSEHOLD NON-COMMUNICABLE DISEASE BURDEN IN GHANA: A CASE STUDY OF ASHIEDU KETEKE SUB-METROPOLITAN AREA



BY

HENRY ARMAH TAGOE

THIS THESIS IS SUBMITTED TO THE UNIVERSITY OF GHANA, LEGON IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF PhD POPULATION STUDIES DEGREE

OCTOBER 2014

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ACCEPTANCE

Accepted by the College of Humanities, University of Ghana, Legon in partial fulfilment of the requirements for the award of the Degree of Doctor of Philosophy (Population Studies).

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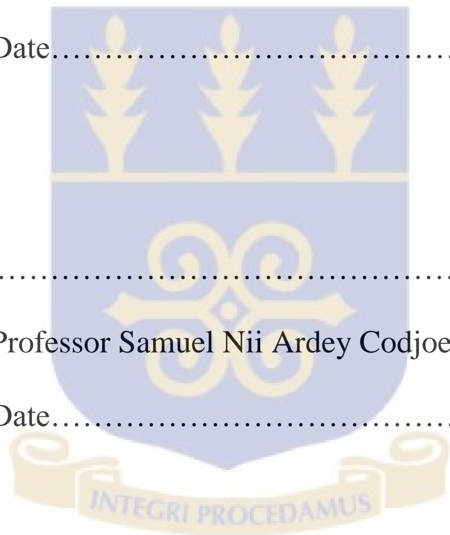

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DECLARATION

I declare hereby that this thesis, 'Urban poverty and household non-communicable disease burden in Ghana: a case study of Ashiedu Keteke sub-metropolitan area, unless specifically indicated to the contrary in the text, is my own original work and that it has not been previously submitted for any degree or examination in any other university. All sources I have used or quoted have been indicated and acknowledged as complete references.

Signed……………………………………….

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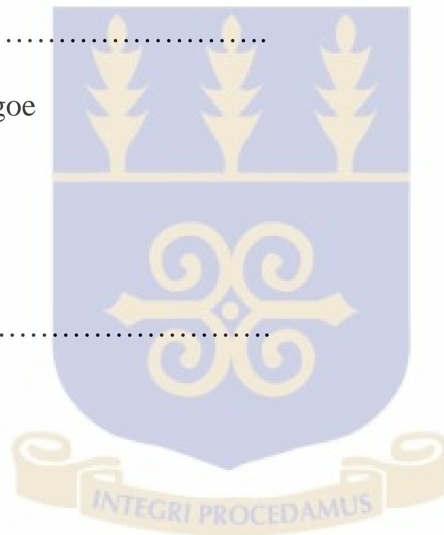

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TABLE OF CONTENTS

Content **Page**

ACCEPTANCE i
DECLARATION ii
ACKNOWLEDGEMENTS iii
TABLE OF CONTENTS iv
LIST OF APPENDICES vii
LIST OF TABLES viii
LIST OF FIGURES ix
LIST OF ABBREVIATIONS x
ABSTRACT....................xi
CHAPTER 1 1
INTRODUCTION 1
1.1 Background....................1
1.2 Statement of the problem....................4
1.3 Objectives 10
1.4 Justification....................11
1.5 Thesis structure....................14
CHAPTER 2 16
LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK 16
2.1 Introduction....................16
2.2 Non-communicable diseases 16
2.3 Determinants of burden of non-communicable disease....................21
2.3.1 Urbanisation and non-communicable disease 22
2.3.2 Poverty and non-communicable disease burden 24
2.4 Non-communicable disease burden 29
2.4.1 Global burden of non-communicable disease 29
2.4.2 Non-communicable disease burden in Ghana 32
2.4.3 Household burden of non-communicable disease....................35
2.5 Conceptualisation of burden of disease measurement....................38
2.6 Conceptual framework of household burden of non-communicable diseases44
CHAPTER 3 49
METHODOLOGY 49
3.1 Introduction....................49
3.2 Study area and location....................49
3.3 Data collection method and procedure 52
3.3.1 Sample design and procedure....................53

University of Ghana http://ugspace.ug.edu.gh

3.3.2 Survey data collection 54
3.3.3 Segmentation approach for qualitative interview....................................55
3.4 Measurements 57
3.4.1 Demographic and economic characteristics 57
3.4.2 Non-communicable disease prevalence and household healthcare expenditure..59
3.5 Methods of Analysis 61
3.5.1 Univariate analysis 62
3.5.2 Bivariate and multivariate analyses..63
3.5.3 Analysis of variance (ANOVA) 64
3.5.4 Multivariate linear regression analysis...65
3.5.5 Thematic network analysis...65
3.6 Limitation of study 68

CHAPTER 4 69

PREVALENCE OF NON-COMMUNICABLE DISEASE AND HEALTH SEEKING BEHAVIOUR 69
4.1 Introduction...69
4.2 Type and prevalence of non-communicable disease 69
4.2.1 Prevalence of non-communicable disease among urban poor households 70
4.2.2 Disease specific prevalence among study population 70
4.3 Determinants of health seeking behaviour by persons living with NCD 73
4.3.1 Relationships between socio-demographic characteristics and health-seeking behaviour 74
4.4 Determinants of health seeking behaviour among persons diagnosed with non-communicable disease 77

CHAPTER 5 81

DIRECT BURDEN OF NON-COMMUNICABLE DISEASES ON URBAN POOR HOUSEHOLDS..81
5.1 Introduction...81
5.2 Household characteristics 81
5.3 Relationship between household characteristics and treatment behaviour.....84
5.4 Direct burden of non-communicable disease on urban poor households 86
5.5 Determinants of household healthcare expenditure.....................................91

CHAPTER 6 94

INDIRECT AND INTANGIBLE BURDEN OF NON-COMMUNICABLE DISEASE ON URBAN POOR HOUSEHOLDS 94
6.1 Introduction...94
6.2 Indirect burden of disease on urban poor households 95
6.2.1 Loss of income 96
6.2.2 Investment and savings challenges 100
6.3 Intangible burden of chronic disease on urban poor households..................102
6.3.1 Psychosocial stressors 103
6.3.2 Healthy lifestyle behaviour 106

University of Ghana http://ugspace.ug.edu.gh

CHAPTER 7 111

COPING MECHANISMS OF HOUSEHOLD DIRECT BURDEN OF DISEASE.111

7.1 Introduction..111

7.2 Household coping mechanism of direct burden of disease 112

7.2.1 Sale of household assets 113

7.2.2 Savings and investments 115

7.2.3 Waiver of health seeking privileges 116

7.2.4 Family and social support 118

7.2.5 Health insurance 120

CHAPTER 8 126

SUMMARY, CONCLUSION AND RECOMMENDATIONS...............................126

8.1 Introduction..126

8.2 Objectives 126

8.3 Summary of findings 127

8.3.1 Prevalence of non-communicable diseases among urban poor households. 127

8.3.2 Direct burden of non-communicable diseases on poor urban households ... .128

8.3.3 Intangible burden of disease on poor urban households 130

8.3.4 Limitation of social support network as a coping strategy.....................132

8.3.5 Poverty as a determinant of non-communicable disease complications, treatment and management adherence 133

8.4 Conclusion 134

8.5 Recommendations...138

8.5.1 Collaboration of agencies for social protection schemes 138

8.5.2 Non-communicable disease indicators in national surveys....................139

8.5.3 Insurance improvement 141

8.5.4 Further studies 142

REFERENCE..144

APPENDICES 163

University of Ghana http://ugspace.ug.edu.gh

LIST OF APPENDICES

Appendix Page

1: Population Training Research Capacity for Development (PopTRCD) 163

2: Socio-demographic characteristics of participants in the individual interview 165

3: Coding frame 167

4: Crude prevalence of non-communicable disease 171

5: Service covered under the National Health Insurance Scheme 172

6: Mean comparison of household healthcare expenditure by household type..................... 173

7: Mean comparison of household healthcare expenditure by household type..................... 174

8: Ethical review and approval 175

9: Household questionnaire... 176

10: Individual interview guide 185

University of Ghana http://ugspace.ug.edu.gh

LIST OF TABLES

Table Page

3.1: Socio-demographic and economic characteristics by categories 59

3.2: Thematic network analysis framework 67

4.1: Prevalence of non-communicable diseases among study population 71

4.2: Socio-demographic characteristics of persons diagnosed with NCD by treatment seeking behaviour 76

4.3: Socio-demographic and economic determinants of health seeking behaviour among persons diagnosed with non-communicable disease 78

5.1: Socio-demographic characteristics of household 83

5.2: Household characteristics and treatment behaviour 85

5.3: Mean comparison of household healthcare expenditure by household type 88

5.4: Mean comparison of household healthcare expenditure by household NCD diagnosed status 89

5.5: Mean comparison of household healthcare expenditure by household NCD treatment status 89

5.6: Determinants of household total household healthcare expenditure 92

7.1: Percentage distribution of participant by NCD status and health insurance status 121

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LIST OF FIGURES

Figure Page

2.1: Causes of non-communicable disease 18

2.2: Poverty and non-communicable disease 25

2.3: Conceptual framework of household burden of non-communicable disease 48

3.1: Map showing the study locations 51

4.1: Distribution of persons with single disease condition by disease type 72

4.2: Distribution of persons with co-morbidity condition by disease types 73

6.1: Thematic network for indirect burden of disease on urban poor household..................... 96

6.2: Thematic network for intangible burden of disease on urban poor household.............. 103

7.1: Thematic network representation of coping mechanism of disease burden in urban poor households 113

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LIST OF ABBREVIATIONS

ACP	-	African, Caribbean and Pacific
AMA	-	Accra Metropolitan Assembly
ANOVA	-	Analysis of Variance
BMI	-	Body Mass Index
CDC	-	Centre for Disease Control
COI	-	Cost of Illness
CVD	-	Cardiovascular Disease
DALY	-	Disability Adjusted Life Year
EA	-	Enumeration Area
EU	-	European Union
GDHS	-	Ghana Demographic and Health Survey
GDM	-	Gestational Diabetes Mellitus
GDP	-	Gross Domestic Product
GNP	-	Gross National Product
GPHC	-	Ghana Population and Housing Census
GSS	-	Ghana Statistical Service
IFG	-	Impaired Fasting Glycaemia
IGT	-	Impaired Glucose Tolerance
IRB	-	Institutional Review Board
JHS	-	Junior High School
LMIC	-	Low- and Middle Income Country
NCD	-	Non-Communicable Disease
NMIMR	-	Noguchi Memorial Institute for Medical Research
PopTRCD	-	Population Training Research and Capacity Development
PRB	-	Population Reference Bureau
QDA	-	Qualitative Data Analysis
SADHS	-	South African Demographic Health Survey
SES	-	Socio-Economic Status
SHS	-	Senior High School
SSA	-	Sub-Sahara Africa
UN	-	United Nations
VSL	-	Value of Statistical Life
WEF	-	World Economic Forum
WHO	-	World Health Organisation
WHS	-	World Health Survey

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ABSTRACT

The epidemiological and demographic transitions in low- and middle-income countries (LMICs) and the accompanying health and economic challenges have resulted into a high burden of disease particularly on households. Urbanisation and poverty are two major drivers of the burden of non-communicable diseases (NCDs). Drawing on the concepts of cost-of-illness and biographical disruption, this thesis investigates the burden of NCDs on urban households in the context of poverty.

Cross sectional survey of 806 households (2,524 individuals) and in-depth interviews (27 individuals living with NCDs) were analysed by triangulating quantitative and qualitative methodologies. Analysis of variance (ANOVA) was used to determine the statistically significant differences between mean total household healthcare expenditure while accounting for household NCD status. Predictors of health seeking behaviour among diagnosed household members were determined using binary logistic regression and to determine the predictors of household healthcare expenditure, multivariate linear regression was used. Thematic network analysis was used to identify how indirect and intangible burdens of chronic disease manifest in poor households and the coping mechanism adopt to navigate direct burden of disease.

One in five (20.1%) households had at least a member diagnosed with at least one NCD condition with hypertension being the most prevalent condition. A third (33.3%) of persons diagnosed did not treat (use medication or any other therapy) the condition during the two weeks preceding the survey. The predictors of treatment behaviour are age, marital status, and insurance status of infected person. The mean total household healthcare expenditure for the three types of households show a statistically significant differences $F(2,799) = 4.58$, $p = 0.011$). Indirect burden of disease manifests in households in the forms of income loss and investment challenges. Adoption of healthy lifestyle behaviours and psychosocial stressors are the forms of intangible burden of disease on households.

While it comes with challenges, health insurance is the major means by which households cope with direct burden of disease. Other mechanisms that poor urban households depend on to cope with direct burden of disease are sales of household assets, savings and investments, social support and waiver of health-seeking privileges. The lack of effective coping mechanism options including social support systems results in the use of strategies that perpetuate poverty at the household level. Poverty is also a major determinant of treatment behaviour and adherence to healthy lifestyle behaviour. Poverty and NCDs mutually reinforce each other and lead to increase vulnerability and exclusion.

Based on the results of this thesis, recommendations include: developing healthy lifestyle interventions aimed at reducing the risk of exposure to NCDs, re-engineering the current health insurance scheme to reduce administrative congestions and out-of-pocket payment, and investing in economic empowerment interventions to accelerate poverty reduction in the study communities.

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CHAPTER 1

INTRODUCTION

1.1 Background

There is growing global epidemic of non-communicable diseases (NCDs) with conditions such as cardiovascular diseases, diabetes cancers and chronic respiratory diseases responsible for two thirds of the 57 million deaths worldwide each year, with low- and middle-income countries (LMICs) accounting for 80 per cent of deaths attributed to NCDs (WHO, 2013). Projected estimates indicate that deaths attributed to NCDs will rise from 36 million in 2008 to 52 million in 2030 (WHO, 2012). Given the significant social and economic impacts of NCDs on society, The World Economic Forum (WEF) in 2010 ranked NCDs among the most important threats to global economic development (WEF, 2010).

Contrary to the widely held notion that NCDs are diseases of affluence (disease conditions that affect the wealthier nations and populations), growing scientific evidence indicates the significant effect and impact of NCDs on less developed economies (Abegunde et al., 2007; Boutayeb and Boutayeb, 2005; Boutayeb, 2006; de-Graft Aikins et al., 2012; Miranda et al., 2008). Out of the global estimated 39 million NCD deaths recorded in 2008, 29 million (approximately 80%) occurred in low- and middle-income countries (LMICs) (WHO 2011a, 2011b). Projected estimates indicate that by the year 2020, NCDs will account for 80 per cent of the global burden of disease causing seven in ten deaths in developing countries (WHO, 2002).

The growing incidence and burden of NCDs in LMICs is attributed to the epidemiological, nutritional and demographic transitions in the region. The

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behavioural changes that accompanies these transitions result in increased exposure of individuals to the modifiable risk factors of NCDs accounting for the increased prevalence of NCDs and the double burden of disease in LMICs (Abegunde et al., 2007; Agyei-Mensah and de-Graft Aikins, 2010; Allender et al., 2011; Alwan et al., 2010; Boutayeb and Boutayeb, 2005; Boutayeb, 2006; Kinra et al., 2010; Lopez and Mathers, 2006; Stephens, 1995; Sverdlik, 2011; Tsolekile, 2007; Unwin et al., 2001; WHO, 2011b; Young et al., 2009).

The epidemiological transition increases the exposure of poor communities to higher risk of chronic and infectious disease resulting in the double burden of disease. Double burden of disease is a situation where countries are still struggling to meet the challenges of existing problems with infectious diseases and also at the same time facing the challenges of chronic degenerative health disease conditions such as stroke, hypertension, type 2 diabetes, cancers and other cardiovascular disease conditions.

Behavioural changes associated with growing economic development and rapid urbanisations in LMICs are known to be the major drivers of the increasing incidence and prevalence of NCD in LMICs. Physical inactivity, poor diet, high and harmful consumption of alcohol and smoking constitute the major risk factors for major NCDs (Vorster et al., 2000, Reddy, 2001; Daar et al., 2007; Nugent, 2008; Suhrcke et al., 2006). The major NCDs (cardiovascular diseases, stroke, hypertension, diabetes, cancers, etc.) share at least one behavioural risk factor and at least one physiological risk factor. The behavioural risk factors also referred to, as modifiable risk factors are tobacco smoking, alcohol consumption, unhealthy diet, and inadequate physical activity. The physiological risk factors (non-modifiable risk factors) are high

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blood pressure, overweight/obesity, high blood cholesterol, and high blood glucose. The behavioural and the physiological risk factors are known to lead to elevated blood pressure, raised blood glucose and cholesterol levels, and excess body weight (WHO, 2011a) resulting in the major NCDs.

Poverty is identified as another major driver of high rates and burden of NCDs in LMICs as there exists a cyclical relationship between poverty and NCDs (WHO, 2011a). Poorest people are known to have the highest risk of developing chronic disease and they are the least able to cope with the resulting financial consequences (Bosu, 2013; Goldstein et al., 2005; Schneider et al., 2009; Suhrcke et al., 2006; WHO, 2011a). Urbanisation drives risky behaviours that expose individuals to the modifiable risk factors of NCDs (Allender et al., 2008; Allender et al., 2011; Allender and Lacey, 2010).

The urban poor are also disproportionately affected by disease burden due to the challenges and the dynamics of the their environment (Montgomery and Hewett, 2005; Schneider et al., 2009; Stephens, 1995; Sverdlik, 2011). The relatively low economic opportunities and high urban cost of living, limited access and utilisation of healthcare services in poor settings result in the urban poor disproportionally affected by disease burden. With infectious diseases continuing to be a major public health concern in LMICs, increase in the incidence and prevalence of NCDs and its burden on the households will aggravate the poverty status of the urban poor.

There is increasing global and regional interest in the burden of NCDs and the challenges it poses on health, social and economic development at the national and regional levels. Many LMICs have experienced a paradigm shift in healthcare cost

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with significant shift of cost from the state to individuals and households. However, there is limited research attention on the burden of disease at the household level, particularly among socially disadvantaged populations. Urban poor households therefore provide a unique platform to advance the understanding of the burden of disease at the micro level.

This thesis aims to provide empirical evidence to fill the gap created due to the paucity of research and understanding disease burden at the household level. It also aims to demonstrate that the burden of disease transends beyound the prevalence of disease conditons, economic burden at the macro level to both the socio-economic and psychosocial burden of disease at the micro (individual/household) levels.

1.2 Statement of the problem

Non-communicable diseases are known to be the major causes of death globally and are projected to increase in the coming years. The WHO in 2005 re-emphasized the importance of NCDs as a neglected global health issue (WHO, 2005). Globally, NCDs were estimated to cause more deaths from 60 per cent (35 million) of all deaths in 2005 (Abegunde et al., 2007) to approximately 63 per cent (36 million) of the 57 million deaths that occurred globally in 2008 (WHO, 2011a). In 2008, around 80 per cent of all deaths (29 million) from NCDs occurred in LMICs (Alwan et al., 2010), and a higher proportion (48%) of the deaths in the LMICs are premature (under the age of 70) compared to 26 per cent in the case of high-income countries.

The burden of NCDs is not only a health problem by causing premature deaths but it has reached a stage where it has also become a joint economic and developmental issue. Non-Communicable Diseases have major adverse effects on the

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quality of life of affected individuals and create large adverse economic effects on families, communities and societies (WHO, 2005; 2011a). The significant burden of NCDs necessitated the United Nations (UN) high-level meeting on NCD prevention and control in 2011 (Beaglehole et al., 2011). This is only the second time in the history of the UN that the General Assembly met on a health issue (the last issue was on HIV/AIDS).

According to "The 2009 Revision of the World Urbanization Prospects" in 1980, 38.9 per cent of the world population lived in urban areas. This proportion increased to 46.6 per cent in 2000 and for the first time in 2010 more than half (50.5%) of the world's population lived in urban areas. Available statistics indicate that 53 per cent of the world population in 2014 and 2015 live in urban settings (Population Reference Bureau, 2014, 2015). Rapid urbanisation is associated with behavioural changes that increase the population's exposure to the modifiable risk factors of NCDs. The implication of this rapid urbanization is increased risk, prevalence and burden of NCDs in the population.

Rapid urbanisation has both economic and health challenges and in LMICs it has resulted in increasing urban household poverty. The global rapid urbanization is not limited to only developed economies but also in LMICs. The 2010 Ghana Population and Housing Census (GPHC) report indicated that in 1980, the urban population of Ghana was 31.2 per cent and it increased to 36.4 per cent in 1990. In 2010, Ghana also experienced urban population with 50.9 per cent of the population living in urban settings compared to 43.8 per cent in 2000 (GSS, 2012). The Greater Accra Region recorded the highest proportion (90.5%) of urban population (GSS,

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2012). There is a further indication of increasing urbanisation in Ghana with annual urban growth rate projected to be 4.1 per cent compared to 1.5 per cent for rural areas between 2000 and 2015 (GSS, 2012).

Africa currently still reports more deaths attributed to infectious diseases than that of NCDs (Young et al., 2009). However, the prevalence of NCDs in the region is rising rapidly and is projected to cause almost three-quarters as many deaths as communicable, maternal, perinatal, and nutritional diseases by 2020, and to exceed them as the most common causes of death by 2030 (WHO, 2008). In LMICs, a higher proportion (48%) of all NCD deaths are estimated to occur in people under the age of 70, compared with 26 per cent in high-income countries (Strong et al., 2005).

Other studies have reported marked differences in age of unset of NCDs, prevalence and mortality between higher- and low-income countries. While 29 per cent of NCDs occur among people under 60 years old in LMICs, in higher-income countries this is 13 per cent (WHO, 2011a, 2011b). Half of cardiovascular disease deaths in LMICs occurs among people 30-60 year old which is 10 or more years younger as in the case of developed countries (Baingana and Bos, 2006). Also, premature mortality attributed to NCDs range from 22 per cent among men and 35 per cent among women in low-income countries compared to 8 per cent among men and 10 per cent among women in high-income countries (WHO, 2011b). This situation deprives countries of the economically active labour force resulting in unproductivity and income loss. The loss to Gross Domestic Product (GPD) and Gross National Product (GNP) do not only has economic implications but also health and social consequences on the state and populations.

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The burden of NCDs in Ghana mirrors the situation in many other LMICs particularly those in the sub-Saharan African region. There is a lack of nationally representative data both at the macro or micro levels to examine the burden of NCD and also weak national response to the epidemic (Bosu, 2013). In 2003, the WHO conducted the World Health Survey (WHS) in 70 countries including Ghana that provided a nationally representative sample data on the risk factors and the burden of NCDs at the national level. In Ghana, about 18 per cent of household members reported ever being diagnosed with at least one NCD condition with 45 per cent of diagnosed persons treating the condition during the 2 weeks preceding the survey (Tagoe, 2012a). In the top 20 newly diagnosed cases in health facilities in Ghana, NCDs were found to be among the top rankings (Bosu, 2013) taking the position of many infectious diseases. The 2008 WHO comparable estimates of NCD mortality indicated that NCDs kill 78,000 persons in Ghana annually, representing 354 deaths per 100,000 population (WHO, 2011a). The report also estimated the proportion of deaths in Ghana attributed to NCD as 39 per cent (WHO, 2011a).

Overweight, a major risk factor of diabetes, hypertension and other cardiovascular disease has increased among women (15-49 years) in Ghana from 25 per cent in 2003 to 30 per cent in 2008 with 9 per cent being obese (GSS et al., 2009). This risk factor (overweight) is not limited to adult populations but among children, 5 per cent overweight was reported with more urban children (7%) compared to rural children (4%) overweight (GSS et al., 2009). Also, Ghanaians spent 2.6 per cent of their total annual household expenditure on alcoholic beverages and 1.6 per cent on tobacco in 2005 (GSS, 2008). These stituation increases the population risk of NCDs.

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In Ghana, both males and females, in urban areas are less likely to engage and adhere to healthy lifestyle behaviours compared to their rural counterparts (Tagoe and Dake, 2011). Fruit and vegetable consumption in Ghana was found to be the lowest among 52 mainly LMICs including 19 African countries at the end of the WHO-WHS 2002-2003 (Hall et al., 2009). The risk factors and unhealthy lifestyle behaviours are not only prevalent among adult population but also young adults and youth. Evidence from the Global School-Based Survey in Ghana (2008) indicate that 7.8 per cent of Senior High School adolescents were overweight or obese (Males 2.4%, Females 13.9%) with lower prevalence of physical activity (Owusu, 2008). These unhealthy behaviour and risk factors drives the increasing prevalence of NCDs in the population.

In the Greater Accra Region of Ghana, Amoah et al. (2002) reveal that the crude prevalence of diabetes was 6.3 per cent of Ghanaians aged 25 years and older with 209 (69.7%) of the subjects with diabetes having no prior knowledge of the disease. The disease condition was more common in males compared to their female counterparts (7.7% vs. 5.5%) $P<0.05$ (Amoah et al., 2002). Prevalence of hypertension in Accra increased from about 25-28 per cent in the 1976-1998 period to about 37-45 per cent in 2002-2006 (Bosu, 2010). In the 2009 Civil Servant study in Accra, 19 per cent of participants had severe (Grade 3) hypertension while 48 per cent of those examined had evidence of organ damage (Addo et al., 2008, 2009). Also in the Women Health Survey conducted in Accra 2002/2003, more than 60% of the participants were overweight or obese (Hill et al., 2007). The Greater Accra Region

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recorded the highest proportion of women overweight/obesity (44.5%) and obese (19.4%) among the ten administrative regions in the 2008 GDHS (GSS et al., 2009).

A study conducted in three localities (James Town, Ussher Town and Agbogbloshie) located in the Ashiedu Keteke sub-metropolitan area reveal that participants associated diabetes to smoking, excessive alcohol consumption, and physical inactivity (de-Graft Aikins et al., 2014). Another study in the same localities reveal a 28.3 per cent hypertension prevalence among adult populations in their reproductive age (Awuah et al, 2014). This reveal a situation of high risk behaviour that exposes the population to the modifiable risk factors and increase prevalence of NCD in these localities.

The epidemiological transition in LMICs has led to a situation where less developed countries face the challenges of both infectious and non-communicable diseases. However, as identified in the 2005 WHO report, policy makers do not fully understand that chronic non-communicable diseases have also become diseases of poor people especially in the developing economies (WHO, 2005). The age onsets of NCDs in many LMICs are relatively lower compared to that in developed nations. Non-communicable disease impact for the societies and economics are devastating but more significantly so among the poor, vulnerable and disadvantaged populations.

Poor populations are highly exposed to aliments and the associate mortality occurs much earlier than their wealthier counterparts (WHO, 2008; Suhrcke et al., 2006; Abegunde et al., 2007). In LMICs, there is late detection of NCD resulting in extensive and expensive healthcare for complications that often are covered through out-of-pocket payment leading to catastrophic healthcare expenditure (WHO, 2010,

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2011a). Health policy reforms have resulted in high levels of out-of-pocket payment for healthcare services. The result is a significant burden on households, causing households to employ other means for finance healthcare expenditures. The impact of NCDs on any society can be equated to a double-edged sword as it leads to loss of income through disability and mortality and poverty as a result of catastrophic healthcare expenditure.

To generate additional understanding on the factors influencing vulnerability to illness costs, such as income insecurity or social networks, psychosocial burden and the coping strategies to navigate chronic disease burden in the phase of urban poverty, this thesis attempts to address the following research questions within the urban Ghanaian context:

i. What are the prevalence of NCDs among urban poor households and the factors that determine healthcare-seeking behaviour among persons diagnosed with NCD?
ii. What is the direct burden of NCDs to urban poor household?
iii. How are indirect and intangible burden of NCDs presented in urban poor households?
iv. Through what social and economic mechanisms do urban poor households navigate the burden of NCDs?

1.3 Objectives

The main objective of this study is to assess the burden of non-communicable diseases on urban poor households. Specifically, this study seeks to:

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i. Examine the types and the prevalence of NCDs among urban poor households in Ashiedu Keteke sub-metro and the socio-demographic and economic predictors of healthcare seeking behaviour among households with member diagnosed with an NCD;

ii. Investigate and estimate the direct burden of NCDs on poor urban households;

iii. Explore the psychosocial burden of NCDs, in terms of indirect and intangible burden on urban poor households;

iv. Identify the social and economic means through which chronic disease burdens are managed among urban poor households.

1.4 Justification

Poverty is known to have major implications for the health outcome and well-being of households and societies (Campbell and Campbell, 2007; Fink et al, 2012; Goldstein et al., 2005; McIntyre et al., 2006; Stephens, 1995; Sverdlik, 2011; van Agt et al., 2000). Poverty is also recognised as having a cyclical link with NCD burden (WHO, 2011a). Rapid urbanisation is documented as one of the major drivers of the risk factors of NCDs resulting in increasing incidence and prevalence of NCDs particularly in urban settings (Allender et al., 2008; Allender and Lacey, 2010; Allender and Wickramasinghe, 2011).

Driving the current global discourse on the burden of disease are the "Global Burden of Disease" studies (1990; 2002; 2004; 2010) that focus significantly on macro (national) level burden of disease and injury using the Disability Adjusted Life Years (DALYs) index measuring disease burden in terms of loss of Gross Domestic Product (GDP) and Gross National Product (GNP) (Suhrcke et al., 2006; Abegunde et

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al., 2007). The DALY combines years of life lost due to premature death (YLLs) with the years lived with disability (YLDs) into a single measure that can be aggregated across different diseases and injuries (Fox-Rushby and Hanson, 2001; Boutayeb and Boutayeb, 2005).

Other studies both in developed and developing economies that have examined the disease burden have focused mainly on the economic burden (cost) of NCDs (Birabi, et al., 2012; Bredenkamp, et al., 2011; Engelgau, et al., 2012; Fabricant, et al., 1999; Koopmanschap, et al., 1995; Mahal, et al., 2010; McIntyre et al., 2006; Nugent, 2008; Russell, 2004, 2005; Sauerborn et al., 1995; Suhrcke et al., 2006) with a neglect to other components of disease burden. Income losses caused by illness, particularly serious and prolonged illness, are often a more significant cause of impoverishment than direct costs (cost of treating/managing the condition), undermining household members' command over essential goods and services (Russell, 2005). Access to the services needed to prevent or control NCDs, and the extent to which infected and affected persons suffer financial catastrophe or impoverishment in obtaining the services is less well researched (Boutayeb, 2006; Daar et al., 2007).

Despite the fact that disease burden has over the last two-decade or so witnessed significant research interest, there is limited attention on micro (individual or household) level burden of disease in spite of the current paradigm shift in healthcare cost significantly from the state to the household. The burden of disease particularly NCDs, it the economic cost as well as the psychosocial and the intangible

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burden, are not confined only to institutional or national level burden but significantly at the individual and household levels.

Current existing literature and the global discourse on the burden of disease particularly NCDs, broadly revealed some gaps which necessitate this current research to advance the knowledge of disease burden. Firstly, there is a paucity of research that centres on measuring the direct, indirect and intangible burden of disease, particularly at the household level, and among sub-populations or the most disadvantaged in the society. The continual neglect of micro level burden of NCDs has created a relatively limited understanding on how NCDs affect household's social and economic dynamics, particularly in LMICs where poverty is still a daily challenge.

Evidence from scientific studies indicate increased prevalence of the risk factors and burden of NCDs in Accra (Addo et al., 2006; Agyei-Mensah and de-Graft Aikins, 2010; Amoah et al., 2002; Amoah, 2003; Amonoo-Lartson and Pappoe, 1992; Awuah et al., 2014; Cappuccio et al., 2004; de-Graft Aikins et al., 2014; de-Graft Aikins et al., 2012; Hill et al., 2007; Williams et al., 2013). The Greater Accra Region is reported to be the most urbanised region in Ghana with 90.5 per cent of its population living in urban areas (GSS, 2012). The city of Accra therefore presents an opportunity and a challenge to study the prevalence, impact and burden of diseases associated with urbanisation and modernity given its multi-cultural and cosmopolitan setting.

Also, the multifaceted nature of disease burden and the characteristics of urban poverty pose challenges in understanding how chronic disease affects both the

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infected and affected persons in the context of poverty. However, this area is where earlier researches have neglected in investigating the disease burden. It is important therefore for a new research agenda that advances understanding of the nuances of NCDs' effects on household social and economic circumstance that also shape individual's daily experiences and ultimately that of the household in the context of poverty.

Relevant dimensions to policy in the areas of social, psychological, illness experience and coping strategies to the burden of disease cannot be reduced to quantitative measurements. Large-scale surveys have the potential to undermine the context-specific processes operating at the household level that influence individual paths in and out of poverty caused by illness (Russell, 2005). This thesis makes the case for research designs that employs both quantitative and qualitative research approaches to explore nuances of NCD burden at the micro level. This will provide the evidence of the dimension of disease burden that are overlooked in many national large-scale surveys.

1.5 Thesis structure

The structure of the thesis is organized as follows - Chapter 1 provides an introduction to the thesis. This includes a background and justification, statement of the problem, research questions, and objectives. Chapter 2 focuses on review of the current literature on non-communicable disease burden at the household level. It outlines the factors that drive the increasing incidence and prevalence of NCDs globally and in low- and middle-income countries (LMICs). The current discourses

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on the burden of NCDs particularly in Ghana are examined to identify research gaps. Presented also in this chapter are the concepts and theories that underpin the study.

Chapter 3 focuses on the methodological approaches employed in this thesis to answer the research questions. Included in this chapter are a description of the study area, data collection and analysis methods and study limitation. Chapter 4 presents the types and prevalence of NCDs and the health seeking behaviour among persons diagnosed with NCDs. The main socio-demographic and economic predictors of health seeking behaviour were examined in this chapter. Chapter 5 address the direct burden of disease on urban poor households. Included in this chapter are the results of household characteristics that influence health seeking behaviour and predictors of household healthcare expenditure. Chapter 6 presents indirect and intangible burdens of NCD to the household. Chapter 7 presents the types of coping mechanisms households employ to navigate the direct burden of NCDs. Chapter 8 provides the summary of the main findings of the thesis as well as a conclusion, and recommendations drawn from the findings.

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CHAPTER 2

LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

2.1 Introduction

This chapter reviews available literature on the burden of non-communicable disease (NCD). The purpose of the review is to provide insight into the burden of NCDs at the household level in the context of poverty. Identifying and describing the major types of NCDs as documented in the scientific literature is made. Also, factors that have significant influence on the burden of NCDs such as urbanisation and poverty with particular attention at the individual and household levels are examined. Some highlights of the global and regional burden of NCDs are also reviewed and presented in this chapter. To contextualise the thesis, a review of research on NCDs in Ghana was conducted to bring into sharper focus the existing knowledge gaps in NCD research. Concepts and approaches use in measuring cost or burden of disease use in this thesis are also presented in this chapter as well as the conceptual framework guiding the thesis.

2.2 Non-communicable diseases

The term non-communicable disease (NCD) is the terminology used in burden of disease studies. The term is used to denote disease conditions whose classification is based on cause and effect (Unwin et al., 2004). Non-communicable diseases are defined as:

> "Diseases or conditions that occur in, or are known to affect, individuals over an extensive period of time and for which there are no known causative agents that are transmitted from one affected individual to another." (Daar et al, 2007, pg 494).

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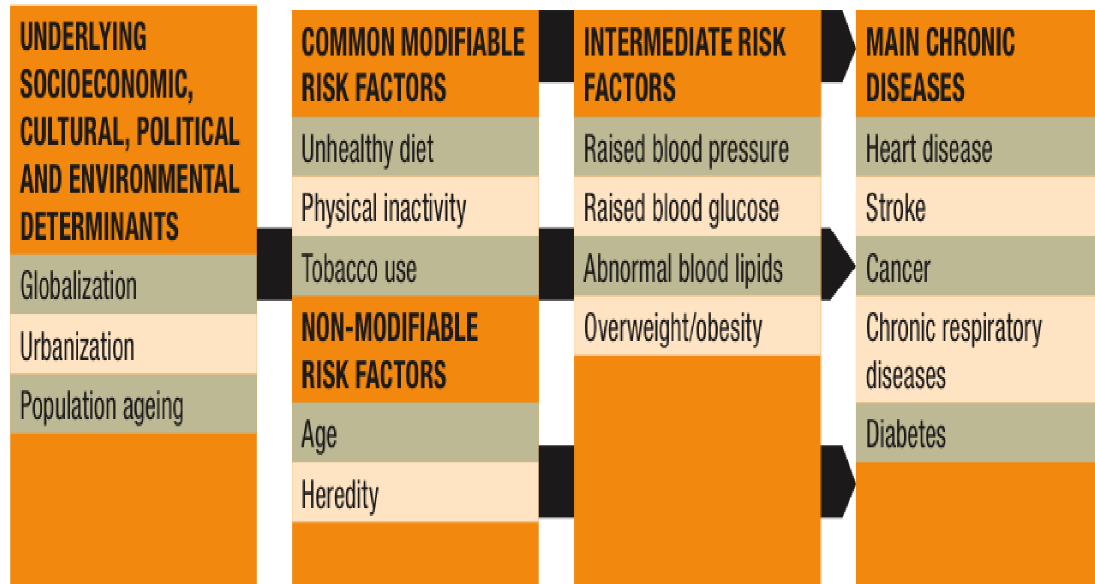
Key major commonalities in the definitions of NCDs are non-transmissible of the condition from one person to the other, long duration and generally slow progression. In 2005, the World Health Organisation (WHO) identified the causes of NCDs. The underlying socioeconomic, cultural, political and environmental determinants of NCDs were globalisation, urbanisation and population aging. Based on these underlying determinants, two major risk factors were posited: common modifiable risk (unhealthy diet, physical activity and tobacco use) and non-modifiable risk (age and heredity). Identified also are the intermediate risk factors in terms of raised blood pressure, raised blood glucose, abnormal blood lipids and overweight or obesity (Figure 2.1). These risk factors are known to increase individual susceptibility to the major NCDs like hypertension, stroke, cancers, diabetes, and other cardiovascular diseases.

Clearly demonstrated in Figure 2.1 are the socio-economic, demographic and cultural factors that underpin the increasing incidence and prevalence of NCDs globally and particularly in LMICs. The main types of NCDs are cardiovascular diseases (like heart attacks and stroke), cancers, chronic respiratory diseases (such as chronic obstructed pulmonary disease and asthma) and diabetes. The cause and manifestation of these disease conditions vary from one sub-population to the other.

Another factor that drives the incidence and prevalence as well as the burden of NCD is poverty (WHO, 20011b). (Schneider et al., 2009; WHO, 2011a). Poverty increases the population exposure to modifiable risk factors of NCDs, as well as the economic burdens associated with it. Unhealthy lifestyle behaviours such as

unhealthy diets, physical inactivity, alcohol and tobacco use are relatively higher among poor populations.

Figure 2.1: Causes of non-communicable disease



Source:WHO,2005a

The major NCDs affecting LMICs are diabetes, stroke, hypertension cardiovascular diseases, stroke, cancers, and respiratory diseases. These conditions are lifestyle diseases that are driven by behavioural changes associated with globalisation, urbanisation, population ageing and poverty. These diseases cause significant burden in terms of economic and social cost, mortality and disability due to late detection and complications (WHO, 2014a).

Hypertension, also referred to as high blood pressure, is a condition in which the arteries have persistently elevated blood pressure. Medi Lexicon's medical dictionary defined hypertension as:

> "High blood pressure; transitory or sustained elevation of systemic arterial blood pressure to a level likely to induce cardiovascular damage or other adverse consequences." (Medi Lexicon's medical dictionary)

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The normal level for blood pressure is below 120/80, where 120 denote the systolic measurement (peak pressure in the arteries) and 80 denote the diastolic measurement (minimum pressure in the arteries). Blood pressure between 120/80 and 139/89 is called pre-hypertension (to denote increased risk of hypertension), and a blood pressure of 140/90 or above is considered hypertension.

Hypertension may be classified as essential or secondary. While essential hypertension is the term for high blood pressure with unknown cause, secondary hypertension is high blood pressure with a known direct cause, such as kidney disease, tumours, or birth control pills. There are ranges of factors that are known to be highly associated with the cause of hypertension. These factors could be lifestyle and behavioural factors such as smoking, sedentary lifestyle, high salt intake (sodium sensitivity), and high alcohol consumption. The other factors are more related to other disease conditions such as diabetes, obesity or overweight, adrenal and thyroid problem or tumours and chronic kidney disease. Insufficient consumption of certain vital minerals like potassium, calcium, magnesium, and vitamin D deficiency are also known to be associated with hypertension. Genetics and family history of hypertension, aging and use of some medications including birth control pills as well as stress are the other causes of hypertension.

Stroke is described as the rapid loss of brain function as a result of a stop or disturbance in the blood supply to the brain. According to Sims and Muyderman (2009) this can be brought about by ischemia (lack of blood flow) caused by lockage (thrombosis, arterial embolism), or haemorrhage (Sims and Muyderman, 2009). Thus, there are two major categories of stroke: ischemic and haemorrhage. Ischemic stroke

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is caused by interruption of the blood supply to the brain and this accounts for about 87 per cent of strokes while haemorrhagic strokes results from rupture of a blood vessel or an abnormal vascular structure.

The loss of brain function might result in the inability to move the limb(s), inability to understand or formulate speech, or an inability to see (Donnan et al., 2008). Stroke can also cause permanent neurological damage and mortality. The risk factors for stroke conditions are aging, high blood pressure, diabetes, atrial fibrillation, high cholesterol, and risky lifestyle behaviour, like tobacco smoking (Donnan et al., 2008).

Diabetes is “a chronic disease that occurs either when the pancreas does not produce enough insulin or when the body cannot effectively use the insulin it produces” (WHO, 2015). There are two major types of diabetes namely “Type 1 diabetes” and “Type 2 diabetes”. However, there is also gestational diabetes (GDM). Type 1 diabetes is also termed insulin dependent diabetes and is usually caused by an autoimmune reaction where the body’s defence system attacks the cells that produce insulin. People with Type 1 diabetes need injections of insulin every day in order to control the levels of glucose in their blood. Type 2 diabetes is also called non-insulin dependent diabetes and is characterized by insulin resistance and relative insulin deficiency. The diagnosis of Type 2 diabetes can occur at any age. It is often, but not always, associated with overweight or obesity, which itself can cause insulin resistance and lead to high blood glucose levels. Gestational diabetes (GDM) is the type of diabetes consisting of high blood glucose levels during pregnancy. This type of diabetes occurs in one in 25 pregnancies worldwide. Though GDM disappears after

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pregnancy, both mother and child have an increased risk of developing Type 2 diabetes in later life.

Diabetes mellitus is one of the major causes of death and disability in sub-Sahara Africa (SSA). The increasing prevalence in type 2 diabetes in the region can be attributed to behavioural change; decreased physical activity; diets rich in saturated fat, sugar and salt; tobacco and alcohol use. These risk behaviours are often linked to modernization and urbanization and result in interrelated conditions like hypertension, obesity, and type 2 diabetes mellitus (Steyn and Damasceno, 2006).

There is a possible gene–environment interaction influencing the exposure of individuals to the risk of NCDs. However, altered diets and diminished physical activity due to globalization and urbanization are critical factors contributing to the acceleration of non-communicable diseases especially cardiovascular diseases, along with tobacco use (Reddy, 2002). Chitson (1994) identifies lifestyle factors, including smoking, poor dietary habits, obesity and low levels of physical activity as major risk factors, but he also points out hereditary factors as those related to diabetes mellitus (Chitson, 1994).

2.3 Determinants of burden of non-communicable disease

The major factors known to drive the increasing incidence and prevalence of NCDs are globalisation, urbanisation, population ageing and poverty. These factors interact to cause changing pattern of disease called the epidemiological transition. The transition is characterised by relative decline in the prevalence of communicable and infectious diseases and the emergence of non-communicable diseases becoming a significant cause of morbidity and mortality. Behavioural changes (sedentary lifestyle

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including reduced physical activity, tobacco use, harmful use of alcohol, unhealthy diet, etc.) are associated with the factors that drive the epidemiological transition. These behavioural changes are the modifiable risk factors of NCDs and are also associated with loss of household income from unhealthy behaviours. This section of the thesis examines how these factors influence the burden of disease particularly at the household level.

2.3.1 Urbanisation and non-communicable disease

Urbanization increases the population exposure to the modifiable risk factors of NCDs as it is accompanied by behavioural change (WHO, 2011a; Popkin, 1999; Vorster et al., 2000; Allender et al., 2010; 2011). Risk factors such as unhealthy diet practices, physical inactivity, tobacco and alcohol consumptions are associated with urban living. Urbanization is a vital factor in the epistemology of obesity, and a major risk factor for NCDs. It accelerates the changes in diet from food rich in fibre, low in fat and high in complex carbohydrates to diets high in animal fat and low in complex carbohydrates. These behavioural changes are known to have negative health outcomes such as obesity, diabetes mellitus, hypertension, cardiovascular diseases and certain types of cancers (Popkin, 1998; Vorster et al., 2000).

Urbanisation is a major public health challenge in many countries. Populations are increasing rapidly, basic infrastructure is insufficient and social and economic inequities in urban areas result in significant health inequalities (Vlahov et al., 2007). Rapid urbanisation and changing demographic profile have clear implications for disease pattern particularly for the emergence of NCDs (Lutz, Sanderson, and

Scherbov, 2008; Murray and Lopez, 1997c; Murray, 2005; Popkin, 1998; WHO, 2007).

Urbanization is found to increase body mass index (BMI) and cholesterol rapidly (Ezzati et al., 2005) and the prevalence of diabetes was two and a half times higher in urban areas compared to rural areas (Mohan et al., 2008). Allender et al. (2010) in a study in Tamil Nadu, India came to a conclusion that among men, urbanicity was positively associated with smoking, body mass index (BMI), blood pressure and low physical activity while among women it was associated with low physical activity and high BMI (Allender et al., 2010). The relationship between urbanisation and NCDs is driven by the influence of urbanisation on the modifiable risk factors of NCDs. The urban environment tends to increase the exposure of urban dwellers to the modifiable risk factors of NCDs. These observations underpin the linkage between urbanisation and the determinants of health. The literature shows that even though there are non-modifiable risk factors of NCDs, the modifiable risk factors are the major drivers of the increasing prevalence and the burden of NCDs. Not only does urbanisation expose the population to the risks of NCDs but it also results in the double burden of disease because of the challenges of the urban environment.

Rapid urbanization is not a negative phenomenon as it is associated with industrialization, employment and wealth creation. These benefits of urbanization to the nation and populations are acknowledged and documents in many studies (Annez et al., 2010; UN-Habitat, 2008, 2010; Yeboah et al., 2013a; 2013b). However, in many LMICs rapid urbanization drives poverty and conflict (UN-Habitat, 2008). The

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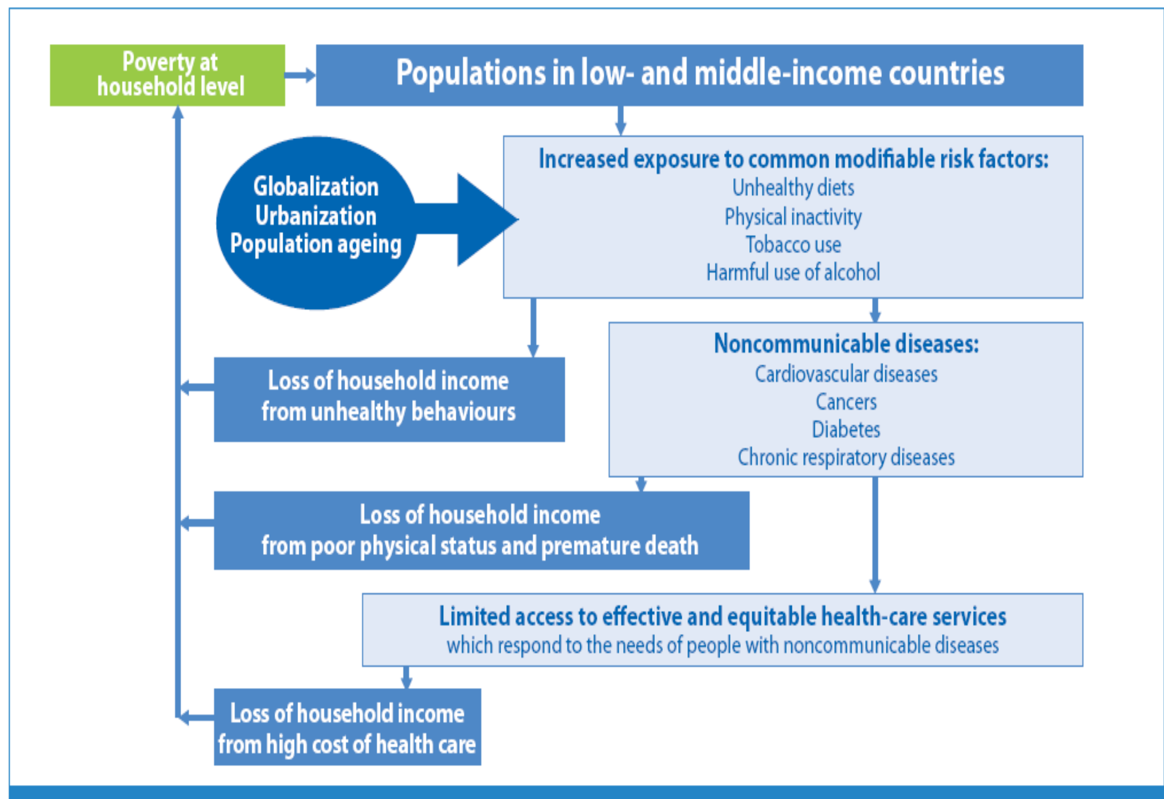
significant benefits of urban growth are not experienced in LMICs because of existing socio-economic challenges in the region. Rapid urban growth presents challenges for the provision of better and sustainable jobs, infrastructure development, governance, poverty alleviation, service provision and environmental sustainability by LMICs' urban systems.

2.3.2 Poverty and non-communicable disease burden

There exists a cyclical link between poverty and non-communicable disease (WHO, 2011a). The poverty-NCD link is attributed largely to the increased exposure of poor populations to the common modifiable risk factors of NCDs driven by globalization, urbanisation and population ageing. These result in household poverty due to loss of household income as a result of unhealthy lifestyle behaviours, ill health, premature mortality and high healthcare expenditure (Figure 2.2). Morbidity, mortality and disability associated with NCDs causes loss of productivity and income, and catastrophic healthcare expenditure through out-of-pocket payment for health services associated with the management of NCDs results in household impoverishment. This is because people are pushed into poverty as people living near the poverty threshold; even small payments push them below the threshold (WHO, 2012b).

Figure 2.2: Poverty and non-communicable disease



Source: WHO, 2011a

Poverty is a prominent determinant of the global burden of disease (WHO 2002a) and this is more prominent in developing economies. Rijken and Groenewegen, (2008) posit that people who are chronically ill have lower income and higher illness-related cost than the general population. In developed countries, the society bears the burden of ill health resulting from NCD through the health systems cost. However, in LMICs, the infected person and or his/her family bears the immediate cost of treatment and management of NCDs (Nugent, 2008).

Non-communicable diseases are known to have a huge negative economic impact on affected households and society (Suhrcke et al., 2006). This is because NCDs and their risk factors limit individual's opportunity and access to employment and also causes long absenteeism from work. The resulting loss on productivity and

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income associated with the health shock of NCDs are significant. The WHO (2005) projected that in 2015 China, India and the United Kingdom will lose $558 billion, $237 billion and $33 billion respectively, in national income as a result of NCDs (heart diseases, stroke and diabetes). The World Economic Forum (2008) estimates that countries such as Brazil, China, India and the Russian Federation lose more than 20 million productive life years annually to NCDs. In Taiwan, China, the probability of being in the labour force was reduced by 27 per cent by cardiovascular disease and 19 per cent by diabetes (Mete and Schultz, 2002).

Not only does the morbidity and premature mortality caused by NCDs causes loss of productivity and income but also the associate risk factors also result in the loss on household income (WHO, 2011a). Studies in China show that tobacco use increases the odds of sick leave by between 32 and 56 per cent (Qun and Dobson, 1992; Tsai et al, 2005). Goldstein et al. (2005) conducted a study in Peruvian cities and measured NCD burden at the level of prevalence and risk factors such as overweight, obesity, smoking, cholesterol level, physical activity etc. The results also indicate a relationship between poverty (measured here as socioeconomic status) and risk factors associated with NCD. The results from the South African Demographic and Health Survey (SADHS) 1998 shows that the risk factors of hypertension and obesity increased with increasing wealth, while most of the lifestyle factors (light smoking, domestic exposure to ‘‘smoky’’ fuels and alcohol dependence) associated with poverty and treatment status for hypertension and asthma were worse for poor people than for rich people (Schneider et al., 2009).

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Households in LMICs are currently burdened with healthcare cost due to healthcare reforms. There is a high level of out-of-pocket payment for healthcare particularly among households and individuals with NCDs (Bredenkamp et al., 2011; Dalaba et al., 2014; Davidoff et al., 2013; Joshi et al., 2013; Karan et al., 2014; Leive and Xu, 2008; Mahal et al., 2010; Mondal et al., 2010; Nguyen et al., 2011; WHO, 2011a, 2015).

The social and economic challenges in LMICs push households into impoverishment and poverty. One of every four families living in the world's poorest countries borrows money or sells assets to pay for healthcare (Kruk t al, 2009). In the slums of Dhaka, ill-health was found to cause more loans being taken out, assets being sold and more adults resorting to begging (Pryer, 1993). This situation is not different from the results of other studies (Engelgau et al., 2012; Kankeu et al., 2013; Karan et al., 2014; Kengne et al., 2013; Kruk et al., 2009; Rahman et al., 2013).

Poverty is relatively high among chronically ill people as van Agt et al. (2000) found that 14 per cent of chronically ill people are poor as compared with 5 per cent of their counterparts who were not chronically ill. Poverty was still more prevalent among chronically ill people than others ($p<0.001$) after medical expenses are accounted for (van Agt et al., 2000). Bjorntorp (1991) suggests that poverty and material deprivation affect chronic stress and lack of control of life circumstances, resulting in the development of NCD through a disruption in the physical equilibrium and related impact to the hypothalamic–pituitary-adrenal axis. This result came from a study conducted with British civil servants aimed at investigating the link between employment grade and the development of heart disease and metabolic syndrome.

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The study reports that the lowest wage-earning grades had the greatest risk of associated NCDs.

Some selected socio-economic factors are associated with NCDs prevalence as they promote unhealthy behaviours that drive the risk on NCDs. Hosseinpoor et al., (2012) quantified and compared education and wealth based inequalities to the prevalence of five NCDs (angina, arthritis, asthma, depression and diabetes) and comorbidity in 41 LMICs in adults aged 18 years or above. Their findings reveal that both wealth and education were inversely associated with selected NCDs and comorbidity prevalence, with strongest inequalities reported for angina, asthma and comorbidity. Also a study in Peruvian cities reveals that the burden of NCDs is highest in the lowest socio-economic strata (Goldstein et al., 2005). The results further reveal that being in low as opposed to high SES was significantly associated with a two to three fold increased risk of high cholesterol for both men and women after adjusting for other factors (Goldstein et al., 2005). Another study among residents of Buenos Aires, Argentina, reveals an inverse association between BMI and obesity and income of women, but not for men while low education and income were also associated with increased odds of hypertension diagnosis in all adults (Fleischerel et al, 2008).

The presence of NCDs in any society exacerbates social inequity because most payments for healthcare in LMICs are private and out-of-pocket. Such costs weigh more heavily on those least able to afford them, increasing the risk of impoverishment (WHO, 2011a, 2015). Thus, the link between NCDs and poverty is cyclical as health

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shock resulting from NCDs causes poverty, and poverty also increases the exposure to the modifiable risk factors of NCDs.

2.4 Non-communicable disease burden

The burden of NCDs has come to the attention of researchers and policy makers in the recent past (Adeyi et al., 2007; Ebrahim and Smeeth, 2005; Horton, 2007; Leeder et al, 2004; Strong et al., 2005; WHO, 2005). The progressive increase in the burden of NCDs has been attributed to several factors including longer average lifespan, tobacco use, decreasing physical activity, and increasing consumption of unhealthy foods (Daar et al., 2007). While those in urban settings who are relatively better off financially may be able to change their levels of risk factors (e.g., tobacco, excess calories from saturated fats and sugars), the poor may find it difficult to live healthy lifestyle in urban areas.

2.4.1 Global burden of non-communicable disease

Worldwide, the burden of NCDs is on the increase and is projected to continuously increase in the coming decades. Non-communicable disease mortality is projected to increase from 28.1 million deaths in 1990 to 49.7 million in 2020 (Murray and Lopez, 1997a). About 60 per cent of all deaths and 47 per cent of the global burden of disease in Asia is attributed to four major NCDs (Ghaffar et al., 2004). The non-communicable disease country profile for 2014 indicate that NCDs cause 38 million deaths each years and over 37 per cent of the deaths occur between the ages of 30 and 70, of which 85 per cent are in developing countries (WHO, 2014).

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Non-communicable disease decades ago were refers to as "the disease of affluence" as it affects wealthier population significantly (Anderson and Horvath, 2004; Gwatkin et al., 1999; Hosseinpoor et al., 2012; Schneider et al., 2009). Among the world's richest 20 per cent, NCDs caused 85 per cent of death and disability (Gwatkin et al., 1999). Approximately 125 million Americans (45% of the population) had NCDs, and 61 million (21% of the population) had multiple NCD conditions in 2000 (Anderson and Horvath, 2004).

Murray and Lopez (1997b) in a study aimed at investigating the global mortality, disability and the contribution of risk factors under the Global Burden of Disease Study, reported that developed regions account for 11.6 per cent of worldwide burden from all causes of mortality and disability. Also, communicable, maternal, perinatal, and nutritional disorders explain 43.9 per cent of DALYs worldwide while NCDs causes 40.9 per cent of DALYs (Murray and Lopez, 1997b). The 2002 World Health Report indicate that in 2001, about 60 per cent of the 56.5 million total reported global deaths and about 46 per cent of global burden of disease were attributed to NCDs (WHO, 2002). Prevalence is not the only major challenge but also health resource and health financing, as 78 per cent of health spending is devoted to person with NCD conditions (Anderson and Horvath, 2004).

The global poor are not exempted from the impacts of the burden of NCD both at the regional and national levels. Finding from a study (Gwatkin et al., 1999) that examined the burden of disease among the global poor indicate that in 1990, NCDs accounted for 59 per cent of death and disability among the world's poorest 20 per cent. Abegunde et al. (2007) estimated that NCD accounts for about 80 per cent

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of the total burden of diseases in 23 LMICs through economic productivity loss. Abegunde et al. (2007) point out that unless measures are taken, about US$84 million in economic productivity will be lost due to heart disease, stroke and diabetes in those 23 LMICs between 2006 and 2015.

Chronic disease burden is currently now affecting every region of the world in all aspects of human endeavour. Non-communicable diseases are now health, social and economic burdens as they deprive individuals and nations of their health and productive potential. Sub-Saharan African is known to be a region where majority of deaths are still attributed to infectious disease as against NCDs (Young et al., 2009). However, the region has seen increasing morbidity and mortality caused by NCDs in recent years (WHO, 2011a, 2014). The epidemiological transition in LMICs has resulted in high prevalence and incidence of lifestyle diseases with it associates disease burden. Hall et al., (2011) systematic review on diabetes in sub-Saharan Africa between 1999 and 2011 indicate that Type 2 diabetes accounts for more than 90 per cent of diabetes in sub-Saharan Africa. A study in The Gambia indicate 19.8 per cent, 9.9 per cent and 23.4 per cent increments in morbidity, hospitalisation and mortality due to NCDs respectively between 2008 and 2011 (Omolake, 2013).

Urban poor populations are known to be disproportionately affected by disease burden particularly NCDs. A study conducted in Kibera (a Nairobi slum) in Kenya reveals an age adjusted diabetes prevalence of 5.3 per cent among a sample of 2,061 man and women (Ayah et al., 2013). There is high economic cost of NCD in many countries in the SSA region. Hall et al. (2011) reported that the total annual cost of diabetes in the region was estimated at US$67.03 billion, or US$8,836 per diabetic

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patient. Absenteeism due to NCD illness and care giving efforts in India in the year 2004 resulted in annual income loss of US$23 billion.

2.4.2 Non-communicable disease burden in Ghana

Ghana like many low- and middle-income countries has seen an increasing research interest in the area of NCD. Majority of these studies have been carried out in the last two decades with focus on disease specific prevalence and illness experiences. Population-based, community and facility studies in Ghana have revealed increased prevalence of NCDs as well as the risk factors associated with these conditions across the country.

Urban populations are highly burdened in the prevalence of NCDs. Addo et al. (2007) in a systematic review of population-based prevalence of hypertension reveals a higher prevalence rate in urban than rural areas. The odds of being hypertensive are higher among urban men and women (1.9 (1.3–2.9; $P<0.01$) and 1.9 (1.3–2.8; $P<0.0001$) respectively) with urban women more likely than their rural counterparts to be aware of their hypertensive condition (odds ratio 2.3, 95% CI, 1.2–4.2; $P<0.001$) (Agyemang, 2006). The prevalence of NCDs and the risk factors are not just an urban phenomenon but also affect rural populations. Williams et al. (2013) conducted a cross-sectional survey among a sample of 425 adults aged 35 and older in a rural community in the Barekese district in the Ashanti Region of Ghana. The study distinguishes between hypertension and systolic hypertension from anthropometric measurement rather than self-reported. High prevalence of hypertension (44.7%) and isolated systolic hypertension (32.7%) were reported with 64.9 per cent on treatment.

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Increasing age and level of education were positively correlated with increasing blood pressure.

Consistent across studies, the prevalence of a NCD such as hypertension is reported to be on the increase. Among 4,733 participants in a study in Greater Accra, crude and age standardized prevalence of hypertension was estimated to be 28.3 per cent and 28.4 per cent respectively with systolic and diastolic blood pressure increasing with age (Amoah, 2003). The population-based prevalence of hypertension in Ghana has seen an increase from 19 per cent in 1970 to 48 per cent in 2009 (Bosu, 2010). Escalona et al. (2004) found a 26.8 per cent prevalence of hypertension among populations in selected urban communities in Accra and the result is positively associated with obesity. Not only has the general prevalence rate of hypertension increased but also the risk factor of hypertension has also equally increased. About one in four (25.4%) of 362 participants age 18 years and older had blood pressure measurement ≥140/90 mm Hg with only about one-third (32.3%) knowing of their condition and less than half of the persons with hypertension treating the condition (Addo et al., 2006).

The impact of NCDs in Ghana is not limited to morbidity and disability but also has a significant mortality effect on the population. Wiredu and Nyame's (2001) study at the Korle Bu Teaching Hospital in Accra, Ghana to determine stroke related mortality and patterns over a five years period (1994-1998) reveals that stroke accounted for 11 per cent of mortality. Agyemang et al., (2012) determine stroke morbidity and mortality in adult in-patients admitted to the Komfo Anokye Teaching Hospital to be approximately 9 per cent of the total medical adult admission and 13

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per cent of all medical adult deaths during a period of 24 months from January 2006 to December 2007.

Other studies have also examined community-based prevalence of diabetes in Ghana with striking results. Amoah et al. (2002) reported a crude prevalence rate of diabetes of 6.3 per cent with about 70 per cent of the 4,733 participants aged 25 years and older identified as diabetic having no prior knowledge of the condition. The study results also indicate the relatively high prevalence of NCD (diabetes) among males and the association between age, body mass index (BMI) and systolic and diastolic blood pressure.

Factors such as smoking, alcohol consumption, job-related physical activity, family history of NCDs, education, and occupation are found to be associated with NCDs (Addo et al., 2006; Addo et al., 2007; Bosu, 2010). Studies in Ghana has found age, and urban residency as significant factors associated with the prevalence of a NCD conditions like stroke (Agyemang et al., 2012; Birabi et al., 2012; Walker et al., 2003; Wiredu and Nyame, 2001), hypertension (Agyemang, 2006; Amoah, 2003) and diabetes (Amoah et al., 2002). The findings from these studies bring to the forefront the social, economic and other dimensions of burden that NCDs poses on the individuals and households, which often are given less prominent in the literature.

Illness experience is another component of disease burden that has witnessed research interest in Ghana. One of such studies is the study that examined the link between social knowledge, illness experience and illness action among persons living with diabetes in rural and urban settings in Ghana. The study used an individual approach to tap into diabetes sufferers' illness experiences and action. Findings from

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the study point out that there are four shared knowledge modalities namely common-sense, scientized, religious and emotional that participants drawn on to make meaning of their illness experiences (de-Graft Aikins, 2003). The results further reveal that diabetes caused disruption to body-self, social identity, family and social relationships, economic circumstance and nutrition (de-Graft Aikins, 2003).

Research attention on NCDs in Ghana has centred mainly on the prevalence of specific disease condition both in rural and urban populations, community and facility based studies. Other studies have also examined the risk factors and their contributions the prevalence of NCDs. Less frequent are studies that focus attention on illness experiences in living with some specific NCD conditions. The least focus area in the current existing scientific discussion both globally and locally is the social and economic burden on NCDs. Particularly in the era where there is significant shift in the burden of disease from the nation to the household and individuals. The lack of attention on the economic cost of NCD at the national or household level has created a knowledge gap in the understanding of the burden of NCDs.

2.4.3 Household burden of non-communicable disease

Relatively, few studies have investigated the household level burden of disease, particularly NCD. Minh and Tran (2012) assess the household financial burden associated with the NCD in a rural district of Vietnam among 800 randomly selected households. Approximately 29 per cent of households had at least someone with NCD and 33.4 per cent prevalence among individuals with men being in the higher proportion. The authors also assess burden associated with NCD by measuring catastrophic health expenditure and impoverishment rates using WHO definitions.

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Their results indicate that households with at least a member with NCD reported 14.6 per cent catastrophic health expenditure rate and 7.6 per cent impoverishment rate compared to those households with no member with NCDs reporting 4.2 per cent catastrophic health expenditure rate and 2.3 per cent impoverishment rate. (Minh and Tran, 2012).

Mahel et al. (2010) also found that between 40 and 60 per cent of health conditions are financed using savings and income. In addition, between 30 and 35 per cent of health conditions are financed with borrowed funds. In terms of catastrophic health expenditure, cancer accounted for 170 per cent while cardiovascular disease and injury accounted for 22 per cent (Mahal et al., 2010). Mondal et al. (2010) also found the prevalence of chronic disease in the household is associated with an odds ratio of 3.0 (95% CI) of catastrophic healthcare expenditure. Another study in India also reveal that there was an increase from 31.4 per cent (1995/6) to 47.3 per cent (2004) of the share of NCDs in out of pocket payment for healthcare by households (Engelgau et al., 2012). The result from a study in Ghana indicates that in 2003, the mean healthcare expenditure for households with a member currently living with NCDs is 49 per cent higher than households with no member living with NCD (Tagoe, 2012a).

Synthesis of findings from available literature reviewed indicates that there is some significant research interest in the burden of NCDs. However, most studies limit the burden of disease to the prevalence of the disease condition in the population. The limited few that investigate the financial burden also stops at the direct burden or cost neglecting the indirect and intangible burdens. The indirect costs are loss of income

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and productivity due to withdrawal from economic activity and disability associated with the condition as well as economic time spent seeking healthcare. The intangible burden or cost are the psychosocial stress, pains, stigma and other sufferings related to the condition.

As stated earlier, NCD is known to have a cyclical relationship with poverty (WHO, 2011a). Non-communicable diseases' impacts and burden are unequally distributed within populations, often disproportionally affecting the socioeconomically disadvantaged (Sakdapolrak et al., 2013; WHO, 2011a) Urbanisation is among the major drivers of the epidemiological transition with increased burden of chronic disease. In most LMICs like Ghana, the national response to NCD is still weak (Bosu, 2013). Individuals and households are significantly impacted by behavioural changes and also changing health policies and weaken of health system. The presence of NCDs in the household results in catastrophic health expenditure and household impoverishment (Engelgau et al., 2012; Karan et al., 2014; Minh and Tran, 2012). The household impoverishment is caused by the high cost of healthcare, high levels of out of pocket payment for healthcare, loss of income and productivity and the type of coping mechanism household adopt to cope with the economic burden of chronic disease.

There are other relevant components of disease burden vital for theorising: policy formulation and intervention, such as the disruptions to life trajectory, resource mobilization for healthcare finance, illness experiences, and livelihood. These have not received significant attentions due to the reliance on quantitative measurement of disease burden mostly in larger-scale surveys. Limited studies have focused on the

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burden of disease, particularly NCDs, at the household level. More significant in the literature is the paucity of the influence of two of the major drivers of NCDs (poverty and urbanisation) and its resulting burden both at the national and individual/household level. Knowledge of the burden of NCDs at the individual and household levels, which is the focus of this current study, will complement the already existing knowledge of NCD burden at the national level.

2.5 Conceptualisation of burden of disease measurement

Different methods or approaches have been employed to measure the burden of illness across many studies at macro and micro levels. At the macro level, the WHO Disability Adjusted Life Year (DALY) has often been applied since the development of the metric in 1990 (Lopez et al., 2006; Mathers et al., 2007; Morrow et al., 1998; Murray et al., 1994; Murray et al., 2006; Murray and Lopez, 1997a, 1997b). The cost-of-illness (COI) approach is another approach often employed by health economist and anthropologist to measure the direct, indirect and intangible cost of disease (Kankeu et al., 2013; Rice et al., 1985; Rice, 2000; Shepard et al.1991; Suhrcke et al., 2006; Byford et al., 2000; Heijink et al., 2008; Heijink and Renaud, 2009). Two other approaches i) The value of lost output (the economic growth) approach, and ii) The value of statistical life (VSL) approach in addition to the Cost of Illness (COI) approach was used by Bloom et al., (2011) in the Global Economic Burden of Non-Communicable Disease report. At the individual/household level, the most often used and cited is Bury's concept of Biographical Disruptions has been used (Bury, 1982, 1991; de-Graft Aikins, 2003, 2004; Kenen et al., 2003; Larsson and Grassman, 2012).

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The Global Burden of Disease study (1990; 2002; 2004; 2010) is one of the major studies that examine the burden of diseases and injuries. The attention of the Global Burden of Disease study centred mainly on the macro or national level using the DALYs and gross domestic product (GDP) with no attention on the micro level analysis (individual or household). The first Global Burden of Disease study (1990) introduced the metric of the disability-adjusted life-year as a method of quantifying the burden of diseases, injuries and risk factors based on: (1) years of life lost from premature death and (2) years of life lived in less than full health. The series, which is reported separately for eight geographic regions and ten age-by-sex groupings, quantifies the burdens of 483 pathological conditions related to 109 major causes of death and disability.

The importance of the DALYs matrix developed through the WHO and the World Bank out of the Global Burden of Disease study is that it provides a conceptual and methodological framework to quantify and compare the health of populations using a summary measure of both mortality and disability. However, critics of the DALY approach argue that its underlying design systematically undervalues the importance of chronic disease, such as neglected tropical diseases, emphasizes the concept of individual risk rather than an ecological perspective, and pays too little attention to the burden of disease for the poor.

Cost of illness (COI) approach identifies and measures the costs of disease on individuals and societies (Byford et al., 2000; Heijink et al., 2008; Heijink and Renaud, 2009). According to the US Centre for Disease Control (CDC) Cost of Illness (COI) is defined as the value of the resources that are expended or foregone as

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a result of a health problem (http://www.cdc.gov/owcd/eet/Cost/fixed/3.html). The COI categorised the cost of illness into direct, indirect and intangible cost (Shepard et al., 1991; Suhrcke et al., 2006).

Direct costs measures expenditures for direct medical goods and services (e.g., medications, doctor visits, and hospitalization) and can also be categorized into direct medical and direct nonmedical costs (Larg and Moss, 2011). Direct cost can also be measured at the facility or health sector level and at the household level. Health sector costs include hospitalization, medication, emergency (ambulance) transportation and care, and outpatient and primary clinic visits. At the household level, direct costs include user fees (out-of-pocket payments) for hospitals and medications, transportation of patients and caregivers, cost for taking care of dependents and modification of living space due to illness.

Indirect costs of disease are defined as the value of production lost to society due to absence from work, disability and death (Koopmanschap and Rutten, 1993). Indirect cost is thus the productivity losses or labour earning forgone as a result of ill health. The productivity losses can be attributed to illness, side effects, mortality, or time spent seeking healthcare. Earnings and productivity losses are not limited to infected persons but also to family members (affected persons) who provide care and support to patients.

Indirect costs are often estimated to be significantly higher than direct cost (Asenso-Okyere and Dzator, 1997; Attanayake et al., 2000; Koopmanschap and Rutten, 1993). Asenso-Okyere and Dzator (1997) estimate indirect cost at the household level in seeking malaria treatment care as 79 per cent of the total cost and

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attribute the high indirect cost to time spent seeking healthcare and caring for the sick. Koopmanschap and Rutten (1993) report that indirect costs represent 52 per cent of the total cost, or total costs saved by healthcare intervention. In Attanayake et al. (2000) direct cost was 24 per cent; indirect cost was 44 per cent for the patient and 32 per cent indirect cost for the household. The evidence is that in studies where both direct and indirect costs are investigated, indirect cost are always higher than direct cost.

Intangible costs capture the psychological dimensions of illness. These include pain, bereavement, anxiety, stigma and suffering. This category of disease burden is difficult to measure and often not included in COI studies (Tarricone, 2006). The difficulties associated with the measurement of intangible burden or cost of illness such as disfigurement, functional limitations, pain, stigma and fear are due to the difficulties in the quantification in monetary terms intangible burden. Willingness-to-pay (WTP) approach are sometimes used to measure intangible burden of disease (Felder et al., 2000; Su et al., 2007; WHO, 2009).

The concept of Biographical Disruption was put forward by Bury in a publication in 1982. The concept provides an insight into the experience of individual with chronic illness. Bury's (1982) study draws upon interviews with patients who were recently diagnosed with rheumatoid arthritis. The concept highlights the complex and multifaceted nature of the experience of chronic illness and this has resulted in the rethinking of a person's biography and self-concept. From the concept of Biographical Disruption, chronic illness causes disruptions to the physical capabilities, social identities and life trajectories of sufferers (Bury, 1982). The

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disruptions identified have symbolic as well as physical, financial, medical, social and cultural meanings (Bury 1991). The concept identified that illness permeates and restructures both the physical and social identities of the sufferer and these changes engender a quest for meaning which spans both everyday aspects of self-care as well as the broader implications of illness on one's life trajectory (Bury, 1982).

Other studies that followed the publication of Bury's paper and conception of Biographical Disruption presented other dimensions and further understanding of living with chronic illness and illness experiences. Using participants with a variety of chronic diseases and limiting the analysis to extreme cases, Charmaz (1983) came up with a "Loss of Self" concept to describe participants' experiences of former self-images crumbling away without a simultaneous development of equally valued new ones. The study highlighted how due to the illness, participants often led restricted lives, experienced social isolation, discredited by self and other, and experienced the humiliation of being a burden on others (Charmaz, 1983). Charmaz's concept of Loss of Self brings into focus patients' perspective of suffering and how it affects the day-to-day life rather than the medicalized view of suffering as physical discomfort. Also, it highlights the complex and overlapping ways in which different aspects of illness experience may reinforce and amplify one another.

Williems (1984) study of professionals living with rheumatoid arthritis explores the longer-term effects of chronic disease on self-concepts and pioneers the "narrative reconstruction". The study highlights the conceptual strategies people employ to create a sense of coherence, stability and order in the aftermath of biographical disruption as a result of the onset of illness. Williems' study

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demonstrates how narrative reconstruction can be used to reconstitute and repair ruptures between body, self, and world through linking and interpreting different aspects of biography in order to realign present and past as well as self and society.

These studies of Biographical Disruption demonstrated the overlapping and interdependent nature of body, self and society. They provided the framework to analyse and to understand the multifaceted nature of living with disease, and illness experiences. However, some recent studies (Pound et al., 1998; Sanders et al., 2002; Williams, 2000) have criticised the theory of Biographical Disruption particularly the absence of the factor of age, timing and setting in the concept of biographical disruptions. Carricaburu and Pierret (1995) describe the effect of illness on everyday life as “biographical reinforcement”. This denotes the reinforcement of the components of identity that prior to the illness had already been built and not a disruption to self and life trajectory.

Biographical Disruption has been a leading framework in studies on the everyday experience of chronic illness. Interviewing stroke survivors among three population groups (Puerto Rican Hispanic, African-American, and non-Hispanic white) with the aim of understanding stroke recovery experience, Faircloth et al. (2004) findings suggest biographical flow more than biographical disruption after accounting for social indicators like age, other health concerns and previous knowledge of the illness experiences. Felde's (2011) study conducted in Denmark from 2006 to 2008 focused on participants with elevated cholesterol and illness experience was described as “biographical work” de-Graft Aikins (2003) in a study with patients living with diabetes in rural and urban Ghana (drawing on social

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representative theory), examines the links between social knowledge of diabetes, illness experience and illness action using a qualitative research methodology. The results reveal that diabetes causes disruption to body-self, social identity, economic circumstance, nutrition, and family/social relationships. The results further indicate that factors that frame illness actions are common sense and scientized notions of health, illness and diabetes (de-Graft Aikins, 2003). Hubbard and Forbat (2012) study in Scotland explores the extent to which cancer disrupts people lives using Biographical Disruptions as the theoretical framework. The results of the study indicate that participants construct cancer as a biographical disruptive event with on-going physical and psychosocial impacts, as a permanent threat to life resulting in increasing awareness of survivors own mortality and invoking positive changes to self.

Larsson and Grassman (2012) analysed and compared results from two qualitative studies in which a life course perspective was used as a methodological framework. Larsson and Grassman (2012) indicate that disruption is not a single event that characterised the early stage of chronic illness but there are repeated disruptions that shape the lives of patients. Their study results also indicate that disruptions are still relevant to people in later life and is a continues events (Larsson and Grassman, 2012).

2.6 Conceptual framework of household burden of non-communicable diseases

The conceptual framework of this thesis is drawn from elements of two main theoretical underpinnings - Cost-of-Illness (COI) (Shepard et al, 1991; Suhrcke et al,

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2006) and the theory of Biographical Disruptions (Bury, 1982, 1991) discussed in the health burden and chronic disease illness experiences literature. The study triangulates the various components of the two theories or approaches to answer the research questions and to achieve the objectives of the study. The two approaches are used in this thesis because of their strengths in answering the research questions and achieving the research objectives. While the COI framework is used in the context of estimating the direct cost of management and treatment of illness and mapping the opportunity cost associated with living with illness, Bury's concept of Biographical Disruptions deals with the physical, financial, medical, social and cultural disruptions to body self, life trajectory of infected and affected persons resulting from illness.

The main criticism of the COI concept is that the concept is not grounded in welfare economics theory resulting in rejection of the concept by welfare economists (Tarricone, 2006). Bury's concept of Biographical Disruptions thus provide a platform to explore the psychosocial burden and illness experience. Combining these two concepts allow for a robust analysis and greater in-depth understanding of chronic disease burden at the household level. Combining the concepts also enhance the strengths and reduce the effects of the limitations of each individual concept.

Theoretically and methodologically, this thesis uses components of the cost of illness approach and biographical disruption to measure the direct, and indirect and intangible burden of NCD, respectively. Schematically, the conceptual framework is presented in Figure 2.3. The framework is drawn from a review of studies that investigate cost of illness at the household level (Suhrcke, et al, 2006; McIntyre et al., 2006; Russell, 2004; Sauerborn et al., 1996; Sauerborn, Nougtara et al., 1996;

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Sauerborn et al., 1995) with modifications to fit the current study. The household is the preferred unit of analysis because other studies (Berman et al., 1994; Sauerborn et al., 1995) have identified that decisions about treatment of disease and the choice of coping mechanism are based on negotiations within the household with some differentials in the bargaining power among members.

The incidence of illness in the household will result in distress and a resultant health-seeking behaviour. The behavioural options available to the household are either to seek treatment or not to seek treatment. The choice of behaviour by the household is informed directly and indirectly by the household's previous interaction with the health system. Access to healthcare facility, health insurance availability and coverage and other healthcare policies (all of which are outside the control of the household) influence treatment behaviour. Not seeking treatment results in indirect and intangible burden or cost of illness to the household. Indirect cost include the loss of income and productivity associated with absence from economic activity (Asenso-Okyere et al., 2011; Koopmanschap and Rutten, 1993; Shepard et al., 1991; Suhrcke et al., 2006).

Pain and suffering, withdrawal from social activities, stigmatisation and psychosocial stressors associated with the illness constitute an intangible burden or cost. The concept of Biographical Disruptions is use to examine how intangible burden of disease manifest on the infected persons. Direct cost is also incurred in addition to the indirect and intangible cost if the response from the household is to seek healthcare (Shepard et al., 1991; Suhrcke et al., 2006). Direct cost include all healthcare expenditure which can be categorised into direct medical cost and direct

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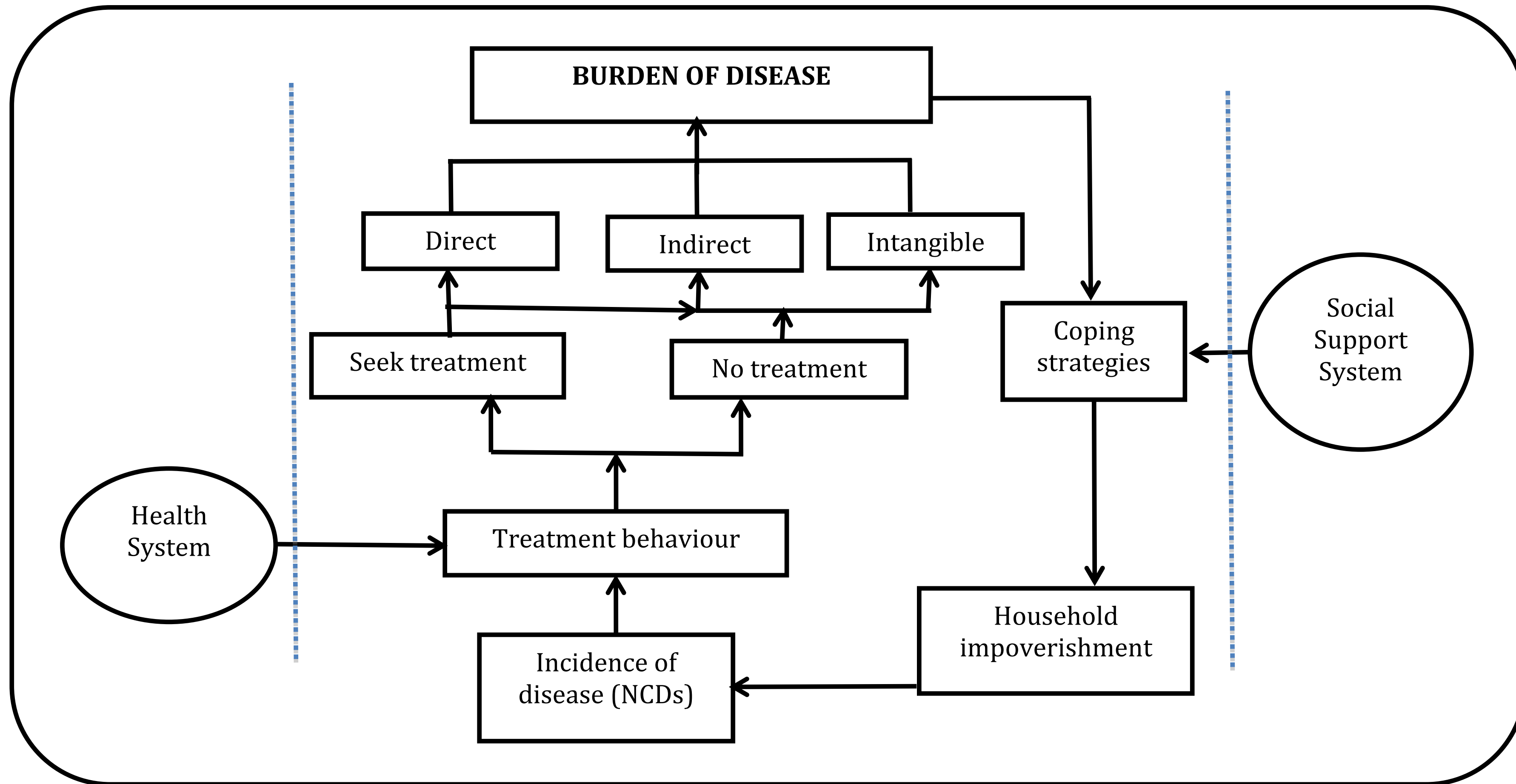
non-medical cost (Larg and Moss, 2011). Direct medical cost includes out of pocket payment for medical consultation, medication, laboratory investigations, hospitalisations, etc, while direct non-medical cost includes transportation, special foods and modification of living space due to illness.

Direct, indirect and intangible costs together constitute total burden of disease on the household. If burden of disease is above the household's budget, other coping strategies have to be located and used. However, the type of coping strategies available to the household is a function of the social support system and household resource availability. Available social support networks including support from friends, family and relations. These social support networks potentially influence the level of disease burden on the household. Household savings and income, selling of household assets and borrowing are the main strategies adopted by affected households to cope with health shock (de-Graft Aikins, 2005; Russell, 1996, 2004, 2005; Sauerborn, Adams, et al., 1996; Sauerborn, Nougtara, et al., 1996; Sauerborn et al., 1995; Tagoe, 2012b). These coping mechanisms increase risks of poverty at the household level that are known to increase the risks of NCDs (WHO, 2011a).

Figure 2.3: Conceptual framework of household burden of non-communicable disease



Source: Culled from Russell (2004) and Mclntyre et al. (2006) with modifications by the author

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CHAPTER 3

METHODOLOGY

3.1 Introduction

This chapter presents the methodologies employed to answer the research questions. Section 3.2 looks at the study area and location. Section 3.3 focuses on the main sources of data. It also includes sampling design and procedure as well as data collection and measurements. The last section, section 3.4 is dedicated to methodological approaches. It explains the quantitative and qualitative techniques employed to answer the research questions.

3.2 Study area and location

Three localities (James Town, Ussher Town and Agbogbloshie) all located in the Ashiedu Keteke sub-metropolitan` area of the Accra Metropolitan Assembly (AMA) were selected for study. Figure 3.1 shows the geographical location of the study localities within the AMA. Based on socio-economic status, the three communities are classified as poor communities in Accra by AMA's classification of localities. The average monthly household income for the three localities is GH¢126.13 (Accra Assemble Matropolitan-UN-Habita, 2011). James Town and Ussher Town are two Ga indigenous communities (also referred to as Ga-Mashie), and are characterised by multiple generations of families living together in large family houses. These two communities are both low-income and relatively stable traditional communities organised around social structures such as chieftaincy. However, different population sub-groups of other ethnicities have moved into these two traditional areas resulting in the multi-cultural and cosmopolitan setting of the

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area. Agbogbloshie is a migrant community consisting of several different ethnic groupings. Agbogbloshie generally has weaker social ties and less organised social structures compared to James Town and Ussher Town. The main economic activities in Ga-Mashie areas are fishing and petty trading. In the case of Agbogbloshie, trading and artisanship are the most dominant economic activities the population engage in.

Results from the 2010 Ghana Population and Housing Census (GPHC) indicates that the total population of Ashiedu Keteke is 117,525 of which 53.1 per cent are females and the remaining 46.9 per cent are males. A total of 29,278 person (3 years and older) reported ever attending school. About 23 per cent of this category of the population completed less than primary education. The results indicates that 44.5 per cent of this category of the population have attained primary education with another 18.1 per cent attaining completing Junior High School education. Only about one in ten (10.1%) have Senior High School education and only 3.0 per cent have attained Tertiary education. The rest have Vocational/Technical/Commercial and Post middle/secondary education.

Of the 117,525 persons residing in the sub-metro, a total of 85,115 are aged 15 years and older. The economically active population (persons working/looking for work) was at 67,088 (78.8%) of which 63,373 (94.5%) are employed. Among the employed population in the sub-metro, almost nine in ten (87.6%) are employed in the private informal sector. Only 4.0 per cent and 7.9 per cent are employed in the public (Government) and private formal sectors respectively.

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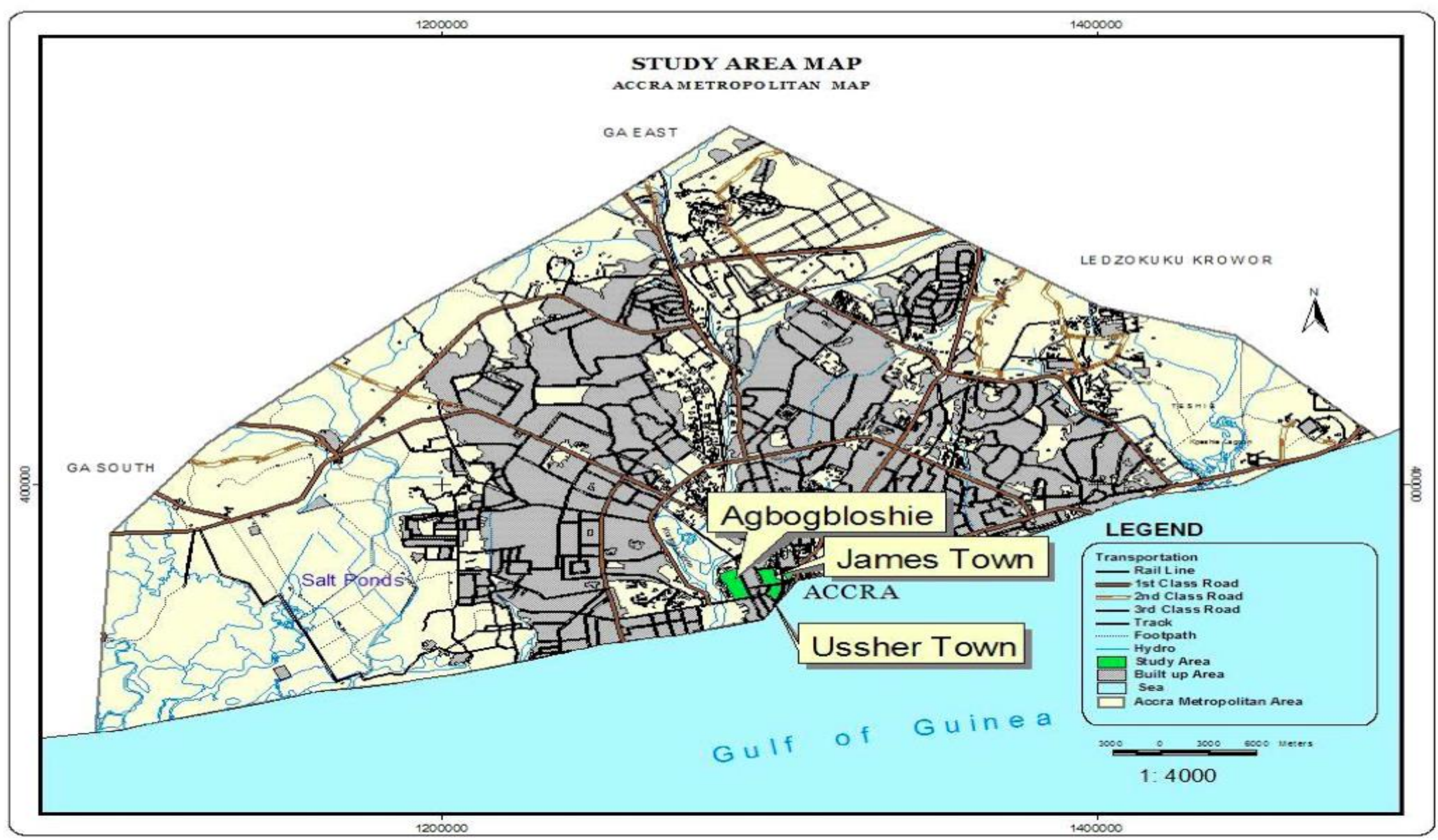
Figure 3.1: Map showing the study locations



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3.3 Data collection method and procedure

This thesis triangulates quantitative and qualitative research methodologies for both data collection and analysis approaches. Two primary data sets were used for the study. A cross-sectional household survey constituted the quantitative component of the study. The survey was conducted between 25th November 2011 and 21st December 2011 in three urban and relatively poor localities (James Town, Ussher Town and Agbogbloshie) in Accra. The survey was part of the Round II of the Population Training Research Capacity for Development (PopTRCD) urban health and poverty study. The PopTRCD project is a cross-sectional survey initiated and implemented by the Regional Institute for Population Studies at the University of Ghana in collaboration with the Southampton University and Cape Coast University and Fourah Bay University. The PopTRCD project had successfully implemented three rounds of data collections with varying sample size and areas of coverage. Details of all three rounds of PopTRCD projects are presented in Appendix 1. The PopTRCD project received financial support from the European Union (EU) under the EDULINK programme for the initial implementation of the project.

EDULINK represents a harmonised approach for the implementation of European Commission funded programmes in the Africa, Caribbean and Pacific Group of States with a view to improving the effectiveness, management, visibility and hence the impact of ACP-EU co-operation in the field of higher education. (http://acp-edulink.eu/content/about-edulink-0). The overall objective of the EDULINK programme is to foster capacity building and regional integration in the field of higher education through institutional networking, and to support a higher

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education system of quality, which is efficient and relevant to the needs of the labour market, and consistent with African, Caribbean and Pacific (ACP) socio-economic development priorities.

The qualitative component of the study draws on in-depth interviews conducted between August 11 and September 30, 2012 among identified household member(s) aged 18 years or older living with at least one NCD condition.

3.3.1 Sample design and procedure

Each of the three localities that constitute the study area is sub-divided into enumeration areas (EAs) based on population density. The distributions of the EAs according to the localities are Ussher Town (48), James Town (24) and Agbogbloshie (8). A three-stage sampling procedure was used and the first stage employing a systematic sampling procedure with probability sample proportional to size for all three localities. Agbogbloshie was oversampled to account for the nature of the population and the number of housing units in the area. The result of the first stage of sampling resulted in the selection of 29 EAs in total with the breakdown as followed: Ussher Town (16), James Town (8) and Agbogbloshie (5).

In developing a household sampling framework, all structures within the defined EAs were listed including dwelling units. In each identified and listed structure or dwelling unit, household units were identified and also listed and assigned unique structure and household number. The second stage of the sampling procedure involved a systematic sampling of 40 household units out of the total number of households listed from each of the selected EAs factoring in 15 per cent non-response rate. The non-response rate was based on round one of the PopTRCD urban health

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and poverty study conducted in the same study site and respondent fatigue. A total of 1,160 households were drawn from the sample frame for the household and individual surveys.

3.3.2 Survey data collection

The household data used to identify households with person(s) living with NCDs was collected under the second round of the PopTRCD urban health and poverty study. One-on-one, face-to-face interviews using a structured survey instrument were used to collect data at the household level. The household survey instrument was administered to the head of household and in the absence of head of household within the household during the survey period, a responsible adult household member aged 18 years or older was interviewed for the household survey.

The quantitative survey provided data on households with person(s) currently receiving or treating the NCD condition. A framework of NCD households was developed which included all individuals with NCD and the type of NCD condition(s) they are living with. The segmentation to select individuals for interviews was based on the type and the number of conditions the individual is currently living with.

The individual interviews tapped into individual biographical distribution and also capture household level disruptions from the perspective of the infected person. The researcher conducted interviews with the assistance of trained research assistants. All interviews were conducted one-on-one with participants in their homes. For ethical consideration and privacy, efforts were made to ensure the absence of a third party during the interview as far as possible.

Permission was sought from respondents and granted to record all interviews

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in consonance with Noguchi Memorial Institute for Medical Research (NMIMR) Institutional Review Board approval. Interviews were audio taped using digital audio-recorders. The researcher and transcribers transcribed the interviews using Microsoft Word and F4 transcribing package.

3.3.3 Segmentation approach for qualitative interview

Using three sets of questions asked to the head of household, the NCD status for all individuals listed in the household roster was established. Based on the responses the household NCD status is determined and categorised. Households classified as a NCD household (households with at least a member treating at least one NCD condition) were segmented based on the two main criteria for recruitment for the qualitative interview. Firstly, the type of condition and secondly, the number of household members living with NCD.

Three main NCD conditions were considered for recruitment and these are hypertension, stroke and diabetes. The rationale for selecting these three conditions is that these conditions share common modifiable risk factors and also there is a relatively high prevalence of the conditions in the study sample (from the quantitative survey). To account for single or co-morbidity conditions, the segmentation factored in individuals living with one, two or all three of the conditions. Another consideration made in the segmentation under this criterion is a household with individual(s) living with any of the NCDs under consideration as well as any other NCDs such as asthma, arthritis, cancer, angina (coronary heart diseases) and depression.

The number of household members living with NCDs was considered as a

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criterion for segmentation and recruitment for interview. This is because the number of household members living with NCD will significantly influence the burden of disease on the household.

In all, 162 (20.1%) households out of the 806 households that responded to the survey had at least a member who had ever been diagnosed with at least one NCD condition. Of the 162 households, 107 (66.0%) had at least a member who treated the NCD condition during the last two weeks preceding the survey. Approximately 90 per cent of the 107 households had one member currently living with NCD while the remaining 10 per cent had two members living with NCD. The distributions of the household with a member currently living with NCD are as follows Agbogbloshie, (4), James Town (37) and Ussher Town (66).

At the individual level, a total of 2,524 household members were listed in the 806 households surveyed. A total of 177 (7.0%) reported ever been diagnosed with at least one of the NCD condition. Among respondents who indicated ever been diagnosed with at least one NCD, about four in five (79.1%) received treatment or therapy for the condition during the 12 months preceding the survey. In all, 118 (66.7%) individuals out of the 177 received treatment or any form of therapy for the disease condition two weeks preceding the survey.

A total of 114 persons living with NCDs were aged 18 years and older. The segmentation resulted in the selection of 36 participants. Among the selected participants, 3 persons died before the interview was conducted. Caregivers of deceased persons were interviewed to understand the circumstances leading to the demise. Two (2) persons refused interview while four (4) other persons selected for

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interview could not found. In total, 27 persons living with NCDs granted the interviews and were made up of nine (9) males and eighteen (18) females. Among the participants interviewed, 3 males and 8 females were living with more than one NCD conditions while the remaining 6 males and 10 females were living with one NCD condition. The socio-demographic characteristics of participants are presented in Appendix 2.

3.4 Measurements

3.4.1 Demographic and economic characteristics

Two sets of research instruments were employed (see Appendix 9 and Appendix 10) in line with the objectives and methodology of the thesis. Firstly, a standardised structured questionnaire was used to solicit information about household and household member characteristics. Nine socio-demographic and economic characteristics were considered and these characteristics were considered because they are known influence on the prevalence of NCDs and health seeking behaviour.

Presented in Table 3.1 are the selected socio-demographic and economic characteristics and the categories under each characteristic. These are (1) Age of respondent in completed years, (2) Sex of respondent, (3) Highest level of educational attainment, (4) Ethnicity, (5) Religious affiliation, (6) Occupation that was also categorised into employed/working and unemployed/not working, (7) Household size, (8) Health insurance status, and (9) Household wealth quintile.

Household wealth index was created based on selected household asserts and characteristics. Factor analysis was used to derive one factor that would summarize variables related to household wealth. Factor analysis is an exploratory multivariate

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analysis that is used to detect relationships among variables. The goal of the analysis is to try to identify factors that underlie the variables.

An index of quality of housing, assets, and environmental quality was created based on selected assets possession: car, motorcycle, bicycle, boat/canoe, truck, outboard motor, refrigerator, freezer, generator, washing machine, radio, telephone, clock, electric/gas stove, sofa set, sewing machine, electric fan, computer and fishing net. Factor analysis was then used to derive one factor that would summarize variables related to the quality of housing (construction material for roof, walls, and floor, number of rooms for sleeping), the "possession" index, the source of drinking water, and the availability of sanitary facilities.

We first use the principal components method of extraction and then the principal components factor method of extraction. Factor loadings smaller than 1.0 were excluded from the initial model. The final model had 49 variables (floor, walls, water source, possession index, and sanitary facilities) and explained 46 per cent of the variance. The resulting wealth index generated form the score was divided into quintiles (20 per cent in each group). The first 20 per cent was labelled "Poorest", the next 20 per cent (Poorer), "Middle", "Richer" and "Richest" in that order.

Table 3.1: Socio-demographic and economic characteristics by categories

Characteristic	Category
Age	In completed years
Sex	Male Female
Highest level of education	No education Primary Middle/Junior High School Secondary/Senior High School Higher/Post-secondary and Tertiary
Ethnicity	Ga Akan Ewe Other
Religious affiliation	Christian Islam Traditionalist/spiritualist Other
Occupation	Not working Professional/technical/managerial/clerical Sales/services Agriculture sector Household/domestic Manual labour (skilled/unskilled) Other
Household size	Total persons in household
Health insurance status	Insured Not insured
Household wealth quintile	Poorest Poorer Middle Richer Richest

3.4.2 Non-communicable disease prevalence and household healthcare expenditure

Non-communicable disease status of each household member(s) listed in the household roster was captured and examined. Information on each household member

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concerning the status of NCDs - stroke, hypertension and diabetes, arthritis, cancer, angina (coronary heart diseases), asthma, and depression status were considered. Three sets of question posed to head of household was used to established NCD status of each household member. The details are as follows:

i. Has (*name household member*) ever been told by a health professional that he/she had *specified NCD condition*?
ii. Is (*name household member*) taking any medications or other treatment/therapy for (*specified NCD condition*) during the **last 2 weeks**?
iii. Is (*name household member*) taking any medications or other treatment/therapy for (*specified NCD condition*) during the **last 12 months**)?

The household survey was not focused on specific NCD condition(s). The objective was to capture and estimate the prevalence of all NCD condition among the population in the three localities under consideration. The examples of NCD conditions (stroke, hypertension and diabetes, arthritis, cancer, angina (coronary heart diseases), asthma, and depression) were given as a guide and any other NCD condition(s) reported are captured. The results from the household survey were used to segment the households and individuals for in-depth interview. The segmentations for selecting individuals for interview were guided by the three common NCD conditions (Hypertension, stroke and diabetes) and the comorbidity effects as they share common risk factors.

Total household healthcare expenditure during the 30 days preceding the survey was estimated. The cost items used to measure the total household healthcare expenditure are indicated in Box 1. The sum of these items constitutes total household healthcare expenditure in the last 30 days.

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Box 1: Items for total household healthcare expenditure

- Registration and consultation fees by doctor(s) or medical health professional (s) that did not require an overnight stay
- Health care by traditional or alternative healer(s) (masseur, herbalist, acupuncture or aromatherapy practitioners,)
- Diagnostic and laboratory tests such as X-rays or blood tests
- Medications or drugs (prescription, non-prescription, traditional, homeopathic…………..)
- Dentists or dental care
- Ambulance or transportation
- Any other health care products or services that were not included above Specify …………………….

Source: WHO, World Health Survey 2003

For the qualitative component of the study, a semi-structured interview guide was used during the in-depth interview with individuals living with NCDs. All households identified with at least a member currently living with at least one NCD condition (treated NCD condition during the 2 weeks preceding the survey) and aged 18 years and older constituted the sampling frame for the qualitative study. The interviews tapped into the indirect and intangible burden of disease from the perspective of infected person (Box 2).

Box 2: Thematic areas of indirect and intangible burden of disease

- Chronic disease condition
- Illness experiences at the individual level
- Disruptions at the household level
- Adaptive and coping mechanisms to the disease condition
- Social support network and resource mobilisation for financing healthcare expenditure
- Total healthcare expenditure in the last 30 days preceding the interview.

3.5 Methods of Analysis

Quantitative and qualitative analytical techniques were employed to analyse the data. Four research questions were answered by the thesis and the statistical

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techniques used are determined by specific research question and objectives. To determine household NCD status and NCD prevalence in the study area, the univariate technique was used. Bivariate and multivariate techniques were used to identify the factors that determine health-seeking behaviour among persons living with NCDs. To estimate the direct burden of NCD on the household, analysis of variance (ANOVA) was used. To predict household expenditure characteristics, a multivariate linear regression model was fitted. Thematic network analysis technique was used to investigate the indirect and the intangible burden of NCDs on household. To examine the coping strategies employed by households to deal with direct burden of NCDs on the household, thematic network analysis was also used.

3.5.1 Univariate analysis

To answer the first research question, univariate, bivariate and multivariate analytical techniques were employed. These techniques were applied on the three questions that determine the NCD status of households in order to estimate the prevalence of NCDs. These are ever diagnosed, treated the NCD condition during the last 2 weeks and treated the NCD during the last 12 months preceding the survey.

The crude prevalence rate for each specific disease type was computed by finding the proportion of the sample population reported ever having been diagnosed or treated (with medication or any other therapy) for the NCD condition during the last 2 weeks or 12 months preceding the survey by the total sample population expressed per 100 or 1,000. The expression in denoted by the equation below.

$$y = \frac{x}{z} \times k$$

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y = prevalence rate.
x = the number of persons reported ever diagnosed with or treated for the specific condition.
z = total number person exposed to the risk – total sample population
k = a constant factor (100, or 1,000).

3.5.2 Bivariate and multivariate analyses

Both bivariate and multivariate analysis techniques were employed to identify the factors that determine health-seeking behaviours among persons diagnosed with NCD. Bivariate analysis was used to investigate the socio-demographic and economic characteristics that are significantly associated with health seeking behaviour. This was done specifically using the chi square test statistic 0.05 level of significance.

A binary logistic regression model was fitted at the multivariate stage of analysis to determine the main socio-demographic predictors of health-seeking behaviour among persons ever diagnosed with NCD. This type of regression technique was employed at this stage of the analysis because the outcome variable (treatment status) is dichotomous (did not treat = 0, did treat =1). Dummy variables were created for all indicator (categorical) variables and a reference category selected for which all other categories in a particular variable are compared to. For example, in the case of the sex variable, the outcome is ether 1=male or 2=female. If male is selected as the reference category, the estimate (odds ratio) of the female is compared to the male (the reference). Statistical tests for significance were performed at a 95 per cent confidence level ($P<0.05$).

$$y = \alpha + \beta_1 X_1 + \beta_2 X_2 + \ldots\ldots + \beta_n X_n + \varepsilon$$

Where y is the dependent or the outcome variable (treatment status), α is the intercept which denotes the unit of y when $X = 0$. That is, the treatment status of an individual

when other socio-demographic factors have not been accounted for in the regression model. β_1 is the coefficient of the explanatory variable X_1 (example: age of individual, sex, education etc.) and ε is the error term.

3.5.3 Analysis of variance (ANOVA)

To estimate the direct burden of disease on urban poor household, the analysis of variance (ANOVA) technique was used. The total household healthcare expenditure in the last 30 days was used to measure direct burden of disease. The ANOVA was used as the technique that allows for investigating and determining mean difference between groups. The three groups of households investigated at this stage are:

1. Never diagnosed (No household member diagnosed with NCD);
2. No treatment (household member diagnosed with NCD but did not treat the condition during the 2 weeks preceding the survey); and
3. Treated (household member diagnosed with NCD and treated the condition during the 2 weeks preceding the survey).

Another comparison test was carried out to investigate the mean differences in total household healthcare expenditure between never diagnosed households (households with no member ever diagnosed with NCD) and diagnosed households (households with a member ever diagnosed). This was also done by treatment status (diagnosed but did not treat against diagnosed and treated).

The Shapiro Wilk normality test was used to test for the normality distribution of total household healthcare expenditure. The results indicate that total household healthcare expenditure data is not normally distributed (p=0.000). The data violated the normality assumption and was transformed using the log transformation technique. The transformed result was used to investigate the direct burden of disease

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on households by comparing mean differences in total household health expenditure between the different categories of households in an ANOVA model.

3.5.4 Multivariate linear regression analysis

A multivariate linear regression was fitted to predict the main characteristics of household healthcare expenditure. In the model, total household healthcare expenditure was the outcome variable and selected household characteristics were explanatory variables. The selected household characteristics are: household NCD treatment status (0 = no treatment, 1 = treated), household size (continuous variable), health insurance status of person living with NCD (0 = uninsured, 1 = insured), and household wealth status (0 = poorest, 1 = poorer, 2 = middle, 3 = richer, 4 = richest).

3.5.5 Thematic network analysis

Research question 3 and 4 were investigated using the qualitative approach. The research questions were answered by employing thematic network analysis. The qualitative analysis was carried out employing thematic analytical technique (Attride-Stirling, 2001). The strength of the thematic analyses is its ability to unearth the themes salient in a text at different levels (Attride-Stirling, 2001). Themes were developed based on the conceptual framework that guides the thesis, pivoted on existing literature. In addition, other emerging themes from the interviews were included. The themes centred on health and illness experience, individual and household representation of illness, disease burden (direct, indirect and intangible), health seeking behaviour, coping mechanism, etc.

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Of interest is the burden of disease on the individual and other household members from the perspective of the person living with the disease condition. The contextual effect and role of poverty in chronic disease burden both at the individual and household levels were also explored in the interview and analysis thereafter. The data were organized in cases with each participant representing a case with identifier "Case 1" through to "Case 27". All completed individual interviews with persons living with chronic disease(s) were transcribed.

The transcripts were imported into qualitative data analysis (QDA) computer software package - QSR Nvivo. Deductive and inductive coding techniques were employed. Coding allowed for the data reduction (Attride-Stirling, 2001; Lee and Fielding, 1996) and to capture the range of views on the thematic areas of the discussion. The theoretical framework of the study guided the deductive codes around thematic areas of burden of disease (indirect and intangible) and the coping mechanisms used to manage the burden of disease. All transcripts were coded twice at different time intervals for intra-coder reliability (Morse, et al., 2002). Attention was paid to commonality, differences and conflicts on themes under discussion and any emerging themes, which were not part of the initial coding frame (Appendix 3).

Drawing on the thematic network approach, themes were categorised into basic, organising and global (Table 3.2) and represented on a web like-map depicting the main themes at each od the three levels and it relationships. The basic themes are the lowest order premises, which together constitute the organising themes. Global themes are the highest order themes encapsulate the main idea in the discussion. Thus,

the global themes are the main ideas that respond to the research question that drives the thesis.

Table 3.2: Thematic network analysis framework

Basic theme	Organizing theme	Global theme
Early retirement Time spent seeking healthcare Withdrawal from economic activities or inability to take-up job opportunity	Income loss	**INDIRECT**
Inability to invest Use of investment resources	Investment challenges	
Risk of isolation Challenges in the health system Socialization Sexual weakness	Psychosocial Stressors	**INTANGIBLE**
Nutrition disruptions	Healthy lifestyle	
Household members Friends and family	Social support	**COPING MECHANISM**
Access to services Access to medication Reduce cost of service	Health insurance	
Skipping routine appointments and check-ups Skipping medication	Waiver of health seeking privileges	
	Sales of household asset	
	Savings and investments	

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3.6 Limitation of study

The data used in assessing the direct burden of disease are cross-sectional in nature and only allow for an assessment of cost of illness for a short period of time (prevalence) rather than incidence. Another issue is that the study could not determine whether or not the NCD household healthcare expenditure was actually for only chronic disease or for other health services. Also, the social and economic mechanism depended on by poor households to deal with the burden of NCDs were limited to direct or the finical burden of healthcare.

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CHAPTER 4

PREVALENCE OF NON-COMMUNICABLE DISEASE AND HEALTH SEEKING BEHAVIOUR

4.1 Introduction

This chapter presents results on the prevalence of NCD and the factors that predict health-seeking behaviours among persons diagnosed with NCD. The incidence and prevalence of NCDs in many LMICs is documented to be on the increase and expected to continue in the coming decade (Mathers and Loncar, 2008; Strong et al., 2005 and WHO, 2005) with significant burden at country, regional, and individual levels. Association between socio-demographic characteristics and knowledge, and prevalence of NCDs have been found by some studies (Hosseinpoor et al., 2012; Kinra et al., 2010; Wilkinson et al., 2009). In addition, this chapter presents the distribution of persons diagnosed with NCD by selected socio-demographic characteristics.

4.2 Type and prevalence of non-communicable disease

The specific type of NCDs and the prevalence of each disease condition in a population reflect the general stage of epidemiological transition of the society. Different disease conditions have different direct and indirect burdens on both infected and affected persons. Knowledge of the prevalence of NCDs among the study population provides a significant framework in understanding the burden of NCDs in the households. Prevalence of NCD was measured at three levels. These are "ever diagnosed with NCDs", "treated or received any therapy during the 12 months

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preceding the survey" and "treated or received any therapy for the NCD condition during the 2 weeks preceding the survey".

4.2.1 Prevalence of non-communicable disease among urban poor households

Among the 2,524 individuals, 177 (7.0%) reported ever having been diagnosed with at least one chronic disease. One hundred and forty (5.5%) and 118 (4.7%) received treatment for the disease condition during the last 12 months and 2 weeks preceding the survey, respectively. The level of treatment among the ever-diagnosed persons (177) was about four in five (79.1%) who treated the condition during 12 months preceding the survey, and 67 per cent who treated the condition during the last 2 weeks preceding the survey.

4.2.2 Disease specific prevalence among study population

The most common condition reported in terms of ever been diagnosed is hypertension (5.3%). This is followed by diabetes (0.9%), asthma (0.7%) and stroke (0.6%). Other disease conditions recorded less than 0.5 per cent prevalence (arthritis, depression, angina and cancer). The trend is not different with regard to treatment during the last 2 weeks preceding the survey but relatively lower compared to ever been diagnosed.

A total of 15 persons reported ever been diagnosed with stroke and the majority (86.7%) of them treated the condition during the last 2 weeks preceding the survey with medication or with some other therapy. A similar pattern exists for hypertension where 134 reported ever been diagnosed and 90 treated the condition during the 2 weeks preceding the survey. Twenty-two persons reported ever been

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diagnosed with diabetes and 16 treated the condition during the 2 week preceding the survey. The prevalence distributions of other NCDs are presented in Table 4.1.

Table 4.1: Prevalence of non-communicable diseases among study population

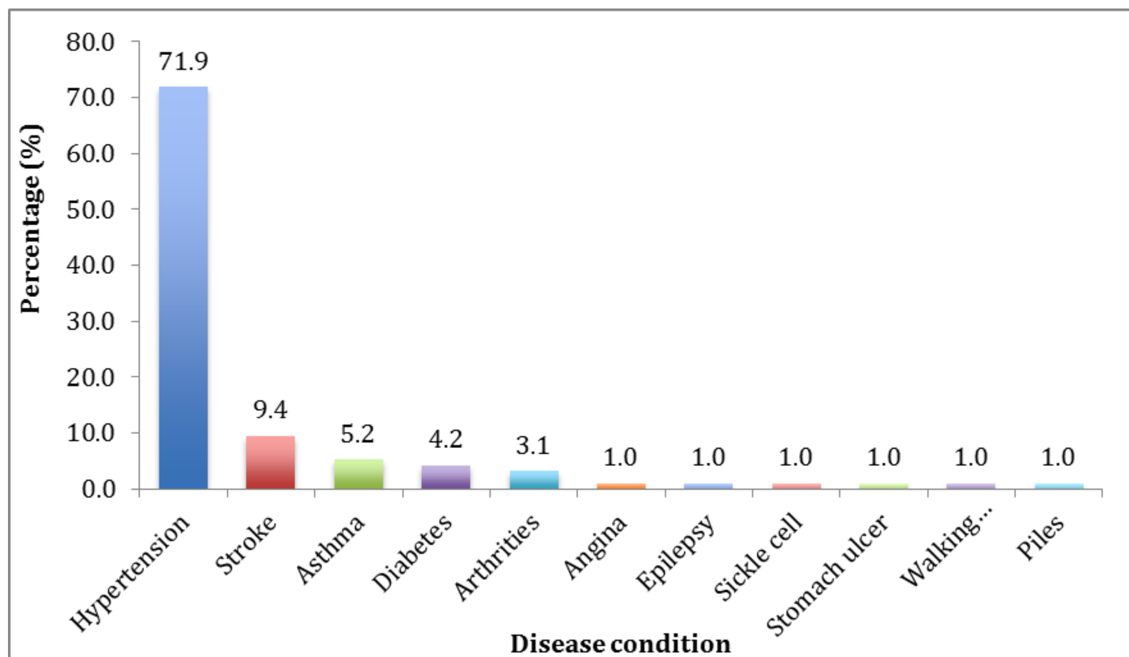
Disease condition	Ever diagnosed	Treatment (12 months)	Treatment (2 weeks)
Stroke	15 (0.6)	14 (0.6)	13 (0.5)
Hypertension	134 (5.3)	109 (4.3)	90 (3.6)
Diabetes	22 (0.9)	20 (0.8)	16 (0.6)
Arthritis	10 (0.4)	8 (0.3)	10 (0.4)
Angina	1 (0.0)	0 (0.0)	1 (0.0)
Asthma	18 (0.7)	8 (0.3)	18 (0.7)
Cancer	1 (0.0)	0 (0.0)	1 (0.0)
Depression	2 (0.1)	1 (0.0)	1 (0.0)
Other	9 (0.4)	7 (0.3)	9 (0.4)

Ninety-six or (81.4%) of the total 118 persons living with NCD, currently live with a single condition. Co-morbidity was reported among 20 individuals representing 16.9 per cent and 2 individuals (1.7%) live with more than two conditions. Co-morbidity is known to be commonest among persons living with NCD because of shared common risk factors associated with NCDs (WHO, 2010). Comorbid conditions may be independent of one another and can also arise because of common risk factors or the presence of one disease increasing the likelihood of developing another.

Among the 96 individuals living with single disease conditions, majority (76.0%) are females while the remaining 23 (24.0%) are males. Majority of the persons living with 2 conditions are females (85.0%) with males constituting the remaining 15.0 per cent. Two persons, a male and a female reported living with 3 NCD conditions. The two persons living with 3 NCD conditions are both living with hypertension and diabetes and the third condition is asthma and stomach-ulcer respectively.

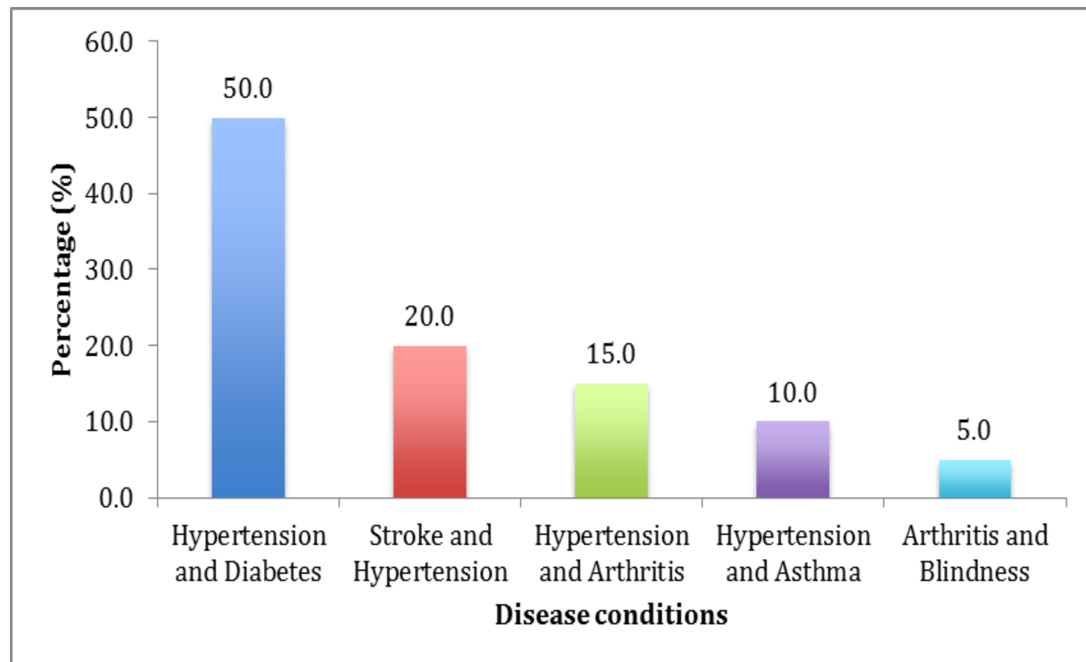
Ninety-six persons reported living with a single NCD condition. The distributions by disease conditions are presented in Figure 4.1. Majority (71.9%) of this category of persons are currently live with hypertension. This was followed by stroke (9.4%), asthma (5.2%), diabetes (4.2%) and arthritis (3.1%). One person each representing 1.0 per cent reported currently living with angina, epilepsy, sickle cell, walking disability and piles (Figure 4.1).

Figure 4.1: Distribution of persons with single disease condition by disease type



Among the 20 persons living with 2 NCD conditions, one in two (50.0%) live with hypertension and diabetes, one-fifth (20.0%) live with stroke and hypertension (Figure 4.2). Hypertension and arthritis was reported by 15.0 per cent, 10 per cent reported living with hypertension and asthma and 1 person representing 5.0 per cent of the 20 persons live with 2 NCD conditions - arthritis and blindness.

Figure 4.2: Distribution of persons with co-morbidity condition by disease types



4.3 Determinants of health seeking behaviour by persons living with NCD

The results of bivariate analysis on the association between socio-demographic and economic characteristics and health seeking behaviour are presented in this section. Chi-square test was used to test the statistical significance of the association between selected socio-demographic characteristics and health-seeking behaviour. Multivariate analysis, which determines the main socio-demographic and economic predictors of health seeking behaviours are also presented. The result of the multivariate analysis was achieved after fitting a binary logistic regression with the outcome variable, treatment status (0 = no treatment, 1 = treated), and selected socio-demographic characteristics as explanatory variables. Selected demographic characteristic are age, sex, highest level of educational attained, marital status, religion, ethnicity, employment status/occupation, household wealth status and health insurance status of the respondent.

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4.3.1 Relationships between socio-demographic characteristics and health-seeking behaviour

Relationships between some selected socio-demographic characteristics and health-seeking behaviour of persons diagnosed with NCDs were examined. The Chi-square test statistics was used to test the association at an alpha level of 0.05. The results reveal age and health insurance status of diagnosed person are the factors statistically significantly associated with health-seeking behaviour. The other factors show no statistical significant association with health-seeking behaviour at alpha level of 0.05 (Table 4.2). Approximately a third (33.3%) of diagnosed respondents did not treat (medication or any therapy) their condition. Health insurance status of persons diagnosed with NCDs influenced health-seeking behaviour (p=0.003). The result reveals that more insured diagnosed persons (76.0%) treated their conditions compared to their uninsured counterparts (54.5%). Age is another factor that statistically significantly influenced health-seeking behaviour (p=0.023). Older persons (61 years and above) diagnosed with NCD are more likely than their counterparts in younger age groups to treat their condition (Table 4.2).

Though the results are not statistically significant, more females diagnosed with NCD treated their condition during the 2 weeks preceding the survey than their male counterparts (Table 4.2). Also, the proportion of never married persons diagnosed with NCDs who treated NCD condition was relatively higher compared to persons currently or formerly married. Education shows no specific pattern in relation to health-seeking behaviour. The proportion of persons diagnosed with NCDs with no formal education that treated their condition during the 2 weeks before the survey was higher than those with primary and JHS/middle level education but relatively lower

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that those with secondary/higher education. This can be attributed partly to education-employment/occupation relationship. The low level of education among the study population also reflects on the level of employment and the type of occupations. Household wealth quintile is not statistically significantly associated with health-seeking behaviour and no specific pattern was shown across the five household wealth categories.

Health insurance coverage increases access and utilisation of healthcare services as reveal in the qualitative interviews. The relatively high proportion of diagnosed persons insured is as a result of high healthcare costs, and education by health professionals for health insurance as captured in the interview in the quotes below:

> *"It was when I went to the hospital and the doctor gave me to the specialist. The person at the drug store said "old lady, old lady next time when you are coming bring your health insurance" ..... then the next time when I was going I want to do the health insurance"*
>
> (Female age 82 with hypertension)

> *"When I went, when they took my blood* [laboratory test] *GHC 25.00 and medication all was GHC 50.00. All the GHC50.00 got finished there. After which he had a discussion with me and told me that I should go for the health insurance and that will help me. So I went and did the health insurance and since then I have taken it to the doctor (hospital) only once".*
>
> (Female, 69 years old with hypertension)

> *"I did not have health insurance when I was admitted at Korle Bu. I was bleeding because I ate a lot of pineapple and had stomach ache. I told the doctor and he said it was ulcer. So a nurse advised me to do the health insurance, so I did it"*
>
> (52 years old female with hypertension and ulcer)

Table 4.2: Socio-demographic characteristics of persons diagnosed with NCD by treatment seeking behaviour

Characteristics	NCD Status		P-value	Total N=177
	No treatment	Treated		
Sex			0.535	
Male	37.2	62.8		43
Female	32.1	67.9		134
Age category			0.023**	
< 15	50.0	50.0		6
15 – 60	42.0	58.0		88
61+	23.2	76.8		82
Marital status			0.711	
Never married	28.6	71.4		14
Married/cohabiting	36.8	63.2		57
Formerly married	31.0	69.0		100
Ethnicity			0.880	
Akan	35.1	64.9		37
Ga-Dangme	32.8	67.2		125
Ewe	20.0	80.0		5
Other	40.0	60.0		10
Religious affiliation			0.350	
No religion	50.0	50.0		12
Christian	31.0	69.0		145
Islam	41.7	58.3		12
Traditionalist/Spiritualist	37.5	62.5		8
Other	100.0	0.0		1
Educational attainment			0.871	
No formal education	32.7	67.3		55
Primary	37.9	62.1		29
JHS/Middle	34.4	65.6		61
Secondary/Higher	28.1	71.9		32
Occupation			0.322	
Not employed	25.0	75.0		68
Professional/technical/managerial /clerical	16.7	83.3		6
Sales/services	42.0	58.0		69
Agricultural sector	0.0	100.0		2
Household and domestic	0.0	100.0		1
Manual labour (skilled/unskilled)	35.3	64.7		17
Student	50.0	50.0		10
Other	25.0	75.0		4

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Table 4.2 continued

Characteristics	NCD Status		P-value	Total N=177
	No treatment	Treated		
Household wealth quintile			0.337	
Poorest	43.2	56.8		37
Poorer	38.7	61.3		31
Middle	25.0	75.0		32
Richer	36.4	63.6		33
Richest	25.0	75.0		44
Health insurance status			0.003***	
Not insured	45.5	54.5		77
Insured	24.0	76.0		100
Total	**33.3**	**66.7**		**177**

* p<0.10 ** p<0.05 *** p<0.01

4.4 Determinants of health seeking behaviour among persons diagnosed with non-communicable disease

The bivariate analysis reveals that age and health insurance status of diagnosed persons are statistically significant influences treatment behaviour. The multivariate analysis, using binary logistic regression model also reveals age, health insurance status and marital status of diagnosed person as statistically significant predictors of treatment behaviour (Table 4.3). The regression model explains about 14 per cent of the variations with 170 observations and log likelihood of -91.011.

A unit increase in age is associated with 1.052 odds of seeking healthcare. Currently married and formerly married persons diagnosed with NCDs are less likely compared to their never married counterparts to treat the NCD condition diagnosed with (Table 4.3). The results reveal that being diagnosed and insured increases the odds of treating the NCD condition more than twice (odds = 2.329). Ethnicity, religious affiliation, education, employment and household wealth quintile are all not statistically significantly associated with treatment behaviour. Females, diagnosed

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with NCDs were associated with 1.631 odds of treating the NCD condition compared to males. Married/cohabiting and formerly married persons diagnosed with NCDs have lower chance to treat their conditions compared to their never married counterparts. Being employed and diagnosed with NCD is associated with 1.126 odds of treating the condition. Detailed results of the regression model are presented in Table 4.3.

Table 4.3: Socio-demographic and economic determinants of health seeking behaviour among persons diagnosed with non-communicable disease

Socio-demographic characteristics	Odds ratio	Robust Std. Err.	Z	P>|z|
Sex (male)				
Female	1.631	0.793	1.01	0.314
Age (in single years)	1.052	0.019	2.77	0.006
Marital Status (never married)				
Married/cohabiting	0.100	0.093	-2.49	0.013
Formerly married	0.099	0.091	-2.51	0.012
Ethnicity (Ga-Dangme)				
Akan	0.936	0.464	-0.13	0.894
Ewe	4.023	4.273	1.31	0.190
Other	1.526	1.536	0.43	0.668
Religious Affiliation (No religion)				
Christian	2.143	1.515	1.08	0.281
Islam	1.059	1.226	0.05	0.960
Traditionalist/Spiritualist	4.092	3.833	1.50	0.132
Other	1.000			
Educational attainment (No formal education)				
Primary	2.089	1.336	1.15	0.250
JHS/Middle	1.358	0.726	0.57	0.567
Secondary/Higher	1.385	0.900	0.50	0.616
Employment Status (Not employed)				
Employed	1.126	0.477	0.28	0.776
Household wealth status (Poorest)				
Poorer	1.221	0.681	0.36	0.721
Middle	3.473	2.490	1.74	0.082
Richer	1.265	0.709	0.42	0.675
Richest	2.329	2.238	2.02	0.043
Health insurance status (uninsured)				
Insured	2.329	0.940	2.09	0.036
Constant	0.077	0.098	-2.02	0.043

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Number of observations = 170 Pseudo R^2 = 0.141
Log pseudo likelihood = -92.586 Note: Reference category in superscript.

In conclusion, this chapter examined the prevalence of NCDs among the study population and the treatment behaviour among persons diagnosed with NCDs. A total of 177 (7.0%) out of 2,524 reported ever having been diagnosed with at least one NCD condition. Not all (66.7%) treated the condition during the two weeks preceding the survey. Hypertension is the most prevalent condition followed by diabetes, asthma, stroke, and arthritis. Other conditions are depression, cancer and angina. The level of co-morbidity was 1 in 5 which is in line with other studies that indicates co-morbidity among person with living with NCDs due to common risk factors (Anderson and Horvath, 2004; Nimako et al, 2013; WHO, 2010). The relatively high prevalence of NCD conditions like hypertension, diabetes, stroke and cancer, cardiovascular disease (angina) indicates the stage of epidemiological transition in an area such as Accra.

One hundred and eighteen, representing 66.7 per cent of diagnosed persons, treated their condition during the last 2 weeks preceding the survey. The socio-demographic factors associated with, and predict treatment behaviours among persons diagnosed with NCDs are age, marital status and health insurance of diagnosed persons. The non-treatment by 33.3 per cent of persons diagnosed with NCDs during the two weeks preceding the survey can be attributed to poverty that leads to non-adherence to treatment regimes due to the relatively high cost of treatment and management of NCDs. The results from the in-depth interviews indicated also that some patients out of ignorance and some perceptions skip treatment, including regular

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medication for short or extensive period of time before returning back onto the medication after complications or deterioration of their conditions.

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CHAPTER 5

DIRECT BURDEN OF NON-COMMUNICABLE DISEASES ON URBAN POOR HOUSEHOLDS

5.1 Introduction

This chapter examines the direct burden of non-communicable disease on urban poor households. Direct burden or cost of disease is one of the measurements of burden of disease (Suhrcke et al., 2006). It is measured in terms of direct healthcare costs associated with receiving healthcare services and products to manage and treat ailment. Healthcare expenditure is known to cause significant burden on households resulting in financial catastrophes and impoverishment (Bredenkamp et al., 2011; Daivadanam, 2012; Minh and Tran, 2012; Mondal et al., 2010; Russell, 2004; Su, Kouyaté, and Flessa, 2006; Xu et al., 2007).

This chapter presents answers to the research question on the direct burden of NCDs on urban poor households. These results are arrived at after ANOVA test were carried out to compare total household healthcare expenditure during the last 30 days preceding the survey accounting for households NCD status. Bivariate analyses that examine the relationship between selected household characteristics and health seeking behaviour are also presented. Results of multivariate linear regression models fitted to determine the main predictors of household healthcare expenditure are also presented in this chapter.

5.2 Household characteristics

The distribution of household selected characteristics are presented in Table 5.1. A total of 806 households completed the survey administered to household heads

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or eligible adult (18 years or older) household members in the absence of household head. The results reveal that more than half (51.2%) of the households interviewed are male headed. The average age of head of household is 45.07 (± 16.55) and the age range is between 16 years and 98 years old. The average level of education among household heads is Junior High School (JHS) or Middle level education with 63.2 per cent of household heads belonging to the Ga-Dangme ethnic group. Majority (77.7%) of the households are headed by persons belonging to the Christian faith with less than one in ten (8.1%) of the household headed by persons with no religion. In all, 81 per cent of the 806 households interviewed are headed by persons currently or formerly married (married/living together (43.4%), formerly married (37.6%)) and 19 per cent headed by never married persons. About 16 per cent of household heads are currently unemployed.

The average household size is 3.1 (± 2.3) persons with the largest household having 22 household members and about a third (31.1%) being single member households. The distribution of households across the wealth quintile is approximately 20 per cent for all categories. Approximately, 87 per cent of the 806 households had no member treating NCDs during the 2 weeks preceding the survey. The results revealed that about 12 per cent of the households had at least 1 person living with at least 1 NCD condition with 1.4 per cent of the households having 2 persons living with at least 1 NCD condition.

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Table 5.1: Socio-demographic characteristics of household

Characteristic	Per cent	Frequency
Sex of household head		
Male	51.2	413
Female	48.8	393
Age of household head		
31 and below	24.6	198
32-41	22.6	182
42-55	28.7	231
56 and above	24.1	194
Ethnicity of household head		
Akan	23.8	192
Ga-Dangme	63.2	509
Ewe	4.5	36
Other	8.6	69
Religion of household head		
No religion	8.1	65
Christian	77.7	626
Islam	11.3	91
Traditional/Spiritualist	2.4	19
Other	0.6	5
Marital status of household head		
Never married	19.0	153
Married/living together	43.4	350
Formerly married	37.6	303
Educational attainment of HH Head		
No education	15.1	122
Primary	18.6	150
JHS/Middle	40.7	328
Secondary/Higher	23.9	193
Don't know	1.6	13
Occupation of household head		
Unemployed	16.1	130
Professional/technical/managerial/clerical	11.5	93
Sales/services	44	355
Agriculture sector	3.5	28
Household and domestic	0.7	6
Manual (skilled/Unstill)	19.2	155
Student	0.6	5
Other	2.7	22
Don't know	1.5	12
Total	**100**	**806**

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Table 5.1 continued

Characteristic	Per cent	Frequency
Household size		
Single member	31.1	251
2 – 4	45.5	367
5 and more	23.3	188
Household wealth status		
Poorest	20.0	161
Poorer	20.0	161
Middle	20.0	162
Richer	20.0	161
Richest	20.0	161
Number of household members who treated NCDs		
0	86.7	699
1	11.9	96
2	1.4	11
Total	**100**	**806**

5.3 Relationship between household characteristics and treatment behaviour

Bivariate analyses to examine the association between household characteristics and treatment behaviour of the household member diagnosed with NCD were conducted and the results are presented in Table 5.2. A total of 162 households had at least 1 member diagnosed with at least 1 NCD conditions. Treatment behaviour was examined for all 177 individuals and the results revealed that only age of household head is statistically significantly associated with treatment behaviour (p=0.006). There exists a direct relationship between age of household health and the proportion of diagnosed persons who treated NCD during the last 2 weeks preceding the survey. Household head occupation and household wealth quintile were also statistically significant predictors of treatment behaviour at 90 per cent CI. The relationship between the other socio-demographic characteristics and treatment behaviour were not statistically significant (see Table 5.2).

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Table 5.2: Household characteristics and treatment behaviour

Characteristics	Treatment status of NCD		P-value	Total
	No treatment	Treated		N=162
Sex of household head			0.910	
Male	33.3	66.7		51
Female	34.2	65.8		111
Age of household head			0.006**	
31 and below	42.9	57.1		4
32 – 41	53.8	46.2		12
42 -55	46.2	53.8		21
56+	22.5	77.5		69
Marital status of household head			0.362	
Never married	25.0	75.0		12
Married/cohabiting	40.7	59.3		59
Formerly married	30.8	69.2		91
Ethnicity of household head			0.793	
Akan	38.2	61.8		34
Ga-Dangme	32.8	67.2		116
Ewe	20.0	80.0		5
Other	42.9	57.1		7
Religious affiliation			0.587	
No religion	40.0	60.0		15
Christian	31.7	68.3		126
Islam	41.7	58.3		12
Traditionalist/Spiritualist	37.5	42.1		8
Other	100.0	0.0		1
Educational attainment			0.786	
No formal education	34.9	65.1		43
Primary	40.7	59.3		27
JHS/Middle	32.7	67.3		55
Secondary/Higher	27.3	72.7		33
Don't know	50.0	50.0		4
Occupation			0.091*	
Not working	25.4	74.6		59
Professional/technical/ managerial/clerical	0.0	100.0		7
Sales/services	47.1	52.9		68
Agricultural sector	0.0	100.0		2
Household and domestic	0.0	100.0		1
Manual labour (skilled/unskilled)	31.6	68.4		19
Student				
Other	33.3	66.7		3
Don't know	33.3	66.7		3

* p<0.10 ** p<0.05 *** p<0.01

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Table 5.2 continued

Characteristics	Treatment status of NCD		P-value	Total
	No treatment	Treated		N=162
Household wealth quintile			0.073*	
Poorest	46.0	54.0		37
Poorer	32.4	67.6		37
Middle	11.5	88.5		26
Richer	38.5	61.5		26
Richest	36.1	63.9		36
Household size			0.412	
Single member	40.5	59.5		42
2 – 4	28.8	71.2		73
5 and more	36.2	63.8		47
Total	**34.0**	**66.0**		**162**

* $p<0.10$ ** $p<0.05$ *** $p<0.01$

5.4 Direct burden of non-communicable disease on urban poor households

A total of 806 households completed the survey of which 162 (20.1%) had a member(s) ever diagnosed with at least one NCD condition. Among households with a member diagnosed with NCD, 107 (66.1%) had a member treating the NCD condition during two weeks preceding the survey. In estimating the direct burden of NCD on household, the total healthcare expenditure to the 30 days preceding the survey was computed. This includes direct medical and direct non-medical cost that the household incurred during the period under review (last 30 days).

The mean total household healthcare expenditure during the last 30 days preceding the survey were analysed and compared using analysis of variance (ANOVA) for the three sets of households. The three household types are (1) households with no member ever diagnosed with NCD, (2) households with at least a member diagnosed with at least one NCD condition but did not treat the condition during the two weeks preceding the survey and (3) households with a member(s)

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diagnosed with NCD and also treated the condition during the two weeks preceding the survey.

The results present in Table 5.3 reveal a statistically significant differences in the mean household healthcare expenditure during the last 30 days preceding the survey between the three sets of households (F (2,799)=4.58, p=0.011). Four households out of the 806 households surveyed did not report on household healthcare expenditure. Household NCD status has an influence on household healthcare expenditure. The mean for diagnosed and treated households is almost 70 percentage points higher than that of never diagnosed households. Between the diagnosed and did not treat and never diagnosed households, the mean is more than double (116.8%). This indicates that the expenditure for households with no one diagnosed with NCD on the average is relatively lower than households with a member diagnosed and also those who treated a NCD condition. Generally, the result of total household healthcare expenditure during the last 30 days was skewed (6.17 skewedness) with about 60 per cent reporting no healthcare expenditure (GH¢ 0.00). Of the households that reported GH¢ 0.00 healthcare expenditure, majority (88.6%) are households with no member ever diagnosed with NCDs. Households with a member diagnosed and treating NCD during the two weeks accounted for 10 per cent, and 6.4 per cent were households with member diagnosed but did not treat the NCD during the two weeks preceding the survey.

Due to the skewness, the median of the total household healthcare expenditure was also reported. The results shows a median of GH¢ 0.00 for never diagnosed and

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diagnosed but did not treat households while in the case of diagnosed and treated households, the median reported was GH¢ 5.50 (Table 5.3).

Table 5.3: Mean comparison of household healthcare expenditure by household type

HH NCD status	N	Mean	Std. Devi.	Median	Maxi.	Grouped Median	Skewed-ness
Never diagnosed	641	15.44	45.61	0.00	610	0.30	6.51
Diagnosed but did not treat	55	33.48	106.26	0.00	530	0.75	4.07
Diagnosed and treated	106	26.19	43.50	5.50	251	5.50	2.44
Total	**802**	**18.1**	**51.93**	**0.00**	**610**	**0.33**	**6.17**

ANOVA Table

Source	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	24488.29	2	12244.15	4.58	0.011
Within Groups	2135966.28	799	2673.30		
Total	2160454.57	801			

Bartlett's test for equal variances: chi^2 (2) = 120.4852 Prob>chi2 = 0.000
Note: HH= Household, NCD= Non-communicable disease

The distribution of the total household healthcare expenditure failed the Shapiro Wilk normality test as the test shows statistical significant in the distribution (p=0.000). The data was therefore transformed with the log transformation technique. The transformed results are also used to investigate the direct burden of disease presented in Appendix 6 and Appendix 7. The result shows that there is no statistically significant difference between the mean household healthcare expenditure and the NCD status. The mean difference was not statistically significant for the transformed data (F (2,318) = 2.97, p = 0.053) and also for data on households with total household healthcare expenditure greater than GH¢ 0.00 (F (2,318) = 2.53, p = 0.081).

The results from the ANOVA reveal a statistically significant difference between the mean total household healthcare expenditure by household NCD status. Further analyses were carried out to investigate the burden of disease by diagnosed and treatment status. The results show statistically significant differences in the mean household healthcare expenditure by NCD diagnosed status of household but was not significant in the case of NCD treatment status of household (Tables 5.4 and 5.5).

The results presented in Table 5.4 indicate that the mean by diagnosed status reveals an average of GH¢15.44 (±GH¢45.61) for never diagnosed households and the mean of GH¢28.68 (±GH¢70.99), F (1,800) = 8.444, p = 0.004). The mean difference between diagnosed and never diagnosed households is 85.8 percentage points higher. However, in the case of treatment status (this among all diagnosed households) presented in Table 5.6 reveal that the mean difference was not statistically significant [F (1,159) = 0.380, p = 0.538].

Table 5.4: Mean comparison of household healthcare expenditure by household NCD diagnosed status

HH NCD status	N	Mean	Median	Std. Devi	Maxi	Grouped Median	Skewed-ness
Never diagnosed	641	15.44	0.00	45.61	610.00	0.30	6.51
Diagnosed	161	28.68	2.00	70.99	530.00	1.67	4.99
Total	**802**	**18.10**	**0.00**	**51.93**	**610.00**	**0.33**	**6.17**

ANOVA Table

Source	Sum of Squares	Df	Mean Square	F	Sig.
Between Groups	22564.71	1	22564.71	8.444	0.004
Within Groups	2137889.86	800	2672.36		
Total	**2160454.57**	**801**			

Note: HH= Household, NCD= Non-communicable disease

Table 5.5: Mean comparison of household healthcare expenditure by household NCD treatment status

HH NCD status	N	Mean	Median	Std.	Maxi	Grouped	Skegness

				Devi		Median	
No treatment	55	33.48	0.00	106.26	530	0.75	4.07
Treated	106	26.19	5.50	43.05	251	5.50	2.44
Total	161	28.68	2.00	70.99	530	1.67	4.99

ANOVA Table

Source	Sum of Squares	Df	Mean Square	F	Sig.
Between Groups	1923.58	1	1923.58	0.38	0.538
Within Groups	804305.77	159	5058.53		
Total	806229.37	160			

Note: HH= Household, NCD= Non-communicable disease

The relatively high healthcare expenditure among household with at least a member diagnosed with NCDs compared to their counterparts with no member diagnosed with NCD indicates the significant direct burden of NCD on urban poor households. The results of relatively high direct burden of disease on affected households was also evident in the qualitative interviews with persons living with NCD(s). Regular routine visits to health facility come with additional healthcare cost on the household. These additional healthcare costs pose economic and social challenges on individual and households as these were common manifestation in the households with person living with NCD and was expressed by many participants in the interviews captured in the quotes below:

> *"… I spent a lot of money. When I was going to buy medicines, I spent a lot of money. When you go here you pay this. When you go here you spend GH¢50.00. Aaah! I had money …. When we were going to Korle Bu, I had money in my pocket. If I will estimate I had about GH¢1,000.00 in my pocket when they took me to Korle Bu. My children and those who took me there didn't know I had money and so they made contribution to pay the bills. When their money got finished, I had money, not that I didn't have money. So I gave it to one of them to use it…"*
>
> (70 years old male with hypertension)

> *"When I went* [to the health facility]*, when they took my blood [laboratory investigation] GH¢25.00 and medication all was GH¢50.00. All the GH¢50.00*

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got finished there. After which he had a discussion with me and told me that I should go for the health insurance and that will help me."

(69 years old female living with hypertension)

5.5 Determinants of household healthcare expenditure

There are known factors that influence household healthcare cost which includes the presence of illness or illness frequency in household, health seeking behaviour, health insurance status of infected person, household size and household socio-economic status (Minh and Tran, 2012; Mondal et al., 2010; Su et al., 2006). To determine if household NCD status is still a significant predictor of household healthcare expenditure after controlling for other households factors, a stepwise linear regression model was fitted. Total household healthcare expenditure was the outcome variable and household NCD status, household size, health insurance status of the infected person, and household wealth quintile as the explanatory variables.

The results indicate that household NCD status and household size are the statistically significant predictors of household healthcare expenditure, even after accounting for other household factors (Table 5.6). Health insurance status of an infected person is not a statistically significant predictor of total household healthcare expenditure but it effect is a marginal reduction in the total. The results are in line with the findings of Minh and Tran (2012) and Mondal et al, (2010) whose results indicate that multiple spells of illness in the household, prevalence of chronic disease among household members, and household size are factors associated with catastrophic healthcare expenditure.

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Table 5.6: Determinants of household total household healthcare expenditure

Socio-demographic factor	Model 1 B (robust Std err)	Model 2 B (robust Std err)	Model 3 B (robust Std err)	Model 4 B (robust Std err)
HH NCD status				
No treatment	0.174 (0.334)	0.126 (0.330)	0.140 (0.333)	0.077 (0.335)
Treated	0.484 (0.172)**	0.424 (0.175)*	0.451 (0.175)*	0.443 (0.175)*
HH size		0.079 (0.035)*	0.083 (0.036)*	0.082 (0.035)*
Health insurance status				
Insured			-0.158 (0.155)	-0.176 (0.155)
HH SES				
Poorer				0.317 (0.267)
Middle				0.104 (0.244)
Richer				0.228 (0.255)
Richest				0.299 (0.237)
Constant	2.860 (0.091)***	2.614 (0.145)***	2.675 (0.155)***	2.500 (0.207)***
N	321	321	321	321
R-square	0.018	0.037	0.040	0.047
Adjusted R-square	0.012	0.028	0.028	0.023

Reference category: Never diagnosed, Not insured and Poorest

Standard errors in parentheses * $p<0.05$ ** $p<0.01$ *** $p<0.001$

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In conclusion, it is evident the presence of NCD in the household results in financial burden on the household and increases the risk of poverty in the household. On the assumption that households face almost the same socio-economic and environmental challenges with the difference in household NCD status. Thus, any significant difference in healthcare expenditure can be partly attributed to the presence of NCD in the household. The statistically significant difference ($F(2,799) = 4.58$, $p = 0.011$) observed in the mean total household healthcare expenditure is accounted for by the presence and treatment of NCDs. The relatively high cost of healthcare and also the level of out-of-pocket payment for NCD care pushes NCD households to spend significantly higher than their non-NCD households.

The presence of NCD in the household and household size as identified as predictors of catastrophic healthcare expenditure in other studies (Minh and Tran, 2012; Mondal et al., 2010) was also found in this thesis. The results from this thesis indicate that treatment status of NCD patients in the household and household size statistically significantly ($p<0.05$) predict total household healthcare expenditure even after accounting for the health insurance status of NCD patients and household wealth quintile.

The presence of NCD in the household and its associate high healthcare expenditure constitute a health burden on the household. This is accompanied by both social and economic burden as many households are already faced with resource constraints. The presence of other infectious diseases and NCDs also put the household under the strain of double burden of disease that results in catastrophic healthcare expenditure and household impoverishment.

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CHAPTER 6

INDIRECT AND INTANGIBLE BURDEN OF NON-COMMUNICABLE DISEASE ON URBAN POOR HOUSEHOLDS

6.1 Introduction

Chapter 5 focused on the direct burden of disease on the household. The result reveals statistically significant associations between household NCD status (diagnoses) and household healthcare expenditure. In this chapter, the other two measurements of disease burden (indirect and intangible) are examined and presented as they manifest in urban poor NCD households. The chapter is in two parts and the first focuses on examining how indirect burden of disease are presented in urban poor households. The second presents the intangible component of disease burden on households. The results are achieved after triangulating the quantitative and the qualitative data, identifying and segmenting individuals from the households living with NCDs for in-depth interviews.

The indirect burden of disease measures the value of loss of income, economic productivity or economic opportunity and opportunity cost to individuals or households resulting from illness (Suhrcke et al., 2006; Sauerborn et al., 1996). Intangible burden of illness captures the psychological dimensions of illness including pain, fear, stigma, bereavement, anxiety and suffering (Suhrcke et al., 2006; WHO, 2001). In this thesis however, indirect burden of disease are measured as the means by which such burdens are present in urban poor households and not in terms of monetary value. Psychosocial stressors such as worries, pains, social and family isolation or abandonment are the means by which intangible burden of disease is

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measured in this thesis using the biographical disruptions as a conceptual framework for analysis.

6.2 Indirect burden of disease on urban poor households

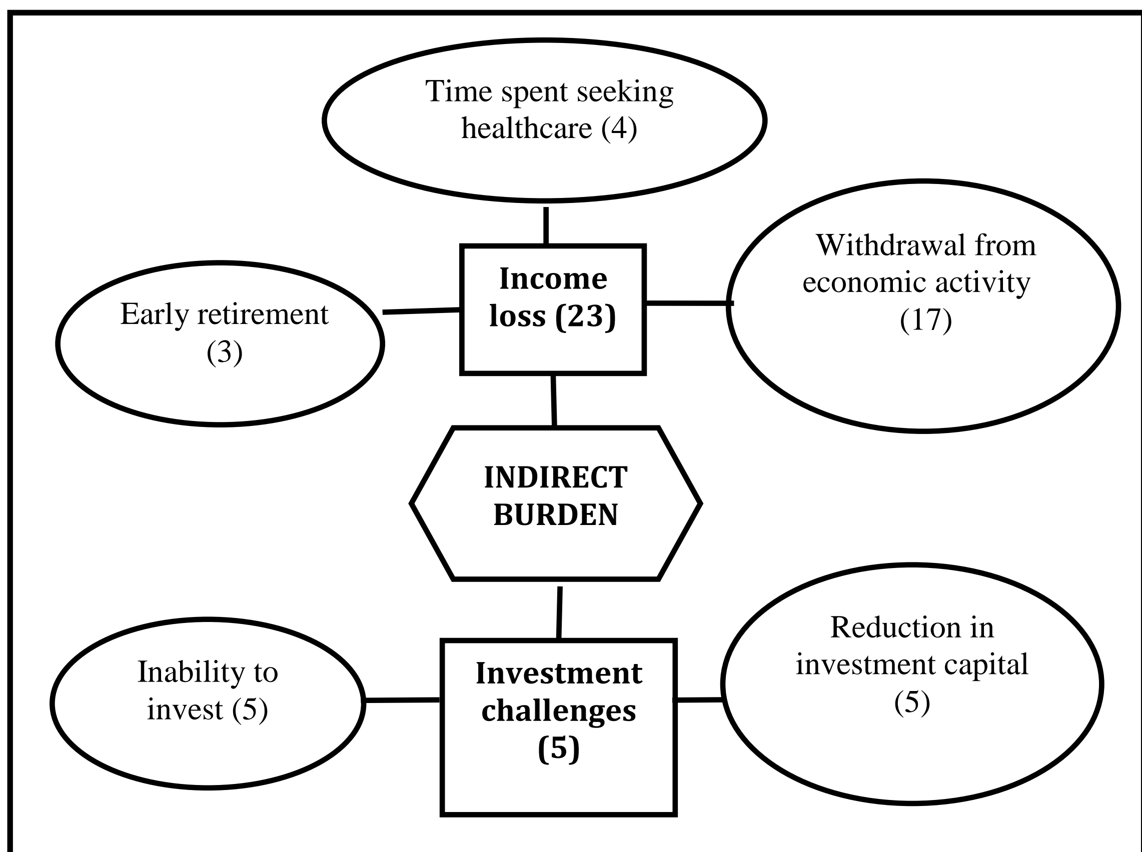
Indirect burden of disease as manifested within households with persons living with NCDs were captured and presented under the themes guided by the conceptual framework underpinning the study. Income loss and reduction in investment or savings were major indirect burden of disease (Figure 6.1). Income loss was as a result of early retirement, long productive time spent at healthcare facility seeking healthcare as well as withdrawal from economic activity by either or both infected persons and affected persons to provide home base care are the main indirect burden of NCD on households.

There are also investment challenges through the inability of the household or the infected person to invest economic resources to generate additional income or economic resources. There is also reduction in already invested or savings incomes resulting from the use of investment capital to finance healthcare expenditure. Economic opportunity or opportunity cost of forgoing investment opportunities in place of healthcare needs and loss of income are known to cause household impoverishments (Bredenkamp et al., 2011; Chowdhury, 2011; Li, 2013; Su et al., 2006; WHO, 2011a, 2013b; Xu et al., 2003).

As Figure 6.1 indicates, among the 27 respondents living with NCDs interviewed, 23 (85.2%) mentioned income loss and 5 (18.5%) mentioned investment challenges as how indirect burden manifest in their households. Three respondents (13.0%) attributed income loss to early retirement from economic activity, 4

respondents (17.4%) attributed income loss to long productive time spent seeking healthcare, and majority, 73.9 per cent, indicated withdrawal from economic activity caused loss of income to patient and household. All 5 respondents who mentioned investment challenges indicated that it was as a result of the inability to invest and reduction in investment capital. The numbers in brackets indicate the number of participants who mentioned the theme.

Figure 6.1: Thematic network for indirect burden of disease on urban poor household



Source: Fieldwork 2012

6.2.1 Loss of income

The indirect burden of disease relates to the loss of income and economic activity by both infected and affected persons of the household with chronic disease.

The loss of income to the household emerges as a result of household member(s) (infected and affected person) withdrawal from economic activity (inability to engage in income generating activity) or take up economic opportunity due to ill health.

6.2.1.1 Withdrawal from economic activity

The incidence of any chronic disease in a household may have significant effects on both the infected person and other household members (affected persons). Withdrawal of affected person(s) from economic activity (partially/short term or completely) to provide care and support to an infected household member was a common issue that emerged during interviews. Captured here are a caretaker's account of disruptions to economic activities and the potential loss of income due to provision of care and support to a household member with stroke.

> *"Even recently when he (infected person) got sick I took him to Korle Bu. I was there the whole day and the following day too. I had to be there day-to-day but I did not keep long. ……Yesterday for instance, somebody came here to sew and I charged one for GH¢15.00 and it was 3. He gave me GH¢40.00 and will give me GH¢5.00 after completion because he wants it immediately you see what I mean. I also sew suit and for that the vest, jacket and trouser is GH¢150.00. Just imagine that somebody comes by all means I will reduce it but it will not be less than GH¢100.00. Imagine the person came and I am not around, the person will leave so you see how the tailoring work is. For these things especially the units (call cards) sometimes by evening I would have sold GH¢50.00 or GH¢60.00 you see what I mean. So if I close it [shop] for a day for those ones a day I can get GH¢40.00 or GH¢45.00. You see, so if I should close it for a day is not easy"*
>
> (Affected person (caregiver) of a male with Stroke).

Such situations are common among the urban poor households affected by chronic disease. Withdrawals from economic activities are not limited to only infected

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persons but also affected persons both within the household and outside the household. Few of the issues are illustrated in the quotes below:

> *"… Once I came back from work and was not feeling well so was admitted at the hospital for three days and my daughter took care of me"*
>
> (39 years old female with Hypertension)

> *"No, they go. My sister's daughter she is at home and sell pipe [pipe water] so she does those things and takes me to the hospital, and taking of my medications"*
>
> (Female, 65 years old with Diabetes, hypertension and Asthma)

> *Yes it has changed sometimes I don't even feel like going to work because if I work small I feel tired so I go with my little son who helps me*
>
> (46 years old female with Diabetes)

6.2.1.2 Time spent seeking healthcare

Long waiting time at health facilities seeking healthcare is also a disruption and reduces productivity hours and raise the risk of income loss. The long waiting times are attributed partly to challenges in the health system. Both infected and affected persons suffer time spent seeking healthcare. Productive time as economic resource is used in seeking healthcare rather than in economic productivity. There is loss of productivity and income to infected persons for the time used is seeking healthcare. In the case of affected persons, it is the time spent accompanying an infected person to seek healthcare.

> *"Is like, when I am going to the hospital, then is a problem …. First when I use to go to Korle Bu, I leave home dawn at 5am and 5:30am. I will be at Korle Bu going for check-ups. I will be at Korle Bu till 3 or 4pm before I can return home"*
>
> (Female, 69 years old with diabetes and hypertension).

> *"Even recently when he (infected person) got sick, I took him to Korle Bu. I was there the whole day and the following day too. I had to be there day-to-day but I did not keep long.*
>
> (Affected person (caregiver) of a male with Stroke).

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Every household member's income is very important not only to the individuals but also to the entire household. This is more critical in urban poor settings where current income is highly depended upon to meet every day basic needs. Withdrawal from economic activity and the resulting loss of income limits household disposable income and pushes households into impoverishment.

6.2.1.3 Early retirement from labour force participation

Ill-health conditions can result in early retirement particularly in case of formal employment. Retirement of such nature, though voluntary, can be classified as compulsory, as often, the infected person may not have attained the retirement age. This emerged particularly from the discussion with a co-morbid female participant who retired 4 years earlier due to ill-health condition.

> *".... I went to work normal. But when I saw that today I am sick and not feeling well, I was left with 4 years to come on retirement. So I ask and left because I don't want today.... the children I teach. Today I go to school and tomorrow I don't, I will be a disservice to the children. And from the beginning I was not like that. Every day I go to work and I am fine and so when I saw that it would be a problem for me so I retired"*
>
> (Female, 69 years old with Diabetes and hypertension).

Another respondent present a case where she was advised by a medical professional to stop her occupation due to its impact on her health.

> *" I was smoking fish and traded in Nima, Mokola, Kaneshi and ended in Nima* [market]. *But the way my eyes were the doctor told me that if he tells me to stop smoking the fish, I will ask him what would I eat but if I stop I will be better. But if I don't and I continue then is not his problem. So I also stopped for so many years now"*
>
> (Female, 59 years old with hypertension and blindness)

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Early retirement not only result in loss of income but psychological burdens on both infected and affected persons. Inability to work or engage in any economic activity has the potential to be seen as social misfit resulting in social isolation and abandonment. The result is a high indirect and psychosocial burden on the affected households.

6.2.2 Investment and savings challenges

The majority of the economically active population of the study population work in the informal sector of the economy. Particularly, 42.2 per cent of the active labour force engaged in sales and services, 16.7 per cent are engaged in manual (skilled/unskilled), about 9 per cent are in the professional/ technical/ managerial/ clerical fields and 16.4 per cent are unemployed.

With high informal employment among study the population, the profits made through such economic activities are central for meeting household and individual everyday basic needs. Resorting to using working capital as a source for financing healthcare expenditure can result in stagnation and eventual collapses of such economic activities. The effect will not only limit household economic resources but also influence health-seeking behaviour of infected persons in the household. The effect will be an intangible burden on both infected and affected persons.

6.2.2.1 Inability to invest

Another emerged theme from the interviews in relation to indirect burden of NCDs on households is reduction in investment capital and challenges to invest economic resources in productivity. The interviews revealed a high dependence on

current household income and investment as well as savings to finance healthcare expenditure. This does not only impede savings for investment but also increases the reliance on working capital and investments resources. This is captured in a discussion with a female respondent who presented a situation of the inability to maintain working capital due to treatment and management of her disease condition.

> *"You see that the medicines are expensive so if you are not working you have to have medicines all the time so the money* [working capital] *that you use to work will be getting finished"*
>
> (52 years old female with hypertension and diabetes)

6.2.2.2 Reduction in investment capital

Depreciation in investment capitals was another means by which indirect burden of disease manifest in urban poor household. Limitation for economic activity caused by ill health reduces individual and household income. The effect is the reliance on savings and investments to meet health and daily sustenance.

As presented by a male participant with a stroke, his savings and investments in the banks are depleted as a result of his condition:

> *"Before I had this condition I was very hard working. I even bought cars and land to build a house and some money but because of this disease I have used everything ……I had money and even saved in 2 banks, Ghana Commercial Bank and Barclays Bank at the Makola and High Street branches but because of treatment all the money got finished. So now I don't have any money at the bank"*
>
> (76 years old male with Stroke)

Indirect burden of disease on urban poor households manifest in divest forms and result in reductions and also limits household resources. Resources that households can use to generate additional resources are lost through high health expenditure or inability to generate the resource through withdrawal from economic

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activity and loss of economic opportunities. This presents an indirect burden of disease to households and impoverishment.

6.3 Intangible burden of chronic disease on urban poor households

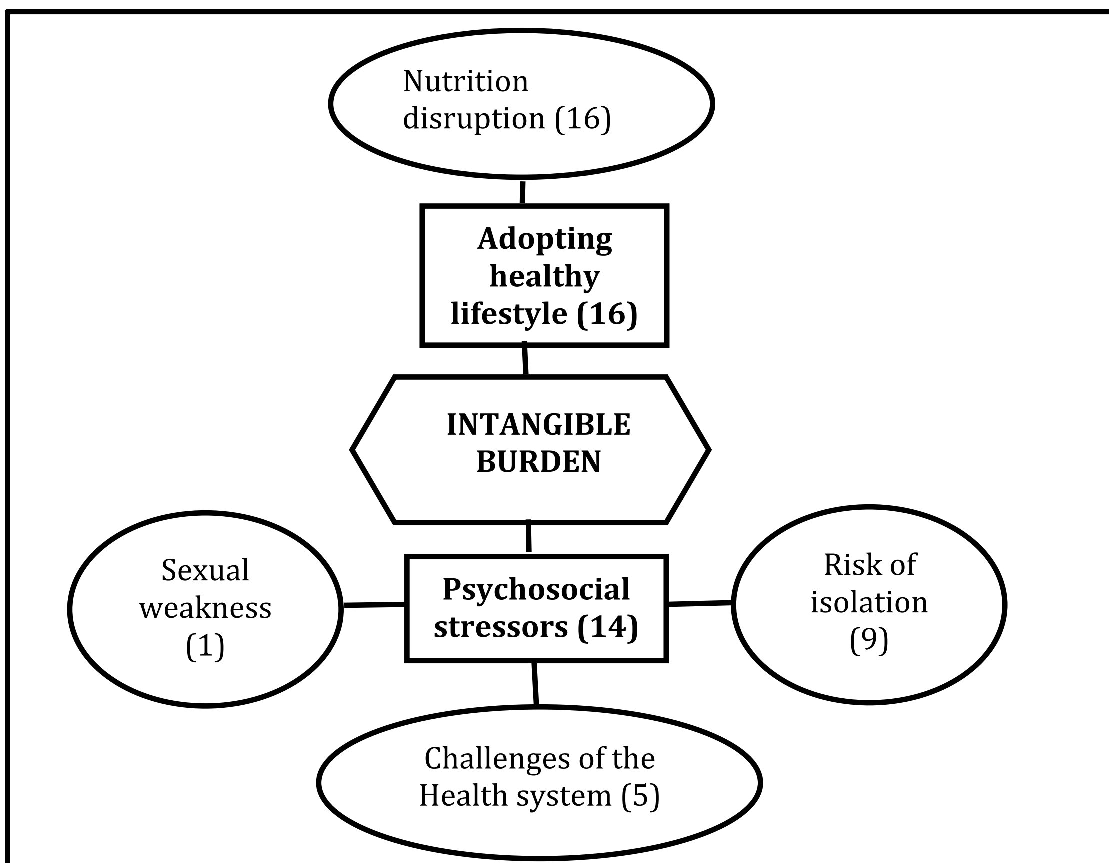
The third component of the COI is the intangible burden of disease associated with pain, disability and suffering resulting from chronic disease (Suhrcke et al., 2006). This is the psychosocial burden associated with living with illness and its associated effects on both infected and affected persons. This component of the COI is often missed in health cost analysis because it does not lend itself to be quantified in monitory terms. However, these psychological burdens of living with NCD affect health-seeking behaviour and thus influence both direct and indirect burden.

This section focuses on the intangible burdens identified among urban poor persons living with NCD using the biographical disruptions framework. The results indicate that intangible burden of disease among urban poor households manifest in psychosocial stressors, healthy lifestyle challenges and difficulties due to adherence to socio-cultural norms (Figure 6.2). Modifications of lifestyle behaviours and adherence to some health practices pose a burden on infected persons which are often very difficult to quantify in monetary terms and therefore neglected in health cost analysis. The number of participants who mentioned each theme is presented in the thematic network diagram in brackets.

A total of 16 respondents out of the 27 interviewed mentioned adopting healthy lifestyle behaviours all related to nutritional disruptions as intangible burden of NCD. Fourteen respondents (51.9%) mentioned psychosocial stressors as the form of intangible burden experienced due to the disease condition they are living with.

Majority (64.3%) of the respondents, who mentioned psychosocial stressors, indicated the risk of isolation due to the ailment as the cause of psychosocial stress, 5 (35.7%) respondents reported a challenge of the health system poses psychosocial stress on their lives. One respondent mentioned sexual dysfunction resulting from his disease condition as psychosocial stressor.

Figure 6.2: Thematic network for intangible burden of disease on urban poor household



Source: Fieldwork 2012

6.3.1 Psychosocial stressors

Psychosocial burden of chronic disease manifests in different dimensions both on infected and affected persons. The psychological stress relating to inability to engage in economic active due to ill-health condition was a common denominator for

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both male and female infected persons. The interview results revealed gender differences in intangible burden of chronic disease. However, while a male respondents recounted psychological burden due to sexual weakness as a result of the ill-health condition, female respondents recounted inability to engage in social activities as their psychological stressor. Differentials in the public and the private health systems in the country are also recounted as a major psychological burden among persons living with NCDs.

6.3.1.1 Risk of social isolation

In a society where all elements of culture are held in high esteem, non-involvement in family and social gatherings can result in some social isolation and stigmatisation. Social gatherings such as marriage ceremony, child naming ceremony, funeral rites and the like are means of creating and perpetuating social networks and bonding. Non-involvement in such activities is seen as reason for non-reciprocity of other community and family members when one needs their support. In order not to feel isolated and stigmatized, infected persons ignore danger signs and risk their health to attend such functions as narrated by a female participant:

> *"Recently, it really disturbed me. My brother died and we were going to greet our relatives at Russia. My sister came early in the morning and I had finished everything but when we were going and got to the church building I felt dizzy. So I leaned against the building and my sister asked what was wrong with me but I told her it was nothing. So I used my left hand to wipe my face then she asked what was wrong with me and I told her nothing but she realized I was going down and I was still wiping my face with my hand. She asked what are you doing and I told her that we should go but she said no there is something wrong with you. Then I didn't see anything again so she held me and my hand was shaking so a young man called a taxi for us. It was as if a long hole had been dug and I couldn't cross so the young man carried me into the taxi and my sister took me home and then took another taxi and sent me to the clinic"*
>
> (Case 16: Female with hypertension and stroke)

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6.3.1.2 Sexual weakness

Masculinity and sexuality are two important issues among every society. Therefore any inhibition that limits one's ability to perform his sexual function and show his masculinity as a man poses psychological burden. A male participant expressed such intangible burden relating to sexual dysfunction as captured in the quote:

> *" Oh right now .... If I am taking the medication correctly I don't have problem. But what I have seen is that sex wise I have come low ..... Yes. If you talk to them* (Doctors) *there is nothing ... one doctor told me that it is better to live than to have sex* (laughter) *so I should take it like that. But when I was at our place* (Port Clinic) *sometimes they give me enhancing drugs"*
>
> (Male, 64 years old with hypertension, diabetes, prostate cancer and Gout)

Such biographical disruptions raise the risk of both direct and indirect burden of disease through management and treatment, and healer shopping for opportunistic disease conditions. This is because such disruption to diabetic patients masculinity and sexuality affects both domestic and public positions (Kolling, 2012).

6.3.1.3 Challenges of the health system

The healthcare system in Ghana is characterised by low per capita density of health facility and low doctor-patient ratio. These characteristics put a strain on the already overstretched health system resulting in long waiting period and delays in service delivery. These difficulties in the health system are exacerbated by the gap in policy and practice by the health insurance system posing psychological burdens on persons living with NCD:

> *"...going to the hospital, then was a problem .... First, when I go to Korle Bu, I leave home dawn at 5am and 5:30am. I will be at Korle Bu going for check-ups. I will be at Korle Bu till 3 or 4pm before I can return home. And if you have not been attended to you can't eat. Morning when you wake up and go*

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early at least by 10am, doctor should have been able to attend to you so that even if is porridge you can have. But sometimes 11am, 12pm you haven't been attended to and you can't eat. You have to be attended to before. Those were the things that use to worry me"

(Female, 69 years old with diabetes and hypertension).

"...when you go to the hospital they will say those with the Health Insurance you sit this side and those who don't have and are going to pay money we sit this side. You will see that while we are sitting down, those people [those with health insurance] *they will not mind them. Those of us with money to pay, is us that they will attend to."*

(Female, 65 years old with Diabetes, hypertension and Asthma)

Ineffectiveness and inefficiencies in the healthcare system and policies raise the exposure and risk of intangible burden of disease and aggravate the overall burden of disease on persons living with NCD. This type of intangible burden of disease resulting from challenges in the healthcare system and health policy has the potential to influence health-seeking behaviour. The outcome of the difficulties in the healthcare system and health policy will be low-level utilisation of healthcare services and healer shopping with great impact on direct, indirect and intangible burden of disease.

6.3.2 Healthy lifestyle behaviour

Unhealthy dietary practices are major risk factors of non-communicable diseases (Alrabadi, 2012; Amuna and Zotor, 2008; Bosu, 2010). As a result, healthy lifestyle behaviours are recommended for improvement in health status. Notwithstanding the health benefits of healthy lifestyle behaviours to infected person, there are intangible burdens associated with adopting and sustaining healthy lifestyle

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behaviour. This burden is not limited to the infected person but also affected persons of the household.

Poverty is identified as the formidable challenge toward adherence to recommended healthy lifestyle behaviour. Apart from poverty serving as a barrier to adherence to healthy lifestyle behaviour, other challenges that emerged from the interviews are the desire to conform to social norms and the opportunity to partake in social events without compromising health status.

6.3.2.1 Nutritional disruptions

Nutritional disruption is a common phenomenon among persons living with NCDs. This is because Unhealthy dietary practices are a major risk factor of NCDs and adapting to diet modification over a long lifespan is associated with increased indirect burden of disease. Results of the interview reveal different modes of nutritional disruption resulting from the presence of NCD in households. Presented here are quotes drawn from discussion with persons living with NCDs demonstrating nutritional disruptions.

> *"Yes, I have stopped salt. I have stopped pepper. I eat but not much. Myself, I don't like pepper because my father if you cook for him, he will say there is too much pepper in the food so I didn't like pepper. They say we shouldn't eat oil but the oil we eat. You yourself if you get some stew with rice you will enjoy it."*
>
> *(Female, 70 years old with diabetes and hypertension)*

> *"I was worried because my stepsister had some* (diabetes). *She was told not to eat toffee* (sweets) *and other things but when the condition improved, she felt it gone so she started eating and she died. Since my sister died, I have been thinking about it a lot."*
>
> (52 years old female with hypertension and diabetes)

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> *"I eat with all of them but they know that I don't eat sugar, l don't eat salt so when they cook food they do not add much salt. Even this lady* [participant referring to daughter*] if I haven't cooked and buy food outside, she will make a lot of noise that they might have put Maggi cube* [seasoning]. *Now I cook without putting Maggi cube inside."*
>
> *(69 years old female with Diabetes and Hypertension)*

Adherence to recommended healthy lifestyle behaviour to reduce the risk of NCD, improves and sustains healthy life are confronted with social and economic challenges. The desire to fit-in and participant in social activities compels persons living with NCD to downplay the risk associated with unhealthy dietary practices in order to engage in such practices. Also, poverty limits the financial resources to enable infected persons to adhere to recommended healthy dietary practices, due to the relatively high cost associated with such practices. These sentiments are captured in the quotes with persons living with NCDs presented here:

> *"I was here for 1 month and over or 6 weeks and haven't been there* [hospital]. *But when I went again he* [Doctor] *told me that he had seen that my sugar is up a little. So he even asked how come. I told him before I came last week last…. 2 weeks we had a funeral and when there, the truth is, when they were eating all those things I also ate some few. Because I said it's been a long time I ate some. So I also drank some minerals* [soda] *like the Malt and this orange drink. So I saw that that is what may have worried me."*
>
> *(69 years old female with Diabetes and hypertension)*

> *"…. hmmm, if you have money this is not difficult. But when you are poor and they take you away from some things* [restricted from eating some food items] *it worries you, you see."*
>
> (Female, 65 years old with diabetes, hypertension, asthma and blindness)

In conclusion, the other two components of burden of disease (indirect and intangible) manifest in urban poor households broadly as income loss and investment delay and limitation, adoption of healthy lifestyle behaviour and psychosocial

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stressors. These two forms of disease burden are economical and psychological in nature that aggravates the poverty position of the affected household. The economic nature of indirect burden of disease are known to b significantly higher as compared to the direct burden of disease. Also the psychological nature of the intangible burden also have not only psychosocial but have health and economic implications resulting in increased direct and indirect cost.

Indirect burdens of income loss are pivoted on early retirement from formal employment and this is not a common occurrence due the low level of formal employment among the study participants. Withdrawal from economic activities and long hours spent seeking healthcare or accompanying patients to seek care are the other forms of indirect burdens of disease that result in income loss. Delay and reduction in investments resulting from income loss and high prevalence of out of pocket payment for healthcare services constitute indirect burdens.

Among the complications of NCDs is sexual weakness. The issue of sexual weakness due to diabetes condition also was reported in a study in Brazil (Kolling, 2012). In patrilineal societies where reproductive and sexual function (masculinity) command respect, any sign of sexual weakness will be seen as weakness in male identity and loss of masculine power. This will result in significant psychosocial stress resulting in intangible burden of disease. Common among female participants/patients is the risk of social isolation particularly among patients advanced in age. This can be attributed partly to the relatively close social ties and networks within the study area with high level of interdependency.

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Limitation in mobility, loss of income and stigmatisation associated with chronic disease result in withdrawal of infected persons from social activities. Inability to fully participate in, or contribute to, social activities both physically and financially due to ill health condition is a potential cause of social and family abandonment. The fear of social isolation constitutes additional psychosocial burden on infected persons that result in non-adherence to healthy lifestyle behaviour and neglecting danger signs. Nutritional disruption and the long delays at the health facility to seek care are age or gender defined. However, these are determined by the socio-economic status of the household. The poverty level of the household limits access to recommended nutritional change and also private healthcare service or facilities that will eliminate long delays and waiting times.

Psychosocial stress is seen in the areas of the challenges and limitation of the health system and challenges to socialize effectively within the context of the socio-cultural norms. To manage the disease condition, healthy lifestyle behaviours are required and recommended. Changing lifestyle behaviours to conform to recommended healthy lifestyle behaviour tend to be a significant burden on infected persons. Diet and nutritional change are also a major intangible burden that face infected person living with NCD in urban poor households. Modifications of lifestyle behaviours and adherence to some health practices pose a burden on infected persons which are often very difficult to quantify in monetary terms and are therefore neglected in health cost analysis.

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CHAPTER 7

COPING MECHANISMS OF HOUSEHOLD DIRECT BURDEN OF DISEASE

7.1 Introduction

Urban poor household with member(s) living with NCDs are known to experience significant burden of disease. Economic life and day-to-day life trajectory of infected and affected persons impacted upon by NCDs. Catastrophic healthcare expenditures are associated with ill health condition particularly chronic disease condition (Chuma and Maina, 2012; Daivadanam, 2012; Mondal et al., 2010; Shi et al., 2011; Su et al., 2006; Van Damme, 2004; Wagstaff and Van Doorslaer, 2003; Wagstaff, 2005). To cope with these burdens, various strategies are adopted by the household and they include sources such as savings, selling assets, selling consumables and borrowing to finance healthcare expenditure related to chronic disease (Bogale et al., 2005; Chuma and Maina, 2012; Russell, 2004, 2005; Sauerborn et al., 1996; Tagoe, 2012b).

The quantitative survey results reveal a statistically significant difference in the mean total healthcare expenditure and household NCD treatment status. Relatively high healthcare cost was also recounted by participants in the qualitative interviews indicating high direct burden of illness on the household. The objective of this chapter is to assess the coping mechanisms employed by urban poor households with persons living with NCD to navigate direct burden of disease on the household. The results are based on in-depth interviews with household members living with, at least one NCD condition as well as affected household members. The major issues interrogated are the primary source of healthcare finance and other sources use by households to

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finance healthcare expenditure as well as the reliability of such sources from the infected persons' perspectives.

7.2 Household coping mechanism of direct burden of disease

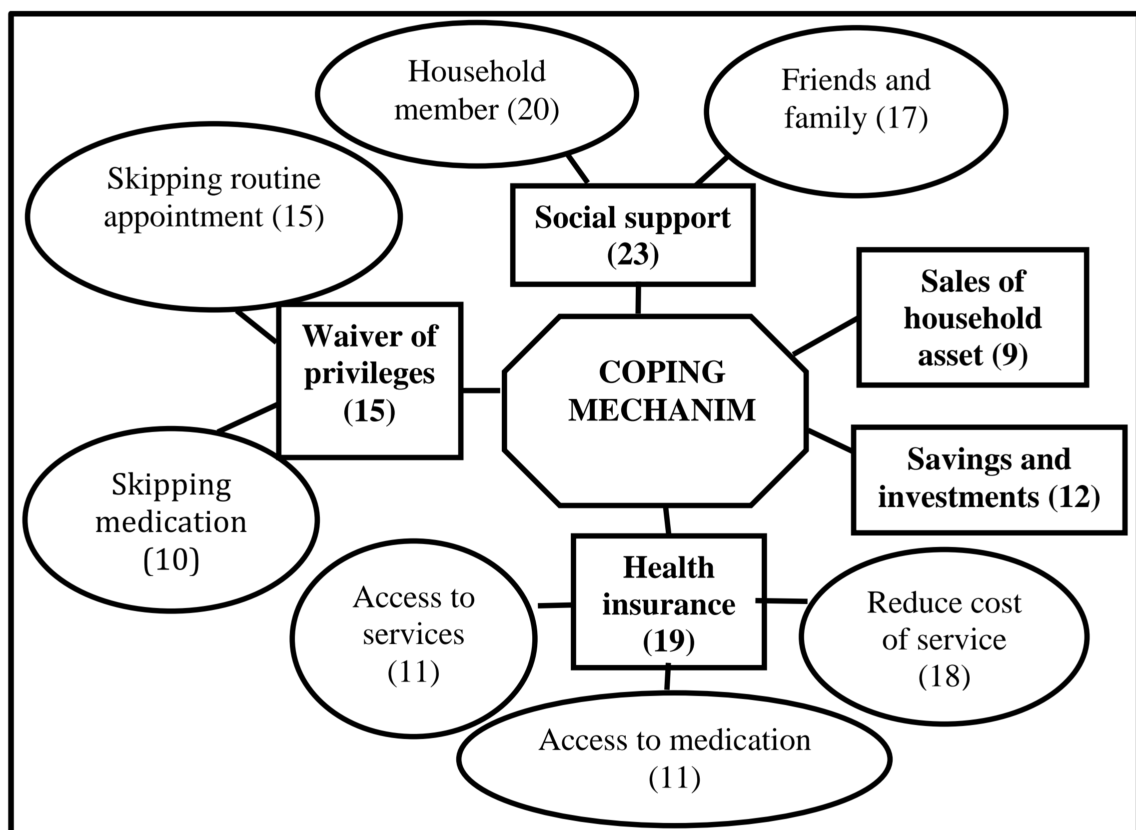
Households adopt six main strategies to navigate the burden of disease. These strategies are: i) Use of health insurance, ii) Sale of household assets, iii) Savings and investments, iv) Health seeking waiver privileges, v) Family and social support systems, and vi) Social insurance systems.

Figure 7.1 presents the thematic network of means by which households navigate disease burden. The results from the qualitative interviews reveal that social support is the most common means used by a household to deal with direct burden of disease as 23 (85.2%) respondents out of 27 mentioned using such mechanism. The social supports are often drawn from household members 20 (87.0%) and 17 (73.9%) from friends. The results also indicate that 33.3 per cent and 44.4 per cent of the respondents also mentioned sales of household assets, and saving and investment respectively. In all, 19 (70.4%) respondents pointed to health insurance as the coping mechanism for direct burden of disease. The dependence on health insurance is because it reduces cost of service (94.7%), access to medication and services (57.9%). Waiver of health seeking privileges was another mean as it was mentioned by 15 (55.6%) of the respondents. This is done through skipping of medication (66.7%) and skipping routine appointment (mentioned by all 15 respondents).

Remittance received from family members and relations outside the households is be categorized under social support systems. This kind of coping mechanism was not a common or regular means of coping with direct burden of

disease among the study population. The results from the thesis indicate that only one out of the 27 participants mentioned remittance from abroad that is used to finance healthcare expenditure. This type of strategy in coping with direct burden of disease though maybe relatively substantial, is not regular and therefore cannot be relied on as a regular or significant means of coping with direct burden of disease.

Figure 7.1: Thematic network representation of coping mechanism of disease burden in urban poor households



Source: Fieldwork 2012

7.2.1 Sale of household assets

Dependence on household assets, as a means of financing household healthcare expenditure was significantly common among urban poor households with person living with NCD. The main items that are disposed of by the household to

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finance healthcare are personal belonging (cloths, jewellery, shoes, cooking utensils, stoves, etc.) of infected persons. Missing in the list of items relied on are high value properties such as cars, houses, land etc. identified in other studies. Such items are not accessible to an urban poor household partly because of the high level of poverty that limits the acquisition of such properties.

A third of the respondents (33.3%) indicated they have sold household asset or personal belongings at one point (within the last six months) to finance healthcare expenditure. The extent to which household sell household asset to raise funds to finance health expenditure is captured:

> Interviewer: Madam please I like to ask if you have ever sold any of your belongings to buy medication or pay for healthcare services?
> Participant: *Oh yes, I have sold a lot. My sister here* [participant pointing to another lady in the compound] *I give it to her. If I take two or three, I go and sell to buy medicines.*
> Interviewer: What kind of items?
> Participant: *My cloths, and those that I haven't sewed. If I have to sell, is those cloths that I haven't sewed and will sew them in the future and clothe myself with is what I sell. Just about 3 days ago I sold some.*
> Interviewer: How many did you sell?
> Participant: *About 4*
> (Dialogue with a 69-year-old female with hypertension)

> *Yes, because of my condition. First when it started, there were times I didn't have money to buy medication and at that time I didn't have friends. So I took my belongings like cloths and took them to the Makola* [market] *and sold them and took it to the hospital for care. After that I have sold my things even recently I sold my things. .... I sold my rice cooker, gas cylinder. Brand-new empty one, I sold it. I have also sold my gas cooker ……you see.*
> (Female, 26 years old with hypertension)

The analysis further reveals that in the effort to meet financial obligations due to health, there is high level of devaluation of items sold to raise money to finance healthcare expenditure. The devaluation of assets sold is a common occurrence and

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this may be linked to the type of item sold. Based on quotes from two female participants both living with hypertension, shows the type of items sold and the devalue price of the items.

> *"...aaah ok. I bought the cylinder GH¢55.00 but the person who bought it bought it for GH¢30.00. My gas cooker is 3-in-1. I bought it for GH¢60.00 but the person gave me GH¢40.00. If I will estimate roughly the things I sold, I sold things almost . . . is not up to GH¢100.00. But the things I bought and sold was more. It may be GH¢200.00* [cost of items sold] *but when I sold them I didn't even get GH¢100.00."*
> (female 26 years old with hypertension).

> *"They don't buy it well* (the price of the cloth). *If they will buy it, maybe you've bought something at GH¢30.00 or GH¢40.00 and when they will buy they will pay GH¢15.00. That is how much they will only pay. They will not pay much but because you have to buy medicine and also be a little happy by putting some small money on you clothe* [some money in your pocket] *to buy something. Now when you have money on you clothe that is your happiness and when you don't have money on your clothe you are not happy"*
> (Female, 69 years old with hypertension).

Selling of household assets to raise money to finance healthcare expenditure tends to reduce household resources and also increase household risk of impoverishment from catastrophic healthcare expenditure. Available items sold are not high in value and therefore households needed more resources to meet increasing healthcare expenditure due to direct burden of disease.

7.2.2 Savings and investments

The level of income is relatively lower particularly among chronically ill persons compared to their healthier counterparts (Rijken and Groenewegen, 2008). The relatively low employment and revenue generation among the study population limited the use of current household income to finance healthcare expenditure. Household therefore rely on savings and other investments as another means to cope

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with the economic burden of NCD in the household. As recounted by 12 of the 27 participants from the qualitative interviews, bank savings, savings from petty trading and investment (revenue from rent of rooms and houses) are others means used to deal with the direct burden of disease.

> *'Yes. I have a house at Weija behind the school. I have a house at White Cross. I have a house at Chorkor Cheamuanaa. So any time it* [the condition] *starts worrying me, those in the rooms .....by the time it will worry me their rent may be due. So when I ask for three years they will say oh they will only give one year. Then I will take that and use it to treat myself."*
>
> (Male, 70 years old with hypertension)

> *"Sell biscuits and save the money and use it. But if I go and the money is not enough .... if my mother or my siblings ... I can borrow money. When I sell or work and I get paid at the end of the month, I go back to pay."*
>
> (Female, 39 years old with hypertension)

The results indicate that these saving and investments relied on to finance healthcare expenditure are resources acquired before the incidence of the disease condition. Thus, during the time of needs, individuals depend on already acquired savings to finance healthcare expenditure. Savings and investments are particularly important especially when the infected person is the economic head of the household or the main breadwinner.

7.2.3 Waiver of health seeking privileges

Another coping mechanism that is independent of type of disease condition and gender is the waiver of health seeking and treatment privileges. The waiver of health seeking privileges is the phenomenon where ill individuals forgo the opportunity to seek healthcare (Bogale et al., 2005). This was identified among more than half (15 out of the 27) of participants as a means to cope with direct burden because of healthcare cost. Persons living with NCDs at many points after diagnoses

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with the disease waive health-seeking privileges (even when appointments dates with physician are set) and seek healthcare only when there is clear evidence that their health status has worsened or a complication has set in.

> *"When my medication finishes, I don't go* [the hospital] *immediately. I wait for about 2 months, 3 months and see if it is coming down or is going up. But for about 3 months now that my medication finished, I don't feel it, my heart is not beating faster* [palpitation]. *And is not coming at all so I haven't been to the hospital .... Like I said, almost getting to 3 to 4 months I haven't been to the hospital and I am happy that I don't go to the hospital to go and check."*
> (Female, 26 years old with hypertension)

An opinion held by some infected persons reveal in the interviews was one need not continually take the routine medication prescribed for the condition "drug holiday". A common practice among participants with hypertension which has resulted in non-use of medication for some period till the condition get worse before going back on medication.

> *"... Recently, I nearly lost my life. I didn't know what happened but the doctor said the BP medication when you are taking it, when you take it to a point you should stop for a while. But when you take and your blood gets used to, then it will not have any effect. So if I take.... I will take it for a long and then will stop for about 2 days and see how I am doing".*
> (Female, 69 years old with hypertension)

The result of such behaviours (waiver of health seeking privileges/drug holidays) is self-medication and resultant health complication and drug resistance.

> *"When I go to Korle Bu you see, when the thing comes* [the condition aggravate] *that is when I go to Korle Bu. But when is not intense like the way I am.... My legs get swollen. It gets swollen such that one leg will be like two legs. In the past one month I haven't been to the hospital. I am waiting to.... Hey! It came and I nearly died. Then immediately went and bought the medicine. It was when I bought the medicine I got better".*
> (Male, 70 years old with hypertension)

> *"All this I just forget them* [medications] *and when it becomes serious then I look for some medication and use".*
> (Female, 65 years old with diabetes, hypertension and asthma)

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The use of waiver of health seeking privileges as a means of coping with direct burden of disease can be attributed a combinations of factors, namely, resources limitation, health system bottlenecks, stubbornness of patients and a combinations of all three factors. This is highlighted in the statement of one of the participant:

> *"When I took it* [disease condition] *to Korle Bu, they said it* [the health insurance] *does not cover the disease so they asked me to pay GH¢1,000.00 but I couldn't because I had already spent GH¢500.00 elsewhere and since then I have not been there and I even have the folder".*
>
> (Male, 76 years old with stroke)

> *"Is like, when I am going to the hospital, then it was a problem .... First when I use to go to Korle Bu, I leave home at dawn at 5am and 5:30am. I will be at Korle Bu going for check-ups. I will be at Korle Bu till 3 or 4pm before I can return home"*
>
> (Female, 69 years old with diabetes and hypertension).

7.2.4 Family and social support

Family and social support is one of the common means by which chronically ill persons get financial support (de-Graft Akins, 2005; Bogale et al., 2005). Consistent with the results of other studies in this field, the results of this thesis reveal that dependency on family members and other social support networks are a major means of navigating the economic burden of NCDs among the urban poor.

Family support is not only drawn from household members and extended family members but extend beyond. Social support is not geographically limited to the immediate locality. Wherever a family member may be (within and outside the country), support are drawn from there in the form of remittance.

> *"My friends are on good terms with me. Sometimes they visit me and give me some money. Sometimes, GH¢5.00 or GH¢20.00 to help me buy my medicines. So I am happy but actually my family members are not on good terms with me"*
>
> (Male, 76 years old with stroke)

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"… I can borrow money. When I sell or work and I get paid at the end of the month, I go and pay back."

(Female, 39 years old with hypertension)

"My brother, second born after me, my father's child but not my mother's child. He act Ghana film and he is called [name withheld]. *He is second born after me. I get a lot of support from him and my stepsister. Their elder sister, their mother had her before coming to marry my father. Their father is an Ewe and she is in America. She also, I get a lot of small small support from them and also my children ….. I bring it [prescription] home and those that I have money, I buy them there* [at the health facility]. *Those I don't have enough money to buy, when I bring it, I give it to the children and they will go and buy them for me".*

(Female, 65 with diabetes, hypertension and asthma)

"As for that one I thank God that He helps me. Because if they prescribe medication for me and I come home and sit down my friends that I said I go to, they all know I have this problem [hypertension]. So when I come to you and I am telling you that I am down, you will ask me what is worrying me and I will tell you that my medication is finished and have to buy some. So even if is two money that you can give me, I feel safe and will look for some to add and will go and buy"

(26 years old female with hypertension)

"So small, small and by God's Grace now I don't go to the hospital and waste money. Because my daughter and the doctor have a connection [an arrangement]. *So she had given the doctor…. he takes care of me and where she is when she come back she immediately come and pay the bills. So right now the moment I feel something, then I have to go and when they prescribe medication for me, I will come and buy and take. So now it does not make me think about it like is worrying me. But before, is like if I am going to the hospital, is a problem …."*

(69 years old female with diabetes and hypertension)

"…just like the way you are sitting here, someone may come here and say oh this is our house but has been a long time since I came here. Oh how are you old ladies and when leaving maybe gives me GH¢5.00 or GH¢10.00. Then I will save it….
When I go to my doctor, I tell him the truth. He gives me on credit. He give's me medicine if is 10, he [Doctor] can give me 5 and then when I go back and pay, then I get another. He also helps me a lot."

(65 years old female with diabetes, hypertension and asthma)

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The dependence on family members and social support networks is not universal and according to some participants it is not a reliable means to cope with direct burden of NCDs. Poverty was cited, as the factor that limits the strength of social support networks, as family members need to meet their household economic needs before extending any support to others. Example is presented in the quote:

> *"That one* [family and social support] *I can't depend on them because this place* [locality], *the moment you give birth then you have to find your way to do things you need for yourself. There are sometime that it* [hypertension] *comes impromptu and will be here. My mother will come and say she does not have money. My siblings will also come and say they don't have money. But will… all my hope ….I believe that there is some* [they have money] *but I am not given. ….. So I can't count on or depend on my family member because everyone has his/her problem. Maybe having 1, 2 or 3 children and what they need would it be given to me? Please do you understand?"*
>
> (Female, 27 years old with hypertension)

Among persons living with NCD, there is some level of dependence on family and social support to navigate the burden of disease. However, social and family supports are becoming weaker means of coping with the direct burden of NCDs at the household level. The high levels of poverty within a household and community are eroding the social support derived from family member. Poverty is therefore significantly shifting the burden of disease onto the infected person alone. The effect and influence of extended family support in the areas of direct and indirect burden is currently being undermined due to poverty. Individuals tend to meet their individuals and household needs before extending support to others outside their household.

7.2.5 Health insurance

Studies indicated that health insurance does not only directly offset the potential negative economic consequences of ill health through financial protection,

but also indirectly decreases the economic burden by increasing access to and the utilisation of healthcare services. This thesis reveals that health insurance status of infected persons is a significant predictor of health seeking behaviour during the two weeks preceding the survey.

A significant association exists between health insurance status of infected persons and treatment behaviour among those ever diagnosed with NCD respondents ($p < 0.001$) as reveal in the quantitative survey. While among never diagnosed persons, 822 (35.0%) have health insurance, in the case of persons currently living with NCD, 76 (64.4%) have health insurance (Table 7.1). Of those household members who were diagnosed but did not treat the condition during the 2 weeks preceding the survey, about three in five (59.3%) did not have health insurance.

Table 7.1: Percentage distribution of participant by NCD status and health insurance status

NCD Status	Health insurance status		Total
	Not insured	Insured	N
Never diagnosed	65.0	35.0	2,347
Diagnosed but no treatment	59.3	40.7	59
Diagnosed and treated	35.6	64.4	118
Total	**63.5**	**36.5**	**2,524**

$\chi 2 = 42.286$ Sig.= 0.000

In line with the result from the household survey, the in-depth interviews also reveal that health insurance is one major source that affords poor insured persons to continue treatment-seeking behaviour. Twenty out of the 27 persons living with NCD in the qualitative interviews had health insurance. Among the 20 (74.1%) insured, 14 (70.0%) had valid health insurance cards at the time of the study. Significantly, all insured participants except one registered for the health insurance only after diagnosis of the disease condition. Health insurance supported infected persons in three main

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areas: utilisation of healthcare services; access to medication; and reduction in the level of out-of-pocket payment.

7.2.5.1 Service utilisation

Health insurance provided a means for infected persons with health insurance coverage to access healthcare services. Discussions with many of the participants, particularly those with health insurance coverage shows how their health insurance status provides them access to healthcare services as shown in the quote:

> *"I told my son that if I have to go to doctor (hospital or clinic) it is really difficult for me. So one day when he got paid he went and did it* [Health insurance] *for me and whenever it expires he renews it. That is what I am managing small, small. If left with only money* [out-of-pocket payment] *I would have died. In my current situation if not the insurance I will be dead. That is what is helping me small, small."*
>
> (Female, 64 years old with hypertension).

7.2.5.2 Access to medication

Under the national health insurance scheme (NHIS), medications that are on the insurance drug list are provided to insured clients free of charge both at designated health facilities and private pharmacy shops. The high reliance on the health insurance to access medication is captured and presented in the quotes demonstrating how health insurance is vital in some households in accessing medication for the management of NCD conditions due to high cost of prescription.

> *"When I went, they gave me medicines and those I didn't get, they asked me to go to the drug store to buy ..... Now because of the health insurance that we have when you go and they give you what they have, what they don't have for you, when you have a child you have to talk to your child to find some money for you to go and buy."*
>
> (Female, 69 years old with hypertension)

> *"If I go and I get two* [if two of the prescribed medications are on the drug list and I get it from the pharmacy] *I manage it till I will get money to purchase*

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the rest. Those that the health insurance does not cover, I will have to go and buy. There are a lot of papers [prescriptions] there that I have to go and buy but I don't have the money….. But those that are prescribed for me I can't buy them. There are a lot there that I'm supposed to buy but I haven't. Maybe those are the ones that will cure me but I don't have the maney to buy them."

(Female, 64 years old with hypertension)

7.2.5.3 Reduction in cost of healthcare service received

The national health insurance scheme in Ghana is administered under an exemption policy. This tends to minimise cost of health service received (lower out-of-pocket payment). The effects of health insurance on reducing out-of-pocket payment were recounted by many of the participants of the interview. The following quotes demonstrate how health insurance reduces healthcare cost.

"Because I have their paper [Health Insurance], I don't spend much unless I am going and have to take a taxi and those things. Or if the medication is not available before I will go and buy."

(Female, 70 years old with diabetes and hypertension)

"The insurance helps me small. Whatever it covers, it helps me and those that it does not cover… one of my sons when he comes and he has some money then he will buy them for me. Sometimes I could stay for two weeks and he hasn't gotten money for me to go and buy."

(64 years old female with hypertension)

All healthcare insurance systems are aimed at achieving the main financing functions of raising revenues and pooling resources for risk sharing. However, the challenges of the overstretched health system and health insurance scheme and widening gap between policy and practice make health insurance non-beneficial to the most poor and the vulnerable in the society. These were evident in the analysis where insurance holders narrated the level of challenges under the scheme. Most of the challenges are attributed to systemic failure and the gap between policy and practice.

"I don't like it because when you go to the hospital they will say those with the Health Insurance, you sit this side and those of us who don't have and are

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going to pay money we sit this side. You will see that while sitting down, those people [those with insurance] they will not mind them. Those of us with money to pay, is us that they will attend to. Sometimes when you go they will say this medicine, the Health Insurance that you have is not covering it. So is of no use to have it and take it to the hospital."

(Female, 65 years old with diabetes, hypertension and asthma)

"na na na!" [look look look*]! If you go, medicines that are expensive that you have to be given they will not give you. You will be given Paracetamol."*

(Female, 82 years old with hypertension)

"Oh, they take money. They take small. When they started they were not taking money from pensioners but now they are taking small, small. But is not expensive I can pay."

(69 years old female with diabetes and hypertension).

Health insurance status of infected persons determines and influences treatment behaviour as it increases access and utilisation of healthcare services, access to medications (particularly those covered by the insurance scheme) and reduction in out-of-pocket payment for healthcare services. However, due to some systemic failures and the gap between policy and practice of the scheme, the main effects of the scheme to policyholders are undermined by these challenges. Although the retirement age is 60 years, exemption from premium payment for the aged is 70 years. The limited medications on the NHIS drug list and the long bureaucratic processes at the health facility for policyholders are the major barriers that limit the full benefit of the current health insurance scheme for persons living with NCD.

In conclusion, health shocks that are beyond household budgets compel households to adopt some coping strategies to navigate the health shock. Key strategies adopted by affected households are social support, sales of household assets, reliance on household savings and investments, health insurance scheme and waiver of health seeking privileges. The findings are in line with results of other

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studies that have examined the coping mechanisms for burden of disease (Bogale et al., 2005; Sauerborn, et al., 1996; Tagoe, 2012b).

All these strategies are influenced by poverty, social support networks available to the household and household socio-economic dynamics that can prevent or push them into impoverishment. These types of coping strategies, although useful in the short-term, lead to household impoverishment. Poverty is a major driving factor for type of coping strategy that a household will adopts. Pro-poor national polices such as the NHIS utilisation and impact are affected by poverty due to out-of-pocket payment associated with the current scheme. The impact of social support systems that households' draws on to support health needs are undermined by level of poverty. Poverty also pushes poor households to use savings and investments as well as selling of households assets to finance healthcare expenditure. The types of household assets sold are also determined by the poverty level of the affected household. Households also cope with financial burden of healthcare by skipping routine appointment for medical review and medications. These are not because the infected persons have given-up on treatment or management of the condition, but patients are unable to afford them due to poverty. Patients are able to cope with this mechanism in the short-run but often experience worsen health outcomes in the long run.

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CHAPTER 8

SUMMARY, CONCLUSION AND RECOMMENDATIONS

8.1 Introduction

Non-communicable diseases are not only a health problem in many LMICs but they also pose significant social and economic burden on affected and infected persons. Non-communicable diseases are responsible for 68 per cent of the world's 56 million deaths in 2012 with more than 40 per cent of the premature deaths occurring under age 70 years, and 85 per cent of NCD mortality occurs in LMICs (WHO, 2014a). The urban poor are disproportionately affected by the burden of NCDs. This chapter presents the summary of key findings of this thesis that investigated the household level burden of NCD in the context of urban poverty in Accra, Ghana. Using cost of illness and biographical disruptions as conceptual and analytical approaches, the thesis triangulated quantitative and qualitative methodological approaches in data collection and analysis to arrive at the findings.

8.2 Objectives

The key objective of this thesis is the assessment of disease burden at the household level in the context of urban poverty. Of particular interest are the prevalence of NCDs among poor urban households, the direct, indirect and intangible burdens of NCD on poor urban households with member(s) living with at least one NCD condition. Direct burden of disease was estimated using the prevalence approach where total household healthcare expenditure during the four weeks preceding the survey was computed and the difference across different households (Non-NCD, NCD but no treatment, and NCD and treated) were investigated. How

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indirect and intangible burdens of disease manifests in urban poor households were also investigated. The coping strategies employed by affected households to deal with the direct burden of NCDs are also examined in this thesis.

8.3 Summary of findings

This thesis contributes towards the ever-growing body of research investigating the burden of disease particularly NCDs at the household level. The major findings are presented and discussed under five main headings. These are - prevalence of NCDs among urban poor households; the direct burden of NCDs on poor urban household; limited financial resources availability to individuals and households; limitation of social support network as coping strategy; and poverty as a determinant of NCDs complications and treatment and management adherence.

8.3.1 Prevalence of non-communicable diseases among urban poor households

The prevalence of NCDs is estimated to increase in the coming years particularly in LMICs (WHO, 2005). This is attributed to the economic development and rapid urbanization and the accompanied behavioural change resulting in nutritional and epidemiological transitions. A wide range of NCDs are affecting urban poor persons that either before were not the case. Hypertension was the most common condition followed by diabetes and asthma. Other conditions are stroke, arthritis, depression, cancer and angina.

The shared common risk factors associated with NCDs was also evident from the results as approximately 17 per cent of persons living with NCD are living with two or more conditions. Hypertension and diabetes accounted for half of comorbidity

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cases with hypertension and stroke also accounting for another 20 per cent. Hypertension and arthritis and hypertension and asthma accounted for 15 per cent and 10 per cent respectively while the remaining 5 per cent is for arthritis and blindness. Other studies also found high prevalence of comorbidity particularly hypertension and other chronic diseases (Nimako et al., 2013) as in the case found in this thesis.

This existence of NCDs coupled with other parasitic and infectious disease such as malaria, diarrhoeal diseases etc. resulting from environmental and sanitations challenges in urban poor communities poses both health and economic burden on the households. This put urban poor households under the strain of double burden of disease where there is a struggle to deal with infectious disease and also manage to live with chronic disease. With the paradigm shift in healthcare expenditure significantly onto individuals and households, there is increased risk of impoverishment resulting from catastrophic healthcare expenditure and out-of-pocket payment for healthcare services.

8.3.2 Direct burden of non-communicable diseases on poor urban households

Studies have reported that lower socio-economic status (SES) is associated with high prevalence and highest burden of NCD (Goldstein et al., 2005; Schneider et al., 2009). Financial catastrophe due to health shock is aggravated when the individual or the household is already faced with financial inhibitions or is found in the lower socio-economic strata of the society. This phenomenon tends to reinforce the cyclical link between poverty and NCDs (WHO, 2011a). The relatively low health insurance coverage and enrolment in Ghana has resulted in high prevalence of out-of-pocket payment for healthcare services. Results from the fifth round of the Ghana Living

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Standard Survey indicate that 97.6 per cent of ill persons settled healthcare bills through out-of-pocket payment (GSS, 2008).

While the 2010 Ghana Population and Housing Census reported the unemployment rate among the economically active population (15-69 years old) in Greater Accra Region as 8.3 per cent (GSS, 2012), the rate of unemployment among the economically active population in the study population is about twice the regional rate (16.4%). This level of unemployment among the study population translates into the high level of poverty in the areas. The occupational spectrum available to the population also aggravates the poverty risk as majority of the working populations are in the informal sector (sales and service, fishing and fish processing, seasonal food produce and petty trading). This increases the risk of poverty and lowers household income resulting in relatively lower disposable income for health expenditure.

Health shock in the household caused by NCD and its associated high healthcare cost results in high direct burden of disease. The financial or direct burden of disease and the resulting catastrophic healthcare expenditure increases the risk and aggravates household impoverishment thereby perpetuating the vicious cycle of poverty. Healthcare expenditure causes significant financial catastrophe and impoverishment (Bredenkamp et al., 2011; Daivadanam, 2012; Minh and Tran, 2012; Mondal et al., 2010; Russell, 2004; Su, Kouyaté, and Flessa, 2006; Xu et al., 2007). The results from the thesis reveal a significant difference in the mean total household healthcare expenditure between the different household types (Non-NCD, NCD but no treatment and NCD and treated). Households with a member who treated NCD during the two weeks before the survey spend significantly more on the average on

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healthcare than their counterparts with no member diagnosed or treating NCD. With limited household resources, any additional cost incurred by household due to treatment seeking behaviour becomes a strain on the household budget. The low household income and high prevalence of out-of-pocket payment for healthcare means households spend a significant proportion of household income on healthcare resulting in financial catastrophe and household impoverishment.

8.3.3 Intangible burden of disease on poor urban households

Intangible burden of disease, one of the components of disease burden that is often neglected or not accounted for in many healthcare cost analysis was captured in this thesis. The results indicate that infected persons and affected households are very much burdened under this particular type of disease burden. The psychosocial stressors in the form of sexual dysfunction, the fear of social isolation or stigmatization and the physical and psychological stress emanating from the health system and nutritional disruptions associated with chronic disease are very difficult to ecumenically quantify.

Intangible burden of disease such as sexual dysfunction among male type 2 diabetes patients are well documented. The impact of sexual dysfunction is both intangible and direct. Intangible as it affects the domestic and public position of affected men (Kolling, 2012). There is increase in the direct burden of disease because efforts are made to avoid and treat such associate complications. The impacts of intangible burden related to the nutritional disruptions are much more significant particularly in poor households. The financial position of ill populations are known to be lower than healthier population due to health expenditure (Rijken and

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Groenewegen, 2008; van-Agt et al., 2000). This occurs through loss of working days due to ill health or provision of care (Bogale et al., 2005) and time spent seeking healthcare, reduced productivity and income. This limits resource availability to the infected and affected persons with NCDs due to long absenteeism from economic activity.

Individuals in urban poor settings have restricted range of financial resources. The relatively low level of education and economic opportunities in urban poor settings results in limited economic or financial resource availability. Limited financial resources causes households that experience health shocks to rely on other unsustainable means to finance healthcare expenditure. Means such as borrowing, selling of household assets and other social support networks are depended on by poor households to finance healthcare expenditure (Bredenkamp et al., 2011; Engelgau, Karan, and Mahal, 2012; Kankeu et al., 2013; Minh and Tran, 2012; Mondal et al., 2010; Rahman and Gilmour, 2013; Tagoe, 2012). Borrowing and selling of household assets reduce and delay investments and this increase the risk of household impoverishment.

The NHIS is one major resource depended on by majority of persons living with NCDs (64.4%) for access and utilization of healthcare services. The NHIS just like other pro-poor policies is not protective enough for the poor, as reported in other studies (Ettling et al. 1994; Liu et al. 1996; Fabricant et al. 1999; Onwujekwe et al., 2004). There is a limit to the coverage of services and benefit products under the NHIS package. The gap between policy and practice also significantly reduced the main effects of the scheme as a driver for universal healthcare coverage, particularly

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among persons living with NCDs and the poor in the society. Policyholders continue to settle health bills out-of-pocket resulting in financial catastrophe and impoverishment.

8.3.4 Limitation of social support network as a coping strategy

Coping strategies adopted by individuals and households in the event of health shocks are multifaceted particularly in a poor socio-economic setting. Lack of financial resources in poor households and high healthcare cost results in high dependency on other means such as social support networks, to cope with the catastrophic health expenditure (Bogale et al., 2005; de-Graft Aikins, 2005; Tagoe, 2012b). Social supports from family members, friends and other social groups are known to be one of the common strategies adopted by individuals and households to cope with health shock. This means of coping with direct and indirect burden of disease is currently not dependable according to the results of this thesis and this is attributed to high level of poverty. Family members and friends who provide social support for their infected household members and relations are also economically challenged.

The high prevalence of poverty in the study area limits the availability of social support networks in the area. None of the persons living with NCDs that participated in the qualitative interview belong to any social or self-help group except religious groups. The only social support available for infected persons and households are support from family members outside the household and friends. Poverty limits individuals to meet their basic individual and households needs before providing any support (material or cash) to persons or relations outside their

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households. Direct and indirect burden of disease are currently shifting with the full impact on the individual and the household as poverty undermine the influence of social support systems.

Abandonment and isolation of persons living with NCDs by family members and friends due to their inability to effectively support them can be attributed to the prevalence of poverty. Poverty therefore challenges the ability of individuals to meet their social obligations towards persons outside their household. Some persons living with chronic disease conditions may feel abandoned by family members and relations due to their inability to provide them with the needed support as is the case found in this study. However, the underlying reasons for not receiving the support required may be partly attributed to the poverty situation of people.

8.3.5 Poverty as a determinant of non-communicable disease complications, treatment and management adherence

Scientific evidence indicates that poverty has major implications on the health and wellbeing of an individual and also the household (Campbell and Campbell, 2007; Fink et al., 2012; McIntyre et al., 2006; Sverdlik, 2011; van Agt et al., 2000). Treatment and management of NCDs are associated with high cost. The result from this study revealed the prevalence of skipping of regular routine check-up similar to what was found by Bogale et al. (2005). Also found in this thesis is the prevalence of skipping of recommended and prescribed medication due to ignorance and poverty. Such situations result in other complications and drug resistance with its resultant high cost of treatment and premature mortality.

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According to the WHO report in 2005, up to 80 per cent of premature mortality from major chronic diseases (heart disease, stroke and diabetes) can be averted with known behavioural and pharmaceutical interventions (WHO, 2005). The results of this thesis reveal that poverty is a significant barrier to adherence to healthy lifestyle behaviour particularly dietary practices. Poor households are unable to adhere to recommended change in dietary practice or the nutritional disruptions caused by the presence of NCD(s) in the household.

8.4 Conclusion

The WHO (2011a) and other studies (Goldstein et al., 2005; Schneider et al., 2009) have demonstrated the influence of poverty on NCD prevalence and burden. The urban poor are disproportionately affected by NCDs. Socio-economic development and urbanisation and its accompanied behavioural changes are the drivers of the epidemiological transition (Agyei-Mensah and de-Graft Aikins, 2010; Allender and Lacey, 2010; Allender et al, 2011; Ekpenyong and Akpan, 2013; Ford and Caspersen, 2012). Rapid urbanisation and economic development increase the populations exposure to the modifiable risk factors associated with NCDs.

Non-communicable diseases burden is not limited only to affluent populations as the WHO reported a link between poverty and NCD (WHO, 2011a). The results of this thesis also confirm that the urban poor are not exempted from the burden of NCDs. About one in five of the 806 households interviewed had at least a member diagnosed with at least one NCD condition. The odds of underestimation of the prevalence rate among the study population cannot be ignored due to non-diagnosis and non-disclosure of disease status to other household members. One out of every

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three (33%) persons ever diagnosed with NCD did not treat, medicate or receive any therapy for the condition during the least two weeks preceding the survey. This phenomenon of non-treatment of chronic diseases can be attributed partly to high level of poverty and high cost of healthcare.

The prevalence of the various NCD conditions among the urban poor epitomised the stage of the epidemiological transition in the country. Hypertension, one of the major risk factors of stroke and other cardiovascular disease conditions is the most prevalent NCD condition among the study population. The relatively high prevalence of hypertension among the study sample is also consistent with other studies in the country (Addo et al., 2013, 2006, 2007; Agyemang et al., 2005; Agyemang, 2006; Amoah, 2003; Bosu, 2010; Cappuccio et al., 2004; Escalona et al., 2003; Plange-Rhule et al, 1999). This demonstrates the high risk of the population to other chronic disease conditions particularly stroke, cardiovascular disease among others in the future if the current situation remains unchecked.

Households are burdened in three fronts – direct, indirect and intangible which become a disease burden or health shock (Kankeu et al., 2013; Rice, 2000; Shepard et al.1991; Suhrcke et al., 2006; Byford et al., 2000; Heijink et al., 2008; Heijink and Renaud, 2009). Out-of-pocket payment for healthcare services are documented to result in household financial catastrophic and impoverishment (Bredenkamp et al., 2011; Daivadanam, 2012; Minh and Tran, 2012; Mondal et al., 2010; Russell, 2004; Su et al., 2006; Xu et al., 2007). High cost of medication is found to result in non-compliance to medication and treatment (Buabeng et al, 2004). A significant

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association between household NCD status and total household healthcare expenditure was found in this thesis (P=0.011).

The results of this thesis also point that the high healthcare cost result in non-compliance to medication and treatment among persons living with NCDs, and is consistent with the findings of other studies (Asenso-Okyere et al.,,1998; Asenso-Okyere and Dzatorb, 1997; Buabeng et al., 2004; de-Graft Aikins, 2005). The lack of medical options and social protection systems for the urban poor presents significant health burden. Poverty therefore is a major determinant of adherence to management and treatment regime of NCDs. The relatively high cost of healthcare results in catastrophic healthcare expenditure and household impoverishment.

All healthcare insurance systems are aimed at achieving the main financing functions of raising revenues and pooling resources for risk sharing. However, results from this studies indicate that pro-poor public policies such as the NHIS in the health sector have not effectively protected the poor as also found in other studies (Asenso-Okyere et al., 1998; Nyonator and Kutzin, 1999; Van der Geest, et al., 2000). The current policy and structure of the NHIS provide some level of support for access and utilisation of healthcare services and products with major challenges. Health insurance status of diagnosed persons is statistically significantly associated with health seeking behaviour ($P<0.036$) and insured patients have a 2.5 higher odds of seeking treatment two weeks preceding the survey. However, the gap between policy and practice in the implementation of the health insurance scheme poses a significant barrier for the benefit of the full potential of the insurance scheme particularly for the poor. Not all effective medication and services needed for effective management on

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NCDs are covered by the NHIS. This may have accounted for the marginal effect of the insurance status and total healthcare expenditure and high prevalence of out-of-pocket payment by insured patients. Households are pushed to adopt various mechanisms to cope with high out-of-pocket payment for healthcare.

While it is common for the general household to depend on productive resources such as land (Russell, 1996, 2004), this study revealed that urban poor NCD households depend on the selling of personal belongings and household items such as cloths, jewelleries, cooking utensils, stoves etc. The kind of social and economic mechanisms poor household adopt to cope with the direct burden of disease are determined by poverty. This is potentially risky as it may lead to current and future household impoverishment and social and family isolation and abandonment. Household coping strategies from health shocks result in impoverishment, social and family isolation and abandonment. This result is in line with the results of other studies that have examined household coping strategies of health shocks (de-Graft Aikins, 2003, 2006,; Meessen et al., 2003; Russell, 1996, 2004)

Chronic disease is associated with biographical disruptions (Bury, 1982, 1991; Carricaburu and Pierret, 1995; de-Graft Aikins, 2003, 2004; Faircloth et al., 2004; Hubbard and Forbat, 2012; Kenen et al., 2003; Larsson and Grassman, 2012; Reeve et al., 2010; Taylor and Bury, 2007). The results from this thesis indicate that the participants' experience of illness complications and functional losses similar to what Bury (1982) referred to as a "biographical disruption". Participants living with NCD life trajectory are disrupted from the physical, financial, medical, and socio-cultural perspectives. The disruptions affect the life trajectory of both infected and affected

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persons. There is loss in income resulting from withdrawal from economic activities including early retirement and long hours accompanying infected person or seeking healthcare. Delay in investment, reduction in household income and depletion of household resources due to catastrophic healthcare expenditure do not only result in economic impoverishment but also significant psychosocial stresses. Such indirect and intangible burdens are known to be significantly higher than direct burden in many LMICs (Asenso-Okyere and Dzatorb, 1997; Attanayake et al., 2000; Ettling and Shepard, 1991; Sauerborn et al., 1996).

8.5 Recommendations

Drawing on the results of this thesis, four broad recommendations are made. These are in the areas of collaboration between national and local agencies to provide social protection for the most vulnerable population in the society. Also, the incorporation of NCD risk, prevalence and burden into national surveys to provide the requisite data needed to study the burden of NCD at the national level. There is also the need for policy reforms in the national health insurance scheme to account for the epidemiological transition-taking place in the country, and further studies to build on the findings of this study.

8.5.1 Collaboration of agencies for social protection schemes

Collaboration of national and local agencies in the country to provide social protection to the most vulnerable in the society is recommended. Results from this study indicated that except for church, none of the persons living with NCD reported belonging to any social, self-help group or association. This provides an avenue for

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stakeholders in the health, economic, and development sectors to collaborate to provide the needed ground for the creation and enrolment of infected persons in social and self-help groups. This will provide needed social protection to the vulnerable people living with NCD. Lack of social security and low employment among the study population, particularly persons living with NCD put poor households at higher risk of impoverishment. Collaboration to provide social protection to the vulnerable in the society could be through the making of available and accessible governmental supports interventions such as the Livelihood Empowerment Against Poverty (LEAP) to poor households with persons living with NCDs.

The Ministry of Health, Ghana Health Service, Ministry of Gender, Children and Social Protection, Ministry of Education and all other concerned agencies can collaborate on the fronts of not only providing social protection but also through education and sensitisation on risk factors and preventions of NCDs. Studies have demonstrated the link between increased incidence and prevalence of NCD and unhealthy lifestyle behaviour including dietary practices (Addo et al., 2007; Hosseinpoor, et al., 2012; Petersen et al., 2005; Phaswana-mafuya et al., 2013; Son et al., 2011). Behavioural and pharmaceutical interventions are known to avert about 80 per cent of premature deaths from heart disease, stroke and diabetes (WHO, 2005a). Reviving and intensification of the Ministry of Health's regenerative health and nutrition policy by these agencies will promote healthy lifestyle behaviour among the population, thus reducing the health risk of NCD.

8.5.2 Non-communicable disease indicators in national surveys

There are still research gaps in quantifying the prevalence and burden of

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NCDs in Ghana. Understanding the burden of chronic disease at the micro level is pivotal in any effective health policy intervention. However, there are limited researches in this area to provide in-depth understanding of the significant challenges of NCDs on households. Sub-Saharan Africa is noted to lack reliable data on causes of disease and the overall burden (Unwin et al., 2001).

Demographic and Health Surveys (DHS), Multiple Indicator Cluster Surveys (MICS), Ghana Living Standard Surveys (GLSS), are the most common household level national surveys available and used by researchers. However, these surveys do not routinely include chronic disease indicators (risk, prevalence and burden). The lack of national level data has been a major impediment for further in-depth research on the implications of the epidemiological transition and NCDs on health and national development.

This thesis and other earlier studies have provided the evidence of the level of health, social and economic challenges NCDs poses on individuals, households and the nation. Therefore, there is no justification for these omissions of NCD indicators in national representative surveys undertaken to assess the health and living conditions of the populations. The inclusion of measurements and indirect and intangible indicators identified in this study at the household level into already well-established surveys like the DHS, MICS, GLSS and national census would be a highly cost-effective way of filling in current research and data gaps. Field sites like the RIPS EDULINK – urban poverty and health (in urban Accra) and INDEPTH Demographic Health and Surveillance System (DHSS) in the three health research centres across the country serve at a platform and employ mixed methodological

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approaches.

8.5.3 Insurance improvement

Health insurance was identified as one major source that allows infected persons to access healthcare services. The Insurance Act, Act 650, which established the National Health Insurance Scheme (NHIS) in 2003, aims at improving financial access of the citizens, especially the poor and the most vulnerable, to quality healthcare services across the nation. However, the challenges particularly in the areas of policy and practice, poses extra strain and burden on policyholders. The perceived preferential treatment granted to non-insured (out-of-pocket payment) clients in terms of quick service as against long delay by insured persons affect the use and efficiency of the policy and service utilisation. The issue of low quality and generic drugs, which are prescribed under the insurance policy medicines list, has become a major issue affecting the level of client satisfaction.

With current evidence of epidemiological transition and increasing prevalence of chronic non-communicable diseases among the poor, there is a call for the restructuring of the health insurance policy with focus on the current epidemiological transition in the country. The restructuring could introduce new premium rate for chronic disease clients that will afford clients to access more quality services and medications for effective management of chronic diseases. Expansion of services and medications provided under the NHIS to cover many of the essentials (if not all) services and medications for the effective management and treatment of chronic diseases are needed in the new reformed NHIS.

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The challenges of the NHIS are multifaceted and will demand a multi-sectorial approach to overcome the challenges. Collaboration between stakeholders in the health sector namely the Ministry of Health (MoH), Ghana Health Service (GHS) and the National Health Insurance Authority (NHIA) to effectively monitor health service delivery at health facilities across the country will promote quality service delivery and eliminate other anthropogenic factors that result in the service quality differentials for insured and uninsured clients.

8.5.4 Further studies

Micro level investigation of burden of chronic non-communicable diseases is receiving significant attention at various levels – locally, nationally, regionally and internationally. This is attributed to the growing health and developmental challenges that chronic disease pose at the individual, household and national levels. This thesis provides empirical evidence on the burden of NCDs at the household level and it understanding. There are however, some areas that warrant further research due to varying dynamics and the multifaceted nature of disease burden.

The costs associated with a disease can be measured either by the 'prevalence approach' (this approach measures costs at a single point in time) or the 'incidence approach' (costs are measured over a lifetime). This current research used the prevalence approach in assessing the cost of illness at the household level. These results can be further improved by the use of the incidence approach of assessing the cost of illness. This approach has the potential to reduce recall biases, which can result in both overly and underestimation of direct burden of disease at the household level. A longitudinal study is therefore required to quantify chronic disease impact on

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the household. One of the objectives of the current study was to investigate how indirect and intangible burden of disease manifest in the household. Valuations of such burdens and putting economic costs on the indirect and intangible burden of disease on the household can also be effectively achieved through the use of a longitudinal approach.

The current study focused on the social and economic mechanism employed by urban poor households to navigate, mainly, the direct burden of NCD in the households. Other key components of chronic disease burden are the psychosocial burdens. Further studies that examine the mechanisms adopted by poor households to navigate the psychosocial burden in terms of indirect and intangible burden as well other socio-cultural factors will complement the results of the current study and provide in-depth understanding of the burden of chronic disease at the household level.

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APPENDICES

Appendix 1: Population Training Research Capacity for Development (PopTRCD)

Round	Year of survey	Enumeration Areas	Total households covered	Household members	Area covered in the survey
1	2010	29	497	1,544	• Household composition and characteristics • Individual background and morbidity • Community and environment • Reproduction • Family planning and contraception • Maternal health • Child health • Marriage and Fertility preference • AIDS and other sexually transmitted diseases • General health and health seeking behaviour • Emotional, nutrition and mental health matters • Household burden of disease (NCDs) and risk factors • General lifestyle issues
2	2011	29	806	2,524	• Household composition and characteristic • Individual background and morbidity • Community and environment • Reproduction, Family planning and contraception • Maternal health • Child health • Marriage and Fertility preference • AIDS and other sexually transmitted diseases • General health and health seeking behaviour • Emotional, nutrition and mental health matters

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					• Non-communicable disease prevalence • Dietary practices • Household general and healthcare expenditure • Household and family support network and transfers • Climate change, health and food security • Health insurance • Disability and home based care • Anthropometric measurements (Height, weight, blood pressure)
3	2013	29	675	2,474	• Household composition and characteristics • Individual background and morbidity • Community and environment • Reproduction and Family planning and contraception • Maternal health • Child health • Marriage and Fertility preference • AIDS and other sexually transmitted diseases • General health and health seeking behaviour • Emotional, nutrition and mental health matters • Non-communicable disease prevalence • Household general and healthcare expenditure • Household and family support network and transfers • Climate change, health and food security • Health insurance • Disability and home based care • Anthropometric measurements (Height, weight, blood pressure) • Blood sugar level

Appendix 2: Socio-demographic characteristics of participants in the individual interview

Case ID	Disease condition(s)	Sex	Age	Marital status	Employment Status	No. of Children	Religion	HH size	Ethnicity	Social support Network
1	Hypertension, diabetes, prostate cancer and Gout	Male	64	Married	Retied (worked with Ghana Port and Harbour	4 they live in this house but not with me in this household	Christian Presbyterian	3	Akan	None
2	Diabetes, hypertension	Female	69	Divorce	Teacher on retirement	5	Presbyterian	3	Ga	Retired teacher Association
3	Diabetes, hypertension and Asthma	Female	65	Divorce	Unemployed (trader)	2	Catholic	4	Ga	None
4	Hypertension	Female	26	Separated	Unemployed	3	Charismatic	4	Ga	None
5	Diabetes and Hypertension	Female	70	Widowed	Unemployed (trader)	10 but 2 death and 4 are currently living with her	Methodist	6	Ga	None
6	Hypertension	Female	82	Widowed	Retired (factory worker)	6	Presbyterian	5	Ga	None
7	Hypertension	Female	64	Divorce	Unemployed (fish monger)	4	Catholic	4	Ga	None
8	Hypertension	Female	69		Unemployed (fish monger)	5	Methodist	4	Ga	None
9	Stroke	Male	56	Married	Unemployed (carpenter)	2	Christian	4	Ga	None
10	Hypertension	Male	70	Married	Service	5	Christian	7	Ga	None

11	Hypertension	Female	39	Single	City guard	7	Muslim		Ga	None
12	Stroke	Male	76	Separated	Unemployed	6	Christian	2	Ewe	None
13	Stroke	Male	65	Cohabiting	Barber	0	Christian	1	Ga	None
14	Diabetes	Female	46	Married	Labourer	2	Christian	4	Ga	None
15	Diabetes	Female		Single	Trader	6	Christian	6	Akan	None
16	Hypertension and Diabetes	Female	79	Widowed	Unemployed	7	Christian		Ga	None
17	Hypertension	Male	62			4	None		Ga	None
18	Hypertension and Ulcer	Female	52	Single		2	Christian	2	Ewe	None
19	Stomach ulcer	Female	21	Single		0	Christian	5	Ga	None
20	Hypertension	Female	42	Single		0	Christian		Guan	None
21	Diabetes and Hypertension	Female	52	Married	Pure water seller	8	Christian	18	Guan	None
22	Hypertension and Stroke	Female	72	Widow	Former	4	Christian	3	Ga	None
23	Hypertension and Blindness	Female		Widow		-	-	4	Ga	None
24	Hypertension and stroke	Male	59	Married		6		2		None
25	Arthritis	Female	37			1	Christian		Ga	None
26	Hypertension	Female	64	Single	Sells pure water	5	Christian	6	Ga	None
27	Asthma	Female	91		Unemployed (trader)		Christian		Akan	None

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Appendix 3: Coding frame

Lifestyle	Healthy lifestyle behaviour before diagnosed with condition	Lifestyle behaviours that relates to exposure or prevent NCD such as consumption of fruit and vegetables, healthy diet, physical activities, non smoking and excessive alcohol consumption	*Oh, me in the morning I can't eat properly. Because of the teaching we go early like that so when I woke up, I am going to work. So at break time I will get time to eat something small…* *I was very active. I go to work very early and all that. I mean I walk to work and all that so nothing worries me. I don't fall sick and nothing worries me*
Disease condition	The condition has to be NCD	NCDs that participant is currently living with	*Hypertension, Diabetes, Stroke, Asthma, Cancers, Arthritis, Angina, Depression*
Comorbidity	Diagnosed and treating two or more NCDs	The participant should be treating all the conditions	*Apart from the hypertension and diabetes, Oh, I also have prostate and Gout*
Healer shopping	Before or after diagnosis, the participant seeks treatment for the same episode of condition from more than one source without being referred to by medical professional	The participant must seeking healthcare for the same disease condition from another place without referral from the initial place of healthcare. This should include faith healing	*I am treating it small small, church and all that are helping me.*
Current health seeking behaviour	How the participant seek	Any form of health seeking related to the disease condition (NCD(s))	*Let me see last year, yes, last year February, I was not feeling well. When I got the asthma I got BP [Hypertension]*

	healthcare. Is it on regular basis or as at when needed	under consideration	*too. All this I just forget them and when it becomes worse then I look for some medication and use.* *When my medication finishes, I don't go [to the hospital] immediately. I wait for about 2 months 3 months and see if it is coming down or is going up.*
Disruption (individual Level)	Any form of disruption to the life of the participant as a result of the illness	The disruption must be linked directly to the illness and it can be direct or indirect (including psychosocial)	*It has worried me. It has worried me because this leg also would not allow me to walk to anywhere. If I walk small then I am short of breath and when it happens then the condition also starts.*
Employment/ Economic opportunity	How the illness affected work/employment and economic opportunity	The illness resulted in loss of income/withdrawal for economic activity etc.	*No, I went to work normal. But when I saw that today I am sick and not feeling well, I was left with 4 years to come on retirement. So I asked and left*
Dietary behaviour	Change in diet as a result of illness or recommended diet practice by health professional	Making the conscious effort to keep to healthy diet due recommendation or knowledge about its effect on health (disease condition)	*My diet has change. My diet has change because there are foods I don't eat now* *So I find it difficult to eat. They said I shouldn't eat sugar at all. And me if I am around and feel hunger and can't get anything to eat, if I buy minerals [soda] and bread then I eat but now they said I shouldn't eat. I shouldn't eat sugar bread, cake, biscuit all these are worrying me.*
Disruption (Household Level)	From the participant point of view how the illness affected other member of	Only when the disruptions were as a result of the participant NCD condition.	*I am in the room with my children and they want to go out and apply a spray [perfume] then the asthma will come.*

	the household		
Household Food preparation	How the preparation of food at home been affected by the disease condition of participant	Any change in food or dietary practice at home resulting from recommendations or knowledge to manage the disease condition. Eg. Preparation of participant food separate from that of the rest of the household or not adding some specific ingredients during cooking	I eat with all of them but they know that I don't eat sugar, l don't eat salt so when they cook food they don't add much salt.
Withdrawal of HH member for economic activity or school	Has the illness resulted in any household member withdrawing from economic activity or school to provide care or support including accompaniment to hospital	The person providing the home-based care or accompanying participant to seek care should be engaging in some economic activity or attending school and has to withdraw to undertake such supporting activity for the participant. The withdrawal could be a day, short while or permanent.	*Even recently when he got sick I took him to Korle Bu. I was there the whole day and the following day too. I had to be there day to day*
Adaptive and coping mechanism	Means by which participant and household cope with the direct burden of the disease	The adaptive or coping mechanism must be directly linked to the NCD condition and not any other related.	*Because my daughter and the doctor have a connection [an arrangement], so she had given the doctor ….he takes care of me and where she is when she come back she immediately come and pay the bill.* *When I go to my doctor, I tell him the truth. He gives me on credit. He give me medicine if is 10, he can give me 5 and when I go and pay then I get another. He also helps me a lot*
Resource	Main sources of	The resource should be for	*I took my belongings like cloths and took them to the Makola*

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mobilization	health finance (including Primary and Secondary sources)	healthcare finance. These could be formal or informal. Eg. Selling house assert to purchase medication is directly linked to the disease condition. But if the selling of the assert is to pay school fees that should not come under this particular code	*[market] and sold them and took it to the hospital for care.* *I sold my rice cooker, cylinder brand-new empty one I sold it. I have also sold my gas cooker*
Health insurance	Insured or not insured, premium payment and benefits	The insurance status of participant (registered with valid card or not). The use of the insurance policy and the benefit.	*Oh the medical thing I have National Health [health insurance policy] you see. But now I have come home [retirement] the money given me too is small, is not enough so I have that problem financially* *Because I have their paper [Health Insurance], I don't spend much unless I am going have to take taxi and those things. Or if the medication is not available before I will go and buy*
Social support	Social support networks – individuals or groups	The social support of any kind should be support due to NCD condition. The support can be formal, informal, family and friends, within the household, community, country or outside.	*I get a lot of support from him and my stepsister. Their elder sister who their mother had her before coming to marry my father. Their father is Ewe and she is in America. She also I get a lot small small support from and also my children*

Appendix 4: Crude prevalence of non-communicable disease

NCD condition	Frequency	Percentage (%)	95% Confidence Interval	
			Lower	Upper
Stroke	15	0.6	0.3	1.0
Hypertension	134	5.3	4.5	6.5
Diabetes	22	0.9	0.5	1.3
Arthritis	10	0.4	0.2	0.7
Angina	1	0.0	0.0	0.2
Asthma	18	0.7	0.3	1.0
Cancer	1	0.0	0.0	0.2
Depression	2	0.1	0.0	0.2
Epilepsy	1	0.0	0.1	0.6
Sickle cell	1	0.0	0.0	0.2
Stomach ulcer	2	0.1	0.0	0.2
Knee/Walking disability	2	0.1	0.0	0.2
Eye disease (blindness)	1	0.0	0.0	0.2
Piles	1	0.0	0.0	0.2
Fibroid	1	0.0	0.0	0.2

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Appendix 5: Service covered under the National Health Insurance Scheme

Services

- Out-patient services – general and specialist consultations reviews, general and specialist diagnostic testing including, laboratory investigation, X-rays, ultrasound scanning, medicines on the NHIS Medicines list, surgical operations such as hernia repair and physiotherapy.
- In-patient services – General and specialist in patient care, diagnostic tests, medication-prescribed medicines on the NHIS medicines list, blood and blood products, surgical operations, in patient physiotherapy, accommodation in the general ward and feeding (where available).
- Oral health – pain relief (tooth extraction, temporary incision and drainage), dental restoration (simple amalgam filling, temporary dressing)
- Maternity care – antenatal care, deliveries (normal and assisted), Caesarean section, post-natal care
- Emergencies – these refer to crises in health situations that demand urgent attention such as medical emergencies, surgical emergencies, paediatric emergencies, obstetric and gynaecological emergencies and road traffic accidents.

Excluded services

- Appliance and prostheses including optical aids, heart aids, orthopaedic aids, dentures etc.
- Cosmetic surgeries and aesthetic treatment
- Anti-retroviral drugs for HIV
- Assisted Reproduction (e.g. artificial insemination) and gynaecological hormone replacement therapy.
- Echocardiography
- Photography
- Angiography
- Dialysis for chronic renal (kidney) failure
- Organ transplants
- All drugs that are not listed on the NHIS list
- Heart and Brain Surgery other than those resulting from accidents
- Cancer treatment other than breast and cervical
- Mortuary Services
- Diagnosis and treatment abroad
- Medical examinations for purposes other than treatment in accredited health facilities (e.g. Visa application, Education, Institutional, Driving license etc.)
- VIP wards (accommodation).

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Appendix 6: Mean comparison of household healthcare expenditure by household type

HH NCD status	Median	Mean	N	Std. Devi.	Maxi	Grouped Median	Skewedness
Never diagnosed	3.00	2.86	239	1.39	6.41	3.0097	-0.166
Diagnosed but did not treat	2.00	3.03	24	1.60	6.27	3.0307	0.425
Diagnosed and treated	3.40	3.34	58	1.11	5.53	3.4012	-0.294
Total	3.00	2.96	321	1.37	6.41	3.0396	-0.162

ANOVA Table

Source	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	11.08	2	5.542	2.969	0.053
Within Groups	593.51	318	1.866		
Total	604.59	320			

Note: This is computed from log transformed household healthcare expenditure data.

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Appendix 7: Mean comparison of household healthcare expenditure by household type

HH NCD status	Median	Mean	N	Std. Devi.	Maxi	Grouped Median	Skewedness
Never diagnosed	20	41.4	239	67.19	610	20.2857	4.295
Diagnosed but did not treat	20	76.73	24	151.81	530	20.75	2.505
Diagnosed and treated	30	47.87	58	48.56	251	30	1.839
Total	20	45.22	321	74.30	610	20.9	4.166

ANOVA Table

Source	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	27699.33	2	13849.66	2.532	0.081
Within Groups	1739076.80	318	5468.79		
Total	1766776.12	320			

Note: This is computed from data on households with healthcare expenditure greater then GH¢0.00

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Appendix 8: Ethical review and approval

This study was reviewed and approved by the institutional review board (IRB) of the Noguchi Memorial Institute for Medical Research (NMIMR) at the University of Ghana. The proposal for this study accompanied with the structured questionnaire for the household survey and the question guide used for the in-depth interview were submitted for ethical review and approval. The protocol was reviewed by the ethical review board and approved and given ethical clearance on 30th November 2011 – NMIMR-IRB CPN 038/11-12. All IRB protocols including voluntary participation, inform consent, confidentiality and respondent and data protection were strictly adhered to at all stages of the thesis both on field and off field.

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Appendix 9: Household questionnaire

URBAN POVERTY AND HOUSEHOLD CHRONIC NON-COMMUNICABLE DISEASE BURDEN

Household Questionnaire

IDENTIFICATION	
LOCALITY NAME* E.A. BASE ______ NAME OF HOUSEHOLD HEAD ______ E.A. /EDL NUMBER …………… STRUCTURE NUMBER…………… HOUSEHOLD NUMBER …………… GREATER ACCRA…………… * **CODES FOR LOCALITY NAME:** 1=AGBOGBLOSHIE 2=JAMES TOWN 3=USSHER TOWN	0 3

INTERVIEWER VISITS				
	1	2	3	FINAL VISIT
DATE INTERVIEWER'S NAME RESULT*				DAY MONTH YEAR 2 0 1 1 INT. CODE RESULT
Next visit: Date Time				TOTAL NO. OF VISITS

***RESULT CODES:** 1 COMPLETED 2 PARTLY COMPLETED 3 NO HOUSEHOLD MEMBER AT HOME OR NO COMPETENT RESPONDENT AT HOME AT THE TIME OF VISIT 4 ENTIRE HOUSEHOLD ABSENT FOR EXTENDED PERIOD OF TIME 5 POSTPONED 6 REFUSED 7 DWELLING VACANT OR ADDRESS NOT A DWELLING 8 DWELLING DESTROYED 9 DWELLING NOT FOUND 10 OTHER (SPECIFY) ______	TOTAL PERSONS IN HOUSEHOLD TOTAL ELIGIBLE WOMEN TOTAL ELIGIBLE MEN LINE NO. OF RESP. TO HOUSEHOLD QUEST.

LANGUAGE	
LANGUAGE OF QUESTIONNAIRE: **ENGLISH** LANGUAGE OF INTERVIEW** ______ NATIVE LANGUAGE OF RESPONDENT** ______ WAS TRANSLATOR USED? (YES=1, NO=2) …………… ****LANGUAGE CODES**: 1= ENGLISH 2 =AKAN 3= GA 4 =EWE 5 =DAGBANI 6= HAUSA 7= OTHER (SPECIFY) ______	1

SUPERVISOR	FIELD EDITOR	KEYED BY
NAME ______ DATE ______	NAME ______ DATE ______	

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INFORMED CONSENT HOUSEHOLD
Title: **Urban Poverty and Household Chronic Non-Communicable Disease Burden**
Principal Investigator: Henry Tagoe
Address: Regional Institute for Population studies, University of Ghana, Legon

General Information about Research
My name is .... from the Regional Institute for Population Studies (RIPS) at the University of Ghana. We are conducting a research in your community. This study aims at investigating the burden of chronic non-communicable disease at the household level in the context of urban poverty. We will ask you questions about general characteristics of your household and members of your household: the composition, age and sex, educational attainment, healthcare expenditure, how household healthcare expenditure is financed, social support network, etc. If you agree to be part of the study, the interview will last approximately 30 minutes and the responses you provide will be recorded in this questionnaire.
Possible Risks and Discomforts
There are no known physical, social and financial risks or discomforts associated with participating in this study.
Confidentiality
All information you provide for this study will be treat with strict confidentiality. We will protect all information about you to the best of our ability. You will not be named in any reports. Only academic advisers may have access to this research records.
Voluntary Participation and Right to Leave the Research
Participation in this research is voluntary, you have the right to withdraw at any point without penalty to you, and all information provided will be deleted from the study. Have I explained everything well enough to you? Do you have any questions for me?
Contacts for Additional Information
For additional information or any concern about this research after the interview, please contact the principal investigator Henry Tagoe on 0278134072 or at the Regional Institute for Population Studies, University of Ghana, Legon.
Your rights as a Participant
This research has been reviewed and approved by the Institutional Review Board of Noguchi Memorial Institute for Medical Research (NMIMR-IRB). If you have any questions about your rights as a research participant you can contact the IRB Office between the hours of 8am-5pm through the landline 0302916438 or email addresses: nirb@noguchi.mimcom.org or HBaidoo@noguchi.mimcom.org . You may also contact the chairman, Rev. Dr..Ayete-Nyampong through mobile number 0208152360 when necessary.

VOLUNTEER AGREEMENT

The above document describing the benefits, risks and procedures for the research title ***(Urban Poverty and Household Chronic Non-Communicable Disease Burden)*** has been read and explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate as a volunteer.

__________________ __________________
Date Name and signature or mark of volunteer

Thumb print

If volunteers cannot read the form themselves, a witness must sign here:
I was present while the benefits, risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

______________________ ____________________________________
Date Name and signature of witness
I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual.

______________________ ____________________________________
Date Name Signature of Person Who Obtained Consent
START TIME FOR INTERVIEW HOURS MINS

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HOUSEHOLD SCHEDULE

I would like some information about the people who usually live in your household or who are staying with you now.

LINE NO.	USUAL RESIDENTS AND VISITORS	RELATION-SHIP TO HEAD OF HH	SEX	RESIDENCE			AGE	ELIGIBILITY		
	Please give me the names of the persons who usually live in your household and guests of the household who stayed here last night, starting with the head of the household.	What is the relationship of (NAME) to the head of the household?*	Is (NAME) male or female?	Does (NAME) usually live here? (6months or more)	Did (NAME) sleep here last night? **YES→**8	Why did (NAME) not sleep here last night?**	How old is (NAME)?	CIRCLE LINE NUMBER OF ALL CHILDREN UNDER AGE 5	CIRCLE LINE NUMBER OF ALL WOMEN AGE 15- 49	CIRCLE LINE NUMBER OF ALL MEN AGE 15-59
(1)	**(2)**	**(3)**	**(4)**	**(5)**	**(6)**	**(7)**	**(8)**	**(9)**	**(10)**	**(11)**
01			M F 1 2	YES NO 1 2	YES NO 1 2		IN YEARS	01	01	01
02			M F 1 2	YES NO 1 2	YES NO 1 2		IN YEARS	02	02	02
03			M F 1 2	YES NO 1 2	YES NO 1 2		IN YEARS	03	03	03
04			M F 1 2	YES NO 1 2	YES NO 1 2		IN YEARS	04	04	04
05			M F 1 2	YES NO 1 2	YES NO 1 2		IN YEARS	05	05	05

TICK HERE IF CONTINUATION SHEET USED | **NUMBER OF ELIGIBLE WOMEN** | **BER OF ELIGIBLE MEN**

*** CODES FOR Q3** **RELATIONSHIP TO HEAD OF HOUSEHOLD:**

01 = HEAD
02 = SPOUSE
03 = SON OR DAUGHTER
04 = SON-IN-LAW/DAUGHTER-IN-LAW
05 = GRANDCHILD
06 = PARENT
07 = PARENT-IN-LAW
08 = BROTHER/SISTER
08 = BROTHER/SISTER
09 = CO-WIFE
10 = ADOPTED/FOSTER/STEP-CHILD
11= OTHER RELATIVE (AFFINAL)
12= OTHER RELATIVE (CONSANGUINE)
13= NOT RELATED
98=DON'T KNOW

****CODES FOR Q7**

01=AT WORK 02=NO SPACE FOR SLEEPING 03=TRAVELLED 04=BOARDING HOUSE 98=DON'T KNOW

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LINE NO.		EDUCATION (IF AGE 3 OR OLDER and IF ATTENDED SCHOOL)			IF AGE 15 OR OLDER MARITAL STATUS	ETHNICITY	RELIGION
	Has (NAME) ever attended school? **NO→16**	What is the highest level of education (NAME) attended?*	What is the highest grade (NAME) completed at that level?**	**IF AGE IS LESS THAN 25 YEARS** Is (NAME) still in school?	What is the marital status of (NAME)? ***	What is the ethnic group of (NAME)? ****	What is the religion of (NAME)? *****
	(12)	**(13)**	**(14)**	**(15)**	**(16)**	**(17)**	**(18)**
01	YES NO 1 2			YES NO 1 2		OTHER SPECIFY …………………. …………………	
02	YES NO 1 2			YES NO 1 2		OTHER SPECIFY …………………. …………………	
03	YES NO 1 2			YES NO 1 2		OTHER SPECIFY …………………. …………………	
04	YES NO 1 2			YES NO 1 2		OTHER SPECIFY …………………. …………………	
05	YES NO 1 2			YES NO 1 2		OTHER SPECIFY …………………. …………………	

Just to make sure that I have a complete listing:

1) Are there any other persons such a small children or infants that we have not listed? YES → ENTER EACH IN TABLE NO
2) In addition, are there any other people who may not be members of your HH, such as domestic servants, lodgers or friends who usually live here? YES → ENTER EACH IN TABLE NO
3) Are there any guests or temporary visitors staying here, or anyone else who slept here last night that I have not listed? YES → ENTER EACH IN TABLE NO (SKIP ONE ROW)
4) Are there any persons who used to live in your household but have moved out in the past 1 year? YES → ENTER EACH IN TABLE NO

HOW MANY?

***CODES FOR Q13**
0=PRE-SCHOOL 1=PRIMARY 2=JHS/MIDDLE 3=SHS/SECONDARY 4=HIGHER 8=DON'T KNOW

****EDUCATION GRADE Q14**
00=LESS THAN 1 YEAR 98=DON'T KNOW

*****CODES FOR Q16**
0=NEVER MARRIED 1= LIVING TOGETHER 2= MARRIED 3= SEPARATED 4=DIVORCED 5= WIDOWED

******CODES FOR Q17**
01=AKAN 03=EWE 05=GURMA 07=GRUSI 96=OTHER (SPECIFY) **RECORD ADJACENT TO TO THE CODE ABOVE.**
02=GA-DANGME 04=GUAN 06=MOLE-DAGBANI 08=MANDE

*******CODES FOR Q18**
01= NO RELIGION 03= PROTESTANTS 05=OTHER CHRISTIAN 07=TRADITIONAL/SPIRITUALIST 96=OTHER (SPECIFY)………..
02= CATHOLIC 04= PENTECOSTAL/CHARISMATIC 06=ISLAM 08=EASTERN RELIGIONS

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LINE NO.	**DISABILITY**	**FOR VISITORS AND USUAL RESIDENTS**	**VISITORS ONLY**	**FOR FORMER RESIDENTS/VISITORS ONLY**	**If person was a household member in EDUL 2010, but is now NOT a household member, continue with Q023. If person is a NEW household member or was household member in 2010 and is still a household member today, move to NEXT SECTION**		
	Does (NAME) have any serious disability that limits his/her full participation in life activities?*	**FOR VISITORS:** How long has (NAME) been staying here? ** **FOR USUAL RESIDENTS** How long has (NAME) lived in this household? **	Where did (NAME) come from?	**ONLY IF '2' IS CIRCLED IN BOTH COLS. 5 and 6** How long did (NAME) live here before moving out?**	Was (NAME) a member of this household during the 2010 EDUL survey? 1=YES → **Q26** 2=NO	What is the reason for [NAME]'s absence?	Where did [NAME] go to?
	(19)	**(20)**	**(21)**	**(22)**	**(23)**	**(24)**	**(25)**
01							
02							
03							
04							
05							

***CODES FOR Q19**
0=NO DISABILITY
1=SIGHT (BLIND, VISUAL LIMITATION)
2=HEARING (DEAF, HARD AT HEARING)
3=COMMUNICATING (SPEECH IMPAIRMENT)
4=PHYSICAL (e.g. NEEDS WHEEL CHAIR, CLUTCHES OR PROSTHESIS, LIMB, HAND USAGE LIMITATIONS)
5=INTELLECTUAL (SERIOUS DIFFICULTIES IN LEARNING)
6=EMOTIONAL (BEHAVIOURAL, PSYCHOLOGICAL)
8=OTHER (SPECIFY)……………………………

CODES FOR Q21
1= WITHIN THE SAME COMMUNITY
2= ANOTHER COMMUNITY IN ACCRA
3= ANOTHER TOWN
4= RURAL
5= BOARDING SCHOOL
8=DON'T KNOW

****CODES FOR Q20 AND Q22**
1= DAY
2= WEEKS
3=MONTHS
4= YEARS
5=SINCE BIRTH
8=DON'T KNOW

CODES FOR Q24
01 = EMPLOYMENT
02 = LOOKING FOR WORK
03 = SCHOOL
04 = VISIT FAMILY
05 = VISIT FRIENDS
06 = MARRIAGE/COHABITATION
07 = PERSONAL REASONS
08 = ESCAPE VIOLENCE OR POLITICAL PROBLEMS
09 = PRISON
10 = HOSPITAL /CLINIC
11 = NURSING HOME/OLD PERSONS HOME
12 = DIED _ go to Next HH member
87 = OTHER, SPECIFY………..

CODES FOR Q25
1 = DIFFERENT HOUSEHOLD IN SAME COMMUNITY/LOCALITY/ NEIGHBOURHOOD
2 = RURAL AREA IN DIFFERENT PART OF THE COUNTRY
3 = CITY IN DIFFERENT PART OF THE COUNTRY
4 = RURAL AREA IN ANOTHER COUNTRY
5 = CITY IN ANOTHER COUNTRY
88 = DON'T KNOW

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HEALTH INSURANCE, DISABILITY AND HOME-BASED CARE

LINE NO.	Does (NAME) have **health insurance** coverage?	Does [NAME] need care due to is/her health condition, such as a long-term physical or mental illness or disability, or because he/she is getting old and weak? 1=YES 2=NO→Q29	How much care does he/she need?	Is [NAME] presently in an institution (hospital, after care home, home for the aged, hospice) due to his/her health condition? 1=YES 2=NO
	(26)	**(27)**	**(28)**	**(29)**
01	☐	☐	☐	☐
02	☐	☐	☐	☐
03	☐	☐	☐	☐
04	☐	☐	☐	☐
05	☐	☐	☐	☐

CODES FOR Q23
1 = Yes, mandatory insurance
2 = Yes, voluntary insurance
3 = Yes, both mandatory and voluntary insurance
4 = No, none.

CODES FOR Q25
1 = Needs help/watching all the time (day and night)
2 = Cannot be without help/watching or be left alone at home for more than an hour
3 = Can be left on his/her own at home for several hours but requires accompaniment when leaving home
4 = Needs some help at home and sometimes needs to be accompanied when leaving home

CHRONIC NON-COMMUNICABLE DISEASE CONDITIONS

LINE NO.	Has (Name) ever been told by a health professional that you have had a **stroke**? 1. YES 2. NO→ **Q33**	Is (Name) taking any medications or other treatment for it… a. During the last 2 weeks? 1. YES 2. NO	Is (Name) taking any medications or other treatment for it… b. During the last 12 months? 1. YES 2. NO	Has (Name) ever been diagnosed with high blood pressure (**hypertension**)? 1. YES 2. NO→**Q36**	Is (Name) taking any medications or other treatment for it during … (Other treatment might include weight loss program or change in eating habits.) a. During the last 2 weeks? 1. YES 2. NO	Is (Name) taking any medications or other treatment for it during … (Other treatment might include weight loss program or change in eating habits.) b. During the last 12 months? 1. YES 2. NO
	(30)	**(31)**	**(32)**	**(33)**	**(34)**	**(35)**
01	☐	☐	☐	☐	☐	☐
02	☐	☐	☐	☐	☐	☐
03	☐	☐	☐	☐	☐	☐
04	☐	☐	☐	☐	☐	☐
05	☐	☐	☐	☐	☐	☐

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CHRONIC NON-COMMUNICABLE DISEASE CONDITIONS							
LINE NO.	Has (Name) ever been diagnosed with **diabetes** (high blood sugar)? (Not including diabetes associated with a pregnancy) 1. YES 2. NO → Q39	Is (Name) taking insulin or other blood sugar lowering medications… a. During the last 2 weeks? 1. YES 2. NO	Is (Name) taking insulin or other blood sugar lowering medications … b. During the last 12 months? 1. YES 2. NO	Has (Name) ever been diagnosed with any other chronic non-communicable disease apart from conditions mentioned in (Q40, Q42, and Q44 - Stroke, hypertension and diabetes) 1. YES 2. NO → **Q43**	If Yes in Q46, please specify: ***(Interviewer, record all mention)***	Is (Name) taking any medication or therapy for the condition… a. During the last 2 weeks? 1. YES 2. NO	Is (Name) taking any medication or therapy for the condition… b. During the last 12 months? 1. YES 2. NO
	(36)	**(37)**	**(38)**	**(39)**	**(40)**	**(41)**	**(42)**
01							
02							
03							
04							
05							

Code For Q40
1=ARTHRITIS **2**=ANGINA **3**=ASTHMA **4**=CANCER **5**=DEPRESSION 6= OTHER

HOUSEHOLD ASSETS

NO.	QUESTION	RESPONSE	SKIP
43.	What is the main source of drinking water for members of your household? **PIPED WATER** 11=PIPED INTO DWELLING/INDOOR 12=PIPED TO YARD/PLOT 13=PUBLIC TAP/STANDPIPE 21=TUBE WELL OR BOREHOLE **DUG WELL** 31=PROTECTED WELL 32=UNPROTECTED WELL **WATER FROM SPRING** 41=PROTECTED SPRING 42=UNPROTECTED SPRING 51=RAINWATER 61=TANKER TRUCK 71=CART WITH SMALL TANK 81=SURFACE WATER (RIVER/DAM/LAKE/POND/STREAM) 91=BOTTLED WATER 92=SACHET WATER 96=OTHER (SPECIFY)...................		
44.	What kind of toilet facility does your household use? 1=NO FACILITY (BUSH/BEACH/FIELD) 5=BUCKET/PAN 2=WATER CLOSET (W.C)/FLUSH TOILET 6=PUBLIC TOILET (W.C,KVIP, PIT LATRINE,BUCKET/PAN) 3= KVIP 8=OTHER (SPECIFY)………………… 4= PIT LATRINE		
45.	What is the main source of cooking fuel for this household? 01=NONE/NO COOKING 04=ELECTRICITY 07=CROP RESIDUE 02= WOOD 05=KEROSINE 08=SAW DUST 03 = GAS 06=CHARCOA 09=ANIMAL WASTE 10=OTHER (SPECIFY)……		

46.	Does your household have:	YES	NO
	a. A CAR	1	2
	b. A MOTORCYCLE	1	2
	c. A BICYCLE	1	2
	d. A BOAT/CANOE	1	2
	e. A TRUCK	1	2
	f. AN OUTBOARD MOTOR	1	2
	g. A REFRIGERATOR	1	2
	h. A FREEZER	1	2
	i. A GENERATOR	1	2
	j. A WASHING MACHINE	1	2
	k. A TELEVISION	1	2
	l. A RADIO	1	2
	m. A TELEPHONE	1	2
	n. A CLOCK	1	2
	o. AN ELECTRIC/GAS STOVE	1	2
	p. A SOFA SET	1	2
	q. A SEWING MACHINE	1	2
	r. AN ELECTRIC FAN	1	2
	s. A COMPUTER	1	2
	t. FISHING NET	1	2

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47.	In general, would you say that you/your household has: 1=MORE MONEY THAN YOU NEED 2=JUST ENOUGH MONEY 3=LESS MONEY THAN YOU NEED		
48.	Who is the primary source of income for this household? 1=HEAD OF HOUSEHOLD 2=PARTNER 3=BOTH SHARED EQUALLY (HEAD AND SPOUSE) 4= A DIFFERENT MEMBER OF THE HOUSEHOLD 8=OTHER(SPECIFY)..		
49.	How do you feel about the economic opportunities available to you in this community? 1=VERY DISSATISFIED 2=DISSATISFIED 3=INDIFFERENT 4=SATISFIED 5=VERY SATISFIED		
50.	How much can you rely on relatives outside of your household or friends for financial support if you need it? 1=A LOT 2=SOME 3=A LITTLE 4=NOT AT ALL		
51.	What is the present holding/tenancy arrangement of this dwelling? 1=OWNING 2=RENTING 3=RENT FREE 4=PERCHING 5=SQUATTING 6=OTHER (SPECIFY) ……………………		
52.	Who owns this dwelling? 1=OWNED BY HH MEMBER 2=BEING PURCHASED (e.g., Mortgage) 3=RELATIVE NOT HH MEMBER 4=OTHER PRIVATE INDIVIDUAL 5=PRIVATE EMPLOYER 6=OTHER PRIVATE AGENCY 7=PUBLIC/GOVERNMENT OWNERSHIP 8=OTHER (SPECIFY)		
53.	How many rooms does this household occupy? **(COUNT LIVING, DINING, BEDROOMS BUT NOT BATHROOMS ,TOILET and KITHCEN)**	**NO. OF ROOMS**	
54.	How many of the rooms are designed primarily for sleeping?	**NO.**	
55.	How many household members sleep outside the rooms? **CODE 00 IF NO HOUSEHOLD MEMBER SLEEPS OUTSIDE**	**NO.**	
56.	What type of dwelling does this household occupy? **RECORD OBSERVATION** 01=SEPARATE HOUSE 02=SEMI-DETACHED HOUSE 03=FLAT/APARTMENT 04=ROOMS 05=SEVERAL HUTS/ BUILDING 06=TENT 07=KIOSK 08= CONTAINER 09= ATTACHED TO SHOP 10= COMPOUND HOUSE 96=OTHER (SPECIFY) ________________________		
57.	What is the main material of the floor? **RECORD OBSERVATION** 01=EARTH/SAND 07=WOOLEN CARPET 02=BURNT BRICKS 08=LINOLEUM/RUBBER CARPET 03=CEMENT/CONCRETE 09=CERAMIC TILES/PORCELAIN GRANITE/MARBLE 04=WOOD 10=VINYL TILES 05=WOOD PLANKS 11=STONE 06=TERRAZO 96=OTHER (SPECIFY)..................................		
58.	What is the main material of the roof? **RECORD OBSERVATION** 01=THATCH/PALM LEAF/SOD 06=ROOFING SHINGLES 02=RUSTIC MAT 07=ASBESTOS/SLATE ROOFING SHEETS 03=CARDBOARD 08=PALM/BAMBOO 04=METAL SHEETS 09=WOOD 05=BRICK TILES 10=CEMENT 96=OTHER (SPECIFY)................................		
59.	What is the main material of the wall? **RECORD OBSERVATION** 01=CANE/PALM/TRUNKS 08=MUD BRICKS 02=BAMBOO WITH MUD 09=STONE WITH MUD 03= WOOD 10= PLYWOOD 04=CARDBOARD 11=BAMBOO 05=LANDCRETE 12=CEMENT BLOCKS/CONCRETE 06=BURNT BRICKS 07=METAL SHEETS/SLATE/ASBESTOS 96=OTHER (SPECIFY)...		

HOUSEHOLD AND FAMILY SUPPORT NETWORKS AND TRANSFERS

The next questions are about your family and friends, specifically those not living with you in this household. Families and friends sometimes help one another in a variety of different ways, and each type of help or support can be important. Part of our survey involves finding out how they do that. We would now like to ask some questions about your family and friends who do not live with you, and the different ways in which you help or support each other. The next questions are about help received by your household in the last 12 months.

60.	In the last 12 months, has anyone in the household **received** any financial or in-kind support from your family (children, siblings or parents) and relatives (other kin) who do not live with you? 01=YES 02=NO 98=DON'T KNOW		**IF CODE 01 OR 98 SKIP TO Q64**
61.	What type of assistance did your household receive? 1=MONEY 2=KIND 3=OTHER (Specify)…………………		
62.	What is/are the main purpose of these supports? a. ……………………………………………………… b. ……………………………………………………… c. ………………………………………………………		
63.	About how much would this assistance amount to over the last 12 months (GH₵)*(if in kind impute and*	GH₵	

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	estimate the value)		
64.	In the last 12 months, has your household **provided** any financial aid or in-kind support to any of your children, grandchildren and/or other family (and those of your spouse) who do not live in this household? 01=YES 02=NO 98=DON'T KNOW		**IF CODE 01 OR 98 SKIP TO Q68**
65.	What type of assistance did your household receive? 1=MONEY 2=KIND 3=OTHER (Specify)…………………		
66.	What is/are the main purpose of these supports? a. ……………………………………………………… b. ……………………………………………………… c. ………………………………………………………		
67.	Can you give an approximate total amount for this for the last 12 months (GHC)***(if in kind impute and estimate the value)***	GHC	
68.	During the past year, did you or someone in your household provide help to a relative or friend (adult or child), because this person has a long-term physical or mental illness or disability, or is getting old and weak? 1=YES, for a person living in the same household 2=YES, for person living in separate household 3=NO		

			YES	NO
69.		Please tell me the kind of care was provided:	YES	NO
	a	You helped with personal care, such as going to the toilet, washing, getting dressed, and eating	1	2
	b	You helped with medical care, like changing bandages and giving medicines	1	2
	c	You helped with household activities, such as meal preparation, shopping, cleaning, laundry	1	2
	d	You watched over them since their behaviour can be upsetting or dangerous to themselves or others	1	2
	e	You helped them to get around outside the home	1	2

HOUSEHOLD EXPENDITURE

I would like to ask you more specific questions about how much your household and all its members spent in cash or in-kind on all health care and services that did not require an overnight stay. Again, we want expenses in the last 30 days. If payment was in-kind, please estimate a monetary value. Please exclude costs to be reimbursed by insurance.

70.		In general, what is your household's average overall monthly spending?	GHC	
		In the last 30 days, how much did your household spend on:		
71.	i	Food, including such things as [rice], meat, fruits, vegetables, and cooking oils. Include the value of any food that was produced and consumed by the household, and exclude alcohol, tobacco and restaurant meals.	GHC	
	ii	Housing, gas, electricity, water, telephone, and heating fuel	GHC	
	iii	Education fees and supplies	GHC	
	iv	Health care costs, excluding any insurance reimbursements	GHC	
	v	Voluntary insurance premiums or prepaid health plans	GHC	
	vi	All other goods and services	GHC	
		In the last 30 days, how much did your household spend on:		
72.	I	Registration and consultation fees by doctors or medical health professional (s) that did not require an overnight stay?	GHC	
	Ii	Health care by traditional or alternative healers (masseur, herbalist, acupuncture or aromatherapy practitioners,)?	GHC	
	Iii	Diagnostic and laboratory tests such as X-rays or blood tests?	GHC	
	Iv	Medications or drugs (prescription, non-prescription, traditional, homeopathic…)?	GHC	
	V	Dentists or dental care?	GHC	
	Vi	Ambulance or transportation	GHC	
	vii	Any other health care products or services that were not included above? Specify………………………	GHC	
		Total health care expenditure in the last 30 day	GHC	

END TIME FOR INTERVIEW HOURS MINS

RESPONDENT: Comments/questions

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INTERVIEWER: Comments/observations

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Appendix 10: Individual interview guide

URBAN POVERTY AND HOUSEHOLD CHRONIC NON-COMMUNICABLE DISEASE BURDEN

Interview guide

INFORMED CONSENT
Title: **Urban Poverty and Household Chronic Non-Communicable Disease Burden**
Principal Investigator: Henry Tagoe
Address: Regional Institute for Population studies
University of Ghana, Legon

General Information about Research
My name is .... from the Regional Institute for Population Studies (RIPS) at the University of Ghana. We are conducting a research in your community. This study aims at investigating the burden of chronic non-communicable disease at the household level in the context of urban poverty. How individuals living with at least one of the following ill health conditions: stroke, hypertension and diabetes manage their day-to-day life, their health-seeking behaviour and social and family support in management and care. This research involves individual in-depth interviews using a semi-structured interview guide with questions covering areas including respondent sex, age, marital status, employment status (including occupation), number of children ever born, religious affiliation, household size the type of chronic disease condition(s) respondent currently living with, effects of the disease condition on everyday life activities of the individual and the household, adaptive and coping mechanisms, sources of payment for healthcare, social support network and healthcare expenditure. If you agree to be part of the study, the interview will last approximately 50 minutes and the conversation will be recorded and transcribed later.

Possible Risks and Discomforts
There are no known physical, social and financial risks or discomforts associated with participating in this study.

Confidentiality
All information you provide for this study will be treat with strict confidentiality. We will protect all information about you to the best of our ability. You will not be named in any reports. Only academic advisers may have access to this research records.

Voluntary Participation and Right to Leave the Research
Participation in this research is voluntary, you have the right to withdraw at any point without penalty to you, and all information provided will be deleted from the study. Have I explained everything well enough to you? Do you have any questions for me?

Contacts for Additional Information
For additional information or any concern about this research after the interview, please contact the principal investigator Henry Tagoe on 0278134072 or at the Regional Institute for Population Studies, University of Ghana, Legon.

Your rights as a Participant
This research has been reviewed and approved by the Institutional Review Board of Noguchi Memorial Institute for Medical Research (NMIMR-IRB). If you have any questions about your rights as a research participant you can contact the IRB Office between the hours of 8am-5pm through the landline 0302916438 or email addresses: nirb@noguchi.mimcom.org or HBaidoo@noguchi.mimcom.org . You may also contact the chairman, Rev. Dr.Ayete-Nyampong through mobile number 0208152360 when necessary.

VOLUNTEER AGREEMENT
The above document describing the benefits, risks and procedures for the research title ***(Urban Poverty and Household Chronic Non-Communicable Disease Burden)*** has been read and explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate as a volunteer.

________________________ __________________________________
Date Name and signature of witness Date Name and signature or mark of volunteer

Thumb print

If volunteers cannot read the form themselves, a witness must sign here:
I was present while the benefits, risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

______________ ____
Date Name and signature of witness

I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual.

___________________________ ____
Date Name Signature of Person Who Obtained Consent

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INTERVIEW GUIDE

A: Respondent demographics

1. Demographics – sex, age, marital status, employment status (including occupation), number of children ever born, religious affiliation, household size, ethnicity, any social support group or network

B: Chronic disease condition and biographical disruptions

2. Which chronic disease are you currently living with?
    a. Identify all other conditions as well as other disease conditions (co-morbidity – NCDs and infectious disease conditions)

3. Length of living with the condition – year and month diagnosed with the condition.
   Estimate age at first diagnosis of the disease condition, where diagnosed

4. How was condition diagnosed – experiences (before and after)
    a. Probe for signs and symptoms
    b. Examine the issue of healer shopping
    c. Current health seeking behaviour

5. Any significant changes or modification of life after diagnoses
    a. Home or accommodation rearrangement,
    b. If not employed is that due to ill health condition.
    c. If employed, any significant effect of ill health on productivity

6. Making meaning of the current conditions
    a. Illness experience – experiences living with the disease condition such as emotional, physical, support (family (immediate and extended) and friends), and social – neighbours and social groups.

C: Household disruptions

7. How respondent illness has directly and indirectly affect other member(s) of the household
    a. Rearrangement of living space/accommodation
    b. Withdrawal of household member from economic activities or schooling to provide home based care and support.

D: Adaptive and coping mechanisms

8. How do you cope with your condition

E: Resource mobilisation

9. How do you finance your health care expenditure (Health Insurance/out-of-pocket)
    a. Respondent insured under any health insurance policy
    b. If yes to health insurance, was it before diagnosis of the condition, or after
        i. If after why?
    c. How insurance premium is paid
    d. Benefit of health insurance to respondent, level of satisfaction of services under the insurance scheme, intention to renew insurance policy.

10. Source of health finance
    a. Source of health finance (distinguishing between primary and secondary sources)
    b. Ever sold household or personal asset or property to finance health care expenditure

F: Social support networks

a. Is there any family member or any individual you depend on for care and support
b. Are there any support group you belong to
c. If any, how important is such groups to you

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G: Healthcare expenditure in the last 30 days

I would like to ask you more specific questions about how much your household and all its members spent in cash or in-kind on all health care and services that did not require an overnight stay in relation to your health. We want expenses in the last 30 days. If payment was in-kind, please estimate a monetary value. Please exclude costs to be reimbursed by insurance.

In the last 30 days, how much did your household spend on:								
I	Registration and consultation fees by doctors or medical health professional (s) that did not require an overnight stay?	GHȻ						
Ii	Health care by traditional or alternative healers (masseur, herbalist, acupuncture or aromatherapy practitioners,)?	GHȻ						
Iii	Diagnostic and laboratory tests such as X-rays or blood tests?	GHȻ						
Iv	Medications or drugs (prescription, non-prescription, traditional, homeopathic…)?	GHȻ						
V	Dentists or dental care?	GHȻ						
Vi	Ambulance or transportation	GHȻ						
Vii	Any other health care products or services that were not included above? Specify……………………………………	GHȻ						

Are you engaged in any economic activity that you earn some form of income?
How much do you earn on the average in a month?

GHȻ						

Thank you for your attention and corporation. Do you have any question, comments or suggestions or any experiences you would want to share with this study?
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INTERVIEWER: Comments/observations
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