


RESEARCH ARTICLE

Building cardiovascular disease competence in an urban poor Ghanaian community: A social psychology of participation approach

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Abstract

This paper describes conceptual, methodological, and practical insights from a longitudinal social psychological project that aims to build cardiovascular disease (CVD) competence in a poor community in Accra, Ghana's capital. Informed by a social psychology of participation approach, mixed method data included qualitative interviews and household surveys from over 500 community members, including people living with diabetes, hypertension, and stroke, their caregivers, health care providers, and GIS mapping of pluralistic health systems, food vending sites, bars, and physical activity spaces. Data analysis was informed by the diagnosis-psychosocial intervention-reflexivity framework proposed by Guareschi and Jovchelovitch. The community had a high prevalence of CVD and risk factors, and CVD knowledge was cognitive polyphasic. The environment was obesogenic, alcohol promoting, and medically pluralistic. These factors shaped CVD experiences and eclectic treatment seeking behaviours. Psychosocial interventions included establishing a self-help group and community screening and education. Applying the "AIDS-competent communities" model proposed by Campbell and colleagues,

we outline the psychosocial features of CVD competence that are relatively easy to implement, albeit with funds and labour, and those that are difficult. We offer a reflexive analysis of four challenges that future activities will address: social protection, increasing men's participation, connecting national health policy to community needs, and sustaining the project.

KEYWORDS

cardiovascular disease, community health competence, Ghana, participation, task shifting, urban poverty

1 | INTRODUCTION

The global burden of chronic physical and mental illnesses is disproportionately carried by the world's poorest communities. In a recent analysis of the global burden of disease data, Bukhman, Mocumbi, and Horton (2015) observed that chronic non-communicable diseases (NCDs) and injuries (NCDIs) "are responsible for a substantial proportion of the suffering and death endured by the poorest populations" (p. 1221), accounting for more than a third of their disease burden and disproportionately affecting individuals younger than 40. Poverty is a powerful driver and consequence of health inequalities (CSDH, 2008). Chronic disease, for example, can draw individuals and families "into a downward spiral of worsening disease and poverty" (WHO, 2005). Poor communities affected by diseases, also experience health disadvantage at multiple stages, from beliefs about health and illness, social responses to health care access and use (Capewell & Graham, 2010).

The complex social determinants of health, and unequal health care outcomes, for poor communities pose critical challenges for health promotion. One popular approach has emphasised the need to educate and empower communities affected by multiple disease burdens to recognise and understand their public health challenges in order to minimise their health risks and manage their conditions more effectively. However, the dominant approach in health promotion, that privileges individual determinants of ill health and socio-cognitive models of health education and lifestyle change, is particularly inadequate for such settings (Clarke, 2014; Campbell and Murray, 2004).

A second approach emphasises the importance of community participation in health promotion and health care for disadvantaged communities. Community participation, community empowerment, and community engagement are viewed as important approaches to addressing the complex health and developmental needs of poor communities and to reduce health inequalities imposed by structural and geopolitical factors.

Community-based initiatives have been developed in marginalised and poor communities in low and middle income countries (LMICs) of Africa, Latin America, and Asia, as well as poor communities in high income countries in Europe and North America to address wide ranging health problems, including infectious diseases, cardiovascular disease, obesity, and mental health disorders (Campbell & Burgess, 2012; van de Vijver, Oti, Addo, de Graft-Aikins, & Agyemang, 2012; Wagemakers, Vaandrager, Koelen, Saan, & Leeuwis, 2010). Projects are informed by a variety of concepts, methods, and practices depending on the health problem, disciplinary ideology, context, and resources available.

In this paper, we describe a community participation project on cardiovascular disease care in Ga Mashie, a poor community in Ghana's capital, Accra. The project, which began in 2010, aims to build CVD competence in the community by blending a "social psychology of participation" approach with best practice global health models on NCD control. We describe the conceptual, methodological and practical insights and consider the lessons the Ga Mashie

project provide for other urban poor African communities affected by NCDs with minimal community and health systems resources.

2 | CONCEPTUAL FRAMEWORK

We applied the social psychology of participation framework proposed by Campbell and Jovchelovitch (2000) and developed in their respective projects in South Africa (e.g., Campbell, 2003; Campbell et al., 2007) and Brazil (e.g., Guareschi & Jovchelovitch, 2004; Jovchelovitch & Priego-Hernandez, 2013). The framework synthesises various approaches proposed by social psychologists working within the critical community psychology tradition, in ways that clarify theory, method, and practice, as well as the role of context in building theory and advancing the field.

2.1 | Social psychology of participation: A framework for community health development

The “social psychology of participation” framework aims to examine the complex drivers and consequences of health inequalities in marginalised communities (Campbell & Jovchelovitch, 2000). Campbell and Jovchelovitch emphasised the importance of examining the individual-social interface, in order to integrate individual, inter-individual, and macro-social levels of analyses in community-based work. The authors outlined three social psychological features essential to understanding community in participation:

1. An identity through which the community conceived of, and articulated, itself. This identity was typically heterogeneous and therefore informed complex ways of being, relating, and knowing in social life.
2. A set of social representations, or local systems of everyday knowledge, which underpinned the community's worldview and mediated its interpretation of social reality and everyday practices. Social representations, like identity, were heterogeneous and “cognitive polyphasic” (defined as the “tendency to employ diverse and even opposite ways of thinking” in everyday life; Moscovici, 2008, p. 245).
3. Power, in terms of conditions and constraints of access to material (e.g., money) and symbolic (e.g., respect) resources. Bourdieu's (1986) notion of social capital and Paulo Freire's (1973) concept of conscientisation were viewed as central to understanding the structure and contestation of power within communities.

Reporting on projects in Brazil and Southern Africa, Campbell and Jovchelovitch offered practical approaches to guide the development, implementation, and evaluation of community participation projects.

Guareschi and Jovchelovitch (2004) reported on community-based work in Porto Alegre, Brazil that led to the development of a framework involving three interlinked foci, which operated both conceptually and empirically: diagnosis, (psychosocial) intervention and critical reflexivity. Diagnosis aimed to identify the three essential social psychological features—identity, social representations, power—of a community with health needs. Psychosocial intervention aimed to produce “productive alliances” between different social actors with divergent knowledge, experiences, expertise, and status. These productive alliances then facilitated exchange and transformation of knowledge, experience, and action between the social actors. Finally, critical reflexivity facilitated critical engagement with communities in need. The task of critical reflexivity was to engage with social reality as “a field of open possibilities” and to identify alternative possibilities that transformed reality.

Campbell's community-based work on HIV/AIDS intervention and advocacy in Southern Africa centred on building “AIDS-competent communities” (e.g., Campbell, 2003; Campbell et al., 2007). Reporting on one rural project, Campbell et al. (2007) offered a model for developing psychosocial interventions that aimed for long-term sustainability and social change under conditions of poverty and structural neglect. They described six interacting psychosocial features of AIDS-competent communities: (a) building knowledge and basic skills; (b) creating social spaces for dialogue and critical thinking; (c) promoting a sense of local ownership of the problem and incentives for action;

(d) emphasising community strengths and resources; (e) mobilising existing formal and informal local networks; and (f) building partnerships between marginalised communities and more powerful outside actors and agencies, locally, nationally, and internationally.

2.2 | Intersections between the social psychology of participation framework and global best practice models on NCD control

At the heart of the social psychology of participation framework is the focus on theorising the individual-society interface through multi-level analysis. This provides conceptual and methodological points of convergence with global health models of NCD control. To cite two prominent examples, the WHO (2005) proposed a multi-level multifaceted intervention approach, and the UN High Level Meeting on NCDs (UN, 2011) proposed a “whole of government, whole of society approach.” Both approaches pay attention to the epidemiological and economic challenges facing LMIC health systems and the social determinants of NCDs, and they place emphasis on interventions that operate at individual, community and structural levels.

We developed a conceptual framework that synthesised the social psychology of participation framework with the global health models of NCD control (see Figure 1). Guareschi and Jovchelovitch's (2004) diagnosis—psychosocial intervention—critical reflexivity foci informed the overarching framework. Within this we synthesised concepts and models as follows:

1. In diagnosing the social reality of CVD in Ga Mashie, we focused on the three features of a community in participation: identity, social representations, power.
2. In developing psychosocial interventions we applied the six features of community health competence to our conceptualisation of “community CVD competence.” For the 5th and 6th features which focused on “productive alliances” between community actors and external local, national and international actors and agencies, we explicitly focused on the key actors identified as important for NCD control at the individual (e.g., pharmacological interventions), community (e.g., mass media and advocacy organisations) and structural (e.g., policy, industry) levels, paying attention to specific needs in African contexts (de-Graft Aikins, Boynton, & Atanga, 2010).
3. We viewed critical reflexivity as a fundamental process of conscientisation informing all stages of the project, for the research team and research participants. Practically this involved systematic recording and team discussion of community engagement, and actively exploring, with community members, a range of possibilities for transforming the social reality of CVD in the community.

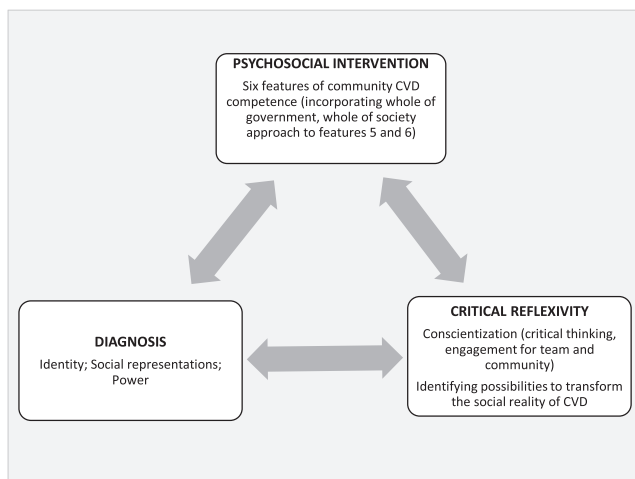


FIGURE 1 Conceptual framework for the Ga Mashie CVD Project

3 | METHODS

3.1 | The Ga Mashie CVD project: Background

Ga Mashie consists of twin towns, Jamestown and Usshertown, which are two of the oldest communities in Ghana's capital Accra. The area they occupy, along the Atlantic coast, is referred to as Old Accra because both communities existed before Accra became the nation's capital in 1877. For multidisciplinary scholars of Accra, Ga Mashie became urban, global and multicultural long before other parts of Accra and the Gold Coast/Ghana (Quayson, 2014).

Ga Mashie is a study of contrasts. It has a vibrant history of arts, popular culture and political activism. It is situated in prime real estate, surrounded by the Central Business District, Houses of Parliament, various government ministries, and Ghana's first and premier teaching hospital, the Korle-Bu Teaching Hospital. It has received a succession of development funds and assistance from international and local non-governmental organisations (NGOs),

TABLE 1 Research questions and concepts applied to the Ga Mashie CVD Project

| The three interlinked foci | | Research questions | Concepts |
|----------------------------|---------------------------|---|--|
| Critical reflexivity | Diagnosis | How did people with diabetes, hypertension, and stroke, their significant others, lay healthy individuals, and health professionals make sense of these conditions? What were the sources, contents and functions of their knowledge? | Social representations (Moscovici, 1988), cognitive polyphasia (Moscovici, 2008) |
| | | How were diabetes, hypertension, and stroke experienced, and how were these experiences interpreted by significant others, community members and health professionals? | Biographical theories: biographical disruption (Bury, 1982), biographical flow (Faircloth, Boylstein, Rittman, Young, & Gubrium, 2004), biographical transformation (Reeve, Lloyd-Williams, Payne, & Dowrick, 2010) |
| | | What illness practices did individuals adopt and what were their goals? How were illness practices influenced by significant others, friends and strangers, and by the resources offered by pluralistic health care systems? | Illness action (Dingwall, cited in de-Graft Aikins, 2005), social capital (Bourdieu, 1986; Campbell & Jovchelovitch, 2000) |
| | Psychosocial intervention | How could CVD care and knowledge be improved using existing local resources, as well as external (national and international) resources? | Six psychosocial features of community health competence (Campbell et al., 2007), productive alliances (Guareschi & Jovchelovitch, 2004), "multi-level multifaceted interventions" (WHO, 2005)/"whole of government whole of society" (UN, 2011), social capital (Bourdieu, 1986; cited by Campbell & Jovchelovitch, 2000), conscientisation (Freire, 1973, cited by Campbell & Jovchelovitch, 2000) |

including being earmarked for urban regeneration through the millennium cities project (MCI, 2015). Yet Ga Mashie is one of the poorest and most densely populated non-slum communities in Ghana. The most recent national census survey in 2010 recorded a population size of 44,361, occupying an area of 242 acres. About three quarters of the population have received Junior High School, or middle school, education and higher. The main economic activities are fishing and petty trading. The average monthly household income, in 2010, was GHC126.13 (\$78.83), which placed the community in the fourth and lowest income class within the Accra Metropolitan Area (AMA-UN-HABITAT, 2011). Like other urban poor African communities, Ga Mashie faces a “double jeopardy” of infectious and chronic conditions with serious health and development consequences (Agyei-Mensah & de-Graft Aikins, 2010). Despite being surrounded by wealth and social amenities, community members have limited access to education, employment and formal (biomedical) health services.

In 2010, the Regional Institute for Population Studies (RIPS), University of Ghana, secured a competitive grant to establish a demographic research site in Ga Mashie and the neighbouring Agbobloshie, a multi-ethnic migrant community. The RIPS Urban Health and Poverty project aimed to study inequalities in health and welfare of the community, and to sensitise local and regional stakeholders on urban poverty and health issues. The first author began an interview study on diabetes experiences with a group of women, with the aim of following their lives over time to examine coping and care strategies and to develop small scale psychological interventions. Over subsequent years the project developed into a larger mixed method study on diabetes, hypertension, and stroke with over 500 community members. Although the project has been social psychological in conceptual and interpretive approach, the team has been multidisciplinary and has included medical, public health and pharmacy researchers, graduate students in population studies, social policy studies and social psychology, and undergraduate students in pharmacy.

3.2 | Research Questions and Methods

The research questions and concepts guiding the project over time are summarised in Table 1. Table 2 describes the research methods and target social groups and social spaces. The project used the WHO definition of CVD: a group

TABLE 2 Research methods and target social groups and social spaces for the diagnostic phase of the project

| Methods ^a | Social groups; social spaces (<i>number where appropriate</i>) |
|--|---|
| Interviews | People with diabetes, people with hypertension, people with a stroke history, caregivers of people with diabetes/hypertension/stroke, pluralistic health care providers (including religious leaders; <i>N</i> = 115) |
| Focus group discussions | People with diabetes (and comorbidities), lay community members (<i>N</i> = 100) |
| Observations | Food joints; drinking spots; shops; pluralistic health centres (and itinerant versions); communal areas (e.g., streets, football park, beachfront; <i>over 200 concrete social spaces</i>) |
| Surveys (CVD knowledge scale) | Households; churches; mosque; pluralistic health care providers (<i>n</i> =251) |
| Blood pressure, Body-Mass Index, Blood glucose measurements | Lay community members (including people with diabetes, hypertension and other chronic conditions; <i>N</i> = approximately 1000 across two measurement periods) |
| GIS mapping | Food joints; drinking spots; shops; pluralistic health services (clinics, pharmacies, churches, mosques, traditional shrines) |
| Household Surveys (RIPS UPHS Project; incorporating CVD knowledge scale; Kessler scale; food knowledge and attitude questions) | Households: 497 households, 736 individuals (Edulink Round 1, June 2010); 806 households, 947 individuals (Round 2, December 2011); 664 households, 782 individuals (Round 3, September 2013) |

^aData were gathered between 2010 and June 2018. Some interviews, observations, and mapping exercises were repeated across this period.

of disorders of the heart and blood vessels, which include coronary heart disease and cerebrovascular disease. CVD is associated with heart attacks and strokes which are typically caused by the presence of a combination of risk factors including unhealthy diet and obesity, physical inactivity, harmful use of alcohol, tobacco use, hypertension, diabetes and hyperlipidaemia. We focused on three major conditions affecting the community (hypertension, diabetes, stroke) and the five cross-cutting risk factors (unhealthy diet, overweight/obesity, physical inactivity, harmful use of alcohol, and tobacco use). We also focused on psychosocial stress and social anxiety, as both are increasingly viewed as risk factors for chronic conditions, particularly for disadvantaged communities.

4 | RESULTS

4.1 | Diagnosing the social reality of CVD

4.1.1 | Objective reality of CVD in Ga Mashie

Ga Mashie has a high prevalence of hypertension and diabetes and their risk factors. Our measurements of blood pressure, BMI, and blood glucose levels showed that hypertension prevalence was 28.3% (women at 25.6%, men at 31%), overweight/obesity prevalence rates were just over 30% (with higher rates among women than among men), and diabetes prevalence was 5% (with men at 3.8% and women at 5.5%; Awuah, Anarfi, Agyemang, Ogedegbe, & de-Graft Aikins, 2014). These rates were comparable with the national prevalence rates for hypertension (25–48%), obesity (15.3 among women), and diabetes (6–9%; Awuah et al., 2014).

Structurally the community is obesogenic and alcohol promoting (see Figures 2 and 3). In our GIS mapping of food vending spaces we identified 228 food joints. Just under half of the joints ($N = 103$) sold a blend of healthy and unhealthy foods including processed foods high in sugar, salt and fat, as well as traditional and contemporary foods

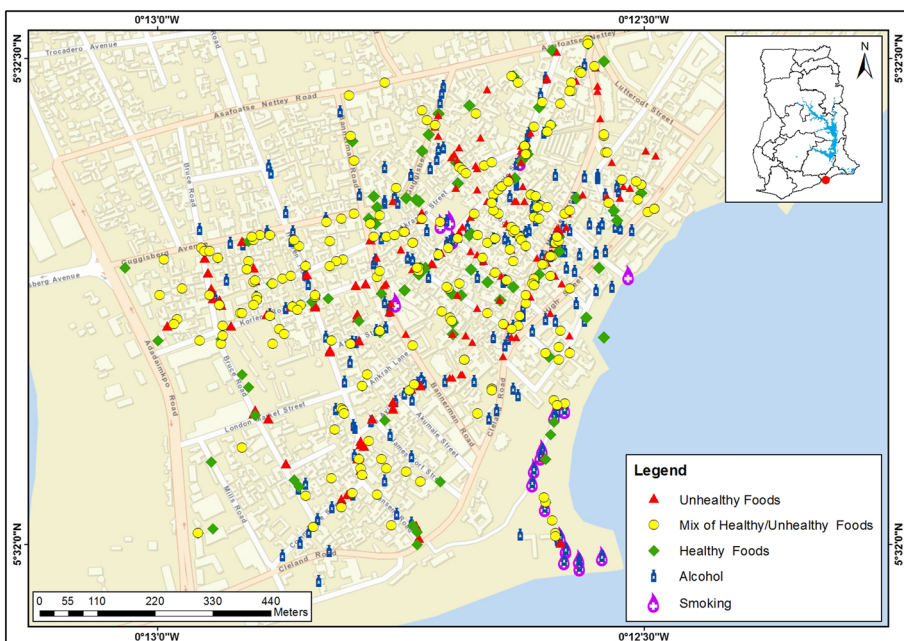


FIGURE 2 Map of the community showing food vending sites and drinking spots

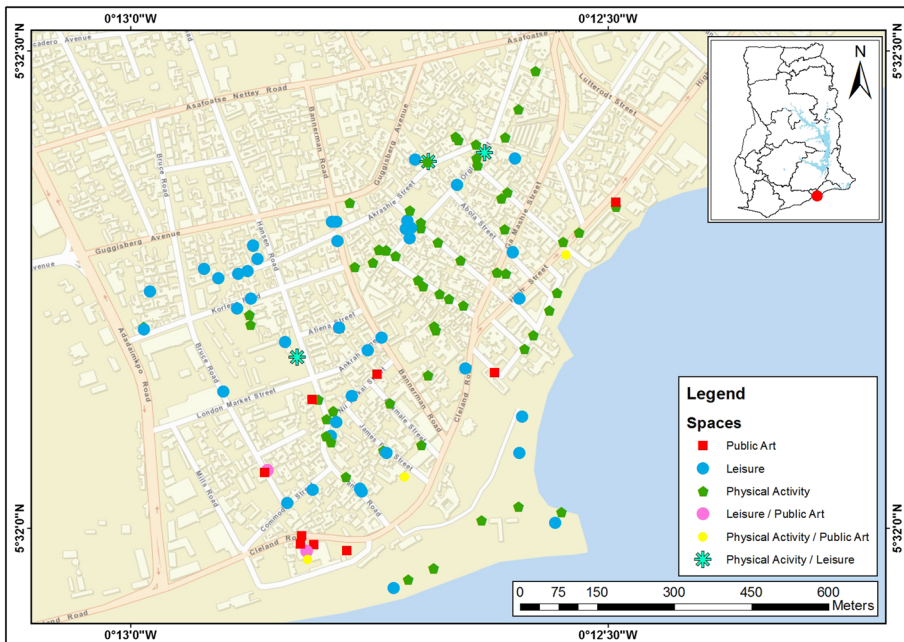


FIGURE 3 Map of the community showing physical activity and leisure spaces

fried in oils of poor quality; 71 spots sold healthy foods (of which 23 were fruit stands), and 54 sold unhealthy foods (see Figure 2). In our GIS mapping of drinking, smoking, and associated lifestyle spaces, we recorded 174 drinking spots (see Figure 2). The majority of drinking spots sold hard liquor, including local alcoholic bitters (which blend high content alcohol with herbs and spices, and sometimes pharmaceutical drugs that aid male virility); about a quarter sold tobacco products, and most opened their doors for almost 24 hr of trade for a largely male clientele. Only two spots sold fruit juices. The GIS mapping exercises involved walking along every community street, including walkways between compound houses—this exercise highlighted the severe lack of appropriate spaces for physical activity for the community (see Figure 3).

4.1.2 | Subjective reality of CVD

We focus on knowledge, experience, and treatment practices relating to CVD in Ga Mashie.

Community knowledge of CVD

There was general awareness of diabetes, hypertension, and stroke as growing health problems in the community (de-Graft Aikins, Awuah, et al., 2014; de-Graft Aikins, Kushitor, et al., 2014). People with diabetes, hypertension, and stroke, their caregivers and lay community members attributed the three conditions to multiple causes: physical, psychological, socio-behavioural, structural, environmental and supernatural/spiritual (see Appendix A on the perspectives of people living with the three conditions). Knowledge was cognitive polyphasic. All groups of participants drew their knowledge from eclectic sources including family members, health care providers, churches and church communities and the mass media. People with diabetes, hypertension, and stroke also drew on “body-self-knowledge” to explain why they got their condition and/or complications of their condition (de-Graft Aikins et al, 2014b, Sanuade, Doodoo, Koram, & de-Graft Aikins, 2019). Representations were rooted in lived embodied experiences that

had been reflected upon over time, and often with significant others. The content of knowledge varied in depth and accuracy depending on one's proximity to lived experience of the conditions. There was near consensus on legitimate sources of knowledge: doctors and other biomedical professionals were perceived as the most legitimate; traditional and alternative medical professionals were perceived as powerful and efficacious but with questionable diagnostic and treatment practices; and the information coming from family and social sources was perceived as double-edged (well-meaning but potentially harmful).

Many lay participants had low CVD risk perceptions, despite the objective reality of high overweight/obesity, diabetes and hypertension rates, and a social awareness that their social environment was obesogenic and alcohol promoting.

Our examination of community health worker knowledge using the CVD scale, and interviews with herbalists and faith healers, showed that health care providers lacked fundamental knowledge on CVD risk, prevention, control, and treatment (de-Graft Aikins et al 2014a). For example, there was poor knowledge on diabetes as a risk factor for heart disease, the relationship between family history and individual risk of heart disease, and the need for individuals with hypertension to use blood pressure medicine for life. The scope and quality of knowledge differed across the different categories of health workers, with longer serving health workers, like community health nurses, gaining the highest total knowledge score.

Experiences of CVD

Medical sociologists have offered useful concepts to examine the complex impact of long-term illness on individual biographies. Theorists suggest that chronic illness can disrupt the physical body and the life trajectory of the sufferer: Bury (1982) introduced the concept of "biographical disruption" to describe this process. Chronic illness can also slot into the normal flow of life of the sufferer: Reeve et al. (2010) refer to this as "biographical flow." Finally, chronic illness can lead to "biographical transformation" (Charmaz, 1983), a transformation of one's life. These are not universal or linear processes, however. As Martin and Sturmberg (2008, p. 571) observe long-term illness forces attention on "chronicity," a trajectory "with simple and complicated, complex and chaotic phases, through long term asymptomatic disease to bodily dysfunction and illness." This trajectory is "located in" and shared with specific "family and communities." There are "good days and bad days" (Charmaz, 1983), and individuals can experience flow, disruption and transformation in complex ways.

Experiences of diabetes and hypertension in Ga Mashie were shaped by biographical disruption and biographical flow; stroke experiences were shaped largely by biographical disruption. The disruption affected five key domains of everyday life: physical (minor and major complications), psychological (worry, anxiety, depression), spiritual (attributions, crises of faith), social (stigma) and financial (prohibitive cost of care). These disruptions were particularly intense and protracted for people who had financial struggles, limited social support, experiences of stigma, and those living with comorbid and multi-morbid conditions, such as hypertension, post-stroke complications and prostate problems.

Biographical flow occurred for a number of people who understood their conditions were chronic and needed to be managed, and who also expected "good days and bad days" (Charmaz, 1983) with their condition. Three key markers of good management were medical adherence, a healthy diet and healthy family and social relationships.

Disruption and flow were psychosocial conditions shared by caregivers also. Disruptive elements were shaped by the impact of illness and the resulting demands (psychological, physical) of care giving. They were also shaped by the tensions arising from spiritual causal theories of diabetes and the psychosocial and financial difficulties of long-term diabetes management. For example, for some people with diabetes and hypertension, family members were viewed negatively as people who caused illness and illness complications through sorcery, witchcraft, social undermining and abandonment. As illness progressed and cost of care increased the risk of family estrangement increased. Family support and caregiving were crucial to the chronically ill, but both could be double-edged and required careful management as illness progressed.

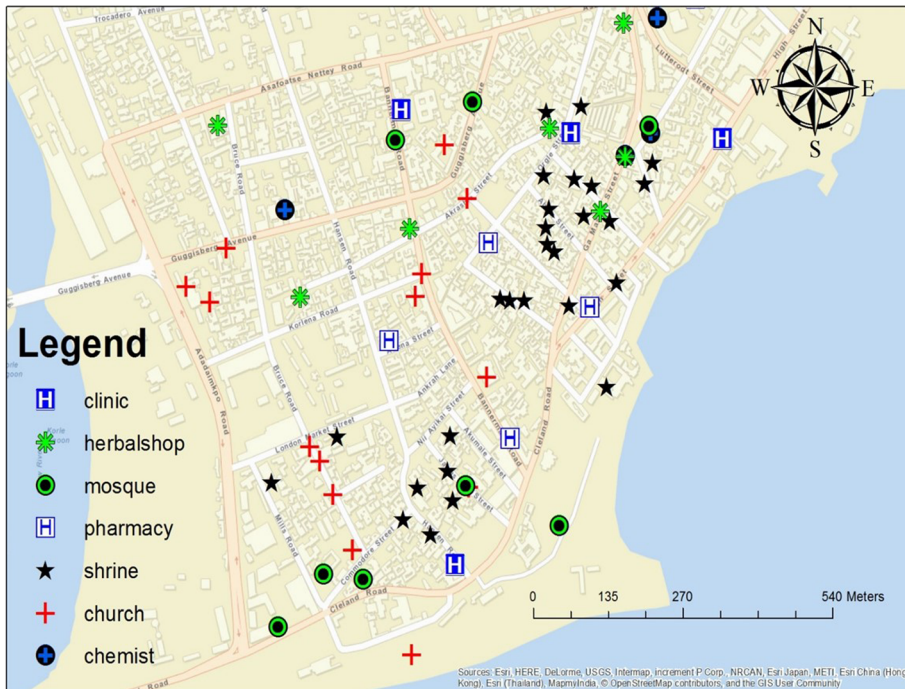


FIGURE 4 Map of pluralistic health systems in Ga Mashie

CVD illness action/treatment practices

Treatment and care behaviours were shaped by multiple factors, including the disruptive impact of the conditions, the shifting quality of subjective and inter-subjective experiences, and the availability of pluralistic health systems. Figure 4 shows the spatial distribution of pluralistic health services in Ga Mashie.

There were 66 facilities: one polyclinic, three private clinics, four private pharmacies, three chemical shops, 13 churches, eight mosques, and 27 traditional shrines. Of these, only one facility was government owned. Individuals used most of these centres, and they also sought treatment from other parts of Accra and beyond. The complex experiences and treatment seeking practices highlighted the need for nuanced forms of support from the family, community, faith-based, health systems and broader policy environments.

4.2 | Developing psychosocial interventions

4.2.1 | Identifying the needs of the community

Based on the results from the diagnostic exercise we identified six intersecting needs for people with diabetes, hypertension, and stroke and community members at risk: (a) CVD education (including risk factors and co-morbid conditions); (b) access to safe and affordable medicines and medical technologies; (c) access to affordable nutritious food; (d) self-care and psychosocial support; (e) stronger health systems; and (f) a health enabling environment.

Through interviews and situated conversations with community leaders and health policymakers, policy document reviews, and a synthesis of previous research on NCDs in Ghana, we identified internal and external actors who would be key to transforming CVD care in the community. Table 3 outlines the results of the mapping exercise, highlighting at individual, community and structural level: (a) the self-reported needs of people with diabetes,

TABLE 3 Existing alliances at Ga Mashie (based on global framework for NCD control)

| Level of social organisation | Strategies/actors | Description | Self-reported needs of people with diabetes, hypertension, stroke, caregivers, community members | Existing strategies/actors/alliances in Ga Mashie (strategies/actors/alliances required to improve CVD care) |
|------------------------------|----------------------------------|--|--|--|
| Structural | Policy | Targeting specific chronic diseases or risk factors | Government help in improving livelihoods and health (by association) | National NCD policy that targets major NCD risk factors exists but yet to be implemented Key actors: NCDPCP; GHS; MOH; WB, WHO |
| | Fiscal | Taxes on food, alcohol or tobacco. Subsidies on exercise equipment. | — | Key actor MOFEP: to address problematic growth of fast food culture and local alcohol industry (also MOH, GHNCDA) |
| | Industry and private businesses | Working with food industry to lower fat, sugar and salt content of products | Interventions needed to curb the growing problem of toxic staple foods and dangerous food production practices | Key actors: Ministry of Food and Agriculture (MOFA) focuses on all aspects of agriculture; Food and Drugs Authority (FDA) focuses on food safety (also GhNCDA) |
| | Academia/research institutions | Research on NCDs; partnerships with communities, policymakers, DPs | — | Multidisciplinary research on development, population health, nutrition, NCD care exists Key actors: UG academics and collaborators, e.g., NYU, Columbia University |
| | International collaboration | Building intellectual, technical and financial capacity through partnerships | — | Millennium Cities Project (Earth Institute, Columbia University; Accra Mayor's Office, GAMADA) |
| Community | Mass media | Public health education via radio, television and newspapers targeting communities or the nation | Better, clearer and more consistent information | Public health education via national mass media, but not specific to Ga Mashie Future actor: Local radio (providing content on evidence-based health education for broadcast) |
| | Voluntary/advocacy organisations | Public education, patient support, lobbying by special interest groups. | Access to education, psychosocial support from trusted groups | Ongoing engagement by research team with GAMADA, Butchers Association, Fishermen's Association, Market women's association, |

(Continues)

TABLE 3 (Continued)

| Level of social organisation | Strategies/actors | Description | Self-reported needs of people with diabetes, hypertension, stroke, caregivers, community members | Existing strategies/actors/alliances in Ga Mashie (strategies/actors/alliances required to improve CVD care) |
|------------------------------|--|---|--|---|
| | Institutions (schools, work, churches) | Institution-based interventions on diet, physical activity and smoking | — | Basic Needs, Sports Clubs, Arts Clubs, Jamestown Café, Jamestown Health Club (GHNCDA) Church-based CVD education and Community-based engagement with school-age children by research team <i>Future alliances: School-based CVD education and risk-reduction activities facilitated by research team</i> |
| | Primary health care | Routine advice given by doctors and nurses on major risk factors; quality of care; community outreach services. | Improved doctor-patient, nurse-patient communication; ethical care from herbalists and faith healers | Routine advice given by doctors and nurses at public health facility (Ussher polyclinic) and private clinics (Seaview, Cathedral). Community health nurses' engagement with the research project <i>Future alliances: pharmacists, herbalists, faith-based healers (as individuals and members of official groups)</i> |
| Individual | Behavioural interventions | Tobacco cessation, increased physical activity and dietary change and promotion of weight loss | Address barriers that undermine motivation and attempts to adopt healthier lifestyles | Interventions in progress with monthly self-help group sessions and community engagement <i>Future alliances: MOH/GHS to implement NCD policy, especially in relation to improving access to standardised dietary guidelines and pharmacological interventions</i> |
| | Pharmacological interventions | Pharmacological interventions for high risk individuals | Address the cost and safety of medicines and medical technologies | Engagement at the local level with NHIS, through renewal of pilot participants' health |

(Continues)

TABLE 3 (Continued)

| Level of social organisation | Strategies/actors | Description | Self-reported needs of people with diabetes, hypertension, stroke, caregivers, community members | Existing strategies/actors/alliances in Ga Mashie (strategies/actors/alliances required to improve CVD care) |
|------------------------------|-------------------|-------------|--|--|
| | | | | insuranceFuture alliances: NHIA to consider coverage of CVD medicines and technologies; MOH and Pharmacy Council to address problem of counterfeit medicines; MGCSP to advocate for comprehensive social health protection for LEAP recipients, elderly and indigent community members |

Abbreviations: GAMADA, Ga Mashie Development Agency; GHS, Ghana Health Service; LEAP, Livelihood Empowerment Against Poverty Programme; MGCSP, Ministry of Gender Children and Social Protection; MOFEP, Ministry of Finance and Economic Planning; MOH, Ministry of Health; NHIA, National Health Insurance Authority; RIPS, Regional Institute for Population Studies; UG, University of Ghana; WB, World Bank.

hypertension, and stroke, and their caregivers; (b) the self-reported needs of community members; (c) the broader needs emerging from data analysis; and (d) available and proposed productive alliances. We identify, where appropriate, the groups and actors the research team has collaborated with over the course of project.

4.3 | Developing psychosocial intervention

The long-term goal of the CVD project has been guided by the six interacting psychosocial features of AIDS-competent communities, proposed by Campbell et al. (2007). We have engaged in a series of intervention projects aimed at addressing most of the features.

We began with a pilot project, in 2016, aimed at developing lifestyle modification for a group of 63 Jamestown members with hypertension and diabetes. Participants attended weekly group classes targeted at lifestyle changes for 12 weeks (the intensive therapeutic lifestyle phase), followed by individual motivational interviewing sessions conducted once a month for three months. Health insurance payments were covered for all study participants for the duration of the study. Using a task-shifting model, the project team included trained community health nurses and graduate students in psychology and population studies. Blood pressure, blood glucose, cholesterol, weight, level of physical activity, fruit and vegetable consumption were measured at baseline and at the end of the study. Medical and self-care practices were measured through qualitative (interviews) and quantitative (inventory) approaches. Preliminary data analysis showed a moderate impact of the intervention on blood pressure and blood glucose control and a high impact on intrinsic motivation towards healthy eating, physical activity and associated lifestyles. Participants cited four key barriers to adopting healthier lifestyles: poverty, lack of access to cheap and effective medicines, the lack of healthy food spaces and options, and a lack of spaces for physical activity. The results of the pilot study provided the evidence-base to expand the project from a small group-based intervention to facilitating CVD competence at a broader community level.



FIGURE 5 Jamestown Health Club members at the inaugural meeting (photo used with permission)

We established a self-help group, with permission and support from our pilot project members, in 2017. The group was launched after the dissemination of the pilot study results to community members and leaders. The group, named Jamestown Health Club (JTHC), is the second health-oriented self-help group established in the community (see Figure 5 showing the core JTHC members after the inaugural meeting of the club). The first is a mental health self-help group focusing on providing support for people living with psychosis and epilepsy, which was established in the community by Basic Needs, an international mental health NGO with a Ghanaian branch.

JTHC is based on the professional expert model of self-help groups in which groups are led by specialist professionals or are funded through professional sources. However, the goal is to empower self-group members, materially and symbolically, to transition into the peer participatory model, in which peers with the same condition form and/or manage the group. Through these processes, group members can create a new social reality of CVD for the group and the broader community (Krause, 2003). The research team has organised themed sessions based on expressed needs of group members focusing on medication adherence, the challenges of healershopping, diet management, eye care, doctor-patient communication, physical activity and livelihood strategies. Local experts (e.g., from Ussher Polyclinic and GAMADA) and external experts (e.g., from the Korle-bu Teaching Hospital, UG) have been invited to cover themes. The research team has tackled other themes where internal research group expertise exists and reported results of ongoing research, such as our food and alcohol mapping activities. We have used the monthly sessions to respond to health emergencies such as poorly controlled blood pressure that requires clinical care. We have also expanded membership of the group to include members from Usshertown.

In addition to our monthly engagement with JTHC, we have conducted screening and education exercises for the broader community for four social groups: fishermen/women, market women, butchers and school age children (aged 6 to 12). Community engagement exercises with adults have involved ethnographic observations, and recording of objective (e.g., BP and BMI) and subjective (e.g., illness perspectives) measures, followed by team discussion, critical reflection and analysis, to inform the next phase of engagement.

Over the three year period of developing psychosocial interventions, we have identified the psychosocial features of CVD competence that are relatively easy to implement (albeit with sustainable funds, labour and time; features 1–4) and those that pose significant challenges (features 5 and 6). It has been easy to implement the following: building knowledge and basic skills (e.g., *the pilot study and community screening and education exercises*), creating

social spaces for dialogue and critical thinking (*convening monthly meetings to discuss chronic illness experiences and care, and responding practically to evolving problems*), promoting a sense of local ownership of the CVD problem and incentives for action and emphasising community strengths and resources (e.g., *creating awareness of community spaces that are health enabling, such as healthy food spaces*).

Features that will be difficult to implement include mobilising existing formal and informal local networks, and building partnerships between marginalised communities and more powerful outside actors and agencies, locally, nationally and internationally to address CVD risk, experiences and care. As Table 4 shows, the interventions that can yield the most important and sustained changes—such as strengthening health systems and creating a health enabling environment—are situated at the structural levels and require careful facilitation of productive alliances with powerful national and international actors, with competing priorities and/or with vested financial interests.

4.4 | Critical reflexivity and future work

We have identified four interrelated challenges that cut across the six psychosocial features of community CVD competence. Future activities will address these challenges.

First, poverty is a driver and outcome of ill health. The psychosocial support element in our psychosocial interventions has improved the quality of life of self-help group members, by their subjective accounts. However, community members who have financial difficulties, require social and financial protection, in addition to psychosocial support. Facilitating access to social and financial protection will require productive alliances between JTHC and other patient groups (within and outside the community) as well as the newly launched Ghana NCD Alliance (GHNCDA), GAMADA, and the NHIA (which provides health insurance to the extreme poor and elderly) and the Ministry of Gender, Children and Social Protection (which administers social grants through the LEAP scheme) to address the needs of community members.

Second, gender matters in health and health care in Ga Mashie. The burden of NCD and NCD risk is gendered; men and women engage with health care and health research projects differently. Throughout our 8-year engagement with the community we have had support and engagement from women (young, middle aged and elderly), but we have struggled to recruit men into our various activities. We have addressed this problem, partly, by segmenting our community outreach activities by occupation and gender. A second approach has been to develop a doctoral project, in progress, to examine masculinity, health and NCD care in the community, in order to develop targeted interventions for men.

Third, understanding the political economy of health and health care at the national level is essential. Despite the launch of a draft NCD policy in 2012 that is aligned with global best practice models, NCD prevention and control is marginalised in Ghanaian health policy (de-Graft Aikins & Koram, 2017). Key issues that remain under-researched and impact on all communities—but with insidious effects on poor communities like Ga Mashie—include poor regulation of pluralistic health services; the role of food market globalisation and a powerful local alcohol industry on the creation of obesogenic and “alcohol risk” environments; and unequal power relations between local health policymakers, local health care professionals and development partners. A major challenge will be make the CVD burden in urban poor communities visible to national and international actors and agencies and to leverage the visibility towards concrete investments in CVD policy and care. We aim to draw lessons from actors in Ghana's disability, mental health and ageing policy communities who advocated successfully for policy implementation after decades of grassroots action.

A final challenge is sustaining our project and its long-term goals. Campbell et al. (2007) observe: “it is a myth to regard the mobilisation of grassroots community participation as a cheap way of delivering services and addressing social problems in deprived communities ... those seeking to implement such approaches need to recognise that they are extremely resource intensive to initiate and sustain” (p. 361). The project has been funded largely through seed and small grants, and through in-kind support of the research team and our institutions. A major approach we have

used to maximise our limited research funding is “task-shifting.” We have operationalised task-shifting in the classic sense of involving CHNs in our psychosocial interventions. But we have also expanded the concept by involving multidisciplinary graduate and advanced undergraduate students. The strategy has contributed to the progress of the project, as well as supporting student research projects including three masters dissertations in social policy studies and psychology, three PhD theses in population studies, and two current social psychology PhD projects. The task-shifting approach is a best practice model for cost effective NCD care in LMICs. But even this approach requires sustained funding. Running a fully costed self-help group of approximately 50 members is \$1,000 per session; a community screening of 100–150 community members costs \$2,000. A full year’s engagement in community education, conscientisation and support will therefore cost at least \$36,000. At present, our project activities benefit from in-kind support and the task-shifting model and cost a third less than fully costed rates. We are actively working towards securing competitive and other grants to fund patient support, community outreach and support activities.

5 | CONCLUSIONS

The key task of critical reflexivity, as Guareschi and Jovchelovitch (2004) argued, is to engage critically with communities in need to identify alternative possibilities for transforming their reality. There is a strong tendency to focus solely on the disabling effects of poverty, social exclusion, and marginalisation when conducting research in poor communities. But to do so is to restrict the field of possibilities for facilitating social change. Many poor communities, like Ga Mashie, have complex and dynamic histories and forms of capital and agency that structure and guide their internal and external relations. Ga Mashie, as noted earlier, possesses recognised human and cultural capital, despite the objective reality and subjective experiences of material deprivation. This gives the community critical bargaining power in negotiating for improved community health. To address the fifth and sixth features of community CVD competence, we aim to draw on the community’s cultural capital to design arts-based participatory interventions, in addition to forging productive alliances with external actors in the national policy and global health communities. In so doing we aim to legitimise the value of existing symbolic resources within the community, that can be leveraged towards improved health and quality of life for all members.

CONFLICT OF INTERESTS

On behalf of all authors, the corresponding author states that there is no conflict of interest.

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APPENDIX A: SOCIAL REPRESENTATIONS OF DIABETES, HYPERTENSION, AND STROKE: CONTENT AND SOURCES OF KNOWLEDGE AND SAMPLE QUOTES

A1 | Social representations of diabetes

| Causal theory | Description of content | Sources of knowledge | Spread of views | Sample quote |
|---------------|---|---|-----------------|---|
| Natural | Family history/heredity; physiological states or malfunctioning including overweight/obesity | Doctors, family, subjective experience | | (body-self-knowledge) |
| Minority | <i>My father had it, but we did not know. (FGD, woman with diabetes) You see, sometimes if it is in the blood and you inherit it. Though it is very difficult to treat that one if you are able to follow instructions you will be ok. (FGD, woman with diabetes)</i> | | | |
| Psychological | Psychological stress (worry, thinking too much, stress) and life stressors (e.g. death of child and job loss) | Doctors, subjective experience | Minority | <i>I think it is caused by too much thinking. If you think too much then that's what brings about these illnesses (woman with diabetes, 64 years)</i> |
| Psychosocial | Socially mediated behavioural and lifestyle factors, everyday habits shaped by socio-economic status, including: unhealthy dietary practices, physical inactivity, alcohol overconsumption, and smoking | Doctors, dietitians, mass media, subjective experiences | Dominant | <i>Oil that settles off when placed down can give you the illness as well as eating of rich, rich stuff [...] someone would want to pour a whole tin of milk into the gari (processed cassava granules) and add a lot of sugar too – it can give you diabetes [...] (women with diabetes, 47 years)I think it is due to lack of exercise since I can't walk. But I believe if I begin to walk properly and I am able to exercise, it will go away (woman, 64 years).Smoking marijuana and cigarette could also give you the illness, since both are dangerous for our system. [...] For me, I think it is the drinking of too much beer</i> |

(Continues)

| Causal theory | Description of content | Sources of knowledge | Spread of views | Sample quote |
|---------------|--|--|-----------------|--|
| | | | | <i>and eating of too much fufu since both contain sugar (woman, 47 years)</i> |
| Supernatural | Supernatural causes: witchcraft, sorcery (or bought disease), the devil, and general spiritual action (through nonspecific evil forces and dark spirits) | Pastors, churches, herbalists, family, subjective experience | Minority | <i>The pastor took me through prayers and concluded that this diabetes is not mine but was bought and given to me (man with diabetes, 39 years)</i> <i>Some people say it is caused by some forces, but for mine, I think it is due to lack of exercise since I can't walk (woman, 47 years) I know it's real. It runs in the family. My grandmother also ate something spiritually, and she had a stroke (woman, 64 years)</i> |
| Structural | Toxic agricultural practices (using toxic agrochemicals for growing, harvesting and storing) and toxic staples (tubers, vegetables, fruit) | Social networks, everyday social practices (e.g., cooking) | Minority | <i>Now when you are eating something, even fruits, they will say don't eat this and that. This is because most of them contain fertilizer, so you need to know how to take them (Female, 64 years)</i> |

A2 | Social representations of hypertension

| Causal theory | Description of content | Sources of knowledge | Spread of views | Sample quotes |
|---------------|---|--------------------------------|-----------------|---|
| Natural | Family history/heredity; Physiological states or malfunctioning including overweight/obesity and pregnancy. | Doctors, subjective experience | Dominant | <i>... my mum's BP also got high and she died on her way to Korle Bu hospital. The same thing again also happened to my aunty, her BP kept rising after she delivered triplets and after a month and week, she had stroke and died last year, her kids will even turn eight this year. This sickness is like a hereditary in our family, particularly with the asthma, but it looks like when one gives birth in our family, that is when the BP issues rises and</i> |

(Continues)

| Causal theory | Description of content | Sources of knowledge | Spread of views | Sample quotes |
|---------------|---|---|-----------------|---|
| | | | | <i>adds to the asthma (Woman, 32)</i> |
| Psychological | Psychological stress including: <i>thinking too much, shouting, worrying, anger, intense spontaneous emotions, shock, panic and fear, sleeplessness</i> and life stressors including disappointments. | Community wide perception of hypertension, subjective experience, | Dominant | <i>In order for us to prevent BP, hmm, we should avoid thinking too much. Because too much thinking brings about BP. So when one stops thinking too much, he or she is not at risk of getting BP (Man, 64)</i> |
| Psychosocial | Socially mediated behavioural and lifestyle factors, everyday habits shaped by socio-economic status, including: unhealthy dietary practices, physical inactivity, alcohol overconsumption, and smoking | Doctors, subjective experience, mass media | Dominant | <i>Yes I don't like oily or fatty foods because they cause heart attacks and worsen the BP but dry fish and herring when used for cooking maintains your BP (Male, 60 year old pensioner from Jamestown)</i> |
| Supernatural | Supernatural causes: witchcraft, sorcery (or bought disease), the devil, and general spiritual action (through nonspecific evil forces and dark spirits). | Social networks, churches, subjective experience | Minority | <i>I walked over a spell some time past and I did not know. I kept visiting the hospital gradually without luck. I also visited these spiritual churches until I was told that someone had cast a spell on me (Male, A 75 year old from Usshertown)</i> |
| Structural | Toxic agricultural practices and toxic staples; working environments and conditions (e.g heat, labour-intensive activities); health systems barriers (cost of medicines in relation to complications) | Social networks Work environment Subjective experience | Minority | <i>Interviewer: What causes hypertension? Respondent: it is from our diet. I sell tomatoes at Achimota, when the fruits is left overnight the amount of water that collects around tomatoes is amazing. Sometimes they bring the tomatoes and they are very green[unripe] the man will ask to leave them covered. Within a twinkle of an eye the green tomatoes become ripe with the help of chemicals. so by the third day, if the tomatoes are not sold they begin to rot. They use chemicals to grow and forcefully cause the vegetables to ripen by using chemical. The chemical foods is our problem now causing all kinds of sickness. (Female 38 year old trader from Usshertown) I used to prepare kenkey but not anymore, the heat from tripods caused the heart sickness to increase</i> |

(Continues)

| Causal theory | Description of content | Sources of knowledge | Spread of views | Sample quotes |
|---------------|------------------------|----------------------|-----------------|--|
| | | | | (Female, 56 year old Former trader from Usshertown)Blood pressure medicine is very expensive. (Female, 22 year old from Jamestown) |

A3 | Social representations of stroke

| Causal theory | Description of content | Sources of knowledge | Spread of views | Sample quotes |
|------------------|--|--------------------------------|-----------------|---|
| Natural/physical | Family history/heredity; Physiological states or malfunctioning including hypertension, diabetes, high cholesterol and kidney failure. | Doctors, subjective experience | Dominant | <i>I know because as for hypertension even in my mother's side a lot of them have the hypertension. Even this stroke they normally get it. Even my mother had the stroke two months before me (stroke survivor, female, 43 years)They said my BP (hypertension) had gone up. They said it was because of the blood pressure ... I don't know so much about stroke but what I think I know is only the BP that causes stroke. That is all I know (stroke survivor, female, 43 years)In my mother's case, it was the BP (hypertension) that caused her to get stroke. So if someone has BP, the person should take care of him/herself so that it doesn't affect other things which could bring the stroke (stroke caregiver, female, 32 years)</i> |
| Psychological | Psychological stress (e.g. worry, thinking too much), and life stressors (e.g. hard work and inadequate sleep). | Subjective experience | Minority | <i>As for me, I think stroke is brought about by thinking or worrying. Maybe life is not going the way you plan it therefore, when you think too much, it can trigger stroke (stroke survivor, female, 57 years)</i> |

(Continues)

| Causal theory | Description of content | Sources of knowledge | Spread of views | Sample quotes |
|---------------|---|--|-----------------|--|
| Psychosocial | Socially mediated behavioural and lifestyle factors, everyday habits shaped by socio-economic status, including: unhealthy dietary practices, physical inactivity, alcohol overconsumption, and smoking | Doctors, family, social networks, media | Dominant | <i>When I went to the hospital they told me that when you are drinking alcohol and smoking and a lot of things you can get stroke. I know at the hospital (stroke survivor, male, 69 years)As for stroke, those who usually get it are those who like eating oily foods a lot (stroke survivor, male, 44 years).</i> |
| Supernatural | Supernatural causes: witchcraft, sorcery (or bought disease), the devil, and general spiritual action (through nonspecific evil forces and dark spirits).Social infection (stroke as socially contagious) | Herbalists, social networks, family, subjective experience | Minority | <i>After they told me at the hospital that I had a stroke, we took it as the work of witches ... this is because I was not sick and I was even planning to travel the following day when it happened (stroke survivor, male, 52 years)I don't know. I feel it is an attack (spiritual attack I guess) because we have gone to check for any heart problem, kidney, liver, all are normal. He is not diabetic (stroke caregiver, female, 60 years)It (stroke) is an illness that can be transferred to another. If someone around you has it, you can also get it (stroke survivor, female, 86 years)</i> |
| Structural | Health systems barriers (cost of medicines in relation to complications) | Subjective experience | Minority | <i>..hmm, it cost me a lot because before that, I have some money. The money I have put down for my girl who sells the food right now for her to go to WASS (secondary school) ... So I kept some money for her which she was supposed to use to start the school but because of this sickness, we have used all the money to buy medicine, because they are expensive.. (stroke survivor, female, 43 years)</i> |