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“Ne nnipadua mmpe” (the body hates it): Exploring the lived experience of food allergy in Sub-Saharan Africa

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**“ne nnipadua mmpe” (the body hates it): exploring the lived experiences of food allergy in Ghana****Abstract**

Allergic diseases have closely followed the rise of non-communicable diseases (NCDs) especially in western societies. As prevalence of NCD is increasing in sub-Saharan Africa (SSA), researchers are hinting that the same future may hold for (food) allergic disease in this world region. Already, researchers are beginning to record prevalence, though with little attention to the social experience of individuals and parents with food allergic children. This paper presents the first qualitative analysis of the daily realities of adults and parents of children with allergies in SSA, using Ghana as a case study. Drawing on political ecology of health, this study contextualizes the psychological (e.g. anxiety and fear), social (e.g. stigmatization, social exclusion), and economic (e.g. impact on work & household expenditures) wellbeing of affected persons within the broader sociocultural environment. By exploring the sociocultural environment, the results provide insights into the likely structures (e.g. the lack of familiarity, absence of local discursive repertoire on food allergy, infrastructure deficit) which interact to shape anxiety, and social exclusion of people with allergy. The case study provide evidence suggesting food allergies do have a global reach, and policy makers must heed the message to integrate food allergy into the broader chronic disease prevention agenda.

**Key words:** Ghana, Chronic disease, Food allergy, Political ecology of health, Sub-Saharan Africa

## 1 Introduction

Globally, food allergies are an emerging key health concern in most developed countries, affecting between 2% and 10% of people (Sicherer, 2011). Among children and adults, prevalence is estimated at 7.5% in Canada (Soller et al., 2015a); 8% in the United States (Gupta et al., 2013) and 10% in Australia (Osborne et al., 2010). Though fatality rates are generally lower, food allergy impose a challenge on the physical, social and economic wellbeing of allergic individuals and families as they interact with others within and across different spaces of risk – home, school, and work, and other public places (Cummings et al., 2010; Ostblom et al., 2008). Among allergic individuals in the United States, approximately 40% have a history of adverse allergic reactions (Gupta et al., 2011) including (but not exclusive to) breathing difficulties, swelling, abdominal cramps and vomiting (Hadley, 2006). Without prompt treatment, food allergy can trigger anaphylaxis, a life threatening condition that can cause death (Hochstadter et al., 2016). As food avoidance remain key to preventing allergic reaction, food allergy can increase anxiety and stress (Munoz-Furlong, 2003; Primeau et al., 2000), stigma (Dean et al., 2015), bullying especially among children (Torabi et al., 2016) and increase household finances (Gupta et al., 2013).

In western societies, evidence suggests food allergies have lagged behind the rise of many chronic health problems – e.g. other allergies (e.g. asthma, hay fever) and autoimmune diseases (e.g. type 1 diabetes, multiple sclerosis) (Prescott and Allen, 2011; Bach, 2002). Considering the growing prevalence of chronic diseases (e.g. cardiovascular, diabetes, asthma), in settings like sub-Saharan Africa (SSA), researchers are hinting food allergies may be next to follow (Atiim and Elliott, 2016; Kung et al., 2014). Across Africa, food allergic studies are beginning to grow, though most focus on recording incidence and prevalence. For example, one study estimates overall self-reported prevalence among Ghanaian urban

schoolchildren at 11% (Obeng et al., 2011) compared to 6.9% in Canadian children <18years (Soller et al., 2015b). In South Africa, challenge proven allergy to any food in an unselected population was estimated at 2.5% (Basera et al., 2015) similar to the 2.3% reported in Denmark (Osterballe et al., 2005) though much lower than the 10% recorded in Australia (Osborne et al., 2010). In a retrospective survey in Harare, Zimbabwe, about 10% of patients (14, 000) seen at an allergy clinic between 1997 and 2002 reportedly had food allergies (Sibanda, 2003). Recognition of food allergy in healthcare settings also appears to be increasing as evident by discussions of clinical cases in medical journals in Ghana (Affa et al., 2017), Nigeria (Adeniyi and Renner, 2015) and Mozambique (Okezie et al., 2010). Although national data on food allergy prevalence is lacking, which potentially obscures insights of its true extent, the collective message of these studies suggest the need for decision makers to heed calls to incorporate allergic disease in the broader agenda on preventing chronic disease (Atiim and Elliott, 2016; Prescott, 2013).

While these extant studies in SSA helps to paint a picture of prevalence, providing insights into the future landscape of food allergy, little is known about how individuals experience and cope with allergy. A diagnosis of food allergy can transform the lives of affected individuals and their families, often requiring constant vigilance, food avoidance, and carrying epinephrine auto-injectors. The empirical literature on the lived experience of allergy largely come from developed countries, and are very limited in developing countries. To the best of our knowledge, no study has undertaken to understand the experiences of food allergic persons and (or) parents/guardians with allergic children in SSA. Understanding these unique experiences especially in a context where infectious disease dominate public discourse on health and health promotion activities can provide important insights to help mitigate the associated health risks.

This study employs a political ecology of health lens to help understand the lived experience and perceptions of food allergy in SSA using Ghana as a case study. Previous studies suggest food allergy is an emerging health concern yet a neglected and often unrecognized 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 individuals and parents with food allergic children are embedded within and shaped by the wider 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.

## **1.2 A political ecology of food allergy**

The study is informed by political ecology of health (PEH) which explicitly attends to the interactions between biology, and factors within sociopolitical, cultural, economic and ecologic environment (e.g. political, social, ecological) operating across multiple scales and how they shape people's health (Jackson and Neely, 2015; Neely, 2015; King, 2010). It recognizes that peoples' experience of illness, and vulnerabilities are deeply embedded and cannot be divorced from the intricacies of the environment in which they live and work (Neely, 2015, Guthman and Mansfield, 2012). For example, Sultana (2012) has shown how the promotion of tubewells in Bangladesh which were aim at enhancing domestic water and irrigation practices conversely became the conduit for arsenic and water interaction, eventually leading to increasing rates of arsenicosis among residents. Despite interventions, arsenicosis persisted due to inequalities related in poverty and a lack of access to safe water. In Canadian Namgis First Nation communities, Richmond et al (2005) have revealed that

community wellbeing is linked to several structural processes (e.g. imposed governance, aquaculture development) that disempowers residents, resulting in declining community social support and a lack of social trust, important elements for sustaining community health.

Studies of PEH are also interested in questions of individual or collective agency and their interactions with structural determinants (Krieger, 2011, King, 2010). For example, while structural forces (e.g. unemployment, unequal resource distribution) shape access to safe water and sanitation, individuals, and communities also organize to prevent pollution of water sources and the construction of sanitation facilities (Bisung et al., 2015). Also, though HIV may impose barriers for people living with HIV (Makoae et al., 2008), the coping strategies adopted to prevent stigmatization for example highlight the importance of their agency to improve their wellbeing.

Furthermore, PEH also explores how local perception of (ii)health and competing health knowledge reveal gaps in official and unofficial institutional discourses around health and wellbeing in society (King, 2010). The examination of such processes is critical to interrogating “long- held assumptions and over-simplifications of nature–society entanglements” (Robinson, 2017, p. 286). For example, in her work on tuberculosis in a context of AIDS in South Africa, Neely (2015) demonstrates how attention to the peculiarity of individual cases of tuberculosis can help physicians and allied staffs avoid the pitfall of assuming that unique instances of tuberculosis necessarily indicate HIV.

In allergy research, few explicitly invoke a PEH lens, and where they have, they’re largely from developed countries. For example, scholars (e.g Smith 2015; Jackson, 2006) have helped to shed some light on the history of (food) allergic diseases within the context of the

wider sociopolitical environment. They point out the role structural processes and actors' (e.g. increased media reporting of allergic reaction, public health regulations) have played in transforming allergy from relative obscurity to an important global health concern that permeates people's daily lives (Waggoner, 2013). In their analyses of how legislation structures social bodies of allergic individuals, Rous and Hunt (2004) suggest regulatory policies often have unintended consequences as they socially differentiate between allergic and non-allergic populations, while also expanding care roles beyond the realm of parents and the home to include new actors - teachers and schools. Although PEH is often implicitly stated, these studies call attention to the need to look beyond the individual bodily characteristics of allergy, to incorporate the complexity of the broader environment to analyses of food allergy.

In this paper, we extend and contribute to the emerging research on allergy and social models of health by exploring how food allergy is perceived and experienced, while linking these experiences to the sociopolitical and sociocultural dimensions: e.g. inadequate health system infrastructure, and local discourses of public health risk. Understanding what it means to live with a health condition, people's perceptions and interactions with their environment and how they actually treat illness – i.e. efforts that do or do not make - can provide insights into “the ways in which people at the local level” differentially interact with their environments as well as how they differentially conceptualize their health and environments” (Harper, 2004; p.320).

## **2 Study area and methods**

This study employed a qualitative research design (Miles et al., 2014) consistent with the practice of political ecology, which focuses on people, sensitivity to context as well as

situated knowledge (Wisner, 2015) to understand both the experience of food allergy, and the local social, cultural and political structures (King, 2010) influencing health experience and risk perceptions. We undertook this study in the Greater Accra Region (GAR), one of the most economic and cosmopolitan of the ten administrative regions in Ghana. The choice of the GAR was informed in part by existing literature which show allergies tends to be more common among urban populations and households with higher socioeconomic status (SES) (Viinanen et al., 2005, Hijazi et al., 2000). The GAR is the most urbanized, with an estimated 90% of the urban population (Ghana Statistical Service [GSS], 2012) and can boast of relatively well resourced health facilities. Over the years, social changes (e.g. improving SES standards, lifestyle) and a context of globalization is leading to shifts in the disease landscape with NCDs 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.

In this exploratory study, twenty [20] semi-structured interviews were conducted with food allergic individuals [n=10] and parents with allergic children [n = 10] between June and August, 2015 to gain insights into the everyday experiences and adaptive responses. As two parents had more than one allergic child, total allergic persons were twenty-two [22] comprising: 10 individuals >18 years and 12 children <18years. We recruited through social media and social networks, with recruitment posters strategically placed on boards at public places (e.g. churches, mosques) to generate participation interest. Also, snow balling was employed to maximize variations in the sample composition.

To be eligible, participants had to (a) self-report or be a parent/guardian of a child with food allergy or (b) report a physician diagnosed or suspected allergy, and (c) must report at least

two relevant symptoms which must (d) occur within two hours of contact with the allergen (Boyce et al., 2010). Information letters were given to participants and those interested directly contacted the first author. Consent was obtained from all participants prior to commencing interviews.

Interviews were conducted at a place of participant's choice, most [17] occurring in their homes. Interviews lasted between 45mins and 1h focused on experiences of diagnosis, managing and coping with allergy. All interviews were conducted in the English language (with one exception) and audio recorded. Ethical clearance was obtained from the University of Waterloo Ethics Review Board and 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, an inter- and intra-rater reliability was assessed (Miles and Huberman, 1994) and we reached 80% agreement with a second coder. All transcripts were entered into QSR International's NVivo 11 for data management and analysis. We employed pseudonyms in the attribution of quotes to ensure anonymity.

## **2.1 Sample characteristics**

Approximately half of participants were diagnosed/realized their food allergy at a very young age [Table 1a]. Most parents and adult sufferers were told by a physician that their allergic reaction was due to food following an examination of their medical history and food elimination. However, the vast majority [n=10] reported self-realizing the specific allergen while for six people, a physician identified the allergenic food [see table 1b]. Participants life stage notwithstanding, the data suggest they were learning about their allergy during the same

historical time period [starting in the early 2000s], with most reporting multiple food allergies [n=17].

The major known allergens include fruits (41%), peanut (36%), seafood (27%), vegetable (23%), egg (18%), yam (14%), and maize (3%). While the most common allergens - e.g. peanut, seafood, eggs, milk - are consistent with allergens in developed countries (Soller et al., 2015, Branum and Lukacs, 2009), some local and novel allergens: fruits (e.g. pineapple, “local” banana), vegetable (e.g. okra, kontombire) and cereals (e.g. maize) were identified underscoring the need to pay attention to cultural differences in diets. The primary reported symptoms are presented in Tables 1a and 1b and as the latter suggests, symptoms may be suggestive of immunoglobulin E (IgE) mediated food allergies as opposed to food intolerance. Most [n=13] reported symptoms often occurred immediately, with no one indicating symptoms beyond 2 hours after allergen ingestion or contact.

**Insert Table 1a Characteristics of food allergic individuals [n = 22]**

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**Insert Table 1b Summaries of food allergy characteristics of individuals [n = 22]**

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### 3 Findings and discussion

#### 3.1 Lack of familiarity and limited awareness on food allergy

While awareness around food allergy appears to have increased in developed countries, in part due to increased media reportage on fatality, and regulatory policies that manage risk (see Waggoner, 2013; Nettleton et al., 2009), the accounts of participants reveal the need to pay attention to the “ways that concepts and interventions do, or do not, translate across borders, languages and cultural groups” (Hansen et al, 2013, p. 116). In all cases, we found a lack of familiarity (also see Nettleton et al., 2009) with many lamenting the absence of shared or a known name to describe food allergy or anaphylaxis in their native language. The absence or lack of a discursive repertoire (Nettleton et al., 2009) created an environment where the non-allergic population not only “*take [food allergy] for granted*”, but also made it difficult for those at risks to communicate its associated risks to others:

“If we had it [a local name], people would have been used to it and it would have been a lot easier talking about the effects or seriousness of the issue. People wouldn’t take it for granted like they do” - Phil, adult sufferer

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, mother of allergic boy

As Conrad and Barker (2010) argued, disease conditions do not necessarily inhere in themselves but arise through interactions in place. If food allergy is to be known, and well understood, it cannot occur outside the language in which they are described. As the above examples illustrate, sensitivity to context such as the ability to communicate through shared language is absolutely essential. To speak therefore about a local name is to emphasize the peculiarities of place – e.g. language, and learning about how food allergy is a culturally determined health issue.

Perhaps, this may help to explain why the vast majority of individuals and parents hadn't heard about food allergy prior to diagnosis, though overtime, awareness and knowledge was enhanced through first-hand experiences of allergic reactions or encounters with health systems. Just a few (n=4), primarily mothers with allergic children (n=3) had prior knowledge, which they acquired during pregnancy. This proved valuable especially with respect to their attitudes following initial allergic reactions. Of those without prior knowledge (n=13), reactions often came as a surprise, sometimes even scary in sharp contrast to those with prior knowledge as this example of a mother of two children with egg & soya allergy recalls:

“With my first pregnancy, I was reading a lot of materials not just about my health but also the unborn child. It was this time I came to know allergy. So it was not a big surprise. I was calm, not too worried because I already knew at least the symptoms”

Despite this apparent lack of awareness, and irrespective of perceptions of etiology, many perceived that food allergy is growing as an important issue. Both parents and adult-sufferers thought that, cases of food allergy were less common, or even “not a problem” in the past (usually reference to the 80s and 90s) compared to current realities as Akwasi, a father of two children with peanut and egg allergies indicates:

“If I look back, this was not a problem but children like these [those with allergies] are now many and growing in numbers. At that time, the common issues were the six childhood killer diseases. But this [food allergy] is definitely higher now than in the past”

Perceptions that food allergies are only a recent public health risk in Ghana should be understood within the larger sociopolitical context. For example, why was food allergy not a problem in the past? or why are children like these now many? As the PEH lens suggests, answers to these go beyond the discourse on risk factors of health to examining large-scale structural factors (King, 2010). While immunologic mechanism is one answer, the relative lack of information, coupled

with the absence, or limited conversation on food allergy in normal discourse of common health issues may have also contributed to obscuring food allergies as a health condition requiring medical and social intervention. As one mother indicates “*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 [food allergy] is really not there*”. Clearly, comments such as “there’s [*not*] a lot of talk” imply someone ought to be talking about allergy. While recognizing their own role to raise awareness, the bigger responsibility in participants’ view laid with health authorities. Several decades of persistent government (in)actions in the domain of infectious diseases, may be framing and reinforcing perceptions chronic illnesses and in particular food allergy are nonfatal problem. In the context of food allergy, such discourse can lead to social isolation or exclusion (Fenton et al., 2011; MacKenzie et al., 2010). Even when a strategy for chronic illness has been developed, (food) allergic disease are rarely considered, with policy supportive of diseases identified in global NCD strategy documents (see Ministry of Health, 2012). In this sense, policy decisions at the global stage affects the geography of disease in far-off places in low and middle income countries (LMICs), in this case food allergies in urban Ghana.

### **3.2 Psychological effects associated with food allergy**

Many also articulated the effects of food allergy on quality of life and their accounts of psychological wellbeing were similar to those identified in the literature (Cummings et al., 2010). Previous studies (see Nettleton et al., 2009) reveal that food allergy diagnosis is often difficult, and the status of being ‘allergic’ is usually not obvious. Parents particularly frequently expressed their frustrations over health providers’ inability to provide a timely diagnosis despite countless visits to and medical consultations at different healthcare settings (i.e. public or

private). The desire to know “what is wrong” and a context of persistent sub-optimal care, evident by the difficulty getting a diagnosis was a constant source of irritation and helplessness especially when reactions reoccur.

“Every parent want 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, mother of girl with multiple allergies

As a result, the realization that reoccurring reactions “could be allergy”, or “because of the food they ate” was a welcomed “relief” that not only “took part of the worry away” but also provided a step forward towards improving their wellbeing as highlighted by the case of Henry, an adult with multiple allergies:

“It was really an exciting day. For once, we were finally getting somewhere. That alone took part of the worry away. We could now focus on food to avoid these reactions and everybody could also have some peace”

Even when a diagnosis is eventually accomplished, the lack of a consistent and clear management information can affect psychological wellbeing (see Hu et al., 2007; Mandell et al., 2005). Participants mentioned medical information was often not specific, making it difficult to manage risk and to meet the food needs of children.

“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, father of allergic boy

As this case demonstrates, individuals and parents often require critical information on “what to *eat or feed their children* rather than what to avoid” (Hu et al., 2007, emphasis added).

Equipping healthcare workers with the tools needed to provide both timely diagnosis, and adequate information about management (e.g. cross-contamination) is important to help improve the lives of those with food allergy.

Beyond frustration, many also shared stories highlighting a heightened sense of anxiety and fear. As symptom severity is always unpredictable (LeBovidge et al., 2014), most were always anxious about the risk of reoccurrence and uncertainty surrounding future symptoms severity. In particular, the fact that children could accidentally or deliberately be exposed to allergens was a constant source of uneasiness:

“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, father of girl with multiple allergy

Such sentiments highlight the risks children face outside the boundaries of the home or safe spaces provided by parents. As outlined in their review (Cummings et al., 2010) and consistent with the literature on PEH (Neely and Nading, 2017), attention to contextual factors can enhance our understanding of individual and parental anxiety with food allergy. For example, many parents noted that children inability to recognize or manage risk (see also Pitchforth et al., 2011), along with their desire to be accepted by their community of friends (see Akeson et al., 2007, Sampson et al., 2006) meant they were always at risk of exposure to unsafe food. This constant threat made parents anxious and unwilling to leave the control and responsibility of care to children.

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, mother of boy with multiple allergy]

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, mother of girl with multiple allergy

As these examples imply, overcoming parental anxieties are dependent to a large extent on children demonstrated ability to assess and appreciate the risks they face. As Rose aptly indicate,

it is only “*when we get to the point he is in control, this [fear] would naturally go away*”. Until then, many felt there was need to stay vigilant if one were to be successful at preventing exposure and reactions. However, as others do indicate such constant vigilance in itself can also be a source of anxiety and stress (Munoz-Furlong, 2003).

For many parents, anxiety and stress was further sustained by the broader cultural context of child raising and welfare. In Ghana, child care is regarded a collective responsibility that involves not just biological parents, but also the extended family or even neighbours. While acknowledging the benefits of such social organization (e.g. social support during illness), for many parents, this was also a reminder of the risks their children face. They were worried and concerned that someone might “unknowingly” expose children to allergenic foods, potentially rendering their preventive strategies ineffective:

“People give food to children all the time, even if they are not their own. It’s a natural thing but that’s also where the fear is for me. Unknowingly, they put her in danger, and so what becomes of all the struggles to prevent the reactions?” – Sheila, mother of allergic girl

Keeping children safe from exposure thus involve “issues of trust or mistrust of the vigilance and understanding of others” (Stjerna, 2015, p. 288). As parents emphasized, they did not trust others will take the same necessary precautions to reduce the risk of exposure to children, hence their discomfort when others feed their children or anxiety about the source of food.

Among adult sufferers, uncertainty surrounding the severity of allergic reaction in the future was particularly emphasized. While many [n=7] perceived their symptoms were mild (e.g. itching, vomiting, hives), the knowledge that reactions could become “serious” or even “fatal” caused fear and worry. Like Henry, an adult sufferer, others including parents shared the concern that:

*“It [was] the fear of what can happen [...] in the future that frightens [them]. I have heard you may have mild reactions today, and the next, it can become serious. That’s what makes me feel worried”.* Thoughts of the “unthinkable” happening highlight the potential risk of anaphylaxis, the life threatening condition that can lead to death which studies show is also linked to parental anxiety (see Gillespie et al., 2007; Mandell et al., 2005). While most participants reported using or being recommended antihistamines (e.g. diphenhydramine, cetirizine), strikingly none reported having, using or mentioned an EPI-Pen was recommended. Even though, the first author showcased a prototype, no one recognized it (though some had heard about it) or knew where one could be purchased. Similarly, at the time of data collection, no major pharmaceutical outlets sold EPI-Pens in the country. This is disconcerting given most of the reported symptoms (see table 1b) suggested IgE mediated allergies. Although adrenaline injections are administered in hospitals, the noticeably absence or unavailability of epinephrine auto-injectors (e.g. EPI-pens) will increase the likelihood of mortality for individuals at risk.

As studies of PEH emphasize, health experiences and risk perceptions are embedded in the social context and places within which people live and go about their daily activities (King, 2010). These experiences of frustration and anxiety should therefore not be taken for a given, but interrogated to understand how they are produced and sustained by structural factors beyond the individual – e.g. the role of the local healthcare system as manifested by persistent delays in diagnosis, or lack of EPI-Pens. Of course while their anxiety maybe influenced by the healthcare system, delayed diagnosis may also be a reflection of the apparent lack of resources in hospitals (e.g. diagnostic tools, allergists) which directly affects the ability of health professionals and agencies to effectively respond (King, 2010).

### 3.3 Responding and managing food allergies have social consequences

To date, cure for food allergy remains elusive although allergy immunotherapy is an emerging promising outlet (du-Toit et al., 2015). Avoiding food allergens (Munoz-Furlong, 2003) and use of an epinephrine autoinjector, which reverses, delays or halts the progression to anaphylaxis (Kim et al., 2005) is key to preventing and treating allergic reactions. The experiences of past allergic reactions and knowledge that fatality is possible at any time informs the adoption of several preventive actions including food avoidance, keeping medication, acceptance of allergic status, and educating children about management. These are similar to the findings of studies exploring food allergies preventive or mitigation strategies across multiple social contexts – e.g. home, school, (see Nettleton et al., 2010; Akeson et al., 2007).

In a few instances, mostly adult sufferers still living with parents or staying with relatives/friends, allergenic food was not completely avoided - i.e. food is still prepared or eaten by the non-allergic population at home. In home environments where they were the only ones with an allergy, adult sufferers recognized the need to create a conducive atmosphere by balancing the foods needs of others within the household. Each time an unsafe food is prepared, alternative foods were provided (though not at all times), and separate cooking utensils were used to prevent exposure through cross-contamination. Notwithstanding, exposure due to inhalation (Ramirez and Bahna, 2009, James and Crespo, 2007) is possible as someone indicated: *“when they are cooking or frying fish, the mere smell of it can make me vomit”*. Considering such risks, health workers, individuals and families ought to recognize “the fact that reactions can be triggered by food ingestion, inhalation, and skin contact” (Muraro et al., 2014, p. 1012) so as to adopt strategies that takes account of the diverse pathways to exposure.

In contrast, many participants [n=14] practiced complete avoidance of allergens which often involves “a ban” on cooking, or eating any food(s) suspected to contain the allergen within and outside the home environment. For these individuals, the frightening experience of past allergic episodes, and a commitment to avoid a repeat meant that avoidance was a “non-negotiable” and “absolutely necessary” action as the examples below illustrates:

“Is a no go area, there is no bargaining. It is just non-negotiable [why]. Because, I won't put myself in a situation where anything can happen. I'm the only one who know what it feels like to struggle to breathe, so why would I take the risk” -

“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, mother of allergic boy

Though recognizing that exposure was still possible, they also emphasized that by being vigilant about food sources and consumption, risk could be reduced. By making safety and prevention the primary concern, these coping strategies, particularly avoidance also creates tensions that affects social relations and interactions between affected individuals and the non-allergic population. As food is often the lifeblood in many social situations (e.g. family gatherings, naming ceremonies, weddings) across most societies, food avoidance or a request for accommodation by allergic individuals was often met with disapproval or protest by others. This can be manifested both verbally and non-verbally – e.g. body language - as the case of Charles, a father of girl with multiple allergy illustrates:

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”

As we indicate earlier, for most people, avoidance is a non-negotiable issue and consequently, the unwillingness of others to accommodate or appreciate the food needs places allergic persons

in a position where they have to make decisions around perceived risky environments and (or) maintaining their social relations. While in extreme instances allergic individuals have compromised to eating the food allergen due to social pressure (see Nettleton et al., 2010), for the vast majority, restriction on social events was an appropriate strategy both to prevent allergen exposure and at the same time, preserving social relationships as Serwah, a mother of two girls with allergy recounts:

“If they won’t make or allow some adjustments, why go? It’s better not to go at all than go and spoil relations because some people don’t take this thing seriously”

And for the most part, unlike adult sufferers, parents generally restricted involvement in social activities with allergic children, especially if they could not guarantee children safety.

Consequently, when others are considerate of their needs (e.g. avoiding their allergen or supporting their claims of food allergy), they saw this as an important step towards making them feel welcomed. However, the failure to accommodate these needs can be perceived as a form of social exclusion or discrimination (also see Pitchforth et al., 2011).

A closely related issue is social stigmatization, which is regarded as a social process that can be felt or enacted, and produced through labelling, stereotyping, status loss and exclusion (Dean et al., 2015, Scambler, 2009). Most stories shared reflected examples of “felt” stigma, which describes situations where an individual may internalize experiences of shame, or anxiety of being rejected (Pitchforth et al., 2011, Link and Phelan, 2001). In several cases, parents reported that because some skin symptoms (e.g. rashes, blisters) often leave physical marks on children bodies, they anticipated their children will be mocked, or likely be excluded from their circle of friends potentially impacting their 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, Father of boy with allergy

In few cases, adult sufferers also perceived their food allergy as a misfortune, and sometimes felt angry at themselves (n = 2) and stress (n=1) as Lamisi, a female with fish and peanut allergy recounts: *“I have always wondered, was this bad luck? Why me? If you take my sisters, none of them have it. So sometime I just get sad or angry at myself. Why is it me?”*. Such sentiments were also echoed by a mother who wondered why her daughter could not eat peanut, pineapple and kontombire (vegetable) as others: *“I would be lying if it didn’t bother me. I mean, why can’t [name of child] eat them like other children do. She should be able to eat anything she likes”*. Such frequent self-introspection, and comparison about why others have (or do not have) food restrictions meant they were often drawing a distinction between themselves/children and others whom they considered as *“normal”* or with *“nothing wrong with them”*.

Others also emphasized the experience of being labelled and how this impacted their wellbeing and social life. Both parents and adult sufferers recall being nicknamed because of their or children allergy. By imposing on them new identities (e.g. *“the one who is afraid of fish”*, miss aller), they were being conceptualized by powerful individuals such as uncles, and superiors as different, or even perhaps undesirable (Mukolo et al., 2010), the effect being a feeling of isolation as Mavis, an adult sufferer indicates: *“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 makes me feel alone”*. Like Mavis, many others also reacted to regain control of the loss of self, which often involve social

distancing (including but not limited to self-isolation, or refusing to discuss personal or social matters) of the perpetrator.

“Oh, it was okay at first but when morning, afternoon and evening, all you hear from others is miss aller, miss aller [miss allergic], you just have to do something. And that thing for me was to stop being nice and taking my matters to them” – Sally, female adult sufferer

Interestingly, “enacted” stigma which may comprise blatant discrimination and differentiation, bullying or physical threats because of one’s food allergic status, which characterizes the experience of allergic children in western societies (see Dean et al., 2015; Shemesh et al., 2013) did not emerged as a dominant issue. In one case, a parent witnessed her child being threatened with exposure to an allergen which prompted a reassessment of the risks her child faced.

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, mother of allergic girl

Structurally, many situated these social risks within the larger context of public (mis)representation and misconception of food allergy. Community beliefs that food allergy is “not a serious issue” or is an attribute of social class also fuels stigmatization. This creates uneasiness and discomfort, limiting opportunities to discuss allergic experiences, or disclosing status for fear of being judged:

“Even if we needed it, we won’t ask. We don’t tell people because of how our people think. They tell you “na adi kitowaayi” (but this small thing too). For them, you are overacting or making a big deal from nothing” - Kwame, a father of allergic boy

“They think it’s because we are well to do, I have a luxury of what foods to eat and so because I prefer something else, I am claiming to react to seafood [...]. That always come up and that can make you feel down” – Henry, adult male sufferer

Notable in the last case was others belief that food allergy constitutes a social marker of inequality. Historical analysis suggests (food) allergic diseases were assumed to be a hallmark of affluence – i.e. the educated, the wealthy, even taking on a symbolic value as an indicator of socio-economic progress and advancement (see Smith, 2015, Jackson, 2006). As many other chronic illness (e.g. obesity, diabetes) in SSA are perceived to be social maker of affluence, (Danquah et al., 2013), it perhaps not surprising food allergy is framed in the same light. But to insist that their coping strategy was simply a matter of preference is to implicitly challenge their allergic status which as Henry indicates can have emotional consequences i.e. “...can make [him] feel down”.

### 3.4 Direct and indirect costs associated with food allergy

Studies document that financial costs are an important determinant in the prevention and management of food allergy (Minaker et al., 2014). For example, interventions such as use of epinephrine auto-injectors (EPI-Pens), or even access to allergen free foods can be difficult especially for low income food allergic families (Bilaver et al., 2016; Minaker et al., 2014). Parents and adult sufferers indicated, regular hospital visits and admissions had significant financial implications on household resources. Prior to children diagnosis, several visits to hospitals and consultations with different health workers was made, often “*without getting anything positive about what was wrong*”. As service fees were paid “out of pocket” (e.g. costs from hospital visits, admissions) at each visit, many indicated that their household expenditure increased especially during the initial stages of seeking a diagnosis:

“The expenses began to go up because we were 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, father of allergic boy

As we indicate much earlier, diagnosis is often not straightforward and is further compounded by the lack of diagnostic testing facilities in both public and private health facilities. At the time of data collection, only one laboratory established in 2013 specifically provided a food allergy diagnosis. However, high costs and the knowledge that multiple tests may be needed in order to ascertain allergic status was a major deterrent:

“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, adult male sufferer

As high SES is generally thought to enhance people access to, affordability, and utilization of health services (Quansah et al., 2016), concerns about financial costs were surprising especially given the reported high levels of education and type of employment (see table 1a). However, it became apparent when probed further that their SES (e.g. current employment) did not necessarily translate into higher earnings for most people. As a participant stated “*it is more like a big post, small money thing*”. This disconnect, coupled with other social responsibilities (e.g. financial support to siblings/relatives, funerals) meant that, recurring medical costs were adding to an already overburdened situation. Additionally, the physical location of health facilities and a context of heavy daily traffic often increased time and travel costs in the process of seeking care. Time spent in traffic meant gas frequently ran out, and the continuous purchase was contributing to overall medical costs.

“Most go into fuel and if you take the traffic situation, it doesn’t take long before you 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, father of allergic boy

While the finding that food allergy imposes significant financial costs is consistent with previous studies (see Gupta et al., 2013), the location of health facilities and traffic congestions as a contributor to economic burden is rarely highlighted in the food allergy literature although not

necessarily new in the broader context of barriers to healthcare access in developing countries (Atuoye et al., 2015).

Several studies (Minaker et al., 2014; Peniamina et al., 2014, Lamb et al., 2006) also observe that the burden of food allergy care extends beyond financial costs to other indirect effects such as difficulty obtaining allergenic foods, increased time use, reduced work productivity through absenteeism (absence from work or school) or presenteeism (diminished capacity to work). Our participants also shared stories that revealed indirect burdens of food allergy. For example, they indicated while they were committed to avoiding exposure, the application of their preventive strategies significantly affected their time use, with many spending considerable time planning meals, or ensuring food or its ingredients did not contain allergens before eating or cooking:

“Too much time is spent thinking ahead what should be eaten today, tomorrow, tomorrow next and so forth. We didn’t have to before and it was fine but today, we actually have to sit and plan”- Akosua, mother of boy with multiple allergies

“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, mother of allergic boy

Striking a balance between the needs of allergic and non-allergic members of the household also provides a lens to understand the burden of time use. Adult sufferers faced with the fact allergenic foods are cooked at home ought to find or cook alternative foods. As Mark indicates, “...if mom does not cook something different, I have to prepare something which is simply a waste of my time”. Most were often irked having to cook especially after a tiring day at work or if they were not informed in advance to make an alternative arrangement for food before arriving home.

Beyond the time burden, participants also recounted stories to illustrate the challenge of negotiating a balance between work and managing children's allergy. Like other allergies, food allergy symptoms are often unpredictable and reactions can occur at any time and place. Care and management therefore requires that parents or guardians are readily available to attend to needs of children, which as Timmermans and Freidin (2007) have observed in mothers with asthmatic children can be difficult to combine especially given an inflexible working schedule. In this study, most participants had full-time jobs, the vast majority working in the private sector. Many parents [8 out of 10], irrespective of gender (although mothers frequently stressed the impact on their job) reported frequently having to ask permission to stay away from (or leave) work early in order to take children to the hospital or pick them up from school following an allergic reaction.

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

“There's been times you've just drop him off at school and before you have fully settled in at work, you are rushing out again to take him to the clinic because there's been an incident. From the clinic, what do you do, take him back to school or take him home?” – Kwame, father of allergic boy

Even when parents succeed in finding a place for their children to stay while they work (e.g. taking children along to work, or back to school), children conditions often led to presenteeism, a situation where people are at work yet are unable to perform to their capacity (Widera et al., 2010). As Serwaa demonstrates, the distractions and inability to concentrate on work responsibilities may go beyond the individual and directly affect the productivity of others.

“There are times you are simply not in the right frame; you are distracted at work because it's [reaction] happened again. You are slow and there are little mistakes you don't normally make which sometimes affects the way others work too”

While no one mentioned receiving a reprimand or complaint from their superiors for missing work or leaving work early, they suggested comments such as “*why don’t you try and bring someone from the village*” or “*let your relatives come and help*” meant, it was only a matter of time that the implicit support they enjoyed would seize. Calls to seek support were invariably calls to ensure a balance of the competing demand from parents’ work and child care. Also, while no one indicated a loss in salary due to absenteeism or presenteeism, many especially adult sufferers were worried about both the short and long term consequences on their job security or job promotions. For parents, it was argued that under no circumstances should the safety and wellbeing of their children be a measure to determine their benefits. Children health was just not a choice, but a necessary choice to minimize the risk exposure and hospitalization.

## **Conclusion**

Our core aim has been to paint a picture of perceptions and experience of food allergic individuals and families in a LMIC context. We situate this within a PEH lens to understand the psychosocial, and economic burdens of allergy and how they are shaped by the sociocultural and political setting in Ghana. We argue that anxiety, social exclusion, increased household expenditure associated with food allergy are products of structural forces such as the lack of familiarity and awareness, lack of health system resources, policy guidelines and cultural norms surrounding childcare and raising. A PEH lens therefore draw attention not only to the experience and emotions of individuals, but underscores the ways societal factors shape emerging realities of food allergy in LMICs (King, 2010). While the existing extant studies in SSA attempt to capture prevalence (e.g. Basera et al., 2015, Obeng et al., 2011), to our knowledge, this is the first qualitative study to share some light on how food allergy is shaping

the lives of allergic population. In doing so, we advance scholarship that seek to understand the perspectives of allergic populations and families in a LMIC context (Gallagher et al., 2009).

This study is not without limitations. First, it is restricted to one large urban area, and it is possible these reported experiences may differ in other regions in Ghana. Also, despite our maximum variation sampling strategy (e.g. snowballing, posters, advertisement), the sample mostly reflects those with high SES, and does not capture people with low incomes or education. Capturing this population can enrich our understanding of food allergy experiences in SSA. Also, we do not directly engage children, and subsequent studies can help shed light on their unique experiences as they interact across different scales – siblings, peers, school.

Our results highlight a number of key messages for both policy and future research. Although prevalence data is lacking, our findings suggests food allergies are an important health condition that is impacting health, social and economic well-being of people in Ghana. A particular challenge for the allergic population was the sub-optimal care and lack of service availability, an issue also highlighted in studies of neglected chronic diseases in LMICs (Dotchin et al., 2007). Considering limited diagnostic services, diagnosis is a challenging experience, which may result in anxiety, increase household costs or lead to misdiagnosis. A related challenge is that, health systems in Ghana like many places in SSA are often designed to respond to acute infectious disease. Compounding this is the relative invisibility of chronic illnesses in terms of funding compared to communicable diseases (Dotchin et al., 2007).

Responding to food allergy in part lie in building the evidence on prevalence to help inform policy. While efforts to capture the prevalence of chronic illness is ongoing, food allergy has received little attention. One way is to incorporate standardized self-reported questions in existing national demographic and health surveys to address data gaps (Atiim and Elliott, 2016). Additionally, health promotion programs are needed to raise public awareness (e.g. allergen identification, symptoms) and decision makers could extend existing sensitization campaigns to include food allergy. Increased awareness and knowledge can help to minimize stigmatization and reduce risk of exposure and potentially increase contact with health facilities. Also, as food allergies are particularly common among children, maternal and child care units present a unique opportunity to provide parents with information, and to learn about allergic conditions in children. Beyond Ghana, the findings also has implication for other LMICs – e.g. those in SSA undergoing an epidemiologic transition. This case study and the emerging evidence suggest food allergies have a global reach, and public health officials must heed the message to integrate food allergy into the broader chronic disease prevention agenda in LMICs.

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Table 1a Characteristics of food allergic individuals [n = 22]

Participant ID	Allergic Individual in household				Age of allergic person	Age of diagnosis	Food allergens	Highest educational attainment	Occupation
	Child		Self						
	M	F	M	F					
Akwasi*		X			5	1	Peanut	University	Research
		X			5	1 <sup>1/2</sup>	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, local 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 <sup>**</sup>	University	Student
Sally				X	24	10	Snail, milk, pineapple	College	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 <sup>**</sup> , "cantose" <sup>**</sup>	Vocational	Clerk
Akosua	X				4	2	Milk, eggs, peanut	University	Public relations
Sheila		X			3	1	Kontombire <sup>**</sup> , pineapple	University	Administrator
Suweiba		X			4	2	Peanut, kontombire <sup>**</sup> , pineapple	University	Nursing
Total	12		10						

\* Families with more than one food allergic children

<sup>\*\*</sup> Local foods [kontombire, and cantose are vegetables]

**Table 1b** Summaries of food allergy characteristics of individuals [n = 22]

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

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**Highlights**

- Food allergies are a global health problem linked to the epidemiologic transition
- Explores experiences of living with food allergies in Sub-Saharan Africa (SSA)
- Impacts psychosocial, and economic wellbeing of the allergic population in Ghana
- Need to contextualized lived experiences within the sociocultural environment
- Incorporate allergy into the broader chronic disease prevention agenda in SSA.