**living with multimorbidity in ghana: A QUALITATIVE STUDY GUIDED BY THE CUMULATIVE COMPLEXITY MODEL**

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## Abstract

Defined as the co-occurrence of more than two chronic conditions, multimorbidity has been described as a significant health-care problem: a trend linked to a rise in non-communicable disease and an ageing population. Evidence on the experiences of living with multimorbidity in middle-income countries (MICs) is limited. In higher income countries (HICs), multimorbidity has a complex impact on health outcomes, including functional status, disability and quality of life, complexity of healthcare and burden of treatment. This study aimed to explore the perceptions and experiences of women living with multimorbidity in the Greater Accra region, Ghana: to understand the complexity of their health needs due to multimorbidity, and to document how the health system responded.Guided by the cumulative complexity model, and using stratified purposive sampling, 20 in-depth interviews were conducted across three polyclinics in the Greater Accra region. The data was analysed using the six phases of Thematic Analysis. Overall four themes emerged: 1) the influences on their health experience; 2) seeking care and the responsiveness of the healthcare system; 3) how patients manage healthcare demands; and 4) outcomes due to health. Spirituality and the stigmatisation caused by specific conditions, such as HIV, impacted their overall health experience. Women depended on the care and treatment provided through the healthcare system despite inconsistent coverage and a lack of choice thereof; although their experiences varied by chronic condition. Women depended on their family and community to offset the financial burden of treatment costs, which was exacerbated by having many conditions.The implications are that integrated health and social support, such as streamlining procedures and professional training on managing complexity, will benefit and reduce the burden of multimorbidity experienced by patients with multimorbidity in Ghana.

**Research highlights**

* Stigmitising conditions, such as HIV, were particularly salient in the interviews.
* Women valued biomedical care.
* Healthcare was often focused on one condition to the exclusion of others.
* Inconsistent health service coverage places a high financial burden on patients and families.

**Keywords**
multimorbidity; subjective experiences; Ghana; healthcare system; chronic disease; cumulative complexity model; national health insurance scheme;

## Introduction

Ghana has a population of approximately 26 million and is classified as a lower middle income country with a per capita Gross Domestic Product of 1642 USD (World Bank, 2017) . In recent decades, the country has witnessed improved health outcomes, most notably in the area of maternal and child health. The leading causes of death have now shifted away from communicable towards chronic non-communicable diseases (de-Graft Aikins et al., 2010). Improved public health, living conditions, and the availability of health services, are among the factors contributing towards increased life expectancy. (McKeownT et al., 1962; Seeman and Crimmins, 2001).

Multimorbidity, the *simultaneous occurrence of two or more chronic conditions within an individual*, is common amongst older populations (Fortin et al., 2012). The co-occurrence of disease is attributed to a variety of factors; shared risks, the ageing process, and complications related to existing disease (Valderas et al., 2009). Over their life-course, individuals are increasingly exposed to factors that affect health, resulting in the accumulation of risk over time. With age, the human body is also subjected to wear and tear which, at increasing levels, lead to disease occurrence. In a study conducted in a large county in the US, the incidence of multimorbidity was 6.5/1000 person-years amongst 0-19 years olds versus 260/1000 for those aged 80 and above (St Sauver et al., 2015). Multimorbidity therefore increases with age and commonly, in higher income countries, with poorer socio-economic status (Barnett et al., 2012). Such socioeconomic gradients also exists in middle income countries (MICs), where multimorbidity is not uncommon (Afshar et al., 2015). Evidence in MICs also show that multimorbidity is occurring earlier in adulthood, compared to HICs. In a study conducted at an inner city clinic in Accra, Ghana, where the prevalence of multimorbidity was 38.8%, almost half of patients attending the outpatient clinic with multimorbidity were aged between 18–59 years old (Nimako BA et al., 2013). In the same study, multimorbidity was most common amongst unskilled workers and amongst women, compared to men; suggesting that unskilled women represent a vulnerable population.

Knowledge on the subjective experiences associated with multimorbidity can improve healthcare development by providing a patient-informed approach. However, studies describing the subjective experiences of patients living with multimorbidity have only been conducted in higher income countries. This body of literature asserts the importance of an individual’s social environment within their lived experiences of multimorbidity. Factors related to the social environment include their family, community and health care systems. Studies report differences in the way individuals describe their symptoms and prioritise their illnesses. Patients commonly experience concerns around a loss of independence. One study conducted in the Netherlands concluded that the management of multimorbidity needs to focus on *individualisation*: to adapt to personal circumstances and retain independence as an ultimate goal (Luijks et al., 2012). A recent study conducted in Canada identified a number of health system barriers affecting the management of individuals with multimorbidity. Such challenges included the lack of coordination of health services and chronic disease management (Gill et al., 2014). In Germany, limitations in time have meant that primary care doctors prioritise diseases that affect prognosis, and defer other problems for later consultations (Hansen H et al., 2015). The dismissal of symptoms by healthcare providers has also been explained by the limitations of contextual pressures, such as the way in which the health system is organised (Bower P et al., 2011). Non-adherence to treatment has also been attributed, in the USA, to side effects and costs (Elliott RA et al., 2007). Rising costs continues to be a major issue, particularly for patients who have to pay out of pocket for treatment, as opposed to those who can access treatment free from the point of delivery (e.g. through insurance or taxation).

Current national policy and clinical practice guidelines, however, are often orientated towards single disease (Barnett K et al., 2012). Such findings have important ramifications for policy development, healthcare organisation and clinical practice. Given the lack of data in MICs, this study seeks to understand whether patient experiences are consistent with those found in the literature. The study aims to explore the perceptions and experiences of women living with multimorbidity in the Greater Accra region of Ghana. Specifically, to explore how women deal describe their illnesses and health needs; how they deal with their competing health needs; and how well the health system responds to such needs.

## **Materials and methods**

### Study Setting: The Greater Accra Region Health Directorate

The Greater Accra Region, with the highest population density in Ghana, is predominantly urban. The Greater Accra Region Health Directorate provides healthcare services across six Health Administrative Districts, including the Accra Metropolis, Tema Municipality, Ga West, Ga East, Dangme East and Dangme West.

Under the National Health Insurance Scheme (NHIS), individuals aged 70 and above, children under 18 whose parents are enrolled, the core poor, and pregnant women, can access certain healthcare services without point of service payment. (Dixon J et al., 2011). The NHIS replaced the earlier ‘cash and carry’ system which required point of service fees in 2003, with the main aim of achieving more universal health coverage. Beneficiaries are given cards that enable them to receive treatment in any hospital managed under the Health Directorates, including access to outpatient services, inpatient services, oral health, maternal care and emergencies. Financing of the healthcare system is classified as progressive in Ghana, as groups with a higher income contribute a higher percentage of their income compared to groups with a lower income (Mills A et al., 2012). The bulk of the costs of the NHIS are paid from sales taxes and other taxes rather than from the monthly subscription fees (National Health Insurance Authority, 2013). Despite the move towards universal health coverage, however, the NHIS excludes a number of health services that deal with chronic disease, including the detection and treatment of cardiovascular diseases and some cancers.

### Experiencing multimorbidity: conceptual framework

The cumulative complexity model (CCM) used here is a framework that extends previous work on illness experience whilst considering the complexity of multiple illnesses (Shippee ND et al., 2012). The main topics included in the interview guide therefore explore the notion of *patient capacity* and *treatment workload*. As outlined in the model, patient workload encompasses all the demands in the patient’s life, including their daily responsibilities, whereas patient capacity encompasses the resources that affect the patient’s ability, such as their economic situation, and physical or mental functioning. Specifically, the topic guide explores how both capacity and workload are influenced by the presence of two or more chronic conditions. Whilst being developed to understand the UK context the CCM has not considered, in much detail, the influence of culture and belief. In a recent study on living with diabetes in Ghana, biomedical goals were ‘undermined by traditional notions and structures of illness management.’ (de Graft Aikens A, 2003) Therefore, for the purposes of this study, the CCM was adapted to incorporate factors related to belief systems (see Figure 1).

Between May and September 2015, in-depth interviews were conducted across two polyclinics in Greater Accra. Polyclinics are primary care centres based across Ghana. Each polyclinic serves the local population and run diabetes, hypertension, HIV/AIDS and mental health clinics weekly. One polyclinic, the Shai OsuDoku district hospital, is located in *Dodowa*, with a local population estimated at around 100,000. Given its proximity to the capital Accra, parts of Dodowa were defined as *peri-urban*, as they form the interface between the urban outskirts of the capital city and the rural countryside. The second polyclinic, named Maamobi Polyclinic, is based in the Accra Metropolis – an *urban* area –in the Accra Metropolis.

### Sampling

Based on feasibility and costs, up to 25 participants were to be recruited. Stratified purposive sampling was applied to allow for comparison, and was based on two characteristics of interest: residence (urban, peri-urban and rural) and education (less than secondary, secondary and above) (Patton MQ, 2001). These characteristics were based on a prior recognition that multimorbidity and health care use may vary according to where the individual lives and their level of education (Wang H et al., 2014). Furthermore, as age trends show that women are affected by multimorbidity earlier in adulthood, a broad age range was chosen, selecting 35 years as the minimum age to ensure that pregnancy was not an included factor. Participants recruited for the study included women seeking treatment and/or care who had at least two chronic conditions. Chronic disease was defined as a condition that had lasted a year or more and had required ongoing medical attention (Warshaw G, 2006). The eligibility criteria included females: living with two or more chronic conditions; aged between 35-75 years and; who were permanently residing in rural, urban or peri-urban areas. Women were excluded if they were unable to communicate easily due to disability or illness or were pregnant.

The clinic nurses identified eligible patients and acted as ‘gatekeepers’ to the patients, gaining access to patient files (Ritchie et al., 2014). During the clinic times, patients were approached in person by the research team. Outside clinic hours, the clinical files were consulted to check for eligible patients, and nurses consented to contact them by phone. Eligibility checking took place mostly from the diabetes clinic, hypertension clinic, HIV clinic and mental health clinics; at each polyclinic.

**Interview Protocol**

The main languages spoken by the patients at the polyclinics were English, Ewe, Ga, Gadangme, Hausa and Twi. All interviews were carried out by one of the authors, along with one of three research assistants, whose primary responsibility was translation during the recruitment and interview stages. In-depth interviews were chosen as the appropriate method of data collection as they are effective at exploring a participant’s views, experiences and beliefs in detail (Bryman A, 2012). A semi structured interview guide was developed based on the conceptual framework, which had both structure and flexibility, so that the order in which the topics were discussed followed a natural course. The interview guide included topics related to the patient’s capacity and workload. These included: background information about the individual; perceptions related to their ill health, such as their ability to do everyday activities; if, and how, living with more than one condition leads to competing interests and how they cope; self-care; support-networks; and how they interact with the healthcare system, such as getting to appointments or organising time off work. All interviews took place in a private location without any outside disturbances. Some participants preferred to be interviewed in their home, whereas some participants were willing to meet at the polyclinic. Consent was required from each participant before the start of the interview. Due to illiteracy amongst some study participants, the consent form was spoken out loud to all participants. All interviews were later transcribed directly into English by a transcriber. Direct translation involved translating directly from the local spoken dialect into written English. As the languages are primarily spoken languages, it is more common to use their spoken form rather than their written form.

To ensure the quality of evidence, the research was conducted in line with the four main criteria as proposed by Guba (Guba EG and Lincoln YS, 1994). First, to address *credibility*, several provisions were made; for example negative case analysis was undertaken to look for patterns that contradicted patterns in the dataset, research notes were conducted to evaluate the effectiveness of the research techniques employed, and several transcripts were second-coded by CE. Second, to ensure *transferability*, information about the contextual environment was written up as field notes. Third, to ensure *dependability,* the processes of the study were comprehensively reported. Finally, to ensure *confirmability*, an audit trail was developed and a reflexive summary was written.

 **Data Analysis**

The transcripts were exported into NVivo version 10, a qualitative data management software package. Using the thematic approach outlined by Braun and Clark, a six phase process was undertaken; in which patterns were identified, analysed and reported within the dataset (Braune V and Clarke V, 2006). During Phase 1, the anonymised transcripts were read several times and initial thoughts and queries that emerged whilst reading the transcripts were noted. During Phase 2, portions of the text were labelled as initial codes. During Phase 3, initial codes were generated and the codes were clustered into groups. The next phase, Phase 4, involved reviewing the initial themes to ensure that they formed a cohesive pattern at two levels: the first level checked the themes worked in relation to the coded extracts, and the second level involved checking the themes across the entire dataset. A thematic map was then produced. Phase 5 involved naming and defining the themes. The final Phase 6 involved refining the names and definitions, which meant searching for key factors or processes that accounted for patterns of association in the data and arriving at the most logical inference. Several transcripts were second coded to ensure that the codes were directly informed by the data, and to prevent premature theme formation, enhancing the credibility of the research.

## Results

 A total of 20 participants were successfully interviewed during the time available for data collection. Twelve (60 %) participants were recruited from an urban area, five (25%) participants were recruited from a peri-urban area and three (15%) participants were recruited from a rural area. The mean age was 55.6 years; 54.0 years; and 52.7 years, respectively. The presence of HIV was most common amongst women less than 55 years old; whereas the co-occurrence of diabetes and osteoarthritis was particularly common amongst women 55 years and older. Shizophrenia, although rare (2 out of 20 participants), was present at both a younger age (38 years old) and an older age (63 years old) within the participant group. By contrast, hypertension affected approximately half of the participants across all ages. The presence of three or more conditions (versus two only) was more common amongst those older than 55 years and older (7 out of 9 participants) but not uncommon for those aged less than 55 years (4 out of 11 participants).

Very few women attending the Maamobi polyclinic had secondary school education or above so to ensure that women of a higher education were represented, a third recruitment site, Legon Hospital in the Accra metropolitain area, was added and all the required permissions were sought. In total five women who were educated to secondary school education, and above, were interviewed. Four themes were apparent from the dataset: a visual depiction on how they relate to the individual and the healthcare system is shown as Figure 2. The links between sub-themes (of the major themes) have been represented in a network view in Figure 3.

### The influences on their health experience

‘Influences’ have been used to describethe underlying context of an individual’s experience of ill health. Here the influences can be ascribed to the participants’ self or “internal world,” such as to their emotions and spirituality, or those that relate to events or people in the participants’ “external world” or environment. Spirituality has been used here to describe matters that relate to their belief in a higher being rather than the participant’s interaction with a religious group. These influences are akin to those broadly described in the CCM as the social and psychological aspects that may influence a patient’s capacity (See Figure 1).

Spirituality consistently emerged as a factor even amongst those with different socio-economic characteristics. Many participants, particularly those who suffered from potentially life-threatening illnesses such as HIV and diabetes, expressed gratitude to God and spoke of their faith. When discussing why they became ill, two women even attributed the disease to ‘spiritual causes.’

*I sometimes dream of my first husband trying to have sexual relationship with me. I have been to several prayer camps and am being told the same story that the man who appears in my dream is the cause of my diseases so I believe it’s spiritual…’* ***(S.U. Respondent with diabetes and HIV. Lives in urban area 66 years old.)***

Participants with HIV, in particular, discussed the stigmatisation they had suffered on account of their illness:

*“At first I was worried but now I am use to it. Around last year December it really worried me and I even left my community but still I have the courage to stay there whether they point finger at me or not I will still stay there.”* ***(R.T. Respondent with HIV and osteoarthritis. Lives in urban area. 46 years old.)***

There was also congruity in these influences, between those living in urban areas or rural areas; and equally, those of lower education or higher education. Everyday interactions with their family, community and work-place, as well as the constructs belonging to these groups, played an important role in their health experiences; regardless of their age, residence or level of education. Some women discussed the use of herbal medicine bought from the church or local vendors. Although it was not a common belief across women, a few women learnt that *‘leaves’* were able to help their illnesses. Ten participants were currently, or had previously used, herbal medicines. A couple of participants purchased herbal medicines from local sellers and either used them instead of, or at the same time as, the treatment regime prescribed by their doctor,

 *“The one who was selling the herbs told me that I should stop taking the orthodox medications and take only the herbs so I stopped taking the orthodox medications.”* ***(L.S. Respondent with diabetes, heart disease and musculo-skeletal pain. Lives in urban area. 52 years old.)***

By contrast, two participants took quite a pessimistic view on the herbal medicines, as conveyed by the following quote,

*“I don’t really trust alternative medicine so I stick to the hospital and aside that it’s not advisable to mix orthodox medicine with her herbal medicine.* ***(W.W. Respondent with asthma, hypertension, diabetes, schizophrenia. Lives in rural area. 63 years old.)***

### Seeking care and the responsiveness of the healthcare system

The second theme examined the participants’ motivations for seeking healthcare from a health facility; and the way in which the healthcare responded to, or satisfied, the needs and choice of the patients.

Here some beliefs and preconceptions about ill health were discussed. Interestingly, a powerful narrative emerged relating ill health to superstitious beliefs or values,

*‘Sometimes if someone falls sick the person starts thinking it’s a witch, not for me I went to the hospital when I was told what was wrong with me.’ (M.N.* ***Respondent with diabetes, heart pain and arthritis. Lives in rural area. 52 years old.)***

Despite this underlying belief for some women, all participants chose to access healthcare. Three participants explicitly mentioned following the advice and opinion of others, such as family members; or those from their social network,

*‘I went to him and he (traditional healer) told me that I had diabetes and my sister advised that, if that is the case, then I should go to the polyclinic for proper medical care.’ (S.T.* ***Respondent with asthma and diabetes. Lives in urban area. 50 years old.)***

These findings also suggest that the community valued modern medicine, and that these values may supersede the traditional views that underpin traditional healing.

Twelve participants reported visiting a health facility on account of their symptoms. The symptoms included coughing severely, growing lean, urinating very often, feeling faint, and having severe pains. In most cases the symptoms disrupted their everyday life, and presented a matter of urgency.

 *“I was always feeling sleepy most of the times and I have been to the hospital several times to report on it. Most of the times too, I urinate very often and I was advised to go the hospital.”* ***(W.V. Respondent with HIV and TB. Lives in urban area. 53 years old.)***

Four women, however, felt that the health system did not respond to their entire needs, and focused on one condition rather than the other(s). These women felt they lacked choice, and often did not receive the required care or treatment for all their conditions,

 *‘When your leg is paining you, they should have patience and treat that one too but they tend to focus more on the diabetes and hypertension more than the leg.’ (****Y.S. Participant with diabetes, hypertension and osteoarthritis. Lives in a peri-urban area. 65 years old.)***

The same participant later described how she was unable to get adequate care for her chronic arthritis and suggests that patients should be referred for further care if the same doctor cannot treat all conditions. This finding highlights a lack of choice in healthcare and, in particular, that patients often did not receive the required care for all their conditions, which was a common finding across the women.

### How patients manage healthcare demands

This theme captures how the women deal with the *demands*, or requirements, placed on them by the healthcare system; in order to manage their illnesses. Women varied in their ability to manage both their treatment, and their hospital visits. Here the contextual factors, described in the first theme, influenced how women adhered to treatment, and how they were able to honour their appointments. For example, six women describing gaining financial support from their family, which meant they could purchase certain treatments not covered by their health insurance,

 *‘There was a time that a medication was prescribed for me and that costs GH¢150.00. It was my sister’s child who gave me money to purchase that medicine.’* ***(L.S. Participant with diabetes, heart disease and musculoskeletal pain. Lives in urban area. 52 years old.)***

By contrast, a few women described not buying treatment as they were unable to afford it. To avoid not taking treatment altogether, they only took the treatment that was freely available under the health insurance scheme,

 ‘*The money really affects me. This was the medication I use to buy but I have stopped buying that because I can’t afford that now. I told the doctor that I do not have money so when he/she prescribes that, I do not buy it. That particular drug too would help with my heart condition and the health insurance doesn’t cover that medication. I buy these ones because the health insurance covers them.’* ***(L.S. Participant with diabetes, heart disease and musculoskeletal pain. Lives in urban area. 52 years old.)***

Even for drugs covered by the national insurance scheme, two women described not being able to get them due to medication shortages. The medication would frequently be out of stock at the pharmacy,

*‘The medication shouldn’t get out of stock or finish so that one alone wants me to be consistent so that my condition does not worsen.’* ***(K.Y. Participant with HIV, asthma and hypertension. Lives in rural area. 43 years old.)***

There were several factors that influenced whether a participant decided to take treatment for a particular condition: whether the prescription was easily obtained by the doctor, the treatment was available on their health insurance scheme, the treatment was in stock, and whether they had the financial means to purchase treatment. Therefore for women with co-occurring illnesses, the risk was that one of their conditions would be left untreated if they were unable to purchase the medication themselves,

 *‘When I came here the only thing they did for me was to give me a note that I go do a test for them to know the severity of the diabetes, but I was told nothing about the HIV, but when they read the report from the other hospital they decide to give me drugs so I can take, even that I was told they did not have the drugs so I was given prescription to go and buy from the drug store so that later I can come for the drugs, but today I have been given drugs for diabetes.’* ***(S.S. Patient with diabetes and HIV. Lives in rural area. 36 years old.)***

These quotes summarise the difficulties in obtaining treatment, which was common to all women regardless of age, residence, and education. There were no consistent patterns on which conditions could be treated continuously, although some heart disease and HIV medication were reported as unavailable. Furthermore, it highlights the inevitable financial difficulties for those are unable to pay, particularly those who were not able to work. Several women depended on family members to purchase their medication, whereas a couple of women reported asking their pastors for help. A couple of women also avoided a particular drug altogether if they were unable to afford it. Clearly some women were unable to meet the demands of the health system with regards to their treatment.

The process for scheduling appointments during clinic days was the same for all women. Most of the scheduled appointment times were set for specific clinic days, where care was provided for one of their conditions. This meant that they would often attend multiple appointments; and different clinic days for each of their conditions. During their visit a follow-up appointment was scheduled by the doctor. The date and time was written down for the patient,

 *‘They write it for me. I have a book for that and I give it to my child for keeps.’* ***(S.T. Respondent with asthma and diabetes. Lives in urban area. 50 years old.)***

This quote also illustrates the support given by family members regarding their ill health, and visits to the doctor. Family support was also essential for those needing financial assistance to travel to, and from, their appointments:

 ‘*It worries me if I have to walk here. If my brother’s son sends me money, I pick a taxi here. I also feel that I am supposed to come and see the doctor so I force to come and see the doctor once every month.’* ***(T.N. Respondent with hypertension, diabetes and osteoarthritis. Lives in urban area. 63 years old.)***

There was a noted difference regarding getting to appointments; between women who were employed in the formal and informal sector, such as street trading: the latter had a comparatively lower educational background. Three women were educated at secondary school level or above, and employed within the formal sectors, for example, as school teachers or clerical staff. One woman expressed the difficulty she experienced in getting to her appointments, due to responsibilities within the workplace, as conveyed by the following quote:

 *“Formally it was about three appointments, I was going here two times in month then I go here once but this time like yesterday that was the second month, two months it was only yesterday, the other month I asked permission, then I didn’t go again until yesterday .. this time we have KG1 (class) and KG2 so when am not there am in KG2 they ask the KG1 to combine the class”* ***(T.Q. Respondent with hypertension, diabetes, glaucoma and lumbar spondylitis. Lives in rural area. 59 years old.)***

### Outcomes due to ill health

Throughout the interviews, all participants expressed how their ill health had impacted their daily lives. As they discussed their illness, it was common for women to relate their ill health to their ability to perform everyday tasks. Twelve women reported an improvement in their symptoms on account of seeking healthcare, and taking the prescribed treatment. Improved symptoms encouraged them to continue taking the prescribed medication and to visit the health facility,

 *‘When I came here, the symptoms that I use to get all stopped so I saw the need to continue to seek treatment.’* ***(T.A. Participant with HIV and osteoarthritis. Lives in urban area. 48 years old.)***

As a consequence of their ill health, four women described a loss of independence related to work. Compared to other women, they were younger and engaged in work as part of their daily lives,

*‘Yes it does, you know to smoke fish you need energy, but now I can’t get that kind of energy... This disease has entered my bones so I can’t work anymore, I would have to hire people to smoke the fish for me.* ***(M.N. Participant with diabetes, heart pain and arthritis. Lives in rural area. 52 years old. )***

This quote also highlights their dependence on others to continue work. The idea of a ‘loss of independence’ is apparent for some, but not all women. A few older women, who were no longer working, continued to remain independent, and described continuing their activities as before. One woman recognised that she had to rely on her for family for certain activities, but not for others,

 *‘I do, but who will do all for me if I don’t do them. If I get tired, I sit and rest and call people to get/bring me things as and when I want. I have the assumption that if you sit and do nothing, the conditions would become worse. So I do my chores little by little.’* ***(A.B. Participant with diabetes and osteoarthritis. Lives in urban area. 65 years old.)***

This participant states *‘...but who will do all for me if I don’t do them.’* Here she is referring to tasks such as bathing and dressing. It was unclear whether she was unwilling to ask others for help or whether she simply did not have anyone to help her in this regard. She further explained that the activity she endures whilst doing her chores will help her condition. This was also discussed by other older retired women, who tried to pursue physical activity in order to improve their health, in spite of the symptoms that she suffered.

Some women experienced a change in how much they were able to do socially. One woman described how her social activities were restricted because of their finances; a few others felt that they were unable to take part in social activities on account of their ill health, as this quote illustrates:

 *‘I am not able to go to church on Sundays because when you are well, you do not feel like going anywhere. Most programmes that I am invited to, I can’t go because most of these invitations comes in at the time that I am unwell.’ (****L.S.******Participant with diabetes, heart disease and musculoskeletal pain. Lives in urban area. 52 years old.)***

When asked about the limitations to their daily activities, women often attributed their limitations to the ‘pain’ they felt. For this respondent, she could not relate the feeling of pain to a particular condition, but were sometimes able to locate the sensation,

*‘If my heart is not paining me, I am able to do everything but when it is paining me, then I can’t do anything. It would be like a year since I stopped doing household chores.’* ***(L.S. Participant with diabetes, heart disease and musculoskeletal pain. Lives in urban area. 52 years old. )***

The majority of women experienced some financial difficulties in the face of healthcare costs. When discussing their financial problems, it was apparent that this was a cause of stress. A few women broke down in tears. One woman described her very vulnerable financial situation, which not only meant that they struggled with healthcare costs, but that they could not even buy the basic necessities, such as food. She also did not receive much financial support from her family

 ‘..*as for that one my child, eating is even difficult for us. …The time that I am supposed to eat, I don’t get food to eat…. It is only the boys who support me a little. It is almost one year since I got paralyzed and none of them have called on phone to find out how I am doing. If I don’t call them, then I would not hear from them. They are all into businesses but they do not mind me, let alone to support me financially.'* ***(W.V. Participant with HIV and TB. Lives in urban area. 53 years old.)***

It was evident that many women felt pressured to keep up with their treatment regimes, and purchase the prescribed medication. The financial burden placed on women as a result of their ill health has also limited their ability to continue their daily-life, as before they were ill. A few women described the impact this has had on their social lives,

*‘my movement has become difficult because when I am going to church now I need to pick a taxi which is very expensive so I am not able to go to places I would have love to go.’* ***(Y.S. Participant with diabetes, hypertension and arthritis. Lives in peri-urban area. 65 years old.)***

As described above, the participant was unable to take public transport due to her restrictions in movement. She had no other choice but to take a taxi, but even then, she was unable to afford it. This conveys the lack of choice women face on account of their ill health and their financial implications.

## Discussion

To our knowledge, this is the first qualitative study to explore the subjective experiences of living with multimorbidity in a middle income country, and to explore how women deal describe their illnesses and health needs; how they deal with their competing health needs; and how well the health system responds to such needs. Several interesting findings emerged from the study, which are dicussed in more detail here.

### The influence of stigmatisation due to HIV on individual capacity

For women with HIV, their community and environment seemed to had an important influence on their health experience and their decision-making. As specified in their conceptual model, Holzemer and colleagues describe a stigmitisation process that is dependent upon ‘agent’ (such as people, workplace and community), ‘healthcare system’ and ‘environment’ (such as culture, economics and politics) (Holzemer WL et al., 2007). Stigmitisation of HIV is a known phenomenon in Ghana, and encompasses the three domains described in this model (Ulasi CI et al., 2009). These findings undoubtedly emphasise the complexity of disease burden which, for some, is shaped by social perceptions and behaviours. For women with HIV, a greater emphasis was placed on their stigmatising condition over and above their other comorbidities. Women were motivated to seek proper biomedical healthcare. This is consistent with the literature, which suggests that most participants seek biomedical care in the first instance. The decision to seek biomedical care is related to the public legimitisation of health causes, which supersedes the lesser causation models offered by spiritual healers (de-Graft Aikins A, 2005). Some women, however, attributed their ill health to spiritual causes despite the health education they received at the clinic. Such findings highlight the nature of belief, and its influence on women, and in particular, links to their overall *capacity* to manage their illnesses. Stigmitisation and spirituality are shown to play a significant role in influencing their health experience and individual capacity. In this respect, the cumulative complexity model should ascribe more value to the underlying mechanisms that influence an individual’s capacity; extending to their interactions with their community, and the events or people around them.

### The lack of choice in healthcare provision and its influence on workload

Consistent with the literature, the discussion of symptoms with the family, as well as how the women perceived their symptoms, was an important trigger to healthcare seeking (Brittain K et al., 2001; Smith LK et al., 2005; Danso-Appiah A et al., 2010). However, even when under the health insurance scheme, women felt that they lacked choice in the care given and that they did not receive the required care for all their conditions. The focus on individual disease management, rather than a holistic approach, is common across health systems in HICs, and is understood to be related to the expansion of specialised services (Gill A et al., 2014). On the one hand individual disease management promotes efficiency and continuity of care, for example, through the scheduling of subsequent follow-up appointments; on the other hand it may result in the neglect of other comorbidities not being discussed at clinic. In relation to the cumulative complexity model, the patient’s workload may be skewed towards a particular condition which, in turn, results in further limitations of the neglected condition(s) and the patient’s capacity by affecting their symptom burden. To attain a balance between patient’s workload and capacity, the healthcare system should respond to, and address, the needs of all symptoms and diseases within an individual.

Women lacked choice in their healthcare, and were also unable to choose their appointment times. As a result of this, they had to fit their other responsibilities around appointment times, even for just one of their conditions. This resulted in an increase in their *workload* which, for women with limited capacity, presented key challenges. Despite this, all women expressed a need to honour their appointments and, at times, appeared to be almost fearful of what would happen if they did not. For women who were in full-time employment, affording less flexibility, they had no option but to take their appointments and risk the consequences in the work-place. These findings reinforce the idea that the health system procedures are bereft of ‘patient-centredness’, which is consistent with findings from a study examining health system barriers in maternal health in Ghana (Ganle JK et al., 2016).

### The financial burden and loss of independence

For women in the Greater Accra region, there was an evident reliance on the healthcare system, although this was met by inconsistent coverage under the national health insurance. Despite the availability of a health insurance package, the majority of women experienced a financial burden related to meeting their health care demands, and were dependent on family and community members to offset this. There were inconsistencies in the provision and accessibility of treatment under the national health insurance scheme. Some women reported accessing free treatment easily; some reported not being able to get treatment without paying; and some reported treatment shortages, which meant that they were unable to access treatment which would otherwise be freely available. This was true regardless of age, residence, and socio-economic background. In Ghana, treatment for some chronic diseases are covered under the national health insurance scheme, whereas others have been excluded from coverage. However it was not possible to determine which treatments (and for which conditions) were continously available and in stock; this finding merits further investigation. Clearly lack of coverage for some treatment was a deterrent to being insured. The issues faced through lack of coverage resulted in a complex scenario for women with multimorbidity. Overall, for such women, there was an apparent risk was that one of their conditions would be left untreated if they were unable to purchase the medication themselves. As described in the cumulative complexity model, an individual’s capacity is dependent on the amount, controllability and extensiveness of their financial ability (Shippee ND et al., 2012). This, in turn, influences their access, utilisation and ability to self-care which, in turn, influences their health outcomes. The ability to finance health care is therefore an integral part of the cumulative complexity model when applied to the situational context in Accra.

Participants commonly expressed how their ill health had impacted their daily lives. Consistent with other studies, preserved autonomy, or ‘independence,’ was an important factor for women (Löffler C et al., 2012) regardless of their age, education and residence. Limitations in their daily activities were often described in relation to their symptoms. Those who were able to manage and treat their symptoms, through consistent use of healthcare and treatment, were able to reduce their symptom burden which, in turn, affected their ability to continue daily life as before. Pain was often described as the most difficult symptom, which is consistent with other study findings on multimorbidity (Duguay C et al., 2014). Therefore morbidities that resulted in pain (e.g. chronic arthritis), when not managed, were more limiting than conditions, which were currently being managed or resulted in milder symptoms.

To summarise, the findings from this study suggest that both psychological domains (belief, values) as well as social (family support and finances) are integral to patient’s experiences of multimorbidity, and have an influence on both *workload*: an example is the organisational support from family to make appointments; as well as *capacity*: an example is the financial and psychological support offered from members of the church community. Future iterations of the cumulative complexity model, particularly for application in MICs, should therefore seek to examine in greater detail the psychosocial mechanisms that influence both the capacity and workload of patients with multimorbidity.

###  Strengths and Limitations

The experiences of women living with multimorbidity is under-studied, particularly amongst women residing in MICs. This qualitative study was therefore a useful opportunity to explore the experiences of women in Ghana, a middle income country in West Africa. The sampling methods considered both their type of residence and their level of education. There were, however, some limitations in how well the stratified purposive sampling strategy was achieved. The initial sampling strategy attempted to recruit, in equal measure, women from both higher education relative to their context. However, few women were of the higher education category and resided in rural areas, making a comparative analysis difficult to achieve. Despite this, the attempts to ensure maximum variation in sampling were made by recruiting across several clinics within the recruitment sites, and by using a relatively wide age range. It is not possible to generalise to the national popuation from the qualitative findings but they do give an indication of the nature of women’s experiences, which may be transferable to other settings. A further limitation is that women were recruited from outpatient clinics, and therefore: excluded women who do not attend, or rarely attend, healthcare centres; and included conditions currently detected and treated within the primary care system. Finally, no men were sampled and interviewed as this was beyond the scope of the study. Further qualitative work to explore mens’ experiences is therefore necessary.

## Implications

As the first qualitative study of its kind, this study provides novel insights into the experiences of women living with multimorbidity in the Greater Accra region. The limited and inconsistent coverage of chronic disease treatment under the national health insurance scheme may be a barrier to achieving holistic care, and will continue to place a considerable financial burden on women and their families. Pain was also considered to be the biggest contributor to social loss, and a lack of independence. The implications are that improvements in social welfare coverage, including access to facilities and care support (such as home nursing, physiotherapy and income support), are necessary to promote independence and reduce the treatment burden on families. In light of these findings MICs, particularly in Sub-Saharan Africa, would benefit from an integrated system for health and social care that minimises disruption, and improve both coordination and efficiency. Such an integrated system does not even exist within many high income countries. Therefore policymakers in MICs should consider avoiding the simple replication of what has been done in developed countries, and seek to develop a more novel, efficient approach to health and social care that responds directly to the needs of a multimorbid population.

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**Ethical Approval**

Ethical approval was granted on the 27th May 2015 (Protocol ID NO: GHS-ERC 06/05/15) by the Ghana Health Services Ethical Committee; and granted by the University of Southampton, Faculty of Medicine Research Ethics Committee on the 5th May 2015 (ID: 14535). Before commencing research, approval letters were sought from the Regional Health Director and the District Health Directors for the Ghana Health Services. Informed consent was obtained from each participant before interview.

**Conflicts of interest**

The authors have no conflicts of interest to declare.

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## References

Afshar S, Roderick PJ, Kowal P, Dimitrov BD and Hill AG (2015) Multimorbidity and the inequalities of global ageing: a cross-sectional study of 28 countries using the World Health Surveys. *BMC Public Health* **15,** 776.

Barnett K, Mercer SW, Norbury N, Watt G, Wyke S, and Guthrie, B (2012) Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *Lancet* **380.**

Bower P, Macdonald W, Harkness E, Gask L, Kendrick T, and Valderas JM (2011) Multimorbidity, service organization and clinical decision making in primary care: a qualitative study. *Journal of Family Practice* **28.**

Braune V and Clarke V (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* **3:** 77-101.

Brittain K, Perry S and Williams K (2001) Triggers that prompt people with urinary symptoms to seek help. *British Journal of Nursing* **10,** 74-6, 78, 80 passim.

Bryman A (2011) Interviewing in qualitative research. In *Bryman, A (eds) Social Research Methods.* Oxford: OUP.

Danso-Appiah A, Stolk WA, Bosompem KM, Otchere J, Looman CW, Habbema JD and De Vlas SJ. (2010) Health seeking behaviour and utilization of health facilities for schistosomiasis-related symptoms in Ghana. *PLoS Neglected Tropical Diseases* **4,** e867.

De-Graft Aikins A (2003) Living with Diabetes inRural and Urban Ghana: A CriticalSocial Psychological Examination of Illness Action and Scope for Intervention. *Journal of Health Psychology* **8(5)** 557–572; 035258.

De-Graft Aikins A (2005) Healer shopping in Africa: new evidence from rural–urban qualitative study of Ghanaian diabetes experiences. *BMJ* **331.** 737.

De-Graft Aikins A, Unwin N, Agyemang C, Allotey P, Campbell C and Arhinful D (2010) Tackling Africa's chronic disease burden: from the local to the global. *Globalization and Health.* **6,** 5.

Dixon J, Tenkorang EY and Luginaah I (2011) Ghana's National Health Insurance Scheme: helping the poor or leaving them behind? *Environment and Central Planning: Government and Policy,* **29,** 1102-115.

Duguay C, Gallagher F and Fortin M (2014) The experience of adults with multimorbidity: a qualitative study. *Journal of comorbidity* **4,** 11.

Elliott RA, Ross-Degnan D, Adams AS, Safran DG and Soumerai SB (2007) Strategies for coping in a complex world: adherence behavior among older adults with chronic illness. *Journal of General Interal Medicine* **22,** 805-10.

Fortin M, Stewart M, Poitras ME, Almirall J and Maddocks H (2012) A systematic review of prevalence studies on multimorbidity: toward a more uniform methodology. *Annuals of Family Medicine* **10,** 142-51.

Ganle JK, Fitzpatrick R, Otupiri E and Parker M (2016) Addressing health system barriers to access to and use of skilled delivery services: perspectives from Ghana. *The International Journal of Health Planning and Management,* **31,** e235-e253.

Gill A, Kuluski K, Jaakkimainen L, Naganathan G, Upshur R and Wodchis WP (2014) "Where do we go from here?" Health system frustrations expressed by patients with multimorbidity, their caregivers and family physicians. *Healthcare Policy* **9** 73-89.

Guba EG and Lincoln YS (eds) (1994) *Competing paradigms in qualitative research.* London, Sage.

Hansen H, Phontsch N, Van Den Bussche H, Scherer M and Schafer I (2015) Reasons for disagreement regarding illnesses between older patients with multimorbidity and their GPs – a qualitative study. *BMC Family Practice* **16,** 1-12.

Holzemer WL, Uys L, Makoae L, Stewart A, Phetlhu R, Dlamini PS, Greeff M, Kohi TW, Chirwa M, Cuca Y and Niadoo J (2007) A conceptual model of HIV/AIDS stigma from five African countries. *Journal Advanced Nursing* **58,** 541-51.

Loffler C, Kaduszkiewicz H, Stolzenbach CO, Streich W, Fuchs A, Van Den Bussche H, Stolper F and Altiner A (2012) Coping with multimorbidity in old age – a qualitative study. *BMC Family Practice* **13,** 1-8.

Luijks HD, Loeffen MJW, Lagro-Janssen AL, Weel C, Lucassen PL and Schermer TR (2012) GPs’ considerations in multimorbidity management: a qualitative study. *British Journal of General Practice* **62**.

McKeown T, Record RG (1962) Reasons for the decline in mortality in England and Wales during the nineteenth century. *Journal of Population Studies* ***16:****94-122.*

Mills A, Ataguba JE, Borghi J, Garshong B, Makawia S, Mtei G, Harris B, Macha J, Meheus F and McIntyre D (2012) Equity in financing and use of health care in Ghana, South Africa, and Tanzania: implications for paths to universal coverage *The Lancet* **380,** 126-133.

National Health Insurance Authority (2013): National Health Insurance Authority Annual Report. Accra, Ghana.

Nimako BA, Baiden F, Sackey SO and Binka F (2013) Multimorbidity and chronic diseases among adult patients presenting to an inner-city clinic in Ghana. *Globalisation and Health* **9**:61

Patton MQ (2001) *Qualitative evaluation and research methods,* Newbury Park, CA: Sage Publications.

Ritchie J, Lewis J, Nicholls CM and Ormston R (eds) (2014) *Qualitative research practice : a guide for social science students and researchers*.

Seeman TE and Crimmins E (2001) Social Environment Effects on Health and Aging. *Annals of the New York Academy of Sciences* **954,** 88-117.

Shippee ND, Shah ND, May CR, Mair FS and Montori VM (2012) Cumulative complexity: a functional, patient-centered model of patient complexity can improve research and practice. *Journal of Clinical Epidemiology.* **65(10)**:1041-51.

Smith LK, Pope C and Botha JL (2005) Patients' help-seeking experiences and delay in cancer presentation: a qualitative synthesis. *Lancet* **366,** 825-31.

St Sauver JL, Boyd CM, Grossardt BR, Bobo WV, Rutten LJF, Roger VL, Ebbert JO, Therneau TM, Yawn BP and Rocca WA (2015) Risk of developing multimorbidity across all ages in an historical cohort study: differences by sex and ethnicity. *BMJ Open* **5.**

Ulasi CI, Preko PO, Baidoo JA, Bayard B, Ehiri JE, Jolly CM and Jolly PE (2009) HIV/AIDS-related stigma in Kumasi, Ghana. *Health & Place* **15:1,** 255-262.

Valderas JM, Starfield B, Sibbald B, Salisbury C and Roland M (2009) Defining comorbidity: implications for understanding health and health services. *Annals of Family Medicine* **7,** 357-63.

Wang H, Wang JJ, Wong SYS, Wong MS, Jian F, Wang PI, Zhou ZH, Zhu CY, Griffiths SM and Mercer S (2014) Epidemiology of multimorbidity in China and implications for the healthcare system: cross-sectional survey among 162,464 community household residents in southern China. *BMC Medicine* ***12:****188*

Warshaw G (2006) Introduction: advances and challenges in care of older people with chronic illness. *Generations* ***3****: 5-10*

World Bank (2017) National accounts data and OECD National Accounts data files. Accessed online via: <https://data.worldbank.org/indicator/NY.GDP.MKTP.CD>

**Table 1: The full details of each patient, their social and demographic characte****ristics; and chronic conditions** (n=20)

|  |  |
| --- | --- |
|   | **Residence** |
| **Demographic Characteristics** | **Urban**  | **Peri-urban** | **Rural**  |
| **Total number of participants** | 12 | 5 | 3 |
| **Mean Age ± standard deviation** | 55.6 ± 10.0 | 54.0 ± 11.1 | 52.7 ± 10.0 |
| **Mean Household members**  | 4 | 5.8 | 5 |
| **Mean Chronic conditions**  | 2.3 | 2.8 | 4 |
| **Employment status** |  |  |   |
|  Number in full time employment | 4 | 5 | 1 |
|  Number in part time employment | 2 | 0 | 0 |
|  Number unemployed | 6 | 0 | 2 |
| **Education** |  |  |   |
|  Number with below secondary  | 9 | 4 | 2 |
|  Number with secondary and above | 3 | 1 | 1 |
| **Religion** |  |  |   |
|  Number of Christian religion  | 8 | 5 | 3 |
|  Number of Muslim religion  | 4 | 0 | 0 |
| **Marital Status** |  |  |   |
|  Number Married | 5 | 2 | 2 |
|  Number Separated | 2 | 0 | 0 |
|  Number Widowed | 5 | 3 | 1 |

Figure 1 The ‘cumulative complexity’ conceptual framework for study

(Adapted from Shippee et al to include uniquely identifying realms within ‘patient workload’ and ‘patient capacity’ relevant to both a local and international context – highlighted in red)

Figure 2. Major themes associated with women’s experiences living with multimorbidity

Figure shows the interaction between the individual and the health system

**Figure 3. The links between sub-themes. A network view.**

Figure shows the links between within sub-themes related to the broader themes depicted in Figure 2.