# "What the mind does not know, the eyes do not see": understanding the emerging health risk of food allergy in Ghana

by George Atiim

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This thesis consists of material all of which I authored or co-authored: see Statement of Contributions included in the thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

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#### **Statement of Contributions**

This thesis consists in part of three manuscripts that have been submitted for publication. Exceptions to sole authorship:

## Chapter 3:

Atiim, A. G., Elliott, S. J. and Clarke, A. E. (2017). "If we waiting for numbers, we will miss the point": a qualitative study of the perceived rise in food allergy and associated risks in Ghana. *Global Health Research and Policy*. 2:20. DOI: 10.1186/s41256-017-0040-0

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I declare that as lead author, I was responsible for conceptualizing the research, data collection and analysis. Also, I was responsible for preparing drafts of articles, submission to peer reviewed journals as well as addressing comments from reviewers. Co-authors played key supervisory roles, providing critical feedbacks and reflections in data collection and draft of manuscripts. As the principal supervisor, Dr. Susan Elliott provided significant research direction and editorial assistance.

#### **Abstract**

The epidemiologic transition demonstrates a relationship between infectious disease decline and the rise of chronic disease. In many developed countries, as rates of infectious disease fell from the 19<sup>th</sup> century, several chronic diseases including cardiovascular, cancers, and allergies evolved as critical public health problems. In developing countries, similar changes in population health and disease are occurring as chronic diseases have become an important health issue requiring urgent interventions. However, much of public health and research directions remain focused on the most common chronic diseases – heart disease, diabetes, cancers and chronic respiratory diseases. There is limited understanding of the health risk of allergic disease in developing countries.

This thesis examines the emerging risk of allergic disease, with particular emphasis on food allergies, in Ghana, a lower-middle income country (LMIC) in sub-Saharan Africa experiencing rapid challenges in its population health. The broad objectives of the research were: to explore the perceptions, risk factors and coping strategies associated with food allergy and to understand how the local context shapes risk perceptions, practices and food allergy management. The thesis adopts a qualitative research approach – in-depth interviews and documentary review – to address the research objectives.

The results reveal that food allergies are a growing health issue in Ghana, though often unrecognized in the community and at healthcare settings. Results also indicate that there are significant psychological (e.g. anxiety and fear), social (e.g. stigmatization, social exclusion), and economic (e.g. impact on work & household expenditures) impacts on the wellbeing of those affected by food allergy. Further, the findings reveal the importance of broader sociopolitical, and sociocultural factors such as the lack of policy, inadequate financial resources and cultural norms and how these shape risk perceptions, diagnostic practices and management of food allergy.

The research makes several important contributions. First, by integrating several theoretical perspectives, this research sheds light on the epidemiology of food allergy by revealing the contextual factors influencing risk perceptions, experiences and disease management. In doing so, the research proposes a framework for understanding emerging health risks within LMIC contexts. Further, the research enhances understanding of the impacts of food allergy on the health, social and economic wellbeing of the affected population. Second, the research also makes methodological contributions by demonstrating how a qualitative research design can provide a pathway to understand the rise of food allergy in contexts where data is limited. In addition, it demonstrates the importance of

inductive knowledge as a first step toward identifying allergic individuals, and key food allergens in resource-constrained settings. Third, from a policy perspective, the research highlights the need for public health policies to incorporate allergic disease in the broader chronic disease prevention agenda, as well as addressing individual, community and structural factors that act to constrain food allergy risk perception, and management.

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# **Dedication**

This work is dedicated to Edward K. Atiim and Mildred A. Adeetuk

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#### **CHAPTER ONE**

"Genes are not Stalinist dictators. They live in a democracy, and what they do is conditioned by what else is going on around them".

David J. P. Barker

## 1.1 Introduction and research problem

Between the 17<sup>th</sup> and 19<sup>th</sup> centuries, infectious diseases constituted major public health problems and were the most common cause of (ill)health and mortality (Mercer, 2014, McKeown, 2009; Omran, 1971). In the United States, as in many parts of the Western world, pneumonia, tuberculosis (TB) and diarrhea accounted for 1 in 3 deaths in 1900, 40% of which were infant deaths (CDC, 1999). Along with malaria, and TB were other important concerns including influenza, smallpox, diphtheria, and scarlet fever, which together imposed significant human suffering on the lives of many Europeans (Jensen and De Fine Licht, 2016; Mercer, 2014). These infectious diseases produced acute short term sickness and high mortality, consequently limiting life expectancy – life expectancy was estimated to be between 30-40 years (Mercer, 2014, Omran, 1971).

In the following decades, significant improvements in living standards, enhanced nutrition, housing, sanitary reforms and personal hygiene practices, combined with advances in medicine contributed to a significant fall in infectious disease mortality (Mercer, 2014, Defo, 2014; McKeown, 2009) increasing life expectancy (Mensah et al., 2017). As historical accounts suggest, as rates of infectious disease fell (and in some cases even disappeared), a range of chronic diseases<sup>1</sup> evolved, replacing infectious diseases as major causes of mortality (Mercer, 2014; Stuckler and Basu, 2011; Omran, 1971). This process is commonly referred to

<sup>-</sup>

<sup>&</sup>lt;sup>1</sup> Chronic diseases often (1) have multiple but shared risk factors; (2) may occur at any point in a person's life (3) is persistent and tend to be long lasting; (4) not at present curable but can be controlled through medication or therapy. Though some infectious diseases such as HIV and AIDS, hepatitis, and Chagas are chronic in nature, the term is used in a restricted sense referring collectively to noncommunicable diseases (NCDs) such as heart diseases, diabetes, cancers, allergies and autoimmune diseases etc.

as the epidemiologic transition, first occurring in the developed world in the 20<sup>th</sup> century and subsequently in most other parts of the world. In England and Wales, cardiovascular diseases (CVDs) accounted for only 5% of deaths in the mid-ninetieth century, rising to 15% at the dawn of the twentieth century and more than tripling (48%) by 1951 (Mercer, 2014). In the United States, heart disease and cancer ranked as the 4<sup>th</sup> and 8<sup>th</sup> leading causes of death in 1900, yet by 1960, these diseases were 1<sup>st</sup> and 2<sup>nd</sup> (Grove and Hetzel, 1968).

Around the same time, allergic diseases – hay fever, asthma, eczema – appear to have followed a similar rise (Jackson, 2006; Bach, 2002). In a sense, allergies were also filling the "epidemiological vacuum left by the retreat of infectious disease..." (Inglis, 1981 in Jackson, 2006, p.17). By 1941, about 6 million people suffered from hay fever, and between 600, 000 and 3.5 million people lived with asthma in the United States (Vaughan, 1941 in Jackson, 2006). In England, the proportion of people consulting physicians (GPs) for asthma more than doubled from 8.5 to 17.8 per 1,000 between 1955-56 and 1981-1982 respectively (Jackson, 2006.). By the millennium, as incidence and prevalence of asthma, eczema and rhinitis stabilized – at least in the developed world - new waves of allergies – food allergies, were assuming epidemic proportion, particularly among children (Prescott and Allen, 2011). While allergies have low case fatality when compared to other chronic conditions (e.g. CVDs, cancers, diabetes), they engender significant psychosocial health issues, and add considerable healthcare costs to individuals (Primeau et al., 2000; Gupta et al., 2013, Patel, 2011).

Similar changes in population health and disease are now occurring in many developing countries. An estimated 80% of global deaths from chronic diseases now occur in developing countries (WHO, 2011a), and even in sub-Saharan Africa (SSA) where infectious disease persists, they are responsible for at least 20% of adult deaths (WHO, 2014a). Analysis of future trends suggest that deaths from chronic disease will continue to rise, with

projections indicating an increase from a rate of 46% in 2002 to 59% by 2030 (Stuckler, 2008). Coupled with this projected increase is growing evidence that lifestyles and behaviours are changing throughout the population. For instance, smoking, drinking alcohol, consuming unhealthy diets, and limited physical activity (i.e. key risk factors) have become prevalent in developing countries (Allen et al., 2017), increasing the risk of chronic illness in these populations.

Since the early 1990s, evidence in developing countries also points to an increase in rates of respiratory and skin allergies similar to rates in developed countries (Lai et al., 2009, Asher et al., 2006). For example, the ISAAC<sup>2</sup> multi-country studies found comparable high prevalence of current wheeze in children 13-14 years with symptoms of "severe asthma" recorded in Africa (51%), Asia Pacific (40), North America (48.6%) and Western Europe (40.8%). In lower age groups (6-7 years), similar high rates were observed (Lai et al., 2009). Country-level analysis in Africa demonstrates that asthma is a major public health risk which is rising in prevalence in urban communities and among populations with high socioeconomic status (SES). This suggests the potential role of environmental determinants associated with urbanization and lifestyle changes (Obeng et al., 2008; Addo-Yobo et al., 2007; Ait-Khaled et al. 2007, Zar et al., 2007).

Considering the increasing rates of chronic disease, and demonstrated high prevalence of respiratory and skin allergies in the developing world, some studies hint food allergies may be next to follow (Du-Toit et al., 2015; Lee, 2013; Boye, 2012; Prescott et al., 2012). In Africa, while population level data do not exist, a small body of empirical studies and clinical case reports demonstrate that food allergies are beginning to rise especially among children

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<sup>&</sup>lt;sup>2</sup> The International Study of Asthma and Allergies in Childhood (ISAAC) is a worldwide epidemiological research programme established in 1991 to investigate asthma, rhinitis and eczema in children in western and developing countries

 $<sup>^{3}</sup>$  Individuals with current wheezing who had > 4 wheezing attacks in the last year or sleeping disturbance > 1 nights per week in the last year or whose wheezing affected speech in the last year.

(Basera et al., 2015; Hossny et al., 2011; Obeng et al., 2011). Though these studies are heterogeneous in their methods, they nonetheless suggest that common allergens in the western world (e.g. egg, peanut, sesame) are also becoming an important source of allergic reaction in this region. In addition, they reveal the need for researchers to pay critical attention to local allergens (e.g. vegetable, maize, potato) and their potential role as triggers for allergic reactions.

While a policy and research agenda has now emerged regarding chronic disease in Africa, the current focus to date remains on four widely recognized diseases: cardiovascular, cancer, diabetes and chronic respiratory diseases and their modifiable risk factors. Allergic disease including food allergy is neglected, despite being one of the most common and earliest onset chronic diseases (Prescott, 2013). In part, this arises because of perceptions that allergies are "...a scientific conundrum of only limited epidemiological, economic, social and political significance" (Jackson, 2006, p.11) contrary to studies demonstrating that allergic diseases impose significant psychosocial and economic impacts that affect quality of life (du-Toit et al., 2015; Dean et al., 2015, Gupta et al., 2013).

This research explores the social dimensions of the emerging health risks of food allergy in SSA. The existing research focuses on the incidence and prevalence, paying limited attention on experiences of food allergy or the social and environmental factors that shapes these experiences and risk perceptions. This research was designed to understand how food allergy is perceived, experienced and manifested in a different sociocultural context. Aligned with this was the need to examine the responses and ability of individuals affected by food allergy. These areas are important to obtain critical information to inform policy making and enhance public health risk communication (Leiss and Powell, 2004). Specifically, the research objectives are:

- a) To explore the perceptions, risk factors, and coping strategies associated with food allergy in Ghana; and,
- b) To understand how the local context shapes food allergy perceptions, practices and management.

## 1.2 Geographies of health and food allergy

Health geography is a sub-discipline that applies geographical perspectives, and methods to understand population distributions of health, disease and health care (Luginaah et al., 2015, Gatrell and Elliott, 2015). Following a period of critical introspection in the 1990s, the focus of the sub-discipline expanded from dominant "concerns with disease and the interests of the medical world" to an increasing focus on "wellbeing and broader social models of health and health care" (Kearns and Moon, 2002; 606). This shift brought greater attention to the effect of place on health, explored through a plurality of methodological approaches – quantitative (and, or) qualitative tools (Harrington et al., 2017, Andrews and Moon, 2005). As a result, health geographers explicitly attend to individual characteristics (e.g. age, sex, genetics), physical dimensions of the environment (e.g. location, vegetation, rainfall) and structural (e.g. policies, power, social norms) influences on heath, wellbeing and health care. In short, both individual level and contextual determinants are critical to understanding population distribution of health and disease (Macintyre et al., 2002).

While health geographers have contributed to research on chronic diseases: obesity, type 2 diabetes, multiple sclerosis, arthritis, asthma (Crighton et al., 2010; Vine and Elliott, 2013; Robinson et al., 2007; Cravey et al., 2001, Moss, 1997; Dyck, 1995), with few exceptions, little attention has been given to food allergy (see Dean et al., 2015, Harrington et al., 2015; Fenton et al., 2013; Harrington et al., 2012). Much of the existing scholarship is dominated by researchers in clinical allergy, sociology and psychology (Haeusermann, 2014; Nettleton et al., 2010; Sicherer et al., 2003). Considering health geography and other allied

disciplines have contributed to revealing how local geographies – physical, economic, and political – shape disease diffusion, health risk perceptions, social determinants of health and health inequalities (Harrington et al., 2017, Gatrell and Elliott, 2015), they are well positioned to substantively contribute to the literature on food allergy. The links between food allergy, environment and lifestyle factors provide a clear avenue to explore how the environment may facilitate or inhibit risk across and within places.

## 1.2.1 Geographies of food allergy

Food allergy is an immune based disease that describes adverse reactions to proteins in food (Boyce et al, 2010). An allergic reaction occurs when the body's immune system treats an otherwise harmless food or substance in food as a dangerous pathogen and consequently overreacts by producing specific IgE antibodies to the particular food substance. Symptoms of allergic reactions include rash, hives, swelling of the lips, vomiting, diarrhea, difficulty breathing and in extreme cases anaphylaxis, often occurring within minutes to a few hours (>2hours) following ingestion or exposure to the allergen (Sicherer, 2011; Boyce et al., 2010). As food allergy is unpredictable, those affected live with a constant sense of risk, striving to balance physical safety with social wellbeing (Dixon et al., 2016).

Although interest in food and health linkages can be traced back to the writings of Greek philosophers such as Hippocrates, only in the late twentieth century has public and research interest grown in the area of food allergy as a critical health issue. While the volume of work on food allergy is large, current literature can be classified under four broad areas of inquiry. First, a significant volume of research focus on the spatial distribution of food allergy at various geographic scales. For example, studies have analyzed distributions at the global level (Prescott et al., 2013; Boye, 2012, Lack, 2008; Rona et al., 2007), in specific regions such as Europe, Asia and Africa (Nwaru et al., 2014; Kung et al., 2014, Lee et al., 2013), and the country level (Soller et al., 2015; Gupta et al., 2011, Osborne et al., 2011).

At the global scale, food allergy is estimated to affect between 1% and 10% of people in the world (Sicherer, 2011; Chafen et al., 2010), 7.5% in Canada (Soller et al., 2015), 8% in the United States (Gupta et al., 2011) and about 10% in Australia (Osborne et al., 2011). While prevalence in western countries appears to have stabilized (Ben-Shoshan et al., 2009, Venter et al., 2010), the available evidence from the developing world suggests food allergies are beginning to rise (Lee et al., 2013; Prescott et al., 2013; Boye, 2012). For example, in African populations, studies report the prevalence of food allergy range from 2.5% in South Africa (Basera et al., 2015), 3% in Egypt (Hossny, 2011), to 11% in Ghana (Obeng et al., 2011). In the Asian region, self-reported food allergy prevalence has also been reported to vary between 3.4% to 11.1% (Lee et al., 2013). Together, these studies show marked heterogeneity in food allergens with some allergens restricted to certain geographic spaces. For example, bird's soup in Singapore, royal jelly in Hong Kong, mustard seed in France (Lack, 2008) and sesame in Israel (Dalal et al., 2002). The geographic variations in prevalence while partly reflecting differences in measurement and evaluative criteria, may also reflect cultural differences in lifestyles and accessibility to health care services (Harrington et al., 2013; Rona et al, 2007).

A second strand of research focuses on analyzing individual and environmental risk factors that predispose people to developing food allergy. Researchers have identified family history, demographic factors (e.g. sex, ethnicity), and timing of allergen exposure (Sicherer, 2011; Lack, 2008) as important etiologic risk factors. For example, studies indicate that familial history of allergy (e.g. eczema, asthma) increases the risk of food allergy in children by 50% (Koplin et al., 2013, Sicherer et al., 2000; Hourihane et al., 1996). In addition, the gradient of food allergy risk is positively associated with sociodemographic and economic status (Ben-Shoshan et al., 2012; Gupta et al., 2012; Kotz et al., 2011). Food allergy, in particular peanut allergy, is more prevalent in male than female children, though this trend

reverses beyond teenage years (Kotz et al., 2011; Sicherer et al, 2003). Further, delayed introduction of allergenic foods during infancy and early childhood has also been shown to increase food allergy risk in children (Du-Toit et al., 2015; Koplin et al., 2010). Lastly, the decline in infectious disease, the waning microbial environment, and reduced gut flora have also been hypothesized to explain the rise in (food) allergic disease (Bager et al., 2008; Eggesbo et al., 2003; Bach, 2002). Importantly, these studies highlight how changes in the physical and built environments act in concert with our genetics to shape immunological changes that predispose disease risk. In short, gene and environment interactions matter to understanding the spatiotemporal rise in food allergy.

More recently, a third strand of studies has emerged that focus on understanding the experiential and lived worlds of food allergic persons and their families. These studies draw on qualitative methods including but not limited to interviews (Dean et al., 2015, Lu et al., 2014), draw and tell (Fenton et al., 2011), photovoice (Valentine and Knibb, 2011) and focus groups (Gupta et al., 2008) to highlight the health and social experiences of living with allergy, and the discourses surrounding food allergy risk. For example, studies show that a diagnosis of food allergy can lead to stigma and discrimination (Dean et al., 2015; Minaker et al., 2015); psychosocial stress (Pitchforth et al., 2011); and disruptions of normal life (Fenton et al., 2013: 2011, Rouf et al., 2012; Bollinger et al., 2006). In response to these burden, studies also reveal a broad range of strategies – e.g. avoidance, risk acceptance, vigilance, and attention to detailed food labelling - allergic individuals and families employ to cope (Rouf et al., 2012; MacKenzie et al., 2009). Beyond health and social related impacts, studies have also quantified the economic burdens of food allergy on households and society (Gupta et al., 2013, Patel et al., 2011). For example, the overall food allergy associated household annual costs including hospitalization, emergency visits, and visit to pediatricians - was estimated at 4.3 billion dollars in the United States (Gupta et al., 2013).

As a result of these burdens and associated risks, the fourth strand though limited has focused on governance of food allergy. At one level, researchers have been concerned with developing guidelines for diagnosis, and management across a range of settings including hospitals (Boyce et al., 2010) and schools (Sicherer et al., 2010, Young et al., 2009, Baumgart et al., 2004). In hospital settings, these guidelines provide physicians and allied health professionals a guide to determine what counts as food allergy and how it should be treated. In the school however, policy goals focus on prevention and outline strategies that involve setting up both individualized and institutional management plans to recognize allergic reactions and respond to emergencies (e.g. administration of epinephrine in cases of anaphylaxis). At a broader scale, regulatory policies have also focused on ensuring the declaration of known food allergens on goods and services (Gendel, 2012). While regulatory policies have been shown to lead to increased awareness around food allergy risks (Dean et al., 2015), their unintended consequences have been the subject of recent analysis. There is indication that regulatory guidelines can led to discriminatory practices such as the differentiation of allergic and non-allergic populations (Marklund et al., 2007, Rous and Hunt, 2004), and the transfer of risks to school administrators and teachers thereby increasing their responsibilities (Rous and Hunt, 2004). By critically examining these policies, these studies provide insights into the role of policies in structuring social interactions of affected persons and how this impacts their health and wellbeing.

The geographies of food allergy reveal significant gaps on the social dimensions especially in developing countries. Research has largely been restricted to recording prevalence, incidence and sensitization to food (Gray et al., 2016, Kung et al, 2014; Obeng et al., 2011). As prevalence data grow, there is need for systematic studies on understanding the construction of food allergy, especially in contexts such as Africa where infectious disease has long tended to dominate public health discourse. Attention to the local context can

provide useful insights to understand how health and exposures to health risks are shaped in the context of food allergy.

#### 1.3 Research context

## 1.3.1 The sociodemographic and economic context of Ghana

Ghana is a lower-middle income country located in West Africa, with a total land area of 238,537 km² (Ghana Statistical Service [GSS] et al., 2015). It is divided into ten administrative areas with a total projected population of 28 million (GSS, 2016). The fertility rate has been declining (from 6.4 in 1988 to 4.2 children per woman in 2014) and reflects the sustained decline in proportion of the under 15 population since the 1960s - from 45% to 38% by 2010 (GSS et al., 2015). Several factors including urbanization, contraceptive use, increased age of marriage and delayed sexual activity, wealth, and education have contributed significantly to fertility decline (GSS et al., 2015; Martine et al., 2013; Blanc and Gray, 2000). Life expectancy has also increased, rising from approximately 38 to 60 years for males and 43 to 63 years for females between 1970 and 2014 (GSS et al., 2015).

Over the last two decades, prudent economic management policies, investments in agriculture, and the recent discovery of oil resources have contributed to sustained growth in the economy. Between 2001 and 2012, the economy grew from 4.2% to 7.9% (GSS, 2013; Saleh, 2013). Growth however declined to 4% in 2014 (GSS, 2015) due in part to a crisis in the energy sector but is expected to rise to 7.5% by 2018 (World Bank, 2017). Across the country, poverty incidence has declined from a peak level of 51.7% in 1992 to 28.5% in 2006, although the gains have not been evenly spread (Saleh, 2013; World Bank, 2011). In the southern regions, declines have been significant (from 47.9% to 19.8%) compared to the northern regions (from 68.8% to 62.7%). By 2013, incidence of poverty further declined to

24.2% ensuring Ghana had achieved Millennium Development Goal 1 before the 2015 benchmark (Cooke et al., 2016).

Since the mid-twentieth century, the rate of urbanization has been increasing. The urban growth rate in 1931 was estimated at 9%, and has increased from 31.3% in 1984 to 43.8% in 2000 (Yanson and Bertrand, 2012). The last census (2010) indicated more than half (50.9%) of the population lived in urban areas (GSS, 2013). Several factors have contributed to this growth including natural increase and rural-urban migration in response to livelihood opportunities in commercial and industrial activities in cities (Cobbinah and Niminga-Beka, 2017; GSS, 2013, Yanson and Bertrand, 2012). Urbanization has helped to sustain economic growth, increasing incomes and enabling access to higher quality education (World Bank, 2014). At the same time, the nature of urbanization and globalization processes (e.g. built environment, access to information, sedentary and poor lifestyle practices) present a conducive climate to develop chronic disease.

## 1.3.2 Overview of epidemiological changes in Ghana

In the period prior to and during colonial rule, infectious diseases were the most common and serious health threats to life and wellbeing. Historical data show that, among insect vectored diseases (e.g. dengue and yellow fever, onchocerciasis, trypanosomiasis), malaria was the most serious, accounting for about 4,000 child deaths annually by the mid-1900s (Patterson, 1981). Intestinal infections such as dysentery and diarrhea, typhoid fever, poliomyelitis, and schistosomiasis were also frequently reported cases at colonial hospitals and clinics. Though guinea worms had a low fatality rate, they caused much disability. For example, guinea worms were responsible for partially or completely disabling an estimated 100,000 people especially in the Northern Territories of Ghana. Between 1918-1919, the influenza epidemic caused an estimated 80,000 to 100,000 deaths. By 1935, over 80% of

residents in Accra under 20 years of age responded positive to skin tests for *C. diphtheriae* (Patterson 1981). Interestingly, until the 1970s, the disease landscape did not include cholera. Its absence was attributed to "simply a matter of luck" (Patterson, 1981, p.54). To a large extent, the disease burden were linked to the poor nature of sanitation and sewerage, housing, overcrowding, and poor hygienic practices. As climatic conditions created conducive environments for pathogens to thrive, transportation facilitated their spread, exposing populations to new strains of virus, bacteria and helminths (Patterson, 1981).

In the mid-1950s, non-infectious diseases were recognized as a growing health problem – though mortality and morbidity were often masked by microbial and helminthic infections (Patterson, 1981). Between 1921 and 1953, out of 3,645 autopsies undertaken, about 12.8% were due to cardiovascular diseases. Between 1945 and 1955, in-patient and out-patient records suggested rising cancer incidence. For example, a total of 3,503 cancer inpatients, and 398 deaths were observed during this period. Out-patient records showed an increase from 94 cancer cases in 1945 to about 1, 427 cases in 1955. In addition, data showed that psychological disorders were increasing. By 1951, an estimated 730 patients were seen daily at the colonial mental health hospital. Thus by the mid-twentieth century, the epidemiologic landscape was already characterized by a coexistence of infectious and non-infectious diseases (de-Graph Aikins et al., 2013).

Little has changed over the last six decades in the epidemiologic profile in Ghana. Infectious and chronic diseases continue to coexist, though the proportion of deaths attributed to chronic disease is beginning to rise. In 2008, chronic diseases accounted for 39% of deaths, rising to 42% by 2012 (WHO, 2011b; 2014a). Cardiovascular (18%), cancer (5%), diabetes (2%) and chronic respiratory diseases (2%) were the leading cause of deaths attributed to chronic disease in population under 70 years (WHO, 2014a). Across the country, high incidence rates of hypertension and diabetes have been reported (Ghana Health Service,

2015) and chronic diseases are expected to further rise given high rates of adult risk factors – tobacco smoking (10%), alcohol consumption (4.8%), raised blood pressure (27.3%) and obesity (7.5%) (WHO, 2014a). This has serious implications for healthcare access and quality, especially for affected individuals and households.

Yet infectious diseases remain prevalent. While several common infectious diseases [e.g. yellow fever, meningitis, cholera, influenza (H1N1, H1N3) and neglected tropical diseases] exist, malaria, diarrhea, pneumonia and other respiratory disease are major causes of death especially among those under the age of 5 (GSS et al., 2015; Saleh, 2013). The Ghana Demographic and Health Survey (GDHS) reports the prevalence of malaria as measured by blood smears via microscopy at 27%, 12% for diarrhea and 4% for acute respiratory diseases among children under 5 (GSS et al., 2015). However, communicable causes of death are declining though marginally, 53% to 51% (WHO, 2011b; 2014a). In the case of malaria, in-patient deaths have fallen from 34.9% to 27.3% between 2010 and 2014. Over the same period, malaria rates for the under 5 population recorded significant declines from 19.5% to 7.2% (Ghana Health Service, 2015). These gains have been attributed to several health policy measures including a malaria control program (e.g. promotion of insecticide treated nets), insurance for children under 18 years and maternal health services. Furthermore, since 2000, national HIV prevalence has declined, from 4% in 1998 to 1.2% in 2013, albeit pockets of high prevalence in the country – e.g. 8.5% in Agomanya, Eastern region (WHO Country Office, Ghana, 2015; Agyei-Mensah, 2001).

While chronic diseases have not replaced infectious diseases as the experience of western countries exemplifies, the declining burden of infectious disease, changing population demographics, improved socioeconomic conditions, rapid urbanization, and globalization means that they will likely represent a significant health risk in decades to come (Tagoe, 2012; Agyei-Mensah and de-Graph Aikins, 2010). In response, a national policy

embedded within regional (Brazzaville declaration) and international (e.g. UN High level meeting, WHO Global Action Plan) frameworks has been developed to control and prevent chronic disease. Its goal is to reduce incidence and associated morbidity, minimize exposure to unhealthy lifestyles, as well as improve overall quality of life for affected individuals and families (Ministry of Health, 2012).

This policy focuses on cardiovascular disease, cancer, diabetes, chronic respiratory diseases and sickle cell (Ghana Health Service, 2015). Reflecting these priority areas, the Ghanaian chronic disease literature is characterized by interests in diabetes (Amidu et al., 2012, Amoah 2002); cancers (Ghartey et al., 2016; Clegg-Lamptey et a., 2009), cardiovascular (Cappuccio et al., 2004), mental health (Ofori-Atta et al., 2010, de-Graft Aikins et al., 2007) and their modifiable risk factors (Aryeetey and Ansong, 2011; Dickerson et al., 2011; Agyemang, 2006). With one exception (Obeng et al., 2011), there is a dearth of empirical studies on food allergy. As food allergy has tended to follow the rise of chronic diseases, Ghana provides an important case study to explore and to understand the emerging risks associated with this growing public health problem.

As chronic diseases tend to be lifelong, an effective health system infrastructure including universal health coverage is also key to responding to the health burden (WHO, 2014b). Since 2000, health reforms culminated in the establishment of the National Health Insurance Scheme (NHIS) in 2003, which aim to provide affordable and accessible health care to the population. The scheme is financed by a 2.5% tax on goods and services, 2.5% monthly deduction on individual contributions to pension funds, budgetary allocations, grants and donations as well as returns on the funds' investments. While overall membership has increased from a little over 8.8 million people in 2012 to over 10 million in 2013 (NHIS, 2013), poverty and geographical inequities in health resources for example act as barriers to the enrollment and utilization of services (Alhassan et al., 2016; Kusi et al., 2015; Dixon et

al., 2011). Further, though the scheme covers about 95% of health conditions reported in the healthcare system, with exceptions (e.g. hypertension, diabetes mellitus), the scheme does not cover treatment for other chronic diseases – e.g. dialysis for chronic kidney failure, cancer other than cervical and breast cancer.

## 1.3.3 The Greater Accra Region

The Greater Accra Region (GAR) is the smallest of the ten administrative areas in Ghana with a total land area of 3,245 km², sharing boundaries with the Central, Eastern, and Volta regions as well as the Gulf of Guinea (Figure 1.1). Administratively, the GAR is divided into ten areas with an overall population estimated at a little over 4 million, the second largest in the country (GSS, 2012). It has a youthful population structure with 85.7% of the population under 60 years (GSS, 2013). The major indigenous ethnic group is the GaDangme although Akans comprise the largest ethnic group living in the Greater Accra region (GSS, 2013).

Over the years, globalization has led to an increased flow of goods and services, people and ideas in part due to advances in communication and transportation technologies. In Ghana, the GAR is the hub of much of these processes. Foreign investments – e.g. hostels, gated communities, luxury apartments, fast food chains, mobile telephony and entertainment industries – have increased since 1980, drawing the highly educated and skilled population into the GAR and as a result, creating a "visible group of wealthy, cosmopolitan consumers of [the region's] global products" (Agyei-Mensah and de-Graph Aikins, 2010). Analysis of the GDHS data shows about 52% of people in the GAR are within the highest wealth quintile compared to just 2% each for people in the Northern and Upper East regions (GSS et al., 2015).

Further, urbanization rates are increasing in the GAR. While all towns have experienced an increase in population, the GAR has seen the most increases with about

90.5% of its population residing in urban areas (GSS, 2013). Urbanization has been shown to accelerate economic growth resulting in a surge in rural-urban migration (World Bank, 2014). This has also engendered the rise in peri-urban towns as housing gaps and high rent prices in the GAR force people to leave inner city areas (Yanson and Bertrand, 2012). Access to safe water and sanitation remain a challenge posing serious urban health problems. For example, 102 new cholera cases were reported in January 2015, the overwhelming majority (98%) were reported from the GAR (Ghana Heath Service/Ministry of Health, 2015) highlighting the persistent challenge of environmental sanitation.

BURKINA FASO UPPER WEST BENIN OWa OTamale NORTHERN TOGO COTE D'IVOIRE BRONG-AHAFO ASHANTI Ho О EASTERN REATER ACCRA WESTERN CENTRAL O Cape Coast Gulf of Guinea

Figure 1.1 Map of Ghana showing the Greater Accra region

Source: google images

The combined effects of globalization, urbanization, and economic growth are key drivers of unhealthy lifestyle and behavioural practices – e.g. reduced physical activity, increased stress, unhealthy eating (WHO, 2014b) thereby increasing chronic disease risk. Reviews of the changing health landscape from 1877 to 2007 demonstrate that Accra is experiencing a rapid epidemiologic transition characterized by a double burden of infectious and chronic disease (Agyei-Mensah and de-Graph Aikins, 2010). The Greater Accra region therefore provides an ideal setting to explore emerging environmental health risks such as (food) allergic disease.

#### 1.4 Outline of dissertation

In the next Chapter, a summary description of the research design and methods that informed data collection is presented. The three chapters that follows constitute the substantive chapters of this dissertation. These chapters have been submitted to, and published in peer-reviewed journals. Chapter 3 addresses perceptions, associated risk factors and how food allergy is framed. In doing so, it helps to paint a picture of the emerging health risk of food allergy in a low and middle income country (LMIC) context. In Chapter 4, the focus turns to the lived experiences of affected individuals and families, and the strategies they employ to cope. Chapter 5 explores local level factors and how they affect risk perceptions, behaviours and practices. In Chapter 6, a summary of the key findings of the substantive chapters is presented. This is followed by a discussion of the implications of the research, the research contributions as well as directions for future research.

#### **CHAPTER TWO**

#### 2.1 Introduction

This thesis aimed to gain insights into the local perceptions and experiences surrounding food allergy in a low and middle income country (LMIC) context. In this chapter, an overview of the links between theory and research design is discussed. Next, it provides details of the ethical consideration of undertaking the research. This is followed by a detailed discussion of the research design and rationale, data collection, as well as data management, and analysis. This chapter therefore consolidates the methods used in the substantive chapters (3, 4 and 5).

## 2.2 On theory, research design and doing food allergy research

In health geography and allied health disciplines, there is a recognition that researchers and policy makers stand to gain by explicitly engaging with theory (Farmer et al., 2013; Krieger, 2011; Kearns and Moon, 2002; Litva and Eyles, 1995). Theory provides the lens through which we understand, analyze, explain, confirm, or shed light on a social phenomenon by enhancing researchers' ability to conceive, ask the "right" questions, and to generate the right answers (Krieger, 2011). In doing so, relevant information can be obtained to inform the "design *of* better programs, guide practical solutions to challenges, and [importantly] develop habits of critical self-reflection" (Hanna and Kleinman., 2013, p.31).

Engaging with theory is thus both an empirical and practical necessity (Krieger, 2011). As some have pointed out, theory structures what is observed, collected and interpreted (Krieger, 2011; Litva and Eyles, 1995). Krieger aptly observes that, "if our theoretical ideas do not include micro-organisms, we would not devise methods to see them – and [even] if *we are* offered a microscope, we would not know what we are seeing regardless of the magnification employed" (2011, p.24). In this regard, health geographers have

employed several theoretical perspectives including positivist, constructivist, structuralist and structurationist to guide their research. Each of these perspective differs in terms of their ontology, and the methods utilized to identify, classify and to explain phenomenon (Gatrell and Elliott, 2015). For example, while a positivist may be concerned with the spatial patterning of disease, or the aetiological factors that shape health outcomes using surveys or experiments, a social constructivist will privilege the subjective meanings and experiences of health outcomes, and how they are negotiated and produced over time (Gatrell and Elliott, 2015). For the social constructionist, emphasis will focus on qualitative methods (e.g. case studies, ethnography, focus groups) to highlight the embodied experiences of people and how they make sense of health within their social context.

In the literature on food allergy (see chapter 1), most studies have largely drawn on a positivist approach with the aim of "accurately" measuring food allergy. In this regard, researchers employ a variety of techniques such as a skin prick test (SPT), testing for antibodies (i.e. Immunoglobulin E [IgE]) or food challenges (Boyce et al., 2010) to obtain objective measures of food allergy. In this body of work, food allergy is defined as constituting cases where a clear immunological mechanism can be demonstrated (Fleischer et al., 2011; Osborne et al., 2011; Eigenmann et al., 1998). Consequently, a biomedical perspective is invoked as a basis for understanding (ill)health, treatment and interventions. The body of the allergic person is conceptualized as a well-functioning "machine" where allergic reactions are an indication of distortions within the "machine" (Gatrell and Elliott, 2015) triggered by allergenic substances.

Concomitant to shifts in biomedical approaches to disease and in concert with growing burden of food allergy, researchers have called for an expansion of methodological approaches that gives greater emphasis towards understanding the experiences of allergic and affected individuals (Smith, 2015; Gallagher et al., 2009, Nettleton et al., 2009). Gallagher et

al., (2009) for instance asked clinical allergy researchers to engage with qualitative methods in order to address gaps related to compliance, treatment and management challenges. In response, several studies have utilized various qualitative methods such as textual and pictorial analysis, interviews and focus groups (Dean et al., 2015; Fenton et al., 2013, Gupta et al., 2008) to address questions on the lived experience of affected individuals and families. While they often do not explicitly outline their theoretical perspectives, these studies appeal to social construction frameworks to understand how society makes sense of health risks and the social processes that act to transform and create these risks.

In contexts such as sub-Saharan Africa (SSA) where population prevalence data is lacking, how should researchers conduct investigation of food allergy? While there is space for both quantitative and qualitative approaches, Elliott (1999) suggests attention to the purpose and nature of the research question as a guide to choosing the appropriate research approach. In this research, the goal was threefold. First, to obtain a detailed account of the nature of food allergy in a setting where data is generally lacking. Second, to understand the complex contextual factors shaping food allergy risk perceptions and practices and thirdly, identify food allergens to inform prevalence studies in the future. Studies that seek to answer questions about people's social experiences and why they act, or chose to act the way they do are better addressed by qualitative research techniques (Winchester and Rofe, 2010; Creswell, 2007). Accordingly, this research utilizes qualitative research to understand the following research objectives:

- To explore the perceptions, risk factors and coping strategies associated with food allergy in Ghana, and
- b) To understand how the local context shapes food allergy perceptions, practices and management

## 2.4 Study design

This research was informed by works of the epidemiologic transition, social construction and ecological (e.g. ecosocial and political ecology) perspectives of health. The epidemiologic transition provided the framework to situate the rise of allergic disease in developed countries, and to speculate on the future trajectory of food allergy in LMICs experiencing rapid changes in health and disease. While current transition studies continue to be heavily influenced by quantitative techniques (Santosa and Byass, 2016, Defo, 2014), this research utilized methods that helps to capture the characteristics of the local context and how they shape the embodied experience of (ill)health.

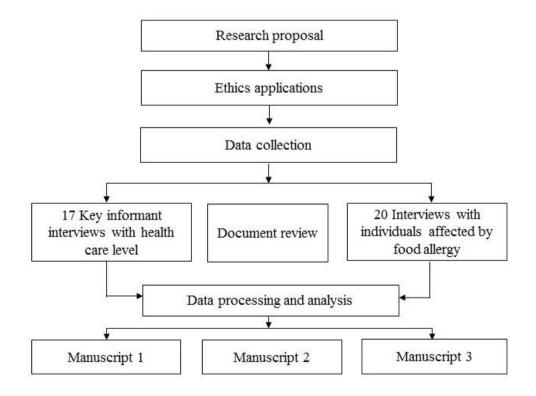
In this research, qualitative in-depth interviews, and documentary analysis were the primary techniques utilized in order to obtain a better understanding of food allergy as well as paint a picture of the realities of food allergy in the Ghanaian context (Berg, 2004). The choice of this design was informed by the overall goal of the research which sought to understand perceptions at the individual, community and structural (e.g. healthcare level), and how the social context shapes the meanings, beliefs and attitudes towards food allergy (Winchester and Rofe, 2010, Berg, 2004). Figure 2.1 provides an illustration of the research process – from research conception, ethical considerations, data collection to analysis. However, before proceeding to outline and describe the data collection and management process, the next section highlights the ethical consideration of the research.

#### 2.4.1 Research ethics

Ensuring planned research activities do no harm to research participants and adequately reflect their perspectives is a key component of the research process. To ensure compliance with research ethics guidelines, the researcher participated, and received a certificate for successfully completing the online TCPS 2: Course on Research Ethics

(CORE) in Winter 2015. Between January and May 2015, ethics approval for this study was received from the University of Waterloo Ethics Review Board and the Ghana Health Service Ethics Review Committee to implement the research protocol (see appendix 1). Both institutions required the need to demonstrate how the target population will be recruited, ensure informed consent, and safeguard privacy and confidentiality of the data and participants as well as an outline of the potential benefits and risks. By successfully obtaining ethical clearance, Silverman (2013) suggests, researchers can be confident planned research activities do not pose a threat to participants and participants can be assured the research has the legitimate backing of an institution.

Figure 2.1 A diagrammatic representation of the research process



### 2.4.2 Data collection and management

## 2.4.2.1 Sampling, sample size and recruitment

Purposive sampling techniques were utilized in this study to recruit participants. The goal was to reach a specific population group to obtain in-depth insights, and understand changing disease landscapes, particularly food allergy in Ghana (Silverman, 2013; Creswell, 2007). The research first employed criterion sampling (Bradshaw and Stratford, 2010) to select participants. To understand food allergy in the context of changing burden of disease in healthcare settings, healthcare professionals including physicians, nurses, dieticians, and traditional medicine practitioners were recruited. Participants (especially physicians & nurses) must have been working for at least three (3) years, and should have some experience working either in out-patient departments (OPD), or child health units of hospitals or clinics.

In healthcare institutions, the research team sought and obtained permission to conduct interviews with healthcare workers from heads / directors of administration. While a total of twenty-two (22) public and private health facilities were invited to participate using information letters, only twelve (n=12) institutions responded. The remaining ten (10) health institutions either did not response (n=6) to the information letter despite follow-up visits or health workers were unavailable for interviews (n=4). At each facility, a contact person (mostly administrative secretary) was designated to act as a liaison and to assist with recruitment. In addition, frequent visits to health facilities were undertaken during the duration of data collection to respond to any inquiries as well as address concerns regarding interview confidentiality. These processes were critical in providing easy access to healthcare workers and building credibility for this research. Interested participants who met the eligibility criteria were invited to participate in the research.

Based on prior literature on the characteristics of food allergy (Boyce et al., 2010) the research used screening questions to help assess food allergic individuals. To be eligible, an

individual ought to either (a) report a physician diagnosed or suspected food allergy or (b) self-report allergy and (c) report symptom manifestations within 1 to 2 hours of ingestion (of) or contact with food and (d) exhibit at least 2 symptoms of an allergic reaction (e.g. hives, itching, swelling, rash, coughing, wheezing, shortness of breath, throat tightness, nausea, vomiting, diarrhea). In addition, a participant must be 18 years or older, able to speak English, or Twi (the widely spoken local language) to be eligible.

Further, snowball sampling was also used to help identify and to reach other participants (Bradshaw and Stratford, 2010). At the close of each interview, participants were encouraged to identify, or suggest others who met the inclusion criteria, as well as facilitate meetings with potential participants. In contexts where the target populations may be hard to reach, snowball sampling is considered an appropriate strategy to engage such individuals or groups in research or health interventions (Walters, 2015). In the absence of a food allergy registry, or support groups, snowballing was an appropriate strategy to recruit allergic individuals and their families. Studies suggests while time constraints, disinterest in the subject matter, and inadequate office staff are critical barriers restricting healthcare professionals' involvement in research, snowballing can be an effective strategy to increase access and participation (Asch et al., 2000; Levinson et al., 1998).

Further, to maximize participation especially among those affected by food allergy, online advertisement on the social media platform Facebook was undertaken. Further, physical flyers were posted at churches, mosques, and educational institutions. Presentations about the research objectives were also made at churches, mosques, as well as at social gatherings. Existing social networks in school settings – teachers and administrators - were also used as a medium to reach allergic individuals (especially children) and their families. In all cases, participants contacted the research team and those meeting the inclusion criteria were invited to participate in the research. A total of forty-eight (48) individuals and families

with perceive allergies expressed interest and of this, thirteen (13) did not meet the eligibility criteria and were excluded. Of the remaining thirty-five (35) affected individuals who were eligible and included in the study, five (5) withdrew due to unavailability leaving a sample pool of thirty (30) to recruit participants for interviews.

## 2.4.2.2 In-depth interviews

In-depth interviews are data gathering tools (Silverman, 2013; Dunn, 2010) best conceived as a partnership, involving both the interviewer and interviewee, where both are engaged in a communicative performance (Miller and Crabtree, 2004, Briggs, 1986). The goal is to document and gain insights of the variety of opinions, meanings and experiences on a given subject within their social context (Dunn, 2010). Following Miller and Crabtree (2004), this study utilized in-depth interviews to document and understand food allergy experiences because (a) participants are familiar with interviews as a communication tool; (b) discourse about (ill)health is regularly expressed in the form of stories (by patients) and cases (by healthcare workers); and (c) the goal is to paint a picture of both individual and community perceptions of food allergy.

Participants were first presented with information letters that outlined the research objectives, potential risks and benefits, privacy and confidentiality issues, as well as key contacts for the research project. All questions and clarification regarding the research were addressed in person or through telephone. Further, before commencement of interviews, critical issues – e.g. consent, recording, privacy – in the information letter were discussed with participants again. The time, location and manner of the interview was determined by participants. Though some participants provided actual names, to ensure confidentiality, pseudonyms were used as exemplified in the substantive papers in Chapter 3, 4 and 5.

In-depth interviews with healthcare workers and those affected by food allergy were conducted simultaneously. In all, a total of thirty-seven interviews comprising 17 healthcare workers and 20 affected persons were undertaken between June and August, 2015.

Discussions were guided with the aid of interview guides (see appendix 2) allowing the researcher some flexibility during interviews to probe for additional information. Interviews generally lasted between 30 minutes and 1 hour, and were mostly conducted in the English language. To ensure all relevant data was captured, in addition to tape recordings, notes of internal and external interruptions were taken in order to help provide further context for the data.

## 2.4.2.3 Documentary review

Documents are an important source of secondary data that can provide rich contextual information to track changes on a subject over time, as well as provide a means of collaborating research findings collected via other data collection tools (Bowen, 2009). In order to understand the policy context and current guidelines regarding food allergy in Ghana, the researcher searched the Ministry of Health and Ghana Health Service websites for any publicly available document (comprising health policies, and guidelines) with direct relevance to allergies. As a result, a total of seven (7) documents were purposively retrieved for subsequent review. This was complemented by a web-based search (using Google) with the key words *food allergy, allergic disease, policy, guidelines* and *Ghana* to ensure all relevant documents were captured. This resulted in the addition of one document from the Ghana Food and Drugs Board. Documents focusing on specific program areas (e.g. tuberculosis, transport operation manual, training manuals, grant calls) were excluded. The goal was to understand the health policy environment and the extent to which food allergy is considered an important health priority issue in the health system context.

## 2.4.3 Data management and analysis

All interviews were recorded, and following completion, recordings were transcribed verbatim. All transcripts were reviewed while listening to interview recordings to ensure accuracy of data. Next, a sub-sample (n = 4) of the interview transcripts of both healthcare and individuals affected by food allergy were randomly selected and used to develop an initial thematic coding scheme. Coding describes the process where texts (can be portions or whole) is described or categorized in order to facilitate data analysis (Silverman, 2013; Saldana, 2013). The coding scheme was derived from responses to the research questions (deductive coding) as well as emerging categories from the interviews (inductive coding).

The coding scheme was assessed for intra-coder reliability. The process refers to the extent to which two or more coders coding independently agree on the same code for a text of interest (either a portion or whole) when the same coding scheme is deployed (Campbell et al., 2013; IkCho, 2008). The objective is to ensure reasonable confidence that coding can be reproducible by external persons if the coding scheme and data were available (Campbell et al., 2013). The coding scheme then was applied to all the remaining transcripts. Throughout this process, the coding scheme was continually adjusted for the purposes of capturing new categories or sub-categories that may have been missed in the development of the coding scheme (Campbell et al., 2013; Bowen, 2009). Subsequently, the research utilized NVivo 11, a computer software program to facilitate coding, data analysis, and distilling large volumes of transcribed texts.

The selected documents provided a description of the policy context of health and healthcare. These policies and guidelines were initially reviewed individually to understand their content and the priority given to certain health issues. Coding for documents were manually done and designed to provide information on the title of document, year of publication, as well as their key priority focus (see table 6.1). In addition, an electronic search

within individual documents was undertaken using the words "food allergy" or "allergic disease" or "allergic reactions" to identify and quantify references to (food) allergic disease. Throughout the process of review, implicit and explicit illuminative statements within documents directly relevant to food allergy were selected. Analysis of health policy direction was guided by the extent to which these documents were interested in allergic diseases by paying particular attention to "the absence, sparseness, or incompleteness of documents" on food allergy (Bowen, 2009, p.33).

Following data analysis and the synthesis of results, three key outputs emerge from this research and are discussed in the subsequent chapters. Chapters 3 and 4 paint a picture of the perceptions and experiences of healthcare professionals as well as individuals affected by food allergy. Chapter 5 provides a political-social-ecological perspective on food allergy in order to understand how contextual factors shapes perceptions, the practices, as well as management of food allergy in LMICs.

### CHAPTER THREE

Manuscript #1: "If we are waiting for the numbers alone, we miss the point": A qualitative study of the perceived rise of food allergy and associated risk in the Greater Accra region, Ghana

Atiim, G. A., Elliott, S. J. and Clarke, A. E. (2017). "If we are waiting for the numbers alone, we miss the point": A qualitative study of the rise of food allergy and associated risk in the Greater Accra region, Ghana. *Global Health Research and Policy*, 2:20. DOI: 10.1186/s41256-017-0040-0

### Overview

## Background

Globally, food allergy [FA] is considered a growing health epidemic. While much of what is known comes from developed countries, there is growing interest in the epidemiology of FA in developing regions such as sub-Saharan Africa. Indeed, researchers are beginning to document the incidence and prevalence of FA and sensitization. The results outlined in this paper stem from an exploratory qualitative study examining the emergence of the health risk of FA in Ghana, a country undergoing epidemiologic changes.

### Methods

Between June and August, 2015, we conducted thirty-seven (37) semi-structured in-depth interviews. This comprised seventeen (17) healthcare workers across 12 public and private hospitals and twenty (20) individuals with FA and families with allergic children. All interviews were recorded and transcribed verbatim. Transcripts were analyzed to develop thematic areas that characterize perceptions and experiences around FA.

### Results

Three key broad themes arise from this study. First, FA is an emerging health risk, whose incidence is perceived to be increasing. Second, participants expressed mixed perceptions about the public health burden of FA. Third, participants identified individual and societal factors that may be influencing FA risks and susceptibility.

## Conclusion

Our research suggests FA is a growing but unrecognized public health concern. There is the need for health policies and researchers to consider the full extent of ongoing epidemiologic changes for the health of populations in developing regions.

**Keywords:** Food allergy, Chronic illness, Epidemiologic transition, Qualitative, Ghana

### 3.1 Introduction

Allergic diseases including asthma, rhinitis, eczema and food allergy (FA) are a growing global public health challenge (Prescott, 2013). Globally, between 40 to 60 percent of the world's population have at least one allergic condition (Pawankar et al., 2011) creating serious psychosocial and economic impacts for individuals at risk, their families, and healthcare systems. The interaction between one's genetics and environmental factors are thought to increase one's susceptibility and disease occurrence (Ben-Shoshan and Clarke, 2011). While the specific pathways remain unclear, researchers suggest a direct relationship between infections and the rise in allergic disease, especially in western societies (Graham-Howe, 2011, Bach, 2002). For example, a notable review revealed that between 1950 and 2000, as rates of infectious disease declined, the incidence of allergies and autoimmune disease [e.g. multiple sclerosis, type 1 diabetes] increased (Bach, 2002). Other studies and reviews highlight linkages between exposure to micro organic environments [e.g. living on farms], heightened risk of developing allergies [e.g. asthma, hay fever] and atopic sensitization compared to those living on nonfarm lands or urban places (Elholm et al., 2015, von Mutius and Vercelli, 2010; Braun-Fahrander, 2000). Allergies, therefore appear to follow a gradient along socio-economic status (SES), geographic locality (e.g. rural vs urban) and measures of national incomes. The assumption is that individuals with high SES, an urban lifestyle, and residency in high income countries have increased risk of developing allergies and vice versa.

In North America and many parts of Western Europe that have moved through the epidemiologic transition, an *epidemic* of food allergy [FA] has emerged following similar increases in asthma and allergic rhinitis. Studies reveal 7.5% of children and adults in Canada (Soller et al., 2015), 8% in the United States (Gupta et al., 2011), and 10% in Australia (Osborne et al., 2011) self-report a FA. These rates come with many health and social

consequences. For example, FA impose a considerable psychosocial and financial burdens on individuals and their families (Du-Toit et al., 2015, Minaker et al., 2014). Moreover, FA detrimentally shapes one's quality of life (Dean et al., 2015) and forces people to constantly negotiate physical safety and social wellbeing (Fenton et al., 2013). In the most extreme cases, FA can trigger anaphylaxis, a serious life-threatening condition (Turner et al., 2015, Hochstadler et al., 2016). To date, the only mechanism to manage an anaphylactic allergy is complete avoidance of allergens and use of an epinephrine autoinjector when a severe reaction occurs.

While much of what is known about (food) allergic disease comes from developed countries, there is growing interest in allergic diseases in regions such as sub-Saharan Africa (SSA). Especially, given evidence that prevalence of allergic symptoms (e.g. asthma, allergic rhinitis and atopic eczema) have increased in SSA and represent central challenges for child and adolescent health (Ait-Khaled et al., 2007), there is growing suspicion that FA will soon be a challenge. Researchers are beginning to ask if countries in Africa will follow the experience of western countries as they complete their health transitions (Atiim and Elliott, 2016, Gray and Kung, 2014).

In the absence of population and hospitalization based studies (see Sibanda, 2013, Basera et al., 2015; Van Der Watt et al., 2015 for exceptions), a body of small-sample studies are beginning to document the incidence and prevalence of FA and sensitization in SSA. In unselected populations, challenge proven FA was 2.5% in South Africa (Basera et al., 2015). In the same context, other studies report high rates of FA – between 18% and 40% (Van Der Watt et al., 2015, Gray et al., 2014) and food sensitization - 5% and 66% (Gray et al., 2014; Levin et al., 2011). In Ghana, self-reported FA and sensitization is estimated at 11% and 5% of schoolchildren respectively (Obeng et al., 2011). It is important to note that sensitization – that is a positive response to an immunoglobulin E (IgE) antibody to the offending food -

does not always imply FA. The latter is evaluated partly on the basis of reproducing allergic symptoms [e.g. hives, eczema, shortness of breath, anaphylaxis] upon exposure to an allergen and a confirmation of sensitization to the specific food. In the few recent extant studies and reviews on FA in Africa, the high sensitization rates are increasingly suggestive of clinical symptoms of FA (Kung et al., 2014). In addition, they reveal an urban and SES bias in rates of FA and sensitization (Obeng et al., 2008). Taken together, these studies suggest FA is becoming an important health issue in urban SSA locations. Consequently, there is need for research to understand the changing allergy landscape.

Allergies occur and are experienced differently in various settings. Spatial differences in prevalence is likely mediated by factors such as (but not limited to) variation in access to medical care, culture and language (Mercer et al., 2004). For example, studies show FA is an unfamiliar health risk among immigrants in Canada (Harrington et al., 2015). We argue that placing FA's within the sociocultural and political environment can provide insights toward understanding the experiences and practices around FA in developing regions. Understanding FA in the context in which they arise will help develop context-dependent responses that address the unique needs of the allergic population.

While available studies characterizing FA incidence and prevalence in the African context use quantitative approaches and markers (e.g. IgE antibodies), they explain very little about the unique ways in which FA is experienced. For example, little is known about local perceptions of FA risk, diagnostic decision-making, management, or the subsequent socioeconomic impact of FA. Qualitative methods are an effective way to describe these health experiences, beliefs, and practices as well as illustrating how processes at multiple levels (Winchester and Rofe, 2010) shape health experiences and outcomes. However, only recently are researchers engaging with qualitative methods to explore FA experiences related to psychosocial responses, management, and coping strategies (Peniamina et al., 2014,

Gallagher et al., 2012). These studies highlight the importance of understanding how social context affect FA and allergy related behaviours.

In Ghana, the extent of FA is unknown and research to identify and understand the FA front is limited. To focus attention on this health risk, we draw on in-depth interviews with healthcare workers and the allergic population to understand the scope of FA risk in Ghana. Specifically, we ask how do healthcare workers and allergic populations perceive FA and its associated health risks? In so doing, we highlight FA as an emerging public health problem and contribute to the scarce literature on (food) allergic disease in SSA.

# 3.2 Embodied epidemiology of food allergy

This study employs a lens from ecosocial theory (Krieger, 2011), a relational approach to health that characterizes health risk within social and political structures. Ecosocial perspectives to health have been applied in studies that address questions around cholera vulnerabilities (Dasgupta et al., 2010), race, discrimination, and health disparities (Krieger, 2015; Krieger, 2012), maternal health experiences and pregnancy outcomes (Rishworth et al., 2015), and the water-health nexus (Bisung et al., 2015).

This paper particularly emphasizes the two core constructs of ecosocial theory, namely *embodiment* and *accountability and agency* in order to understand the health risks of FA. The term embodiment, refers to how people incorporate, biologically, their lived experiences in societal and ecological contexts (Krieger, 2011, Bisung et al., 2015). Implicit in this construct is how people negotiate, interpret and interact with their environment within particular historical, cultural and political contexts (Jaye, 2006). While embodiment has traditionally focused on the experience of people with disease, we also paid attention to the embodied experience and knowledge of individuals about "normal or abnormal" bodies in order to paint a picture of FA in Ghana.

Accountability and agency focuses on the perceptions and precepts (e.g. definitions, markers, and practices) that shape understandings of FA research and policy. It deliberately draws attention to institutional (e.g. health authorities, media) and individual (allergic persons, physicians) capacity to inform discourses around FA burdens. The debates about the epidemiology of FA – what is FA? how can it be measured? what treatment strategies are appropriate? – for example is a testament of the role played by stakeholders (e.g. researchers, experts, patients) in the exploration of the relationship between food and disease (Smith, 2015). In the context of FA, this construct suggests that while the allergic population (agency) can powerfully affect conditions around health policies, "expert knowledge" (by physicians, allergists) and structural factors (e.g. food and medical-industrial complex; public policy) are more likely to act as either facilitators or barriers (Waggoner, 2013, Krieger, 2011, Dasgupta, 2010).

## 3.3 Research setting and methods

# 3.3.1 Study area

Ghana is undergoing a rapid epidemiologic transition amidst concerns of growing incidence of noncommunicable diseases (NCDs). For instance, analysis of public and faith-based health facilities data (excluding tertiary hospitals) show an 11-fold increase in outpatient hypertension cases between 1990 and 2010 (Ministry of Health, 2012a). Regionally, the majority of reported cases of chronic diseases occur in the Greater Accra Region (GAR) located in south-eastern Ghana [see fig 3.1]. It is one of the most densely populated, and urbanized regions in the country. An estimated 90% of the population reside in urban areas in the GAR (Ghana Statistical Service, 2012). The GAR has one of the highest number of public health infrastructure in the country with 1 regional hospital, 10 district and sub-metropolitan hospitals, 4 polyclinics, 31 health centers and 38 community health and

planning service (CHPS) compounds (Amoakoh-Coleman et al., 2015). Consequently, populations in the GAR may have better access, diagnosis and treatment for their health conditions.

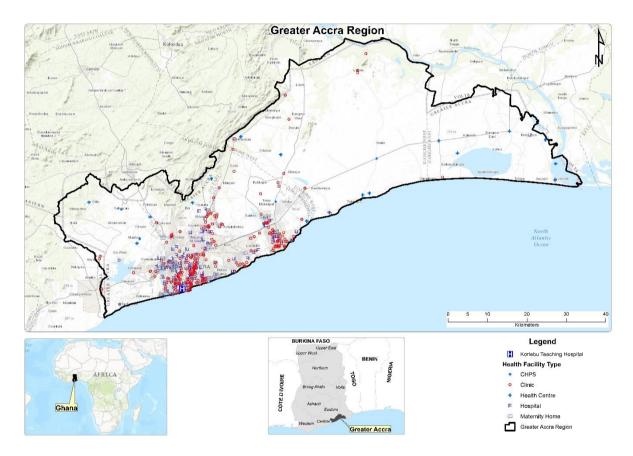
Studies show that since the 1950s, chronic diseases have featured as a principal cause of death in the country. For example, cardiovascular diseases (CVDs) rose from being the 17<sup>th</sup> to 10<sup>th</sup> leading cause of death by 1966. By 2001, CVDs were considered the leading cause of deaths in the GAR (Agyei-Mensah and de-Graft Aikins, 2010, de-Graft Aikins, 2007). While the national burden of allergies is unknown, outpatient data suggest a 3-fold increase in asthma cases between 2005 and 2010 (Ministry of Health, 2012b). These changing health profiles stem from a combination of factors related to the country's sustained economic growth, rapid urbanization, increasingly westernized lifestyle (including poor diets) from globalization, and improved healthcare accessibility and utilization.

### 3.3.2 Data collection and analysis

Between June and August 2015, we conducted in-depth interviews with seventeen (17) health workers and twenty (20) individuals and families (if child is <18 years) with food allergic children in the GAR. For the purposes of this paper, we refer to the latter group collectively as "allergic or affected population" (AP). Interviews provided a means to explore and collect information on a variety of meanings, opinions and experiences with different groups of people (Dunn, 2010). Health workers comprised general physicians (GP), pediatricians (PD), registered dietician nutritionists (RDN), nurses (NR) and traditional health-care practitioners (TP) as well as policy makers (PM). They were recruited in two ways: first, information letters about the study were submitted to heads of health facilities and they informed focal persons at their facility of their interest to participate. Health workers were then contacted by the first author to schedule an interview day and time. Second, we

also recruited using snowballing where health workers were encouraged to suggest others who they felt might be interested in this study. Affected persons (AP) were recruited through social media and social networks, flyers (posted at churches, and mosques) and the use of snow ball techniques. If the allergic person was less than 18 years old, we interviewed the parent or guardian.





To be eligible, participants had to (a) self-reported food allergy or be a parent/guardian of a child with food allergy, or (b) have a physician-diagnosed or suspected food allergy, and (c) must report at least two relevant symptoms, and (d) the symptom(s) must occur within two hours of coming in contact with the allergen. Recruitment continued until no new data emerged (saturation) from the interviews (Miles and Huberman, 1994). For health workers and affected persons, saturation was reached on the 14<sup>th</sup> and 17<sup>th</sup> participant

respectively. We explored participants' experiences and perceptions related to FA risks, signs, diagnosis, and management.

With respect to health workers, interviews were conducted in an office at the premise of participants' place of work, at a time of their convenience and lasted between 30 mins and 1 hour. For the allergic population, most interviews were conducted in their personal residence. All interviews were audio-recorded, collected in the English language and transcribed verbatim for subsequent thematic analysis using QSR International's NVivo 11. A theme code set was developed both deductively (in line with research objectives and the interview guide) and inductively (themes arising from interview transcripts). Further, interand intra-rater reliability for coding (Miles and Huberman, 1994) was assessed and reached a 90% consensus with a second coder.

Ethical clearance was obtained from University of Waterloo Ethics Review Board (ORE #20670) and the Ghana Health Service Ethics Review Committee (GHS-ERC 02/03/15). In addition, permission was received from administrators of health institutions and our participants.

### 3.4 Results

Table 3.1 and 3.2 presents a summary of the sociodemographic characteristics of the participants. The major food allergens reported in this study are presented in table 3.3 whereas the key clinical symptoms from the perspective of health workers are illustrated in table 3.4. In all, three [3] main themes emerged around food allergy (FA) as an emerging health risk, perception of public health significance, and food allergy risk and susceptibility. Results are organized around these themes, and are punctuated by direct quotation from participant interviews.

Table 3.1 Characteristics of healthcare participants [n=17]

Participant		Number [%]
Characteristics		
Sex	Male	6 [35]
Age group	28 – 35	2 [12]
	36 – 43	4 [24]
	44 – 51	3 [17]
	52+	8 [47]
Profession	General Physician [GP]	4 [24]
	Pediatrician [PD]	4 [24]
	Nurse [NR]	4 [24]
	Dietician [RDN]	2[11]
	Alternative Medicine Practitioners	1 [6]
	[AMP]	
	Public Policy [PPM]	2 [11]
Length of working years	3 – 5	3 [8]
	6 - 10	5 [29]
	11+	9 [53]
Practice setting*	Public hospital services	6 [35]
	Private hospital services	9 [53]
	Hybrid [public & private hospital]	3 [18]
	Public service sector	1 [6]

<sup>\*</sup> Sum not equal to total number of participants and percentage due to multiple responses.

# 3.4.1 An emerging health risk

There was a high level of consensus among most healthcare workers [n = 15] and allergic population [n = 18] that food allergies are a "new" health phenomenon that is in "its early stages "or "just beginning" or 'springing up" in Ghana. Drawing on their knowledge of disease in the past, participants suggested that food allergies were absent compared to the present reality.

I began to deal with these issues only in the last 5 to 10 years. I have been working since the 90s and this wasn't an issue we treated [GP 1, public hospital].

They are certainly very common these days than when we were children. It did not exist in those days because none of us had a food allergy [PP 9, mother of allergic child]

Table 3.2 Characteristics of allergic population [n=22] \*

Participant	Aller	gic Individ	dual in hou	ısehold	Age of allergic	Age of	Diagnosis
ID [PP]	C	hild	Self		person	diagnosis	
	M	F	M	F			
1 <sup>x</sup>		X			5	1	PD
		X			5	1 1/2	7
2				X	25	15	
3	X				3	1	
4			X		26	18	PD
5	X				12	4	
6				X	20	11	
7			X		23	17	
8				X	25	15	PD
9		X			3	1	
10			X		22	13	
11				X	24	10	
12			X		25	19	
13 <sup>x</sup>	X				12	3	PD
		X			8	2	
14			X		25	14	
15	X				4	1	PD
16			X		23	12	
17	X				5	2	
18	X				4	2	
19		X			3	1	PD
20		X			4	2	
Total		12	1	0			

<sup>\*</sup> Participants have more than one child with food allergy

On the contrary, a few participants felt that food allergy is an old but unrecognized health problem. These participants acknowledged that poor health seeking behaviours for example may have contributed to under-reporting of FA in the past and consequently the perception that this is a new phenomenon.

It has always existed. I think the problem is people often don't report these issues [AMP 1]

Further, most participants, especially healthcare workers [n = 13] suggested that there was an increase in the incidence of children and adults reporting allergic reactions to food at health facilities.

PD – self-report of a physician diagnosis of food allergy.

There is a rise in the frequency of new cases. We used to get one case out of a hundred people referred here. But now we are seeing an increase in the number of people coming. So there is a rise in the frequency of new cases [RDN 1, public hospital]

Many parents are bringing their children. Every now and then, you are treating a case of food allergy. The numbers coming are higher now than before [GP 2, private hospital].

Interestingly, we observed apparent differences between public and private healthcare participants concerning incidence of food allergies. Though public healthcare workers felt incidence was increasing, they were less likely to report any rise in new cases of FA. On the other hand, their counterparts in private institutions were more frequently reporting a rise in new cases of FA at health facilities.

However, healthcare workers were unanimous in their perception that FA prevalence was unknown. Many acknowledged that the lack of baseline data (i.e. no national prevalence data) and an inadequate disease surveillance system (i.e. existing system does not capture FA cases) were a barrier to gauging the prevalence of FA in the country.

We don't have national data on it. And that's the problem. There are no surveys to tell us how many people have a food allergy [GP 2, private clinic].

The current system we have does not record food allergy cases. It is mostly surveilling the regular ones; cholera, malaria, hepatitis, TB and others. Without surveillance data, it will be difficult to tell whether prevalence is increasing or not [PPM 1].

Notwithstanding this, when asked to speculate, the majority [89%] felt that prevalence of FA is lower, less than "one percent" of the population. Others also compared FA prevalence to the existing burden of infectious disease, and perceiving that prevalence was lower:

It's difficult to estimate but my guess is it has not reach the level we are seeing for the infectious ones. I think it is very much lower [GP 4, public sector]

Many allergic individuals however perceived that the prevalence of food allergies was increasing. Most [n = 15] articulated that allergies are more common in recent times especially among children, particularly in school-based settings.

I think this is increasing. There are many children in his school who also have food allergies. They are really very common [PP 13, mother of allergic boy]

Many of my friends also say their kids have food allergies. They tell me when I give him this, he throws out or gets hives and things like that. So is like a lot of children these days have it [PP 18, father of allergic girl]

Overall, these examples illustrate FA as an emerging public health concern whose incidence is perceived to be increasing. The characterization of FA as "common" and "new" highlights the need to pay attention to ongoing changes of the health of the population. At the same time, they also suggest the need to unpack factors within the socio-cultural environment that act as barriers to understanding FA prevalence

Table 3.3 Participants report of food allergens

Food allergen	Healthcar	e workers	Allergic population**		
	# of participants	% of participants *	# of participants	% of participants*	
Peanut	[n = 17] * 10	59	[n = 20]*	36	
Fruits (e.g. pineapple)	7	41	9	41	
Seafood (e.g. fish,	6	35	6	27	
shrimps, prawn)					
Vegetable (e.g.	5	29	5	23	
kontombire)					
Tubers (e.g. yam, cassava)	4	24	3	14	
Sesame	3	18	-	-	
Egg	3	18	4	18	
Milk	3	18	3	14	
Cowpea	2	12	2	9	
Soy	-	-	2	9	
Corn	2	12	1	3	

<sup>\*</sup> Sum is not equal to number of participants and percentage due to multiple responses.

<sup>\*\*</sup> Total number of food allergic individuals in the study

Table 3.4 Healthcare workers report of clinical signs and symptoms of food allergies

Description of symptoms	# of mentions	# of respondents	
	[%]	mentioning	
		[n=17, %]	
Skin / Cutaneous			
Itching	21 [41] *	12 [71] **	
Rashes	14 [27]	9 [53]	
Hives	9 [18]	7 [41]	
Swells [e.g. face, lips, eyes]	7 [14]	5 [29]	
Gastrointestinal			
Diarrhea	18 [51]	15 [88]	
Vomiting	11 [31]	10 [59]	
Abdominal pains	6 [17]	6 [35]	
Respiratory			
Breathing difficulties	12 [41]	7 [41]	
Persistent cough	8 [28]	4 [24]	
Swelling [e.g. tongue, throat]	5 [17]	3 [18]	
Running nose	4 [14]	2 [12]	

<sup>\*</sup>This represents the number of mentions of sign/symptom, and percentage of total mentions; \*\*Number of participants mentioning sign/symptom and percentage of total participants.

# 3.4.2 Perception of the public health importance of food allergy

The results indicate that most healthcare workers [n = 14] felt FA was not a major public health problem of great concern. A key criterion for assessing the public health significance of FA was its relative size and impact compared to infectious disease:

FA is not a big public health issue at the moment. If you look at the last five years, it has never been a top 10 cause of visits or admissions compared to malaria and the other chronic ones [PD 3, private clinic].

It does not reflect in attendance to clinics. It's not an issue we should be worried about. Any public health issue must affect up to 5% of the population and I don't think we are there yet with food allergy [GP 4, public hospital].

On the contrary, others [n = 3] articulated that "the risk" or "potential" negative outcomes should be the consideration for measuring the public health significance of FA. Physiological (e.g. anaphylaxis) and psychosocial impacts (e.g. quality of life) were key concerns for these participants:

We know it can cause death and anything that can lead to death is a serious issue. So the numbers are important but if we are waiting for the numbers alone, we will miss the point [NR 4, private clinic]

It already affects people and its changing lives. When you deal with parents whose child struggles with this, they are always frustrated and anxious. They are worried because they fear the unknown [PD 4, private clinic]

Such perspectives and framing were also pervasive in discussions of the public health significance of FA with the allergic population. Many participants [n=12] acknowledged that FA was not given the same importance as other health challenges, with many alleging that this was not often taken seriously [n=9] in the community. In calling for public health focus, an allergic individual intimated:

Something bad should not happen before they start taking this issue seriously. This thing is uncomfortable. You miss school because of that and the dangerous part is you can also die when it gets serious. It's time they made this a major issue [PP 2, girl allergic to fish and peanut]

Particularly for parents of allergic children, the general lack of a health system focus on FA arise from a poor understanding of its impacts, especially on work – related productivity.

People are affected at their job places. So they should look at it from this point. People are missing or leaving work to take kids to clinic or look after them. Is this not affecting productivity? [PP 1, father of allergic girls]

## 3.4.3 Factors influencing FA risk and susceptibility

Two main interrelated sub-themes emerged in discussions around FA risk: risk populations (who is susceptible?) and factors or causes of FA (what is driving this?). Most healthcare participants believed infants and children, those of high socioeconomic status (e.g. "the educated", "people who have money") and place of residence (e.g. living in an urban area) were the most vulnerable to developing FA. Indeed, they frequently characterized clients seeking care as belonging to the "middle" or "high class" or "those with higher education" as illustrated in this example:

They are mostly children. Those from middle class families. I mean with the degrees, the white collar jobs and often with behaviours akin to western societies [NR 2, private clinic]

Both healthcare workers and allergic population also identified factors at the individual [e.g. genetics] and societal level [e.g. globalization of foods, new methods of food production, urbanization] that influenced population vulnerability to FA risk. At the individual scale, most participants believed a genetic predisposition may increase risk of developing FA:

We know it's more of a genetic issue. It's more inherent and so if a parent or family member has any allergies, it is very likely one of the children will have one allergy or another [PPM 1]

I was told you don't get it the way you get like malaria or TB. They say it's usually a family thing. They said she has it because her dad suffers from asthma [PP 20, mother of allergic girl]

Also, most participants acknowledged that risk and susceptibility increases as societal changes become apparent. For example, a key concern was the globalization of foods.

Participants believed the change from local to baby formula foods had compromised the immune system of children and as a result "modern day" children are more susceptible to FA:

The foreign baby foods I believe are one of the reasons. No one feeds babies with local foods these days. Is all about "cerelac" and baby formula foods. It is not surprising that; a lot of babies today have bodies (immune system) that are not very strong [NR 1]

We all grew up eating local porridge and local foods as kids but that's all changed today. We have been quick to switch to many of the foreign food varieties. Maybe that is why these things are coming up lately [PP 11, allergic female]

Others identified behavioural and lifestyle changes as a contributory factor for the emergence of FA. Participants acknowledged that changes such as reduced frequency of personal cooking [n = 9], eating from outside sources [n = 6], and storage of food [n = 2] over time has increased the risk of having a FA.

I think it's because we are cooking a lot less these days and doing a lot more eating outside. The food is not fresh. We come into contact with new things that our system does not like [PP 14, allergic female].

We have copied everything, trying to live western life. We have introduced alien foods in our diets. We are refrigerating and storing more food than we did before. The end result is we are also getting their health issues. If you are copying everything, that is what you will get [RND 4]

Overall, these varied accounts highlight participants' perceived links between broader changes in the social environment and FA risk.

### 3.5 Discussion

Embodiment and accountability helps us to understand the relation between ongoing socio-environmental processes and changing disease profiles, and health outcomes in Ghana (Bisung et al., 2015; Krieger, 2011). They draw attention to how bodies negotiate and interact to characterize experiences of health. By drawing on the perceptions and experiences of healthcare workers' and allergic populations, this study highlights three main characteristics of FA health risk while hinting of the need to pay attention to the role of broader contextual factors (e.g. data availability, absence of FA surveillance system) that shape the understandings of FA in a developing country context.

First, we show that in a context where infections and chronic conditions are considered to be "established" health problems in the healthcare system, FA is becoming an important health issue. This is important, especially given the tendency in the theoretical and empirical literature to implicitly assume the rarity of FA in SSA. Participants suggested that FA might be in its "initial phase" in Ghana. This was evident in the frequent use of phrases such as "it's just beginning", "now coming up", or "springing up" to describe FA risk. This result is consistent with recent reviews that suggest FA is an emerging health problem that is increasing in Africa (Kung et al., 2014) and Asia (Lee et al., 2013). FA has largely been linked to the effects of exposure to microbes, increased hygiene, lack of vitamin D, genetics, dietary fat, caesarean section, obesity and affluence (Sicherer and Sampson, 2014, Lack, 2012). In short, FA results from changes in our environment. The perception that FA is an

emerging health risk suggests the environmental triggers of FA may already be underway in countries like Ghana that are experiencing rapid social, health and economic changes.

Table 3.3 show the most common food allergens and symptoms reported. Prior studies show differences in allergens in developing countries. For example, whereas beans, fruits and peanuts predominate in Ghana (Obeng et al., 2011), in South Africa and Colombia, eggs, peanuts, fruits/vegetables, seafood and meat respectively are the most common (Gray et al., 2014, Marrugo et al., 2008). In Ghana, national data do not exist, and the identification of peanut, a major trigger in 60-80% of anaphylactic reactions in western societies (Turner et al., 2016; Hochstadter et al., 2016) raise serious public health challenges. Beyond, peanut being a major ingredient in local diets and its nutritional value (vitamins & minerals), peanut, tree-nut and seafood allergy tend to be persistent, and a recurring issue in adult life (Sicherer and Sampson, 2014) with serious socioeconomic, healthcare, and management implications. We also found that local allergens (e.g. tubers, corn) are important sources of allergic reactions, highlighting the need to pay attention to the role of novel foods such as legumes, potato, sesame etc (Sibanda, 2013; Dias et al., 2008). While reports of symptoms may suggest food allergy, in the absence of testing, uncertainty remains whether these symptoms are immune-mediated especially the possibility that some symptoms (e.g. itching, water eyes, running nose) could also be induced by other irritants (e.g. pollen, dust mites, pets).

This study also reveals differences in the perception of FA incidence between public and private healthcare workers. The latter frequently indicated an increase in new cases of FA than the former. Given the availability of universal health coverage regardless of one's status in Ghana, we think an increase in the use of private healthcare services by the allergic population may explain this difference. Public health services are often perceived to be of low quality with deficiencies in the provision of essential supplies and infrastructure compared to their private healthcare counterparts (Basu et al., 2012, Bakeera et al., 2012).

Second, we also found disparities in perceptions around the public health significance of FA. Most especially health workers perceived that FA does not yet represent a major public health problem. They suggested because FA is not a major cause of hospitalization and it extent is unclear; expectations of a public health response was consequently unrealistic. This raises important questions around the role of lack of data, under-diagnosis and health priority setting in mediating the distribution of FA. For example, how does FA "become" a major public health problem when there are no attempts at counting it? While the assertion that FA is not a regular feature in healthcare settings may reflect lower rates, given that there are no reliable data, it is possible FA may be occurring at the periphery of the formal healthcare system. Indeed, studies of diabetes in Ghana suggest that patients often seek care from traditional health services first before utilizing hospitals (Amoah et al., 2002). Other factors such as levels of awareness and familiarity, access, availability, and costs associated with health service utilization may also affect documentation of FA incidence (Lu et al., 2014; Basu et al., 2012; Crighton et al., 2010).

Following this, the study hints of the need to focus on the sociocultural context in understanding perceptions and experiences around FA. In Ghana, the focus of integrated disease surveillance strategies continues to target infectious disease (Government of Ghana, 2002). Even in the context of NCD prevention, FA is still a neglected condition. Participants' assessment of FA in the context of the current burden from communicable and NCDs for example raise an important question around "who is responsible for the occurrence of embodiment"? (Yamada and Palmer, 2007). In a context of limited resources, and uncertainty over the magnitude of FA, policy makers face a dilemma over where to place priorities in terms of health investments. However, given the psychosocial burden of FA and the fact that FA is a high risk fatal health problem, we think FA rates do not have to be comparable to those of infectious or other NCDs in order to trigger a public policy response. There is need

to find ways of balancing health priorities to protect the needs of the allergic and general population.

Third and lastly, the findings also illustrate participants' ability to connect FA risk to ongoing socio-environmental changes. In identifying FA production, participants blamed the emergence of FA on a number of factors, including rising incomes, improved education, growing rates of urbanization, increased adoption of westernized lifestyles and genetics. While studies examine knowledge, perceptions and attitudes towards FA, diagnosis, management, and capacity needs of health workers (Maslin et al., 2014, Ribeiro et al., 2013), with few exceptions (Gupta et al., 2008), perceptions around FA risks and etiology remain largely underexplored. In the context of 'new' health risks, understandings perceptions around the etiology and drivers of FA is critical to starting conversations around measuring and managing FA.

Addressing data gaps and incorporating FA into existing disease surveillance systems is an important first step to understand and obtain a complete picture of FA, its associated risks and underlying causes. Second, it is critical to informing the development of appropriate policies and initiatives to address FA. However, discussions with participants in this research lead us to believe that nobody will count it until it becomes a major public health problem. In short, decision makers are still waiting for the numbers. But as the history and experience of the rise of NCDs in developing countries suggest, we cannot adopt a "wait and see" reactionary approach to rapidly emerging health risks such as FA.

To address data gaps, we have suggested elsewhere for the inclusion of validated FA questions into existing population-based projects (e.g. Demographic and Health Surveys; Multiple Cluster Indicator Surveys) to begin measuring prevalence and to understand its distributions (Atiim and Elliott, 2016). In addition, health promotion initiatives on the symptoms and signs associated with FA can give much needed visibility to this emerging

health risk. The expectation is that such increased awareness in concert with the removal of barriers to health care would lead to more encounters between the healthcare system and allergic individuals.

This study has limitations. The small sample restricts generalization though providing a rich, diverse and nuanced accounts of food allergy (FA) in Ghana. Also, we were unable to confirm from medical records, self-report or self-report of physician diagnosis of FA. In the absence of gold standards of testing FA in the country, we cannot be certain of the allergic status of individuals. As a result, our findings should be interpreted with caution.

## 3.6 Conclusion

To our knowledge, this is the first study to qualitatively explore health workers' and allergic population perspectives of FA in Ghana and the broader African context. Only one study (Stear et al., 2011) has quantitatively explored knowledge and practices of health professionals in healthcare setting in Africa. By illustrating perceptions and experiences, a nuanced understanding of FA in Ghana is provided. While we recognize there are many debates in the literature regarding the epidemiology of FA, it is important to note that current "consensus" about FA have been shaped by the experiences and concerns of researchers, clinicians, the allergic population and advocacy groups [Smith, 2015, Waggoner, 2013). By focusing on health workers and allergic population, this study highlights valuable knowledge that can help shape our understanding of FA in the developing world. We believe such context-based information are meaningful to "shed light on the social processes at play in the emergence of new epidemic" (Waggoner, 2013).

Our study also suggests that health in the so-called "developed" and "developing" region is beginning to share more similarities than differences. As most parts of the developing world experience rising burdens of NCDs, and evidence emerge about common

risk factors with allergic disease, FA can no longer be framed as an isolated disease of western societies. Policy makers therefore need to consider the full scope of the implications of the ongoing social, economic and environmental changes for the health of populations in developing countries. This study therefore provides a starting point in shining a spotlight on a growing public health problem.

### **CHAPTER FOUR**

Manuscript #2: "ne nnipadua mmpe" (the body hates it): Exploring the lived experiences and coping strategies of food allergy in Ghana

Atiim, G. A., Elliott, S. J. and Clarke, A. E. (forthcoming). "ne nnipadua mmpe" (the body hates it): exploring the lived experiences and coping strategies of food allergy in Ghana. Under review in *Social Science and Medicine* 

### Overview

The rise of noncommunicable diseases (NCDs) in developed countries has been followed closely by an apparent epidemic of allergic disease. As prevalence of NCDs increases in sub-Saharan Africa, researchers are hinting that the same future may hold for this world region. Through a political ecology of health lens, this study explores the lived experiences of those affected by food allergy in SSA, using Ghana as a case study. We draw on in-depth interviews with twenty (n = 20) individuals affected by food allergy. Results reveal that food allergy is a growing health concern, with significant psychological (e.g. anxiety and fear), social (e.g. stigmatization, social exclusion), and economic (e.g. impact on work & household expenditures) impacts on the wellbeing of the affected population. By exploring the sociocultural environment, the results highlight the coping strategies employed and the constraints experienced when living with a food allergy. While some of the findings are similar to those uncovered in the developed world, important regional differences have been uncovered that underscore the importance of place in shaping health experiences. The paper is an important first step towards understanding the needs and experiences of people affected by food allergy in a LMIC context. Moreover, these findings highlight policy and research gaps requiring immediate attention.

**Key words:** NCDs, food allergy, political ecology of health, sub-Saharan Africa

### 4.1 Introduction

Around the world, noncommunicable disease (NCDs) are a significant global health problem (Beaglehole et al., 2011, WHO, 2011). In 2010, four now recognized NCDs (cardiovascular disease [CVDs], cancer, diabetes and chronic respiratory disease) accounted for 2 in every 3 of the 52.8 million global deaths (Lozano et al., 2012). In Europe, they are the leading cause of (ill) health and disability, accounting for almost 86% of deaths and 77% of the burden of disease (WHO, 2012). In 2012, of the 28 million deaths attributed to NCDs, 3 in every 4 occurred in low and middle-income countries ([LMICs], WHO, 2014). Even in contexts such as sub-Saharan Africa (SSA) where communicable and maternal issues persist as the leading cause of years of life lost (Lozano et., 2012), research show an increase in diabetes and depression by 88% and 61% respectively between 1990 and 2010 (IHME, HDN, The World Bank, 2013). The poor and rich are equally at risk especially in LMICs – the former more likely to engage in risk behaviours (e.g. alcohol & tobacco use) and the latter more likely to be inactive, consume more fats, salt and processed food (Allen et al., 2017).

While historically much discussion on NCDs has focused on western societies, in the last three decades, global health action has galvanized attention towards the current and future burden of chronic illness in LMICs. This has been driven in part by increased life expectancy, an indication of gains in infectious disease decline, and sustained economic development, coupled with the effects of globalization and rapid urbanization which accelerates the rise of behavioural (e.g. unhealthy diets, smoking, physical inactivity) and physiological (e.g. obesity, blood pressure) risk factors for NCDs in LMICs (WHO, 2011, de-Graft Aikins et al., 2010). This changes have resulted in growing similarities in the health worlds of developed and developing countries (Atiim and Elliott, 2016).

In developed countries, in addition to the four main NCDs, the last three decades has also witnessed a concomitant rise in allergic disease including asthma, eczema, rhinitis

(Bach, 2002) and more recently food allergies (Prescott and Allen, 2011). Research suggests food allergy affects an estimated 7.5% of children and adults in Canada (Soller et al., 2015); 8% in the United States (Gupta et al., 2013: 2011) and 10% in Australia (Osborne et al., 2010). In LMICs and in particular SSA, studies show high prevalence of symptoms of asthma, eczema and rhinoconjunctivitis (Lai et al., 2009, Ait-Khaled et al., 2007) similar those observed in developed countries. As NCDs and some allergies become more prevalent in SSA and other LMICs, researchers are hinting that (food) allergic disease – one of "the most common and earliest onset of NCDs" – is not far behind (Atiim and Elliott, 2016; Du Toit et al., 2015; Gray and Kung, 2014, Prescott, 2013). Indeed, a small number of studies in Africa show that food allergy affects 11% of school children in Ghana (Obeng et al., 2011) and between 18% and 40% of children attending pediatric clinics in South Africa (Gray et al., 2014; Van Der Watt et al., 2015). Though their sample size is small (e.g. Gray et al., 2014), these studies do provide insight into the future landscape of food allergy in SSA and raises questions about the social dimensions of living with food allergy in a context where infectious diseases dominate public discourse on health and health promotion activities.

Food allergy imposes serious challenges on the physical, social and economic wellbeing of allergic individuals and families, affecting quality of life as they interact with others at home, and in schools (Cummings et al., 2010; King et al., 2009; Ostblom et al., 2008). For example, among allergic individuals in the United States, approximately 40% have a history of adverse allergic reactions (Gupta et al., 2011). These may include breathing difficulties, swelling, abdominal cramps and vomiting (Hadley, 2006). Without treatment, food allergy can trigger anaphylaxis, a life threatening condition that is increasing among allergic individuals in developed countries (Turner et al., 2015; Hochstadter et al., 2016). In addition, it often leads to the disruption of family social activities (Bollinger et al., 2006); increases anxiety and stress (Munoz-Furlong, 2003; Primeau et al., 2000); and leads to

frustrations from a lack of understanding of the risks of food allergy (Mandell et al. 2005). Besides the financial and economic costs (Gupta et al., 2013, Patel et al., 2011), food allergy result in stigma (Dean et al., 2015; Pitchforth et al., 2011) and bullying (Torabi et al., 2016) as allergic persons interact within and across different spaces of risk – home, school, and work, and other public places (Canada Transportation Agency, 2016, Smith, 2015).

Given the general dearth of population-based data on food allergy prevalence and absence of food allergy policies in SSA, affected individuals face serious challenges mitigating food allergy health risks. To help understand and unpack the lived experiences and perceptions of food allergy, the study uses a political ecology of health lens to gain insights into how sociocultural contexts of places inform the experience of (food) allergic people in SSA using Ghana as a case study. Previous studies suggest food allergy is an emerging critical health concern yet neglected and often unrecognized as a public health issue (Atiim et al., 2017). By employing political ecology, the paper provides a nuanced account to examine how perceptions, experiences and coping strategies of allergic individuals and their family members are embedded within and shaped by the sociocultural context. Specifically, we address the following questions: (1) what does it mean to have and to live with a food allergy in SSA? and (2) how do individuals and families with (food) allergic children manage and cope with allergy? Overall, we aim to highlight perceptions of food allergy burdens and to identify barriers that impede responses to meet the needs of this newly allergic population.

## 4.2 A political ecology of food allergy

Political ecology of health is an enduring lens in health geography that helps to understand how biology, sociopolitical structures and ecological factors operating within and across multiple scales shape population health and wellbeing (Neely, 2015; King, 2010).

Political ecology explicitly attends to the role of broader health contexts including but not

limited to global and national health policies, clinical practices, discourse around health and disease, actors (e.g. individuals or institutions), and how these interact to (re)construct health risk perceptions, experiences and disease distributions in places (Neely, 2015, King, 2010). So, while individual biologies are key to understanding health and disease expression, they cannot be divorced from the intricacies of the sociocultural, politico-economic and ecologic environment in which people understand and experience health, or live and work (Neely, 2015, Guthman and Mansfield, 2012; Krieger, 2011). In short, individuals embody their social and ecologic environments or local context.

Further, political ecology lens helps to reveal the tensions, negotiations and contestations around health risks. Studies of the social construction of risk show that food allergy is a contested and evolving health issue, shaped by the interests of key actors including healthcare workers, researchers, institutions [e.g. the media], advocacy groups, and the lay population (Nettleton, 2009, Harrington et al., 2012, Waggoner, 2013). A small number of studies also shed light on the ways in which health policies structure social bodies of allergic individuals. Rous and Hunt (2004) for example show that regulatory policies intended to manage risk exposures, socially differentiate between allergic and non-allergic populations while expanding care and management of food allergy beyond the realm of parents and the home to include new actors such as teachers and schools. Though often implicitly stated, these studies reflect research in political ecology of health that call attention to the need to incorporate the complexity of the local context to understand the patterns of population health and the production of health. In the context of SSA, political ecology provides the opportunity to interrogate the sociocultural environment and health discourse of this emerging chronic illness. We do so by documenting the experiences of (food) allergic individuals and families and their responses to community beliefs and practices shaping the experience of food allergy.

### 4.3 Methods

### 4.3.1 Research context

This study was undertaken in the Greater Accra Region (GAR), the most economic and cosmopolitan of the ten administrative regions in Ghana. The choice of the GAR was informed in part by existing literature on (food) allergic disease which shows that food allergy tends to be more common among urban populations and households with higher socioeconomic status (SES). The GAR is the most urbanized, with an estimated 90% of the urban population (GSS, 2012) and has relatively well resourced health facilities. Over the years, rapid urbanization, improving socioeconomic standards, lifestyle changes and a context of globalization has led to a rapid shift in the disease profile of this region with chronic illnesses becoming prevalent (Agyei-Mensah and de-Graft Aikins, 2010). The GAR therefore provides an ideal setting to explore and attempt to understand the food allergy landscape.

# 4.3.2 Research design, data collection and analysis

In this exploratory study, twenty [20] semi-structured in-depth interviews were conducted with allergic individuals [n = 10] and families with (food) allergic children [n = 10] (herein referred to as those affected by food allergy) between June and August, 2015. Two parents had more than one allergic child bringing the total number of allergic persons to twenty-two [22] comprising; 10 individuals >18 years [45%] and 12 children <18 years [55%]. Interviews provided a way to gain insights into the everyday experiences and adaptive responses to living with an allergy. We recruited through a number of ways using social media and social networks. Recruitment posters were also strategically placed on boards at public places (e.g. churches, mosques). In addition, we used snow balling technique in order to maximize variations in the sample composition.

To be eligible, participants had to (a) self-reported food allergy or be a parent/guardian of a child with food allergy, (b) have a physician-diagnosed or suspected food allergy, (c) must report at least two relevant symptoms, and (d) the symptom(s) must occur within two hours of coming in contact with the allergen (Ben-Shoshan et al., 2010; Boyce et al., 2010). All participants were given information letters and interested participants directly contacted the first author by phone. We received consent prior to commencing interviews. In the case of children <18 years, interviews were conducted with either a parent or guardian.

Interviews were conducted at a place of participant's choice, the majority [17] of which occurred in their homes. Interviews lasted between 45mins and 1 hour focused on perceptions and experiences of diagnosis, living with food allergy, management and coping strategies. All interviews were conducted in the English language (with one exception) and audio recorded. Ethical clearance was obtained from University of Waterloo Research Ethics Committee and the Ghana Health Service Ethics Review Committee.

All interviews were transcribed verbatim for subsequent thematic analysis. Data was coded both inductively and deductively. To ensure credibility and consistency of data, we assessed for inter- and intra-rater reliability (Miles and Huberman, 1994) and reached 80% agreement with a second coder. All 20 interviews were entered into QSR International's NVivo 11. We pooled data from both parents of children and allergic individuals in large part due to the similarities in experiences and concerns shared by participants. In doing so, we attempt to paint a picture of the collective lived experience of affected persons. We employed pseudonyms in the attribution of quotes in this paper to ensure anonymity.

### 4.4 Results

Approximately half of participants were diagnosed/realized their food allergy at a

very young age [Table 4.1] with most reporting allergies to multiple foods [n = 17; 77%]. Major allergens include fruits [41%], peanut [36%], seafood [27%], vegetable [23%], egg [18%] as well as local allergens such as yam [14%], and maize [3%]. The primary allergic reactions are presented in Tables 4.1 and 4.2. The rest of the findings are categorized under three key thematic areas (perception of prevalence, perceived impacts, and coping strategies) and punctuated by direct quotations from participants. Taken together, the results help to paint a picture of the experiences of the allergic population.

# 4.4.1 General perception of food allergy and prevalence

Participants [n = 15, 75%] believed food allergy has increased with time. This was particularly evident by descriptions such as "they are a lot now", "they are widespread now" or "children like these are now many" in discussing their understanding of the state of food allergy in the context of past and current health:

They have been increasing. If I look back, this was not a problem but children like these are now many and growing in numbers. It's definitely higher now than in the past - Akwasi, 38 years, father of children with peanut and egg allergies

It was lower in those days [the past] than today. In high school, it was not many but they are widespread now. As we moved on, it has just increased - Togbe, 23 years, male adult sufferer with multiple allergies

The notion of a growing number of people with food allergy is shaped by experiences and interactions with other allergic individuals or other parents:

At his school, you're asked to fill a form during admission and one of the question on it is "does your ward have an allergy"? and then you indicate what kind. It was there I realized he was not alone. A lot of children have it too – Ama, 32 years, mother of boy with soy allergy

Table 4.1 Characteristics of food allergic individuals [n = 22]

Participant	Allergic				Food allergens	Highest educational	Occupation						
ID .	Individual in		Age of	Age of		attainment							
	household		household		household		household		allergic	diagnosis			
	Child Self		person										
	M	F	M	F									
Akwasi*		X			5	1	Peanut	University	Research				
		X			5	11/2	Peanut, egg						
Lamisi				X	25	15	Fish, peanut	University	Nursing				
Ama	X				3	1	Soy	University	Public servant				
Henry			X		26	18	Shrimps, lobsters, Peanut, banana	University	Entrepreneur				
Ebo	X				12	4	Prawns, lobsters, oysters	University	IT consultant				
Mavis				X	20	11	Fish	High school	Clerk				
Togbe			X		23	17	Yam <sup>xx</sup> , maize	University	Project assistant				
Ewurabena				X	25	15	Pineapple, Peanut	University	Freelancing				
Charles		X			3	1	Peanut, milk, cowpea	University	Security services				
Mark			X		22	13	Plantain, pineapple, kontombire **	University	Student				
Sally				X	24	10	Snail, milk, pineapple		Administrator				
Musah			X		25	19	Prawns, shrimps, pineapple	University	Public servant				
Serwah*	X				12	3	Eggs	University	Insurance broker				
		X			8	2	Eggs, soya						
Alvert			X		25	14	Cowpea, apple, pineapple, snail, lobsters, prawn	University	Teaching				
Kwame	X				4	1	Cowpea	University	Accounting				
Phil			X		23	12	Yam, okra, kontombire	University	Banking				
Rose	X				5	2	Yam, kontombire **, "cantose" **	Vocational	Clerk				
Akosua	X				4	2	Milk, eggs, peanut	University	Public relations				
Sheila		X			3	1	Kontombire **, pineapple	University	Administrator				
Suweiba		X			4	2	Peanut, kontombire **, pineapple	University	Nursing				
Total	1:	2	1	0									

<sup>\*</sup>Families with more than one food allergic children
\*\*Local foods [kontombire, and cantose are vegetables]

Table 4.2 Summaries of food allergy characteristics of individuals [n = 22]

Food allergen	Reported symptoms	Diagnostic process	Reaction time
Fruits [9, 41%]	Skin [n = 19]	Self-realization [n = 10]	Immediate [n = 13]
Peanuts [8, 36%]	Respiratory [n = 8]	Physician [n = 6]	Less than $30$ mins $[n = 5]$
Seafood [6, 27%]	Gastrointestinal $[n = 5]$	Physician and self-	30mins and 1hour $[n = 2]$
Vegetable [5, 23%]	Others $[n = 6]$	realization $[n = 7]^a$	1 and 2hours [n = 1]
Eggs [4, 18%]		Self-realization and	Within 2 hours $[n = 1]$
Yam [3, 14%]		physician $[n = 1]^b$	
Milk [3, 14%]			
Soy [2, 9%]			
Cowpea [2, 9%]			
Maize [1, 3%]			
İ	1		

<sup>&</sup>lt;sup>a</sup> Describes situations where physician suspects food allergy but the identification of the specific allergen is done by the allergic individual or parent of allergic child.

In a few instances [n = 5], some did not want to speculate on food allergy prevalence, often highlighting the lack of information and awareness on food allergy as a constrain.

I'm saying it's not well documented. So I can't say whether its increasing or not. I know am not the only one with allergy but I cannot tell if it is increasing or if it's not – Ewurabena, 25 years, female adult sufferer with pineapple and peanut

I read, not every child gets it and so I think it is difficult to say the number is going up. When a serious health issue or something is beginning to come up, there's a lot of talk on it but the awareness on this one is really not there – Suweiba, 36 years, mother of girl with multiple allergies

Knowledge about food allergy is an important step towards treatment, care and coping. Some parents [n = 4] possessed some prior knowledge, acquired from reading health materials during pregnancy [n = 3] or from interacting with health systems outside the country. As a result, they were not surprised learning about their children's allergic reaction.

My first pregnancy, I was reading a lot of materials not just about my health but also the unborn child too. It was during this time I came to know allergy. So it was not a big surprise - Serwah, 40 years, mother of children with eggs and soya allergies

On the contrary, most participants [n = 13] who had not heard about food allergy before

<sup>&</sup>lt;sup>b</sup> Describe a case where allergic person or parent of allergic child first suspects a food allergy and receives confirmation from a physician

diagnosis, although had some prior knowledge of other allergies [e.g. asthma, eczema and rhinitis], indicated they were surprised [n = 7], scared [n = 4] or worried [n = 2] experiencing the initial reactions. Similar to Lu et al (2014), we did not find a description for food allergy and or anaphylaxis in the native language. Some participants felt that a native name for food allergy would make it easier for the general public to appreciate the adverse reactions.

We don't have a local name for it. The closest I can think of is "ne nnipadua kyiri" or "ne nnipadua mmpe" meaning "the body hates it". So maybe if we have a local name that everyone understands, that will help a lot - Ama, 32 years, mother of boy with soy allergy

Food allergy has severe consequences for the allergic population ranging from psychological, social, financial and non-financial issues. We explore these issues further in the following section.

# 4.4.2 Characterizing the psychosocial burden of food allergy

#### 4.4.2.1 Frustration

Receiving a diagnosis of food allergy engendered feelings of frustration, a dominant issue reported by most of the allergic population (n = 11) and a major issue for parents (n = 8). Parents shared that not knowing "what is wrong with your child" and experiencing 'the same reactions coming back" often resulted in feelings of irritation and helplessness:

Every parent wants to know what is wrong? If after jumping from one hospital to another, you still don't know, you are always boiling within especially when you see the reactions again and there is little you can do - Sheila, 29 years, mother of girl with multiple allergies

Allergic individuals also mentioned that they felt angry at themselves (n = 2) and sometimes even "stressed out" (n = 1) because of what they perceived was a misfortune of having a food allergy.

I have always wondered was this bad luck? Why me? If you take my sisters, none of them have it. So sometime you just get sad or angry at yourself. Why is it me? Not saying they should also have it but like why do I have it? – Lamisi, 25 years, female adult sufferer with fish and peanut allergy

# 4.4.2.2 Living in anxiety and fear

Most participants [85%, n = 17] reported feeling anxious about the risk of a reaction, particularly concerning accidental or deliberate exposure to allergens. Such concerns were more pronounced among parents:

I am always uneasy till I see [name of child] because you are always hoping you don't hear she was given some peanut or milk-based food and so you are always uneasy - Charles, 27 years, father girl with multiple allergies

For allergic individuals [>18years], concerns of anxiety surrounded the uncertain risk of their food allergy. Although most perceived their allergy to be mild [n = 7], nonetheless, the fear of the "unknown" or how their "condition will turn out" in the future shaped their food allergy experiences.

Am not worried about today because mine is mild. It is the fear of what can happen or is going to happen in the future that frightens me because I have heard you may have mild reactions today, and the next, it can become serious. That's what makes me feel worried - Henry, 26 years, male sufferer with multiple allergies

Some parents [n = 6] also expressed children's ability to manage risk outside the boundary of the home was a source of constant worry. Despite actions taken to help prevent exposure, they felt children lack confidence to implement such preventive measures partly because of the desire to be accepted by their community of friends,

I can't take my mind off him getting another reaction. He does not have the confidence to say no please, I can't eat that. When we get to the point he is in control, this [fear] would naturally go away – Rose, 32 years, mother of boy with multiple allergies

From what I have seen, she is not capable. They like their friends very much and are always trying to fit in. So when they are eating, she just joins in. Maybe when she is grown, she will be better able to manage it - Suweiba, 36 years, mother of girl with multiple allergies

Concerns about parental transfer of food allergy risk management to children are common in the literature [DunnGalvin et al., 2009]. Many parents were only willing to give management responsibilities to children if they are able to demonstrate the ability to assess and appreciate the risks associated with their food allergy. As such it is important to engage everyone, not just families, especially in a context where child raising often is a communal activity.

#### **4.4.3** Experiences of social relations

Food allergy affects-social relationships and shapes the interactions of the allergic population in social spaces with participants revealing feelings of exclusion and stigma.

#### 4.4.3.1 Social exclusion

On many occasions, participants expressed that their food allergy presented a "license" for others within their social networks to exclude or isolate them from social activities.

According to them, practices and behaviours such as body language, negative comments and teasing engendered a feeling of rejection as these examples illustrate:

I don't join them to eat [why?] So many times when they see me coming to join them, they say things like "the one who is afraid of fish is coming". I don't want them to use it as a license to say things that make you feel alone – Mavis, 20 years, female adult sufferer with fish allergy

If you go somewhere and someone is like; "that your thing [being protective], if you are going to be doing that, then don't come here". What are they telling you? Is like you are "sitting on their happiness" and so the best thing is you don't go there in the first place - Charles, 35 years, father of girl with multiple allergies

In response, many participants often tried to ignore such attitudes and behaviours. They

nonetheless found such attitudes to be disheartening [n = 1], painful [n = 3], unpleasant [n = 4] and annoying [n = 6]. This was particularly so if such practices were perpetuated by family members and friends, who are often the only form of social support. Besides feelings of exclusion, these examples also subtly highlight the issue of "labelling", a major theme in the allergy and related health literatures.

#### 4.4.3.2 Stigma

Experiences of stigma play out in the daily interactions of the allergic population. Most participants [65%] reported examples of "felt" stigma [the internalized experiences of shame, or anxiety of being rejected] with some parents [n = 4] feeling uneasiness about outdoor activities with their children. This uneasiness arises from "unnecessary" inquiries about the physical effects of experiencing an allergic reaction:

He also has rashes and sometimes blisters that leave marks on his hands and legs. A lot of people are always asking a lot of unnecessary questions when you go out. If you tell them, they don't believe as if I am just imagining it - Akosua, 30 years, mother of boy with multiple allergies

Other parents expected the physical effects of experiencing a reaction to lead to exclusion of their children from their circle of friends and consequently were concerned about its potential impacts on the child's wellbeing.

I wouldn't have been surprised if they made fun of him or shun him. He hasn't complained about any of this so that is a good thing but I worry that someday it will happen and cause him to begin to dislike school – Ebo, 41 years, father of boy with multiple allergies

In the case of allergic individuals [n=6], friends and sometimes family members' accusations often resulted in feeling worried. Friends often linked allergic individuals' avoidance of allergen to their social standing in society and as such perceived their food allergy as a disguise:

The sad thing is they think it's because we are well to do. That I have a luxury of what foods to eat and so because I prefer something else, I am claiming to react to seafood. And that is painful at times but that always comes up and that can make you feel down – Phil, 32 years, male adult sufferer with multiple allergies

"Enacted" stigma was not a dominant issue in participants' experiences. Only one reported a situation where her child was threatened with exposure to an allergen leading her and family to better appreciate food allergy risks.

Her friends told her "we will let you eat peanut if you don't stop" [she was poking fun at friends]. That was my very first time [seeing her being bullied] and that's when we also begun to take seriously the dangers to her – Suweiba, 36 years, mother of girl with multiple allergies.

# 4.4.4 Cost of living with food allergy

#### 4.4.4.1 Direct costs

Food allergy has financial implications for this allergic population. Medical and transport costs associated with seeking a diagnosis and managing food allergy were the two key issues commonly discussed. Some participants (n = 7) reported an increase in household expenditure due to the high medical costs (e.g. diagnosis, consultation, drugs) especially during the initial stages of seeking a diagnosis:

The expenses began to go up because you are moving in-between hospitals. If you pay like Gh80 [\$20] for consultation alone, Gh35 [\$9] each for cetirizine (antihistamine), imagine how much money will be spent on each visit alone Kwame -35 years, father of boy with cowpea allergy

In two interviews, while recognizing there was a need to undertake a food allergy test, the relatively high medical cost<sup>4</sup> was a major barrier to confirming one's allergic status:

65

<sup>&</sup>lt;sup>4</sup> Though Ghana operates a health insurance scheme that provides "free" access to healthcare, barriers related affordability, geographic, socioeconomic, sociocultural environment and health system factors persist, affecting healthcare accessibility, and utilization.

We were actually referred to do a test to know what food. When I asked, the cost was high, around I think GH200 [\$50] there about. And we needed at least two tests. We just couldn't do that – Mark, 22 years, male adult sufferer with multiple allergies

Some participants [n = 4] also reported high transport related costs accrued in the process of seeking care and treatment impacted household finances. In most cases, costs resulted from payments for taxi services to and from hospitals, or expenditures for fuel:

Most go into fuel and if you take the traffic situation, it doesn't take long to run out of fuel. And this is just between Tema and Accra alone. If I am away with the car and the woman [spouse] has to take him, she has to always hire a taxi and that's also money. That's already a lot – Ebo, 41 years, father of boy with multiple allergies

#### 4.4.4.2 Indirect cost

Indirect costs include the burden on time use and work-related productivity. Many felt a considerable amount of time was spent preparing and cooking food [n = 7], and ensuring that processed foods did not have allergens [n = 5]. Commenting on time spent cooking, a parent noted:

My biggest issue is time. Cooking takes a lot of it away because you have to be certain that what he is eating is safe to eat. He must have something when he is going to school, and when he returns – Rose, 32 years, mother of boy with multiple allergies

The time spent in food preparation also results from the need to strike a balance between the needs of allergic and non-allergic members of the household. Allergenic foods were still prepared in some homes [n = 5] for non-allergic members. This was a predominant issue among individuals with food allergy who often described preparing food as a waste of time:

We still cook them because my siblings like them a lot. If mom does not cook something different, I have to prepare something which is simply a waste of my time - Mark, 22 years, adult male sufferer with multiple allergies

Participants also felt that their need to prevent exposure often resulted in a significant amount of lost time ensuring that food or its ingredients did not contain allergens before eating or cooking. In one example, a participant intimated that a lot of time is spent trying to read labels on processed foods:

I try to read every label because there are a lot of baby meals at mothers' care shops with traces of soya. Again because some of the writings can be very small, you have to take more time - Ama, 32 years, mother of boy with soy allergy

Participants, especially parents, also noted challenges in negotiating a balance between work-related responsibilities and managing children's food allergy. Many parents [80%] indicated their child's food allergy had affected their ability to do their job since they frequently had to ask permission to leave work or were often distracted and unable to concentrate on work-place responsibilities:

If he has to go to the hospital at 3pm, it means that I have to leave early around 2. Doing this all the time affects your work output. And even sometimes you have to take days off to care for his needs – Akosua, 30 years, mother of boy with multiple allergies

While such experiences were perceived to be difficult, this was a necessary choice needed to ensure the safety and wellbeing of children with food allergy.

# 4.4.5 Coping Strategies

Coping strategies were primarily in the form of acceptance, avoidance, restriction of social activities and keeping medication. Most participants indicated coping pragmatically, by accepting their allergic status. As a result, many were not "really bothered" or "don't worry" about the (in)actions of others whom they have little control over.

"It is a normal part of life. There are those who will believe you, others won't. That's normal in my eyes so why should I let it bother me? You get used to it and you begin to ignore or laugh over them – Ewurabena, 25 years, adult female sufferer with pineapple and peanut allergy

Others also indicated either completely [n = 14, 70%] or partially [30%] avoiding allergens. In the former category, this was deemed a non-negotiable issue, which is "absolutely necessary" to prevent reactions from reoccurring:

If you have seen him vomit before, you will understand why it's absolutely necessary to avoid anything soy or soya. It was a very frightening experience. So I make sure those things don't come even close to him, so we don't experience any bad reaction again – Ama, 32 years, mother of boy with soy allergy.

In the latter group, though recognizing the potential risks of partially avoiding allergen in the home, participants maintained it was also a necessity to address the food needs of non-allergic household members. In such a context, measures such as providing alternative meals, and using different utensils were employed to help prevent exposure to the allergic individual.

Another strategy is restricting participation in social activities where exposure to allergen was likely to happen. While most social activities [e.g. parties, naming ceremonies, weddings] presented opportunities for strengthening relationships, parents especially noted they also acted as spaces for exposure.

You meet friends and families, but there is also risk because such programs always involve food. We believe there may be some other foods she is reacting to as well. So as a rule, we restrict their involvement at parties unless we are present - Charles, 35 years, father of girl with multiple allergies

Allergic individuals [n = 6] on the other hand participated regularly in group (e.g. church, class & work) activities such as picnics and parties but were "usually" careful to refrain from eating at such events because of the uncertainty of risk.

I attend most of the events. It does not stop me from going. Just that I usually don't take or eat any of the items they provide because I am not sure whether in the process things got mixed up or not – Musah, 25 years, adult male sufferer with multiple allergies

The majority of participants [85%] also reported keeping medication at advantageous places in the home [n = 17], at work [n = 5], in hand bags/bag packs [n = 7] and at children's schools [n = 9] to ensure easy access in case of a reaction. One individual tells why this is important:

I always have cetirizine with me. Have some at work, home and even in my bag right now. Because you can't predict what will happen between the time you have a reaction and when you arrive at any hospital. So it is safe to have them close Alvert, 25 years, male adult sufferer with multiple allergies

Given the risks, some parents worked together with allergic children, sometimes even stimulating reactions to help build their capacity to recognize risks and to respond appropriately to them.

We discuss his symptoms with him and his siblings. We even practiced if a reaction occurs where he can find the antihistamines. They are everywhere around the house. So as soon they see the signs, we know he can quickly grab it — Serwah, 40 years, mother of children with eggs and soya allergy

This notwithstanding, contextual factors such as limited public health focus [n = 15], general lack of public awareness [n = 12] and inadequate food allergy information [n = 7] act to make coping a difficult experience. In such a context, food allergy is often (mis)represented by the non-allergic population as "not a serious issue", limiting opportunities for the allergic population to openly discuss their needs and challenges.

Many people don't take it seriously because there is not much on food allergy. If you say I have a food allergy, people are like what? "You have what"? They don't believe it. How do you talk about this issue when already such a person is ignorant? - Togbe, 23 years, adult male sufferer with yam and maize allergy

Consequently, it was important that adequate information is made available for both the allergic and non-allergic population to deal with food allergy. This is key because among participants

who saw health workers, only a few [n = 5] indicated receiving information regarding what to do about their allergies. Most [n = 12] suggested that the information provided made it difficult to cope with food allergy at least at the initial process of diagnosis.

We're always told "don't eat this" "don't eat this" and at a point I asked them "I rather want you to tell me what he should eat so that I would rather find those foods for him. But if you tell me "don't eat this, don't eat this, don't eat this", I go home and I think about all of that and it is as if he shouldn't eat anything - Ebo, 41 years, father of boy with multiple allergies

#### 4.5 Discussion and conclusion

In sub Saharan Africa (SSA), chronic diseases are growing in prevalence, especially in the under 70 age group (Marquez and Farrington, 2013) as many of these countries move through their epidemiologic transition. Attention to date has focused on cardiovascular, cancers, diabetes & chronic respiratory diseases (WHO, 2014), The experience of western societies shows that food allergies have closely followed the growing rates of NCDs. Researchers are hinting that the same may be true for sub-Saharan Africa (Du-Toit et al., 2015; Kung et al., 2014). This exploratory study examines food allergies in SSA focusing on the perceptions and experiences of (food) allergic individuals and their families. Using Ghana as a case study, the paper employs a political ecology of health lens to explore how those affected by food allergy live, manage and cope. Overall, the results underscore the suspicion that food allergies are no longer the sole purview of developed countries; decision makers must heed this message when addressing chronic disease prevention programs for LMICs.

Three key messages arise from this analysis. First, results show that care and management concerns among those affected are similar to those in developed country settings. For example, participants accounts revealed that food allergy leads to psychological stress, frustrations and anxieties (Peniamina et al., 2014, Mandell et al., 2005). This result from delayed

diagnosis, fears about accidental exposure to allergens, the uncertainty of food allergy risk (e.g. "what will happen next"?) as well as fears of children's inability to manage risk (Gillespie et al. 2007, Akeson et al. 2007). These experiences stress the importance of equipping healthcare workers with the tools needed to provide timely diagnosis, and adequate information related to management (e.g. allergen avoidance, cross-contamination) in order to help decrease anxiety and improve overall food allergy management. Further, food allergy affects the social lives of individuals and families as the adoption of safety practices (e.g. vigilance, food avoidance) can result in social exclusion, stigmatization (Dean et al., 2015, Fenton et al., 2011) and bullying (Torabi et al., 2016). The results also suggest labelling (e.g. "the one who is afraid of fish") and an unwillingness to accommodate needs of affected persons (e.g. "if you are going to be doing so, then don't come here") by non-allergic others often resulted in loneliness and isolation. Such experiences can act as barriers to allergic status disclosure and encourage risky behaviours - e.g. eating foods containing allergens – that increases the risk of an allergic reaction (Fenton et al., 2013; Sampson et al., 2006). In addition, the study found food allergy imposes significant financial – diagnostic & transport costs - and non-financial costs – impacts on time use, absence from work or school (absenteeism) and reduced work productivity (presenteeism) – on those affected by food allergy (Peniamina et al., 2014, Gupta et al., 2013, Lamb et al., 2006).

However, regional differences exist underscoring the importance of place in shaping health experiences. In the Ghanaian context where food can be the lifeblood of social interactions and relations, allergic children may face difficulties coping with food allergy. For example, food avoidance or the persistent refusal of food can be conceptualized as being disrespectful, a rejection of friendship, or simply one showing off. This can be a barrier forcing allergic individuals to adopt risk behaviours in order to maintain their social relations with others

(Nettleton et al., 2010). Moreover, while communal living can provide opportunities to receive social support (e.g. finance, care) in managing one's food allergy, this may also increase the risk of exposure especially among children. It is therefore important to engage children in management (e.g. safe foods, reading labels) in order to build confidence and empower them with the skills and knowledge to mitigate risky behaviours and avoid reactions (Munoz-Furlong, 2003). In addition, educational resources (e.g. allergen identification, cross-contamination, management plans, and food labels) are necessary to help everyone tackle the challenges associated with food allergy.

Second, employing a political ecology of health lens reveals that individuals are indeed active agents undertaking several strategies (e.g. acceptance of allergic status, food avoidance, medication use, reading of food labels) to cope with the impacts of their situation (Sampson et al., 2006). In the context of limited health policies, lack of allergy awareness and good management information for food allergic populations, these practices are intended to prevent allergic reactions from reoccurring, and to mitigate the perceived psychosocial burden. However, we note that some practices, in particular, partial avoidance of allergen at home may increase risk. For example, allergic reactions can occur from the inhalation of cooking fumes from allergenic foods or cross-contamination of foods (Munoz-Furlong, 2003). Indeed, one participant noted "when they are cooking or frying fish, the mere smell of it can make me vomit".

Interestingly, no one mentioned carrying epinephrine auto-injectors<sup>5</sup>, the lifesaving medicine for individuals at risk of anaphylaxis. Though these do not exist in the Ghanaian context, adrenaline injections are readily available in hospitals. Nonetheless, given that most anaphylaxis occur

<sup>&</sup>lt;sup>5</sup> Epi-Pens are generally absent and not available for purchase in both public and private pharmacies. Indeed, during data collection, the first author carried along a prototype of an Epi-Pen and showed to allergic persons, physicians and pharmacists. No one had seen one or knew where one could be purchased.

outside healthcare settings (Simons, 2005), the lack of readily available and accessible Epi-Pens as first line treatment dramatically restricts lifesaving procedures for individuals and their families.

Third, drawing on political ecology of health, the paper demonstrates that the sociocultural environment matters in our understanding of the experiences of coping and management of food allergy (Neely, 2015, Jackson and Neely, 2015, King, 2010). The perception that "people don't take food allergy seriously" may reflect the lack of a priority focus given to food allergy as a key health problem by policy makers. As participants point out "when a serious health issue [...] is beginning to come up, there's a lot of talk...". As a result, the limited "awareness on this one [food allergy] ..." frames it as a nonfatal problem. This affects not just the experience of diagnosis and treatment, but also shapes community views about the importance of food allergy. Further, the continued need to "shop for a diagnosis" by our participants also reveals the weakness of a healthcare system ill-equipped to provide a timely diagnosis. As a result, diagnosis is often time-consuming and costly as those affected move between hospitals and physicians. This way, political ecology refocuses our attention beyond the individual to how structural processes – e.g. lack of infrastructure, public health priorities – inform perceptions about health in Ghana.

This study is not without limitations. While our small sample size limits the opportunity to generalize findings, our aim was to obtain a nuanced understanding of what it means to live with a food allergy in SSA. Even though our findings are restricted to Ghana, similar care and management concerns in western societies suggest LMICs may also be experiencing similar challenges. Also, we did not directly engage children to understand their perspectives. Future

studies can help us understand their unique experiences and interactions across different scales – siblings, peers, school settings.

While studies exploring the experiences of food allergy are not new, this is the first in the African context. As such, we contribute to the scarce literature on food allergy in SSA underscoring the need to examine how public health priorities are constructed. For example, our finding that no name exists for food allergy suggests symptoms are often an unrecognized problem, leading to perceptions of food allergies as an insignificant health problem. Indeed, as table 4.1 shows, almost half of the individuals were diagnosed or realized their allergy much latter than those in developed country setting raising questions about barriers to accessing appropriate care. We show that food allergy is an important emerging health issue that affects the health and wellbeing of the allergic population in a LMIC context. The accounts of participants and the requirement by some schools to indicate allergic status of children during school admittance points to a growing recognition of the risks associated with food allergy. Taken together, participants accounts highlight the importance of future research to help inform public health policies for those affected by food allergy. In a context of continuing rapid health, disease, and lifestyle change in Ghana and most parts of Africa, NCDs appear to be inevitable and this study points to the need to give attention to food allergy as a critical population health issue.

#### **CHAPTER 5**

# Manuscript #3: "What the mind does not know, the eyes do not see": Placing food allergy risks in Africa

Atiim, G. A., Elliott, S. J., Clarke, A. E. and Janes, C. (June 2017). What the mind does not know, the eyes do not see": Placing food allergy risks in sub-Saharan Africa. Under review in *Health and Place* 

#### Overview

Policy makers and health geographers are increasingly intrigued by the global rise of chronic disease. While current engagements coalesce around cardiovascular disease, cancers, chronic respiratory disease, and diabetes, very little attention has been given to other important chronic conditions; e.g., allergic disease. Concerns about how health is shaped by context and experienced in place can provide important insights to understand the trajectory of allergic disease and inform policy especially in developing countries continuing to experience an epidemiologic transition. Using Ghana as a case study, this paper draws on theories of political ecology of health to enhance our understanding of how individual (e.g. care seeking behaviours), sociocultural (e.g. lack of education and awareness), health system (e.g. absence of logistics) and policy environments (e.g. absence of policy) influence the ways in which food allergy is perceived, diagnosed and managed. These findings highlight the need for decision makers to target structural factors that impede access to and utilization of healthcare, diagnostic practices, as well as food allergy coping and management strategies. Moreover, the findings highlight the need for a global health agenda that pays critical attention to place-based factors in the construction of emerging health risks.

**Key words:** Chronic disease, food allergy, political ecology of health, qualitative, Ghana

# 5.1 Introduction

Geographers are interested in the epidemiologic transition (McCracken and Phillips, 2009; Jones and Moon, 1992) which describes the global rise in chronic non-communicable diseases [NCDs] due in part to declining infectious disease and rising life expectancy. While the rise of chronic illness began around the 20<sup>th</sup> century first in most parts of the western world (Mercer, 2014, McKeown, 2009; Omran, 1971), over the decades, populations in many low and middle countries [LMICs] are at risk due to the globalization of chronic disease risk factors - e.g. smoking, drinking alcohol, unhealthy diets, and physical inactivity (Allen et al., 2017; Ruebi et al., 2016; Mercer, 2014, WHO, 2011). Rapid urbanization and migration has further heightened risk by exposing populations to new lifestyles and behaviours (Ruebi et al., 2016).

While the spectrum of chronic disease comprises a number of health conditions, public health priorities have coalesced around cardiovascular disease, cancers, chronic respiratory disease, and diabetes (WHO, 2014a), neglecting other important chronic illness; e.g., allergic disease (Prescott, 2013). In this paper, we focus attention on food allergy, an adverse immune response to food (Sicherer and Sampson, 2010) that affects between 7 – 10% of children and adults in developed countries (Soller et al., 2015, Gupta et al., 2013, Osborne et al., 2010). Globally, they are perceived to be growing in prevalence (Hu et al., 2010, Branum and Lukacs, 2008) and have followed the rise of chronic disease in the western world. Though the case fatality rate is low, it exerts a significant impact on health, economic wellbeing and quality of life (Zuberbier et al., 2014, Gupta et al., 2013).

Considering the rising tide of chronic disease and its risk factors in many LMICs settings, particularly sub-Saharan Africa ([SSA], Allen et al., 2017; WHO, 2014a, 2014b, Llyod-Sherlock et al., 2014, Addo et al., 2012, Lozano et al., 2012), research is hinting at a rise in food allergic

disease (du Toit et al., 2015, Kung et al., 2014). For example, food allergy is reported to affect 11% of school children in Ghana (Obeng et al., 2011) and about 40% of children with dermatitis in South Africa (Gray et al., 2014). This imposes significant psychosocial and economic impacts on health and wellbeing (Gupta et al., 2013, Dean et al., 2015). Nonetheless, food allergies represent an unrecognized and unfamiliar health risk in developing countries (Atiim et al., 2017), and are often assumed to be exclusive to the western world. While the existing extant studies provide insights about prevalence, they scarcely engage with social experiences, and how context shapes experiences or risk perception.

In the face of limited policy and research attention, exploring how food allergy is influenced by context and how this is experienced across the socio-cultural, economic and political environments within which people live (Harrington et al., 2017; Cummins et al., 2007; Macintyre et al., 2002) can provide useful insights to understand the construction of this emerging chronic disease as a public health risk in LMICs. Recently, researchers in sociology and anthropology have begun to critically assess the social and cultural processes in the rise of food allergy (Haeusermann, 2015, Waggoner, 2013, Nettleton et al., 2009), and the effects of public health measures (Rous and Hunt, 2004). With few exceptions and mainly in western countries, there is very little interest in food allergy as an important thematic area for inquiry in health geography (e.g. Dixon et al., 2016, Dean et al., 2015). This is despite the fact that food allergy risk is shaped by a complex interplay of the physical and built environments, both important concerns intrinsic to geographic inquiries.

Given health geography interest of the links between place and health outcomes (Cummins et al., 2007, Macintyre et al., 2002, Curtis and Jones, 1998), important insights can be gain on the trajectory of food allergy especially in developing countries. For example, in a

review of the literature on place effects, Macintyre et al., (2002) has illustrated the importance of individual and contextual factors, and their interactions for understanding variations in health inequalities. Studies for example hint that cultural differences in lifestyle, language barriers, and healthcare accessibility are important considerations that may help to explain global or national variations in food allergy prevalence (Lu et al., 2014, Harrington et al., 2013, Mbugi and Chilongola, 2010, Obeng et al., 2008). Further, structural factors (e.g. role of the media, advocacy groups, policies) have also been identified as critical in the framing of food allergy as a major public health concern (Smith, 2015; Waggoner, 2013, Rous and Hunt, 2004). Yet, few studies have explored these relationships in LMICs. In the African context, virtually no study does so.

Using Ghana as a case study, this study draws on the political ecology of health framework to examine how the political environment and sociocultural contexts in sub-Saharan Africa (SSA) shape the prevalence and experience of food allergy. As part of a larger research project, previous studies reveal that food allergies are often unrecognized health problems in healthcare and community settings (Atiim et al., 2017, Atiim et al., forthcoming). In this paper, we seek to understand why this is the case. Specifically, the paper addresses the following question: what are the local level factors influencing perceptions and management of food allergy in Ghana? Through the accounts of healthcare workers and those affected by food allergy, the results add to the literature on the effects of sociopolitical processes on health. Additionally, the study enables us to better understand the individual and societal factors that inform perceptions, practice and experience of food allergy.

# 5.2 Political ecology of food allergy

The political ecology of health explicitly examines the interactions between biology, broader sociopolitical and environmental processes, and how they interact at different levels to shape population health and wellbeing (Neely 2015, King, 2010). In the context of allergic diseases, Mitman (2008) entreats stakeholders in the allergy community to recognize that they are "not separate from the complex of environmental relations – physical, social, economic – out of which [they] came into being" (as in Smith, 2015, p.10). The implication of such an approach is that while individual characteristics and actions are important determinants, broader societal and environmental structures also play important roles in shaping health experiences and related outcomes. Such orientations resonate with emerging works in public and global health under the rubric syndemics - a theoretical lens which draws attention to the links between macro-level social factors and disease clustering within populations, as well as the pathways of co/multimorbidity of disease within the body (Singer et al., 2017, Mendenhall et al., 2017). Analysis of disease emergence, clustering, and population vulnerability must consider the inherent social and environmental risk factors that shapes co-occurring diseases in people.

The utility of the political ecology of health framework has been demonstrated in many studies. For example, researchers have examined how sociopolitical and environmental processes shape concerns around water and health linkages (Bisung et al., 2015; Mulligan et al., 2012; Hunter, 2003), psychoactive substances and mental distress (Aggarwal et al., 2012), environment, livelihoods and health linkages (Richmond et al., 2005), infectious disease (Mkandawire et al., 2013) as well as maternal and child health (Atuoye et al., 2015; Rishworth et al., 2015).

In the food allergy literature, a small body of studies implicitly invoke political ecology. For example, Waggoner (2013) and Nettleton (2009) presents food allergy as a contested health problem. Much of the contest has focused around questions related to the etiology - what is the nature/characteristics of food allergy? How best should it be managed? (Smith, 2015). These questions highlight issues about power and decision making regarding what counts as a public health risk. As a result, we need to look at current consensus (e.g. definitions, diagnosis, management guidelines) on food allergy as a reflection of the role played by key actors (e.g. researchers, professional bodies, patient support groups) interested in food allergy. Further, increased media reporting of food induced fatalities has also contributed to raising the status of food allergy as a public health risk (Waggoner, 2013, Harington et al., 2013). Others have also noted the unintended effects of risk reducing regulatory policies. Rous and Hout (2004) show such policies tend to socially differentiate between who is allergic or not, and expand the management of food allergy beyond the realm of parents and the home to include new actors teachers and schools. At the heart of these studies is attention to the role of structural factors in (re)structuring health at different levels.

In the global south, Ruebi et al., (2016) have highlighted how the actions of the World Health Organisation, World Bank, and health practitioners helped to problematize four NCDs (CVDs, diabetes, chronic respiratory disorders and cancers) as major global health priorities. By prioritizing these NCDs, we miss the opportunity to understand emerging health risks such as food allergy (Atiim and Elliott, 2016), despite the chronic nature of these illnesses. Using political ecology, we seek to explore how contextual characteristics of place can inform our understanding of individual and community perceptions of food allergy risks, diagnosis and management.

# 5.3 Methodology

#### 5.3.1 Data collection

Between June and August 2016, thirty-seven (37) in-depth interviews were conducted with healthcare workers (17) and people affected by food allergy (20) in the Greater Accra region, Ghana. The former were recruited from across twelve (12) healthcare institutions through information letters. Snowballing methods were also used to extend the sample to ensure maximum variation of participants. With respect to those affected by food allergy, we recruited through advertisement (e.g. social media, flyers posted at churches and mosques), social networks, as well as through snowballing. All participants were presented with information letters and those willing to participate directly contacted the first author. All interviews were conducted at a place of participants' choosing (either place of work or home) and at a time of their choosing. Interviews lasted between 30 mins and 1 hour, focusing on perceptions of food allergy, the health policy context, as well as barriers and facilitators to management. Interviews were conducted in English, except in one case where translation was required. They were all tape recorded with permission and later transcribed verbatim for subsequent thematic analysis. Ethical clearance was obtained from the University of Waterloo Research Ethics Committee and the Ghana Health Service Ethics Review Committee.

We also conducted documentary analysis in order to get a sense of the policy context around (food) allergic disease in Ghana. In doing so, the study explored a range of health policies and technical guidelines to gain insights of the place of food allergy and aspects of policy directly related to allergy. We purposively sampled documents from the Ministry of Health, Ghana Health Service and Ghana Standards Board websites. Eight (8) relevant documents were collected (see table 6.1).

#### 5.3.2 Data Analysis

All interviews were transcribed verbatim, and reviewed after which coding was developed both deductively, on the basis of the research question as well as inductively in line with ideas emerging from the data. We assessed for inter-rater reliability of the codes (Miles and Huberman, 1994) and reached 80% agreement with a second coder. Subsequently, we employed the qualitative data management software QSR International NVivo 11 to facilitate thematic analysis of the transcripts. Pseudonyms are used in the attribution of quotes to ensure anonymity.

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#### 5.4 Results

The results are organized into three key thematic areas, termed here the political or policy domain, the health system domain, and sociocultural context. Each of the major themes was linked to a number of sub-themes

# **5.4.1** The political context

#### 5.4.1.1 Absence of an overall food allergy policy

While no overarching policy addressing food allergy diagnosis and management issues exist, we note two key policy documents with direct implication for treatment and management of food allergy. The first is the Ministry of Health (MoH) Standard Treatment Guidelines which specifically addresses several allergic diseases and symptoms (e.g. asthma, urticaria & eczema and acute allergic reactions). In particular, it specifically focuses on anaphylaxis noting that it is:

"... a life-threatening but rapidly reversible condition if treated promptly. [...] can develop within minutes of injection or ingestion of medicines or contact with trigger factors" – MoH (2010).

The treatment guidelines identify key food allergens (e.g. seafood and peanut) amongst other triggers (e.g. insect bites, drugs, vaccines) and outlines a number of treatment options at the first sign of anaphylaxis. This involves administering adrenaline intramuscular injections, hydrocortisone intravenous therapy, and promethazine hydrochloride intramuscular injections.

The second is a regulatory guideline by the Food and Drug Authority (FDA) on labelling of prepackaged food. The FDA guideline identifies at least eight (8) priority food allergens and requires mandatory declaration of any product containing these food items on the label:

"The following foods and ingredients are known to cause hypersensitivity and shall always be declared: cereals containing gluten (i.e., wheat, rye, barley, oats...); crustacean; eggs and egg products; fish and fish products; peanuts, soybeans; milk and milk products; tree nuts and nut products; and sulphite in concentrations" - FDA (2013)

While the guide recognizes the possibility that some individuals might be at risk of accidental exposure, and was considered a key step towards protecting allergic persons, health workers especially were critical of the capacity of the institution to enforce these regulations as a participant explained:

They are good regulations but the big question is whether they will be capable of seeing this through. Most foreign products [have] the labels but what about those locally produced? - Abigail, physician, 10yrs in health service

Interestingly, only a few health workers (n = 3) made any reference to the standard treatment guidelines when discussing food allergy. Many were primarily concerned about the lack of an overarching policy to guide food allergy management and how this both affected food allergy risk perceptions in healthcare settings and its surveillance. In the absence of policy, many suggested that there's a tendency among health workers to assume that this was not a critical issue deserving attention:

None [policy guidelines] exist, so many of us automatically assume it is not really an important issue. If there's no policy, no one will consciously be looking or thinking about such issues - Sam, physician, 20 years + in health service

Similarly, others [n = 5] suggested that the lack of policy and disinterest of decision makers on issues around food allergy was an obstacle to understanding the prevalence of food allergy as deliberate efforts won't be taken to capture it emergence.

The reason is simple. It is not of interest to policy makers. If we had a food allergy policy, it [would] make provision for gathering information on allergy trends - Ken, nurse, 15 years + in health service

From the perspective of affected persons, the general lack of health promotion activities around food allergy prevention and treatment was a manifestation of the absence of a policy framework and the apparent limited public awareness and knowledge on food allergy:

There's no public campaigns on radio or TV. So a lot of people are ignorant and unware about it. Some are often surprised. Others don't even believe it and it becomes difficult convincing them what you're saying is true - Charles, 35 years, father of allergic boy.

While some isolated guidelines exist, these were regarded inadequate towards addressing food allergy issues. Many participants perceived that the general absence of a policy was a barrier to food allergy surveillance, which not only leads to poor estimates of prevalence but also impedes public knowledge and awareness.

#### *5.4.1.2 Resource* and funding constrains

An important issue that was also apparent concern resource and funding constrains. Many raised concerns over the government or health agency's inadequate financial resources and how this hindered gathering health information on emerging risks to inform policy decisions.

The problem is there is simply little money to go around and this undermines surveillance on these kind of issues [food allergy]. So it's a huge problem because without evidence, it's difficult to change policy - Tim, policy maker, 9 years in health service

Similarly, others considered the lack of financial resources a key barrier to clinical practice of healthcare workers with respect to food allergy. In particular, health workers pointed out that, this often restricted access to diagnostic tools, prompting them to rely on their medical intuition, or knowledge gained from peers in order to diagnose, and to manage food allergy.

Right now, what we do is largely intelligent speculation. So it's an issue of finance. If the money is available, the diagnostic tools will be bought. If we have that, then diagnosis will improve - Adwoa, physician, 6years + in health service

You need to consult your colleagues. That's what I did. You tell them about the clinical symptoms you're observing and hear their opinion to help you make a decision. That's one way to do it - Aseidu, physician, 6ys + in health service

Considering the limited financial resources, health workers intimated decision makers were often faced with a difficult task of allocating resources for competing health needs. As a result, allocation decisions were informed by the pressing health concerns of the present.

It is just realistic and practical if not the sensible thing to do. You have to focus your limited finances on your top five or ten causes of admission in hospital - Tina, physician, 8yrs + in health service

While these accounts provide insights about the impact of lack of finances, the account of Tina draws attention to an important consideration, the role of existing health problems and how these are shaping perceptions and practices around food allergy. Participants suggested that, current challenges related to communicable and maternal/child health issues (e.g. malaria, anemia, cholera) and non-communicable diseases (e.g. hypertension, diabetes, stroke) meant that food allergies were frequently considered "marginal" health concerns, resulting in a missed opportunity to recognize them:

The concern is how do we get dialysis machines to treat kidney issues? How do we treat stroke cases? How do we manage hypertension? Allergy is not really a big concern compared to these issues - Cindy, dietician, 12yrs in health service

I think there has been little room because we have too much to handle in terms of malaria, maternal health and child malnutrition issues. With such pressing issues, everything is focused there - Sylvia, 15 years in health service

Similar perspectives were shared by those affected by food allergy. Many affected persons attributed their negative experiences obtaining an appropriate diagnosis of their food allergy to the lack of a priority focus on food allergy and emphasis on what they described as "traditional health issues".

After our fourth hospital visit, I realized that our system is not really big on this allergy thing compared to say malaria or typhoid. All they know is the malaria, fevers, diarrhea and those kinds of things - Mary, 40 years, mother of girl with allergy

These accounts provide insights of the nature of healthcare and health priorities in Ghana. Health systems are largely designed to respond to infectious disease and the most common NCDs. As a result, food allergy may not attract much public attention.

# 5.4.1.3 Public health interest of "important" stakeholders

An interesting issue to emerge from the interviews was the lack of donor interest around food allergy issues. Participants intimated that while health priority setting can be locally driven, donors, and multi-national organizations are also important stakeholders, highlighting the power relations that can shape what counts as a priority disease. Thus given the focus of donor funding on communicable issues, food allergy is a neglected issue:

A lot of our programs are donor supported and much of their focus is not on allergy issues. They have a specific focus, mostly on the communicable problems. Recently, there is also a lot of talk and focus on diabetes and blood pressure [BP] issues - Maaley, nurse, 7 years in health service.

As a result, many perceived that donor agency interest and commitments were essential to addressing data gaps, mobilizing financial resources and placing food allergy at the center of public health policy.

I don't see government devoting its limited resources to this issue. If our development partners take interest, things will naturally change because funding will be available. We will be able to collect information and all of a sudden you see the commitment from the ministry - Isaac, alternative medicine practitioner 14vrs in health service

Given these accounts, it important to understand the role of key actors in the global health arena and how these actors shape health agendas in developing countries. Understanding their role in the production of disease priorities – through research and funding allocations - can provide important insights of the dynamics of food allergy in LMICs.

# **5.4.2** Health system environment

# 5.4.2.1 Capacity building of healthcare workers

The inability to identify, diagnose, and provide medical advice tailored to the needs of those affected by food allergy affects the quality of service and care provided by health workers. For example, delays in providing timely diagnosis highlighted the importance of equipping care providers with sufficient information on food allergy etiology and management to help ensure early diagnosis.

I always say that what the mind does not know, the eyes do not see. If you don't know or understand the causes of food allergy or how it is diagnosed, providing a timely diagnosis will be a problem. That is the issue we face - Tammy, nurse, 13yrs in health service

Concerns about sub-optimal care were also apparent in discussions with individuals directly and indirectly affected by food allergy. Many participants expressed that poor services including but

not limited to misdiagnosis of their condition or delays in receiving a diagnosis often affected their wellbeing resulting in psychosocial stress.

Well, it was an annoying and stressful period because we were given wrong medicine. In our first visit, they gave us antibiotics because they thought it was an infection. When it reoccurred, and the next person also recommended antibiotics, we honestly felt they didn't know what they were doing - Charles, 35 years old, father of girl with allergy

In addition, personnel shortages (e.g. trained allergists, dieticians) was also identified as an important barrier to effective management. As a result, a major concern that was apparent in discussions with health workers was the potential to misdiagnose allergy:

In other places, allergists are the key focus because of their training in immunology. Most of us are trained in general medicine and so right away, there is a difficulty. We need trained allergists to complement what we are trying to do here - Aseidu, physician, 6ys in health service.

Some of the common diseases have similar symptoms with food allergy. So if one does not know the kind of questions to ask the patient in order to do an accurate diagnosis, it is likely food allergy may be misdiagnosed as something else because of its similarities - Ken, physician, 15yrs in health service.

Considering such a context, equipping health workers with the requisite skill was critical to addressing these concerns. Participants suggested the need to develop refresher courses, or organizing workshops, as well as integrating food allergy in the training curriculum of health institutions with the view of ensuring health professionals have the competency to manage food allergy.

Going forward, we must teach and have programs to train allergists in our institutions. When it starts right from there, people come out already knowledgeable and equipped to know the signs, triggers, and how to deal with them - Julie, dietician, 14yrs in health service

#### *5.4.2.2 Attitudes of healthcare workers*

Previous negative encounters between those affected by food allergy and healthcare workers were identified as important factors that influence healthcare utilization behaviours. Discussions with participants revealed that food allergy was not taken seriously, patients often received inadequate information, and medical treatments failed to improve allergic experience of those affected. As a result, many allergic individuals often adopt self-care practices or defaulted in returning to health facilities for further diagnosis and care.

We decided not to step foot there again because they didn't take her issue seriously and we also didn't see much change anyway. So we started observing by ourselves and luckily we were able to know it was peanut, milk, and cowpea - Dora, 37 years old, mother of child with allergy

When you delay in providing care or skip to another patient because you think the person's reactions are not serious, they will go and never come back because basically you're telling them their issue does not deserve your serious attention - Abigail, physician, 10yrs in health service

The challenges of receiving proper diagnosis in formal hospital/clinic settings notwithstanding, others affected by food allergy (n=6) also recounted positive experiences with health workers, describing their interactions as "helpful" (n = 3), "professional" (n = 2) and "informative" (n = 1).

It took a long time to know it was cowpea and seafood. That's the only part I didn't like and frankly that was something I already knew. They told me they suspected an allergy and that it might take some time because they didn't have the tests to help them easily find out - Jonah, 22 years, adult male sufferer

While the former example suggests the need to address barriers related to the negative attitudes of health workers, the latter account highlights the importance of communication with patients in order to improve the experience of living with or diagnosis of allergies.

#### 5.4.2.3 Lack of FA diagnostic infrastructure and guidelines

An important concern raised by health workers was the absence of diagnostic infrastructure (e.g. skin prick testing, food challenge) in healthcare settings in Ghana. Health workers especially emphasized that this affected their ability to provide an accurate diagnosis. Without such tools, they were most concerned that a misdiagnosis will affect the health and wellbeing of their patients, and create distrust.

Without SPTs or [SIgE, food challenge] testing, you can't really be sure what food it is. That's a concern for me because you can get the diagnosis wrong. If it's not an allergy, then you have sentenced the person and their family to avoid food they shouldn't be avoiding - Adwoa, physician, 6 years in health service

If you get it wrong, you lose the confidence of your patients. And they might decide to stay home, or use others. But if we can run these tests, then you can tell them exactly what the issue is. Everyone becomes happy - Abigail, physician, 10 years in health service

In the absence of diagnostic tools and guidelines, health workers were also worried about the different clinical practices by different health professionals in diagnosis and management of food allergy. In order to streamline diagnostic practice and ensure consistent and accurate diagnosis, they suggested the need for guidelines to inform practice.

Each [physician] goes about it differently. Not that this is bad but we need a logic table that should clearly state what you need to do or look for. If you see for example A, B, and C, conclude is an allergy. In that way, everybody is on the same page - Benjamin, nurse, 10yrs in health service

Given such contexts, health workers reported that diagnostic decisions are often made by taking detailed medical histories in combination with food elimination protocols. As a result, such approaches were often time-consuming, resulting in frustration for patients and often hindering their continued use of health services.

Elimination is not straight forward but a back and forth thing. At some point, people get so frustrated that they stop coming - Tina, physician, 8 years in health service.

I gave up by the third week because we were not seeing light at the end of the tunnel. The whole process was just draining and took too long - Emelda, 32 years old, parent of boy with allergy

Further, accounts of participants revealed that adrenaline auto-injectors, a vital and common tool for mitigating anaphylaxis in high income countries were not readily available in Ghana.

Although no affected individual reported ever experiencing food induced anaphylaxis, their absence raises questions of safety for individuals who might be at risk of anaphylaxis.

# 5.4.2.4 Potential cost limits diagnosis

Diagnosing via skin prick tests or serum specific IgE occurs outside the periphery of both public and private hospitals. Both groups of participants indicated that, the overall cost of diagnosis was an important barrier that discourages continued use of health services and determining "actual" allergic status:

You refer patients for tests at private labs and most come back complaining about the cost. They leave and don't come back because costs are on the high side. And without this, we will never know who has an actual allergy - Tina, physician, 8 years in health service.

We didn't go further because of the cost. It was really expensive for just one visit - Noela, 24 years, adult female sufferer

Indeed, concerns about the overall costs (e.g. medical, transport) associated with diagnosis was raised as the reason for adopting self-management practices as the case of Kwesi, a 25-year-old adult male with multiple allergies indicates:

It's a lot of money especially after going around different hospitals with nothing to show for it. What was the point? So I basically took all they were saying and through observing we noticed shrimps and lobsters

#### **5.4.3** Socio-cultural context

#### 5.4.3.1 Healthcare seeking culture

Healthcare seeking behaviours were also identified as important for understanding the minimal public health focus on food allergy. For example, delayed healthcare seeking behaviours and reliance on self-management practices may result in missed opportunities to understanding prevalence and providing a timely diagnosis. Such decisions were often influenced by the individual perceptions of symptom severity and uncertainty over symptoms. As participants intimated, this has the tendency to obscured food allergy from the health system.

There are those who delay and those who won't come at all because they believe the reactions are not severe and so try to manage it. Until they start reporting to us, we have no way of knowing how many have it and how best to help them - Julie, dietician, 14 years in health service

I didn't go because I wasn't sure this was something to take to hospital. So I managed it myself. So for people like us, we are not in their records - Esi, 20 years' adult female sufferer

In addition, the acceptance and pervasiveness of alternative healthcare systems (e.g. traditional medicine, healers) and easy access of over-the-counter pharmaceuticals was highlighted as one of the factors that act to impede diagnosis, affecting the ability of health workers and policy makers to obtain an adequate picture of food allergy.

Many people do traditional medicine. They are everywhere, cheap, and people believe they are effective. Those people won't be part of official records so we won't know the real numbers. The other problem is the frequent use of these pharmacy shops as the first point of call - Sadia, nurse, 11 years in health service

Interviews with an alternative medicine practitioner confirmed that biomedical health services were sometimes not the first point of call for most people including those allergic to food. However, during interviews with affected individuals, the majority (n=18) recounted that both

the formal public and private hospital/clinics were their preferred first choice for treatment of their allergy or children conditions.

### 5.4.3.2 Limited FA awareness and knowledge

Lack of awareness and knowledge was also highlighted as a barrier to understanding incidence, treatment, and coping strategies. Participants acknowledged that knowledge of the signs and symptoms of food allergy at the individual and community level was poor. Among affected persons for example, majority had not heard about food allergy before they sought medical care.

I didn't know until we went to the hospital. For a while, I actually didn't believe them. It took some time before I came to accept it - Kwesi, 25 years old adult male sufferer

As a result, many affected individuals and health workers also expected poor knowledge and awareness at the community level. They attributed the general lack of awareness to the fact that food allergy was a "relatively new problem", one that is exacerbated further by the focus on other prominent health issues. As a result, food allergy is "a less talked about issue", that leads to an "uninformed population" who contest the allergic status of affected individuals.

I think it is because it is a relatively new problem. As we know more, information will get out there out. And the more informed people are, the more people hopefully will seek treatment - Abigail, physician, 10ys in health service

We have an uninformed population. So it's not a surprise when people doubt that my son has an allergy. For me, it is the ignorance because this is a less talked about issue when you put it beside the others - Bene, 36 years old, parent of child with allergy

Considering the lack of awareness and knowledge, many participants intimated that symptoms of food allergy are often unrecognized and misattributed to unhygienic practices (e.g. unwashed clothes or bedding; irregular bathing).

Everyone said the itching, rashes and hives was because of poor hygiene. So I was changing, washing clothes and my beddings very often for a while because at the time we all thought it was an issue of hygiene - Rob, 22-year-old adult male sufferer with multiple allergies.

In general, participants held that the lack of FA knowledge and general unfamiliarity of FA was a barrier to addressing the concerns of the allergic population and providing optimum care.

# 5.4.3.3 Cultural beliefs, practices and expectations

Cultural beliefs and practices - beliefs about disease causation, stigmatization attitudes and food taboos - shape perceptions and management of food allergy. Health workers often drew links between alternative beliefs about disease causation and how this may impact underreporting of food allergy affecting the ability to gain an accurate assessments of the extent of food allergy.

Some believe certain diseases are not natural. So they go to traditional healers. Others may try faith remedies. We have to keep that in mind when we talk about the number of people with allergy. Such people will ordinarily be missed by our surveillance systems - Sam, physician, 20 years + in health service

Further, fear of being labelled with an unfamiliar condition was also considered a factor that can delay initial visits to hospitals and disclosure of allergic status. Both health workers and affected persons intimated that such behaviours often contributed to under-reporting of cases by modifying people's health seeking behaviours.

We certainly didn't tell them we went to the hospital. They always said it was a normal thing and for them, we were simply spoiling her. We didn't want such uninformed comments - Bene, 36 years old, parent of child with allergy

For others, they also come to accept it as normal and don't see why they should be going to the hospital - Monica, nurse, 7 years in health service

Another important cultural issue is food beliefs and taboos and the impact these may have on late diagnosis and treatment for food allergy. Two affected persons believed their allergic reactions

was caused by a violation of a food taboo, and as a result considered it to be a normal condition of their lives. While this made it easy to disclose allergic status to others, it also hinders utilizing health services because they did not believe this was an issue for biomedical health treatment.

Something that's a taboo does not require going to the clinic. I treat it at home because it is not a hospital issue - Noela, 24-year old adult female sufferer

Understanding the influence of cultural factors on health outcomes is crucial to designing research protocols that aim to document the prevalence of food allergy, and developing appropriate initiatives that are responsive to these cultural and social barriers in LMICs.

#### 5.5 Discussion

As chronic diseases rise in prevalence in LMICs, with African countries expected to bear much of the increase (WHO, 2011), emerging research in this region hint that allergic diseases are following on the heels of NCDs (Du-Toit et al., 2015; Kung et al., 2014). This study examines the local level factors that influence risk perceptions and experiences around food allergy in Ghana. Overall, the findings reveal that perceptions of the public health risks of food allergy, problems with proper diagnosis, and management challenges are best understood within the sociopolitical and sociocultural contexts in which health and wellbeing unfolds.

The findings describe how factors at multiple levels – *individual, societal, and health system* - interact and shape perceptions and understanding of food allergy, diagnosis and management in Ghana. At the political level, the lack of an overarching policy, funding constrains, and the burden from existing health concerns are important factors that frame food allergy risk perceptions. For example, without policy interest, the "true" extent of food allergies may remain unknown and public awareness and knowledge will also remain limited. In addition, there will be no imperative to allocate financial resources to address data gaps by improving

surveillance or providing the tools needed to enhance diagnosis. This is worrying as evidence suggests food allergy prevalence is growing in the African region (du-Toit et al., 2015; Kung et al., 2014l Gray et al, 2014). In Ghana, for example, self-reported prevalence among schoolchildren is estimated at 11% (Obeng et al., 2011) compared to 6.9% in Canada (Soller et al., 2015).

Yet, food allergy remains an obscured health issue in Ghana and many other parts of Africa. Much of the existing public health and policy guidelines shown in Table 6.1 do not mention or consider food allergy as a key health problem. As participants highlight, attention continues to be focused on addressing health priorities such as malaria, maternal and child health issues, hypertension, stroke, diabetes, and cancers. In this way, these "priority" diseases are given legitimacy over other health conditions. While the emphasis on these "priority" health issues is important, we think there is more to the epidemiologic transition in LMICs. As highlighted, food allergies have closely followed the decline in infectious diseases and rise of chronic diseases in western countries. Over the last decades, health concerns in the global "North" and "South" are increasingly becoming similar and food allergy appears to be no exception in the emerging economies of Africa (Kung et al., 2014).

Consequently, there is a need for both research and policy to track food allergy trends in order to mitigate its potential socioeconomic health impacts in rapid transition countries.

Considering the current focus on infections and selected NCDs and a context of resource constraints, food allergy may continue to be a neglected issue. However, as participants indicated if food allergy is to gain public health attention, the global health community, including governance institutions and donors have an important role to play given their contribution in reducing health inequities and shaping disease priorities in Sub-Saharan Africa (Mwisongo and

Nabyonga-Orem, 2016). In short, it is time for the global health community to take interest in food allergy in LMICs.

The findings also point to several health system barriers – e.g. personnel, absence of guidelines, diagnostic resources, and cost – that affect diagnostic practices, quality of health services, and healthcare utilization. Participants perceived gaps in knowledge intimating that many health professionals are not adequately equipped with the skills and knowledge to make informed clinical decisions concerning diagnosis and management of food allergy issues. Knowledge gaps have been highlighted in studies of physician perceptions and parents' experiences with food allergy (Gupta et al., 2008; Hu et al., 2007). In this regard, it is important health workers are trained in the epidemiology of food allergy (Gupta et al., 2008) and deliberate efforts undertaken to disseminate existing diagnostic and best management guidelines (Boyce et al., 2010) in order to address knowledge and competency related barriers. This is especially important as evidence shows significant gaps exist between perceived and actual food allergy risk (Harrington et al., 2012). Additionally, investments in diagnostic tools (e.g. skin prick test, allergen specific IgE or food challenges) are critical to minimizing the risk of misdiagnosis, providing timely diagnosis and treatment strategies to help reduce anxiety in allergic individuals and their families.

Previous studies identified finance as a key barrier in the management of food allergy (Minaker et al., 2014). In this study, the results indicate costs of testing and the overall treatment costs were important barriers to the confirmation of allergic status, continued utilization of healthcare, and the adoption of self-management strategies. Although food allergy associated illnesses are covered under Ghana's National Health Insurance Scheme (NHIS), the fact that diagnostic infrastructure is unavailable and therefore occurs outside public health facilities is an

issue of concern that needs to be addressed. Where opportunity exists (mostly in a few private laboratories), the accounts of participants revealed that the relatively high costs are an obstacle to undertaking confirmatory testing for food allergy.

The results also highlight the importance of addressing barriers at the individual and community levels. We found that individual and community perceptions around health seeking behaviours (e.g. decision use alternative medicine, delay use of formal healthcare) hinders opportunities for early diagnosis. In addition, poor knowledge about the symptoms, severity as well as perception of etiology limited the use of healthcare facilities and affects effective coping strategies. Thus in tackling the constraints of diagnosis, attention needs to focus on the role of the cultural context as manifested in existing beliefs of disease causation, norms, and practices. For example, participants revealed that bodily manifestations of food allergy such as hives, rashes, and/or diarrhea are often considered unimportant, and remained unrecognized as significant symptoms of ill-health. As a result, affected individuals may either delay or not seek treatment, or simply resort to self-management. Consistent with previous studies (Dean et al., 2015; Pitchforth et al., 2011), the findings also show that perceived stigma associated with food allergies can be an important constraint affecting healthcare seeking behaviours and coping strategies.

We recognize these barriers are not unique to food allergy. Several studies in Ghana and elsewhere have revealed how various structural processes such as: poor quality of care, costs, proximity, transportation, and inequality in resource distribution; and sociocultural factors affects vulnerability among population subgroups and produce differential health outcomes. Such studies include but not restricted those that examine enrollment in health insurance (Fenny et al., 2016), access to maternal and child care services (Atuoye et al., 2015), lack of water and water-

related behaviours and practices (Bisung et al., 2015) and nutrition policy implementation (Vine and Elliott, 2013). In the context of allergy, a growing body of research suggests that food allergy is a health problem that has been shaped by multiple actors and institutions (e.g. medical experts, allergic groups, the media), successfully transforming it from being a relatively obscure issue to a major public health risk (Haeusermann, 2015; Waggoner, 2013; Nettleton et al., 2009). In many ways, this literature highlights the need to understand the everyday lived experiences, and perceptions of disease risk in their sociopolitical, sociocultural, and environmental contexts.

Drawing on our findings, we propose a framework (fig. 6.1) for understanding food allergy risk in Ghana. The framework has three key levels of influences: the political context, health system environment, and sociocultural context. As our findings suggest, the political context is a key determinant shaping food allergy risk perceptions and practices. A lack of policy direction for example can restrict allocation of available funding for food allergy (FA) surveillance, and the promotion of public health initiatives to increase awareness of FA risks. The framework also highlights the role of factors at the health system and sociocultural levels. For example, at the health system level, attitudes of health workers, the lack of skills and competence can act with the absence of standard diagnostic guidelines and tools as well as costs (macro-level factors) to hamper diagnosis and management. Lastly, cultural attitudes and beliefs around food, and limited knowledge can also affect reporting of food allergy and shape coping strategies of those affected. The components of this framework should be interpreted as interacting across time to inform people's risk perceptions around food allergy. Both the theoretical and empirical literature position political ecology as a useful framework for obtaining insights into how diseases/health concerns are produced, their distribution as well as interpretations. Our results illustrate that while the lack of empirical evidence may have much to

do with a perceived absence of allergic disease in LMICs countries, factors within the sociopolitical and sociocultural environment are important to our understanding of the state of the food allergy "epidemic".

### 5.6 Conclusion

By placing food allergy in a LMIC context, this research highlights how people (e.g. health seeking attitudes), and place attributes (e.g. social norms, health system and policy characteristics) affects perceptions of prevalence, diagnostic practice, and management of food allergy. In doing so, the paper moves the discussion beyond simply the absence of prevalence data, by identifying the complex interplay of social, political and environmental factors embedded in place that shapes the trajectory of food allergy in developing countries (Cummins et al., 2007, Poland et al., 2005; MacIntyre et al., 2002). It stresses the importance of understanding the everyday realities of inadequate funding, lack of diagnostic resources, and poor health seeking behaviours and how these inform our understanding of food allergy risk. As a result, this paper suggests the need for discussions on the trajectory of food allergy in the developing world to take into account both sociopolitical and cultural barriers influencing health and wellbeing in such settings. From a public policy standpoint, the study reveals important structural barriers for possible public policy intervention: poor management of food allergies, funding priorities and constraints, lack of diagnostic infrastructure, and poor health promotion practices regarding food allergies. Public policies must also seek to address cultural norms and practices around health and disease in order to increase reporting and utilization of health services. In addition, the study revealed that disease priority setting is not simply the sole responsibility of local decision makers and institutions. It is therefore important that global health institutions incorporate allergic

disease in the overall context of the global NCDs prevention agenda in LMICs. We call on researchers and organizations in both developing and developed regions with interest in allergic disease and the changing epidemiology of health in LMICs to build strategic partnerships for research that provides insights into the food allergy front.

Figure 5.1 Factors shaping understanding of food allergy

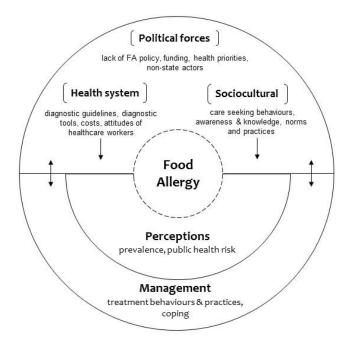


Table 5.1 Summary of health policy documents and guidelines

No.	Policies/guidelines/technical reports	Year	Priority focus
1	Technical guidelines for integrated disease surveillance and response in Ghana	2002	<ul> <li>Identifying and collecting data on 23 infectious diseases</li> <li>Lacks focus on NCDs including allergic disease</li> </ul>
3	National health insurance policy framework	2004	- Providing access to healthcare - Covers asthma & allergic symptoms (e.g. urticaria, atopic eczema, swelling) though no specific mention of FA
2	National health policy	2007	- Set the overall context for health & disease management - Addresses barriers to healthy living including infectious and NCD risk factors
4	Standard treatment guidelines	2010	- Provides treatment for allergic disease (e.g. asthma, eczema, urticaria), anaphylaxis and autoimmune disorders (e.g. rheumatoid arthritis, Lupus)
5	Occupational health and safety policy and guidelines for the health sector	2010	- Medical surveillance questionnaire for staff include two questions on asthma & allergies (Do you have asthma, bronchitis or other chest problems? do you have allergies?)
6	Essential medicines list	2010	- Identifies a number of anti-allergic medicines though no mention of food allergy or anaphylaxis
7	Strategy for the management, prevention and control of chronic non-communicable diseases, 2012-2016	2012	<ul> <li>Identifies asthma as chronic NCD</li> <li>Commit to setting up asthma clinics and development of training modules for asthma management</li> <li>Goal is to address NCDs and its risk factors</li> </ul>
8	Guidelines for labeling of prepackaged foods	2013	<ul> <li>Requires ingredients to be declared on all prepackaged food</li> <li>Identifies priority food allergens that must be declared on labels</li> <li>Recognizes these priority causes hypersensitivity</li> </ul>

#### **CHAPTER SIX**

### **Discussions and Conclusions**

### 6.1 Introduction

The past three decades have seen growing research and public interest in food allergy (FA) as a public health risk, albeit one for which the attention has focused on populations in western countries. In Sub-Saharan Africa (SSA), though the health landscape has been dominated by discussions of the burden of infectious disease (e.g. HIV/AIDS, malaria), there is a growing shift in public health interventions towards chronic diseases – associated with rising globalization, urbanization, lifestyle factors and infectious disease decline (WHO, 2011; Omran, 1971). While there is growing research interest on some chronic diseases in developing countries, with few exceptions, food allergy is a neglected area of research inquiry especially in sub-Saharan Africa (Gray and Kung, 2014; Obeng et al., 2011).

The goal of this research was to gain an understanding of risk perceptions and experiences of food allergy in SSA, using Ghana as a case study. Chapter 3, 4 and 5 address the following specific research objectives:

- The perceptions, risk factors and coping strategies associated with food allergy in Ghana, and
- 2) The local context shaping food allergy perceptions, practices and management.

This chapter highlights the major findings emerging from this research, situating them within the literature on food allergy. This is followed by a discussion of the contributions and limitations of this research. Next, the chapter outlines the implications for policy, practice and directions for future research.

# 6.2 Summary and discussion of findings

The rise in chronic diseases including allergies (e.g. asthma, rhinitis, eczema) and autoimmune diseases (e.g. multiple sclerosis, type 1 diabetes) historically have been attributed to declining exposures to microbial organisms and an increasingly sterile environment – a notion commonly referred to as the hygiene hypothesis (Schaub et al., 2006; Bach, 2002). Theoretically, this suggests that places characterized by a low burden of infections (e.g. urban, affluent communities) are at an increased risk of developing allergic disease. Indeed, empirical evidence from developed countries shows a low risk of developing allergies and atopic sensitization (e.g. asthma, hay fever) in children living on farms compared to those living on nonfarm lands or in urban places (Elholm et al., 2015; von Mutius and Vercelli, 2010, Braun-Fahrländer, 2000). As a result, allergies are assumed to be uncommon in contexts such as Africa, where infections tend to be predominant (Taborda-Barata and Potter, 2012; Obeng et al., 2008).

Since the 1990s, studies of allergies (e.g. asthma, eczema and allergic rhinitis) in Africa show results similar to those in western countries (e.g. Elholm et al., 2015) and reveal rural-urban as well as socioeconomic differences in allergy risk (Addo-Yobo et al., 2007; Ait-Khaled et al., 2007). More recently, researchers have also documented a growing burden of food allergy in African and other developing countries (Kung et al, 2014; Gray and Kung, 2014; Boye, 2012) suggesting food allergies may be following the rise of other chronic diseases. In this current research, the accounts of participants in **Chapter 3** reveal that food allergy is becoming an important health problem in Ghana characterized by a perceived rising incidence being reported to health facilities. According to health workers, case reporting of most food allergies was predominantly by populations with higher socioeconomic status (SES). While this may reflect the ability to access healthcare, it also suggests a relationship between level of socio-economic

status and heightened risk of food allergy (Soller et al., 2015; Ben-Shoshan et al., 2012, Pawlinska-Chmara et al., 2008). While the sociodemographic characteristics of affected individuals and families (see Chapter 4, table 4.1) confirms the perceptions of health workers about the at risk population, it is more likely that sample selection and recruitment strategy may have led to the under-representation of populations with low SES in this research. Nonetheless, the accounts described by participants, taken together, offer a challenge to researchers and practitioners to pay attention to health risks that lie outside the purview of national and global health research priorities in Ghana and Africa as a whole.

The findings in Chapters 3 and 4 also reveal that food allergy is an unrecognized and unfamiliar health risk at the health system and community levels, contributing to poor understanding of its burden in Ghana. Several reasons may account for the lack of recognition of food allergy as a critical public health risk in developing countries. In **Chapter 5**, the research provides clues to understanding how food allergy becomes embodied as a major public health risk (Christakis, 2008, Nettleton et al., 2010) by highlighting some of the broader sociopolitical, economic and environmental factors that influence perceptions about its spatiotemporal rise and management (Smith, 2015; Christakis, 2008, Jackson, 2006). For example, increased media coverage of fatal anaphylactic events and public health safety interventions, particularly in schools, have been critical to raising public awareness and framing food allergy as "a clear and present danger" in developed countries (Christakis, 2008). Analysis of the links between broader societal factors and health can offer useful insights to understand the apparent lack of attention on food allergy in settings such as Africa. For example, how should we interpret the general dearth of studies in this region? Does the absence of evidence suggest the evidence of absence? While the results of chapter 5 provide a partial response, it also suggests structural interventions

at various scales (e.g. policy, health system and sociocultural) are critical to building the evidence-base in order to understand food allergy, to meet the unmet needs of individuals and families affected by food allergy as well as address the capacity needs of health workers.

Within the last two decades, there has also been a growing interest in understanding the social dimensions of food allergy in developed countries (Haeusermann, 2015; Nettleton et al., 2010; Christakis, 2008). Chapter 4 explores the perspectives of affected individuals and parents of children with allergies to understand the burdens associated with food allergy. In doing so, the chapter presents an account of the lived experiences, challenges as well as strategies utilized to cope. As food allergies are an integral part of one's life (Haeusermann, 2015), previous research has explored the experiences of food allergic individuals and their families across a variety of social contexts (Dean et al., 2015; Stjerna, 2015; DunnGalvin et al., 2009). Beyond the health risk, studies confirm that affected individuals and their families also face social risk (Stjerna, 2015; Pitchforth et al., 2011; Rous and Hunt, 2004) which may result in bullying (Torabi et al., 2016), and stigmatization (Dean et al., 2015; Pitchforth et al., 2013, Minaker et al., 2015). Chapter 4 supports findings in the empirical literature in western societies that document several health, social and economic impacts on affected individuals and families. In addition, the accounts of affected individuals highlight the tensions around food allergy risk, drawing attention to the importance of social context – e.g. public discourse of health risk – to understand how risk is perceived and its impacts on the health and social life of affected individuals. As a cure for food allergy does not exist, chapter 4 also offer an analysis of the coping strategies used to managed their food allergies. The findings reveal several preventive measures: acceptance, food avoidance, medication use, and food labels assessments to prevent allergic reactions as well as mitigate the perceived psychosocial burden of food allergy (Akeson et al., 2007, Sampson et

al., 2006). Such measures were primarily shaped by past experiences and anxieties about future allergic reactions.

#### 6.4 Contributions

Globally, the health landscape has changed rapidly, with chronic disease now a defining feature of the health of populations. A major gap in the empirical literature on health transitions especially in developing countries is the limited inquiry on allergic disease, including food allergy. With few exceptions (Basera et al., 2015; Gray et al., 2014; Hossny et al. 2011; Levin et al., 2011; Obeng et al., 2011), most studies to date focus on cardiovascular, diabetes, cancers and chronic respiratory diseases in Africa (Tenkorang and Kuuire, 2016, Day et al., 2014; Mayosi et al., 2009). The case of Ghana shows that food allergy is an emerging public health risk, with serious health, social and economic impacts on individuals and families. The research therefore highlights the need for policies to incorporate food allergy in the overall chronic disease prevention agenda in order to avoid facing a significant public health issue in the future (Atiim and Elliott, 2016).

In addition, while scholarship on experiences and coping strategies related to food allergy is growing in the developed world, a major hindrance is the limited knowledge of how affected individuals live and cope in developing regions such as Africa. This research complements the extant quantitative studies on food allergies (e.g. Basera et al., 2015; Gray et al., 2014) by highlighting the complex everyday lived experiences, challenges and needs of affected persons and families. While research exists on lay perceptions and experiences of chronic diseases such as sickle cell, stroke, diabetes (Rutebemberwa et al., 2013; Dennis-Antwi et al., 2011, Thomas and Greenop, 2008, de-Graft Aikins, 2007), this is the first focusing on lived experiences of food

allergic individuals and families in Ghana. By exploring lived experiences of affected persons, this research provides useful information for a comparable analysis of the similarities and differences between affected persons in developed and developing contexts. Further, the research identifies important food allergens, both international and local, that are critical for studies seeking to measure prevalence of food allergy in Ghana.

By integrating several theoretical perspectives (e.g. epidemiologic transition, ecosocial), this research sheds light on the epidemiology of food allergy by revealing the contextual influences that simultaneously facilitate and constrain disease management. The framework outlined in Chapter 5 can be a useful tool for exploring how structural forces at different scales interact to shape population patterns of food allergy in developing countries. As chapter 3 and 4 demonstrate, food allergies are often unrecognized, and consequently do not attract the same public health investments in Ghana. As several researchers in the food allergic community (Nettleton et al., 2010; Christakis, 2008) and social science disciplines (Ruebi et al., 2016; King, 2010, Neely, 2011) have suggested, attention to social and environmental influences is critical to understanding the construction of health risks and to explaining why certain risks are prioritized over others. This research therefore supports calls for food allergy to be studied in its social context (Nettleton et al., 2010; Christakis, 2008).

Further, the research findings can be applicable to similar contexts in the developing world. Though developing countries are characterized by diverse socioeconomic conditions and environmental changes, there is evidence that the burden of disease is shifting, as chronic diseases have become prevalent (WHO, 2014). In emerging economies in Africa and Asia, food allergies are a growing health concern (Gray et al., 2016, Lee et al., 2013; Obeng et al., 2011). Considering the similarities in health and social concerns with affected populations in developed

countries, the implications of these findings can be applied to other developing countries where food allergies are emerging.

In addition, this research makes an important contribution to health geography by expanding the substantive focus of the sub-discipline to include food allergy. As noted earlier, the contribution of health geographers to the study of food allergy has been limited, though a considerable body of work exist on allergies such as asthma (e.g. Crighton et al., 2010, Corburn et al., 2006; Oyana and Rivers, 2005; Rudestam et al., 2004, Wind et al., 2004). In both past and recent reviews of research trends in the sub-discipline, food allergy is largely under-represented (Gatrell and Elliott, 2015; Luginaah, 2009, Asthana et al., 2002). While the reasons for the apparent lack of interest are unclear, health geographers have much to say about the relationships between people, place and risk of developing food allergy, given concerns regarding how the environment influences the internal ecologies of the body, and experience of health and healthcare (Guthman, 2012, Guthman and Mansfield, 2012). Further, the research responds to calls for a greater research focus on health needs in LMICs particularly in sub-Saharan Africa (Phillips and Andrews, 1998). While an account of progress in health geography in LMICs has yet to be undertaken<sup>6</sup>, this research adds to works in the areas of risk behaviours, HIV and AIDS (Luginaah, 2008; Luginaah et al., 2005; Oppong, 1998), alcohol consumption (Luginaah and Dakubo, 2003), healthcare accessibility (Rosero-Bixby, 2004; Perry and Gesler, 2000) and chronic noncommunicable disease (Ruebi et al., 2016, Smit et al., 2016, Tenkorang and Kuuire, 2016).

<sup>&</sup>lt;sup>6</sup> There are two notable exceptions. The first being, Social Science & Medicine special issue on medical geographic research in Latin America in 1981 and the second, Phillips and Andrews (1998) selected literature review which solely focuses on spatial health research in Africa starting in the 1990s.

Methodologically, the research demonstrates how a qualitative design can provide an effective pathway to understand food allergy in a developing country context. Existing research in this region has largely relied on quantitative indicators, and use allergens (e.g. eggs, peanut, fish) employed in western studies to measure incidence and prevalence of food allergy. Beyond enhancing understanding of food allergy in LMICs, this research also demonstrates how qualitative methods can be a useful approach for validating allergens employed in quantitative studies in this region (Gray et al., 2014; Gray and Kung, 2014; Obeng et al., 2011) as well as identifying important local allergens through analysis that is grounded in the daily and personal experiences of allergic individuals and healthcare workers.

Further, the study provides an example of how interviews can be an effective tool for identifying and assessing a diagnosis of a food allergy. In developed countries, participants have generally been recruited from registries of patient support groups, hospitals, and allergy hospitals/clinics (Monks et al., 2010; Akeson et al., 2007, Hu et al., 2007). In contexts where such opportunities do not exist, there is little guidance on how to identify and assess allergic status. By employing a combination of criteria – e.g. personal histories, clinical manifestation of symptoms and duration of symptoms onset – this research emphasized and provided evidence of the importance of inductive knowledge as a first step toward identifying (food) allergic individuals in resource-constrained contexts.

In addition, the research contributes to calls in health geography (Kearns and Moons, 2002, Kearns, 1993) and more recently clinical allergy (Nettleton et al., 2010; Gallagher et al., 2009) for research approaches that transcend the dominant and often pervasive application of quantitative tools in health research. Qualitative research places participants at the center of the research process, privileging their voices in the construction of knowledge (Cresswell, 2007),

providing an opportunity to document perspectives of affected individuals and obtain valuable context specific knowledge of challenges around food allergy in a developing country. As a result, this research provides an example for researchers seeking to understand the social experiences of health in developing countries, empowering often marginalized populations to share their perspectives and collaborating with them in order to explore critical concerns affecting health and wellbeing.

## 6.5 Policy and practice implications

Chronic diseases are growing in prevalence, and projected to be the major critical health problem in many developing countries by 2030 (Lozano, 2012; WHO, 2011) as the ageing population grows, and unhealthy lifestyles become more prevalent. As public health interventions emerge to address current and future burdens, there is evidence that allergic diseases including food allergy are becoming a feature of health in developing regions such as Africa and Asia (du-Toit et al., 2015; Kung et al, 2014). As many developing countries develop (or begin to develop) national policies to address chronic diseases, it is important that allergic disease is given due consideration. The findings of this thesis have implication for research, practice and policy intervention.

## 6.5.1 Building the evidence-base for policy

The findings of chapters 3 and 4 do not only illustrate that food allergy is a growing health risk impacting the health, social and economic wellbeing of affected persons, they also reveal major gaps in baseline information on its prevalence in Ghana. Without evidence on prevalence, spatiotemporal changes are difficult to track, and decision makers can be hesitant to shift and implement policy changes, particularly when the true extent of a problem is unclear

(Hadley, 2006). Despite a context of resource-constrains, data is still needed in Ghana as in many countries in Africa. Numerous opportunities exit for the national policy maker to improve understanding on prevalence, distribution and potential risk factors. Such opportunities relate primarily to national survey data and health campaigns as outlined below:

- 1) National governments, health ministries and agencies can leverage existing nationally representative household surveys to document food allergy prevalence. In many African countries, the Demographic and Health Surveys (DHS) and Multiple Indicator Cluster Surveys (MICS) for example measure demographic characteristics (e.g. age, sex, fertility) and a range of adult and child health issues every five years. Policy makers can take advantage of these surveys and modify existing standardized survey questions from Canada and the United States (Ben-Shoshan et al., 2010; Sicherer et al., 1999) to record self-reports of food allergy.
- 2) Health promotion campaigns can capitalize on the opportunity to raise awareness and bring attention to food allergies. For instance, this may include extending existing chronic disease public sensitization campaigns to include food allergy through organized workshops, radio and television talk shows. Sensitization of the public in Ghana can be an effective strategy to reducing health illiteracy, increasing visibility on food allergy, and creating opportunities for utilization of health facilities. This is a useful approach considering the success of educational programs on increasing cervical cancer screening rates in the Greater Accra region (Bosu, 2013). Further, given food allergies tend to be common among children, maternal and child care departments provide a unique opportunity to provide parents with information about food allergy, and to learn about allergic conditions in the pediatric population.

### 6.5.2 Improving clinical management of food allergy

As the results of chapters 4 and 5 illustrate, critical challenges in management exist, including but not limited to: the lack of diagnostic and treatment guidelines, lack of epinephrine auto-injectors, delayed diagnosis, and poor healthcare worker attitudes. Several opportunities exist to improve clinical care:

- 1) To address diagnostic and treatment gaps, decision makers could adopt preexisting health guidelines, such as the National Institute of Allergy and Infectious Diseases (NIAID) consensus guidelines on best practices for diagnosing, treating and managing allergies. Equipping health workers with the best available, and better synthesized evidence on the epidemiology of food allergy can help to improve diagnostic quality, counselling, and management strategies. Importantly, these guidelines should be presented in formats that are easily accessible, understandable and of practical relevance to the context of clinical care.
- 2) Policy makers must intentionally undertake measures to build the capacity of primary healthcare providers. In Ghana, as in many developing countries, allergy specialists are few or in many cases do not exist. Allergy is hence neglected in medical education, perpetuating "a cycle of lack of knowledge about the most common allergic diseases..." (Potter et al., 2009, p.151). As a result, many physicians and allied health professionals do not have adequate competency to diagnose, treat and manage allergies as the findings of chapter 4 and 5 highlights. Considering the key role primary health care physicians play in disease diagnosis and treatment, it critical to enhance allergy knowledge through seminars and workshops. In the long term, breaking the cycle of limited knowledge will require integrating food allergy as a critical component of medical education in Ghana.

3) At the patient level, the findings of chapter 3 suggest that empowering affected persons is critical to minimizing the risks and reducing burdens of food allergy. As food allergies impose significant psychosocial burdens, and healthcare costs, it is important to equip affected individuals with adequate information towards self-management across various social contexts — e.g. home, school, work. In addition, deliberate attempts to build patient networks could be helpful considering the key roles such groups have played in advocating for the needs of affected individuals and those at risk of anaphylaxis in the developed world.

## 6.5.3 Mobilizing global partnership for food allergy

Chapter 5 suggests the slow response to (food) allergic disease in Ghana and by extension Africa should be contextualized within the global response to improve health and wellbeing in developing countries. At the global level, while research funding in allergic disease is generally inadequate, this appears to be more acute especially in contexts where infectious disease such as AIDS, tuberculosis, malaria continue to persist. While growing donor interests and support for particular chronic diseases are important, such commitments need to extend to (food) allergic disease as well.

In addition, much can be gained from the collaborative research program of the International Studies of Asthma and Allergies in Childhood (ISAAC). Such large scale partnership was an important source of information on the rise of asthma, eczema and allergic rhinitis in the developing world. As its sequel, the Global Asthma Network proceeds from where ISAAC ended, it is important researchers in both developed and developing countries consider food allergy as a key part of the data collection.

### 6.6 Limitations

This thesis is not without limitations. First, while this research explored the perceptions and experience of a total of 37 participants: comprising 17 health workers and 20 affected individuals and families, and provided a nuanced understanding of the emerging risk of food allergy, the results nonetheless restrict generalization and transferability to all health workers, allergic individuals or their families. For example, despite using a maximum variation sampling strategy (e.g. online advertisement, snowballing, posters at churches and mosques), the sample remained largely skewed toward populations with high levels of education and employment, and consequently does not reflect the lived experiences of those of low socioeconomic status in Ghana. This is an area that will require further research. Similarly, the findings also represent the perspectives of a sample of health workers mostly in public and private formal health institutions. Though sampling included a variety of individuals (e.g. general physicians, pediatricians, dieticians, nurses), additional studies with other important key health stakeholders (e.g. dermatologists, midwives, community health nurses, pharmacists, traditional healers) can provide critical information to further support these findings.

Second, the study was restricted to one large urban center, and may not represent the perspectives of healthcare workers and affected individuals in other urban centres of the country. However, considering the homogeneity in sociocultural and political context in Ghana (albeit differences in climatic conditions), results will likely engender similar experiences, behaviours and practices. Nonetheless, it is important to conduct more comparable studies in other urbanized or socioeconomic contexts to confirm the current findings.

Third, the empirical literature reveals challenges and difficulties about measuring food allergy. While most studies employ questionnaires, serum specific testing and (or) skin prick

tests (SPT) to diagnosis food allergy, few utilize food challenges (OFC) considered the surest way of confirming a diagnosis. Though employing a set of screening questions to determine probable food allergy in individuals, this research was unable to verify allergic claims from participant's physician or medical records. In addition, without testing for confirmation, uncertainties remain about their allergic status. This is important as studies have demonstrated that, there are significant gaps between perceived and actual risks (Makhija et al.,2016; Woods et al., 2002) with a tendency of self-reporting to overestimate perceptions of risk and prevalence (Sicherer, 2011). Further, the selection criteria (Chapter 4) may have excluded affected persons who may be experiencing delayed reactions to food or reported just one relevant symptom of allergy. While most "true" allergies occur within minutes, by excluding outliers, it is possible this research missed opportunities to further gain insights of unique experiences of these individuals.

Lastly, considering the research was focused on the emergence of food allergy in healthcare settings, the study also relied on health workers to assess the changing disease context over time. As a result, the findings are also likely constrained by recall bias as health workers may not have accurate recollections of incidence of reported food allergies, or their experiences diagnosing and treating allergic individuals or engaging parents of allergic children. Given these limitations, the results of this research should accordingly be interpreted with caution.

#### **6.7** Future research directions

In their concluding chapter on *Sick societies: responding to the global challenge of chronic disease*, Stuckler and Siegel remark that:

"One of our daily rituals is to look in the mirror. Every morning, we wake up, take a look at ourselves, and check to make sure everything is in order. The image

we see is a reflection of who we are and who we are becoming" (Stuckler and Siegel, 2011, p.291)

In many developing countries, the reflection depicts a growing burden of chronic disease, occasioned by declining infectious disease, unhealthy lifestyles which have been exacerbated by rapid urbanization and globalization (Lozano et al., 2012; WHO, 2011). In this thesis, an attempt has been made to paint a picture of food allergy, one of the fastest growing chronic diseases in most parts of the world. While the current research provides important insights of lived experiences and how local level factors shape these experiences and perceptions of risks, there are several reflections for which future studies can contribute to our understanding of this nascent research area in Africa. As the substantive chapters highlight, we still do not know much about the prevalence of food allergy. Chapter 3 and 4 identified several important food allergens that will be useful for researchers seeking to measure and understand the prevalence of common food allergens in sub-Saharan Africa.

While households provide an important unit to conduct surveys, the findings in Chapter 4 suggest schools (e.g. nurseries, junior & senior high schools, universities) may also provide an important conduit to document the prevalence of food allergy. As food allergies and allergic reactions tend to be common in schools (Yong et al., 2009; Nowak-Wegrzyn et al., 2001, Sicherer et al., 2001), this setting is an important source of information to understand allergies in children in Ghana. This is particularly important considering that under the Ghana School Feeding Programme (GSFP), public kindergarten and primary schools' children have opportunities to be provided at least one meal at school. An assessment of the GSFP in the context of food allergy, as well as caterers, school nurses or teachers' perceptions, knowledge and attitudes around food allergy can provide valuable information to understand the risks pose to allergic children in Ghanaian schools.

Further, this data set excludes children, an important stakeholder in the management of food allergy. In developed countries, studies have shown the unique experiences and coping strategies of children (Fenton et al., 2013; 2011). Future studies in Ghana can provide important insights into children's experience in multiple settings (e.g. the home, school, restaurants or at social events) and how these experiences compare or contrast with findings in western countries. In addition, there is a dearth of studies exploring food allergy among low SES populations, the exceptions being Goodwin et al., (2017) in the United States and Soller et al., (2015) in Canada. An important area to build on the findings of the present research is understanding the experience of those with low SES to enhance knowledge of their lived experiences and to add to the scant literature on this cohort.

Further, the study did not explore the perspectives of pharmacists. Considering their important role in primary health care – e.g. accessibility to essential medicine, counselling & management (Smith, 2004) – there is much to be gained from exploring the experiences of public and private pharmacists. For example, understanding the frequency of antihistamine purchases could be a useful proxy of the extent of allergic reactions. Also, we still do not know much about the public risk perception around food allergy. Research in this regard can provide critical insights to properly contextualize and understand the lived experiences of affected individuals and their family.

In addition, while an overall food allergy policy to protect and minimize risks does not exist, chapter 4 suggests some schools have some semblance of a regulatory policy to manage risk exposure. The effects of policies have been inconsistent in the developed world. While some have suggested a resulting increase in awareness around food allergy (Dean, et al., 2015), others have also pointed to the potential unintended consequences – e.g. stigma and discrimination – of

these policies on the wellbeing of allergic individuals and others (Rous and Hunt, 2004). The current study did not explore the details of these school-based policies, nor did it assess the impact on children social interactions in school settings. An assessment of the school policy environment – e.g. identifying key characteristics, implementation issues – can enhance understanding of the complex relationships and contestations that arise in such social spaces.

Further, food labels are an essential part of mitigating the risk of allergic reactions and aiding allergic individuals in choosing safe foods (Imamura et al., 2008). However, they can also be a source of heightened anxiety and confusion (Brown et al., 2015). In Ghana, while the Food and Drug Authority (FDA) require the mandatory declaration of key food allergens, little is known about how this shapes the experience of living with allergy. Understanding the perspectives, preferences and challenges of affected individuals can provide insights to shape public education, and to inform policy recommendations that protects against accidental ingestion and at the same time responds to the concerns of the food industry.

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## Chapter 1

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### Chapter 6

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#### **Appendices**

### Appendix 1 Ethics approval

UNIVERSITY OF WATERLOO

https://oreprod.private.uwaterloo.ca/ethics/form101/ad/reports/certifi...

#### **UNIVERSITY OF WATERLOO**

#### OFFICE OF RESEARCH ETHICS

Notification of Ethics Clearance of Application to Conduct Research with Human Participants

Faculty Supervisor: Susan Elliott

Department: Geography

Student Investigator: George Atiim

Department: Geography

ORE File #: 20670

Project Title: EMERGING NEW NCD'S IN SUB-SAHARAN AFRICA: EXPLORING THE EMERGENCE OF

ALLERGIC DISEASES IN THE GREATER ACCRA REGION, GHANA

This certificate provides confirmation the above project has been reviewed in accordance with the University of Waterloo's Guidelines for Research with Human Participants and the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. This project has received ethics clearance through a University of Waterloo Research Ethics Committee.

**Note 1**: This ethics clearance is valid for one year from the date shown on the certificate and is renewable annually. Renewal is through completion and ethics clearance of the Annual Progress Report for Continuing Research (ORE Form 105).

**Note 2**: This project must be conducted according to the application description and revised materials for which ethics clearance has been granted. All subsequent modifications to the project also must receive prior ethics clearance (i.e., Request for Ethics Clearance of a Modification, ORE Form 104) through a University of Waterloo Research Ethics Committee and must not begin until notification has been received by the investigators.

Note 3: Researchers must submit a Progress Report on Continuing Human Research Projects (ORE Form 105) annually for all ongoing research projects or on the completion of the project. The Office of Research Ethics sends the ORE Form 105 for a project to the Principal Investigator or Faculty Supervisor for completion. If ethics clearance of an ongoing project is not renewed and consequently expires, the Office of Research Ethics may be obliged to notify Research Finance for their action in accordance with university and funding agency regulations.

**Note 4**: Any unanticipated event involving a participant that adversely affected the participant(s) must be reported immediately (i.e., within 1 business day of becoming aware of the event) to the ORE using ORE Form 106. Any unanticipated or unintentional changes which may impact the research protocol must be reported within seven days of the deviation to the ORE using ORE form 107.

Maureen Nummelin, PhD Chief Ethics Officer Date

5/8/2015

OR

Julie Joza, MPH

Senior Manager, Research Ethics

OR

Sacha Geer, PhD

#### GHANA HEALTH SERVICE ETHICS REVIEW COMMITTEE

In case of reply the number and date of this Letter should be quoted.



My Ref. :GHS-ERC: 3 Your Ref. No. Research & Development Division Ghana Health Service P. O. Box MB 190 Accra

Tel: +233-302-681109 Fax + 233-302-685424

Email:

Hannah.

Frimpong@ghsmail.org

28th May, 2015

Susan J. Elliot University of Waterloo Faculty of Environment

#### ETHICS APPROVAL - ID NO: GHS-ERC: 02/03/15

The Ghana Health Service Ethics Review Committee has reviewed and given approval for the implementation of your Study Protocol titled:

"Emerging New NCDS in Dub-Saharan Africa: Exploring the Emergence of Allergic Diseases in the Greater Accra Region, Ghana"

This approval requires that you inform the Ethics Review Committee (ERC) when the study begins and provide Mid-term reports of the study to the Ethics Review Committee (ERC) for continuous review. The ERC may observe or cause to be observed procedures and records of the study during and after implementation.

Please note that any modification without ERC approval is rendered invalid.

You are also required to report all serious adverse events related to this study to the ERC within seven days verbally and fourteen days in writing.

You are requested to submit a final report on the study to assure the ERC that the project was implemented as per approved protocol. You are also to inform the ERC and your sponsor before any publication of the research findings.

Please note that this approval is given for a period of 12 months, beginning May 28<sup>th</sup> 2015 to 27<sup>th</sup> May 2016.

However, you are required to request for renewal of your study if it lasts for more than 12 months.

Please always quote the protocol identification number in all future correspondence in relation to this approved protocol

DR. CYNTHIA BANNERMAN (GHS-ERC CHAIRPERSON)

Cc: The Director, Research & Development Division, Ghana Health Service, Accra

# Appendix 2 Interview Guides 1) Participant interviews

Construct	and lived experiences, and coping strategies of individuals and hou Question	Probe
Construct	Question	What is your current role? Length of stay
	Can you tall me comething about you?	•
	Can you tell me something about you?	at current place of residence? Previous
		place of residence? Ethnic background?
	What are they been some of the biggest health	How has these changed over time?
Contaxt	What are [has been] some of the biggest health	What do you know about NCDs
Context	challenges you have observed over the years?	[hypertension, cancer, diabetes, stroke
		etc]?
		Do you think they are increasing? Why do
	How shout allows a conditions foothers acroms whinitis	say so? What do you think is causing this?
	How about allergic conditions [asthma, eczema, rhinitis,	What are the common allergic conditions
	food allergy]?	that you are aware of? Are these conditions
		increasing too? What do you think is
	Tall ma shout your or fallowing newsonl averagion on with	accounting for these changes?  What are they allergic to? When did you
	Tell me about your or [allergic person] experience with food allergy.	[they] have your [their] first reaction?
	rood anergy.	What was the experience like?
	What do you think is harmoning?	*
Food Allaman	What do you think is happening?	Why do you think so?
Food Allergy	Could you please describe to what happens whenever	Symptoms / symptoms onset
	[allergic person] eat this food?	1. abdominal pain, diarrhoea, nausea
		or vomiting
		2. Hives, itching or eczema
	Has there ever been a reaction that you or [allergic	3. Redding of the eyes
	person] had to visit an emergency unit of a hospital?	4. Tingling or itching in the mouth
	TC	5. Swelling lips, face, throat,
	If yes, can you tell me about this?	6. Wheezing, breathing troubles
	<del></del>	7. Nasal congestion or running nose
	Please tell me how you or [allergic person] came to	At what age did you discover this? Where
	know that you have this problem?	was diagnosing done?

	Do you know others with a food allergy?	Where? [church, mosque, school, work] How do theirs [other allergic individuals] compare with yours?
	How big is the problem of food allergy in Ghana?	Why do you say so?
	If you were to guess, how many people do you think have a food allergy?	What do you think is causing this?
Perceptions about food allergy	What do people think about food allergy in your community?	Why do people think so? How did other people react to you or [allergic individual] condition?
	What do you think about the attention given to food by the health system?	-
	What would you say is your biggest source of worry?	
	Where would you normally seek treatment when experiencing symptoms?	Is this the primary source of care? What has been your experience in seeking treatment?
Management and Coping Strategies	Has the food allergy limited this person's daily activities in any way? (e.g. going to school? participating in household chores? Etc)	How has this affected your or [allergic person] daily activities?
	Has there been any changes in the home since you had a reaction?	What changes have been made? Have these changes been made outside the home to? [church, school, work etc]
	What is the biggest challenge for you in dealing with this situation?	
	What kind of support do you receive?	Family? Friends? Health experts? Teachers?
	Is there anything else you would like to add that we have not already discussed?	
Discussion	Is there anyone else you think we should talk to about food and other allergies?	

## 2) Key Informants

**Purpose:** To understand key health stakeholders' perceptions and experiences with allergic diseases and associated risks

Construct	Question	Probe
Context	Please tell me about yourself?	Where are you from? Where did you go to school? What is your current role? How long? What brought you to this position?
	What are [has been] some of the biggest health challenges you have observed over the years?	How has these changed over time? Which ones have changed?
	What do you think is the geographic scope of this?	What has been the experience of NCD in Ghana? Types, risk population, and causes
	How has Ghana responded to these major health challenges?	
	What has been your experience with allergic diseases in Ghana?	How big is the problem of allergies? Do you think these conditions are increasing? Why do you say so?
		Is food allergy one them?
Perception and Experience of Food	In your years of practice, how often have you come across individuals with food allergy?	Has this changed over time? What explains this change?
Allergy and Allergic Disorders	What food (s) are people allergic to?	Category of people reporting or you suspect to have a food allergy [SES, ethnicity]
	What signs and symptoms alert you to a possible food allergy?	
	Can you please share with me how you would diagnose food allergy in a person?	
	When do people often seek treatment for food allergy?	How do you treat them?
	How big is the problem of food allergy in the country?	Why do you say so?

	If you were to guess, how many people do you think have a food allergy?	Do you think this is growing? What do you think may be accounting for this?
		Do you anticipate that food allergy will become major health issues in Ghana? What may be driving this observation?
	Can you please describe to me the important issues you feel that affects how food allergy is seen [healthcare, community settings?	
Facilitators and barriers	In your experience, what are some of the challenges you encounter managing food allergy?	Are there any others that you can think?
	What do you think will be some of the biggest challenges for managing food allergy in Ghana?	What changes do you think need to made to address this situation?
Discussion	Is there anything else you would like to add that we have not already discussed?	
	Is there anyone else you think I should talk to about food and other allergies?	