

**SOCIAL SUPPORT FOR PEOPLE LIVING WITH HIV/AIDS
WITHIN THE ACCRA METROPOLITAN AREA**

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Declaration

I, Hagar Agyir-Binn do hereby declare that this thesis is my original work, which I have produced during the conduct of a research project in partial fulfillment of the requirement for the award of Master of Philosophy Degree in Nursing. References made from other researchers and writers have been duly acknowledged. No portion of this thesis has been presented either wholly or partially to any institution for any degree. The undersigned certify that the supervisors have read and recommended to the School of Nursing for acceptance. A thesis entitled; Social support for people living with HIV/AIDS within the Accra metropolitan Area.

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DEDICATION

I dedicate this work to the glory of God for giving me the strength to do it. I also dedicate it to my late uncle Mr. James Atta-Hagan for promoting female education in the family.

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May God richly bless you.

ABSTRACT

Social support has been identified as one of the coping strategies in chronic illnesses especially in HIV/AIDS disease. The purpose of this study was to explore how the people living with HIV/AIDS (PLWHA) experience social support in the Accra Metropolitan area of Ghana. An exploratory, descriptive and qualitative method was employed in this study. A purposive sampling was used in the selection of the fourteen participants living with HIV/AIDS. They were interviewed using semi structured interview guide and observations. The data were analyzed using content analysis and constant comparison.

The main themes that emerged from the study were; “Lived experiences of PLWHA, biophysical experiences, psychological experiences, socio-economic, and socio-cultural experiences. Others included coping strategies, meaning attached to support, sources and types of support, and perception of support received. Other sub-themes emerged under these major themes. The findings indicated that the PLWHA experienced some unpleasant symptoms of the disease, which limited their ability to work and earn income. This is because the disease has stigma attached to it, and it either made them weak and unable to work or has depleted their capital. A few were stigmatized and isolated by some members of their family. This has created a variety of needs such as employment, getting the necessities of life for themselves and their dependants and the need for healing of their diseases.

Each of the participants had at least one support provider. These providers were; the family, community members, non-governmental organizations, church institutions, and health institutions. The support the participants received covered financial, assistance with basic needs, and social support. Others included medical, emotional and spiritual support. Whilst some of these supports were provided spontaneously to the PLWHA, others had to beg for the support. It was the general view of all except one participant that the support they

received was inadequate. The participants devised some coping strategies to contain the situation. Some of these were projection, disclosure, and mutual support. Most of them expressed their desire to work, preferably sedentary work.

These findings have implications for nursing care and policy making. It is important for policy-makers to consider employment policies that would support the PLWHA to continue being employed, even after diagnosis, in jobs that do not entail strenuous activity. Policies on reaching out to the PLWHA should be intensified to prevent stigmatization and isolation of the PLWHA.

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LIST OF ABBREVIATIONS

AIDS:-Acquired Immune Deficiency Syndrome.

DOTS:-Directly Observed Therapy Short course

GHS:-Ghana Health Service

HAART:-Highly Active Anti-Retroviral Therapy.

HIV:-Human Immunodeficiency Virus.

MOH:-Ministry of Health

NACP:-National AIDS Control Programme

PLWHA:-People Living with HIV/AIDS.

STI:-Sexually Transmitted Infection.

CHAPTER ONE

Introduction

Social support in this context is a crucial coping strategy in all chronic illnesses and most especially for People Living with the Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (PLWHA). According to Barroso (1997), there is a linkage between social support and coping when people are living with Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (HIV/AIDS).

AIDS has a unique presentation with social, economic, and emotional implications that call for sustained social support for people living with it. With the breakdown of the immune system, opportunistic infections affect all the other body systems resulting in physical disfigurement, disabilities, and handicaps.

Additionally, HIV/AIDS has significant social stigma attached to it such that, some of the people with the disease become isolated and neglected by their families, friends, employers, and communities (Barroso & Powell-Cope 2000). The once closely-knit extended family is now broken down with the subsequent withdrawal of home support for the person living with HIV/AIDS. This occurs at a time when persons with AIDS have financial difficulties as a result of reduced capacity to earn money, and the high cost of medical care. According to Caldwell et al. (2000), the withdrawal of support for PLWHA may be due to the fact that AIDS is a disease with no cure and it is interpreted as a curse or punishment for disobedience, and such a situation brings shame not only to the individual, but to the corporate clan as well (Bleek 1981). This is because the stigma is extended to the entire family members of the affected individual.

People Living with HIV/AIDS (PLWHA) who are abandoned and are without any source of income depend on charity and on health facilities for support in such diverse

areas as drugs, food, and money for transport (Ahensa 1993). To continue to enjoy the support of the family, HIV positive persons keep their status secret from the rest of the family. There are families who are willing to accept their members with HIV/AIDS but sometimes their finances and other resources are not enough to sustain their lives and that of their dependants with AIDS. In such a situation, poverty precipitates the death of the PLWHA. Some families go to the extent of borrowing or selling their properties to defray the cost of care. Sometimes they remain indebted even after the death of the patient. PLWHA are individuals of all ages with various roles, status, and responsibilities within society. The disease alters the individual's ability to discharge the responsibilities that go with the roles and status. PLWHA also experience job insecurity, financial losses, malnutrition, and lack of access to social services. Infected women are often afraid of transmitting the virus to their children, since anti-retroviral drugs are not available to majority of them in Ghana. The PLWHA are unable to discuss their condition with people previously closest to them (Aggleton, Homans, Mojsa, Watson, & Watney 1989).

There is the need for the PLWHA to lead a more dignified life through the provision of social support. Nunes, Raymond, Nicholas, Lenner, & Webster (1995), have found that social support improves the quality of life for PLWHA. Friedland, Renwick, & McColl (1996), also noted that social support and income are positively related to quality of life. In another study, increased social support was found to improve the quality of life of PLWHA in Kenya (Aduwa, Lena & Kowi 1998). Again, Stewart, Hart & Mann (2000), observed that PLWHA in Quebec, Canada experienced more stress in the absence of support. Social support prevents or moderates the negative effects of stress in health (Barroso 1997). For the PLWHA and their families there is fear of rejection and discrimination.

1.1 Background of the Study

The HIV/AIDS pandemic continues to send alarming signals globally. The disease has a remarkable impact on all aspects of the socio-economic development of countries. It alters the family structure, drains the economic gains of nations and may, if not checked, wipe out entire generations of the human race [United Nations AIDS (UNAIDS) /World Health Organization (WHO) 2001].

Individuals, communities, governments, and world bodies continue to respond to these signals by instituting various measures to prevent the AIDS epidemic from escalating while increasing efforts to find a lasting cure for it. There has been little progress in the battle against AIDS as the prevalence continues to increase. Globally, there were 34.3 million people living with HIV/AIDS in 1999, 36.1 million adults and 1.4 million children in 2000 (UNAIDS/WHO 2000). As much as 40 million people worldwide were living with HIV/AIDS in 2001 and 42 million in 2002 (UNAIDS/WHO 2002, See Table 1). AIDS is one of the leading causes of death worldwide. There were 3 million AIDS deaths in 2001 (UNAIDS/WHO 2002). The pandemic has left 13.2 million orphans globally.

Table 1: HIV/AIDS Global infection

<u>Year</u>	<u>Total HIV/AIDS infection</u>
1999	34.3 million
2000	36.1 million
2001	40 million
2002	42 million

Source: UNAIDS/WHO 2002

Sub-Saharan Africa is the most affected region in terms of the HIV/AIDS pandemic. In this region, 21 million people were living with the disease in 1999, 25.3 million in 2000, 28.1 million in 2001, and 29 million in 2002 (UNAIDS /WHO 2002, See Table 2). AIDS is the leading cause of death in Africa. It is estimated that in the hardest hit African nations, between one-third and two-thirds of all 15-year-olds living today are expected to die of AIDS by 2015. Available figures indicate that over 12 million children have been orphaned by AIDS in Sub-Saharan Africa alone. This is expected to rise to 40 million by 2010. In addition, (70%) of hospital beds in most African countries are occupied by those with AIDS (UNAIDS/WHO 2002).

Table 2: HIV/AIDS infection in Sub-Saharan Africa

<u>Year</u>	<u>Total infection</u>
1999	21 million
2000	25.3 million
2001	28.1 million
2002	29.4million

Source: UNAIDS/ WHO 2002



1.2. The Scourge of HIV/AIDS in Ghana.

The 2000 population census of Ghana reported that Ghana has a population of about 18.4 million people, with an annual growth rate of (2.7%) (Ghana Statistical Service 2001). The prevalence of HIV infection in Ghana is (3.6%) of the population which gives an indication of possible threat to the population growth.

Even though the prevalence rate of (3.6%) is lower than that of other countries in the West African sub-region, it is of increasing concern because in the year 2000, the prevalence rate was (2.3%). This increased to (2.6%) in 2001, (3.4%) in 2002 and (3.6%) in 2003, See Table 3). If the present trend continues, the prevalence rate of HIV will then

exceed the population growth rate and resulting deaths could lead to a population decline. (Ghana Health Service/Ministry of Health (GHS/MOH 2003) HIV Sentinel Survey 2003 report).

Table 3: HIV/AIDS Prevalence in Ghana

<u>Year</u>	<u>Prevalence</u>
2000	2.3%
2001	2.6%
2002	3.4%
2003	3.6%

Source: The GHS/MOH (2003) HIV Sentinel Survey report for 2003.

The GHS/MOH (2003) HIV Sentinel Survey report for 2003, revealed that HIV infection exists in all parts of the country but with regional differences. Eastern Region has persistently reported the highest levels of infection (7.9%), followed by Western (5.1%), Greater Accra (4.1%) and Ashanti (3.9%) to mention a few with prevalence of more than (3%).

Central, Northern and Upper West regions have low prevalence rate of less than (3%). Considering the sentinel sites, Agomanya town in the Eastern Region tops the list of communities with the highest rate of HIV infection. In Ghana, it is estimated that over 200 people get infected per day. Statistics indicate that 330, 000 adults in 1999 were living with HIV/AIDS and this figure increased to 350,000 by the year 2000 and 380,000 in 2002. It is projected that by 2004, 550,000 people will be living with the virus and further increase to 860,000 in 2009 and 1.2 million in 2014. (NACP, MOH, Ghana 2002).

HIV/AIDS affects all age groups, but the highest infection occurs among the 15 to 49 age group. This age group also represents people in their reproductive period.

According to NACP, MOH, Ghana, (2001), without the AIDS epidemic the population is predicted to grow to about 25 million in 2014 but with AIDS, population growth will most likely be 23.8 million by 2014 (See Table 4). There is an expected difference of 1.2 million.

Table 4: Statistics and projected HIV/AIDS among Adults in Ghana.

<u>Year</u>	<u>No of HIV/AIDS cases</u>
1999	330,000
2000	350,000
2002	380,000
2004	550,000
2009	860,000
2014	1.2 million

Source: NACP, MOH, Ghana, (2001).

These relatively low figures are due to estimated low level of reporting which is about (30%). The main mode of transmission is heterosexual intercourse and therefore women are at a greater risk of contracting the virus because men are culturally permitted to engage in polygamy. The (NACP/MOH, Ghana 2001), reported that about two-thirds of reported cases have been in women. Infected man can thus spread the virus to a number of women and these women can transmit the virus to their unborn babies. In Ghana, mother to child infection is between (30-40%) and the possibility of this increasing cannot be ruled out. This is because prophylactic anti retroviral drugs are not readily available to the majority of the people. The result is more infection and death, which will result in a reduction in population growth (NACP/MOH, Ghana 2001).

Reported rape cases in the Greater Accra Region alone were 238 and 236 for the years 2000 and 2001, respectively (Greater Accra Regional Criminal Investigation

Department 2001). This implies that women are confronted with an additional risk of being infected through rape.

1.3 Statement of the Problem

The emergence of the HIV/AIDS epidemic has stimulated world bodies, scientists, traditional healers, and medical experts to try to find a lasting solution that will eradicate the disease. Drugs available so far are in the trial stages and most of these are to control the opportunistic infections associated with HIV/AIDS. In Ghana, governments and non-governmental organizations have engaged in various HIV/AIDS control programmes.

HIV/AIDS education has been carried out in various forms, including the use of electronic and print media. As a preventive measure, counselling centers have been set up in some communities to counsel people to enable persons who are seropositive to accept the challenges of living with HIV infection and those who are not infected to remain so. In addition, the use of condom has been widely promoted. Apart from these measures, the Ghanaian government has also set up an AIDS commission to supervise the District Assemblies and other Non Governmental Organizations (NGO's) to respond to HIV/AIDS. The commission allocates funds to these organizations for their HIV/AIDS educational programmes. In spite of the level of awareness created by these measures, HIV infection and AIDS cases are on the increase (GHS/MOH, 2003).

One important aspect of HIV/AIDS infection that has received little attention in Ghana is sustained social support for PLWHA. Persons with AIDS cannot be confined to hospitals throughout the period of illness due to high cost and pressure on the facilities. In Ghana, the extended family offers support and care to members who suffer from chronic diseases. Normally a family member, usually a woman, is delegated to stay with the sick and care for them and their dependants. Some families accept PLWHA whilst others

neglect and ignore them at a time when they are physically weak, financially poor and emotionally distraught. In one instance, a PLWHA was isolated by family members as a consequence of a remark made by a nurse which disclosed the patient's HIV status to them. All the support she previously enjoyed from her family was withdrawn from her. Later, when her landlord and the co-tenants learned that her husband had died of AIDS, she was ejected from the rented house because they were afraid to live in the same house with her for fear of infection. An article in 'The Ghanaian Mirror,' a weekly newspaper was captioned "Nine men sack their wives because they have AIDS." The men made the medical reports of these women public subjecting them to pain, embarrassment and stigmatization. The men refused to maintain or support the children. Some of these women and their children returned to their maternal homes to be cared for by their own mothers. Orphans left by some of these women eventually became the responsibility of the grandmothers (Azu 2002).

Families who continue to care for and support their members with AIDS and their dependants encounter financial, time, and emotional constraints, together with stigma from the extended family, friends, and the community. This impedes their ability to effectively help the PLWHA to deal with the illness. Poverty among family members equally hinders their effectiveness in supporting their infected members (Markwaramba 2001). Home and community-based supportive programmes, like provision of care at home and assisting the PLWHA to the hospital, have not achieved the desired objective due to stigmatization, discrimination, and poverty, and it is also not widely established in the country (Mensah, Kissiedu, & Yeboah 1997).

Although the Ministry of Health of Ghana has HIV/AIDS/STI as the first priority for service delivery, supportive community programmes for PLWHA is not on the priority

list of services outlined in the 5-year programme of work 2002-2006. The focus is on reducing the possibilities of mother-to-child transmission, post-exposure prophylaxis for rape victims and personal health care and clinical assistance to HIV affected families including orphans. Other priority services include the introduction of Highly Active Anti Retroviral Therapy (HAART) with Directly Observed Therapy Short course (DOTS) on a pilot basis (Ministry of Health 2002).

Despite the importance of these services, the issue of abandoned PLWHA and the almost total absence of social support available to them remains a concern in Ghana. It is known that social support positively influences the health and quality of life for PLWHA (Stewart et al, 2000). However, families with limited resources are often unable to care for their relatives with HIV/AIDS and their children, particularly when unemployment is experienced in the very presence of the disease. Additionally, there is a general lack of awareness of the presence of organizations that do provide some care and assistance to PLWHA and their families.

While State conferences are held on AIDS, accompanied by the free distribution of souvenirs on AIDS, some of the PLWHA are dying quietly or living in secret and isolation, some abandoned by the family, society, and the health care system. The question then is what is the social support for these PLWHA?

1.4 Purpose of the Study

The purpose of this study is to explore how PLWHA experience social support.

1.5 Objectives of the Study

The main objectives of the study are:

1. to describe the lived experienced of PLWHA
2. to describe the social support experiences of PLWHA.

Specifically, the study is to:

- a. determine the supportive needs of the PLWHA.
- b. find out the sources of support for the PLWHA
- c. identify the nature of support provided to PLWHA
- d. assess the PLWHA perception regarding the support being provided

1.6 Significance of the Study

By conducting this study, it is anticipated that greater understanding into how social support is experienced by PLWHA and the factors that influence this experience will be gained. This increased insight about social support for PLWHA may help nurses and other health care workers to provide more appropriate and sensitive supportive assistance to them. It may also help decision-makers to establish more appropriate supportive guidelines and policies that will enhance the welfare of PLWHA and their families. Finally, the study will generate further questions for future research into this important health problem.

1.7 Definition of terms

Adequacy of support....Satisfaction that the support was enough.

Community members....Refers to friends, co-tenants, celebrities, former employer and relatives of other people living with HIV/AIDS.

Experience...The feeling of how the infection has affected their lives

Institutions....Refers to health facilities and the churches.

Multiple-family source....Where more than one family member provided support at the same time

Nature of support....The type of support.

Organizations....Refer to HIV/AIDS support organization and other non-governmental organizations.

Single-family source....Where only one member of the family provided support.

Support....Help offered to people in need.

Social support....Any assistance provided by the family, institutions, organizations and community members for the needy PLWHA to help sustain their lives and that of their dependants.

Source of support....Those who provided the support.



CHAPTER TWO

Literature Review

In this chapter, literature on social support for people living with HIV/AIDS (PLWHA) will be reviewed. The theoretical components of social support will be presented first, followed by the needs of the PLWHA, and justification for support for them. A detailed review about social support for PLWHA from both the developed and the developing world will be carried out respectively. The literature on the Ghanaian family and its relationship to social support will then be presented. The review will conclude with a summary and a critique of the literature in addition to the research questions being asked in this study.

2.1 Social Support Theory and Measurements

Social support has been defined variously by different people. Stewart (1993) defined it as the interactions among family members, friends, peers, and professionals that communicate information, esteem, practical aid, or informational help. According to her, when these communications are perceived as supportive, they enhance coping, moderate the impact of stressors, and promote health. According to Hupcey (1980), social support is the act of providing a resource, and the outcomes of support include the recipient's sense of well-being or of being cared for. Kozier, Erb, Olivieri (1993) share a slightly different view. Social support, to them, refers to others outside the family unit who provide strength, encouragement and assistance to the family especially during crisis. They claim that illness of a family member is a crisis that affects the entire family system. Social support has three major dimensions which are structure, functions and appraisal (Stewart & Langille 1997).

2.1.1 Social support structure

The structure of social support, according to Stewart & Langille (1997), comprises of lay sources such as partners/spouses, family members, friends, neighbours. Others are co-workers, volunteers, and self-help mutual aid groups, as well as professional sources such as health professionals. The structure, encompassing social integration and social networks, has effects through social regulation or control, relational demands, and conflict. House, Umberson, & Landis (1988) indicated that social structure variables influencing support include community size, socio-economic status, ethnicity, age, marital status, sex, and the size and density of the social network.

2.1.2 Social support functions

The function of social support refers to the benefit that one derives from the flow of resources from the social network (Stewart & Langille, 1997). Support resources have been identified as emotional, informational, affirmational, and instrumental or practical aid. (House et al. 1988; Stewart & Langille, 1997). A general function of social support is to promote psychosocial development and help individuals to negotiate developmental tasks. Catz & Kelly (1998) also found out that social support boosts treatment adherence in HIV patients. It is protective and facilitates coping with crises and adaptation to change.

In a study involving the coping responses of 23 HIV-positive adults, Chidwick & Borrill (1996), identified social support as one of the effective coping strategies in chronic illnesses especially HIV/AIDS. Similarly, Lesserman, Perkins, & Evans (1992), in a study of 52 asymptomatic HIV-positive homosexual men, identified social support as one of the coping strategies for living with HIV/AIDS.

2.1.3 Social support appraisal

Social support appraisal deals with social exchange. It is an individual's perception of the availability of support. Social support may be perceived as potentially available from the social network or may be actually delivered and received (Pierce, Sarason & Sarason 1990). According to Dunkel-Schetter & Bennett (1990), perceived support, which is the psychological sense of support, should be distinguished from received support, which is the actual expression and exchange.

Social support can be unidirectional/non-reciprocal or bi-directional/reciprocal (Barrera 1988). To be consistent with norms of equity and reciprocity, support should be bi-directional (Tilden & Gaylen, 1987). However, people who are ill experience non-reciprocal relationships with their social networks, and this diminishes their self-esteem and increases their sense of indebtedness (Simmons 1994). Social-psychology theories of equity and social exchange indicate that support may involve benefits and costs for both recipients and providers. Support providers might experience overload, overexposure to chronic and acute stressors, overprotection, over involvement and over commitment (Enterlante & Kern, 1995). Difficulties for the support recipient include feared loss of support, advice that constrains options, learned helplessness, relational costs and diminished trust (La Gaipa 1990). Support from the network may have negative as well as positive effects (Brenner, Norwell, & Limacher, 1989).

Various instruments such as Norbec, Arizona and Wortman tools have been developed to measure social support in relation to various disease conditions and other life situations. Instruments developed for measuring social support should be sensitive to sexual orientation, culture, and ethnicity (Hall 1999). Grant & Ostrow (1995) used the Wortman's social support scale to measure differences between mental health and social

support among white (n=16) and African-American men (n=17). There was a strong positive relationship among the white and a negative relationship among African-Americans. The explanation given was that the scale had not been adapted for ethnic groups other than white males. It may also be due to the small number of the sample size.

2.2 The needs of the PLWHA and justification for support for them

According to Katabira, Mubiru & van Praag (1998), HIV infection and AIDS can have prolonged and devastating effects at the personal level. As such, people living with HIV/AIDS have a range of needs and problems related to their condition. Those needs must be appreciated and understood in order to develop practical, realistic, and achievable care. They therefore recommend that HIV/AIDS care must cover clinical, nursing, psychological and social support needs. As Foulkes (1999) puts it "nowhere is support more needed than for persons with HIV/AIDS, which threatens to single-handedly wipe out the development gains of the last three decades" (p 2).

Simaslku (1999) reported that the socio-economic impact of HIV/AIDS cannot be over emphasized as the disease affects the most productive persons of the population. At the Tenth International Conference on HIV/AIDS and STD'S, in Africa, the Administrator of United Nations Development Programmes (UNDP)(1998) observed that some of the most striking images of the HIV epidemic are of unfamiliar families. These include a grand parent surrounded by grandchildren, child headed families, which often include brothers and sisters and cousins bonded together, dying adults tended to, by their children, and, communities of children without parents. According to him, this pathetic situation calls for sustained social support for the grandparents and the orphans who may be living with the virus.

PLWHA experience a number of crises such as the symptoms of the disease and the unpleasant effects of some of the medications and a whole range of situations that make the need for social support imperative (Dupras, Morisset & Pharand 1990; Kadushin, 1996). There are stereotypes and social stigma associated with AIDS (Ropper & Anderson 1994; Bourgon & Renaud 1990). Hence, PLWHA confront many stressors such as isolation, anger, loss of status, and changing roles. Other stressors include loss of hope, fear of job insecurity, loss of friends, lack of financial resources, disfigurement, and fear of imminent death (Stewart, Hart & Mann 2000). These stressors call for support to enable the PLWHA cope with the disease.

2.3 Social support for PLWHA in the developed countries

Robinson, Mayward & Smith (1990) undertook a cross-sectional study to investigate the extent to which the needs of 150 PLWHA in Great Britain were being met by social departments, voluntary organizations and private agencies. They found that the social packages PLWHA received included coverage of housing, financial assistance, support for physical and emotional needs, telephones, and day care centers. Other services included transport, night sitting, counselling and support, home loans, equipment, hospital discharge co-ordination, and hotel-hospice provision. Support from significant others is a prime concern to the PLWHA. Support from family and friends, followed by contact with other HIV infected persons and support from personal physicians were the primary sources of support (Stewart, Hart & Mann 2000).

In another study, close friends provided most types of support. Although respondents generally indicated high levels of satisfaction with support, they expressed a need for more emotional support (Friedland & Renwick 1996). Trainor & Ezer (2000)

conducted an exploratory descriptive study among seven (7) PLWHA on the impact of a new drug treatment in London. Participants mentioned reintegration and redefining their relationships within the social networks as very important to them. They identified one source of support as being in a group forum with other PLWHA in which members could share their experiences.

Barroso & Powell-Cope (2000) conducted a qualitative metasynthesis study in the USA to understand the experience of 307 adults living with HIV/AIDS, of whom 28 were females. The findings were that PLWHA maintained hope through religion and spiritual healing. Emotional support and a sense of belonging from social interaction were more important to them than instrumental support. Social connectedness was mentioned as very important, especially to families, friends, support groups, and the larger community.

There is a linkage between social support, coping, and quality of life. In a study involving 120 HIV positive people in Toronto, Canada, coping and social support were found to improve the quality of life of PLWHA (Friedland & Renwick 1996). They reported that one hundred and seven (107) respondents had good levels of social support and used a variety of coping strategies. In a qualitative study of 18 participants to investigate the use of coping strategies in adapting to an HIV-positive diagnosis, the responses to one of the themes, living with HIV, included that of seeking the support from others in coping with the illness (Reeves, Merriam, & Courtenay 1999).

In a pre-test, post-test quantitative study by Lutgendorf, Antoni, Ironson, Starr, Costello, & Zuckerman et al. (1998) involving 40 HIV-positive gay men, the relative contribution of changes in coping skills was examined in relation to social support. The experimental group (n=22) showed significant improvement in cognitive coping strategies including positive reframing and acceptance of social support involving attachment,

alliances, and guidance at the end of 10 weeks as opposed to the control group (n=18) who showed decline in these coping abilities.

In a longitudinal study to examine the relationship among spirituality and psychosocial factors involving 52 males living with HIV/AIDS, Tuck, McCain, & Elswick (2001), found that social support was positively related to effective coping strategies and higher quality of life.

There are barriers associated with seeking support from others. Stigma, isolation and high death rates among support group members and friends were scary to the PLWHA and these hindered access to supportive healthcare. Some participants found value judgments by providers as dehumanizing which prevented them from seeking support (Barroso & Powell-Cope 2000).

2.4 Social support for PLWHA in the developing countries

In identifying the needs of PLWHA, VanPraag, Schweyan, & Ng'Weshemi (1997), noted that those living with HIV/AIDS require emotional support, access to common drugs, family counselling, support for surviving children, and legal advice. Other areas of needs were food supplies, clothing, house help, financial assistance, and clinical care. The report further stated that the support must be provided not only in times of crisis, but, in all the phases of HIV/AIDS infection and the bereavement process.

A joint WHO/UNICEF HIV/AIDS document, 'Action for children affected by AIDS', the Lusaka declaration enumerated the various supports needed for children affected by AIDS as direct material and financial support, free schooling, legal support, and income generating activities. In a related study on the conditions and care of 141 AIDS patients in Ghana, (60%) of the respondents reported that they needed to rely on others for

additional help. The assistance they needed was mainly in the form of food and general needs as well as payment of hospital bills (Anarfi 1995).

In assessing the current community care package for HIV infected people in Malawi, Katabira, Sekyoma, UNAIDS, WHO/AFRO, Agabu, Kajowo et al. (2000), observed that the support and care provided by the village caregivers were limited to managing simple pain symptoms, helping with housework for the affected families and limited orphan support. The Church Health Institutions, according to Mensah, Kissiedu, and Yeboah (1997), provide spiritual, medical, psychosocial, and economic support until death. They further reported that care for persons living with AIDS is a continuum of formal and informal care involving the hospital, clinic, welfare services, households, and members of the wider community who need to provide affective care.

It was reported in a study in Cambodia conducted by UNAIDS (2001) that the burden of care of PLWHA often falls on elderly female relatives. However, in this region there is a home care network of government staff and volunteers of non-governmental organizations, who provide emotional support, encourage good hygiene and interaction, refer patients to hospitals and give voluntary counselling for PLWHA. Evaluation of these activities by the International HIV/AIDS Alliance in the year 2000 indicated that of the 2000 families visited, (92%) of patients felt that without home care teams their lives would be significantly more difficult. Patients (63 %), felt that the home care team had helped to change their outlook on the future and (33%) felt they had been instrumental in reducing community discrimination (UNAIDS 2001). A UNAIDS study acknowledged the contribution of the Church of Christ in Ivory Coast. It noted that when the vast majority of PLWHA admitted to the disease unit of the University hospital of Treichville, Ivory Coast were abandoned, stigmatized, or neglected by family, friends, and medical personnel, the



Church of Christ provided compassionate psychosocial support for them. The church has established Socio-Medical Centre which started support groups for PLWHAs known as 'Friend's Club' to provide opportunities for PLWHA to share common experiences, hopes and fears, and to rebuild dignity, a sense of self-worth and friendship. The center also provides nutritional, material, and financial assistance to them. Other forms of assistance include support for orphans of AIDS patients by keeping them in school (UNAIDS 2001).

Another UNAIDS study in Ecuador indicated that the PLWHA and health professionals jointly founded a non-Governmental Organization (NGO) known as "God Life and Hope Foundation" (UNAIDS 2001). They formed a home care team that provides psychosocial support to the whole family and taught them basic information about HIV/AIDS, first aid, nutrition, and tips on what to do when the HIV positive person was in crisis.

In a study of personal care strategies of people living with HIV/AIDS, respondents from both developed and developing countries concluded that as women take on the additional burden and care for those with HIV/AIDS, their resources, both social and economic, will not be adequate. The importance of appropriate support and relief programmes for those responsible for informal care were emphasized (Mota, 1996).

Taylor, Seeley & Kajura (1996) conducted a study questioning the assumption that female informal carers of HIV/AIDS were able to cope well with illness episodes in the home. They found that women in this rural Southwest Uganda region were responsible for the bulk of caring activities within the home besides a variety of home and agricultural tasks. The findings also revealed that many women, particularly those in female-headed households, did not own or have direct access to the necessary finances to meet the family's health care needs.

Mann, Tarantola & Netter (1992) explained that in many cases traditional and cultural bonds of extended families might provide support to their members with AIDS. However, they cited that other support options such as economic support for HIV-infected people and their families, self-help groups for HIV-infected persons, and organizations that support children orphaned by AIDS may be provided by governments.

Makwarimba (2001), in a Zimbabwe study involving social support for persons with AIDS and their care-givers revealed that stigmatization resulted in the social exclusion of PLWHA as well as their care givers. This resulted in their social withdrawal; social isolation and diminished social support from significant others. According to the report, this forces PLWHA and caregivers to conceal the nature of disease from "outsiders," including nextdoor neighbours, a move that also works to reduce support from potential providers. He noted that at the end stage of AIDS PLWHA need more support but emotional support easily affordable for network members was withheld from the AIDS patients as the network members saw AIDS as a punishment for one's mischief. This issue was not peculiar to Zimbabwe, for a 12year old Zambian girl had to nurse her AIDS affected mother alone, without support from any family member until her death (Marble 1995).

2.5 Social support and the Ghanaian family

Social support for ill family members in Ghana is embedded in the extended family. Every family has an authority leader who is responsible for making decisions related to the welfare of its members (Nukunya 1992). In the event of ill health of a member, the head of the family and other opinion leaders decide on how and where to send the sick for treatment. Adult members of the family are made to contribute financially towards the maintenance of the sick. A family member, usually a woman, is delegated to

look after the sick and his/her dependants (Mensah, Kissiedu & Yeboah 1997). Another traditional practice is that when a family member dies, the entire extended family organizes and gives a befitting burial to the deceased. A family member is mandated to take responsibility for the needs of the widow/widower and the dependants of the deceased. Other family members contribute towards the sustenance of the dependants of the deceased including family members adopting some of the surviving children.

Even though families are expected to take good care of their sick members, the support received from them may depend on the nature of the disease and the behaviour of the sick family member. Families therefore sanction their members who are of bad character and therefore as HIV infection is associated with impropriety, it can be used as a reason for some families to reject a member with HIV/AIDS. The concept of reciprocity is rooted within the supportive functions of the Ghanaian family. The long-term provision of social support to a recipient who is unable to or unwilling to reciprocate may have deleterious consequences for the caregiver's mental and physical health (Wortman 1984). This is because the disease is terminal and the sufferers may be unable to reciprocate the support they receive from significant others. Again, support providers may dissipate all their resources and may have nothing to offer. This may also explain why some families might stop providing support for their members living with HIV/AIDS.

The type of care provided by family members includes the provision of simple nursing care, assisting with medication and dressing of wounds, maintaining personal hygiene, preparing nutritious food when they can afford it, and palliative care. Other family members provide emotional and financial assistance (Mensah, Kissiedu & Yeboah 1997). In the case of HIV/AIDS, some of the families offer support to their members who are infected with the virus whilst others abandon their members with HIV/AIDS and

withdraw all the social support previously offered to them, because of fear and the stigma associated with the disease. NACP, MOH, Ghana (2001) reported that some families become divided when they learn that a member has the virus. Whilst some accept the member with AIDS, especially the mother, others especially the father, rejects him/her.

Although social support and PLWHA has been extensively researched in western countries, the topic has received limited attention in Ghana. The research seeks to fill this void.

2.6 Summary and Critique

In summary, the theoretical aspects of social support have been extensively developed with the main components including structure, function, and appraisal. Many studies, both quantitative and qualitative, have used various instruments to evaluate the quality and amount of social support. However, this theoretical development of social support has been almost exclusively based on research conducted in developed countries. It is not certain whether these theoretical components of social support are applicable to the developing world and culturally appropriate to countries such as Ghana.

It is well recognized that social support is a major coping strategy for people with HIV/AIDS disease. This is evidenced in the themes such as seeking the support of others and social connectedness, and underscores the connection between social support and positive adaptation of an individual with HIV/AIDS. Research findings from the developed countries emphasized more on emotional support to PLWHA while in the developing countries, participants concern was more on instrumental support such as the provision of food, money and medication than emotional support. In both the developed and developing countries, social isolation and stigma create barriers to some PLWHA

seeking supportive care. However, in the developing countries, the barriers seem to have a stronger negative effect on the PLWHA than is evident in the advanced countries. There is budding evidence that supportive interventions such as home care services are being developed in some developing countries especially in some countries of Africa for PLWHA and their families. Finally, the Ghanaian extended family is the traditional provider of support for its ill members but with HIV/AIDS, this supportive mechanism has become unreliable because some families isolate, shun, and abandon their ill family member with HIV/AIDS. From a cultural perspective it is important to explore who, how, nature, and adequacy of the support that is provided for PLWHA.

2.7 Research Questions

From the foregoing, the broad research questions that emerge are:

1. What are the lived experiences of PLWHA in Ghana?
2. What are the social support experiences of PLWHA in Ghana? In terms of
 - Meaning attached to the social support needs
 - Sources of support
 - Types of support available
 - Participants' perception of support received

CHAPTER THREE

Research Design

This chapter gives a brief description of the research design, the study location, the sampling technique used to select the sample and method of data collection and analysis. Issues related to trust worthiness and ethics will be addressed.

The study employed an exploratory, descriptive and qualitative design. Qualitative research offers the opportunity to focus on finding answers to questions centered on social experience, how it is created and how it gives meaning to human life (Denzin & Lincoln 1994). Qualitative research methods according to Polit & Hungler (1999) give new hope to the discovery of covert and subtle realities and truths about the meanings and expressions of health in individuals. The tradition of using qualitative research arose because aspects of the human experience related to values, culture, and relationships were unable to be described fully using quantitative research methods (Thorne 1997). It was therefore a suitable method to discover the various aspects of social support as experienced by PLWHA. The many truths about the phenomenon of how social support is experienced by PLWHA (Streubert & Carpenter, 1999) were explored in this study.

3.1 Study Location

The study took place in the Accra metropolitan area. Accra is the capital town of Ghana. It is the seat of government and a convergent point for many people from all over the country. It is the site for the nation's largest teaching and referral hospital. The Metropolis shares boundaries with Ga District in the North-west, Tema district in the

North-East, Eastern Region in the north and by the Gulf of Guinea in the south. The total population for the area is 1,730,802 (Ghana 2000 population census).

The initial selection of participants for the study took place at the Fevers unit of the Korle-Bu Teaching Hospital, Accra, Ghana. Korle-Bu is the nation's largest referral health facility with a 1, 500 bed capacity. It is both a health care service and a teaching center.

3. 1.1 Fevers Unit

The Fevers unit, a subsidiary of the department of medicine, is one of the centres for the care of PLWHA. Of its 30-bed capacity, 16 beds are designated for the care of HIV/AIDS patients and the rest are for other infectious diseases such as meningitis, tetanus, measles, and rabies among others. On the average, 270 people living with HIV/AIDS attend the outpatient clinic there every month, with 33 admissions, 18 discharges and 14 deaths. The staff strength comprises 19 professional nurses, and four medical Officers who run 24hour service to both in and out patients.

There is a counselling section with qualified HIV/AIDS counsellors who engage in pre and post HIV test counselling on daily basis except on week-ends. The unit also houses the secretariat of an association of People living with HIV/AIDS known as "Wisdom association", a non-governmental organization. The association offers handicraft training in ornamental beads to its members. Through the association, some non-governmental organizations donate money, food, clothes and medicine to the PLWHA. Other non-governmental organizations donate money directly to the charge nurse of the fevers unit for disbursement to needy PLWHA. She executes this fund to the needy PLWHA under a name called "Comfort Fund".



3.2 Study Sample

Purposive sampling and snowballing were used to select the participants for this study. Purposive in the sense that the researcher selected specific participants who understand and could speak English and “Twi”, and were willing to sign the consent form and provide information. During recruitment, many men were contacted and after going through the information sheet with them, they did not agree to be part of the study. In order to get the views of men, two more males were purposively selected increasing the total number of participants to 14 instead of the initial number of 10-12. With snowballing, the fourth participant belonged to the “Wisdom Association” an HIV/AIDS support organization. She was asked if she could identify some of the members to be in the study. She identified two of them. These two also identified one member each to be participants. This was after the information sheet had been explained to them. The eligibility criteria for inclusion in the study were that PLWHA were volunteers of 18 years and older, of either gender, who were able to understand and speak either Twi or English (the researcher is fluent in both languages), and live within the Accra metropolis.

In all 14 PLWHA, comprising 11 females and 3 males who were either inpatients or outpatients were selected for the study. Two caregivers were also interviewed to give their version of social support for their support recipients in view of the fact that qualitative research acknowledges data from multiple sources about the same phenomenon.

3.3 Data Collection

After receiving approval from the Noguchi Memorial Research Institute Ethics Review Board, the Korle-Bu Hospital administrator, and the charge nurse of the Fevers

unit, 14 PLWHA were interviewed. Initially, it was anticipated that saturation of categories would be achieved with 10-12 participants, that is, when no new information and themes emerge, and redundancy is achieved (Polit & Hungler 1999). Semi-structured interview guide (Appendix A) was used to collect data. The interviews took place in a location acceptable to the PLWHA. Most of the interviews took place in the hospital and a few in the participants' homes. A pilot study was done with one participant to test the feasibility and acceptability of the interview guide. It was found to be appropriate. The interview guide was translated into 'Twi' and the interview transcribed into English. The participants also had the opportunity to talk about other essential problems they were facing.

The researcher used open-ended questions and cues to explore together with the participants about how they experience social support. This open-ended and exploratory approach to data collection allowed the PLWHA to provide in-depth information and understanding about their experiences of living with HIV/AIDS and how social support relates to this experience. Two caregivers of PLWHA were interviewed once using the guide outlined in Appendix B. This was to find out from the caregivers their views on social support to validate the support provided for the support recipients.

The interviews were recorded on tape and transcribed and translated from "Twi" to English by an expert in "Twi" to confirm if the text corresponded to the participants' experiences. During the interview, the researcher captured some salient points which were recorded in the field notes for reference and clarification with the participants. Each interview lasted for about one hour. Some of the participants were interviewed twice because either they were too frail to talk for a long period or they experienced fatigue from expressing deep emotions. This facilitated the full exploration of the topic. The second interview also enabled the researcher to send feedback to the participants regarding the

findings and interpretation of the data to ensure its credibility. This according to Polit & Hungler (1999) is “member checking” and supports confirmability of findings.

3.4 Data Analysis

The goal of the analysis was to systematically search for themes and sub-themes within the data so that the lived experiences of PLWHA and their experiences of social support could be richly described. This process is called content analysis, which involves processes of coding and categorization (Mayan 2001). Data analysis begun after the first in-depth interview was conducted, translated and transcribed from “Twi into English, and it continued concurrently with the data collection until the saturation of categories and themes was achieved at the fourteenth interview. In this study, the transcribed data were assigned line numbers. The data were read and re-read to search for words, phrases, and concepts that persistently emerged. These were highlighted and remarks made at the margins. The underlying patterns were identified and analysed otherwise known as coding (Mayan 2001). These were tallied to find out the number of times they appeared within and between data. These were then grouped meaningfully into categories. The content of these categories were analysed and re-organized into sub-themes. Relationships were established between the sub-themes. The content of these sub-themes were further examined and regrouped under two main themes, “ the lived experiences of PLWHA” and “social support experiences of the PLWHA”.

For example, words like help, aid and support were identified as one concept denoting “support”. Phrases like “I get support from my church, friends, family and HIV/AIDS organization were categorized under a sub-theme “sources of support” and, “ Financial support, assistance with basic needs, medical support” were categorized under the sub-

theme “types of support”. These sub-themes and others were further organized into one main theme, “Social support experiences”

3.5 Trustworthiness of the data

Qualitative study involves researcher carrying out all the research processes from defining the problem to writing it up. As humans are fallible in making decisions and judgements, there is the need to establish trustworthiness of the inquiry in order to eliminate biases. Lincoln & Guba (1985) have outlined four criteria for ensuring trustworthiness of the data. These are credibility, dependability, confirmability and transferability.

Credibility is parallel to internal validity in quantitative study and refers to the believability of the data to establish the confidence in “the truth” of the findings of the study and the context in which the study was carried out. To achieve this, peer debriefing and member checks were carried out. With peer debriefing, the thesis supervisors provided feedback about the quality of the data. Member checks encouraged the participants to comment on the data and whether its interpretation conformed to the participants’ text. This was done during the second interview. Two (2) caregivers were interviewed to compare their perspectives with that of participants.

Dependability is analogous to reliability in quantitative research. Dependability of qualitative data refers to the stability of data over time, and when repeated, the same findings will be replicated with similar persons, in the same settings and conditions.

Confirmability is parallel to objectivity in quantitative research. It questions how one can be sure that the findings were determined by the participants and not by the biases and the interest of the researcher.

Dependability and confirmability were ensured when all the documents related to the study were discussed with the supervisors in stages. These include the interview guide, the tapes, field notes, transcripts and the final write up. The decision-making processes within the study were systematically recorded so that an audit trail was available for inspection by colleagues and research supervisors as required (Rodgers & Cowles, 1993).

Transferability is parallel to external validity in quantitative research. It refers to the extent to which findings from the data can be transferred to settings or other people to determine the “fit” of the data.

3.6 Ethics

People living with HIV/AIDS (PLWHA) are vulnerable members of society whose dignity and rights must be protected particularly during research process. ‘Ethical Clearance’ for the study was obtained from the Noguchi Memorial Research Institute at the University of Ghana. (Reference: NMIMR-IRB CPN 012/02-03).

Letters requesting permission to have access to the PLWHA at the Fevers Unit at Korle-Bu Hospital were sent to the hospital administration and to the Fevers Unit (see Appendix C). After administrative permission had been given, the proposed research study was explained to the nurses, the medical officers and the counsellors of the Fevers Unit who also agreed to the research. Additionally, the researcher joined the staff at their routine ward rounds in order to establish initial contact with the PLWHA who were at the ‘Fevers Unit’. The type and purpose of the research were presented to the PLWHA (Appendix D) and the caregivers, (Appendix E), for them to understand and give informed consent. It was explained to them that they could leave the study at any time, and their treatment and care would not be affected when they stopped. They were informed of the



risk involved in the study such as emotional disturbance as they recount their experiences, loss of time and disclosure of their HIV status to a stranger and possible isolation. The benefits of participating in the study were that a non-judgmental researcher devoted time to listen to the experiences of PLWHA, which was a kind of emotional relief especially to those who were isolated. They were encouraged to ask questions. The consent of the research participants was then sought before the commencement of the interview. The consent forms are outlined in Appendix F for the PLWHA and Appendix G for the caregivers. According to Polit & Hungler (1999), the information provided by participants should not be used against them. In HIV/AIDS, information provided by participants when divulged to other people may lead to isolation, discrimination and value judgment. Their confidentiality was protected as they were given pseudonyms to conceal their real identity. The participants and researcher agreed on the place for the exclusive interview. Every information was kept under lock and key. Only the researcher and the supervisors at the University of Ghana have access to the information.

CHAPTER FOUR

Findings

4.1. Introduction

This chapter focuses on the findings of the study. The purpose of this study was to explore the lived experiences of people living with HIV/AIDS (PLWHA) in Ghana and also describe their experience of social support. Qualitative and descriptive research methods were used to explore this phenomenon. Data were generated from fourteen (14) persons living with HIV/AIDS (PLWHA) within the Accra Metropolis using semi-structured interview guiding questions related to the experience of social support. The demographic characteristics of the study participants will be presented first, followed by the thematic findings. The thematic findings have been organized into themes and sub-themes. The themes that emerged from the study were; “Lived experiences of PLWHA” and “Social support experiences”

The sub-themes under Lived experiences were;

- Biophysical experiences
- Psychological experiences
- Socio-economic experiences
- Socio-cultural experiences
- Coping strategies

The sub-themes that emerged under social support experience were;

- Meaning attached to support
- Sources of support
- Types of support
- Perception of support received

4.2. Demographic characteristics of participants

The demographic characteristics included the age, sex, educational background and ethnicity. Others were religious background, marital status and number of children

Age- Majority (7) were within 30 – 40 year range. Only one (1) participant was in her twenties. The mean age was 38 years.

Sex- There were eleven (11) females and three (3) males.

Educational background –All the three (3) males had secondary education. Only one (1) out of the 11 female participants attained commercial education. Three (3) completed elementary school and the remaining seven (7) did not go to school at all, or dropped out.

Occupation- Before their diagnosis, Ten (10) out of the eleven (11) female participants were petty traders in various goods such as fruits, foodstuffs, cosmetics and second hand clothing. The remaining female participant was a dressmaker.

For the male participants, one (1) was a photographer, another a civil servant and the last one, a petty trader. At the time of interview, ten (10) were not working. Four (4) out of those who were not working had been trained as HIV/AIDS counsellors. The other four (4) who were still working could only do so when they were well.

Marital status- Marital status of participants revealed that only two (2) of them were married and living with their spouses. Four (4) of them were divorced, and three (3) were single but had previous boyfriends. The rest, five (5) of the participants were widowed. The widows indicated that their husbands died of AIDS and they tested positive just before or soon after the death of their husbands. Some of the divorced and the widows blamed their partners for the infection. One of the females who was single, was keeping two boyfriends at the same time.

Number of children –Majority of the participants (11) had between 1-4 children. Out of this number, six (6) of them had two children. One (1) participant had ten (10) children. The remaining two did not have children. Three (3) of the female participants had their last children infected with HIV.

Religion- Twelve (12) of the participants were Christians whilst two of them did not belong to any religious denomination.

Ethnicity-The participants were made up of Akans (8), Ga/Adamgbe (4) and Ewe (2)

4.3. Lived experiences of Persons Living with HIV/AIDS in Ghana

Lived experiences of PLWHA was one of the main themes that emerged from the study. It covers a wide range of experiences the PLWHA encountered in their lives. Some of these experiences were; Biophysical, psychological, socio-economic and socio-cultural. It also focuses on the various coping strategies they employed to enable them contain the situation.

Most of the participants described extensively the symptoms of HIV/AIDS they experienced on daily and periodic basis. Participants viewed HIV/AIDS as a ‘bad disease’. They saw it as deadly as it is without cure. For some participants, most of the symptoms occurred concurrently, whilst in others they appeared one after the other.

Some of them experienced the severe form of the disease with symptoms appearing together.

Lena whose symptoms appeared one after the other described her situation in the following way:

I have never experienced any happiness in a single day in my life ever since I had it. I wake up vomiting, the next day it is fever, followed by toilet and bodily pains. I get tired. I have grown lean and bony, besides I am not dying. I am lying down and suffering like that...

Another participant said:

At first I had malaria which stopped after treatment. I was coughing and when I went to the Polyclinic for treatment and it stopped. I was going to toilet, I had sharp lower abdominal pains and stomach pains. I also had headache but all stopped. I now feel pains in the right cheek (Anna).

Others experienced moderate form of the disease with periodic occurrence of the symptoms. A few of the participants reported they had not experienced the worst form of the disease. For example, Adjoa Serwah:

I am not afraid of that because I have not grown lean. I only go to toilet if I have fever, but diarrhoea for one week or more, by the grace of God I have not experienced that. ... Luckily, by the grace of God from January to this time I have been to the clinic only once.

Coping with HIV/AIDS was among the sub- themes that emerged from this study. Though not the focus of the study, it emanated from the data. Coping refers to the way the participants managed their lives amidst the numerous signs and symptoms of the disease with their limited resources. For the individual participants, coping meant relying on a higher being and in many cases God, to provide hope, trying to help themselves by doing work and caring for their children. The strategies included; disclosure of HIV status, projection, obtaining spiritual support and mutual support among PLWHA.

4.3.1. Biophysical experiences.

In view of the nature of the disease, the participants reacted differently to the diagnosis of HIV/AIDS. They described the symptoms they experienced. The disease presented different symptoms among different participants. The symptoms they frequently mentioned were; loss of physical strength, loss of weight and diarrhoea, Others were inadequate nutrition and skin diseases like rashes, kaposi's sarcoma, chicken pox, oral thrush and shingles.

- **Loss of physical strength**

The disease profoundly influenced the ability of the participants' ability to work. The disease has made most of the participants weak. Among some of the participants the symptoms of the disease and inadequate nutrition contributed to the weakness. Kojo Mensah said,

“When I do any hard work, I become very weak, and when am hungry it disturbs me, walking becomes very difficult. If I get a well-balanced not a one-way food, I mean energy food I will be fine. So when I get food to eat, I am free.

Tina has this to say about limited strength and weakness:

I have limited strength, I wish I could work harder, but I get tired easily. When I wake up from bed I find it very difficult to get out of bed, as if I have been beaten. I get a bit better as the day progresses. If I force myself to work hard, I normally break down. I work at a lesser pace.

Cynthia, a dressmaker had to terminate the contract between her and her apprentices because of limited strength. As she puts it “I asked all of them to go. I experience decreased energy and strength so I was not going to the shop”

- **Loss of weight**

Weight loss was another common symptom the participants frequently mentioned and which caused them distress. Usually they said it was the diarrhoea and loss of appetite that caused it. Some of the participants said they had lost so much weight that all their bony prominences were obvious and they had sunken eyes and necks. Some said their features were so striking that they noticed people taking a second glance at them to confirm what they had seen.

One of the participants described her experience,

Sometimes when some people see me in town, they look at me and then turn again to look at me a second time. When I see that, I ask them if they have not seen someone suffering from AIDS before (Lena).

Abena Amponsah narrates people's reaction to her weight loss, "My church members have realized that I am loosing weight. Some look at me but they do not ask me anything"

- **Diarrhoea**

Most of the participants mentioned diarrhoea as the most common and unpleasant Symptom, Yaw said, "There came a time that I was running (diarrhoea)"

Esther Quaye had this to say about her periodic episodes of diarrhoea, "It is the toilet that normally brings me to the hospital. It is the only thing that disturbs me more than any other thing."

- **Skin diseases**

Skin diseases here refer to rashes, kaposi's sarcoma, boils, oral thrush, chickenpox and shingles. The symptoms were very serious among most of them, and this limited the activities of those participants who experienced them. Cynthia reports:

"About seven months ago, I started developing boils, this was followed by shingles, and rashes developed on my face and my underparts and the entire body. Then nothing happened for all I know my feet started to swell up".

Phillip also describes his condition,

"Kaposi's sarcoma is what I developed. It is like boils and spread all over the body".

- **Inadequate nutrition**

The participants persistently mentioned the importance of good nutrition in health. They reported that the medicine they took stimulated their appetite and they had to eat more but they had difficulty getting food to eat. This leads to weakness and emaciation. The emaciation created situation which, made some of them to avoid public place and some had to change their dresses. For example, Akosua sometimes had to beg for food:

I beg for food from co-tenants. When somebody cooks, then I ask the person to give some of the food to me... No, it is not always that I go to them to beg. It is only when I am very hungry and I have nothing to eat, so when they are cooking I tell them I will eat some of the food. After cooking they dish some out for me.

Anna tells about how she eats:

The drugs that I take make me eat a lot. When I eat, I spend all the two thousand cedis given by my mother. Sometimes I leave some of the monies given me by my brothers to buy kenkey and pepper in the evening to eat... Yes, my mother gives me food but it is not everyday that she cooks.

4.3.2. Psychological experience

The participants reacted differently when they were first diagnosed with HIV/AIDS. Majority reacted initially by denial of the disease. Some reacted by acceptance of the condition and a few had mixed feelings. Almost all of them entertained fear and worry about the disease.

Those who reacted to the initial diagnosis by denial did not believe they could be infected with the deadly disease HIV/AIDS. They stated they had not been promiscuous and therefore had denied their first test result of HIV. They however accepted it when the second test confirmed it.

- **Denial**

This is how Akosua reacted to her initial diagnosis, “That time, I was feeling sick and when I went to the hospital, I was informed I had HIV. I did not believe it at first so I went for a second test before I accepted the results”.

Cynthia also reported:

I did the first test at Cape Coast. I wanted to be sure if it was truly HIV so I repeated it at Korle-Bu and, I am trying to recollect how I had the HIV. I have not taken any man before.

- **Acceptance**

Five of the participants accepted the initial diagnosis because they had nursed their spouses with AIDS. For example, Esther Quaye after nursing her husband with AIDS had this to say about her initial reaction to her diagnosis:

At the hospital during blood and toilet investigations, it was revealed that my husband was suffering from this disease. I cared for him for sometime, there were different diseases that he presented with..... When I was first informed of the disease, I told myself that what has happened had already happened and the disease presents different signs and symptoms among different people. It is the will of God that has happened

One of the participants who had mixed feelings about her diagnosis after her child tested positive said:

My daughter was fine so I did not believe it was AIDS. Later ... I did not believe it but I also did not doubt it when I was asked to see the doctor.... I know that many people are infected with the virus. I do not think too much about the disease despite the fact that I am infected with the virus (Lena)

- **Fears and worry**

Apart from denial and acceptance, almost all the participants expressed their fears about the disease and were worried of being isolated. Mercy expressed her fears in this manner:

Hmm, my fear was that at the initial stages of the illness, the education that was instituted was not good that was why I did not tell my children because I thought they would be angry with me and isolate me if I had told them.

Some participants did not feel comfortable when they saw the emaciated body of other AIDS patients in their terminal stages. This is how Yaw expressed his fears about others in the terminal stages of AIDS,

Very bad, bad experience. When I come to see some people in the hospital, coming here becomes a problem, because when I see them I fear the disease.



- **Hopelessness**

Some of the participants declared they had lost hope because there was no cure for the disease. Tina had her last child also infected with HIV and therefore beset with double agony, “There is no cure for the disease so, sometimes, I lose hope. I become sad at times. It really disturbs me...In my view, the worst has happened. There is nothing I can do about it”.

Anna was not happy about her situation. She said, “I have been telling you that, I am not happy about my situation. It has already happened, what else can I do?” A few of the participants felt death was a better option. As Akosua said, “I am waiting on God. It will be better for me to die early than to become weak because I do not have any helper.” One of the participants indicated that she was not worried of dying if healing was not possible, “The only request I have is healing of my disease. Apart from the disease, it will not worry me if I die” (Cynthia).

- **Loss of self Image**

The symptoms of HIV/AIDS such as the weight loss and lack of good nutrition led to weakness and emaciation. Some of the participants realized they had lost weight to the extent that they were emaciated. They complained of their bony prominence. One of such participants was worried about how people would describe her body after death:

My father should not keep my body at the morgue for a long time. He should not allow people to come and see my body. My body should not be sent to our hometown. Those who should see my body are my father, his wife and my sister. People in my hometown talk a lot. People in my hometown will describe my body especially with the weight loss and fabricate stories about me. (Lena).

- **Fear of being stigmatized**

One of the participants was afraid she might be compelled to disclose her HIV status if she sought for help:

I can go but before I ask for help, the person might want to know what is wrong with me and I can't disclose my status to people. I am not worried to disclose my identity but the person may tell other people and they may be pointing fingers at me and when the news spread then they will begin to isolate me. (Esther Quaye)

Abena Amponsah felt people would talk about her, "If you are not careful, people will talk about you, if you go and ask for help."

- **Auto-condemnation**

Some of the Participants expressed their guilt for contracting the infection. A few felt it was a punishment for disobedience. Two of them blamed themselves for entering into marital relationship only to contract this infection.

One participant narrates her experience, "For the twenty years of my marriage, I never experienced happiness but rather it is the disease that I have contracted" (Adjoa Serwah)

Those who felt they got the infection as result of punishment for sin and disobedient, were asking for forgiveness. Deidei Mary asks for forgiveness of sin from God, "... pray for us. If it is disobedience that has brought us this far, God should forgive us our sins and rescue us from it".

Another participant tries to recollect her past life, "I don't go anywhere. I have tried to recollect if I have sinned." (Cynthia)

4.3.3. Socio-economic experience

The symptoms of the disease prevented most of the participants from working and this limited their ability to earn money to satisfy their basic needs. Almost all the

participants engaged in petty trading before their illness. At the time of interview most of them were not working. All the participants talked extensively about how the disease influenced their employment situations. They gave various reasons for not working. These were: weakness and easily fatigue with the least activity, stigma being a barrier to trading and depletion of capital

The symptoms have created some needs among the PLWHA. The needs arose because of the chronic nature of the disease and the need to constantly seek for medical attention, which was expensive. They were stigmatized, and a few were isolated. The participants had used all their available resources on their illness. This situation created special needs for the participants. The area of needs was: loss of financial income, inability to afford medication and inability to meet basic needs.

- **Loss of financial income**

Participants attributed the loss of financial income to their state of unemployment. They complained that their business capital had depleted because of their own or spousal illness and they have very little or no money to trade. Mercy states, “I am not working because of my husband’s sickness and subsequent death, my working capital is finished”

Mary who was selling second hand bags had this to say:

I was then selling bags. I had some amount of money. When I was attacked by the disease I did not know. I was staying at home and all my money got finished. I was given the bags on credit. After selling I sent the money to the owner. At the moment I am owing four hundred thousand cedis.

A few of the participants who were not very weak and whose symptoms were not very severe felt strong enough to work as long as money was available to them to trade. For example, Esther Ouaye declared her willingness to work:



We are not weak, we are willing to work. If they will investigate and give us some money for trading, it will help us. What I need is work. If I can get someone to help me get work, I would like it. If the person can buy me the wares, I will sell everything. If I sell, I can get money to buy my medications, soap to wash my clothing and food to eat and other nice things.

Some of them were prepared to engage in sedentary work, possibly in a shop. In the words of Kojo Mensah, “The only work that a PLWHA should do is to sell in a shop. A setting in a shop is the only work that is not very difficult. Staying at a point and working. ...I have to work at a slow pace”.

Throughout their conversation about work, there was desperation in their voices. Work was central to their ability to get money, which they needed in order to live, to feed themselves and their families, to get the essential medications, and to pay their rent.

- **Inability to afford medication**

All the participants mentioned medication as another important need because of the numerous health problems associated with HIV/AIDS, they needed to take drugs all the time, which they could not afford. Some of the participants indicated that they had to return their prescriptions to the doctor for less expensive ones. Sometimes, some of them had to resort to spiritual healing when there was no money for medication. This is how one of the participants who used both orthodox and spiritual healing described her mode of treatment:

The medicines were expensive. The doctor had to cancel my prescription that I could not buy and gave me a less expensive one. I have developed scabies, which started just last week. It has affected m breast. By the grace of God, there is a pastor in my house who prayed for me for the scabies to vanish. (Abena Amponsah)

Another participant narrated the amount of money she spent on medication:

Hmm...the medications that I have to take cost eight hundred thousand cedis a month which is very expensive. It is not always that I can get eight hundred thousand cedis every month (Mercy).

In view of their inability to purchase medication, some claimed they were dying prematurely. This was the cry from Esther Quaye, “We are suffering and dying prematurely out of lack of medication.”

Some of them pleaded for assistance in the supply of medication. Abena Amponsah’s plea, was “I am pleading with those of you who are healthy to assist us with the purchase of our medications”

Some of the participants who received medical treatment were calling on the government to produce antiretroviral drugs locally and supply them to the people living with AIDS. Phillip said, “I need antiretroviral drugs to suppress the disease to make it stable. I feel if the government can produce it locally it will help us”

- **Inability to meet basic needs**

The discussion of the participants centered on the inability to satisfy the basic needs of life. All of them talked extensively on getting the necessities of life. To these participants, the basic necessities of life were food, medication, and shelter comprising housing and clothing. Central to all these, was money to enable them fulfill these needs.

- **Food**

Food was the basic need for almost all the participants and formed the basis of their strength and energy. The participants who were not working to earn a living had to rely on others for food, which did not always happen in a regular predictable manner. For example, Kojo Mensah said:

My mother, with whom I live, gives me food when she cooks. The days that she does not cook, in fact I sleep like that. It is difficult. If she does not cook and if nobody comes to my aid with money, then, I have to stay like that. Sometimes I credit the food. I credit until someone comes to give me money.

Shelter

Another basic need, which was a problem to the participants, was shelter comprising housing and clothing. Most of the participants were in rented homes. Some of them needed money to rent rooms or put up their own houses. One of them expressed her desire to have her own house so that she could be together with her dependants. Mercy gave her reason for having her own accommodation:

If I should get financial assistance, I will put up a building so that in the future when I become bedridden, I can live in with my children or bequeath it to them when I die so that they don't become disorganized or wayward.

Lena's rent advance had expired, she comments:

My rent advance has expired. Now I learnt a room costs forty thousand cedis. Some land-lords collect four years rent advance whilst others collect three year rent advance. If I get a little money I will convince the land-lord to take it, if he does not accept it then the three years will be the best option.

4.3.4. Socio-cultural experience

Living with HIV/AIDS has socio-cultural implications. At the initial stages of the infection, most research studies reported that people commonly infected with HIV were homosexuals, intravenous drug users and commercial sex workers. This idea has been maintained in most cultures and, societies tend to sideline the PLWHA. People's perception about these PLWHA generally led to stigmatization and isolation of some of the participants. This situation increased their social burden and their inability to meet cultural expectation.

- **Stigma**

People assigned labels to some of the participants. They were perceived as promiscuous, infectious, and dead, which later led to their stigmatization and isolation. HIV/AIDS is considered a shameful disease. There is also the belief that by contracting

HIV/AIDS, one brings a curse upon the entire family and this normally leads to their isolation. Most of the participants talked extensively about the stigma associated with the disease and the subsequent isolation of some of the participants by some members of their families. One of the participants tells her story of isolation by her family:

They said I have brought a curse upon the family. At that, time I was living with the family and they ejected my husband, the little daughter who is HIV-positive and I from the family. Subsequently, I came to Accra and for two years, nobody visited me. It was a period when I was down with AIDS. Up to date nobody has come to look for me. (Tina)

Another participant perceived she was stigmatized by church members:

There are people in my church who do not respond to my greetings. They have realized I am loosing weight. Some do not ask me anything but they look at me. (Abena Amponsah)

Other participants complained that patrons will not buy from them because of stigma if they knew they were HIV positive, one participant reported:

I was selling bread, now I am not working. I am weak. I am unable to walk quite a distance., more so, my grandmother had spread my HIV positive status in the neighbourhood and people will not buy from me (Akosua)

- **Victimization**

A few of the participants were victimized by some members of their family just because of their HIV positive status.

Akosua whose family members perceived her as infectious commented:

They said a nurse told them I should buy parazole and pour it on my toilet and also use some to scrub the bathroom after each bath so that they also do not get infectected with HIV

Akosua tells of her ordeal, “Formerly, she (aunt) promised to rent a room for me but now she says no. Before she gives me money she insults me”.

Anna also recounted her ordeal, “when I do something that hurts my mother, she insults me, she also denies me food”. It seems the family was not pleased with her lifestyle because she was keeping two boyfriends at

that time and more so, they believed she had the disease when she had sex with another man whilst pregnant by a different man. Sometimes she does not do the work assigned her by her mother.

- **Misperception**

Most of the participants indicated that the public had negative and uninformed perceptions about PLWHA. They were perceived as promiscuous, infectious, dead and people who must be poisoned. One of the participants in defense against the accusation of promiscuity indicated that people living with their spouses could be infected without being promiscuous. She commented:

People think it is only through indiscriminate sex that people get infected but there are times one gets infected whilst living with her husband (Abena Amponsah)

- **Social burden**

The participants expressed the concern about their ability to maintain their dependants. All the participants who had children talked extensively about the care of their dependants. Most of them were either widowed or divorced and were caring for their dependents alone. They were disappointed with the care they were currently offering to their children because of the limitations of their illnesses. Participants had difficulties providing them with adequate food, clothing, and payment of school fees because they were too weak to work or they did not have the money to engage in trading so that they could earn some income. For example Mercy commented on the situation:

My only problem is with the care of the children, their schooling, school fees and feeding. This is because I am not working and because of my husband's sickness and subsequent death, my working capital is finished.

Phillip whose children were always sent home for non-payment of school fees because of his inability to work and earn income also had this to say.

As for money ... If I get millions upon millions, I will take it once I am alive, I will eat and clothe myself and use some for my children's school fees and other things.

Mary who was divorced and caring for her three children alone was particularly worried about her children when she was on admission at the hospital, complained:

Their father does not take care of them...he does not take care of them, and I have been thinking about my children. What they have been eating I do not know. I have been thinking about them.... No, now they are not in school. Their schooling has been disrupted.

The participants felt healing of their illness could be a solution to most of their problems. Some of them felt they were a burden on their support providers. Esther Quaye was particularly concerned about sharing a room with the older children of her support provider, and had this to say, "More so, he has children who have started bringing forth and we are all sharing one big room. I am thinking that I have to be reasonable enough to move out of the pastor's house".

Another participant raised concern about being a burden on the support providers' family, "She has a family and I cannot put my burden on her" (Kojo Mensah).

- **Inability to meet cultural expectation**

Majority of the participants received the help spontaneously. Some of them said they were unable to reciprocate. Reciprocity refers to returning something for a kind gesture or exchange. It was the wish of a few of the participants to return something valuable for their support providers but their wishes could not go beyond 'thank you'. Most cultures in the country believe in bi-directional nature of support and most of the participant could not fulfill this cultural expectation.

They felt they had been a burden on their support providers and to reciprocate was a form of showing appreciation and relieving them of some of the burden.

One of the participants, whose father was the only source of support, was particularly worried she was unable to reciprocate her father's assistance. She puts it this way:

I always think of working seriously to support my father, but still, I cannot work to support my father. This is what worries me. I feel sad about it.... he has not asked me to help him. (.Deidei Mary)

Mary was concerned about reciprocating her sister who has been paying for her medical bills, "If I get someone to help me with my trading, I will pay back to my sister what she has spent on me just like the way I pay for the bags I sell"

4.3.5. Coping strategies

In view of the serious consequences of living with HIV/AIDS, the participants employed some coping strategies in order to contain the situation. These were in the form of projection, disclosure and confidentiality of their status. Other strategies included maintaining faith in God and prayer, mutual support and health seeking behaviours

With the participants who were emaciation, they had to adapt to new dresses. They talked of wearing long sleeves, long dresses with a high neck, or trousers. Lena reported, "see how I have grown lean...I need to wear long dresses to cover my neck and feet". Their concern about how their body appeared to others prevented some of the participant from appearing in public to avoid suspicion.

Abena Amponsah's comments illustrate this point "I was losing weight so I stopped going out... even though they might not have heard anything, they may suspect that I have the disease".

Apart from disclosure, another coping strategy the participants employed was to examine their lives to find out about the source of the infection since they declared they were not promiscuous. Most of the participants blamed their spouses for the infection whilst others felt it was a punishment from God.

- **Projection**

The participants who were widows or divorced blamed their spouses for the infection. Mercy blames her late husband for her infection, “The father of the rest of my seven children is the one who gave me this disease”.

Lena was divorced and she blames her ex-husband for infecting her with the virus, “my husband who infected me, I believe must have infected about 50 women. I am not the only person who will die. We shall all die. Probably I will die first and the others will follow suite”.

- **Disclosure**

Disclose implies making ones HIV diagnosis known to others. In this study, participants chose to disclosure or not to disclose. Disclosure of ones status carried with it, either risk or benefit. The risk attached was stigma and isolation and the benefit was that some of the participants had support from others. For those who disclosed, telling someone about their diagnosis was helpful for some. For example, Cynthia said, “my senior pastor, I informed him and he promised to remember me in his prayer”.

For others disclosing their diagnosis made their lives more difficult for them as it was in the case of Akosua, “At first, we were all sleeping in the bedroom but now I sleep in the sitting room”.

Some of the participants chose to keep their diagnosis secret, in order to continue to receive the support they so desperately needed. Making the diagnosis known to families,

friends and other people was a major problem for most of the participants for various reasons such as isolation.

- **Confidentiality**

One of the participants who was rejected by her parents chose not to disclose it to her siblings for fear of isolation, “My siblings, especially, the one after me, has been helping me but he does not know my problem. I am afraid that when I tell him, he will isolate me, so I have not been able to tell him.” (Tina)

Some also felt reluctant to disclose it because of the stigma attached to the disease. Yaw had not disclosed his status to any body at all:

At all cost people will get to know but for the meantime, I don't want anybody to know because of stigma. So for the meantime I will keep it till when I know that it is off my hands" ... when they realize you have such a problem you will not have that association anymore.

Participants who disclosed their HIV-status were very cautious and selective of the people they wanted to know, “The church members do not know. I have told three of my friends and two of the ministers.” (Mercy)

- **Maintaining faith in God and prayer**

All the participants expressed their faith and hope in God for healing. AIDS is a disease without immediate cure and they believed God had great powers to heal them.

One participant reports, “It is painful but it has already happened. I only have to pray to God to intervene. Ones life will be disorganized initially until one forgets about it later” (Phillip).

Another participant acknowledged the healing power of God:

As for disease, it is God who provides healing. Doctors only help. It is God who heals. God heals in the spirit to manifest physically. It could be that with time I can come out of this sickness to my original state of health, by God's grace. (Kojo Mensah)



Others believe by living exemplary lives and with prayers, God could heal them.

Akosua said, “There is nothing I can do about it. It is only prayer. It is only God who heals. I go to church, my Pastors have been praying for me. I am also living in holiness. God can heal me at anytime.”

Another participant was hopeful that God would help her accomplish the task she had set for herself, “If it is the will of God, he will help me to accomplish the task I want to do before I die. I have hope in God that my disease is not difficult for God” (Esther Quaye).

A few of the participants attributed their relatively low level symptoms to the grace of God. Adjoa Serwah said, “I only go to toilet if I have fever, but diarrhoea for one week or more by the grace of God I have not experienced that. For me I have strength to do hard work. I don’t feel sick”.

The participants realized they also had a role to play to overcome the illness and sustain their lives after committing it to God.

- **Mutual support (PLWHA)**

The participants who were members of the Wisdom Association reported they were comfortable in the company of other PLWHA. They said that by interacting with others in similar situations to their own encouraged them to cope with their circumstances a little better. Some reported they enjoyed free interaction among themselves, and promoted sharing of food and information. One of the participants expressed her happiness for being in the association, “We are not happy in our homes that is why we always come here to interact with each other. We laugh over here but when we are at home we tend to think a lot and set our minds back” (Esther Quaye). They reported being with peers relieved their boredom. Tina said:

If a member is bored at home, he/she is free to come to the center to converse with other members of the association. A lot of conversation

go on there, which is really helpful. It also helps us to gain more knowledge about the disease and helps us understand the disease better.

In the comfort of the Association, the participants exchanged food, ideas and experiences with peers:

We engage in conversation and laughter. More so, when a member has something, we share among ourselves provided you will eat. Sometimes when one has a particular complain, like headache or toothache an association member can counsel the person and advise the one as to what to do. (Abena Amponsah).

This mutual assistance did not happen among the PLWHA alone but also among one of the participants and her co-tenants.

One participant was able to exchange assistance between her and her co-tenants, she commented, “If I need anything they provide for me. If they also need some assistance from me they come to me” (Abena Amponsah).

- **Health seeking behaviour (Western, traditional and allied treatment)**

Healing of the participants illnesses was of great concern to all of them since this could free them of the numerous symptoms associated with HIV/AIDS. It will enable them to work. It will also enable them care for themselves and their dependants. In their quest for healing, some of the participants used both orthodox and non-orthodox treatment. For orthodox means of care, it refers to the treatment from trained medical professionals like doctors and nurses. Non-orthodox system refers to prayers, herbal treatment and seeking care from quack doctors. Majority of them used both orthodox and non-orthodox treatment because when they came to the hospital, after receiving doctor’s treatment, they also received herbal medicine from the wisdom association which some of them belonged to. Others apart from the drugs they received from the hospital prayed for themselves or had

their pastors and church members pray for them. Majority of them combined medical and herbal treatment. Some of them also combined medical and “quack” treatment. Others combined drugs with prayer. A few of them used orthodox treatment only. Majority of the participants prayed for healing. The participants also had pastors and church members praying for them. Deidei Mary said, “I only pray to the Lord to heal me”.

Cynthia who had confided in her pastor about her HIV/AIDS status said, “When I told my pastor I had HIV he told me he will pray for me”

Yaw, who was living with HIV said, “I feel very bad. I only pray I should be able to get healed and care for my children and my wife, and I don’t develop AIDS”.

Majority of the participants sought for medical treatment when they suffered from the numerous symptoms of HIV/AIDS.

Most of them combined orthodox medicine with herbal treatment and sometimes prayers.

Tina describes the benefit of the herbal medicine:

The association also provides us with herbal medicine which does not kill the virus but helps build up the immune system. It stimulates appetite and the individual is able to drink a lot of water and helps one to urinate better.

One participant who sought for medical treatment said:

I developed chicken pox all over my body, I was vomiting and going to toilet. I informed my sister and she brought me to the hospital where I was told I am suffering from this bad disease (AIDS) (Mary).

In an attempt to get healed a few of the participants were deceived by quack doctors that they could cure them of the AIDS disease. Abena Amponsah narrates her story:

A certain man came here that he could cure us so we were taken to Kwashieman. I started receiving treatment from him. Later I was taken to Legon hospital for check-up and there was no change in my condition.

Anna was ready to go for cure from a quack doctor:



Last time a pastor in white robe and a blue belt came here and told us he will give us his telephone number to call him. This is because someone with this type of illness went to stay with him and in no time, the person got healed. I told my mother to take me to the pastor, if he could cure me.

4.4. Social support experiences

The participants in this study received support from many sources. Notable among them were the family, community members, non-governmental organizations, church organizations and the health institutions. The family was the most commonly cited source of support and whilst some of the participants received support from multiple sources, others received support from a single-family source. Most of the participants received the support spontaneously, but others had to beg and sometimes it was packaged with insults.

The participants received support in various forms. These were; financial, assistance with the provision of basic needs, social, medical, emotional and spiritual. Generally, all the participants except one complained that the support was inadequate. However, they were very grateful to their support providers for their assistance without which life would have been unbearable for them.

4.4.1. Meaning attached to Support

Apart from the needs, the support system was the main focus of this study. The meaning of support from the data meant the assistance, be it material or emotional, that the PLWHA received from the family, organizations, institutions and community members. However, the participants perceived this assistance as “grace” or the unmerited favour from others. This was expressed as “Adom” in the local language. Participants also used this word to express their appreciation for the help received from others. The expressions cut across interviews: “Se obi beye me adom” meaning if someone will do me a favour.

For example, when asked about his contribution towards his children's upkeep, Kojo Mensah responded that,

Se obi beye me adom na oma me sika a na medze bi ato books ama me mbofra." meaning if someone shows me favour by giving me money, I give some to the children to buy books.

Another participant said, "Eye adom na yedidi" meaning it is by grace that we eat. (Adjoa Serwah).

4. 4. 2. Sources of Support

Data from the participants indicated that sources of support were the family, organizations, institutions, and community members made up of friends, co-tenants, relatives of other people living with HIV/AIDS and some individuals who offered help to the PLWHA. In their initial reaction when asked what their sources of support were, some of the participants reported not having anybody who helped them.

The initial reaction of one of the participants, "At the moment if I say I have somebody who helps me, then it means am telling lies". (Kojo Mensah).

However, as the interviews progressed, all the fourteen participants could name at least one source of support for themselves. Some of these sources provided support without knowing that the participants were HIV positive.

- **Family members**

All the participants except one mentioned the family as the primary source of support. They received support from both the nuclear and the extended family. The nuclear family involved the mothers, Stepmothers, wife, fathers, a husband and their children. Data from this study indicated that the extended family consisted of the mother, father, children, siblings, uncle, aunt and cousins.

Majority of the participants frequently mentioned their mothers as the key source of support when it came to provision of food and care when they were sick.

One of the participants narrates the enormous help he received from his mother.

... the days that my mother cooks at home, she gives me some to eat... It is my mother who pays my hospital bills (Kojo Mensah).

Anna also told the story about the help provided by her mother,

... my mother spent a lot of money on my child ... I don't eat three times, because when my mother gets up she gives me two thousand cedis. ... she gives me food but it is not everyday that she cooks.

The fathers were infrequently cited as support providers. Only two of the participants mentioned their fathers as support providers. Dedei Mary said, "My father continues to help me, he caters for my feeding, financial needs and sometimes he brings me to the hospital." Lena identified her father as a key source of support.

The father was so much concerned about his daughter's health that he visited very frequently to find out how she was. However, the daughter was also disturbed about her illness that she felt bored with these frequent visits. Lenna commented on her father's visits:

Very early in the morning, my father would come to knock at my door whilst I am in bed. I sometimes get bored with his frequent visits. Sometimes he comes there about four times in a day. ... as for food at times, as soon as I got home my daughter would be at my door waiting with my food. During heavy rain, they carried the food under umbrella to deliver it to me.

In spite of the support from some family members, a few of the participants complained some members of their families had rejected them whilst others accepted them. The data indicated that some of the participants received support from either single-family source or multiple-family sources.

Single-family source means that only one family member provided help to the participants for example, father only, siblings only and mother only.

Tina had a child who was HIV-positive. Her parents rejected her and her child because of their HIV status. They were perceived to have brought a curse on the family. She received help from a single-family source that is support from her sibling only. This sibling did not know about his sister's HIV status. As she puts it, "My siblings, especially the one after me, has been helping me but he does not know my problem".

Mary also mentioned her sister as the only family member who helped her:

My sister is the only one who has been helping me by buying my medications. Now she does not have money. When my sister was working, she helped me to rent the room.

Mercy received help from her children only, "It is my older children who take care of my health."

Phillip also commented on the assistance provided by his sisters, "My sisters also know and they are fine with me, even though they don't give me anything, they converse with me and comfort me".

Different participants had support from different family members and whilst some received help from single-family source, others received help from multiple-family sources.

Multiple-family source means the provision of support to the participants by more than one family member. For example, mother, siblings, aunt and children together were providing assistance at the same time. There were participants who received support from multiple family sources. For example, Lena received help from her father, stepmother and sister:

My father and my stepmother have been caring for me. My father does not have any sustained job, but whether I eat or do anything, they have

been providing me with my needs. My sister gives me money. She is also not in any gainful employment.

Akosua was isolated among her family members she was living with in the same house and especially by her grandmother. However, she got assistance from a multiple-family sources. Her uncle, aunt and mother who live outside the family house assisted her. She commented:

When I went on admission to the hospital, my uncle, the doctor footed my medical bills. He bought my medications for me. My aunt gives me money for food whilst my mother cooks for me and accompanies me to the hospital.

One of the participants received support from his aunt, mother, and cousin.

My aunt does not give me money but she takes care of my children. Anytime I visit my cousin she gives me money for food. My mother, with whom I live, gives me food when she cooks (Kojo Mensah).

Cynthia is the only female participant who had a husband. She had the highest multiple family sources of support. She received support from her husband, mother, sibling and children:

My husband buys all my prescribed drugs. My brother is a doctor so he invited me to the hospital for care. When I am given prescription my sister brings me money. For the past six months my mother has been with me. My child sells my wares for me.

Only one participant indicated that she had received no assistance from her family members. According to her she came from a poor family and she was supporting them before her illness, "I am from a poor family so I do not receive any help from them. I used to care for them and I am now in trouble" (Abena Amponsah).

- **Support from community members**

The help that the participants received were not limited to the family members, organizations and institutions but also, some community members.



Community members such as friends, co-tenants, former employer, some celebrities and some relatives of other HIV/AIDS persons provided some assistance to a few of the participants. The participants defined friends as people they liked and trusted for mutual assistance. Friends were important source of support in the lives of the participants. Some of them confided in their trusted friends by disclosing their HIV status to them. These friends continued to support the participants. For instance, Phillip had three friends but he trusted Kwame more than the rest, “I have three friends. Kwame is the one who is with me. As for him when I need anything, he gives me, ...clothing and other things”

Other friends did not know the HIV status of the participants but they cared and supported them as people who were suffering from any other disease. Some of the participants recounted the support they received from friends. The promise by a friend was enough for a participant to credit food, “At least when a friend visits and promises me money that today he does not have anything, but he will give me money, I rely on that to credit food.” (Kojo Mensah)

One of the participants told a story of how her two friends doubted her initial diagnosis but when it was confirmed later, they offered her assistance:

When I got the infection, I informed only two of my friends. They said they did not understand why I was suffering from the disease. They did not understand how the disease had affected me. They accompanied me to undergo another blood test but the result was the same. Even that, they still do not believe it is AIDS. When I go to them to beg for money, they are able to provide me with the little money I need for food. (Esther Quaye)

Adjoa Serwah received some help from her friend, “I have a friend who is a pharmacist. She gives me medicines. She is my only friend who knows my problem”.

Another participant has this to say about concerns raised by his friends when they noticed he had lost weight, “Even my friends advise me I am loosing weight. ...some of them have been bold enough to advise me to take some leave or go for a check up” (Yaw). These notwithstanding, some of the participants said they were not interested in keeping friends and did not have any friends who could help them.

There was cordial relationship between the participants and some of their co-tenants. This free interaction facilitated the free exchange and provision of support to the participants. Cynthia had this to say about her co-tenants, “people in my community, and even my co-tenants know I buy medication and food, so they made some contributions and gave me two hundred thousand cedis”.

The association has trained some of the PLWHA as counselors, and through this activity, the participants received some donations.

Tina reported, “

...we present ourselves to them to encourage them (PLWHA) to accept their situation that they are not alone. Relatives of other HIV-positives sometimes offer me gifts after counselling their members with HIV-positive. They offered me dresses and sometimes money.

Esther Quaye said, “Miss Ghana, the first one, organized parties for us till her time elapsed. The second one gave us a lot of cloth which were shared among us which I had three half-pieces.

Another member of the counseling team narrates how she got the support spontaneously, “When we get invitation from an organization, we travel to go and talk to them and give testimonies about our lives. After the talk we were given some money” (Adjoa Serwah).

- **Non-governmental organizations**

It was evident from the data that majority of the participants received assistance from majority of the family members. Apart from the family, certain organizations provided support for them and notable among them was HIV/AIDS support organization known as “Wisdom Association”. Other organizations were Family Health International (FHI), Forum for African Women Education (FAWE), and ProLink. However, these ones assisted some of the participants through Wisdom Association.

Majority of the participants belonged to the “Wisdom Association” a non-governmental organization formed by people living with HIV/AIDS and some volunteers. Membership is by registration and payment of monthly dues of one thousand cedis. The organization is within the Fevers unit and PLWHA are encouraged to register with it in order to benefit from the support they provide especially the herbal medicine. One of the participants commented on his registration with the association:

... Yes, Wisdom. I filled the form and added one passport size picture. So the only thing I got to know was, they bring some herbal medicine. So I have been collecting some. (Yaw)

The association mobilized some of the PLWHA into income generation activities in ornamental bead making and locally made soap (Alata semina) through which the participants earned some income:

When it happened like that we mobilized ourselves to process locally made soap (Alata Semina) when we joined the association. At the end of the month, we were given two, two hundred thousand cedis each to buy food. For some time now, they have stopped (Adjoa Serwaah).

Apart from the income generation activities, majority of the participants received material support directly from “Wisdom Association”. One of the participants said, “The other time

when they (Wisdom Association) shared some items, I was given my share. I had something for home. I had rice, beans, oil and other items” (Abena Amponsah).

Some other organizations like the FHI, FAWE, and “Prolink” assisted some of the participants through “Wisdom Association” Tina commented:

In my case there is an Organization called Prolink, through whose influence has led to the adoption of my elder child who is HIV-negative by a certain couple. They are caring for the girl until she gets married. They want a bright future for her.

Adjoa Serwah stated the help she got from another organization, “There is an NGO called FAWE Ghana chapter who helps me in every aspect including the children’s education.”

Despite the enormous assistance provided by these organizations, three of the participants did not know about the existence of any HIV/AIDS support organization. For example Phillip unveils his ignorance about the existence of any HIV/AIDS support organization, “I know of Ghana AIDS Commission and apart from that... I don’t know the particular place that some of these associations are”.

- **Church Organizations**

The church was a significant source of support for most of the participants. Majority of the participants were active church members and belonged to either the Pentecost or Presbyterian churches. The church provided both spiritual and physical support to the participants by offering prayers, money from collection, clothing and visiting the participants when they were sick. In one instance a pastor of a church offered to live with a participant who had been isolated by some members of her family, as reported by Esther Quaye:

The pastor has accepted me in his home for five years now. ...they take collection and give some to me. Periodically, the pastor reminds the church to take collection for me. When I am in need, the pastor himself provides them for me.

Adjoa Serwah tells her story about the church and her pastor:

The church members also come to my aid, sometimes twenty, or ten thousand Cedis, they comfort me and like the widow, they drop something down into my hands ...the pastor has taken it upon himself to give me cloth every Christmas to wear to church.

One of the participants commented on how a pastor healed her of scabies, “I developed scabies, it started just last week and it has affected my breast. By the grace of God, there is a pastor in my house who prayed for me for the scabies to vanish” (Abena Amponsah).

Anna received money from her church after discharge from the hospital, “Pentecost, sometimes they give me some money. When they were told I had been discharged from the hospital, the church brought me some money”.

Only one participant was skeptical about the supportive character of the church:

OK... with this present day if one does not have money, the church does not know him/her. They want those who can offer large sums of money for collection and those who can donate when the need arises. Those are the people the church supports in times of needs. For those of us who are poor, you can be in the church for hundred years, you will never be known so, getting help from them is difficult (Kojo Mensah).

- **Health institutions**

Provision of support from diverse sources enhances the well being of the PLWHA to some extent. Beside these organizations the participants had some of their needs supplied by some health institutions.

The health institution complemented the effort of the religious institution. The health institution refers to Akwatia Hospital and Fevers Unit of the Korle-Bu Teaching Hospital where some of the participants received some assistance. The Principal nursing officer in-charge of the Fevers unit was mentioned as the one who provided them with assistance out of the “Comfort Fund”. The comfort fund is the monies donated by people and some institutions to the fevers unit toward the welfare of needy PLWHA. A few of the

participants said they received monies for their prescriptions. Mercy stated the help she received from the fevers unit:

To be honest with you, I get some help from the hospital. The matron is the one who helps me. When I come here and I have no money to buy my prescription, matron gives me money to buy them. She also gives me money to go and have my X-ray done when I don't have money. There are times I don't have any money to buy food to eat so when I tell her she gives me five thousand or ten thousand cedis to buy food.

There were other health personnel like nurses who helped the participants.

Some of the participants received money from the nurses at the unit, “when I come around, the nurses and the sisters who like us call me and offer me some little assistance. If one nurse gives me five thousand and the other also gives me five thousand I put them in my bag and go”. (Esther Quaye).

One of the participants also received help from Akwatia hospital where she received treatment previously, “they shared a lot of things, there were those who had rice, gari, sardines and other items when I was going to Akwatia. Anytime I went there I was given ten thousand cedis for transport” (Cynthia).

4.4.3. Types of support

Participants in this study had different sources of support and this aspect examines the type of support they received. At the same time, the nature of support also varied. Most of them defined it in terms of material, emotional as well as spiritual assistance.

The participants received support in the form of financial, assistance with basic needs, social medical, emotional and spiritual.



- **Financial support**

All the participants mentioned money as a universal support they received from people who helped them.

Phillip stated the monetary assistance he received from his friends:

Alright, now that I can't go anywhere it is my friends who help me. If any of them gets money, he gives me some.... Oh about twenty thousand, thirty and ten thousand cedis.

One of the participants also had money from his sister.

Right, as at now I have some sisters outside the country. They have learned that I am sick so there was a time they even sent me money. ...about seven hundred dollars. (Yaw)

Anna talks about the money she received from her brother, "my brother who lives at Abeka gives me money."

According to Esther Quaye, her friends showed empathy when she told them her diagnosis, "I have two friends who are fine with me. When I informed them I have HIV, they did not believe it so they took me to the hospital for retesting until they believed it". After the diagnosis they continued to help her by offering her money and other needed items.

- **Assistance with basic needs (food, clothing, shelter)**

Apart from money, some of the participants got food from their support providers.

One of the participants commented on the food she got from her sister, "my sister sends me foodstuffs. She sends it through some people to us or sometimes to the lorry station, where I go to collect it." (Adjoa Serwah).

Another participant also reported, "My parents even if they do not have money, they try to give me food" (Lena).

Esther Quaye described how she received food from the pastor's wife with whom she lives, "After cooking, I present my dish for food".

A few of the participants, apart from the drugs had clothes donated by their church members, or through "Wisdom association" by some celebrities. A few of the participants needed to change their clothing because of gross emaciation. One participant commented, ... "the pastor has taken it upon himself to give me cloth every Christmas to wear to church." (Adjoa Serwah)

The issue of material support goes beyond money, food, drugs, clothes and the care of children to cover accommodation. Two of the participants had people accepting them into their homes, when they were ejected from their family homes because of their HIV status. Esther Quaye described her situation in this way, "I have lived in the home of the pastor for five years. At the moment I live in the home of the pastor."

Tina also recounted her experience,..."they (landlord and co-tenants) ejected me from the house in the night. It was another HIV positive person who sent me to their home."

Apart from the participants receiving these items, some of them had more than one item.

- **Social support**

Some of the participants had people and organizations helping them with the care of their children, which was a great relief to them. Lena commented, "my father has adopted my two children...in the case of the children's school fees, my father pays it."

Anna's brother is taking care of her child, "at first it was my mother who was taking care of my child but now it is my brother who is taking care of him".

A certain couple is caring for another participant's daughter, "in my case there is an organization called Prolink, through whose influence led to the adoption of my elder child who is HIV-negative by a certain couple" (Tina).

- **Medical support**

Another material item the participants received apart from money and food was drugs. Some of these drugs were orthodox medicine whilst others were herbal preparations supplied by the Wisdom association. For example, Yaw said, “The only thing I got to know is that, they (Wisdom Association) bring some herbal medicine. So I have been collecting some.”

Esther Quaye also commented, “it is one thousand and you collect the medication. ... The pastor also prepares herbal medication for me to treat other associated diseases for me to get better”.

Another participant commented on how she got her prescribed medicine, ... “when they write medications for me, my father buys it” (Dedei Mary).

Adjoa Serwah received drug donations from her friend who is a pharmacist, “I have another friend who is a pharmacist. She gives me medicine.

- **Emotional support**

Material and emotional support ensure sustenance of the life of the participants. All the participants received emotional support. Emotional support encompasses advice, conversation, reassurance and prayer. Other areas included counselling and free interaction among the PLWHA, empathy and visits. Most of the participants received advice from their support providers, “even my friends advise me I am losing weight and some of them have been bold to tell me to take some leave or go for a check up” (Yaw). Yaw felt by this advice, his friends were concerned about him.

Most of the time, the providers visited the participants when they were on admission at the hospital or seriously sick in bed at home. The visits nullified any isolation perceived by some of the participants. Dedei Mary said, “He (father) visited me when I

was on admission at Legon.” Kojo Mensah also said, “One of my siblings comes around to visit me”.

Some of the participants viewed conversation as an emotional support. Phillip reported, “my sisters also know of my HIV status, and they are fine with me, even though they don’t give me anything, they converse with me and comfort me”. Phillip felt despite his HIV status, his sisters accepted him, and this was emotionally gratifying.

Cynthia tells about the reassurance she received from health personnel, “I met a certain sister who reassured me that it will be well”. She found this as consoling

- **Spiritual support**

Prayer was a key type of emotional support for almost all the participants. The participants felt that no matter the cause of the infection, they needed to commit the situation into God’s hands by maintaining faith and prayer.

One of the participants said, “My pastor’s wife....The woman helped me with prayers until my husband died” (Adjoa Serwah).

Akosua also reported on the prayer said by her pastor...”my Pastors have been praying for me”.

Cynthia who had confided in her pastor about her HIV/AIDS status said, “When I told my Pastor that I had HIV he told me he will pray for me”

4.4.4. Perception of support received

After participants identified the sources and the type of support, they gave various scenarios regarding the mode in which the support was delivered to them. Some of the participants received the assistance spontaneously, whilst in others it was not spontaneous. Those who received it spontaneously indicated that they had the assistance when they were



seriously sick, whilst a few had it when they visited. For example Phillip received support spontaneously when he was seriously sick, “When I was sick in bed, my friends visited and gave me money”. Kojo Mensah reported, “Anytime I visited my cousin, she gave me money for food”. Three of the participants who did not receive the assistance spontaneously, had to beg for the support. In some extreme cases, some of these assistance was packaged with insults.

All the participants except one indicated that the support they received was inadequate. Adequacy of support involved the satisfaction with the actual assistance the participants received from their support providers as being enough.

Barriers to support limited people’s ability to seek help and as a result, the PLWHA did not get all the needed assistance they required, hence the support was not adequate. For example Mercy was receiving support from the Matron of the Fevers unit on regular basis but of late she said she felt shy to go for further support,

Matron gives me money on regular basis but of late, I feel shy as an elderly woman like me to go to my fellow woman to ask for money or tell her I don,t have money. For the past two weeks, I haven’t been able to go to he for money.

Most of the participants felt they were a burden on those who provided care and support for them. Even though they indicated that the support was not adequate, they were appreciative of the support they received. Participants were concerned about the employment situation of the people who assisted them. They mentioned that most of the providers were not in gainful employment. This situation limited the amount of help given to the participants. Others were concerned that the providers also had families to take care of. In view of these, some of the participants received too small from the onset. A few experienced either a reduction in the amount of assistance received which, initially was sufficient or complete withdrawal of some of the support providers from the networks.

One participant encountered a decrease in the amount of support she received from her aunt and a complete withdrawal of her uncle from the support network. Akosua reported:

Now my uncle is sick. He says his heart, as a result, he is unable to take care of me as he used to. My aunt gives me sixty thousand cedis every two weeks.... the last time I went to her she gave me only fifty thousand cedis which is not enough. ...”.

Others indicated that their support providers have withdrawn from the support networks for various reasons. For example, Kojo Mensah:

Initially my former employer was coming to my aid on weekly basis to offer me assistance. He gave me money, fifty thousand cedis every week for feeding. He did that for several months and stopped.

Tina said:

Madam A, a support provider was giving me fifteen thousand cedis every month, but of late when I went to her house I was told she had traveled to America and the people in the house do not know me so that help is not forthcoming.

Some of the participants complained about the amount of support they received from their provider as inadequate:

The support I receive from my parents and the organization is not enough. No, it is not adequate at all. Sometime my mother gives me ₵2,000 at most, how much do I use to eat breakfast, lunch and supper out of it. So it is not enough sometimes I collapse as I think of it. (Kojo Mensah).

One of the participants appreciated her father’s willingness to help her but she also acknowledges his help as inadequate:

It is not enough. It is my father’s wish to help and willing to help but this is all that his strength can carry him. He has spent a lot on my illness . . . “crying” . . . so he cannot give me money in bulk to carry out business activities. (Dedei Mary)

There was desperation in their conversations as they described the inadequacy of their support and they pleaded for more of it. Two of the feelings were summed up by Tina and Phillip.

I am pleading with people to help us, not I alone but most especially the Wisdom Association. There are other members whose situations are more pathetic than mine so, as for help, people should come to help us. (Tina)

... so people should offer financial support and counselling to people with the disease. The disease is like any other disease but this one is without cure. (Phillip)

Only one participant expressed satisfaction with the support she received as adequate, but felt she needed more. Adjoa Serwah commented:

I will accept it that it is enough for me because God has given me a place to sleep, I have something for food to eat, but he tells us not to be complacent with what we have. What I have is sufficient for me but I still want more. ...If I get additional source of income it will be better.

Living with HIV/AIDS and its numerous symptoms has created unpleasant consequences for the participants. Most of the participants were either widowed or divorced and were caring for their dependants single-handedly. The symptoms have made some of them weak and unable to work to earn an income. The participants, who were mostly traders, have used their business capital on their illness and have virtually nothing or little to live on. These situations have created a need such as employment, food and money among others, to enable them earn income to provide them and their dependants with their basic needs. These needs have necessitated the call for support, which was being provided by some family members, community members, church institutions, and non-governmental organizations. However, these supports have been described by the participants as inadequate. In order to maintain control over the situation, they were calling for more help, and also, they adopted some coping strategies to enable them live with the disease.

Chapter Five

Discussion

The purpose of the study was to explore how PLWHA experience social support within the Accra Metropolitan area. This chapter discusses the findings of the study on social support of fourteen participants. The findings will be linked to other research studies. The discussion will be on the two major themes “Lived experiences of PLWHA” and “social support experience”, and their respective sub-themes.

The participants saw their situation within the context of living with HIV/AIDS. Participants had been living with AIDS between six months and seven years following diagnosis. This gives an indication that the disease has shifted from acute short term deadly to progressive chronic one, similar to those reported by Powell-Cope (1995) and John (1999). This is because they were under constant medical care and even though none of them was on anti-retroviral treatment. When this is made available to them, it will prolong their lives. It could also be as a result of counselling to accept their condition. The participants viewed the HIV/AIDS as a bad disease. Their reaction to the diagnosis was that of denial, acceptance, mixed feelings, fear and worry. This is similar to those of Anarfi (1992) and Russo (1988). This is because PLWHA face uncertain future, as they consider the disease as deadly, having no cure, and are stigmatized. This supports the report by Aggleton et al. (1989).

The participants in this study also presented similar syndrome like those reported by Jones (1986) and Ingram & Hutchinson (2000). These symptoms were in the form of fever, diarrhoea, pain, fatigue, itches and painful boils among others.



The nature of the disease and presentation of the symptoms made them incur expensive medical expenses, which they could not afford. This is quite different from what was reported by Norsk Offentlig Utredning (1987) in Norway where all expenses related to care and treatment are covered by the services which accounts for longer lives of HIV/AIDS patients. This is because access to health services is purely through the “cash and carry” system, where patients make out of pocket payment for services. Some of the participants in this study had to return their expensive prescriptions for less expensive ones or resorted to other forms of treatment such as prayer and herbal treatment.

People had misperception about the PLWHA. The participants were viewed variously as people who were promiscuous, highly infectious and dead. Others felt the PLWHA should be poisoned. This is in support of the findings of Cherry and Smith (1993) that PLWHA's are viewed as a disease and not as individuals. Some of the participants were stigmatized and ostracized by some family members. This is consistent with the findings of Caldwell et al. (2000), Ropper and Anderson (1994) and Barroso & Powell-Cope (2000). This was to prevent shame on the entire family. It also portrays the ignorance of the family.

The fact that all the five widows were diagnosed with HIV after their husbands had died of AIDS is revealing and this may be an indication that they were infected by their husbands. This is in support of Nabila and Fayorsey (1996). This indicates how vulnerable women are. The fact that almost all of them were in sexual relationship gives an indication that they contracted the infection through heterosexual intercourse. This is acknowledged as a major mode of infection and heterosexual intercourse accounts for 80% of HIV infection in Ghana.

The disease has permeated the socio-economic lives of the participants such that it created a number of needs among them. The needs centered on loss of financial income, inability to afford medication, and inability to meet basic needs. This is congruent to the findings of Katabira et al. (1998), who also reported that HIV infection and AIDS can have prolonged and devastating effects at the personal level, as such, PLWHA have a wide range of needs and problems related to their condition.

Most of the participants were self-employed before their diagnosis. The disease had rendered them unemployed because of the following reasons; they were weak and incapable of doing any hard work, and some had used up their working capital on the care of their late spouses who died of AIDS among others. Unemployment led to their inability to take care of themselves and their dependants as well as to re-engage in trading. The issue of unemployment created inconveniences for the PLWHA, similar to what was noted by Friedland et al. (1996) that unemployment was high among relatively healthy and well educated PLWHA. As Mota (1996) puts it, work is one of the factors that enhanced a sense of personal safety among the PLWHA. Some wanted sedentary work.

Some of the participants expressed their disappointment that they were unable to take care of their children as they wished, and felt they were failures. This is consistent with Koopman, Gore-Felton, Marouf, Butler, Field, Gill, and Chen et al. (2000) that low income created greatest stress among the PLWHA. Unemployment affects self-image and security.

In the seeming helpless financial problem coupled with chronic ill health and inability to obtain the basic needs, a few of the participants felt death was imminent. This supports the findings of Bunch (1998). The participant felt death was a better option than to live and suffer but their concern was about the care of their children when they are

dead. This is consistent with the findings of Blachman (1988) and Heckman et al. (2001). Leaving their children orphans was the main concern of many PLWHA and even in normal situation, it is also of great concern.

To overcome this uncertainty, the participants felt the need to seek for the help of others in order to sustain their lives and that of their dependants and prevent premature death. They described how some PLWHA's died prematurely when they were isolated by their families. This supports the report by Aggleton et al. (1989) that in dealing with the situation, the PLWHA deserve a great deal of individualized support in order to help come to terms with their position. It was also noted by Saunders and Valente (1992) that vulnerable persons often cannot intervene on their own behalf and, therefore must rely on the goodwill of others to assure they receive care. It is also consistent with the report of Dupras et al. (1990) and Kadushin (1996) that PLWHA experience a number of crisis that make them need social support. Participants viewed social support as an integral part of their lives.

A major finding of this study was that all the participants in this study experienced some form of social support either from the family, organization, institution or community members. The family was mentioned as the major source of support. Some of the participants received help from multiple family source and others from a single-family source. Even where a family member rejects the PLWHA, another steps in to take care of him/her. In situations where the HIV status of the participant is known, majority of the family members continue to help him/her. This is congruous with the findings of Anarfi (1992); Mann et al. (1992); Bor & Elford (1994) and Brown (1997). This shows how strong and effective the extended family system is. As Nukunya (1992) puts it, social support is embedded in the extended family system. Despite the family as a major source

of support, the mother stands out as a major source. This is consistent with the findings of Stowe & Ross (1993), Powell-Cope (1995) and Mensah et al. (1997), that where the family was involved in support, it was likely to be provided by mothers and siblings. Motherly care and love is manifested in times of crises situation and like HIV/AIDS, mothers are likely to stick to their children. As put by the Hymnist William Cooper (1731-1800), can a woman's tender care cease towards the child she bears? Similarly, women of the home usually take care of sick family members. One participant reported her family was poor and before her illness, she was caring for the family and therefore did not receive any help from them.

However, Friedland and Renwick, (1996) and Stowe and Ross (1993), found friends to be of major support to their participants, contrary to this finding that the family was the major support provider. That study was in a different culture and the researchers also reported that this was so, most especially where the mode of contraction was via homosexual transmission or through injecting drugs.

The chronic nature of the disease, make the participants need massive material support and emotional assistance. Notable among the material support was money for food, medication, and to take care of themselves and their dependants among others. This was also acknowledged by Mensah et al. (1997), Barroso et al. (2000), Robinson et al. (1990), TASO/WHO (1995) in Uganda and Gloersen et al. (1993). These are the basic needs of every individual but it becomes more pronounced in HIV/AIDS disease and other chronic conditions.

As to how support was provided, some of the participants in this study reported receiving the support spontaneously whilst in others it was not spontaneous. For the non-spontaneous one, dissipating ones resources persistently creates tension among the

providers. This reaction could also be that due to the chronic nature of the disease, continuous provision of support may deplete the resources of the providers as Enterlante and Kerni (1995), reported that support providers might experience overload, over involvement, and over-commitment.

All the participants except one reported that the support they received from their support networks was inadequate. This supports Heckman et al. (1998) that PLWHA experience low social support from the family, friends and society. The issue of inadequacy of support posed threats to the sustainability of their lives. Increased distress has been associated with perceiving less availability of support in AIDS. Similar to what was reported by Zich and Temoshok (1987) and Stewart et al. (2000). Conversely, increased social support improved quality of life of the PLWHA's as reported by (Nunes et al 1995 Aduwa et al. (1998). The inadequacy was due to the following reasons: a reduction in the amount of money they received, withdrawal of some members from the support networks, family members who were supporting them were not gainfully employed, and the amount of support being too small. This supports Courtens et al. (1996) and Bernad et al (1990) that social support can either endure or dissipate over time and the changes in the individual's network and patterns of support in chronically stressful situations such as illness or care giving can be significant. This is not strange because in chronic illness support providers themselves are sometimes not able to provide enough for themselves and their dependants. It is evident that before one can effectively provide assistance, he /she should be financially sound.

Only one participant in this study expressed satisfaction with the support she received from her providers. She indicated that her living condition was better than when her husband was alive and before she was diagnosed as HIV-positive. This is in support of

Taylor and Brown (1988) that beneficial outcomes may be a product of stressful situations, and stress may provide an opportunity for adult development. This satisfaction could be attributed to the high quality support network that she had.

In conclusion, the participants described their experience of social support within the context of living with HIV/AIDS. The disease had made them weak and rendered them unemployed. They were unable to meet their basic needs. The situation created a lot of needs that called for the support of others. Most of the participants had multiple sources of support. They provided the participants with financial, assistance with basic needs, emotional support and spiritual support among others. The participants reported that the help they received from their support networks was not adequate. They therefore employed some coping mechanism to enable them sustain their lives. Some of these coping strategies were adaptive whilst others were maladaptive.

CHAPTER SIX

Summary and Conclusion

A brief summary of the findings of the study will be provided. Direction for the course of nursing action and suggestions for policy makers towards the provision of support for the PLWHAs will be recommended. The need for future research into related issues unearthed in this study will be discussed. Limitations encountered during the research process will be included. Questions that the study focused on were; “what was the lived experience of PLWHA and their social support experience. A qualitative design was used to obtain in-depth information from the participants. A purposive sampling method and snowballing were used to recruit participants. Semi-structured interview guide was used to collect data. Data were transcribed from ‘Twi’ into English. The information was analyzed using content analysis and constant comparison.

The findings of this study indicated that the participants experienced the syndrome of AIDS which affected their employment and their ability to earn a living. This created a need for which support was needed. The report from this study revealed that all the participants experienced some form of support, and most of them received support from multiple sources. Notable among them was the family. Even though some family members rejected some of the participants, others accepted them, and provided immense assistance to the PLWHA. The participants also received support from other sources such as community members, church organizations, health institutions and non-organizations organizations. They received support in the form of financial, assistance with basic needs, social, medical, emotional and spiritual.

The assistance was provided either spontaneously or not spontaneously. Almost all the participants except one reported that the support was not adequate. The participants

were appreciative of their support providers. The participants reported that most of their family support providers were not in gainful employment, and more so, they have other family commitments. Only one participant indicated that the support she received was adequate. The participants employed various coping mechanisms to enable them contain the situation. However, some of these coping strategies were adaptive while others were maladaptive.

6.1 Implications for Nursing

From the participants' report, some of the nurses were helpful in providing financial assistance to the participants. Nurses should be recommended for that, They should try to raise funds to solve the impromptu needs of the PLWHA.

Some of the participants employed adaptive coping mechanism and nurses should encourage the PLWHA for that, but for those who employed maladaptive coping, further counseling is required and nurses should ensure confidentiality when counseling.

Nurses should intensify the education of the general public to minimize stigma and isolation of the PLWHA.

Nurses should educate the public on the mode of infection of HIV especially the heterosexual mode of spread. Other area of education should be on universal precaution on infection prevention.

Nurses should also advocate for people living with HIV/AIDS.

6.2. Recommendations for Policy-makers

People living with HIV/AIDS (PLWHAs) are living longer and continue to be capable of employment after diagnosis. Since some of the participants in this study

strongly indicated their desire to continue working, it is important for policy-makers to consider employment policies that would support PLWHAs to continue being employed, even after diagnosis, in jobs that do not entail strenuous activity.

Some of the participants in this study reported of being stigmatized and isolated by a section of the public. Policies on reaching out to the PLWHA should be intensified to sustain them and prolong their lives.

Participants in this study reported they were unable to pay for medical services, which were expensive and beyond their means. This is because they experienced several episodes of the opportunistic infections. In view of this, they could be relieved of this burden if policy-makers could formulate policies that could exempt the PLWHA from payment for medical services and if possible, provide them with free anti retroviral drugs.

6.3 Recommendations for further research

It was the perception of the participants that the support they received was inadequate. There is the need to research into the type and the amount of support that will sustain them.

Another aspect that requires further studies is “Healing by faith in HIV/AIDS diseases” since all the participants in this study relied on God for healing and prayed that they would be cured of the disease.

This study was carried out in the Accra metropolitan area, which is also the capital of the country where there are more infrastructures and organizations. Income in this city is higher than those in the rural areas, and yet the PLWHA reported of inadequate social and monetary support. The situation could be different in the rural areas and therefore there is

the need to conduct a similar study in the rural areas to assess sources of support for PLWHA among rural populations.

Future research should include a longitudinal study to examine if the support the participants received is a sustainable one, and whether the support network is intact, increased or decreased over time.

There should be a study to find out whether NGO'S fighting against HIV/AIDS are responding to the social support needs of the PLWHA, and the type of support they are providing.

6.4 Limitations

Although gender disparity was created as a result of males not wishing to participate in the study, it did highlight the need for more gender specific research in this area. Some of the participants negotiated for a fee to be paid to them as they perceived researchers get money for such projects and this added extra cost to the study.

Language barriers were another limitation envisaged by the researcher before the study. However, the participants represented a wide range of Ghanaians.

Inadequate research funding was a major constraint. Some organizations were contacted for funding but their responses were that they do not sponsor either academic based research or individual projects.

6.5 Concluding comments

Generally, most Ghanaians provide support to people who are sick and in need including, those living with HIV/AIDS. This is because majority of the participants mentioned multiple sources of support, which the family was the key support provider.

Despite the fact that a few of the participants were rejected by some members of their family, majority of the participants enjoyed the support of most of their family members and this is a healthy development.

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APPENDICES

APPENDIX A - A GUIDING

QUESTION ON SOCIAL SUPPORT FOR PEOPLE LIVING WITH HIV/AIDS

SECTION 'A'

SOCIAL-DEMOGRAPHIC DATA

1. What is your age ----
2. What is your highest level of education----
3. What is your ethnic background-----
4. What languages do you speak-----
5. What is your religion-----
6. What is your marital status-----
7. How many children have you-----
8. How many dependants do you have-----
9. Tell me about your extended family
 - Parents
 - Siblings etc.
10. Economic activities/ generate income-----
11. Income level-----
12. Where do you live-----
13. How many times have you been hospitalised in the last year-----
14. Who looks after you when you are sick-----

SECTION B

This section is quite vital and sensitive. It may generate emotional feelings.

You are permitted to express your emotions.

A. Experience of living with HIV/AIDS

1. For how long have you lived with the disease?.....
2. How was your health before the diagnosis?.....
3. What are your views about HIV/AIDS?.....
4. Could you describe your experience as someone living with HIV/AIDS?.....
5. How do people living with HIV/AIDS (PLWHA) experience social support?.....
6. What is your experience with family, friends, employer, and health professionals?....

B. Needs of People living with HIV/AIDS

1. Could you describe your needs that require support?.....
2. Which of these needs are most important to you?.....
3. How do these needs affect you and health?.....

C. Source of support

1. Who among your family, friends, neighbours etc. are aware of HIV-positive status?.....
2. Who among your family, friends, neighbours, co-workers etc. provides you with support?.....
3. Are you aware of any HIV/AIDS support organization in your community...
4. Do you receive any assistance from any organization?.....

D. Nature of support

1. What is the nature of the support that provided.....
2. How is support provided by the family, friends neighbours, health professionals etc.....
3. How do other people/organizations provide support?.....
4. Do you have to provide anything in exchange of the support that you receive?.....
5. How do you get access to support, care and services.....
6. Is there anything that prevents you from seeking the support of others.....

E. Adequacy of the support

1. How much support do you get from those who provide it.....
2. How satisfied are you with the support you receive.....
3. Do you think it is enough?.....

APPENDIX B - A GUIDING

QUESTIONS FOR CAREGIVERS ON SOCIAL SUPPORT FOR PEOPLE LIVING WITH HIV/AIDS

SECTION 'A'

SOCIAL-DEMOGRAPHIC DATA

15. What is your age ----
16. What is your highest level of education----
17. What is your ethnic background-----
18. What languages do you speak-----
19. What is your religion-----
20. What is your marital status-----
21. How many children have you-----
22. How many dependants do you have-----
23. Tell me about your extended family
 - Parents
 - Siblings etc.
24. Economic activities/generate income
25. Income level.....
26. Where do you live.....
27. What is your relationship to the patient.....

SECTION B

A. Experience of caring and providing support for someone living with HIV/AIDS

1. For how long have you known the HIV- positive status of the patient....
2. How has his/her reaction be?.....

3. What are your views about HIV/AIDS?.....
4. Could you describe his/her health status.....
5. Could you describe your own health status.....
6. Tell me your experience as someone providing care and support for a relation living with HIV/AIDS?.....

B. Needs of the person living with HIV/AIDS

1. Could you describe the needs of the patient you are providing care and support for?.....
2. Which of these needs are more important to him/her.....
3. How do these needs affect his/her life and health?....
4. Tell me your needs as a caregiver?.....
5. How adequate are his/her resources.....

C. Sources of support

1. Could you name those who provide support to the patient....
2. Does he/she get other support from other people/organizations.....
3. Do you also get support from people/organizations.....
4. Are there any barriers that prevent him/her from seeking support from others.....

D. Nature of support

1. What is the nature of support that you provide for him/her.....
3. How do you provide it?.....
4. How do other people/organizations provide the support.....
5. How are you rewarded for the care and support you provide.....



6. How adequate are your resources.....
7. How does he/she get access to support care and services.....

E. Adequacy of the support

1. How much support do you provide for him/her.....
2. How do you consider the adequacy of the support.....
3. How satisfied is he/she with the support you provide.....
4. How much support does he/she get from other people/organizations.....

APPENDIX C
UNIVERSITY OF GHANA
DEPARTMENT OF NURSING

phone: 500149/502255/500381/502258
Ext. 6155 (Head of Department)
Ext. 6206 (Secretary)
513250-Direct
513255
mail: nursing@ug.edu.gh
Ref: DN/F/17
Ref:

P. O. Box 43
LEGON, GHANA



November 13, 2002

The Chief Executive
Korle-Bu Teaching Hospital
Accra.

Dear Sir,

PERMISSION TO CONDUCT A RESEARCH
MISS HAGAR AGYIR-BINN

I wish to seek permission for Miss Hagar Agyir-Binn, an M.Phil student of the Department of Nursing to conduct a research study in the Fevers Unit and Department of Medicine, Korle- Bu Teaching Hospital. The title of the study is "HIV/AIDS and Social Support Systems within the Accra Metropolis".

It would be most appreciated if she would be given the necessary assistance.

Yours faithfully,

Mary Opare (Miss)
Ag. Head of Department

Cc: The Head
Dept. of Medicine
K.B.T.H

DDNS
Dept. of Medicine
K.B.T.H

P.N.O.
Fevers Unit
K.B.T.H

APPENDIX D**INFORMATION SHEET FOR PEOPLE LIVING WITH HIV/AIDS**

Project title: Social Support System for People living with HIV/AIDS in the Accra Metropolis.

Researcher: Hagar Agyir-Binn. M'Phil Nursing Student of the Department of Nursing, University of Ghana. Tel. 021 686452

Purpose of the study: HIV/AIDS is a serious disease with a lot of stigma. It has no cure at the moment. A large number of people get infected every day. People are afraid of the disease so much that sometimes their families do not accept those who are infected. I want to find out the type of help people suffering from AIDS get from their relatives, friends, health workers, government and AIDS organizations. I also want to find out if the help is enough. The information you will give is valuable. It will give us a better idea about what it is like for you to get the help you need. The health professionals might be able to give other people living with HIV/AIDS better support because of what you are able to tell us.

Benefits/Risk: There is no monetary or material reward for taking part in the study. You may get relief talking to somebody about your condition. It could also make you sad and upset.

Methods: If you are 18 years and older and have HIV/AIDS, you can be part of the study. You are free to decide if you want to be part of it. You will be asked to talk about how people help you in this time of your illness. Your answer will be recorded on tape and some will be written in a book. You can choose where our talk can take place. This talk will be done on two different days. We will talk for about one hour in a day. If you get tired we will stop and continue on another day. If you agree to take part in the study, you

will be asked to sign or thumbprint an agreement form. You can choose to stop being in the study. Your treatment and care will not be affected if you do so.

Confidentiality: The talk will take place in a place where no one else can hear what you say. I will give you a different name for this interview so that nobody can know it is you. Your name will only appear on the agreement form. All that you say, and the agreement form will be kept in a cupboard and locked up. It is only me, the translator and my supervisors at the University, who will read about it. It will be kept for five years. The information you provide may be used to write and teach about HIV/AIDS but your name will not appear in any of these materials. The information you provide may be used for further studies. If you have any questions feel free to ask me at any time.

Other people you can contact for more information about the study are:

1. Ms. Mary Opare: Head, Department of Nursing, University of Ghana, Legon.
Tel. 500300 Ext. 6089
2. Ms. Joanna L Laryea: My Supervisor, Department of Nursing, University Ghana, Legon. Tel. 500300 Ext. 6089.
3. Prof. J. K. Anarfi: My Supervisor, ISSER, University of Ghana, Legon.
Tel. 233-21-501182

APPENDIX E

CAREGIVERS INFORMATION SHEET

Project title: Social Support System for People living with HIV/AIDS in the Accra Metropolis.

Researcher: Hagar Agyir-Binn. M'Phil Nursing Student of the Department of Nursing, University of Ghana. Tel. 021 686452

Purpose of the study: HIV/AIDS is a serious disease with a lot of stigma. It has no cure at the moment. A large number of people get infected every day. People are afraid of the disease so much that sometimes, their families do not accept those who are infected. I want to find out the type of help you and other people as well as organizations provide for your relative who is suffering from AIDS. I also want to find out if the help is enough. The information you will give is valuable. It will give us a better idea about what it is like for you to provide support for someone living with HIV/AIDS. The health professionals might be able to give other people living with HIV/AIDS better support because of what you are able to tell us.

Benefits/Risk: There is no monetary or material reward for taking part in the study. There is no harm to your life when you take part in the study.

Methods: You can be part of the study If the person living with HIV/AIDS mentions you as someone who provides care and help no matter your age and sex. You will be asked to talk about the help and care you provide for the patient. There will be only one talk which will last for about one-and-a half hours on a day that you are free. Your answer will be recorded on tape and some will be written in a book. You can choose where our talk can take place. We will talk for about one hour in a day. If you agree to take part in the study, you will be asked to sign an agreement form. If you are unable to read and write the

information will be explained to you. If you understand and agree, then you will be asked to thumbprint an agreement form. You can choose to stop being in the study. This will not affect you or the treatment and care of the patient.

Confidentiality: The talk will take place in a place where no one else can hear what you say. I will give you a different name for this interview so that nobody can know it is you. Your name will only appear on the agreement form. The information you provide and the agreement form will be kept in a cupboard and locked up. It is only me, the translator and my supervisors at the University, who will read about it. It will be kept for five years. The information you provide may be used to write and teach about HIV/AIDS but your name will not appear in any of these materials. The information you provide may be used for further studies. If you have any questions feel free to ask me at any time. Other people you can contact for more information about the study are:

1. Ms. Mary Opare: Head, Department of Nursing, University of Ghana, Legon.
Tel. 500300 Ext. 6089
2. Ms. Joanna L Laryea: My Supervisor, Department of Nursing, University of Ghana,
Legon Tel. 500300 Ext. 6089.
3. Prof. J. K. Anarfi: My Supervisor, ISSER, University of Ghana, Legon.
Tel. 233-21-501182

APPENDIX F**CONSENT FORM FOR PEOPLE LIVING WITH HIV/AIDS**

Title of Project: Social support System for People Living with HIV/AIDS in the Accra Metropolis.

Researcher: Hagar Agyir-Binn, M-Phil. Nursing Student, Department of Nursing, University of Ghana, Legon.

Purpose: To find out about the help you receive from your family, friends, health workers, government, and other AIDS organizations. The information you provide may enable people provide more sustained support if this is not enough.

Consent:

Please circle your answer:

- Do you agree to be in this research study?

Yes

No

- Do you understand the information sheet?

Yes

No

If you agree to be in the study it will involve these things:

- One talks with the researcher Yes No
- Each talk will last for about one hour Yes No
- Each talk will be tape- recorded and some written in a book Yes No
- Do you understand that you do not get any monetary gain for participation?
Yes No
- Do you know what I will do with what you tell me? Yes No

- Do you understand that you can stop being in the study at any time?

Yes No

- Do you understand that your treatment and care will not be affected if you do so?

Yes No

- Have you had a chance to ask questions about the study? Yes No

This study was explained to me by.....

I agree to take part in the study

Signature of participant/Thumbprint **Date**.....

Printed Name

I believe that the person signing/thumb printing this form understands what is involved in the study and voluntarily agrees to take part.

Signature of Researcher.....**Date**

APPENDIX G**CAREGIVERS INFORMED CONSENT FORM**

University of Ghana, Legon

Title of Project: Social support System for People Living with HIV/AIDS in the Accra Metropolis.

Researcher: Hagar Agyir-Binn, M'Phil. Nursing Student, Department of Nursing, University of Ghana, Legon.

Purpose: To find out about the help you receive from your family, friends, health workers, government, and other AIDS organizations. The information you provide may enable people provide more sustained support if this is not enough.

Consent:

Please circle your answer:

- Do you agree to be in this research study?

Yes

No

- Do you understand the information sheet?

Yes

No

If you agree to be in the study it will involve these things:

- One talks with the researcher Yes No
- Each talk will last for about one-and-a half hours Yes No
- Each talk will be tape- recorded and some written in a book Yes No
- Do you understand that you do not get any monetary gain/ material reward?
Yes No
- Do you know what I will do with what you tell me? Yes No

- Do you understand that you can stop being in the study at any time?

Yes No

- Do you understand that this will not affect you or the treatment and care of your patient. Yes No

- Have you had a chance to ask questions about the study? Yes No

This study was explained to me by.....

I agree to take part in the study

Signature of participant/Thumbprint **Date**.....

Printed Name

I believe that the person signing/thumb printing this form understands what is involved in the study and voluntarily agrees to take part.

Signature of Researcher.....**Date**

APPENDIX H

Table 1: Summary of the demographic characteristic of the 14 participants

Name	Age	sex	Religion	Ethnicity	Education	Occupation	Marital status	Duration of Infection	No of Children	Infect childr
Lena	30yrs	F	Nil	Akan	No schooling	Trader	Divorced	6months	2	1
Kojo Mensah	38yrs	M	Christian	Ga	Secondary	Not working	Divorced	1year	2	-
Akosua	24yrs	F	Christian	Ewe	Primary 3	Not working	Single	6months		
Mary	35yrs	F	Nil	Ga	Primary 6	Trader	Divorced	6months	3	
Tina	30yrs	F	Christian	Akan	Middle school	Counsellor	Widow	4 yrs	2	1
Anna	30yr	F	Christian	Akan	Middle School	Not working	Single	1year	2	1
Mercy	56yrs	F	Christian	Akan	Middle School	Counsellor	Widow	4 yrs	10	-
Esther Quaye	45yrs	F	Christian	Ga	Primary 3	Counsellor	Widow	7yrs	2	-
Dedei Mary	33yrs	F	Christian	Dambge	Primary 4	Trader	Single	8months	-	-
Abena Amponsah	49yrs	F	Christian	Akan	Commercial School	Not working	Widow	3yrs	1	-
Adjoa Serwah	45yrs	F	Christian	Ewe	Middle School	Counsellor	Widow	4 yrs	4	-
Cynthia	40yrs	F	Christian	Akan	Vocational School	Dressmaker	Married	1yr	2	-
Phillip	33yrs	M	Christian	Akan	Sixth form	Photographer	Divorced	8months	2	-
Yaw	48yrs	M	Christian	Akan	Sixth form	Civil Servant	Married	1yr	3	-