

**REVISITING THE HOUSING-HEALTH RELATIONSHIP
FOR HIV POSITIVE PERSONS: SOME QUALITATIVE
EVIDENCE FROM THE LOWER MANYA KROBO
MUNICIPALITY—GHANA**

By

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ABSTRACT

The relationship between housing and HIV is bi-causal and complex. On the one hand, poor housing arrangements may expose Persons Living with HIV/AIDs (PLWHAs) to opportunistic infections and increase their morbidity and mortality risks. On the other hand, PLWHAs may be more likely to live in sub-standard homes, mainly because of their health conditions, lack of employment and HIV-related stigma. While previous research found support for the former argument, there is a dearth of research for the latter. More importantly, the majority of studies examining the housing and health nexus relied on survey methods with limited focus on context and the experiences of PLWHAs.

This thesis revisited the housing and health debate by filling these important research gaps. The thesis used qualitative in-depth interviews collected from 38 PLWHAs attending Voluntary Counseling services at the Atua Government and St. Martin's de Pores hospitals in the Lower Manya Krobo District (LMKD) of the Eastern region of Ghana.

Results from the study showed that the majority of PLWHAs lived in homes that lacked basic amenities, were overcrowded, had structural deficiencies, were noisy, dirty etc. PLWHAs lived in poor housing conditions mainly because of their HIV serostatus; living with HIV affected their employability and ability to finance adequate homes. HIV-related stigma often led to the forceful eviction from both family and rented homes. In some cases, PLWHAs were forced to change and relocate from relatively adequate homes to inadequate and deficient homes mainly due to self-perceived stigma. There was also evidence to demonstrate that living in these homes affected the health of PLWHAs negatively. The findings are relevant for both researchers and policy makers. It is important for researchers to continue exploring relationships between

housing and health for PLWHAs given the dearth of research in sub-Saharan Africa. Policy makers should consider housing as relevant to improving the health of PLWHAs.

Keywords: HIV/AIDS; housing status; housing conditions; physical health; emotional/psychological health; Ghana.

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TO ALL I SAY, MAWU NE G)) NYE!!!

TABLE OF CONTENTS

| | |
|---|-----|
| ABSTRACT | i |
| ACKNOWLEDGEMENT | iii |
| CHAPTER 1 INTRODUCTION | 1 |
| <i>1.1: Research questions</i> | 4 |
| <i>1.2: Purpose and Relevance of this study</i> | 4 |
| <i>1.3: Outline of thesis</i> | 7 |
| <i>1.4. Conclusion</i> | 7 |
| CHAPTER 2 LITERATURE REVIEW | 9 |
| <i>2.0: Introduction</i> | 9 |
| <i>2.1: Housing and health: Theoretical and empirical evidence</i> | 9 |
| <i>2.2: Housing status and HIV re-infection, transmission, and adherence to treatment</i> | 12 |
| <i>2.3.0: Reverse relationship between housing and HIV</i> | 14 |
| <i>2.3.1: Effects of HIV-related discrimination on housing</i> | 15 |
| <i>2.4: Changing dwelling after HIV diagnosis</i> | 18 |
| <i>2.5: Housing in Ghana</i> | 19 |
| <i>2.6: Conclusion</i> | 22 |
| CHAPTER 3 METHODOLOGY | 23 |
| <i>3.0: Introduction</i> | 23 |
| <i>3.1: Background of the study area</i> | 24 |
| <i>3.2: Sampling</i> | 25 |
| <i>3.3: Data collection procedures</i> | 28 |

| | |
|--|----|
| 3.4: Language and transcription | 31 |
| 3.5: Data analysis | 33 |
| 3.6: Ethical consideration | 35 |
| 3.7: Conclusion | 37 |
| CHAPTER 4 RESULTS | 38 |
| <i>4. 0: Introduction</i> | 38 |
| <i>4.1: Demographic and socioeconomic background</i> | 38 |
| 4.2: EMERGING THEMES | 39 |
| 4.2.1: Current housing situation of PLWHAs..... | 39 |
| a) Lack of basic housing amenities..... | 39 |
| b) Issues with the physical structure of the housing unit | 41 |
| c) Social environment in and around the home | 42 |
| 4.2.2: Changing housing after HIV diagnosis..... | 44 |
| 4.2.3: HIV status affecting Housing situation..... | 48 |
| 4.2.3.1: Direct effect of HIV status on housing | 49 |
| 4.2.3.2: Indirect effect of HIV on housing | 53 |
| 4.2.4: Effect of housing on health..... | 55 |
| 4.2.4.1: Effect of housing on the physical health outcomes of PLWHAs | 55 |
| 4.2.4.2: Effect of housing on mental and emotional health of PLWHAs | 57 |
| <i>4.3: Conclusion</i> | 62 |
| CHAPTER 5 DISCUSSION | 63 |
| <i>5.0: Introduction</i> | 63 |
| <i>5.1 What are the housing situations of PLWHAs in the LMKM, Ghana after HIV diagnosis?....</i> | 64 |

| | |
|--|-----|
| <i>5.2: Are PLWHAs in the LMKM more likely to change their housing situations after HIV diagnosis?</i> | 69 |
| <i>5.3: Does the health (HIV) status of PLWHAs influence their current housing choices and conditions?</i> | 71 |
| <i>5.4: How does the housing situation of PLWHAs further impact their health?</i> | 76 |
| <i>5.5: Conclusions</i> | 80 |
| CHAPTER 6 CONCLUSION..... | 81 |
| <i>6.0: Introduction</i> | 81 |
| <i>6.1: Strengths and limitations of the study</i> | 82 |
| <i>6.2: Recommendations</i> | 83 |
| REFERENCES | 88 |
| APPENDIX..... | 106 |
| Table 1: Demographic and socioeconomic characteristics of respondents. | 106 |
| Figure 1: The housing unit of one respondent | 107 |
| Figure 2: A toilet facility in Ghana. | 108 |

CHAPTER 1

INTRODUCTION

The Human Immunodeficiency Virus (HIV) is one of the deadly pandemics the world has witnessed in recent decades, claiming more than 35 million lives as of 2015 (World Health Organization (WHO), 2016b). In 2016, the WHO indicated that 36.7 million people lived with HIV, with 17 million enrolled in Anti-Retroviral Treatment¹ (ART) (WHO, 2016a). Although many interventions and educational programs like the “ABC” campaign², the distribution of free condoms and the “know your status campaign” have been implemented, countries continue to record new infections (Nel et al., 2012; WHO, 2016b). In 2015 alone, the WHO recorded 2.1 million new infections worldwide (WHO, 2016b). Sub-Saharan Africa is the most affected, as more than 70% of Persons Living with HIV/AIDS (PLWHAs) reside in this part of the world (WHO, 2015; WHO 2016b).

In Ghana, the first case of HIV was diagnosed in 1986 at the Noguchi Memorial Institute of Research after the blood samples of some Ghanaian migrants returning from Cote d’Ivoire, tested positive for HIV. In 2013, the average national HIV prevalence in Ghana was 1.3% with an estimated 224,488 Ghanaians living with the virus (Ghana AIDS Commission, 2015a: Ghana AIDS Commission, 2015b). However, the degree to which each region and district are affected varies. For instance, in 2013 the Northern region recorded a prevalence of 0.6%, compared to the Eastern region’s 3.7% (Ghana AIDS Commission, 2015b). Agormanya — a suburb of the Lower Manya Krobo Municipality (LMKM) in the Eastern Region — leads the urban prevalence

¹ ART is a combination of at least three different antiretroviral drugs commonly known as the Highly Active Antiretroviral Therapy (HAART) to help suppress HIV replication. This combination of drugs also reduces the likelihood of the virus by developing resistance (WHO 2016c).

² The ABC campaign seeks to promote Abstinence from sexual activity, Being faithful to one partner and Condom use.

in Ghana with an estimated rate of 8.4% and 11.6% in 2006 and 2013 respectively (Asante, Fenny & Ahiadeke, 2007; Ghana AIDS Commission, 2015a; Ghana AIDS Commission, 2010). While the national average may be declining (3.2 in 2006 to 1.3 in 2013), in Agormanya the number of affected persons continues to increase.

There are several explanations of the high HIV prevalence in Agormanya: frequent sex trade, irregular use of condoms, multiple sexual partners, and early sexual debut among youth (Asante, Fenny & Ahiadeke, 2007; Kissi-Abrokwah, Agbesi, Andoh-Robertson & Tutu-Danquah, 2015; Lund & Agyei-Mensah, 2008). Cassels, Jenness, Biney, Ampofo and Doodoo (2014) noted that during the economic crisis in the early 1980s, natives of Agormanya migrated to Nigeria and Cote d'Ivoire — then economically stable and vibrant countries in West Africa — in search of greener pastures. It is believed that some of the migrants engaged in commercial sex as a means of earning income. It is important to note that prior to this migration period, incidents of HIV had been recorded only in these two countries in West Africa; engaging in commercial sex exposed some of these individuals to the virus, and they became infected. Upon their return to Agormanya, some of these infected migrants continued sex trading and other risky sexual behaviors, leading to the rapid transmission of the virus to many residents of Agormanya and neighboring communities (Cassels et al., 2014).

The findings of Cassels et al. (2014) set the groundwork for explanations of the high HIV prevalence in Agormanya. However, the findings of studies in other settings could redirect the discussion. These studies allude to a significant connection between housing needs and HIV infection (Aidala, Abramson, Messeri & Siegler 2007; Buchanan, Kee, Sadowski, & Garcia, 2009; Leaver, Bargh, Dunn & Hwang, 2007). According to these studies, homelessness exposes individuals to rape and encourages risky sexual behaviors. In the United States (US), the

homeless or people with unstable housing are 16 times more likely to be infected with HIV than those in stable homes (The North American housing and HIV/ AIDS Research Summit Series, 2011).

These findings can shed light on the high HIV prevalence at Agormanya considering the historical and contemporary deplorable housing conditions in the region (National Catholic Health Service, 2010). Could the poor housing situation account for the high prevalence of HIV in the area? Could the housing needs in Agormanya affect the health outcomes of PLWHAs? These questions are important because studies in the United States and Canada show links between housing needs of communities and HIV infection, as well as the health outcomes of PLWHAs. Understandably, the socio-cultural dynamics leading to HIV infection and the housing challenges faced by HIV-positive persons in Africa may be different from those in North America (Bacon, Lavis & Rourke., 2010; Interagency Coalition on AIDS and Development, 2010; Milloy, Marshall, Montaner, & Wood, 2012). However, we cannot ignore questions about the possible relationship between housing and the health outcomes of PLWHAs in Africa. The lack of research on the housing and health relationship for PLWHAs in Africa is even more problematic considering that the majority of PLWHAs live in sub-Saharan Africa, where housing conditions are much worse than many other parts of the world (Konadu-Agyemang, 2001; Tenkorang, Owusu & Laar, 2017, UN-HABITAT, 2010).

Besides, evidence from these studies suggests a complex and bi-directional/reverse relationship between housing and health, especially for HIV-positive persons. This reciprocal relationship implies that, although housing units/conditions expose HIV-positive persons to poor health outcomes, living with HIV/AIDS could also affect the housing situations of PLWHAs.

Accordingly, this study³ revisits the housing-health relationship for HIV-positive persons to provide evidence supporting this reverse relationship. Previous studies, mainly in western countries, have only explored the effect of housing on the health outcomes of PLWHAs and have relied mainly on survey methods (Kidder, Wolitski, Campsmith, & Nakamura, 2007; Tenkorang et al. 2017). While such methods are important to describe and predict housing and health outcomes, they are limited in helping us understand the context, nuances, and meanings of the experiences of PLWHAs.

Given the gaps in the literature, this study uses a qualitative approach, specifically, in-depth semi-structured qualitative digitally-recorded interviews with PLWHAs, to unpack the subjective experiences of PLWHAs with respect to their housing needs. It asks the following research questions.

1.1: Research questions

- What are the housing situations of PLWHAs in the LMKM, Ghana?
- Are PLWHAs in the LMKM more likely to change their dwelling units after HIV diagnosis?
- Does the health (HIV) status of PLWHAs in the LMKM influence their housing choices and conditions?
- How do the housing situations of PLWHAs in the LMKM affect their health outcomes?

1.2: Purpose and Relevance of this study

This study is important for several reasons. First, it fills an important scholarly gap. Few studies explore the housing and health outcomes of HIV-positive persons, and these focus on establishing the relationship between housing needs and adverse health outcomes of PLWHAs rather than unpacking the lived experiences of HIV-positive persons with poor housing

³ In this work, “this study” will be used interchangeably with “this thesis” or “this research”.

conditions (Bacon et al., 2010; Braistein et al., 2005; National Coalition for the Homeless, 2007; Tenkorang et al., 2017). They show that PLWHAs with adequate/stable housing⁴ are more likely to report better physical health outcomes (in terms of CD4 and T-cell counts) than those with inadequate housing⁵ or who are homeless⁶ (Leaver et al., 2007; Stewart, Cianfrini & Walker, 2005). Yet the HIV literature also suggest that whereas PLWHAs are more likely to experience physical and psychological health problems due to their weak immune system, living in deplorable housing conditions could exacerbate their plight (Ticknor & Belle-Isle, 2010). For this reason, in a systematic review of the literature, Leaver et al. (2007) argued that housing stability for PLWHAs is vital in managing/living with the virus. Other research indicates that after HIV diagnosis, PLWHAs are more likely to resign from their professional trades — possibly due to fatigue, discrimination, or stigma associated with HIV infections — and resort to menial jobs with income that cannot sustain or/and finance quality housing needs (Adaramaja, et al., 2015; Aidala et al. 2007). For instance, about 42 - 44% of PLWHAs in North America are unable to afford quality housing and thus stand the risk of losing their housing units (Bacon et al., 2010; Song, 1999 in National Coalition for the Homeless, 2007). These findings imply that after HIV diagnosis and disclosure, a substantial number of PLWHAs are likely to lose their homes and relocate to sub-standard homes or become homeless. In Ontario, it has also been observed that PLWHAs frequently face eviction due to discrimination; one out of five PLWHA is evicted, and one-third of the remainder is at risk of eviction (Bacon et al. 2010).

⁴ According to the UN-HABITAT conference, adequate housing includes adequate privacy, space, security, lighting, ventilation, infrastructures, and security in tenure, all at an affordable price (Bonney, 2007; Obeng-Odoom, & Amedzro, 2011)

⁵ Inadequate housing is housing with deplorable or poor physical, environmental or chemical conditions, including substandard homes.

⁶ The National Coalition for the Homeless (2007) says the homeless are individuals without any fixed, regular, and adequate night-time residence; they sleep in private or public places not designed for such purposes. These public or private places range from car parks, cars, market shelters, train stations, public spaces to abandoned buildings.

These discriminatory behaviors are more pronounced in sub-Saharan Africa where families are blamed or praised for the behavior of their members. Discriminatory actions directed at a family are profoundly influenced by the stigmatization of all family members by the community when there is an HIV-positive person(s) in the household (Bogart et al., 2007; Mwinituo, & Mill, 2006; Ulasi et al., 2009). For instance, PLWHAs and their caregivers are consistently threatened with eviction; some are ostracized from their communities and some lose their loved ones because they are associated with or accused of having HIV/AIDS (Bharat et al., 2001; Bogart et al., 2008; Mill, 2003). Others become the subject of gossip and name-calling and can be denied access to public spaces (Mwinituo, & Mill, 2006; Ulasi et al. 2009). Within this context, family members are usually compelled to limit contact with PLWHAs to maintain the family's integrity. Limiting contact with HIV infected relatives can include the eviction of PLWHAs from a shared housing unit and facility, rendering them homeless or forcing them into substandard homes.

It is important to note that studies to date have focused on the housing-health relationship of PLWHAs and, in the process, have ignored personal stories of the housing experiences of PLWHAs. This study offers the first known documentation of the housing and health experiences of PLWHAs in Ghana. It also looks for a connection between living with HIV and housing arrangements. Besides contributing to the literature, the study will help the formulation of policy for marginalized and vulnerable populations such as the PLWHAs in Ghana.

At the moment, Ghana does not have housing policies for PLWHAs; this is in sharp contrast to some Western industrialized countries, such as the United States, Canada, and the United Kingdom where there are clear housing policies for PLWHAs (Tenkorang et al., 2017). Yet the development of these policies in Ghana is crucial; scientific evidence from Western

countries shows that PLWHAs living in substandard homes or who are homeless are three times more likely to engage in risky behaviors, exposing them to HIV reinfection and transmission (Aidala, Cross, Stall, Harre, & Sumartojo, 2005). Providing housing assistance to PLWHAs is found to result in a significant reduction of risky sexual behaviors and leads to an improvement in health outcomes (Aidala et al., 2005). Consequently, housing is considered an important HIV intervention mechanism in advanced countries (Aidala et al., 2005; Kidder, 2007). Based on this premise, my thesis examines the qualitative narratives of the housing experiences of PLWHAS in Ghana to help inform the country's housing policies.

1.3: Outline of thesis

Chapter One introduces the thesis. It provides the basis for the thesis and explains its relevance to scholarly discussions of HIV/AIDS and housing needs in the global south. Using the Ghanaian context as a test case, it probes the role of HIV status in exacerbating housing experiences in the global south. *Chapter Two* discusses the relevant literature on the housing and health relationship and the possible ways living with HIV affects the housing needs of PLWHAs in Ghana. *Chapter Three* presents the methods employed for the study and explains how the data were collected and analyzed. *Chapter Four* details the study's findings. *Chapter Five* discusses the study findings in response to the research questions. *Chapter Six* provides a conclusion and makes recommendations for policy makers to improve the housing situation in Ghana.

1.4. Conclusion

This chapter has set the background of HIV in Ghana and briefly outlined the gaps in the literature on the housing and health relationship for HIV patients. Although previous research noted associations between HIV and housing, it provided limited context to these associations. Besides, few studies have explored whether living with HIV could also affect the housing

situation of PLWHAs. This thesis revisits the housing-health relationship for HIV-positive persons by examining this reverse relationship.

CHAPTER 2

LITERATURE REVIEW

2.0: Introduction

This chapter reviews the scholarly literature on the housing and health relationship. It also discusses the emerging evidence of a reverse relationship between these variables. This implies that although housing is a major determinant of health, an individual's health status could also influence his or her housing situation. Using HIV positive persons as a target population, the chapter suggests ways an HIV-positive status might affect the housing conditions of PLWHAs. For instance, research shows that upon HIV diagnoses and disclosure, PLWHAs face discrimination at home and in the workplace; this affects their housing situation and may lead to eviction (dos Santos, Kruger, Mellors, Wolvaardt, & Van Der Ryst, 2014; Oluwagbemiga, 2007; Sprague, Simon & Sprague, 2011; Steward et al. 2008). Upon eviction, they are unable to secure and finance adequate housing, forcing them to live in substandard homes or become homeless.

2.1: Housing and health: Theoretical and empirical evidence

It is widely acknowledged that social factors influence the physical, emotional, and mental health outcomes of humans. Broadly, these social factors are classified as part of the Social Determinants of Health (SDH). The SDH framework posits that health and well-being are influenced by structural (socioeconomic status, social and political context) and intermediary mechanisms (material and psychosocial factors) (Dixon 2000; WHO, 2010). Among these mechanisms is the social and physical environment, including housing. Housing is defined in various ways, but one underlying principle is that housing is not limited to the structural/physical

components of the home but includes the space within the walls of a residential building (Tipple, Amole, Korboe & Onyeacholem, 1994).

Emerging scientific evidence reveals a strong relationship between housing and health, and poor housing is associated with a wide range of adverse health outcomes, including injuries, mental disorders and poor nutrition (Krieger & Higgins, 2002). For instance, results from the 1997 US national survey indicate that 42% of the 34.4 million nonfatal injuries and poisoning occur in and around the home (Warner, Barnes & Fingerhut, 2000). The WHO identifies poor housing as a major public health threat and has proposed that ill-health can be prevented by better housing systems (WHO, 1986 in Bryant, 2004; WHO, 2010). The proposal suggests the need for the establishment of affordable housing units (government subsidized housing) worldwide. The provision of housing is laudable, however; the quality of housing is of equal concern; Substandard homes with mold, rats, and cockroaches augment the occurrence/severity of asthma and other respiratory diseases (Warner et al., 2000). With weak immune systems, PLWHAs are at heightened risk of being affected by substandard housing; scientific evidence indicates that poor housing exposes PLWHAs to opportunistic infections and co-morbidities, such as tuberculosis and hepatitis B & C (Bansal & Saxena, 2002; Bashir, 2002).

The population and health framework, which falls within the broader SDH model, argues that human health is affected by the *physical/material*, *psychosocial* and *location/neighborhood* dimensions of housing (Dunn, Canada Mortgage Housing Corporation, National Housing Research Committee, & Canadian Electronic Library, 2002). According to this framework, the physical component of housing includes the material and physical composition of the home (Dunn et al., 2002). Research confirms that the physical component of the house (poor housing structure, unfavorable thermal conditions, the presence of pests, molds and dust) exposes humans

to a wide range of health hazards, including irritation, asthmatic and allergic conditions (Warner et al., 2000). Studies show that poor housing could compromise the physical and emotional health outcomes of vulnerable populations like HIV-positive persons (Aidala et al., 2007; Milloy et al., 2012, Tenkorang et al., 2017).

The psychosocial component of housing includes the social meaning individuals attach to their homes (Dunn et al., 2002). Housing functions as a psychological space and a symbolic extension of the self; for this reason, it confers power, status, and social networks on its users (Howden-Chapman, 2004). In addition, housing determines the interpersonal and intrapersonal identities of its users (Howden-Chapman, 2004). Therefore, living in substandard homes or being homeless confirms lower social status and this affect psychological and mental health outcomes (Dunn et al., 2002; Haslam, Jetten, Postmes, & Haslam, 2009; Howden-Chapman, 2004). Rourke et al. (2012) adds that living in socially undesirable housing units does not encourage building social ties that improve the mental and physical health of PLWHAs. Studies in other settings acknowledge that social identity is significantly associated with self-reported mental health (anxiety and maintaining control), clinical outcomes (depression) and physiological health (Haslam et al, 2009; James, Lovato & Khoo 1994).

The neighborhood conditions are also major threats to human health (Cubbin, Pedregon, Egerter & Braveman, 2008; Dunn et al., 2002). Less desirable physical, social, and service environments (neighborhood) are associated with violence, mental health, chronic diseases, birth outcomes, disability, obesity, and mortality rate (Cubbin et al. 2008; Howden-Chapman, 2004). Living in neighborhoods without playgrounds, hospitals, clean water or good sanitation exposes people to diseases like cholera and typhoid and may result in impaired cognitive function, obesity, or deteriorated physical fitness. Similarly, the social environment (the quality of

relationships among neighborhood residents) affects health. Residents of tightly knit societies are less likely to have high rates of homicide or social disorders resulting from depression and anxiety because of the high quality of relationship and social support networks amongst them (Cubbin et al. 2008). Given the psychological distress — depression, anxiety, and trauma — associated with living with HIV, many scholars have recommended social networks and social supports as necessary tools for managing and living with the virus (Li, Lee, Thammawijaya, Jiraphongsa, & Rotheram-Borus, 2009; Liu et al., 2013; McDowell & Serovich, 2007; Ndu, Arinze-Onyia, Aguwa, & Obi, 2011; Whetten, Reif, Whetten, & Murphy-McMillan, 2008; Zhou, 2007). Thus, a supportive social environment or neighborhood may improve the health outcomes of PLWHAs while a less supportive one may worsen health outcomes.

2.2: Housing status and HIV re-infection, transmission, and adherence to treatment

Housing status (adequate housing, inadequate housing or homelessness) is significantly related to human health. For instance, research shows that the homeless are more likely to report adverse health outcomes for chronic and infectious diseases than those dwelling in housing units, whether these are adequate or inadequate (Kidder et al., 2007). It is not surprising that previous studies identified homelessness as a major determinant of HIV infection and argued that access to housing (adequate or inadequate) reduces the likelihood of HIV infection and transmission (Kidder et al., 2007; Palepu, Milloy, Kerr, Zhang, & Wood, 2011). Homeless individuals are more likely to engage in risky sexual behaviors such as having multiple sexual partners, engaging in survival sex, or having unprotected sex with unknown persons (Aidala et al., 2005; Kidder, Wolitski, Pals, & Campsmith, 2008; Milloy et al., 2012). For example, research shows that homeless PLWHAs are three to six times more likely to engage in risky sexual behaviors or

use illicit drugs⁷ than their counterparts in stable homes (Aidala et al., 2005; Kidder et al., 2008; Milloy et al., 2012). Although at a reduced risk, PLWHAs in unstable housing were also two to four times more likely to engage in risky sexual activities than those in stable housing (Aidala et al., 2005; Bacon et al., 2010). Aidala and colleagues identify a “dose-response relationship”⁸ between housing status and HIV transmission or (re)infection; they conclude that housing status is directly associated with the health of PLWHAs (Aidala et al., 2005). Based on this and other evidence, inadequate housing/homelessness is associated with higher odds of HIV transmission and re-infection (see *Chapter One*).

This evidence is backed up by a review of the literature. Studies find that homelessness and inadequate housing were significantly related to low health care utilization, poor adherence to treatment, and frequent emergency/ambulatory services (Leaver et al., 2007; Palepu et al., 2011). A study by Spire et al. (2002) of 445 French PLWHAs indicate that the homeless/PLWHAs in inadequate housing units report higher non-adherence rates to treatment than those in stable homes. Similarly, in a New York study, Berg et al. (2004) found PLWHAs in unstable homes as 16 times less likely to adhere to treatment than their counterparts in stable homes. For this reason, they are more likely to report poor physical, emotional, and mental health outcomes (Milloy et al., 2012; Tenkorang et al., 2017).

The high non-adherence rate among those who are homeless or have inadequate housing can be attributed to several factors; lack of basic facilities (refrigerators and toilets), side effects of ART, poor access to regular meals and water, unfixed daily routine, lack of privacy, and poor means of accessing health care (Kidder et al., 2007; Palepu et al., 2011; Spire et al. 2002). The

⁷ The odds of drug use among homeless PLWHAs are reported to be four times higher than among those in stable housing.

⁸ Dose-response relationship between health and housing is the change in health triggered by the change in housing situation/conditions.

lack of basic amenities like refrigerators (to store medications) and toilet facilities (to help in case of diarrhoea⁹) hinders the homeless from adhering to treatment (Carr & Cooper, 2000; Foudraine et al., 1998; Msellati et al., 2003; Wood et al. (2003) in Royal et al., 2009). Medical/health practitioners are reluctant to prescribe ART for homeless PLWHAs because they fear they will not follow the treatment (Kidder et al., 2007; Moss et al., 2004; Palepu et al., 2011; Royal et al., 2009). Unfortunately, this practice could also impede access to ART.

Proper use of ART suppresses HIV replication and reduces the likelihood of the virus developing resistance (WHO, 2016). Without such treatment, PLWHAs develop sensitive immune systems, heightening their risk of morbidity and HIV-related mortality. The high non-adherence rate among those with unstable housing or who are homeless leads to higher co-morbidities (hepatitis B & C) and lower life expectancy. For instance, in a cross-sectional analysis in British Columbia, Braitstein et al. (2005) note that living with Hepatitis C is more common among PLWHAs in unstable housing than among those in stable housing. Studies by Anderson and Weatherburn (2004) and Stewards et al. (2008) confirm that PLWHAs with inadequate housing or who are homeless are sicker/weaker than PLWHAs in stable homes. The death rate of homeless PLWHAs is estimated as five to ten times higher than those in stable homes (Cisneros, 2007; Milloy, 2012)

2.3.0: Reverse relationship between housing and HIV

The housing and health relationship for HIV-positive persons is more complex than hitherto acknowledged. Previous researchers have mostly explored the effect of housing on HIV transmission, non-adherence to treatment and health outcomes (Kidder et al., 2007; Palepu et al., 2011; Tenkorang et al., 2017). Many surmise that living with HIV may heighten the risk of

⁹ Diarrhoea is noted as a recurrent side effect of taking medication for HIV (Carr & Cooper, 2000; Foudraine et al. 1998).

homelessness and even lead to inadequate housing (The North American housing and HIV/AIDS Research Summit Series, 2011), but no study has explicitly explored this reverse relationship. Research evidence shows that after diagnosis/disclosure PLWHAs often face eviction (either due to stigmatization or their inability to finance housing). In North America, almost 50%-70% of PLWHAs have some form of housing issue, including forced eviction or inability to pay rent (Interagency Coalition on AIDS and Development, 2010; Milloy et al., 2012; the North American housing and HIV/AIDS Research Summit Series, 2011). After losing their housing, PLWHAs are often unable to find and afford another suitable place, compelling a substantial proportion (33%) to reside in substandard homes or, in the worst-case scenario, to become homeless (Milloy et al., 2012). In a US-based study, about 50% of PLWHAs were at risk of homelessness because of their HIV positive status (National Coalition for the Homeless, 2009). Arguably, the housing issues faced by PLWHAs can be attributed to HIV-related discrimination (in the home or workplace) and or to the fatigue caused by the disease which prevents them from earning money.

2.3.1: Effects of HIV-related discrimination on housing

HIV is the most stigmatized medical condition in the world (Simbayi et al., 2007), especially in regions where it is associated with sexual promiscuity or socially undesirable behaviors (Gilbert & Walker, 2010). HIV-related discrimination/stigmatization is heightened by misconceptions about transmission, fear of casual contagion, and costs involved in caring for PLWHAs (Malcolm et al., 1998; Wolitski, Pals, Kidder, Courtenay-Quirk & Holtgrave, 2009). As a result of internal (guilt and shame) and external¹⁰ (gossip, staring, name-calling, isolation) stigma, PLWHAS are more likely to face housing issues which directly or indirectly lead to eviction (Bogart, 2008; Gilbert & Walker, 2010; UNAIDS 2000). Some research finds that after

¹⁰ External stigma refers to the negative social identity conferred on PLWHAs by HIV-negative persons.

disclosing¹¹ HIV status to co-workers, relatives, and housemates, PLWHAs are confronted by ostracism/isolation/neglect, moral judgment, relationship/job termination, and their access to children/spouse/relatives/facilities is blocked (Bharat et al., 2001; Bogart, 2008). PLWHAs are therefore required to vacate the common space shared with these relations (intimate, family, friendship and professional relationships).

In the home, discriminatory actions can directly lead to voluntary and involuntary (forceful) eviction of PLWHAs from their dwellings. For instance, in a Ghanaian study by Obiri-Yeboah, Amoako-Sakyi, Baidoo, Adu-Oppong and Rheinländer (2016), an HIV-positive person indicated that after disclosing their status, many of her colleagues were forcefully evicted from their homes. Other research finds that PLWHAs, especially widows, are rejected by their deceased husbands' families and forced not to return to the towns/villages of their birth (Oluwagbemiga, 2007; Steward et al. 2008). In instances where PLWHAs were not forcefully evicted, they were subjected to severe discrimination by housemates and relatives. An example is the case of Asma, a respondent in a study by Bharat et al. (2001), who was subjected to unfair treatment by her mother-in-law and relatives. Asma lamented, "My mother-in-law has kept everything separate for me – my glass, my plate. For me, it's don't do this, don't touch that and even if I use a bucket to bathe, they yell – 'wash it, wash it'. They really harass me... my parents and brother also do not want me back" (Bharat et al. 2001, p. 44). Such discriminatory acts can compel them to voluntarily relocate (Gilbert & Walker, 2010). Discriminatory acts perpetrated by community members could even force PLWHAs to migrate to different communities where their HIV status is unknown.

¹¹ In Ghana, where voluntary counseling is low (13% and 6% of women and men respectively), PLWHAs are mostly diagnosed at the symptomatic stage — when bedridden and showing all possible symptoms of the virus (Ghana AIDS Commission, 2014a). Hence, although PLWHAs are less likely to voluntarily disclose their status, their communities are suspicious and discriminate against them.

HIV-positive persons are often faced with employment-related discrimination (Sprague et al., 2011), although official policies forbid this. Research shows that PLWHAs who are still able to work are denied job opportunities due to their HIV-positive status (dos Santos et al., 2014). This finding is confirmed in a qualitative study by Thi et al. (2008) in Vietnam, where a respondent mentioned: “I was denied the job due to my infection status. I’m sure of it since the employer spoke about it to the person who introduced me. The employer said they were fearful of HIV transmission.... Learning from my previous experiences, the third time I looked for a job I kept silent about my [HIV] status. Then I got the job” (p. 67).

PLWHAs in Africa are no exception. Sprague et al. (2011) found that PLWHAs in Africa were more likely than PLWHAs elsewhere to face barriers to employment, exclusion at the workplace, loss of promotion, discrimination in hiring, and job termination due to HIV-related stigmatization. Asiedu and Myers-Bowman (2014) noted that in Ghana a female PLWHA was sacked after disclosing her status to her employers. Although the fatigue associated with living with the virus may be a factor in the loss of jobs (Dray-Spira, Gueguen & Lert, 2008), research shows that PLWHAs who are fit to work are denied promotion or faced job termination as a result of discrimination (Sprague et al., 2011). Moreover, co-workers may be reluctant to work with PLWHAs, compelling management to terminate their jobs (Parker, Aggleton, Attawell, Pulerwitz & Brown, 2002; Ulasi et al., 2009). Alternatively, the discriminatory attitudes of employers and co-workers may coerce PLWHAs to voluntarily resign (Dahlui et al., 2015; Gilbert & walker, 2010; UNAIDS, 2000; Wolitsi et al., 2009). Daljit, a 25-year-old factory worker stated: “My colleagues didn’t openly say anything to me, but the environment was no longer the same. They avoided me. If I entered the room they would leave abruptly. Then they asked me to keep a separate glass for water. I decided to quit the job” (UNAIDS, 2000, p. 26).

After resigning, many PLWHAs were forced to resort to menial jobs with little income. This significantly affects their ability to finance adequate housing units (Adaramaja et al., 2015).

Employment-related discrimination is not limited to the formal sector but also extends to the informal sector of the economy; about 80% of the Ghanaian working population is in the informal sector (Osei-Boateng & Ampratrawum, 2011). In the informal sector, PLWHAs are at risk of losing their customers upon disclosure (whether voluntary or involuntary). For instance, in a qualitative study by Asiedu and Myers-Bowman (2014) in Ghana, a *koko* (porridge) seller lost all her customers after disclosing her status. Similar attitudes are found in a quantitative study in South Africa, where 29% of respondents confirmed their unwillingness to buy from an HIV-positive vendor (Simbayi et al., 2007). It is important to note that employment-related discrimination is under reported; Bogart and colleagues say most PLWHAs experiencing this form of discrimination are unaware of it (Bogart et al., 2008).

In short, employment-related discrimination against PLWHAs increases poverty and unemployment rates among PLWHAs, thereby reducing their ability to afford rent or finance their housing. Song (1999) indicates that in Philadelphia, 44% of PLWHAs are unable to afford their housing and therefore are potential victims of homelessness and/or more likely to live in inadequate shelters. As this finding and the others cited above made clear, the housing status of PLWHAs is likely to change after HIV diagnosis/disclosure.

2.4: Changing dwelling after HIV diagnosis

A study in Ontario by Bacon et al. (2010) found that in addition to the 25% PLWHAs who lose their shelter, 42% have difficulty financing their housing and are at risk of losing it. Losing housing/inability to finance housing suggests HIV-positive persons are likely to move/change housing after diagnosis. Although this is not necessarily problematic, research by

Bacon et al. (2010) shows that PLWHAs are unable to find appropriate housing after losing their homes. For the above reason, a substantial number of PLWHAs are likely to be homeless or reside in unstable/substandard homes (Bacon et al., 2010; Milloy, 2012). With the extended family systems in Africa, PLWHAs who are unable to afford rent may move into “extended family homes”¹² where they are mostly not required to pay rent (Oluwagbemiga, 2007). However, it is important to note that most extended family housing are seldom well-maintained, making them inadequate and substandard.

Other research evidence, mostly in Western countries, indicates that some PLWHAs refuse to relocate despite discrimination (Bacon et al., 2010). However, these studies also acknowledge that those who refuse to move may do so because they lack adequate income to finance new housing, cannot find housing, or need personal care (Bacon et al., 2010; dos Santos et al., 2014). The study by Bacon et al. (2010) found one out of four PLWHAs who were stably housed felt they no longer belonged to their neighborhood and wanted to move but were inhibited by the lack of income or the need for personal care.

2.5: Housing in Ghana

Unlike countries where homelessness is a major public threat, only 3% of the Ghanaian population is homeless in addition to the 1.9% who rely on temporary or ad hoc dwelling units (kiosks, offices, tents, wooden structures, cargo containers) (Boamah, 2010). Nonetheless, housing in Ghana has been identified as inadequate (Boamah, 2010; Obeng-Odoom & Amedzro, 2011). In 2007, the Bank of Ghana reported that about 56% of the housing in Ghana was inadequate and not fit to be called a home (Obeng-Odoom & Amedzro, 2011). In line with this,

¹² Extended family houses are multi-family apartments owned by previous generations and passed on to the next. Hence, all individuals tracing kinship/ lineage through these ancestors jointly inherit this property. Family houses are commonly assigned on a room by room basis, and with successive inheritance, individual rights become minute (Fiadzo, Houston & Godwin, 2001; Korboe, 1992)

UN-HABITAT (2010) noted that although quality housing is an essential requirement for life, over 50% of Ghanaians were living in poor housing units. In 2010, housing in Ghana was declared inadequate by UN-HABITAT, who pointed to the acute sanitary issues and overcrowding (UN-HABITAT, 2010).

Inadequate housing in Ghana could be interpreted in two ways. The first takes into consideration the gap between housing demand and housing supply, while the second is characterized by the idea of inhabitable dwellings¹³ (Obeng-Odoom & Amedzro, 2011). Inadequate housing in Ghana is caused by expensive building materials, poor maintenance attitudes, rent control, insecure tenure, and lack of rental payment by tenants (Obeng-Odoom & Amedzro, 2011). More than 50% of housing in Ghana is never maintained although some housing structures could be over 40 years old (Obeng-Odoom & Amedzro, 2011). Similarly, Boamah notes that most Ghanaian housing lacks basic amenities and is characterized by deteriorating physical conditions rendering them inadequate (Boamah, 2010). Inadequate housing in Ghana has resulted in increased rent, increased occupancy rate (overcrowding), poor living conditions (lack of essential amenities and poor housing structure), and reduced stability in tenancies (UN-HABITAT, 2010). Individuals unable to afford the high cost of rent compromise by living in more affordable homes with poorer housing conditions.

The Lower Manya Krobo Municipality (LMKM) is no exception. Houses in the LMKM do not meet the criteria of adequate housing units. A report by the National Catholic Health Service notes that “despite the modernization and erosion of the traditional extended family system, the households in the district maintain their traditional character¹⁴” (National Catholic

¹³ Habitable housing is housing with adequate space and with the ability to protect its users from extreme heat, rain, threat and danger (Obeng-Odoom & Amedzro, 2011).

¹⁴ Traditional homes are large rectangular structures with 10-15 rooms facing a courtyard (Fiadzo et al., 2001).

Health Service, 2010, p. 7). As a result, these housing units lack adequate space and basic amenities like toilets, kitchens, lighting, and running water. The most recent Demographic and Health Survey indicates that only 15% of households in the LMKD have access to running water; more than 58% do not have kitchens¹⁵; and more than 58% do not have toilet facilities (GSS, 2014). These poor housing situations are problematic; access to running water and toilet systems in the home improves hygiene and decreases clinical visits for treatment of diarrhoea, skin diseases, food poisoning, respiratory diseases, and other “water-wash”/“waterborne” infections (Hennessy & Bressler, 2016).

Most of the houses in the LMKM are family houses. Since family houses are generational, individual rights become minute over successive generations (Korboe, 1992, Fiadzo et al, 2001), leaving them overcrowded and poorly maintained. About two-thirds of the houses in the district are compound houses¹⁶ (GSS, 2014). Living in a compound or family housing, especially in communities where HIV-related discrimination is rampant and sharing basic facilities could be problematic, as this could augment the stigmatization of PLWHAs.

Another critical issue is overcrowding (Boamah, 2010; Fiadzo et al. 2001). Fiadzo and colleagues (2001) note that about 45% of Ghanaian households live in overcrowded homes — a density of 2.5 persons per room. Overcrowding increases the risk of spreading all types of infectious/communicable diseases, including tuberculosis and skin diseases (Bansal & Saxena, 2002). For this reason, residing in overcrowded homes could expose PLWHAs to opportunistic infections, leading to adverse health outcomes.

¹⁵ Residents who do not have access to kitchens cook on verandas and open spaces within the compound.

¹⁶ Compound homes are large housing structures built around a common open yard and consisting of one or several households that share basic amenities like water, toilets, electricity and bathrooms (Rheinländer, Konradson, Keraita, Apoya, & Gyapong, 2015).

2.6: Conclusion

This chapter has reviewed the empirical and theoretical evidence on the housing and health relationship. It is apparent that just as housing affects the health outcomes of PLWHAs, so too living with HIV can lead to poor living conditions. Although traces of this inverse relationship are apparent in previous studies, no studies explore it. Therefore, this study revisits the housing and health relationship for HIV-positive persons.

CHAPTER 3

METHODOLOGY

3.0: Introduction

This study employed a qualitative approach to data collection and analyses to identify and critically examine the lived experiences of PLWHAs in Ghana as they navigate a web of complex cultural, social, and economic conditions that impact their housing needs and health outcomes. Qualitative research methods enable researchers to unearth how the “macro social structure” (gender, social, cultural, religious/spiritual, economic location, and status) is decoded into the “micro social structure” (the everyday lived experiences and interactions of individuals within society) to guide human behavior (Barbour, 2008; Warren & Karner, 2015). Qualitative research is built on the premise that society is made up of individuals with agency; hence, “an individual’s action is built up by the individual through noting and interpreting features of the situation in which he/she acts” (Blumer, 1969, p. 184). Qualitative research is useful for unpacking the complex mechanisms between variables and the social construct or subjective understanding of variables (Barbour, 2008; Warren & Karner, 2015). Importantly, qualitative research enables respondents to identify and define research problems with reference to their peculiar instances (Barbour, 2008). For these reasons, this research used in-depth qualitative digitally-recorded interviews with PLWHAs to explore the complex and possibly reverse relationship between HIV and housing. Purposive and facility-based sampling were used to select two hospitals and 36 participants.

This chapter explains the background of the study area, the data collection tool (in-depth interviews), and the manner and process of data handling and analysis. The final section discusses ethical considerations.

3.1: Background of the study area

Ghana is in West Africa and shares borders with Burkina Faso, Togo, and Cote d'Ivoire. In 2010, Ghana's population was estimated at 24.6 million (GSS, 2013). The country is divided into 10 administrative regions; the study area is in the Eastern Region. The Eastern Region has a total population of 2,633,154 and covers a total land area of 19,323 square km (GSS, 2013). The region is sub-divided into 26 districts and municipal assemblies, including the LMKM, Yilo Krobo District, and New-Juaben Municipal Assembly.

The LMKM is the study area. Its capital is Odumase. The municipality covers a total land area of 304.4 square km with a population of 89,246 — 41,470 males and 47,776 females (GSS, 2014). Out of this population, the GSS estimates that 83.7% and 16.3% live in urban and rural areas. The majority are Christians (92.8%) and belong to the Krobo ethnic group, although there are other ethnic groups — Ewes, Akans, and Hausas — and religious groups — Muslims and traditionalists (GSS, 2014). The municipality has the highest youth unemployment rate in the region (GSS, 2013). Of the employed, 83.6% are in the private informal sector, predominantly small-scale farmers (GSS, 2014). Although, working in the formal sector in Ghana does not guarantee higher income, studies show that the majority of employees in the informal sector earn below the national daily minimum wage of USD 2 (Otoo, Osei-Boateng & Asafu-Adjaye, 2009). For this reason, there is a high poverty rate in the municipality (Kissi-Abrokwah et al., 2015). Arguably, this situation accounts for the poor housing situation (see previous chapter).

The housing and household population of the municipality is estimated at 12,491 and 87,649 respectively (GSS, 2014). According to the GSS (2014) about 42% of the household population in the district occupy single rooms with an average household size of four persons per household. Clearly, a substantial number live in overcrowded housing units considering the room

density of 2.5 persons per room (Fiadzo et al. 2001). Besides, most of the housing units are extended family houses; about 61.7% of the populace dwell in family homes (GSS, 2014). As mentioned in the previous chapter, many family homes in the district are substandard/inadequate and not well-maintained (National Catholic Service Report, 2010).

Gender differences in inheritance affect the housing needs of the population as well (Kissi-Abrokwah et al., 2015). Most of the populace (Krobos and Ewes) in the LMKM practice a patrilineal descent system whereby males are exclusively permitted to inherit landed properties. Research shows that the patrilineal inheritance system deprives women and their offspring of becoming potential owners of such properties as housing (Kissi-Abrokwah et al., 2015). Not surprisingly, women-headed households in the LMKM were 1.3 times less likely to live in their own house than were male-headed households (GSS, 2014).

The municipality has three hospitals; Atua Government Hospital, St. Martins de Porres Hospital and Akuse Government Hospital. Atua Government Hospital and St. Martin de Porres Hospital were selected by the Government of Ghana in 2002 for a pilot study of Voluntary Counselling and Testing (VCT) and the administering of ART to PLWHAs (Dapaah, 2012). Consequently, both hospitals have served as nationwide learning and training centers for health practitioners on comprehensive services for PLWHAs (Tenkorang et al., 2017). In addition, both hospitals are referral hospitals in testing and treating the virus within the municipality and neighboring districts— Yilo Krobo Municipality, Upper Manya Krobo District, and Asuogyaman Municipality.

3.2: Sampling

The research used purposive sampling method to determine the study area (LMKD) and the two hospitals. The LMKM was selected because, as noted in Chapter One, Agormanya, a

suburb of the municipality, is the leader of urban HIV prevalence in Ghana. Similarly, Atua and St. Martins were selected based on their unique role (as mentioned above) within the municipality and the country since the first incidence of HIV was reported in Ghana, making them specially equipped to manage and treat the virus. The two health facilities were used as focal points for accessing respondents. The sampling technique is called facility-based sampling (Magnani, Sabin, Saidel & Heckathorn, 2005). According to Magnani et al. (2005), facility-based sampling is useful because it recruits participants from facilities frequently visited by hard-to-reach populations. Because of stigmatization and discrimination, the HIV population is a hard-to-reach population within the Ghanaian community. Facility-based sampling opened a door to the study population.

Hospitals are also an assembly point for people with diverse socio-economic and demographic backgrounds, so selecting PLWHAs from a hospital facility provided access to a diverse population of HIV-positive persons, including but not limited to sex workers, illicit drug users, low/high/middle-income earners, educated/uneducated, rural/urban dwellers and the homeless/those living in shelters. Drawing samples from all members of the HIV population was crucial, as the literature on the relationship between demographic/socioeconomic status and HIV infection remains highly inconclusive (Fortson, 2008; Wojcicki, 2005).

Facility-based sampling also enabled access to a greater number of PLWHAs. Although this was a qualitative study, respondents were randomly selected; PLWHAs were asked to pick anonymous codes (Yes/No), and those who picked “yes” were included in the sample. The random selection was to ensure that all PLWHAs in the facility had an equal chance of participating. In addition, randomly selecting participants reduced bias, as I had no control over who should or should not be included in the study.

To ensure the sample was not skewed towards women and to increase the representation of men in the interview, the chances of a man randomly picking a “yes” was enhanced; by increasing the quota of “yes” to “no” for men. This decision was theoretically and empirically driven, as research findings indicate that gender differences in cultural demands and the demographic/socio-economic characteristics of women make them more susceptible to the virus (Türmen, 2003). The Ghana AIDS Commission (2015a) also says women are more likely to access HIV Treatment and Counselling (HTC) than men (ratio 9:1). This makes it difficult to access and randomly sample a large pool of male participants.

Another distinguishing feature of qualitative research is sample size. Unlike quantitative researchers who use large and representative samples to make generalizations about associations, qualitative researchers focus on in-depth knowledge and context to understand the mechanisms that link variables (Barbour, 2008; Neuman, 2011; Warren & Karner, 2015). For this reason, qualitative researchers are advised to avoid fixation with sample sizes and to be more reflexive until data saturation is reached. Thus, qualitative samples are mostly non-probabilistic and data saturation becomes the general rule for selecting sample sizes for qualitative research (Boyce & Neale, 2006). In qualitative research data saturation is reached when “diminishing returns set in” or “nothing new” — themes, ideas, and issues — is perceived to be added to the research findings by new participants (Bowen, 2008). In this study, I was reflexive and noticed data saturation with the 12th female interview in Atua. However, I sampled two more females to verify this and to make up for any data loss. For this reason, sixteen females and four males were selected to participate in the study at the Atua Hospital. At St. Martins, I selected sixteen females and two males as participants. In all 38 HIV-positive persons were selected.

3.3: Data collection procedures

The data were part of a bigger project which employed both qualitative and quantitative data collection to explore the housing situations of PLWHAs. This data was collected between June and August 2015 by Dr. Eric Tenkorang of Memorial University, Newfoundland, Dr. Adobea Owusu of Institute of Social, Statistical and Economic Research- Legon, Dr. Amos Laar of School of Public Health and ten Research Assistants (including me). PLWHAs between the ages of 18 and 68 years were randomly selected and interviewed face-to-face. It is important to mention that I was solely in charge of collecting the qualitative data. I conducted interviews at the VCT center on clinic days (Monday-Thursday). The VCT center was chosen because some PLWHAs came from distant communities and were virtually impossible to reach at other times and places. For instance, some were from Ashiaman and Kumasi, approximately 60 kilometers and 250 kilometers, respectively, away from the LMKM. Another factor in the selection of the location was that PLWHAs were unwilling to be interviewed outside the hospital setting for fear of exposure and further stigmatization in their respective communities.

As indicated in Chapter One, this thesis revisits the housing-health relationship and explores the possibility of a reverse relationship between these variables. This required a data collection tool able to unpack the complex mechanisms linking housing and health. In-depth interview is an ideal choice, as these allows “intensive individual interviews with a small number of respondents to explore their perspectives on a particular idea, program, or situation” (Boyce & Neale, 2006, p. 3). One-on-one in-depth interview also provided anonymity and enabled participants to freely discuss their housing conditions without fear of ridicule.

A semi-structured interview guide was developed and tested prior to the data collection period with two PLWHAs at Atua Government Hospital. Pre-testing the interview guide was to

ensure that: a) the various terminologies and research questions were understood by individuals who shared certain characteristics with participants; b) the interview questions adequately addressed the research aims and objectives. After the pre-testing stage, I revised the interview guide by adopting some terminology frequently used by PLWHAs. One such modification was the use of “this sickness” when referring to HIV/AIDS.

The final interview guide included questions on demographic/socioeconomic background, experiences in previous/current housing, housing conditions and the effects of health on housing choice. Specifically, to answer the first research question, respondents were asked: “Do you currently live in a house?”; “What are the conditions in your current house?” “What amenities do you have in your house?”; “What has been your experience ever since you moved into this house?” The second research question on whether PLWHAs relocate after HIV diagnosis was answered by asking respondents: “How long have you lived in your current home?” and “When were you diagnosed with HIV?” I then compared the year of diagnosis to the number of years PLWHAs had lived in their current home to determine whether they had changed location after HIV diagnosis. A third question, “Where did you live when you were diagnosed with HIV by a physician?” allowed me to confirm whether PLWHAs had changed their dwelling place after HIV diagnosis. To explore the factors that influenced this movement, PLWHAs were asked: “What was your experience in your previous home?”; “Have you ever faced eviction? Can you tell me your experience?”

To identify whether living with HIV influences the housing conditions of PLWHAs, respondents were asked: “How has your HIV status affected or not affected your housing conditions?”; “How has your HIV/AIDS status compromised or not compromised your chances of living in adequate and affordable homes?”; “What has been your housing experience since

you were diagnosed with HIV?"; "Has your HIV status ever resulted or not resulted in house eviction?"; "Do you associate or not associate your housing discrimination experience with your HIV status? (probe: how)". Finally, to explore the effect of housing on health, respondents were asked: "In what ways has your current housing arrangement affected or not affected your health conditions?" and "How does your current housing arrangement affect your adherence to treatment (if any)?"

At the beginning of each interview, I briefly introduced the respondent to the objectives of the research, after which verbal consent was sought. PLWHAs that consented were interviewed, with each interview lasting 40-100 minutes. Key informants (peer counsellors and nurses at the VCT centers) advised that the interviews should start as early as 6:45am although the VCT officially opens at 8:00 am: The long queues at the hospital compel PLWHAs to come to the hospital early if they want to return to their daily routine/activities. By starting this early, I could interview one or two person(s) before clinic sessions started. About four qualitative interviews were conducted on each VCT clinic day.

Conducting the interviews in the hospital was not without challenges, as interviews were disrupted by routine clinic sections. Although respondents were excused from the queues to be interviewed, the interviews were recurrently paused whenever the names of respondents were called by nurses/doctors for check-ups and medical examinations. After completing the process at the VCT center, some HIV-positive persons were reluctant to continue with the interview because going to see the doctor or picking up prescriptions at the pharmacy requires them to join other long queues. To avoid this problem, at St. Martin's Hospital, after PLWHAs consulted the doctor, a retired nurse helped by picking up their drugs while they stayed behind to be interviewed. At Atua Government Hospital, respondents were willing to participate after

understanding the possible benefits of this study to the HIV population. Those who were unwilling to continue with the interview were replaced and excluded from the study. With the help of a digital-recorder, all interviews and oral consents were recorded and later transcribed by four Research Assistants.¹⁷

3.4: Language and transcription

Determining meaning from interviews depends on the researcher's understanding of the language used. In fact, the language may determine the quality of data collected. While some researchers say each word used within a sentence is vital, others say the choice of words is of little importance, as findings are analysed within a larger context (Temple & Young, 2004). To facilitate understanding, researchers are advised to conduct interviews in a language in which respondents are fluent. In addition, they are reminded that the use of interpreters during the interview process could distract the conversational flow of the interview or restrict the researcher's control over the interview (Smith, Chen, & Liu, 2008). Temple and Young (2004) suggest language represents how people see their social world; hence, researchers studying people who speak different languages are highly influenced by how they (the researchers) perceive the social world of their respondents. Because I am fluent in all language preferences (Krobo, Twi, and English) of the respondents, I was, to some extent, able to approach the research as an insider who understands the social meaning embedded in the word choices of the respondents (see Temple & Young, 2004).

Ghana is a multilingual country with over 80 Ghanaian languages (Berry, 1969). Therefore, respondents were asked to choose a language for the interview: Krobo, Twi, and English stood out as the language preference. All interviews were conducted in the preferred

¹⁷ I was one of these Research Assistants. The other three collected the quantitative data by administering questionnaires to respondents using a face-to-face technique.

language of participants except for two; in one, the interview started in English but later switched to Krobo to enable the participant to more clearly articulate his views. In the other, the participant opted for Ewe, but because the interviewer could not speak or understand Ewe, the respondent opted for Krobo, in which both the interviewer and the respondent were fluent.

The literature argues that translation can be a potential source of bias, and researchers should explicitly indicate the language used and acknowledge when a translator was introduced into the research process (Temple & Young, 2004). Although thirty-four interviews were conducted in the Krobo and Twi languages, these interviews were translated into English during the transcription stage; the Twi and Krobo alphabets were not readily available on a computer/laptop keyboard, making it virtually impossible to transcribe the interviews in the Ghanaian languages. In addition, by translating and transcribing the interviews in English, I could present the results in the required academic language for writing a thesis at Memorial University of Newfoundland. Four Research Assistants (I was one of the four) were employed to transcribe and translate the interviews from the local languages into English.

Smith et al. (2008) admit that the translation process runs the risk of misrepresenting, misunderstanding, and losing the intended meaning, especially in instances when local words have no or more than one linguistic equivalence in English. In this case, when the literal meaning was different from the implied meaning, translators were permitted to interpret the meaning of the words within the context (Smith et al., 2008). Researchers also argue that the use of “back translation” can help identify the “correct version of a text;” therefore, the transcribers employed this technique as a check on misrepresentation (Temple & Young, 2004). Note that all the translators were fluent in all three languages and were knowledgeable about the research, as they

had assisted in the quantitative data collection process. This helped reduced the possibility of wrongly translating the interviews (Smith et al., 2008).

3.5: *Data analysis*

The tool used for data analysis distinguishes qualitative from quantitative research (Thomas, 2006; Thorne, 2000). Quantitative research uses mostly deductive reasoning, while qualitative research employs inductive reasoning (Thomas, 2006; Thorne, 2000). Accordingly, this study adopted an inductive approach to the data analysis. In inductive reasoning, researchers generate themes and ideas from the data to interpret the underlying mechanisms linking variables (Thomas, 2006). Although there is software for analyzing qualitative data, the data for this study were analyzed manually. Warren and Karner advise beginners/students to analyze data manually before adopting any technology, as this will give them the “experience to remain true to their analysis” (Warren & Karner, 2015, p. 216) when using qualitative software. They also contend that manually analyzing data helps the “beginner” understand which software is appropriate for which analysis, as not all software is appropriate for all kinds of analysis (Warren & Karner, 2015).

Warren and Karner (2015) say analyzing qualitative data could be time-consuming and stressful because of the lengthy interview transcripts and detailed field notes involved. Based on this, they advise that the first step in qualitative data analysis “is to have an idea of where you want to end at” (Warren & Karner, 2015, p. 210). This idea, however, should be informed by conceptualizing and theorizing during the data collection stage. Since the data for this study were collected in June 2015 and the data analysis began in May 2016, I read the transcript multiple times to familiarize myself with the data, to develop an idea of where the research “should end at”, and to code themes from the data.

Warren and Karner (2015) refer to the process of coding as *open coding* and say researchers should, at this stage, be “open” to all emerging themes. Therefore, I tried to remain open to all possible themes and codes emerging from the data. During the open coding, I highlighted extracts with different colours. Using Microsoft Word allowed me to create a comment box to write comments on excerpts and the possible themes that could emerge from the data. In the comment box, I included short interpretations of each code in relation to an imaginary theme. For instance, a respondent (farmer) indicated that he was unable to vigorously work on his farm after he was diagnosed with HIV, and this situation resulted in his inability to complete his house. From this, I created the code *inability to continue with rigorous work*. I italicized all sentences and phrases in the transcript to that point about being unable to continue with rigorous work in blue. The theme— *the effects of HIV status on housing*—and the comment— *reduced income which could result in their inability to afford adequate housing unit* were inscribed in the comment box. Another respondent, in response to a question on changing housing after HIV diagnosis, mentioned that if not for her HIV status, her husband would not have sacked her from the house. For this reason, a code, *eviction from the house* was created under the theme, *effects of HIV status on housing*. Other themes and codes emerged from the data in the same manner.

The codes were categorized, merged and (re)grouped under four major themes and several sub-themes based on the research questions. The subthemes include: *lack of basic facilities, issues with housing environment, eviction from housing unit, inability to work due to fatigue, inability to finance housing* and *effect of stigma on emotional/mental health*. These subthemes were grouped under the larger themes: *changing dwelling after HIV diagnosis; housing conditions after diagnosis; effects of HIV status on housing; and effect of housing on*

health. Different Word document files were created for each theme and excerpts correlating with each theme and subtheme were pasted into the files (Warren & Karner, 2015). This process helped organize the data for analysis and ensured that the master copy of the entire transcript remained intact.

Because of the small sample size common to qualitative research, quantitative researchers frequently question the validity of qualitative findings. To ensure validity, qualitative researchers are advised to conduct a *goodness of fit test* by using negative case testing or a null hypothesis test. According to Warren and Karner (2015), a goodness of fit test ensures the creation of robust themes and sub-themes. Robust themes are arrived at by revisiting transcripts after coding, to ensure that counter themes cannot emerge from the data. Accordingly, after coding and regrouping themes, I conducted a goodness of fit test using the negative case testing approach to ensure that opposing themes did not emerge from the data (Warren & Karner, 2015). Qualitative researchers are also advised to be transparent and thorough in interpreting and analyzing data, as a way of ensuring rigorous and reliable analysis (Welsh, 2002). For this reason, I used extracts from the various transcripts to support my interpretation of the data (Smith et al., 2015).

3.6: Ethical consideration

Ethical clearance was sought from the Interdisciplinary Committee on Ethics in Human Research (ICEHR) at Memorial University, the Ethics Committee for Humanities (ECH) at the University of Ghana and the Ghana Health Service Ethical Review Committee. In addition, clearance was sought from the Regional Directorate of Health Services in Koforidua and the District Directorate of Health Service in the LMKM. At the hospitals, the Research Assistants sought permission from the hospital administrators and patrons before data were collected from the respondents.

Because HIV is highly stigmatized in Ghana, the personal identity (name and address) of participants was excluded from the interview. Respondents are identified by numbers assigned to them to aid anonymity. Finally, presenting results as themes and subthemes ensures confidentiality, as individual cases were not examined (Warren & Karner, 2015).

Although questions on the personal identities of respondents were not asked in the interviews, at the beginning of each interview, I disclosed my identity, affiliations, and purpose of the research to participants (Warren & Karner, 2015). This was to ensure that the research was open and respondents were fully aware of the research. In instances when respondents could not read or write, the consent form was read to them. The consent form assured them of confidentiality and anonymity. I also specified that there would be no remuneration for participation; however, they were assured of the possible benefit of this research to policy makers and the larger HIV population. In addition, respondents were informed of their right to terminate the interview if and when they deemed fit. After the consent form was read to the participants in their preferred languages, each respondent gave verbal consent, and those who consented were interviewed. Respondents who could read or write were given consent forms; a few minutes were allotted for them to read the forms and ask any questions before consenting to the study. This procedure ensured the voluntary participation of respondents.

Finally, social researchers are advised to protect their participants from harm. This harm according to Warren and Karner (2015) includes stigma. Given the stigma associated with HIV, I ensured that apart from the nurses at the VCT center, only PLWHAs knew about the research. For this reason, the interviews were not conducted in the homes of PLWHAs but at the VCT center. Moreover, to protect respondents from distress and harm, the interview guide was structured in a manner that would not (re)victimize or provoke an emotional reaction from

respondents. These emotional reactions include feeling of guilt, shame, and sorrow (Warren & Karner, 2015). Although the interview did not include (re)victimizing questions, some respondents expressed their sorrow and grief while sharing their experience. I always stopped, sought to counsel these respondents before progressing with the interview (Warren & Karner, 2015). In one instance, a respondent shed tears when asked about the HIV status of her very young daughter. Even though the first test was negative, she felt sad and guilty and thought the second test would be positive. I asked if she was on ART during and after her pregnancy and she said yes. I consoled her and advised her not to share sharp objects like blades with the child or place these objects within the child's reach.

3.7: Conclusion

This chapter highlights the reasons for using qualitative methods in this research and gives some general background details on the study area, the LMKM. It details the sampling techniques, the data collection tool, and the analytical procedure. It ends with a discussion of the study's ethical considerations.

CHAPTER 4

RESULTS

4.0: Introduction

Chapter Four presents the demographic and socio-economic background of the respondents. It outlines the findings related to the themes and subthemes emerging from the data. The main themes identified in the data were: current housing situation; changing housing after diagnosis; the influence of HIV status on housing; the effect of housing on health outcomes. The sub-themes include: lack of basic amenities; attempts to hide HIV status; forceful eviction because of HIV status; inability to find/afford quality housing because of HIV status; effects of stigma on emotional and psychological health; effects of inadequate housing on emotional and psychological health. Note that although excerpts from the transcripts are quoted, identifying markers are removed for anonymity.

4.1: Demographic and socioeconomic background

The demographic and socio-economic background of respondents are shown below (see Table 1). Participants in this study were between the ages of 25 and 68 at their last birthday. For marital status, they reported the following: never married, married, cohabiting, cohabiting but now separated, widowed, and divorced. Majority (30) of the respondents had acquired some form of formal education (grade one to senior high school).

Approximately 32% (12 respondents) were unemployed and 68% (25 respondents) were employed. Even for the employed, the majority were in the informal sector and had occupations like petty trading, farming, dress-making etc. Respondents who worked in the formal sector in this sample were all men. Although, working in the formal sector in Ghana does not guarantee higher income, studies show that the majority of employees in the informal sector earn below the

national daily minimum wage of USD 2 (Otoo et al., 2009). As for housing arrangements, less than half of respondents in this study lived in owner-occupier building units (this category includes joint ownership with spouse and parents). Disturbingly a few (4) were virtually homeless as they slept in kiosks, veranda or were “perching”¹⁸ at the time of the interview. Though there was no clear association between housing arrangements and gender, it is worth mentioning that all four respondents who were virtually homeless were females.

4.2: EMERGING THEMES

4.2.1: Current housing situation of PLWHAs

a) Lack of basic housing amenities

About three quarters of the PLWHAs interviewed lacked toilet facilities, bathrooms, kitchen and running water in their current dwelling units. Respondent 2 said:

There is no toilet facility in the house, no bathroom and no running water in the house. In fact, there is nothing in the house, but I am staying there...The only thing I am not happy about is that the house does not have basic amenities. I have to fetch water on my own... have to go to a public toilet where there are long queues and wait until it's my turn... I have to go out before I can bath or use the toilet facility. (R2- female)

Another respondent said:

No toilet, no running water... We are far from the commercial toilet facility and they charge a fee too when you use it. The private places charge Ghc 1 or 50 pesewas [depending on the type of toilet], while the public/government places charge a 20 pesewas fee, but the government toilet is very far from us. So, during emergencies you cannot go that far. We do not have our own bathroom, so we use the public bathroom, and pay for it. (R22, Female)

¹⁸ Perching is defined as the act of living temporarily with someone who is not a relative but has agreed to host you for some time.

Although the homes of these particular PLWHAs lacked basic housing amenities, they could access them within the community. However, as Respondent 22 made clear, using these facilities requires people to pay a fee which could add to the financial burden of PLWHAs.

Respondents were asked if there were any basic amenities they currently needed. The responses indicated that although PLWHAs could access public toilets and baths, or cook on verandas, they preferred having these basic facilities in their homes. When asked about the benefits of having these amenities in the home, a respondent said:

Yes. Like a toilet, bathroom, kitchen, fridge and television. These things I believe make life easier and better. The fridge I will need very much because I am not able to work very hard, so I will use the fridge to sell pure water and that will be less stressful. Sometimes, you can just get a stomach upset and will want to use the toilet but because it's not available you have to walk far before you can get a toilet to ease yourself. (R3- female)

Another respondent asserted:

I think water, electricity and toilet are necessary amenities and if made available in the house be of help... I will use the lights to see... Also, I can't sleep in darkness. Water is life and if it is not readily available, then you are in trouble. So, water, electricity, toilet and kitchen. I sometimes have problems with my stomach — running stomach [diarrhoea], and before I could walk from here to there, its [faeces] already found its way out -it's disgraceful. So, if the toilet is made available in the house I could rush there before it [faeces] finds its way out. I would prefer the toilet to be very close so as to get there by walking a very short distance. (R23, female)

Respondent 23's comment reveals that the lack of a toilet facility can result in public shame and ridicule whenever there is an urgent need to defecate; this is especially problematic because diarrhoea is a common side effect of using Anti-Retroviral Therapy (ART). Another basic need is electricity; its absence can lead to other health problems, for example, sleep deprivation (see section 4.2.4).

b) Issues with the physical structure of the housing unit

Respondents had serious problems with the physical condition of their housing units. Among these were flooding, overcrowding and blocked gutters. Those who lived in waterlogged areas or near waterways lamented that their dwelling units could be flooded for days whenever it rained. A female respondent who lived in an owner-occupier dwelling unit said:

The only problem I have is that the place is a water-logged area, there is a lot of water there and just recently our neighbors erected a wall so nowadays all the running water rush to our house. Whenever it rains the water just rushes to our house and it stays there for some time before drying up. (R15, female)

Another respondent stated:

The house I currently live in, whenever it rains the place becomes flooded, so I am not happy about it... There is no money and that is the affordable place I had... We are on the Odo [the name of a river] waterway so when it rains the rainwater runs through the house. We drain it [the flood] with the help of a broom when the rain stops. And use a shovel to remove the soil particles which got stuck... From the day it rained [last rain which was days before the interview date] we have not been able to cook in the kitchen because of the water... the whole place becomes flooded so when the rain stops and the heavy water drains before the one which got stuck in the house get its way out of the house... Yes, I don't have the money to rent a better place so if we push the water away with the help of the broom then we sleep. (R26, female)

Even though this respondent was renting and could have moved to a more suitable housing unit, she was unable to do so because she lacked the money to rent a better but more expensive place.

Fiadzo et al. (2001) and GSS (2005) define overcrowding as three or more people living in a single room. Based on this definition, 21 respondents resided in overcrowded homes. One said:

The room (single room) is very small... I am not comfortable because everything is in the room. I even keep my mortar in the room because we don't know what will happen to it when I leave it outside. So, my children (5) and I are managing the place. And also, I don't have enough money on me to pay an advance¹⁹ for any house so even though I am not comfortable we are managing. (R1, female)

¹⁹ In Ghana, rents over a two or three-year period are calculated and paid upfront by tenants before they move into any rented housing unit.

A respondent living in a single room with more than 10 relatives mentioned:

Oh, we are many. We are more than ten... That is what I said: one small room... The room belongs to my father...., and when my brothers' wives come, that is where they go; when my brothers come, it's the same place; grandchildren, same, so even a bag/suitcase takes up a lot of space. If you came to my room to visit me you couldn't look at me. We are overcrowded. (R 35, female)

Overcrowding can facilitate the spread of communicable diseases like tuberculosis. Living in overcrowded homes was obviously detrimental to the health of PLWHAs, as their immune systems are compromised.

Other PLWHAs lived in deteriorated or uncompleted housing units. For instance, one respondent indicated:

The house I live in is a mud house. It's in a bad state and at the verge of collapsing. Recently, people from the town council came to warn us that if the building collapse and result in any death, we will be held accountable... The aluminum roof is also very old, so it leaks when it rains. We collect the water in a bowl. We can't even sleep in the room. (R 31, female)

Another respondent described her housing condition as follows:

It's an uncompleted building, built like a self-contained... my sibling sleeps in the single room, my father sleeps in the chamber and I sleep in the hall. The hall is also full of problems, for instance when it rains I am unable to sleep on the floor, I sleep in a chair, and there are a lot of mosquitos' there... Yes, because the house is uncompleted. The rooms are not cemented, and I sleep on the floor so when it's time to sleep I first lay rubber on the floor, spread boxes [boxes opened to form a flat surface], lay a mat and then a student mattress before sleeping. (R23, female)

Notably, five out of the 11 respondents who lived in owner-occupier housing units were in uncompleted buildings—clearly substandard and inadequate.

c) Social environment in and around the home

As noted above, more than two-thirds of participants lived in housing units which required the sharing of some basic amenities; and a disclosure of HIV status can ignite discrimination. To

navigate stigma and the fear of eviction, some PLWHAs remained shrouded in secrecy and did not disclose their HIV status to relatives even though they could be sharing the same room with them. They even hid their medications to avoid suspicion. For instance, one respondent detailed:

I have not told anyone about it apart from my sister who went to the hospital with me. My daughter I stay in the same house with doesn't know am also HIV positive. I hide my drugs in my bag when am going to work I take it along in fact I take it everywhere I am going... so no one knows I have this disease. (R8, female)

These PLWHAs lived in constant fear of accidental disclosure and its negative implications (discrimination). This was evident in statements like: “I think of how my relatives would relate to me when they get to know I am HIV positive- they will stigmatize me.... I think a lot...” (R28, female). The fear of being stigmatized by relatives makes the housing environment of many PLWHAs unfavorable. This therefore results in isolation, social withdrawal and self-surveillance among PLWHAs, as noted by one PLWHA: “I don't interact with people in the house, so no one tries to invade my privacy. Most of the time I try to isolate myself from others” (R7, female).

Few PLWHAs could not hide their HIV status from relatives. Although they did not personally disclose their HIV status, they were suspected of being HIV-positive and were stigmatized. An example was a female respondent who stated:

They do. They call me names... Oh if you are sick – they will say “she has AIDS, see how it evident on her body; see how she's grown lean”. My biological daughter even told me not to come close to her, because her children can get infected My children don't come close to me when they come to this town. They don't come close to me ... My mother, with whom I stay in this village, even cooks separately because of that. When she cooks she would serve me in a separate bowl. As for the children, they don't know how I contracted the disease, so they don't want to come close to me. The relationship is no longer the same; we no longer cook and eat together in the bowl or take a bath together. Even now I bath using a separate bucket. I use my own earthenware [grinding mortar] ... Everything is separate. I wash my dishes separately. (R35, female)

Outside the family, evidence from this study also showed that PLWHAs were stigmatized by the wider society through gossips, insults or refusals to buy from HIV-positive vendors. A respondent said:

They always do that. As for the insults, it's like the pomade I use on my body every day, but I always say that I am not the inventor of this virus, it was already in the world before I got infected. So, if someone insults me I don't utter any word. I just leave it to God, because he is the one to vindicate me... I was selling uncooked plantain, and someone told me "are you the one with HIV coming to sell to us so that we can also be infected with HIV?" Meaning my intention of selling is to spread the virus. Some people will not even want to sit with me. They stigmatize me because I am sick. They will not allow me to come close to them. (R23, female)

Stigmatization/ discriminatory acts, whether from the family or society, forced many PLWHAs to detach themselves from societal functions, as indicated by Respondent 35:

Because of this sickness, I suffer a lot of stigmatization... What can I do? I don't have strength to do anything. The only thing I can do is to hide so I am always in the room... People feel HIV is easily spread by mere contact. So, I keep to [isolate] myself when I am at home. Because of the disease, people stare at me whenever they come for an occasion. (R35, female)

Isolating oneself from societal functions in a community which stresses and values communal activities affected the social identity of PLWHAs and prevented them from building strong social networks. Thus, they are deprived of possible supports in the course of a debilitating disease.

As the above examples suggest, more than half of participants lived in environments with high levels of stigma and fear (fear of disclosure) which has implications for their health.

4.2.2: Changing housing after HIV diagnosis

The second theme considered whether PLWHAs changed housing units after HIV diagnosis. Two categories of respondents were identified under this theme: PLWHAs who relocated after HIV diagnosis and those who stayed in the same place. Twenty-two out of the 38 respondents (about 58%) relocated after HIV diagnosis. Considering the previous finding that

majority of PLWHAs live in substandard homes, an obvious question was whether those who moved ended up in better or worse housing units.

Respondents who relocated were asked to compare their previous and current dwelling units using several indicators; privacy, space, ventilation, lighting system, the absence of mold/damp and the level of peace they enjoyed. Although these indicators were inadequate to measure the quality of housing, they were preliminarily useful in categorizing PLWHAs. Participants whose current house scored high on three or more of the above qualities were considered to have moved into better housing units and vice versa. Using this criterion, 10 out of the 22 respondents (about 46%) moved into worse housing units. Those who moved to worse housing noted things like the following: “I had more privacy in my former house than my current house... My former house had better lighting system and ventilation... The former one was bigger and better than this current house” (R3, female). Another woman said:

It [current house] is a mud house... I had more privacy in my brother's (former) house. In my current house, I cook in my [single] room... I don't have enough privacy in the house... My brother's [former] house has better ventilation... my former house had better lighting... the former one was bigger. (R4, female)

In other words, although changing housing units could be advantageous, a substantial number of PLWHAs relocated to a worse place after HIV diagnosis.

Twelve respondents (about 54%) relocated into better housing units (based on the above indicators). Among these, five moved into owner-occupier housing. Although these participants indicated their current housing as better than the previous housing, a closer look revealed that such dwelling units were substandard and were actually worse off. For example, four of the five moved into uncompleted buildings, while the only PLWHA who moved into a completed building lived in an overcrowded room with blocked gutters breeding mosquitoes. One participant who moved into an uncompleted dwelling unit stated:

Oh, I like my new place [uncompleted building] ... I don't even have light at my current dwelling... There is no light, there is no kitchen and toilet, but I am happy. I am happy with myself, knowing I have no lights I do my stuff early. I am happy with the way I am living. I don't have any problem. ... And there is nobody to disturb me. (R21, female)

Another was more negative:

We were not having any problem staying there [previous home], we were not disturbed whenever it rained. The room was cemented but since this place is our own house we decided to move... Our current house is an uncompleted building... and I sleep on an uncemented floor in the hall... Yes. And electricity is also a problem in that [current] house, yes, we use those small improvised torches— the one made out of wood, battery and wires, that's what I use.... What I like is the fact that we don't pay for rent. And we don't have running water... (R23, female)

Four participants who moved to better housing relocated to rented and family housing units while the remaining three were virtually homeless — sleeping in kiosks or “perching” at the time of the interview. One of the latter said: “I made a kiosk and I live in it with my children. It is made of wood; I erected the kiosk with woods... Oh, there is nothing I like about it [housing] because when it rains I face a lot of problem. I am living in it because I don't have any option” (R22, female).

The other category of respondents was PLWHAs who did not change their dwelling unit. Sixteen did not relocate after their HIV diagnosis. Of these, six lived in family houses prior to HIV diagnosis, four lived in rented housing and six were in owner-occupier dwelling units. An inquiry into the state of these dwellings revealed that most were substandard and inadequate. Further investigations to identify the motives for remaining showed that majority of these PLWHAS were constrained by finances. For instance, respondents, especially those in family homes, indicated a desire to relocate, but their inability to afford rent or build a house compelled them to stay put. This was clearly stated in comments like the following:

It is not easy living in a family house; it is more comfortable staying in your own house. There is so much noise and quarrel... Sometimes what to even eat is a problem

for me so how can I get money to build or rent a chamber and hall to live in. Even for my transportation to the hospital my children always have to send me money. No one is also sacking me from my family house, so I have no option than to manage the single room... I have not moved because I don't have money. That is the only reason why I am still in that house. (R7, female)

I have a place to sleep but I would have preferred my own place [rented house] like I did before moving here [moved before HIV diagnosis]. That is the only thing that worries me... Concerning my living conditions? I was not supposed to be where I live currently. When I look at myself it's clear my current house is not my place. Yes, I am not happy living there [step father's family house] ... There is no money. My business has collapsed. I can't even think of building a house. It's the money. I can't rent a place either. (R38, female)

Some respondents identified marital relations and responsibilities as restricting their movement. For instance, a widow living in her deceased husband's family house stated:

It is a mud house. It is not bricks. It's a mud house... Although the house is not the best I have no other option. A house built with bricks is durable unlike a mud house which will leak when it rains heavily. Yes. Some time ago it rained heavily, and some parts of the building collapsed. My deceased husband's room and mine. So, those parts are currently broken. I don't have light. We don't have toilet facility. We use the public toilet. We do not have running water. (R37, Female)

When asked why she did not move, she lamented, "There is a reason, that is my husband's family house, where I lived with my deceased husband" (R37, female). Part of the marital obligation of a wife in a patrilineal descent system (especially among Krobos) is that women are required to dwell in their matrimonial homes even after the demise of their husbands. This proves their loyalty and faithfulness. Another widow who lived in her deceased husband's house said that even though there was nothing she liked about the house and she wanted to move, she was unable to do so because of their belongings and fixed property (land). In addition, this respondent said she was unable to move out of the house because relocating somewhere else with the children could lead to the maltreatment and stigmatization of the children — because of her HIV-positive status:

There is nothing I like about the house but since the kids are young they [husband's relatives] said I should stay there to take care of the kids. There is nobody too in my husband's house, so I am just there so that I can take care of the kids. We have our properties there so that is the main reason why I have not been able to move/leave. I can't leave, who will I leave my children with, who will take care of them? My husband's relatives said I should be in the house and not send the children to anybody to maltreat. Since we are not renting the place I should just be in that house and take good care of my kids... It's because of the kids; if I take them somewhere they might be stigmatized. So, those are the main reason why I am staying there. (R24, female)

Marriage among the Krobos is not just a union between a man and a woman but rather between a man's family and a woman. A woman belongs to and remains under the authority of her husband's family — even after the death of her husband. Based on this tradition, this widow remains under the authority of her husband's relatives and could not relocate against their wish.

As the above narratives show, some PLWHAs who did not relocate after diagnosis wished to do so but were inhibited by financial constraints and/or marital obligations.

4.2.3: HIV status affecting Housing situation

Another thrust of this research was to find evidence to argue that living with HIV could influence the housing situation of PLWHAs. Results from this study showed that the HIV status of individuals can directly or indirectly influence their housing situations. For instance, after HIV diagnosis, some PLWHAs were forcefully evicted or subjected to stigmatization and discrimination which forced them to move out of their homes. Other PLWHAs experienced fatigue/weakness after HIV diagnosis which prevented them from working or continuing with previous work. This affected their income level and indirectly forced them to dwell in deplorable homes which were comparatively more affordable.

4.2.3.1: Direct effect of HIV status on housing

a) Forceful eviction from home due to HIV status

Some PLWHAs live in deplorable situations because they were evicted from their previous homes after they disclosed their HIV status. One woman was turned out of her matrimonial home by her husband because she was diagnosed with HIV. Importantly, her previous housing unit contained all the basic amenities such as toilet, bath, and running water while her current dwelling had none of these. She lamented:

I was living with my husband and children in a dwelling unit we owned but my husband sacked me from the house because I am HIV positive. I was sick one day and came to the hospital and the nurses diagnosed I was HIV positive. They asked me to bring my husband. but he was diagnosed HIV negative... After knowing I was HIV positive my husband's attitude changed towards me and some few weeks after he sacked me from the house. He later asked my children to bring all my belongings to me and otherwise he won't give them food to eat. I married this man at a very tender age and had all my children with him. We suffered together to put up a house which had all amenities and now he sacked me out of the house. It is very painful. Now I live alone, none of my children live with me. I am now staying in my mother's room in the family house. There is no toilet facility in my current house, no bathroom and no running water..., I am not comfortable in the house but I have no other choice so I have to manage [with that housing unit]. (R2 female)

This respondent relocated from a housing unit with all the necessary amenities into a unit which lacked all basic amenities simply because of her HIV-positive status.

A PLWHA who slept on the veranda in the family house said something similar. She said her roommates thought sleeping on the same bed could lead to their infection. For this reason, she was not allowed to sleep in the same room with them after she was diagnosed with the virus. This rendered her virtually homeless as she now sleeps on the floor in an open space within the family house. This respondent bluntly stated:

I sleep on the floor; I sleep outside... Just as I said, some complained about sharing the bed with me for fear of being infected; because of this in the evenings I lay a bed

outside and sleep. I sleep on the floor. When they pass by me with the water they fetched to bath, it spills on me. But my belongings are in the room. (R35, female)

For both women, their HIV-positive status led to their full or partial eviction and both were now living in deplorable housing conditions.

b) Unable to find housing due to HIV status

When I asked why respondents could not relocate to adequate housing after eviction, I discovered that two participants were unable to find adequate homes after losing their housing units. Importantly, respondents associated their inability to find adequate housing units with their HIV-positive status. Due to the low level of voluntary testing and counseling in Ghana, many HIV-positive persons are diagnosed at the symptomatic stage of the virus. Although they may not voluntarily disclose their status to house-owners and community members, they suspect their condition. House-owners refuse to rent housing units to suspected HIV tenants. When asked whether PLWHAs were discriminated against in terms of housing, two respondents indicated that their HIV status led to discrimination when they looked for a place to rent. One complained: “Hmm [sighs] I went to search for one and did not get it. I did not get it... For someone, by merely looking at you, just by looking at you some people can even tell your HIV status... That is what I have been telling you. I don’t get it because of my looks” (R35, female). The other confirmed: “I was sick and grew lean, so when I go to look for a place to rent they will look at me ‘from head to toe’ and will refuse me the room” (R20, female).

Although some respondents have not experienced this form of discrimination, they said people will not allow you to live in the same house with them if they know you are HIV-positive. For example, one respondent stated: “If they know you are HIV positive they will never let you stay in the house because nobody wants to be the house with such a

person” (R1, female). Although this participant had not experienced this form of discrimination, her experience with a housemate informed her assertion:

One of the tenants in the house [current house] sent someone to buy water for him. When the water was brought to him he asked the boy where he bought the water so the boy showed him where he bought the water from. The tenant refused to drink the water and I asked him why. And he said someone he suspected of HIV died in that house... I asked him what if a member of his family contracts this disease, what will he do? And he said he was going to leave the house for the person. (R1, female)

The above scenarios imply that living with HIV prevents PLWHAs from finding adequate housing units after HIV diagnosis.

c) Fatigue after HIV diagnosis

Another theme emerging from the data was that fatigue and ill health prevented PLWHAs from dwelling in adequate housing units. For example, the respondent who slept on a veranda noted that after a long search, her son finally found a place for her; however, she was unable to relocate because she was too weak to live alone and do things by herself. She disclosed this in her statement:

But one of my children — when he saw how I was being treated here [current house] — relentlessly searched for a place and had a room. He said he would hire the place for me, but I am now fragile and weak. If I rent a room, I would have to sweep and do other things by myself... For about a year, I have been battling with malaria. I cough a lot because of the HIV medicine... Where can I go? For four days now, I haven't been able to go anywhere. My veins are swollen. (R35, female)

The fatigue/weakness this participant experienced as a result of living with HIV prevented her from relocating although she was greatly stigmatized in her current dwelling.

Another respondent who lived in a house where she was stigmatized and who struggled to get food added that her weak health status prevented her from living with people who would be able to feed her and not stigmatize her:

That [fatigue] is the only reason why I am living in this housing condition. One of my brothers is in Kratsi and the other one is in Cote d'Ivoire. The one in Kratsi wanted me to come and help him- he is a fisherman and he needs someone to smoke the fish for him, his mother is also sick, but I can't because if I go and I become sick what will I do... this virus has prevented me from living with anybody... Because when I told my father I was going to my sister's place he said that "what am I— a sick person— going to do there? What would I do for them? Am I going there so that they should serve me?" Also, when I said I was going to his sisters at Adidome he said the same thing. (R23, female)

The virus-related fatigue prevented this woman from living with relatives. Worse yet, her HIV-positive status forced her to beg for food from neighbors to feed herself.

d) Quest to hide HIV status

The attempt to hide an HIV-positive status led to the residential relocation of some PLWHAs. For instance, one respondent moved from a family house to a worse (rented) housing unit to hide her HIV status. This respondent clearly stated: "I was staying with my husband in his family house, but because of this disease [HIV] we decided to move out of the family house to have more privacy" (R6 female). There is no privacy in a typical Ghanaian family house as "any family member can enter your room anytime he or she likes" (R3, female). A person cannot be completely assured of hiding his/her HIV status in a family house. Thus, PLWHAs vacated the extended family dwelling units— where they were not required to pay rent— and relocated to rented units— where they had to pay rent. This situation could increase the financial expenditure of PLWHAs.

A respondent who was living with a friend prior to his HIV diagnosis added that the attempt to hide his status compelled him to move into his own apartment before it was completed: "We hadn't finished when I made us move in.... We were staying with a friend, so it was after HIV diagnosis that I rush to build my house so that no one gets to know my status" (R34, male).

4.2.3.2: Indirect effect of HIV on housing

Living with HIV indirectly affects the housing situation of respondents through different mechanisms. Many PLWHAs experience fatigue and are unable to work; this affects their ability to earn income, and they can no longer afford adequate housing.

a) Inability to work after HIV diagnosis

Almost all the unemployed participants said the fatigue they experienced after HIV diagnosis prevented them from working and this affected their ability to pay for housing. One unemployed respondent indicated:

I am not able to work... If I am strong and can work as I used to, then I would have rented a better apartment to live in than where I am living now. My husband evicted me but if I had money I would have rented a similar place to stay but because I am not working it's impossible. (R2, female)

The interview with this respondent revealed that before her HIV diagnosis, she was employed in the informal sector of the economy; she was a fish seller in the market. This business was lucrative and allowed her to build a house (together with her husband's income). However, because of the HIV-related fatigue, she was unable to continue working. This resulted in her inability to rent a decent dwelling unit after she was evicted. Another unemployed respondent, previously a retailer, said her inability to work due to fatigue inhibited her movement out of the home where she was greatly stigmatized:

The money, even what to eat is a problem... the person who supplies me with the plantain tells me I am too sick to be working. She refused to supply me with the plantain... I don't have money to rent one [a home] ... I have not gone to look for any room; I told you even what to eat is a problem. (R23, female)

An unemployed respondent affirmed;

I am not supposed to live where I live currently; when I look at myself it's clear to me that this is not where I ought to be. Because I deserve better than that... It's the

money... I used to do some trading but couldn't do that after the disease began to take a toll on me... I was very much affected. I don't know whether I would be able to operate a business like I used to. That's the only thing that worries me. (R38, female)

Respondent 38 felt she deserved a better housing unit, yet her inability to work made it impossible for her to relocate to the housing unit she deserved.

As these narratives show, the inability to work as a result of fatigue prevents many PLWHAs from financing or living in adequate housing units.

b) Inability to continue with previous work after HIV diagnosis

Although other PLWHAs were employed, they said the inability to continue their previous work was caused by HIV-related fatigue. This forces them to resign from previous work and resort to menial jobs. The inadequate income from these jobs prevented them from financing adequate housing units. A female participant stated:

I am staying in this [current] house because I cannot afford to rent an apartment or build a place of my own since the work I am doing doesn't fetch me enough income... The work I was doing before I was diagnosed I am not able to engage in that work anymore because; I am not as strong as I used to be. I was selling firewood before I was diagnosed with HIV. I now work at a public toilet in my area... the business is very bad so getting money is my only problem. (R8, female)

Other respondents noted that although they had not resigned, HIV-related fatigue had compelled them to reduce the level at which they were engaged in the business. This situation affected their profit margins, lessening their ability to afford adequate housing units. For instance, a female respondent living in an uncompleted house indicated:

It's just that I am not able to work as I use to, so as to continue with my building... I don't have a kitchen and toilet, I only have a bathroom. I started [this building] before I was infected with this virus but since I started taking the drugs I was unable to trade/sell like before.... At first, I used to travel to the North, I go to Techiman to buy maize but since I became very sick I am not able to go there anymore, I give my money to colleagues who go on such journeys to buy the maize for me. (R21, female)

A respondent who had been renting a good room was compelled to move to a family house which was on the verge of collapsing because of her inability to finance her previous home:

Now I prepare and sell “suya” sticks... At first, when I returned from Ivory Coast, I sold kenkey [local food made from corn] for a while and then I moved to Ashaiman, where I sold plantain in large quantities. This was before I was diagnosed of HIV... I was taking care of my children, I hired a place I wanted. I could send my children to school till I got this problem [HIV]. As a result, everything came to a standstill, I couldn't continue with that business anymore I [currently] live in a family house. At first, I rented a room but due to financial difficulties I returned to the family house where we usually sleep outside... the family house is old and so it leaks when it rains. You'd have to collect the water in bowls... Even the town council gave us a warning that the house could kill someone but alas! I can't rent a place. My light was disconnected two years ago because I couldn't pay the bill. Whenever it's about to rain and the winds blow strongly I am frightened because the roof shakes fiercely... (R31, female)

In other words, the inability to continue with previous jobs — mainly as a result of HIV-related fatigue — informed the current housing conditions of some PLWHAs.

4.2.4: Effect of housing on health

Finally, this research explores the mechanisms through which housing conditions affect health outcomes. Results show that the housing situations of PLWHAs are major determinants of their mental, emotional and physical health outcomes.

4.2.4.1: Effect of housing on the physical health outcomes of PLWHAs

Findings indicated that the housing conditions of PLWHAs greatly affected their physical health outcomes. Although living with HIV affected the general well-being of all PLWHAs, the majority of those in poor housing conditions reported worse physical health outcomes than those in relatively better housing units. For instance, three out of the four participants who were virtually homeless experienced severe body and joint pain.

Respondents were asked how their current housing situation affected their physical health; the PLWHA sleeping on the veranda stated:

I have a lot of problems with that. My thighs hurt badly, my knees often feel weak and painful I'm not happy. All my legs hurt. The doctors said it's the cement [where she sleeps]. Mosquitoes, they said it's also because of the mosquitoes. My eye as you see it, it itches severely. So now it's both my thighs and my eye. I would say I often feel cold [because I sleep outside]. (R35, female)

In some cases, inadequate housing conditions exposed PLWHAs to mosquito bites, making them vulnerable to malaria. A PLWHA living in an uncompleted building said:

It is as if I share my room with the mosquitoes. It's just the past nine months that I hadn't been admitted to the hospital for malaria and skin rushes. But from the beginning almost six years I have always been sleeping in the hospital. In fact, it came to a time I was telling God to take my soul, so I can be with him. (R23, female)

The deplorable housing situations of PLWHAs aggravate the negative health implications of living with the virus.

The neighbourhoods/location of PLWHAs also influenced their physical health outcomes. Participants living in unfavourable neighbourhood conditions reported worse physical health outcomes. For example, a respondent living in a water-logged area said she experienced constant pains and weakness after pushing rainwater out of her home:

Whenever we try to drain the water out I feel tired with pains all over my body. I don't have anybody to push the flood away for me, so I do it myself... Sometimes I feel sever pains in my hip joint. When I walk for a short distance I have to stop for some time before I can continue my journey. Sometimes I feel pains all over my body. (R26, female)

Another respondent mentioned:

Where we stay, even if it doesn't rain, you notice water in the soil making the place look green-green [molds]... there is dust around... Yes, there is a lot of noise... this ear cannot hear. For some time now, I feel like there is some animal roaming in my ear but when I insert an object into it nothing comes out ... for about a month now I feel pains in my bones as if I have rheumatism... and also some pains in my lower abdomen; even as we are sited now I have chest pains. (R16, female)

Although what this respondent described as rheumatism has not been clinically confirmed, literature associates the presence of mold and damp to the onset of rheumatism (Miller, 1926). It is possible that the rheumatic symptoms noted by Respondent 16 may be linked to mold and damp in her housing environment.

4.2.4.2: Effect of housing on mental and emotional health of PLWHAs

Results also showed that inadequate housing predisposed PLWHAs to negative psychological and emotional health outcomes. For example, some respondents indicated that their poor housing environment (including stigma) clouded their thinking and lowered their happiness level which predisposed them to depression and anxiety.

a) Effects of stigmatization on emotional and psychological health

As evident from the interviews, stigmatization behaviors destabilized PLWHAs and led to depression. One respondent said:

Since I was diagnosed with HIV, my father does not relate well with me, so I am always depressed. I am always not happy with myself... I don't have any happiness in the house, the way my siblings treat me in the house does not make me feel happy at home... "Eii, Chinake", I have first class in thinking because the condition [stigma] I live in worries me. So, I think a lot because of what my father and siblings are doing to me, to the extent that I don't even have food to eat. But people advised me to stop thinking because it won't be of any help to me. I feel I am just in this world for nothing, I feel hopeless. I don't have anywhere to go, and I don't have anything to do... if not for the fact that I attend church, I would have drunk poison. If death did not come to kill me I would have killed myself... in fact it came to a time I was telling God to take my soul, so I can be with him. (R23, female)

The discriminatory behavior of the father and siblings was the main cause of this respondent's psychological health problems as she personally associated her depression with the ill-treatment. Another respondent expressed it even more vividly: "I felt depressed one day. I awoke up one day and didn't know where I was. I myself didn't know where I was, and I felt like talking" (R35, female). Although this respondent did not mention the cause of her depression, like

Respondent 23, she was stigmatized by her relatives, including her biological daughter and mother.

Due to stigmatization (either perceived or implied), respondents constantly feared eviction. When asked if she was afraid of eviction, one respondent stated: “Yes, as long as the house is not mine” (R17, female). Although this respondent was not stigmatized by her mother-in-law with whom she lived, her biological mother had evicted her previously, creating the constant fear of future eviction by her in-laws. Another respondent responded to the question as follows: “Yes, so all the time I am careful so that nobody knows I am HIV positive” (R1, Female). The discrimination and stigma she had suffered in her previous residence led to constant fear of eviction from her current house. Living in fear had negative psychological effects on PLWHAs.

PLWHAs felt compelled to isolate themselves from others because of stigma. Respondents indicated that they could not build strong social ties with their housemates and neighbours. One respondent who was stigmatized in her current home noted: “Because of their attitude I isolate myself. Yes. I keep my distance” (R35, female). Another respondent noted: “I don’t relate to the people in the house. I only greet them when I meet them. I am always in my room with my husband and children. I don’t chat with the other tenants” (R6, female). Still another said:

Yes, I isolate myself because I want to prevent people from discriminating against me. I isolated myself because I felt people knew I was HIV positive. I always think when I am among people they will talk about me and also point fingers at me to their friends, so I isolate myself. (R1, female)

Importantly, PLWHAs who isolated themselves from others believed that doing so enabled them to conceal their status and avoid stigma. In their view, isolation provides some level of privacy.

A few isolated themselves because they felt their HIV status made them unequal to other human beings (self-stigmatized). This was mirrored in statements like the following: “Yes because I am not equal to them” (R23, female); “I don’t go among them and do not take anybody’s thing. I was self-stigmatized” (R20, female).

b) Effect of fear of disclosure on emotional and mental health

Some PLWHAs lived in their dwelling unit — in some cases the same room — with relatives who were ignorant of their HIV status. For this reason, they lived in constant fear that their HIV status would be discovered, and this affected their psychological and emotional health.

For instance, one respondent indicated:

The only thing is; because I don’t want anybody to know [my status], anytime I have to take the drug I have to make sure nobody is around. And I have to keep my drugs well and sometimes when I leave the house and I remember I have not hidden it I start to think of it. My wife doesn’t want me to be putting my drugs anywhere. It’s a problem. (R30, male)

Similarly, a respondent noted:

I stay in the same house with my daughter, but she doesn’t know I am also HIV positive I hide my drugs in my bag when I am going to work, I take it along. In fact, I take it everywhere I am going. but maybe if I had a room to myself and my daughter also has a room to herself I will be more comfortable and stop hiding my drugs since I can just lock the door when I am going out or going to work. (R8, female)

Another PLWHA stated:

You must take your drugs every day and someone might ask you why you are always on medication, what are you going to tell the person? Are you going to say headache? Does your head ache every day that you constantly have to be on medication? They will ask you a lot of questions, so you have to hide before taking your medicine. (R25, Female)

The fear of disclosure compelled respondents to constantly hide their medications or take them in hiding. This imposed incredible emotional and mental burden. As indicated in the second

excerpt, living in a separate housing unit could lessen these burdens. The assertion of Respondent 8 was confirmed by PLWHAs who lived in dwelling units which did not require them to hide their medications. These HIV-positive persons said they could take their HIV medication anywhere (either outside or in the room), without having to hide their drugs from anyone: “I don’t have a problem with hiding it from anybody” (R28); “I have the liberty to take it anytime and anywhere” (R12, female).

Participants who hid their medications normally fabricated stories to cover up when they sought medical service. For instance, one respondent revealed: “Sometimes when I am coming to the hospital I tell them I am going to the market. So, they have no idea where I went to” (R3, female). Another stated: “I just tell them that I am coming home for a visit [relatives] and since I don’t go to the hospital there— in Accra, it is a nice way of not informing them I am coming here [for HIV treatment]” (R11, female). Constantly having to make up stories to hide one’s HIV status could have a negative impact on psychosocial wellbeing. For one thing, it could lead to feelings of guilt.

Although some of these fabricated stories worked for a while, they could be short lived or inadequate over a long period. For instance, one respondent who tried to keep his status a secret had to seek financial assistance (transportation fee) from his children before visiting the hospital:

One of them asked what I was always coming to the hospital to do but has never been cured. He even stated that one of them will one day follow me to the hospital to know what is wrong with me. And I said okay, if they think the doctors are not treating me but I just come for the money, they can come with me to the hospital but after that nobody said anything else. (R29, male)

This respondent’s attempts to keep his secret combined with the need to lie to his children were obviously affecting him.

c) Effect of inadequate housing on emotional and psychological health

When respondents were asked whether their housing had any impact on their mental and emotional health, some attributed their lack of basic amenities to their emotional and mental distress. For instance, one PLWHA who lived in a house without electricity noted:

Yes. It has affected my health in the sense that sometimes when I sleep there is heat in the room and I have a fan but need electricity to power it. So sometimes [during the night] I wet a towel to wipe myself. I don't get enough rest/sleep. When the weather is cool [good] I sleep sound but when there is heat I can't sleep... My only challenge is with the light, if I have electricity I will be able to watch television which will make me happy. (R21, female)

This participant experienced sleepless nights due to high humidity at night. The lack of electricity was another problem; the ability to watch television could have boosted her emotional health. Without electricity, she was less happy.

A few participants said the absence of basic amenities (toilets) in their home exposed them to danger whenever they used the bush as a lavatory. For example, there is a likelihood of encountering snakes and scorpions in the Ghanaian bush. One participant detailed: "We don't have toilet in the house and sometimes my stomach disturbs me at dawn and going to the bush is dangerous" (R25, female). Another respondent testified: "I think a lot because of the nature of the house. Sometimes I feel like using the toilet at midnight but because we don't have a toilet facility I have to go to the bush which is risky" (R2, female). This persistent stress had tremendous effects on the emotional health of PLWHAs. One woman said:

I am not as strong as I used to be so walking long distances just to use the toilet or the bathhouse is a problem for me... Yes, because if I were to be living in a better house [with toilet and bath] I won't be so worried and even when my situation [HIV] becomes worse no one will know. (R7, female)

4.3: Conclusion

This chapter outlines the findings of this study based on data from in-depth interviews of 38 participants. It uses sections of the transcripts to develop the four broad themes that emerged from the data: housing conditions of PLWHAs in Ghana after HIV diagnosis; residential relocation after HIV diagnosis; effects of HIV on housing; effect of housing on health outcomes.

CHAPTER 5

DISCUSSION

5.0: Introduction

Recent evidence shows that housing affects the health outcomes of individuals within populations. For vulnerable populations like HIV-positive persons, the relationship between housing and health is more complex. On the one hand, poor/inadequate housing may be associated with poor health outcomes of PLWHAs, while on the other hand, living with HIV could undermine the ability of PLWHAs to live in adequate homes. Due to HIV-related fatigue and employment-related discrimination, PLWHAs are unable to sustain employment and become financially unstable consequently. For this reason, they are unable to finance adequate homes; making them resort to cheaper and substandard homes. Even at home, PLWHAs are stigmatized and face discrimination by their housemates and relatives after disclosing their HIV-positive status. These discriminatory behaviors include the termination of relationships, name-calling and rejection which directly or indirectly change how common spaces are shared. Many are forced to leave, and as Bacon et al. (2010) observed, to deplorable housing conditions.

In this thesis, I employed qualitative methods to provide the lived housing experiences of PLWHAs and to explore if living with HIV affects the housing conditions of PLWHAs. I asked four main questions:

1. What are the housing conditions of PLWHAs in the LMKM, Ghana, after HIV diagnosis?
2. Do PLWHAs in the LMKM change their housing situation after HIV diagnosis? Why/ Why not?

3. Does the health (HIV) status of PLWHAs influence their housing choices and conditions?
4. How does the housing status of PLWHAs after HIV diagnosis further impact their health?

The sections that follow discuss the findings in light of these research questions.

5.1 What are the housing situations of PLWHAs in the LMKM, Ghana after HIV diagnosis?

The definitions of homelessness and inadequate or adequate shelter are context specific, as different countries employ different indicators to measure them. Triple and Speak (2006) identified differences between homelessness in developed and developing countries. They noted that with ‘homelessness’ defined as “those in shared and transient accommodation, those with certain levels of overcrowding, those in poorly serviced, inadequate or damaged dwellings, and those likely to become homeless in the near future, especially on release from institutions” (Triple & Speak, 2006, p. 60), the concept is sometimes used as a synonym for ‘inadequate housing’ in developed countries. However, in developing countries like Ghana, only individuals “with no roof over their heads” are classified as homeless (Triple & Speak, 2006, p. 65). With this narrow definition, only 3% of Ghanaians can be classified as homeless (Boamah, 2010). This means individuals who live in kiosks, cargo containers, tents and abandoned offices/shops are all grouped under the housed in Ghana (Boamah, 2010; Triple & Speak, 2005). Findings from this study are consistent with those of Boamah (2010), as respondents who dwelled in kiosks did not identify themselves as homeless but rather as individuals with a housing unit. Although study participants did not define their dwelling in kiosks and cargo containers as synonymous to homelessness, given that these structures are often erected on undesignated spaces and could be demolished by town planning committees, the study classified this form of

housing arrangement as “virtually homeless”. It was important to distinguish these individuals from inadequate housing dwellers because health studies, mostly in developed countries, show a significant difference in the health outcome of the homeless and that of inadequate dwellers.

Results from this study confirm the deplorable housing conditions for PLWHAs in the LMKM and Ghana. Averagely, rooms in Ghana are 12 by 12 feet and can adequately house 2 persons, yet respondents shared their sleeping space with 3 or more relatives (including their personal belongings, bags and suitcase). This results in overcrowding: the majority of the respondents I interviewed lived in overcrowded housing units. Coupled with high temperatures (average temperature of 21°C to 28°C with 77% to 85% humidity), overcrowding inhibits proper ventilation and increases room temperatures. This obstructs night sleep. Overcrowding also increases the likelihood of accidents in the home; inhibits privacy; facilitates the spread of opportunistic infections — tuberculosis and Hepatitis B. These findings are consistent with the earlier studies of Bansal and Saxena (2002), Bashir (2002), and Marshy (1999), who similarly identified a relationship between deplorable housing conditions and the spread of tuberculosis and Hepatitis B in the United States and India. Similar findings were noted in a Nigerian study, where one out of three PLWHAs resided in inadequate housing with overcrowding or/and a lack of basic infrastructure (Nussbaum, 2010). As the case was in my study, the housing units of respondents were in deplorable conditions and on the verge of collapsing; a quarter had no electricity in their homes; more than half had no kitchen and running water within their home. This meant that some had to buy water from unhygienic public places exposing them to “waterborne” diseases and increasing their financial burden. Lack of running water within a home increased clinical visits for diarrhoea, respiratory disorders and skin diseases. Perhaps, the words of this respondent capture the experience of living in a deplorable condition, “I dislike a

lot of things in the house. I don't even like the idea of staying in a family house because there is no peace. There are issues and quarrels every day, because of that there is always noise, and you don't also get the privacy you want. There is no toilet facility in the house, no bathroom and no running water. In fact, there is nothing in the house, but I am staying there because I have nowhere to stay".

What does the deplorable housing conditions mean for PLWHAs? Diarrhoea is a common side effect of HIV drugs yet, the majority (3/4) of HIV-positive persons in this study did not have toilet facilities in their homes in case of this emergency. They therefore resorted to public toilets; Public toilet serves a whole community and require its users to take turns by joining long queues (see figure 2). Waiting in long queues in emergency situations, diarrhoea, can result in public shame and disgrace as PLWHAs are unable to hold their faeces for long. Some familiarity with Ghanaian culture also shows that discharging faeces involuntary in public is abhorred even if it happens to children and minors. For an adult, it is completely unacceptable. In smaller communities where rumours and gossips spread quite easily, consistently and involuntarily discharging faeces in public can be a very disturbing experience. Therefore, one could understand the concerns and the enduring pains of my study participants as they shared their stories about access to public toilets as PLWHAs. Furthermore, public toilets are commercialized and require a fee ranging from 20pesewas to GHC1 (USD equivalence of 5cent to 30 cent) per use. Although this may not be a lot of money to many people in Canada, for the average Ghanaian who lives below USD2 a day, this is a lot of money. Frequently using this facility because of diarrhoea adds to the financial burden of respondents. PLWHAs who could not afford the fees resort to indiscriminate defecating in the bush and stand the risk of snake bites. This could also create conditions for spreading cholera in the community. Meanwhile, it is

documented that without these facilities, PLWHAs may not adhere to HIV treatment and therapy like taking their drugs regularly (see Carr & Cooper, 2000; Foudraine et al., 1998; Msellati et al., 2003; Wood et al. 2003).

Another important theme in the HIV literature is discrimination. Many studies show that after HIV diagnosis and disclosure, PLWHAs are subjected to diverse forms of discrimination from their relatives and communities, although the degree of discrimination varies across countries (Bacon et al., 2010; Bharat et al., 2001; Bogart, 2008; Cloete et al., 2010; Mwinituo, & Mill, 2006; Ulasi et al., 2009). Results from this study are largely consistent with the findings above, in that housemates, relatives and communities limited contact with PLWHAs. As shown in this thesis, most of the study participants experienced daily discriminatory attitudes from family and friends. This includes, family members and fellow tenants refusing to share beds, bathing buckets, eating bowls and spoons with them. Some people even refused to sit close to PLWHAs. The experience was even more disturbing for HIV-positive vendors where people in the community refused to patronise their products further creating financial burdens for them. HIV-related discrimination or stigmatisation was mainly informed by misconceptions associated with HIV transmission. Relatives and community members perceived that sharing common space with PLWHAs or buying from HIV-positive vendors made them susceptible to the virus. Some PLWHA were even evicted from the housing units they shared with relative as a result of discrimination. As similar studies in Ghana, South Africa, Ethiopia, India and Vietnam have shown, PLWHAs experience the worst form of discrimination mainly because of a lack of understanding of the nature of HIV and how it spreads (see Aseidu & Myers-Bowman, 2014; Bharat et al. 2001; Cloete et al. 2010; Mill, 2003; Simbayi et al., 2007).

Existing literature indicates that stigma could be perceived. Perceived stigma increases the rate of non-disclosure of HIV status (Derlega, Winstead, Greene, Serovich, & Elwood, 2002). Evidence from this study confirmed this; some PLWHAs perceived stigmatization upon disclosure and, as a result, felt compelled to hide their HIV status and medications. One thing that became clear in my study was that the fear of stigmatization can by itself affect the housing of PLWHAs, especially as some participants relocated from homes with better conditions to others with worse conditions to hide their status. In a previous study in Ghana, Mill (2003) similarly observed that PLWHAs hide because of perceived HIV-related stigma. The downside to non-disclosure of HIV status is that individuals living with the disease were denied an opportunity for receiving support from sympathetic family and friends — thus making their lives more difficult, both physically and emotionally. Many of my study participants were aware that non-disclosure of HIV status can deny them the much-needed support from family members and friends, yet in the event of disclosure they perceived that the risk of being found in the community for living with HIV/AIDS far exceeded any potential help from friends and family members. This was made clear in statements like: “There is no need for me to tell them since they will only discriminate against me and mock me. In my current house no one knows I am HIV positive”.

In summary, the majority of HIV-positive persons in this study lived in poor housing conditions, including tenure insecurity, overcrowding, and a lack of basic amenities. In addition, they were stigmatized or feared stigmatization upon HIV disclosure and made every effort to hide their HIV status.

5.2: Are PLWHAs in the LMKM more likely to change their housing situations after HIV diagnosis?

The finding that some PLWHAs changed their dwelling units due to (perceived) stigmatisation, led me to explore if PLWHAs were more likely to change housing after HIV diagnosis. Although no known study in Africa explicitly examines this relationship, studies in Western industrialized countries speculate that the housing conditions of PLWHAs are likely to change over the progression of the virus (Ticknor & Belle-Isle, 2010). There are arguments that after HIV diagnosis, a substantial number of PLWHAs are unable to finance housing costs and as a result face eviction (Bacon et al., 2010; Nussbaum, 2010). This directly or indirectly results in PLWHAs losing their homes (Bacon et al., 2010; Nussbaum, 2010; Ticknor & Belle-Isle, 2010). Consistent with these arguments, I found that the housing conditions of the majority of PLWHAs changed after HIV diagnosis and disclosure. As discussed in the next section, varied reasons influenced these residential relocations: eviction due to stigmatisation, inability to afford rent, quest to hide HIV status and death of a cohabiting partner.

Although changing housing conditions could be beneficial, this was not generally the case for my respondent. More than half of the respondents who relocated after HIV diagnosis moved to homes that were uncompleted, lacked a basic facility, easily got flooded or had unfavourable housing environment. Importantly, all four respondents whom I classified as “virtually homeless” moved into kiosks and cargo containers after HIV diagnosis. My findings showed that respondents dwelled in substandard homes because they were unable to find and afford adequate shelters after losing their homes. This forced them to accept worse housing conditions which were comparatively affordable or easier to find. These worse housing ranged from overcrowding, to a lack of amenities — toilets, bathrooms, kitchens, and running water —,

to physically deteriorating structures and uncompleted buildings. Findings support the argument of Bacon et al. (2010) and Milloy et al. (2012) that after losing housing units, PLWHAs resort to substandard homes.

A few PLWHAs did not relocate after HIV diagnosis. Importantly, these PLWHAs said their housing were inadequate and no longer conducive. For these reasons they wanted to relocate. Yet, fatigue²⁰ and financial constraints inhibited them from doing so. This was because for some PLWHAs, especially those in family homes who do not pay rent, relocating meant moving to a house that required paying a two-year rent upfront. Considering that PLWHAs in this study were either unemployed or employed in the informal sector where they earned below USD2 a day, most were unable to pay USD220 upfront: findings show that averagely PLWHAs paid a monthly rent of USD9.14 (GHC40). This prevented them from moving out of substandard homes. For others, relocating meant shouldering the responsibilities of sweeping, fetching water or performing other domestic chores previously performed by younger relatives dwelling within the family house. PLWHAs stated that they were unable to engage in these tasks because living with HIV — especially being diagnosed at the symptomatic stage — made them weak and fragile. This compelled them to remain in substandard homes as was the case of one PLWHA: “But when my son saw the way I was treated, he relentlessly searched for a place and had a room, but I am now fragile and weak. If I rent a room, I would have to sweep and do other things by myself, I have been battling with malaria and cough a lot because of the HIV medicine... Where can I go? For four days now, I haven’t been able to go anywhere. My veins are swollen”. This finding is largely consistent with Bacon et al.’s (2010) work in Ontario which showed that some PLWHAs remained in substandard homes because they needed personal care from their current housemates.

²⁰ Fatigue makes these respondents dependent on others for personal care.

Results from this study showed that marital obligations also prevented some PLWHAs (widows) from relocating. Among the Ghanaian patrilineal descent group, marital relation continues even after the demise of the husband: this is because a woman through marriage belongs to her husband's family and literally loses ties with her own family. In some cases, widows are allocated a room in their husband's family house after the death of their spouse. Irrespective of the conditions of the room, these widows are expected to remain in their matrimonial homes with their in-laws as a proof of their loyalty to the deceased husband(s). The widowed PLWHAs in this study affirmed that they were allocated rooms in their husband's family house, but these rooms were substandard. When asked why they did not move out of the substandard homes they responded, "there is a reason, that was the home I got married into". It is important to note that in the Ghanaian cultural setting moving out of such homes without the approval of the husband's family members meant moving out of the marital union. This also requires the widow to leave behind all properties acquired during the union, including the children. This cultural practice makes it difficult for PLWHAs to move out of substandard homes even if they want to. As evident from the results, one PLWHA who desired to relocate was unable to move because her husband's relatives disapproved of her movement. This forced her to live in a substandard home. In other instances, the marital obligation of taking care of children and other immovable properties (farm lands and houses) prevented the residential relocation of participants. For this reason, they remained in substandard homes.

5.3: Does the health (HIV) status of PLWHAs influence their current housing choices and conditions?

Previous studies on the housing-health relationship for PLWHAs mostly examined the effect of housing on HIV re-infection/transmission, adherence to treatment and health outcomes;

it observes that poor housing conditions are significantly related to poor adherence to ART and other important health-outcomes (Aidala et al., 2005; Berg et al., 2004; Kidder et al., 2007; Leaver et al., 2006; Milloy et al. 2012; Palepu et al., 2011; Tenkorang et al., 2017). However, some evidence suggests the housing-health relationship as more complex (Interagency Coalition on AIDS and Development, 2010; Milloy et al., 2012; The North American Housing & HIV/AIDS Research Summit Series, 2011). Although housing directly or indirectly affects the health of PLWHAs, living with HIV could also affect the housing situations of PLWHAs (National Coalition for the Homeless, 2009; The North American Housing and HIV/AIDS Research Summit Series, 2011). In search for evidence to support this bi-directional relationship, this study through qualitative in-depth interviews explored the housing situations of HIV-positive persons before and after HIV diagnosis.

Results from the study confirmed this argument; living with HIV worsened the housing situations of the PLWHAs I interviewed. For instance, the HIV-positive status of participants was arguably the major reason for losing and relocating to substandard homes. Directly, PLWHAs were forcefully evicted from their homes because they were infected with HIV: PLWHAs clearly stated “if not because of this sickness my husband wouldn’t have sacked me from his house”. It is important to highlight that although this respondent contributed to building a home with all the basic facilities, her husband sacked her from the home just because she was HIV positive. Ideally, this woman should have sought justice after she was evicted from the home, yet she could not do so because the cultural norm of the Krobo’s inhibits women from owning landed properties including housing. She could not also seek the support of family members to arbitrate because doing so will only expose her HIV status, further resulting in stigmatization. Coupled with her inability to finance another home, she was left with no option

than to reside in a housing unit that lacked all basic amenities — no running water, no toilet, no bathroom.

For respondents who dwelled in ancestral (family) homes, they noted that although their relations wanted to evict them, they were unable to do so because being a highly religious culture, it is believed that evicting someone from a family home meant disassociating them from their ancestral root. This act can incur the wrath of the ancestors on the perpetrators. For this reason, they were greatly stigmatized as a substitute for eviction. PLWHAs who were unable to withstand being stigmatised, moved out of such units voluntarily for their “peace of mind”. This was shown in statements like: “But they were discriminating against me. There was this man in the house who will scrub the bathhouse after I finish using it before he uses it because he felt I had HIV... yes, he scrubs only when I finish bathing... I move out of the house to avoid all these discriminations. Some insulted me or say bad things about me. I become very worried and begin to re-think. I sometimes cook but I am not able to eat because of the things people are saying. I decided on my own to leave the house so that I could get my peace of mind”.

Stigmatization is very rampant in the Ghanaian society because of misconceptions on HIV infection; HIV is a curse or punishment from the gods for sexual sin or a disease for the sexually promiscuous. Family relations stigmatise PLWHAs because it is believed the family is responsible for the actions of each member, hence, a family can be tagged an “HIV family” because of one PLWHA in the family. Limiting contact with HIV-positive persons is therefore seen as a way of preserving the family’s name and integrity. It was for this reason that the marital relationships of two PLWHAs were terminated and the mother-daughter relationship of two PLWHAs were suspended after they disclosed their HIV status. In line with this, Bharat et al. (2001), Oluwagbemiga (2007) and Steward et al. (2008) noted that because of HIV related

discrimination, PLWHAs, especially women were often asked to vacate their housing units. Once evicted, the respondents I interviewed were unable to find a suitable place to reside because “nobody wants to be in a house with an HIV-positive person”. Landlords and tenants were unwilling to share dwelling units with HIV positive persons because in a communal setting like Ghana the housing design requires its occupants to share common housing facilities if present: Housing discrimination was fuelled by the misconception that HIV can be transmitted by sharing common facilities like toilet and bath with PLWHAs, sitting close or sharing the same meal with PLWHAs. These findings are similar to others from Kampala (Uganda) that showed discriminatory behaviours against PLWHAs by landlords (Nussbaum, 2010).

Hiding HIV status is crucial to evade stigma in a highly HIV stigmatised society like Ghana. Yet, the strong social networks HIV-positive persons build with housemates and community members before diagnosis inhibits privacy and makes it impossible to effectively hide an HIV status. Being a close-knit and communal society relatives and friends can walk into each other’s room with little or no restriction as confirmed in the statement: “any family member can enter your room anytime he or she likes”. Results show that although they did not voluntarily disclose their HIV positive status, some respondents were suspected of being HIV positive by immediate family members. In the quest to hide their HIV status and elude stigmatization, these PLWHAs relocated to new homes where such networks did not exist and privacy can be maximised. However, their inability to pay rent costing USD220 upfront compelled them to settle for substandard and cheaper homes. Some even resorted to uncompleted buildings because they perceived the cost of living in substandard homes to be better than being stigmatised by community members. Other PLWHAs who could afford USD220 rent were unable to find suitable places because landlords by a mere cross-examination were able to suspect PLWHAs,

hence refused to rent their structures. This forced PLWHAs to resort to inadequate homes. If they found new homes, PLWHAs were careful not to build social ties with neighbours by isolating themselves from communal activities.

Likewise, my study revealed that the HIV status of PLWHAs indirectly affected their housing. Due to the low patronage of voluntary counselling and testing, PLWHAs are diagnosed at the symptomatic stage of the virus, when they are bedridden: It is important to understand that due to the close-knit and communal setting of my study area, relatives like to visit family members, but even more so when they hear a member of the family is sick. For HIV/AIDS, the symptoms — growing lean, losing hair, having shingles, goitre, and prolonged diarrhoea — made family members suspicious of PLWHAs, although they do not voluntarily disclose their status. The close-knit and communal nature of the society makes it easier to spread rumours of HIV-suspected persons. As a result, PLWHAs faced discrimination at the work place leading to their resignation or dismissal. In the informal sector PLWHAs were unable to continue with previous jobs because “nobody wants to buy from an HIV positive vendor” so as to be infected. Findings from this study shows that customers refused to even buy uncooked plantain that can in no way be contaminated or infected with HIV from persons they suspect of living with the virus. PLWHAs therefore resorted to poorer paying jobs like farming, selling kebab sticks, etc. with little income or become unemployed. Low income inhibited PLWHAs from meeting housing cost. Inability to finance housing forced PLWHAs to relocate to rented homes which were more affordable or family homes where they do not pay rents: These homes were mostly substandard and were in deplorable structural state. The above finding is in line with studies from Panama, Zambia and the US showing that PLWHAs cannot finance decent homes because of their low income (Adaramaja, et al., 2015; Bacon et al., 2010; Nussbaum, 2010; Song, 1999). Also,

PLWHAs in this study were unable to work or continue with tedious work because of HIV-related fatigue.

5.4: How does the housing situation of PLWHAs further impact their health?

Housing significantly affects health outcomes (Haslam et al. 2009; Howden-Chapman, 2004; Krieger & Higgins, 2002; Warner et al., 2000). For HIV-positive persons, poor housing is related to adverse health outcomes as it exposed PLWHAs to opportunistic infections or inhibits them from adhering to treatment (Aidala et al., 2007; Braistein et al., 2005; Leaver et al., 2006; Milloy et al., 2012; Palepu et al., 2011; Tenkorang et al., 2017). For this reason, my thesis sought to identify the mechanisms through which poor housing negatively influenced the health outcomes of PLWHAs.

The findings shows that the housing conditions of PLWHAs affect their physical, emotional and mental health outcomes. The study's PLWHAs who were inadequately housed reported physical body weaknesses, a finding also reported in the quantitative data collected for this project (see Tenkorang et al., 2017). The qualitative data analysed in this thesis shed light on two mechanisms through which housing could affect health outcomes. a) Poor housing conditions were unable to protect HIV-positive persons from harm, for instance, mosquito bites — making them susceptible to malaria infections. Malaria is a common disease in Ghana and accounts for 32.5% of all OPD visits (Ghana Health Service, 2015). The weak immunity of PLWHAs puts them at a greater risk as they were unable to fight the parasite. For instance, one PLWHA who was exposed to mosquito bites noted: “It’s just the past nine months that I hadn’t been admitted to the hospital for malaria and skin rushes. But from the beginning almost six years I have always been sleeping in the hospital”. Recurrent malaria increases the viral load of HIV positive persons making them weaker and more susceptible to other co-morbidities. b) poor

housing conditions — such as sleeping on the floor and poor room temperature — prevented participants from getting a good night’s sleep. Temperatures in Ghana are usually high and poor ventilation due to overcrowding can obstruct night sleeps. Respondents noted that they were distressed and unable to sleep in hot temperature rooms: they constantly woke up (in the middle of the night) to cool the body’s temperature with wet towels. Although this study did not explore the adverse health effect of sleepless nights, previous research shows a significant relationship between sleep deprivation and cardiovascular diseases (Mullington, Haack, Toth, Serrador & Meier-Ewert, 2009). Insufficient sleep contributes to the development of insulin resistance; inhibits the development of sleep-associated growth hormones; and increases sympathetic outflow to the heart. This exposed individuals to high blood pressure, metabolic changes and type 2 diabetes. Also, Banks and Dinges (2007) and Dahl (1999) found that sleep deprivation results in neurobehavioral defects — lapses of attention, slowed working memory, irritation and low tolerance during the day. It is highly possible that PLWHAs in this study could be facing such neurobehavioral defects and cardiovascular diseases because of sleepless nights.

The lack of basic amenities also had implications on mental and emotional wellbeing of PLWHAs especially in a close-knit society like Ghana. The absence of a basic amenities in the home, triggered fear, hopelessness, tenure insecurity, anxiety and depression among the interviewees (see also Chambers et al., 2014). For instance, PLWHAs were anxious that constantly using public toilets because of diarrhoea can “draw people’s attention to their illness”; people will begin to question their frequent visit to the toilet. Respondents perceived a constant surveillance by community members on their movement because they lacked basic facilities and resorted to communal facilities. This was confirmed in the statement: if I were to be living in a better house with toilet and bath I won’t be so worried and even when my situation [HIV]

becomes worse nobody will know”. Further travelling for long distances and waiting in long queues to use toilet facilities added to the emotional burden of PLWHAs. Respondents were disturbed and concerned about being unable to hold their faeces for long — in case of diarrhoea. This, as stated earlier, could result in public shame and disgrace. The findings show that although PLWHAs did not say they indiscriminately defecate in public, the possibility of doing so because of diarrhoea was of concern to them.

A typical Ghanaian home is shared by 2 or more households and as noted above requires its occupants to share some, if not all basic facilities. This to an extent informs the stigmatization of PLWHAs. Stigmatization makes the housing environment unfavourable for PLWHAs, thus affecting their emotional health outcomes. For example, discriminatory behaviors as simple as eating in separate bowls or not sharing amenities (bathrooms, toilets, bathing bucket and soap) had severe implications on PLWHAs. This was because in a typical Ghanaian household, communal living as such depicts love, togetherness, oneness and belongingness. Separating PLWHAs from this meant rejection, exclusion or the termination of relationships and can be similar to ostracism as PLWHAs were exempted for the societal/family gathering and communal living; thus, the core of life. If the study’s PLWHAs were stigmatized inside the home, it became an emotionally perilous place, not one of refuge. Living in an unfriendly/stigmatized environment did not encourage the development of strong social networks to help manage the mental stress of living with the virus. Stigmatization made PLWHAs feel less human. This led to depression and suicidal thoughts. To evade or mitigate stigma, HIV-positive persons were forced to isolate themselves from social gatherings, yet isolation is also linked with depression, cognitive decline and high mortality rate (Chambers et al., 2014; Cornwell & Waite, 2009).

Perceived stigma compelled the study's PLWHAs to conceal their HIV status from relatives and housemates, although they might be sharing the same room with them. HIV-positive persons in this study were constantly hiding their HIV medications to conceal their HIV status: Respondents were worried about taking HIV medications in the presence of their housemates. They were also burdened with constantly burning the containers or boxes of the drugs as throwing it in the refuse dump — normally an open space — was unsafe: Some even kept their medications out of its box to make the drugs anonymous. Smart and Wegner (2000) report, keeping a secret, no matter the nature of that secret, can be emotionally burdensome as the “secret becomes a preoccupation” (p. 222). This cognitive process results in mental/emotional disturbance; thus, excessive thinking about the secret (Smart & Wegner, 2000). Hiding HIV status and medication was consistently identified as emotionally burdensome by the interviewees; PLWHAs were frequently anxious about an accidental disclosure. Keeping their HIV status, a secret also prevented them from receiving social support from relatives, including housing.

Hiding HIV status led to the fabrication of stories which subsequently resulted in feelings of guilt²¹. Guilt as an internal judgement has been associated with psychosocial disorders in humans (O'Connor, Berry, & Weiss, 1999). Drawing from O'Connor et al. (1999), it is possible that fabricating stories to hide HIV status affected the mental/emotional well-being of PLWHAs although questions on guilty feelings because of lies were not asked in this study. Fabricating of stories to hide HIV status led to the excessive thinking of which stories are not just adequate to cover up but also consistent with previous lies. One respondent stated that over time his children wondered why he constantly visited the hospital for treatment but never get cured: this required him to re-think of other adequate cover-up stories for his frequent visit to the hospital. The result

²¹ Dorahy (2010) defines guilt as an individual's negative/harsh judgement of his or her personal action.

also showed that even PLWHAs who had not been approached by relatives were equally disturbed of an adequate story in case they were approached: “You have to take your drugs every day and someone might ask you why you are always on medication, what are you going to tell the person- headache, does your head ache every day for you to always be on medication? They will ask you a lot of questions, so you have to hide before taking your medicine”. This supports Smart and Wegner’s (2000) argument that keeping a secret becomes a preoccupation as individuals consistently think about the secret.

5.5: Conclusions

This chapter discussed the research findings by situating them within previous studies. Consistent with the literature, PLWHAs in this study lived in poor housing conditions which expose them to poor health outcomes. Importantly, I identified a bi-directional relationship between housing and health of PLWHAs and argued that just as housing exposed individuals to adverse health outcomes, so too living with HIV directly or indirectly informed the poor housing conditions of PLWHAs.

CHAPTER 6

CONCLUSION

6.0: Introduction

Previous research theorized housing as a key determinant of the health outcomes of PLWHAs, but no qualitative study examines the lived housing experiences of HIV-positive persons in Ghana or elsewhere. In particular, few studies have explored how living with HIV can influence the housing conditions of PLWHAs. Given these limitations, this study probed a series of qualitative narratives to explore and re-visit the housing and health literature for HIV-positive persons. The study's sample was 38 PLWHAs receiving treatment in two hospitals in the LMKM, Ghana.

Consistent with previous literature, the study found that the housing conditions of most PLWHAs were directly or indirectly affected after HIV diagnosis. For instance, discriminatory acts against PLWHAs within the home directly resulted in forceful eviction and required them to relocate. Unfortunately, the majority of PLWHAs in this study were unable to work/continue with previous work because of their HIV-positive status. This affected their ability to afford adequate housing after losing their homes. In addition, PLWHAs were unable to find adequate homes after losing their housing because of stigma and discriminatory acts by landlords and tenants. The inability to find or finance adequate housing compelled PLWHAs to relocate into substandard homes as they were more affordable or easier to acquire. However, living in such places complicates the physical, psychological and emotional health challenges of living with the virus. Interestingly, some of the study's PLWHAs moved voluntarily in an attempt to hide their HIV status from relatives/ housemates. Unfortunately, their inability to afford adequate housing landed them in poor housing arrangements.

In short, many participants lived in deplorable, overcrowded housing units with no toilet/bathroom facilities, no kitchen, and no running water. The social environment within the home was equally unfavorable because of (perceived) stigma and fear (fear of disclosure). More importantly, the current housing conditions of most PLWHAs were affected (directly or indirectly) by their HIV-positive status.

The thesis augments the existing literature by adding individual voices to the housing needs of PLWHAs in Ghana and the underlying mechanisms linking these to adverse health outcomes. Evidence from the lived experiences of HIV-positive persons exposes the bi-directional/reverse connection between HIV and housing: just as housing affects the health outcomes of PLWHAs, so too living with HIV worsens the housing issues they face.

6.1: Strengths and limitations of the study

This study is unique in providing the first known qualitative evidence of the lived housing experiences of PLWHAs in Ghana. A substantial number of participants lived in dwelling units which were overcrowded, lacked basic amenities or were in a deplorable structural state. By using qualitative methods, I was able to unearth the contexts and experiences of the housing and health needs of PLWHAs in Ghana. With this, the research expands the housing-health literature by identifying an intricate inverse relationship between these variables. Specifically, just as poor housing is linked with poor health, so too living with HIV aggravates housing issues. Based on this finding, the study provides preliminary evidence to argue that living with HIV accounts for the current housing situations of Ghanaian PLWHAs. It also provides first-hand evidence to support housing policies for PLWHAs in the LMKM, Ghana.

Like all research, the study has some limitations. One major limitation is the transcription process. As Poland (1995) argues, transcription leads to errors, including deliberate altering,

accidental altering and unavoidable altering of interviews (Poland, 1995). Researchers acknowledge that although some of these errors can be controlled or minimized, others cannot be avoided. In this research, the accidental altering of words was inevitable as the language of the interview required the interviews to be translated into English during the transcription stage. However, this error was minimized, as the translators employed “back translation” to ensure the meaning of the audio recordings was the same as the transcribed document.

In addition, selecting respondents from the hospital setting excluded PLWHAs who did not utilize health services. Some PLWHAs, especially those in the denial stage, do not utilize health care (Luseno, Wechsberg, Kline & Ellerson, 2010). Since the HIV population is a “hard-to-reach” population because of stigma and discrimination, I employed a facility-based sampling to help recruit participants.

Another limitation is how overcrowding was defined in this study (number of persons per room). Grey (2001) argues that although indicators such as the person per room/room occupancy rate, bedroom standard and bedroom occupancy rate could objectively define overcrowding, subjective definitions of overcrowding are more appropriate especially in qualitative studies like this. In this research, overcrowding was objectively measured using the bedroom occupancy rate. Gray (2001) noted that subjectively defined overcrowding has tremendous effect on health than the objective definition. However, objectively defining overcrowding as the number of persons per sleeping room is in line with Ghana Statistical Services’ definition, making the study’s findings on overcrowding applicable for housing policy makers and the Ghanaian government.

6.2: Recommendations

The results confirm that housing in the LMKM is inadequate and substandard. Living in substandard homes obviously affected the health outcomes of PLWHAs, but it also has

implications for the general public. The Government of Ghana should prioritize quality housing to meet the health needs of its populace. Housing policies and laws should ensure that both rented apartments and unrented apartments like private family homes meet UN-HABITAT's definition of an adequate home. It is important to note that aside providing basic amenities, housing units should remain affordable to the average citizen. This may help reduce the occupancy rate per sleeping room/overcrowding. Providing quality housing will also reduce exposure to toxic substances, the leading cause of morbidity and mortality (infectious and degenerated diseases — cancer and chronic respiratory diseases) (Bonney, 2007; Perdue, Stone & Gostin, 2003, Warner et al., 2000).

For HIV-positive persons, housing is crucial (Cisneros, 2007; Milloy, 2012). Yet evidence from this study shows that living with HIV undermines the ability of PLWHAs to acquire and live in quality homes. This implies that a greater proportion of PLWHAs are likely to have housing issues over the progression of the virus. Policy makers need to recognize the vulnerabilities of PLWHAs and include them in housing policies. Sumartojo (2000) argues that good housing should be considered a major HIV intervention; able to prevent the transmission of the virus and improve the health of PLWHAs. In Canada and the United States, housing assistance is provided to homeless and inadequately housed PLWHAs. A performance evaluation of this intervention finds a significant reduction in risky sexual behavior, improved adherence to treatment, and improved health outcomes (Aidala et al., 2005; Buchanan et al., 2009; Kidder, 2007). Providing housing assistance for PLWHAs is expensive, yet as Aidala et al. (2005, pp. 261-262) argued:

If there is anything that is even more challenging and expensive than finding adequate housing, it is probably HIV infection itself... The economic costs of ongoing HIV transmissions and HIV treatment failure within this population (Homeless/inadequately housed PLWHAs) are enormous. It is entirely possible that

the cost savings to the medical care system of the provision of housing to homeless HIV-infected individuals are similarly so enormous that the housing costs are offset. If so, an effective intervention that works to reduce the spread of HIV, increase health and longevity of HIV-infected persons and humanize our urban centers will have been identified.

Ghana has no housing policies/interventions for HIV-positive persons, even though the country is recording higher rates of new infections and HIV-related mortality (Ghana AIDS Commission, 2016). In 2010, the National AIDS commission, under the national strategic plan, sought to reduce new infections by half through non-clinical preventive means. The key component of this plan was to prevent new infection by promoting safer sexual intercourse among the general population and HIV-positive persons; yet, the plan failed to include housing. A new national strategic plan has recently been launched (2016-2020) with the aim to fast-track efforts to prevent new infections and AIDS-related deaths by 2020. However, like the previous one, the new plan does not acknowledge housing as a key non-clinical intervention in reducing HIV-related mortality and transmission. Based on previous literature and the findings from this study, Ghana AIDS Commission and the Committee for the 2016-2020 national strategic plan should consider housing as a major and crucial intervention to prevent the spread of the virus and reduce HIV-related deaths in Ghana.

Although numerous educational programs have been provided on the virus, misconceptions about HIV infection and transmission linger in Ghana and these fuels the stigmatization of HIV-positive persons. Ghana AIDS Commission should educate the Ghanaian public on the modes of infection and transmission to reduce discrimination against PLWHAs. Public education about HIV transmission and its progression from an infectious to a chronic disease will help reduce misconceptions. This could reduce stigma and help PLWHAs establish supportive social networks to manage the psychological distress of living with the virus.

Importantly, this education will be essential if housing assistance is provided for PLWHAs in Ghana. Other findings from the data (these findings will be discussed in future work) showed PLWHAs were nervous of moving into supportive housing units, as they perceived such housing will expose their HIV status and lead to discrimination and stigmatization.

Further, the findings of the thesis show HIV-related stigma inhibits PLWHAs from building strong social/ support networks. Yet, these support networks are vital in managing the mental stress of living with the virus (Li et al., 2009; Liu et al., 2013; McDowell & Serovich, 2007 Whetten, et al., 2008). Vyavaharkar and colleagues noted that (perceived and actual) social support networks are inversely related to the mental stress of living with HIV (Vyavaharkar et al., 2011). Individuals belonging to social support groups are able to disclose their HIV status and other HIV- related problems to members of their groups. Those with no such groups are less likely to disclose and more likely to live with depression symptoms. Vyavaharkar et al. (2011) noted that social support networks mediated disclosure of an HIV status and depression. It is therefore important that social support groups are established among PLWHAs to enable them discuss and deal with emotional/ mental stress, and healthy strategies of coping with the virus.

Stigma fueled by misconceptions and prejudice is a recurrent theme throughout HIV studies, especially in Africa. Arguably, misconceptions and prejudices partially stem from HIV intervention campaigns which exclusively treat HIV as a Sexually Transmitted Disease (STD) and associate the virus with already stigmatized groups in society, such as prostitutes, homosexuals and promiscuous individuals (McKee, Bertrand & Becker-Benton, 2005; Parker et al., 2002; Tenkorang & Owusu, 2013). For instance, the ABC campaign (Abstinence from sexual activity; Being faithful to your partner; Condom use) in Africa clearly presents HIV as an STD. Individuals infected with the virus are seen as sexual deviants and HIV/AIDS is perceived as a

punishment from the gods. The proliferation of this belief system in a predominantly religious society like Ghana has led to stereotypical and discriminatory behaviors. Lessons can be learned from the AIDS pandemic; future health intervention programs should be holistic (all-inclusive) and not target a specific social group.

This research has used qualitative measures to provide preliminary evidence of a possible bi-directional relationship between housing and health. Future researchers should build on this work by employing quantitative data to explore the extent to which living with HIV correlates with the housing issues of PLWHAs.

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APPENDIX

Table 1: Demographic and socioeconomic characteristics of respondents.

| Demographic features | <i>N</i> =38 |
|---|-----------------|
| | Frequencies (%) |
| <i>Age</i> | |
| 18-29 | 1(2.63) |
| 30-39 | 8(21.05) |
| 40-49 | 8(21.05) |
| 50-59 | 16(24.11) |
| 60 and above | 5(13.16) |
| <i>Gender</i> | |
| Male | 6(15.79) |
| Female | 32(84.21) |
| <i>Marital status</i> | |
| Never married | 4(10.53) |
| Married | 7(18.42) |
| Cohabiting | 4(10.53) |
| Cohabiting but now separated | 8(21.05) |
| Widowed | 13(34.21) |
| Divorced | 2(5.26) |
| <i>Socio-economic features</i> | |
| <i>Education</i> | |
| No formal education | 6(15.79) |
| Some form of education (grade 1-high school | 30(78.95) |
| Tertiary education | 2(5.26) |
| <i>Employment status</i> | |
| Economically inactive | 1(2.63) |
| Unemployed | 12(31.58) |
| Employed- informal | 22(57.89) |
| Employed - formal | 3(7.89) |
| <i>Housing arrangement</i> | |
| Owner occupier | 11(28.95) |
| Extended family housing | 13(34.21) |
| Rented | 10(26.31) |
| Virtually homeless | 4(10.53) |

Figure 1: The housing unit of one respondent



Source: Field work, 2015

Figure 2: A toilet facility in Ghana.



Source: Smith-Asante, 2016