STRESS FACTORS AND COPING STRATEGIES OF WOMEN CAREGIVERS OF HIV POSITIVE CHILDREN IN MASSEY STREET CHILDREN'S HOSPITAL, LAGOS

BY

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ABSTRACT

Globally Human Immunodeficiency Virus (HIV) infection constitutes a threat to human health. Caregivers, especially women face challenges in performing the multitude of tasks caring for HIV positive children. This burden may result in emotional, physical, psychological, social and financial stress. In Nigeria, the stress experienced by women caring for these children and associated factors has not been adequately studied. This study was designed to assess the stress experienced and coping strategies adopted by women caregivers of HIV positive children at Massey Street Children Hospital Lagos Island, Nigeria.

A cross-sectional study was carried out. In-depth interviews using an in-depth interview guide were used to obtain information from seven consenting purposively selected women at two Anti-retroviral Therapy (ART) clinics in Lagos. Information gathered was used to develop the study questionnaire. This questionnaire was subsequently used to interview 200 consenting purposively selected women caring for HIV-positive children in the Antiretroviral Therapy (ART) clinic. The questionnaire contained questions on socio-demographic characteristics and 22-item 5-point Likert -type scale ranging from 4 (very stressful) and 0 (Not applicable). Maximum total stress score for the scale was 88.0. Caregivers with stress scores ≥40 were categorized as very stressed, caregivers with stress scores 24 – 39 were moderately stressed and those with stress scores ≤ 23 were mildly stressed. Types of coping strategies utilized on the stress inducing factors were identified. The in-depth interview data were analyzed using a thematic approach while descriptive statistics and ANOVA were used for quantitative data.

The In-depth interview revealed that caregivers experienced stress if they are widows, unemployed, lack strong social support network and were not informed on how to access treatment and formal support. Age of the respondents was 32.9±10.6 years, 78.5% were married. Fifty-three per cent had at least a secondary school education. Seventy-three per cent had high stress on discovery of the HIV-positive status of their children, 12.0% had moderate stress and 13.0% reported no stress at all. The women were of low socio-economic status, mostly traders (53.5%). Other high stress inducing factors included admission of child to hospital (38.0%) and waiting to know baby's HIV status (50.5%). Married women had total stress score 31.2±10.3,

widowed women 32.6±13.3, and single women 43.0±10.6. Women caregivers with stress scores ≥ 40(71.0%) were very stressed and ≤ 23(26.0%) were mildly stressed respectively. Acceptance of the child's HIV diagnosis (80.0%) and other stress inducing factors was the main coping strategy. Specific coping strategies employed included non disclosure of child's HIV status to friends (81.5%) and family (53.5%). Analysis of variance showed that marital status of women, educational level and occupation were significantly associated with mean stress scores.

The caregivers of the HIV positive children were very stressed. Acceptance of the child's HIV positive diagnosis was the main coping strategy. Caregivers utilized specific coping strategies which included non disclosure of child's HIV status to family and friends. Linkages to support services offering specific physical, emotional, psychological, social and financial interventions that will help them cope better with the stress of their caregiving role are recommended.

Keywords: Stress, coping strategies, caregivers, HIV positive children
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DEDICATION

This project is dedicated to God Almighty without whom this would not have been possible.

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CERTIFICATION

I certify that this work was carried out by Yetunde Olukemi Sekoni of the Department of Health Promotion and Education, Faculty of Public Health, College of Medicine, University of Ibadan, Nigeria.

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LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral
BAI	Beck Anxiety Inventory
CBT	Cognitive Behavioral Techniques
COPE	Coping Orientation to Problems Experienced
CSI	Coping Strategies Inventory
FMOH	Federal Ministry of Health
FSS	Family Support Scale
GAS	General Adaptation Syndrome
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
LEIS	Life Events Inventory Scale
LGA	Local Government Area
MOEP	Ministry of Environment and Planning
MTCT	Mother to Child Transmission
NACA	National Agency for Control of AIDS
PLWHA	People living with HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission
PSI	Parenting Stress Index
PSSHIV	Perceived Stress Scale for people living with HIV/AIDS
SLE	Stressful Life Events
SRRS	Social Readjustment Rating Scale
UNAIDS	Joint United Nations Program on HIV/AIDS
UNICEF	United Nations Children's Emergency Fund
WHO	World Health Organisation
WOC	Ways of Coping

DEFINITION OF TERMS

Stress:any event in which environmental demands, internal demands, or both taxor exceedthe adaptive resources of an individual, social system, or tissue system.Monat and Lazarus (1991).

Coping Strategies: these are constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person.Lazarus and Folkman (1984).

Caregiver: A caregiver is anyone who provides care for another person in need, such as a child, an aging parent, a husband or wife, a relative, friend or neighbor. A caregiver is an unpaid or paid person who helps another individual with impairment with his or her activities of daily living (Wikipedia).

HIV positive: this is the condition or situation of testing positive for HIV

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CHAPTER ONE

INTRODUCTION

1.1 Background to the study

Many studies and research have been conducted on the subject of stress. The subject of stress is a very complex and multifaceted one. Stress can be considered from several perspectives. Stress is a topic considered in varied disciplines including health, psychology, physiology/biology and engineering. World Health Organization (WHO) has defined health as complete physical, mental and social well being and not only the absence of diseases or infirmities. Stress has been defined as any event in which environmental demands, internal demands, or both tax or exceed the adaptive resources of an individual, social system, or tissue system. Stress has been delineated in literature into various types physiological, social, emotional, mental, psychological and financial. It can therefore be inferred from these that any disruption in physical, social and mental health due to stress can result in ill health. Physiological stress is concerned primarily with the disturbance of tissue and other physical system. Social stress views the social unit as the disrupted factor and psychological stress encompasses those threats to the individual psychological well being.

In this study the population sampled has in common the care of a HIV positive child. Parenting a normal healthy child is considered a challenge. Specifically, the care giving role for a HIV positive child may involve significant stress, and need for adjustment for the mother (Busza, Dauya, Bandason, Mujuru and Ferrand, 2014). The presence of a chronic medical condition in a child is a factor that has been related to increased stress and psychological difficulties (Mullins, Wolfe-Christensen, Hoff Pai, Carpentier, Gillaspy, Cheek and Page, 2007).

There is a paucity of research focusing on the impact of HIV/AIDS on children and families particularly in sub-Saharan African. A review of literature revealed that more research on HIV/AIDS and pediatric HIV/AIDS is going on in the United States of America (USA) and Europe as evidenced by the number of research studies with reference to USA and Europe than in sub-Saharan Africa. This is surprising with the evidence that about 90% of children affected by HIV/AIDS are living in sub-Saharan

Africa (UNAIDS/UNICEF 2016). There is a dearth of research of pediatric HIV/AIDS in sub-Saharan Africa and in particular Nigeria. This is alarming considering that Nigeria has the second largest number of HIV infected people after South Africa. No published literature was found on stress factors and coping strategies of caregivers of HIV positive children in Nigeria though a few related studies conducted in South Africa were available on the internet accessed through Google and Google scholar.

At the end of 2016 the total number of people in the world living with HIV was 36.7 million (UNAIDS/WHO 2017); 1.8 million were children under 15 years of age and about 17.8 million were women and girls. New HIV infections among children have declined by 50% since 2010 however worldwide 160,000 children became newly infected with HIV in 2016 of these 122,000 children newly infected with HIV are living in sub-Saharan Africa and 41,000 specifically in Nigeria (UNAIDS/WHO 2017). In UNAIDS 2015 report; 260,000 children age 0 – 14 are living with HIV and orphans due to HIV are 1.8 million in Nigeria (UNAIDS/UNICEF/WHO 2016). In the same report globally, 1.1 million people were estimated to have died of AIDS-related illness of these 110,000 were children under 15 years. The toll of HIV and AIDS continues to be harsh, especially in sub- Saharan Africa. Sub-Saharan Africa has just over 10% of the world's population, but is home to an estimated 70% of all people living with HIV- 25.5 million people were living with HIV in the region in 2016, 3.2 million of these in Nigeria (UNAIDS 2016). HIV is spread in sub-Saharan Africa mainly by heterosexual transmission and also by vertical transmission from mother to child. HIV affects families and is intergenerational. The presence of HIV in a child almost always means that at least the mother, and possibly the father, is infected as well.

The first AIDS case was reported in Nigeria in 1986 and the epidemic has rapidly grown since then. HIV prevalence has increased from 1.8% in 1991 through 4.5% in 1996 to 5.8% in 2001. In 2003 the prevalence was 5.0% and in 2005 it declined further to 4.4% and then to 3.6% in 2007. The prevalence was 4.6% in 2008 (FMOH, 2008), 3.34% in 2011 and 3.1% in 2015. Although the prevalence rate amongst adults is remarkably small compared to other Sub-Saharan African countries; (South Africa 19.2% and Zambia 12.9%), the size of the Nigerian population means that Nigeria bears the second largest burden of HIV in the world with 3.2 million people living with HIV. The epidemic continues to have a devastating effect on families, the community and the nation at large.

Children are increasingly being infected with the virus through mother to child transmission, or are losing one or both parents to AIDS. In developed countries, Mother to Child Transmission (MTCT) rates have fallen to as low as 1 percent per 100,000 births among HIV infected mothers in recent years through use of HIV medicines during pregnancy, labour and delivery, opting for elective caesarean delivery and the safe use of infant formula instead of breastfeeding. In Africa and in Nigeria specifically these interventions are not generally available and where prolonged breastfeeding is the norm, about 25-35 percent HIV infected mothers pass on HIV to their infants. In Nigeria the MTCT risk of HIV was as high as 34.4% in 2011. The high incidence of the MTCT problem is due to the high rates of HIV infection in women of reproductive age, a large population of reproductive age, high birth rates, and the lack of effective MTCT prevention interventions (UNAIDS 2015).

1.2 Statement of the Problem

One of the means of transmission of HIV is by vertical transmission from the mother to the child. For women who have children diagnosed to be HIV positive this can be a very stressful and traumatic discovery. The chronic nature of the disease, the specialized management of the condition, restricted access to antiretroviral treatment, the stigma that still continues to be associated with infection, and in some cases the burden of maternal guilt associated with mother to child transmission of HIV all combine to increase the stress experienced by such women. As rates of HIV infection in women of child bearing age continue to grow and advances in treatment lengthen women's survival, a greater number of women with children are coping with HIV and AIDS as a chronic health condition (Schuster et al 2000). The presenting signs and symptoms of HIV are often nonspecific in children and the infection progresses rapidly in children. Early infant diagnosis is therefore necessary to facilitate early commencement of treatment for infected children. In 2015, UNAIDS reported that only 9% of infants exposed to HIV received early infant diagnosis and 17% of children living with HIV accessed antiretroviral therapy. In addition, HIV infected children are often afflicted with other health related issues requiring frequent medical appointments. In studies conducted in Africa morbidities frequently seen among HIV infected children include acute respiratory tract infections, diarrhea diseases, malnutrition, developmental delays, anaemia and meningitis (Taha et al 2000, Le Doare et al 2012). The increase in developmental delays is not isolated to HIV positive children. Children born to HIV infected mothers, yet

subsequently testing HIV-negative, are also at higher risk for lower birth weight and other developmental difficulties as well as emotional and behavioural problems due to associated factors such as poor prenatal and perinatal care, poor diet and other bad health habits (Hong et al 2006, Chi and Li 2012).

The issues confronting families with an HIV positive child are more complex than those of other common childhood illnesses. Stigma and discrimination, negative self esteem, guilt and self-blame of biological mothers regarding their perceived inability to protect their children from harm, lack of social support and low socio-economic status contribute to feelings of helplessness (Mosch 2006).

Linsk and Mason (2004) investigated the stresses on grandparents and other relatives caring for children affected by HIV and found that the caregivers infected with HIV themselves experienced the most stress. In a study conducted in Lagos (Adeyemi, 2007) found that older people 60 years of age accounted for about 10% of those infected among the sampled population. This indicates that grandparents that children of the infected persons will want to rely on are also infected. In a study in a resource constrained environment similar to Nigeria with limited economic resources, not many formal social services, weakening family ties, and strong gender role restrictions on women's decision-making, coping by women caring for the HIV positive child is more difficult (Adler et al 2002, Kawachi et al 2001). Previous studies (Olley et al 1999, Salami et al 2003) show that mothers generally must rely primarily on their own resources and social networks to cope with childcare needs. This is unlike what obtains in developed countries where there is progress in medical care, availability of antiretroviral treatment and other statutory benefits such as unemployment benefits, family allowances, established social security measures, availability of formal support networks as well as formal recognition of the role of carers (Kidman and Heyman 2016).

Many studies clearly acknowledge the importance of mothers as primary caregivers and partners in their child's health management. Where biological mothers illness or death prevents this, families affected by HIV/AIDS cope with the mother's ill health or death by ensuring that children affected by HIV/AIDS receive care from a substitute caregiver. The African traditional extended family support network functions through changes in household composition, with relatives moving into households to care for the children or

orphans. Alternatively orphaned children move out into one or more relatives' households (Foster et al, 2000). Women substitute caregivers are often aunts and grandmothers. Coping mechanisms regarding orphans are complex and vary according to socio cultural setting. In most African communities, the concept of "adoption" does not usually exist in the western sense. Children are fostered, a prevalent, culturally sanctioned procedure where biological parents allow their children to be reared by adults other than them (McDaniel and Zulu., 1996). A hurdle related to this is lack of documentation, particularly among caregivers who are fostering children (Kuo and Operario 2011 `). One study by Sherwen et al (1993) compared biological mothers, extended family caregivers, and foster parents of children infected with HIV on measures of coping and family functioning. Another study by Chalfin et al (2002) explored overall levels of caregiver stress in a sample of caregivers of children with HIV infection and compared levels across groups of caregivers e.g. biological mother versus other caregivers.

1.3 Justification of the study

There is no published literature on stress factors and coping strategies of women caregivers of HIV positive children in Nigeria. The knowledge of the HIV induced stress factors affecting women and their coping strategies would facilitate early identification and support of their psycho-social stress, as well as inform interventions to increase their resilience by the development of adaptive coping strategies. The information acquired from the study can also be used in the coordination of efforts among health educators, public social services workers and agencies in partnering with these women to identify, understand and manage stressors that impact on their well being and care of their HIV positive child. The information could also be utilized by community based organizations and policy makers to advocate for policies and formal support that are protective of caregivers and specifically HIV-related caregivers.

1.4 Research questions

What are the stress-factors affecting women with HIV positive children?

What are the coping strategies employed by women with HIV positive children?

How do the socio demographic characteristics of the women affect their level of stress?

How does the type of stress factor experienced by the women influence choice of their coping strategies?

1.5 Objective of the study

The broad objective of this study was

to investigate the stress factors and coping strategies of women who care for HIV positive children in Massey Street Children's Hospital, Lagos.

The specific objectives

The specific objectives of this study were to

1. Assess the current level of stress among women with HIV positive children.
2. Identify the stress factors faced by women with HIV positive children.
3. Determine the coping strategies of women with HIV positive children.
4. Examine the effect of caregivers' personal factors (such as age, marital status and socioeconomic background) on the stress level.
5. Determine the choice of coping strategies employed with the various stress factors experienced by the women.

1.6 Research Hypotheses

1. There is no significant association between level of stress and age of women caregivers

2. There is no significant association between level of stress and marital status of women caregivers

3. There is no significant association between level of stress and educational level of women caregivers

4. There is no significant association between level of stress and occupation of women caregivers

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CHAPTER TWO

LITERATURE REVIEW

HIV/AIDS Epidemic

HIV/AIDS epidemic globally

In 1981, a new syndrome, the Acquired Immune Deficiency Syndrome (AIDS), was first recognized among homosexual men in the United States. By 1983, the etiological agent, the Human Immunodeficiency Virus (HIV) had been identified. By the mid-1980's, it became clear that the virus had spread, largely unnoticed, throughout most of the world.

The HIV pandemic consists of many separate epidemics. Each epidemic has its own distinct origin, in terms of geography and specific populations affected, and involve different types and frequencies of risk behaviours and practises, for example, unprotected sex with multiple partners or sharing drug injection equipment.

In 2015, an estimated 150,000 children (aged 0-14 years) were newly infected with HIV globally, and 120,000 (nearly 85%) live in sub-Saharan Africa (UNAIDS/UNICEF 2016). The majority of these infections occurred during the breastfeeding period as a result of mother to child transmission (MTCT) of HIV.

HIV/AIDS in Sub-Saharan Africa

Some of the most explosive epidemics have been seen in Southern Africa. South Africa has the largest number of people living with HIV/AIDS in the world (UNAIDS 2016). Botswana and Swaziland have the highest prevalence levels. West Africa has been relatively less affected by HIV infection than other regions of sub-Saharan Africa. Half (900,000) of the 1.8 million children (aged 0-14) living with HIV globally did not receive antiretroviral (ARV) HIV treatment in 2015. For those children able to receive antiretroviral treatment (ART), it came too late, at an average age of initiation of 3.8 years in sub-Saharan Africa. Without timely treatment one third of children with HIV will die by age 1, and half by age 2. In children under the age of 1, HIV related mortality peaks occur as early as 2 to 3 months of age, hence the urgent need for these infants to be diagnosed as soon as possible after birth. Yet less than half of children born to mothers living with HIV in 2015 received an HIV test before reaching 2 months of age and in

many cases turnaround time from the test to the results was substantially delayed. This situation is compounded by the estimated 330,000 pregnant women living with HIV who did not receive the most effective ARVs for prevention of mother to child transmission (PMTCT) in 2015 contributing to new HIV infections in children going unnoticed or being lost to follow-up (UNAIDS 2016 estimates)

These gaps in diagnosis, treatment and retention in care have resulted in some 110,000 worldwide-approximately 300 children each day – dying of AIDS in 2015. Special attention is needed to ensure that children have timely access to ART and are retained in care through adolescence and into adulthood. Skovdal et al (2011) have posited that there are contextual and psychosocial influences on antiretroviral therapy adherence. These influences which likely affect women caregivers of HIV positive children will have an impact on the access to ART and retention in care of HIV positive children into adulthood.

Nearly half of 1.8 million children living with HIV are in only five countries: Nigeria, South Africa, India, Mozambique and Kenya (UNAIDS 2016). An estimated 63 percent of children (aged 0 -14 years) living with HIV in Eastern and Southern Africa were on ART in 2015, compared with only 20 per cent of children in West and Central Africa. (UNICEF, UNAIDS and WHO 2015).

HIV/AIDS in Nigeria

The first case of AIDS in Nigeria was reported in 1986. Sentinel survey showed that the HIV prevalence increased from 1.2% in 1991 to 5.8% in 2001. After 2003 the prevalence declined to 4.4% in 2005 before slightly increasing to 4.6% in 2008. Results from the latest round of sentinel survey revealed that the national prevalence was 4.1% in 2010 (FMOH). Trend analysis of HIV prevalence from sentinel surveillance in Nigeria indicates that the epidemic has halted and is showing signs of stabilizing at about 4% from 2005 to 3.2% in 2016. In December 2011 it was estimated that 3,459, 363 people were living with HIV and an estimated 1.5 million requiring Anti-retroviral Therapy (ART), in the same year an estimated 388,864 new infections occurred. Records show an annual total of 217,148 AIDS related deaths and an estimated 2,193,745 children orphaned by AIDS (NACA 2012).

In spite of a stabilising HIV prevalence, Nigeria has a high and persistent burden of HIV. Nigeria's burden is second only to South Africa in the world. Key drivers of the HIV epidemic in Nigeria include low personal risk perception, multiple concurrent sexual partnerships, transactional and inter-generational sex, ineffective and inefficient services for sexually transmitted infections (STIs), and inadequate access to and poor quality of healthcare services. Entrenched gender inequalities and inequities, chronic and debilating poverty, and persistence of HIV/AIDS-related stigma and discrimination also significantly contribute to spread the infection (UNAIDS 2014).

Stress and Stress Factors

Selye (1970) was the first theorist to link stress with physical disease and ill health in human beings. This link, however, is not considered to be a direct link, but is instead affected by other social forces that allow the individual to adapt, or cope, with the stress. Stress can occur from either positive or negative events (Selye 1970). In addition, the same event can have both positive and negative factors (Selye 1970). Selye (1936), while in medical school, discovered a similar process experienced by organisms when exposed to toxins, irrespective of the specific toxic source. He identified three stages through which an individual progresses, and labeled the process the General Adaptation Syndrome (GAS) (Selye 1936). Attempting to maintain a level of homeostasis, an individual exposed to a noxious agent or event will enter the first stage, adaptation. An 'alarm reaction' calls to arms the individual's internal and/or external defense mechanisms. After the individual survives the initial reaction, next is a stage of resistance. However, this resistance is not infinite and, finally, just as a machine under stress wears out, so does an individual. The constant strain of living under stress takes its toll and the individual subsequently enters the stage of exhaustion. As the individual's 'adaptation energy' becomes depleted, resistance is lowered and death eventually occurs (Selye 1936). Selye (1978) described stress as the rate of wear and tear in the human body that accompanies any vital activity. Longman's Dictionary of Contemporary English (2018) defines stress as continuous feelings of worry about your work or personal life that prevent you from relaxing. Monat and Lazarus (1991) have delineated stress into three types – physiological, social and psychological. Physiological stress is concerned primarily with the disturbance of tissue and other physical systems. Social stress views the social unit as the disrupted factor. Psychological stress encompasses those threats to the individual's psychological well-being. While these factors may be related, the nature

of the relationship is not entirely clear (Monat and Lazarus, 1991). Monat and Lazarus, in their attempt to include all pertinent factors, define stress as "any event in which environmental demands, internal demands, or both tax or exceed the adaptive resources of an individual, social system, or tissue system. Therefore, stress can be assumed to arise when one appraises a situation (or combination of events) as threatening or otherwise too demanding and does not have an appropriate coping response (Cohen and Wills, 1985). This is the type of situation in which the person perceives that it is important to respond, but an appropriate one is not available. One single event may not place great demands on an individual's ability to cope with the situation; however, when the problem is persistent and on-going, as is HIV, it may strain the resources and problem-solving capacity of the individual (Cohen and Wills, 1985). Feelings of helplessness arise because of the perceived inability to cope with the situation, taxing one's skill and emotional levels beyond capacity. Without adequate assistance, this may subsequently lay the groundwork for maladaptive stress reactions such as alcohol or substance use, running away or suicide. Hassles encompass the daily inconveniences and irritations of daily living (Nezu and Ronan, 1985; Pearlin, 1989). Poverty, and lack of material resources it represents, is in itself a generator of hassles and stress (Ulbrich et al. 1989).

Coping

There are various perspectives of viewing the concept of coping. Simply, coping implies adaptation by an individual to demands. In the eco-systemic perspective (Donald, Lazarus and Lolwana, 1997), coping is framed as a process of interaction between an individual and an environment, each with its own set of resources, vulnerabilities, potential and needs. Coping is what people do when they successfully manage transactions with their environment. Coping is the reaction to the question: what do I do? Coping can be defined as constantly changing cognitive and behavioural efforts to manage specific external and or internal demands that are appraised as taxing or exceeding the resources of the person (Lazarus and Folkman 1984). Coping is acquired by learned adaptive actions. Diversity in traditional beliefs, rural and urban settings, and socio-economic resources determine a variety of coping responses. Coping response is dependent on the individual and the situation which demands the coping response. The coping response can be located on a continuum from consistently effective to consistently ineffective. Characteristically, people prefer certain coping responses to others. Some people are more resilient in matching available resources with specific environmental demands on them. Protective

factors in the environment (a woman's disposition, a responsive partner and external support for the family) could act as protective factors against the impact of stressors on a woman (Adler et al 2002).

Measurement of Stress and Coping

Instruments for measuring stress

Stressful Life Events

One of the oldest ways of measuring levels of stress is with life events sometimes called Stressful Life Events (SLE). This instrument was developed by Rahe and Holmes (1964) and used among veterans. The instrument originally had 43 stressful items weighted and unweighted (desirable and undesirable). The respondents were expected to indicate how stressful these situations were to them on a four point Likert-like scale. Later modified versions of it were created by Pearlin and Schooler 1978 called Life Event Inventory Scale (LEIS).

The Social Readjustment Rating Scale (SRRS) also known as the Holmes-Rahe life Stress Inventory was developed by Holmes and Rahe in 1967.

Most people experience major life events very infrequently. Therefore a better measure of stress might look at the stress and strains of daily life. These are called "daily hassles", e.g. losing your keys. Most of the 43 items in the SRRS are not every day events.

Hassles Scale

Kanner et al (1981) has designed a Hassles Scale which consists of 117 items, including concerns about losing things, traffic jams, arguments, disappointments, weight and physical appearance. Daily hassles are 'irritating, frustrating distressing demands that to some degree characterise every day transactions with the environment' (Kanner 1981). Kanner et al (1981) empirical study found that the hassles scale tended to be a more accurate predictor of stress related problems, such as anxiety and depression, than the SRRS.

Other stress measuring instruments include the Parenting Stress Index (PSI; Abidin, 1990) and Beck Anxiety Inventory (BAI; Beck and Steer 1993), HIV Stress Scale (Kenneth Pakenham and Rinaldis, 2002) and Perceived Stress Scale for People Living with HIV (Xiaoyou Su et al, 2008).

The Parenting Stress Index (PSI)

The PSI consists of 101 items which assess parenting stress as a function of child characteristics and parent characteristics. Responses are rated using 5 point Likert – type scale ranging from 1 (Strongly agree) to 5 (Strongly disagree). The PSI yields an overall Total Stress Score, a child domain score and a Parent Domain Score. Psychometric properties of the PSI are well established and strong (Abidin, 1990). The validity of the PSI has been studied extensively and there is support for concurrent and construct validity, discriminant validity, predictive validity and factorial validity.

Beck Anxiety Inventory (BAI)

The BAI (Beck and Steer, 1993) was used to assess the presence of symptoms of anxiety. Anxiety is an indicator of the presence of stress. The BAI is a self report measure that consists of 21 items which are rated on a 4 point scale ranging from 0 (not at all) to 3 (severely). A summary score is calculated which yields classifications of minimal, mild, or severe symptoms of anxiety. Psychometric properties of the BAI are well established.

HIV Stress Scale

The development of a HIV Stress Scale has also been made possible by (Kenneth Pakenham and Rinaldis, 2002). The HIV Stress scale consists of a self report measure of stress specific to HIV/AIDS. It takes a measure of emotional/existential stress, social and instrumental stress. Responses are rated using a 4-point Likert-type scale ranging from 4 (very stressful) and 0 (Not applicable).

The development of the HIV/AIDS Stress Scale has been followed by the development of:

Perceived Stress Scale for People living with HIV/AIDS (PSSHIV)

This PSSHIV instrument (Xiaoyou Su et al, 2008) developed in China collected information from qualitative interviews and the items are specific to the HIV/AIDS context. PSSHIV can be used for assessing the level of stress faced by people living with HIV/AIDS (PLWHA) in China

Instruments for measuring coping

The instruments for measuring coping include Coping Orientation to Problems Experienced (COPE), Revised Ways of Coping Scale, Coping Strategies Inventory, Family Resource Scale and Family Support Scale

Coping Orientation to Problems Experienced (COPE)

The COPE (Carver et al 1989) is an empirically derived scale to assess specific dispositional coping strategies utilized that is what a person usually does when under stress and is based on two theoretical models: Lazarus' transactional model of stress and the behavioural self regulation model (Carver and Scheier 1981, 1983, 1985; Scheier and Carver 1988, 1989 cited in Carver et al 1989). The COPE contains 60 items which are rated on a 1 (I usually don't do this at all) to a 4 (I usually do this a lot) scale.

Revised Ways of Coping Scale

The Revised Ways of Coping Scale (Folkman, Lazarus, Dunkel- Scheller, Delongis and Gruen, 1986) is a 66 item questionnaire containing a wide range of thoughts and acts that people use to deal with internal and or external demands of a specific stressful encounter. The questionnaire requires the responses to be selected from a 4 point Likert scale format (0 = does not apply and or not used, 3 = used a great deal. Several items not in the original ways of coping checklist were added

A modified version of the Revised Ways of Coping (WOC) scale has been used in a study (Palathyil and Chakrabarti, 2008), to capture strategies that might be more appropriate for HIV/AIDS. It consists of an 85 item questionnaire containing a wide range of thoughts and acts that people use to deal with specific stressful encounters. The questionnaire used a Yes/No format in order to simplify administration process for individuals who were not used to the Likert Scale format.

Coping Strategies Inventory (CSI)

The CSI (Tobin, 1984) is a 72-item self-report questionnaire designed to assess coping thoughts and behaviours in response to a specific stressor. The format of the CSI is adapted from the Lazarus "Ways of Coping" questionnaire (Folkman and Lazarus, 1981). After describing a stressful situation, persons taking the CSI are asked to respond to 72 questions in a 5-item Likert format. Respondents indicate for each item the extent to

which they performed that particular coping response in dealing with the previously described situation (a. None, b. A Little, c. Some, d. Much, e. Very Much)

Family Support Scale (FSS)

This FSS (Dunst, Jenkins, and Trivette, 2007) survey questionnaire measures parents' satisfaction with the perceived helpfulness of support. There are 18 items included in this questionnaire. The user is asked to respond on a 5–point Likert scale to identify their supports in informal kinship, social organizations, formal kinship, nuclear family, specialized professional services, and generic professional services. The supportive service providers will be able to identify the areas that need to be improved and addressed to better meet the families' needs. Service providers may administer the scale.

Coping strategies

Coping strategies can be grouped into three broad components. These are Biological/Physiological, Cognitive and Learned.

Biological/Physiological – Any threat or challenge that an individual perceives in the environment triggers a chain of neuro endocrine events. These events can be conceptualised as two separate responses, one being that of the sympathetic/adrenal response, with the secretion of catecholamines (epinephrine/nor epinephrine) and the pituitary/adrenal response with the secretion of corticosteroids (Frankanhauser, 1986). The sympathetic nervous system, which secretes epinephrine and nor epinephrine. This is the basic "fight or flight response (Canon, 1929) where the heart rate quickens and the blood pressure rises. In the pituitary adrenal response, the hypothalamus is stimulated and produces the corticotrophin releasing factor (CRF) to the pituitary gland through the blood veins then the adrenal corticotrophic hormone (ACTH) is released from the pituitary gland to the adrenal cortex. The adrenal cortex in turn secretes cortisol, a hormone that will report back to the original brain cortex together with other body organs to tell it to stop the whole cycle. But since cortisol is a potent hormone, the prolonged secretion of it will lead to health problems such as the breakdown of cardiovascular system (heart attack) digestive system (ulcers), musculoskeletal system and the immune system. Also when the individual does not have a chance for recovery, it will lead to both catecholamines and cortisol depletion and result in the third stage of the General Adaptation Syndrome of exhaustion (Selye, 1956). Personality types so called 'Type A'

personality have been defined to have such characteristics as competitive, impatient and hostile. They have a strong orientation towards work responsibilities and task completion. Hostility has been linked to coronary heart disease which is thought to be caused by stress (Rosenman, 1978). Also a high record of coronary disease and mental illness has been associated with this group of people (Evans and Gall 1988). Eysenck (1988) coined the term type C personality for those who are known to be repressors and are prone to cancer. Although it may be possible to modify ones personality, research has shown that it is inherited (Rahe, Herrig and Rosenman 1978; Barret 1992)

Cognitive component – the cognitive approach to coping is based on a mental process of how the individual appraises the situation; where the level of appraisal determines the level of stress and the unique coping strategies that the individual adopts (Lazarus and Folkman, 1984). A primary appraisal is made when the individual makes a conscious evaluation of the matter at hand whether it is either a threat or a challenge. The secondary appraisal or the reappraisal takes place when the individual asks him/herself 'what can I do by evaluating the coping resources around him/her. These resources include physical resources, such as how healthy one is or how much energy one has, social resources such as the family or friends one has to depend on for supports, psychological resources such as self esteem and self efficacy, perceived control, sense of coherence and stress related growth.

Albert Bandura (1997) defined self efficacy as the extent or strength of one's belief in one's own ability to complete tasks and reach goals. Self esteem is a trait measure (a quality that is built over time) whereas self efficacy is a state measure (a capacity experienced at a specific point in time and concerning a specific task).

Perceived control is a resource internal to the individual that involves the individual's perception of the amount of influence she has over the events in her life. Feelings of control have generally been inversely related to indicators of psychological distress. Rotter (1966) put forward that a person with an internal locus of control believes that their achievements and outcomes are determined by their own decisions and efforts.

Aaron Antonovsky (1987) defined sense of coherence as: a global orientation that expresses the extent to which one has a pervasive, enduring, though dynamic feeling of

confidence that (1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable and explicable; (2) the resources are available to one to meet the demands posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement.

Stress-related growth or thriving is a dispositional response to stress that enables the individual to see opportunities for growth as opposed to threat or debilitation. Carver (1998) described thriving as being "better off after adversity". Spreitzer et al (2005) described thriving as a "psychological state in which individuals experience a sense of vitality and sense of learning at work".

Vosvick et al (2002) examined the relationship between psychological quality of life (along dimensions of cognitive functioning, mental health and health distress) and maladaptive coping strategies. Vosvick et al further examined the relationship of functional quality of life to strategies of coping with the stress of living with HIV/AIDS in terms of five domains: physical functioning, energy/fatigue, social functioning, role function and overall health and pain. Research has demonstrated that the ability to maintain well being in these domains is essential to higher quality of life for persons living with chronic illnesses such as cancer (Ben-Zur et al 2001) and AIDS (Schlenk et al 1998)

Two types of coping strategies were identified by Cohen (1980) as 'Problem focused' and 'emotion focused coping'. Endler and Parker (1990) devised the Multidimensional Coping Inventory to assess three major coping strategies which are Task oriented (Problem focused) coping, Emotion oriented coping, and Avoidance coping.

Problem focused coping is defined as effort to act on the source of stress to change it. This involves obtaining information about the stressful situation and about alternative courses of action and their possible outcome. It involves deciding on priorities and acting so as to deal directly with the stressful situation.

Emotion focused coping is effort to regulate emotional states that are associated with the stressful events. This can involve efforts to maintain hope and to control one's emotions.

It can also involve venting feelings of anger and frustration, or deciding that nothing can be done to change things.

More research was carried out by Folkman and Lazarus (1980). Folkman and Lazarus felt that people use problem focused coping when a situation is appraised as changeable and use emotional-focused coping when a situation is appraised as an unchangeable reality which they must accept.

Avoidance Coping – this involves denying or minimising the seriousness of the situation. It also involves conscious suppression of stressful thoughts and their replacement by self protective thoughts. This strategy does not deal with the situation directly. It tends not to be action oriented.

Evans and Gall (1988) described three modes of coping as follows: avoidance, confrontation and resigned modes of coping. Avoidance coping is as previously discussed. Confrontation mode is problem focused, action oriented and direct attack response on the stressful situation. The resigned mode of coping is where the individual does not attempt to solve the problem but submits to or accepts the problem. Sometimes the individual suffers in silence. In extreme cases the individual tries to get away from the problem by physically running away, attempting to commit suicide, using drugs or alcohol. Evans and Gall (1982) scaled these modes of coping on a Likert-like scale, adding 'anger and complaint on the scale. They however explain that on a real life situation, this scale does not run on a continuum.

In this research study, the population sampled has in common the care of a HIV positive child. Parenting a healthy child is ordinarily considered a challenge. Specifically, the care giving role for a HIV positive child may involve significant stress, and need for adjustment for the mother (Kuo and Operario 2011). HIV is a chronic disease. The presence of a chronic medical condition in a child is a factor that has been related to increased stress and psychological difficulties (Thompson and Gustafson, 1996). Previous research has found that active (problem focused) coping is associated with positive psychosocial and health outcomes in people living with HIV including less HIV/AIDS related symptoms, enhanced quality of life, high positive effect, high self esteem, less symptoms of distress, lower frequency of substance use and adherence to antiretroviral treatment. Conversely, avoidant coping has been associated with negative psychosocial and health outcomes including increase in HIV/AIDS related symptoms, decreased

physical function, poor quality of life, low self esteem, more symptoms of psychological distress, more frequent substance use and non-adherence to ART (Martin 2004). Active coping in literature consisted of eight coping strategies namely: acceptance, direct action, positive reframing, religion, emotional support, instrumental support, helping others, information seeking. Avoidant coping consisted of seven coping strategies namely: distraction, escape, denial, emotional venting, out-of-control, self blame, substance use. Resources such as social support and perceived control are considered to have positive effects on psychosocial outcomes. Resources are dispositions and beliefs (perceived control) or individuals and groups (social support) on which individuals can draw for help. Resources are expected to be negatively related to psychological distress, and positively related to perceived adequacy of coping (Mellins et al 2000).

Social support is a resource external to the individual that involves relationships the individual has with other individuals or groups. The family is a particularly important source of support in the African community. Young recent mothers generally and HIV infected mothers specifically have shown an inverse relationship between the level of available social support and various indicators of psychological distress.

Parenting (caregiver) interventions have a wide range of objectives but social support takes the form of access to goods and services (Ayon 2011), information and guidance (Mbenkenga et al 2011), and an opportunity to make friends, share troubles, and counter social isolation (Letourneau, Stewart, and Barnfather 2004; Smith-Fawzi et al 2012). Social support provided by partners, families, peers and professionals have positive effects on a wide range of parenting aspects including self-perception, coping and mental health (Gardner and Derrick 2006). In a model proposed by Kane, Wood and Barlow (2007) social support is core to the mechanisms by which parenting interventions advance parent and child well being.

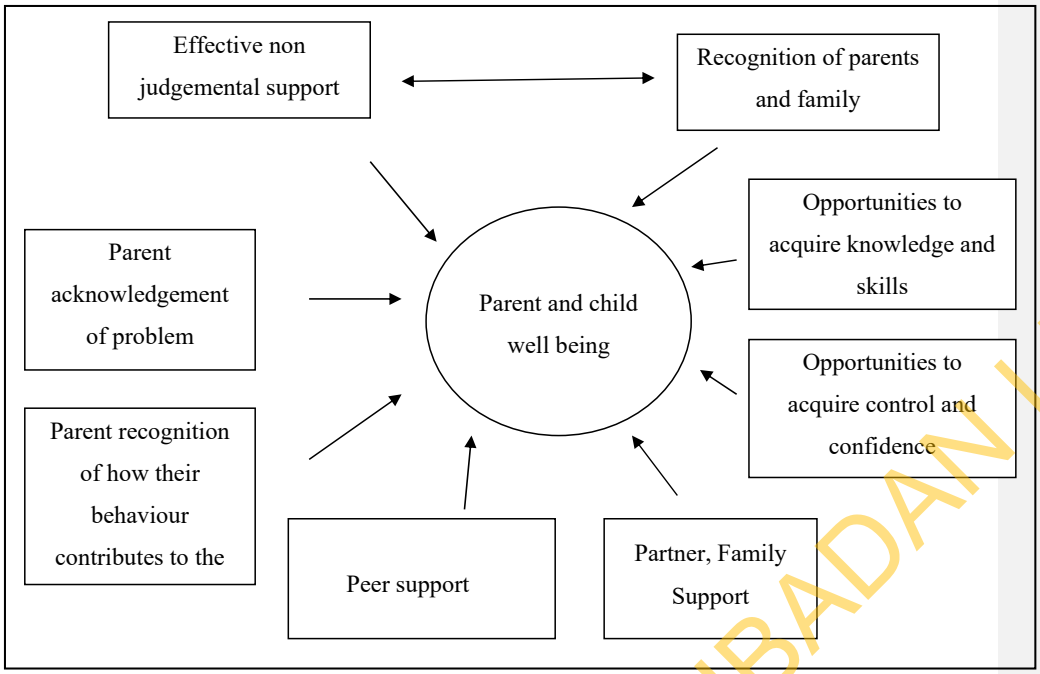

Fig 2.1. Social support in parent and child well-being (adapted from Kane, Wood and Barlow 2007)

Reported coping responses are defined in terms of actions and cognitions, which the individual employs to address stressful events or problems. Groupings of coping responses vary in applied research, however investigations have employed three broad categorizations; active (or approach) coping, avoidant coping (disengagement, avoidance, denial), and support coping i.e. seeking or utilizing support resources (Feaster et al., 2000). The choice of an appropriate coping response to stressors is believed to involve consideration of the level of resources available (Folkman, 1984). Empirical investigations have shown that individuals with higher levels of perceived control are more likely to engage in active coping responses (Ross and Mirowsky, 1989; Ingkedew et al., 1997). Further, in some investigations perceived control has been related to the effectiveness of coping responses in ameliorating distress (Hahn, 2000, Okeke 2009). Rose and Clark-Alexander (1998) attempted to examine the coping styles of a convenience sample of HIV positive and negative caregivers of infected children, within the Lazarus and Folkman framework (Rose and Clark-Alexander, 1998). Social support

was measured using a seven question scale with questions such as, "How lonely are you?" These questions were further divided into measures of support from family and friends, with HIV negative caregivers perceiving significantly stronger support from both sources (Rose and Clark-Alexander, 1998). In addition, 80% of the sample used prayer as a method of coping with the stress of caring for an HIV positive child (Rose and Clark-Alexander, 1998). The authors, citing Lazarus and Folkman's theory, concluded that improved coping skills, including increased social support, will affect healthy outcomes (i.e., buffer the stressful events) (Rose and Clark-Alexander). In their first study, Black, Nair and Harrington (1994), compared four groups of caregivers (HIV positive with intervention, HIV negative with intervention, HIV positive with no intervention, and HIV negative with no intervention) and reported no main effects for child abuse potential, stress, support or functioning related to the child's HIV status. The study only identified support as informal or formal, with no descriptions as to specific sources or support tasks needed. Their second study examined social support and maternal HIV status. Support was dichotomized as high or low, with no consideration of source or function, and there were no main or interaction effects noted for the measures. However, utilizing videotaped mother-child interaction sessions, the authors found that HIV positive mothers with higher support were more involved with their infants during feeding (Black et al. 1994).

Learned component – the learned component of coping includes everything from various social learning theories which assume that much of human motivation and behaviour is the result of what is learned through experiential reinforcement.

Stress management techniques draw on social learning theories. Examples of stress management techniques are cognitive restructuring, relaxation techniques such as breathing relaxation, muscle relaxation, mind relaxation and behaviour modification.

Cognitive Behavioural Techniques (CBT) are the most effective ways to reduce stress which has resulted in an anxiety related disorder or a depressive disorder. They include identifying the sources of stress, restructuring priorities, changing ones response to stress and finding methods for managing and reducing stress. Some of the CBT techniques that are prescribed include relaxation training, goal setting, problem solving, systematic desensitization and cognitive restructuring.

Cognitive restructuring aims to help people reduce their stress through cultivating more positive and functional thought habits (Mills et al 2008). Cognitive restructuring was first developed as a therapeutic tool of CBT and Rational Emotive Behavioural Therapy or REBT (Mills et al 2008). Applied correctly, it will help the client learn to stop automatically trusting his or her thoughts as a representative of reality and begin testing his or her thoughts for accuracy (Mills et al 2008).

Table 2.1 Stress Management Techniques

Cognitive	**Physical**	**Environmental**	**Other**
Therapy	Artistic expression	Music	Conflict resolution
Hobbies	Deep breathing	Nature	Prayer
Meditation	Natural medicine	Pets	
Mindfulness	Physical exercise	Spa visits	
Planning	Relaxation		
Reading	Yoga		
Time management			

Source: https://opentextbc.ca/introductiontopsychology/chapter/15-2-stress-and-coping/

Gender differences in choice of coping strategies

Taylor et al (2000) have argued that there are important differences between men and women in their reactions to stress. Men are much more likely than women to be problem focused, whereas women generally respond with their emotion. Thus women respond to stressors by protecting and looking after their children (the tend response) and by actively seeking social support from others (the befriend response). Some of these effects are found across cultures. Edwards (1993) found in 12 cultures that girls were much likely than boys to provide help and support to infants.

Taylor et al (2000) emphasized the role of oxytocin which is a hormone secreted by men and women as part of the stress response. Oxytocin makes people less anxious and more sociable and so is associated with the tend and befriend response. Its effects are reduced by male sex hormones but increased by the female hormone oestrogen.

There is much evidence that females are more likely than males to respond to stressful situations with their emotions by tending and befriending. Luckow, Reifman and

McIntosh (1998) reviewed 26 studies on gender differences in seeking and using social support. Women sought social support more than men in 25 of these studies and there was no gender difference in the other study.

Adaptive and maladaptive coping

Folkman et al (1986) put forward that planned problem solving tend to be associative with satisfactory outcomes, whereas expressing anger and trying to forget the problem were associated with unsatisfactory outcomes. The lack of adaptive coping strategies has been associated with poorer health outcomes. For example, in a group of men and women living with HIV/AIDS, use of denial as a coping strategy was associated with greater pain Hart et al (2000). Also in a group of 212 people living with HIV/AIDS, coping by avoidance was associated with greater health related stress, Schimtz et al (2002). People living with HIV/AIDS who increase their use of avoidance coping strategies such as behavioural disengagement may have poorer physical and social functioning.

The effectiveness of any coping strategy depends on the individual, the context and on the nature of the stressful situation. One mode of coping strategy cannot therefore be said to be better than the other.

An important point is that many stressful situations change over time and the best coping strategy may also change over time. For example Folkman and Lazarus (1985) found students faced by a stressful examination sought information and social support before the exam. Afterwards, while waiting to hear the results, they typically made use of the avoidance strategy (e.g. forgetting all about the exams)

Caregiving

A caregiver is anyone who provides care for another person in need, such as a child, an aging parent, a husband or wife, a relative, friend or neighbor. A caregiver is an unpaid or paid person who helps another individual with impairment with his or her activities of daily living. Any person with health impairment might use caregiving services to address their difficulties. Caregiving is most commonly used to address impairments related to old age, disability, a disease or a mental disorder. A caregiver within the context of this study is a person who has consistently assumed responsibility for the housing, health, or safety of a HIV positive child; who administers the child's medication daily, and who brings the child for clinic appointments (Anigilaje et al 2014). The caregiver may be a

parent of the child or a biological or non-biological relation. When the caregiver is the sole decision maker, he or she is also called the 'primary caregiver'. And when he or she shares this responsibility with the primary caregiver, he or she is a 'secondary caregiver' (Strug and Barr, 2003). People who are not paid to give care are called informal caregivers or family caregivers (Akintola, 2006). Most family caregivers are women and nearly three in five family caregivers have paid jobs in addition to their caregiving. If stress and coping strategies of caregivers of HIV positive children is not made a concern – it could affect the physical, psychosocial, mental and emotional development of the HIV positive child. Multiple factors contribute to the outcome of child development: of special importance is the quality of the caregiver-child relationship. Recent research has identified two fundamental qualities that determine the caregiver's ability to provide effective care for the child; namely sensitivity and responsiveness. Sensitive and responsive caregiving is believed to be a requirement for the healthy psychosocial development of a child and are key features of caregiving (WHO 2004). Evidence has accumulated about the adverse maternal symptoms on early child development and quality of parenting. Between a third and a fifth of pregnant women and mothers of newborns experience serious mental health problems that can be recognized through use of simple reliable tools (WHO 2004). Poor maternal health nonetheless remains a serious under-recognised public health problem (WHO 2015). Young children can be protected against its ill effects if mothers are helped to improve their caregiving skills and treated for their underlying conditions as needed (Rahman et al 2008). These interventions can be integrated into health services and implemented by paraprofessionals through home visiting, mothers' groups, or by community health workers with specialized training (Busza et al 2014).

Caregiving can and may be provided in any of the locations as listed below
(i) Clinical setting
(ii) Home based setting
(iii) Residential/Institutional setting

(i) Clinic setting

Professionals (doctors, nurses, laboratory scientists, pharmacists, counselors and social workers etc) are primarily responsible for the care of the HIV infected children and adolescents for the duration in which they access antiretroviral therapy in the hospital.

Women caregivers experiences with the public health system could affect their consequent health related behavior such as missing appointments which will impact on the health of the HIV positive child (Sprague, Chersich and Black 2011). The clinical experiences of patients and their families is an area vital to supporting the ongoing response to HIV and ART, particularly for children where access depends on the experience of the caregiver of the HIV positive child (Campbell et al 2011)

(ii) Home based setting

Family caregivers are responsible for enabling HIV infected infants, children and adolescents live and thrive in home based rather in institutionalized communities of care (Eneh 2010). Most family caregivers are biologic parents, adoptive or foster parents, grandparents or siblings, relatives and other informal caregivers.

(iii) Residential/Institutional setting

Children in need of care – abandoned, orphaned or abused children often are placed in residential care. In Nigeria the HIV status of children living in these homes is most times unknown, however most homes have an exclusion policy for HIV positive children. In South Africa these facilities are constitutionally obliged to accept HIV positive children and are faced with the challenge of not being equipped to cope with the consequences of having HIV positive children in their care. Some facilities are completely adapted to cater only for HIV positive children, while others cater for uninfected children and HIV positive children. Specialised care requires appropriately trained staff, 24 hour care, carefully planned diets and medical attention

Caregiving and stigma

Goffman was the first social scientist to conduct extensive research on stigma (Pointdexter, 2005). Goffman, 1965 (cited in Pointdexter, 2005) viewed stigma as powerful discrediting and tainting social labels that radically change the way individuals view themselves (having undesired "differentness" or spoilt identity) and are viewed by others (seeming immoral, a disgrace or irresponsible).

The concepts related to stigma identified by Goffman in his studies are associative stigma and stigma management (Pointdexter and Linsk, 1999). Associative stigma is stigma experienced by individuals who are voluntarily attached as caregivers or acquaintances to

people who are stigmatized (Pointdexter, 2005; Mwinituo, 2006) this results in such individuals being isolated, fearful and stressed (Ehiri et al 2005, Kaplan et al 2005). Caregivers become uncertain how people will identify, receive and treat them and as a result become secretive and defensive.

Internalized stigma is when an individual or groups accept that they deserve to be treated poorly and unequally, making resistance to stigma and resulting discrimination even more difficult (Pointdexter and Linsk, 1999).

Stigma management refers to "purposeful strategies used by a stigmatized person or associate to lessen ostracism and blame by concealing the condition" (Pointdexter, 2005, Ehiri et al 2005). Stigma management can from this be inferred to be a form of coping strategy.

Caregiver response to perceived burden

The most frequent outcome measure utilized in stress-coping research is the level of perceived burden by the caregiver in response to the stressors. Burden, as defined by Webster's Dictionary (2018), is "something that is carried; a load, a duty, responsibility, something worrisome". Applied to this study, it can be translated to indicate the caregiver response due to the impact of the child's positive HIV diagnosis and the time spent in illness related tasks. This response can take two co-existing forms: stress – the internal response (positive/negative) to the perceived unfavourability of the external environment; and, arousal – the active response (positive/negative) to the perceived unfavourability of the external environment (Cox and Mackay, 1985). Thus, the perceived caregiver burden is defined as the cognitive (internal) and behavioral (active) responses caused by caring for a child infected by HIV. The Stress-Coping model suggests that the stressor of child's health status, as well as the level of illness management tasks, will lead to the elevation of stress and arousal levels among caregivers. It is further posed that as the stressors increase there will be an increase in the caregiver's active coping response, sometimes referred to as their 'fighting spirit', that has been correlated with improved health and self-esteem (Leserman et al., 1992). This active response has also been shown to be strongly associated with perceived satisfaction with social support (Namir et al., 1987). This relationship is also direct and positive (i.e., the higher the level of stressors, the higher the level of coping responses among caregivers).

Protective factors impacting on caregivers response to perceived burdens

Protective factors are contextual or situational variables that moderate the caregiver response to the perceived burden (Biegel et al., 1994). Social support has always been a part of this equation. Social support will be defined as interactions, either emotional, task or information oriented, with other individuals and/or groups that provide assistance and validation (Selye, 1993).

Social support

The social support variables discussed below will be utilized as protective factors to the effects of the stressors on the response to the caregiver's perceived burden. There is some evidence of the power of social support as a protective factor for the burden of caring for a child infected or affected by HIV/AIDS Social support variables have been found to alleviate some of the burden placed on caregivers, although the protective effects of these variables may not be as available to biological mother caregivers due to the stigma sometimes placed upon them by traditional sources of support. As such, two social support variable groups (informal and formal social supports), in this model will be explored as potential protective factors to the effects of the stressors, with the contributions of various sub-sources examined.

Informal social support

The first group of protective factors, informal social supports, includes those factors traditionally sought out as the primary line of defense against stressors. Sources included are family, friends, children, support groups, church and religion.

(i) **Family**

Families are the primary source of support for HIV affected children, yet they are too often overwhelmed and under-resourced (Kidman and Thurman 2014, Kidman and Heymann 2009, Miller at al 2006). Olley, 2013) stated that factors like type of marriage point to the fact that stressors and coping mechanisms are culturally based. African and African-American families are often embedded in multigenerational family systems where mothers draw on parenting support of relatives and non relatives (Freeman and

Nkomo, 2006; Bakermans-Kranenburg et al., 2004; Forehand et al., 2002). The stigma associated with HIV, as well as the mode of acquisition for the biological mother and source of transmission to the child, have alienated many families (Ehiri et al 2005, Kaplan et al 2005). Thus, fear of disclosure has prevented many HIV positive mothers from obtaining support from family. Walker (1998) writes that, "for them, the price of disclosure exceeded the benefit of potential support". Stories abound of families rejecting their HIV positive members (Walker, 1998). Rose (1993) reported that rejection from family was a major concern among women, and that rejection was more common from family members if the member had children, fearing their children may contract the virus. Mothers with larger support networks have been shown to be more responsive to their infants and provide more stimulating home environments than mothers with smaller support networks (Burchinal et al 1996)

(ii) **Friends**

Social isolation is evidenced in literature, with the need for social support cited as one of the top concerns of caregivers of children infected or affected by HIV/AIDS (Cluver and Gardner 2007, Cree et al. 2006, Cohen 2005). Friends can offer empathy and shared values, and have been associated with improved psychological adjustment in individuals with HIV. However, even though friends may offer support to HIV positive caregivers, all of the caregivers participating in Kuo et al's 2012 study reported expressing caution and reserve when choosing whom to tell. This indicates a heightened awareness of the potential rejection from this source of social support. Studies have found as cited in Olley et al, 1997 that working class women (which would likely include a majority of women in southwestern Nigeria where this study took place), who often lack strong social support systems, are three times as likely to experience coronary heart disease than their counterparts in white collar jobs (Elser et al 2018). It is noted that caregivers dealing with HIV/AIDS patients lack this type of support as a result of other family members and neighbours being physically, emotionally or psychologically distant from the caregiver and the patient (Mullan, 1998). Families as well as society avoid associating themselves with the infected and the affected as a way of protecting themselves from being stigmatized.

(iii) **Child**

Edwards et al (2012) reported that many mothers received unexpected support from their children. Many HIV positive mothers described having a very special relationship with their child, with this special bond acknowledged throughout literature (Reyland et al 2002). Further, women expected children (8 years old and older) to assist with household tasks, including caring for their younger siblings – some with HIV (Walker, 1998). Children have also been reported to drop out of school due to economic hardship and seek employment to support their family (Adeyemi, 2007).

(iv) **Support groups and Community Based Organization Care Services**

A study was found in literature search citing the activities of a clinic based setting support group for caregivers and HIV positive children accessing antiretroviral therapy in Nigeria (Anigilaje et al 2014) and community based organization care services for caregivers of HIV positive children in Nigeria (Workshop report) however a small, but growing body of literature demonstrating the therapeutic effects of support group for people caring for children and adults with HIV in other countries exist (Wiener, 1998). Through the commonality of experiences, meeting with others who are caring for children infected or affected by HIV/AIDS can allow the caregiver the opportunity to reflect, express and reconcile feelings in a support community format. Through the group, caregivers are sustained in fulfilling their roles. In a study of professional caregivers of HIV positive clients, George et al (1993) found that supportive groups effectively buffered stress and improved the quality of the care provided. In South Africa, hospices and community-based care organizations have been designed to take care of those that are infected as well as affected by HIV-related illnesses. Although these facilities are available, hospices can only offer respite for family/friend caregivers for a period of two weeks. In severe cases, sufferers are taken in for symptom control until opportunistic infections are manageable. Home based care entails the provision of necessary health care by a volunteer caregiver to a patient or family at home often with the support of a Community Caregiver. These support services are offered by Community-Based Organizations and include home visits where assistance is given with physical, medical, and emotional care. This however can only be done for a limited number of hours per week due to the number of patients allocated to a volunteer worker in a specific area. (Shebi 2006, Busza et al 2014).

(v) **Religion**

Although the lifestyle and practices which encourage the spread of HIV infection has been met with opposition by many traditional religious institutions, religion has been found to be a positive coping support (Philips, 2006). Rose and Clark-Alexander (1998) found that the vast majority of their sample used prayer as a method of coping with the stress of caring for an HIV positive child. Many grandmothers expressed a realization to their limits, and found comfort in placing faith that the health of the child was in 'higher hands' (Caliandro and Hughes, 1998). Caliandro and Hughes assert that "being strong and able to cope with problems was clearly linked to their strong spirituality.

The second conditioning group of variables is formal social support provided by professionals such as doctors, social workers and home health aides that have also been shown to be important to this process.

Formal service social support

There are vulnerabilities that are unique to HIV affected caregivers which require specialized services to mitigate. Clearly, HIV positive children need timely access to quality medical care. The help of a professional intermediary, such as a doctor, social worker or a community health worker is likely needed to identify the most vulnerable families, to facilitate linkage to appropriate services and to co-ordinate between sectors, and to monitor progress (Kidman and Heymann 2016). Vulnerabilities may be interdependent e.g food insecurity may amplify caregiver depression (Littrell et al 2011), incidence of food insecurity is also higher for female than for male-headed households although women improve household food and nutrition security by spending more of their income on food (Ajani 2008). Specific maladaptive coping strategies adopted by HIV affected households in Ghana included skipping an entire day's meal, reducing portion sizes, harvesting immature crops, reducing number of meals per day, eating elsewhere and begging (Laar et al. 2015). Poor health status among caregivers results in more poor health among children. Caregivers complain about the lack of practical information provided about their relatives' illness and care (Richardson et al 2008).

In a few sub Saharan countries like South Africa, caregivers of HIV positive children who are official foster parents can apply for a foster care grant of some amount of money per month to provide the child with adequate food, medical care, clothing, schooling and shelter. Also available are Care dependency grant, Child support grant and Social relief.

Care dependency grant is meant for children who are ill or disabled and need special care. It can be used for children who are ill with HIV/AIDS. Parents or foster parents or anyone who is responsible for looking after the child can apply. A care dependency grant can be obtained even if a foster grant has already been given. A child support grant is available for anyone who is poor and looks after a child under 14 years. (DSD, SASSA and UNICEF 2016) A test is administered to work out if a person is poor enough to qualify for this grant. Social relief is a temporary relief administered by social workers to people who are in urgent need of support. This relief could be food or money – it would not be a lot and would be given for a short time. Government sponsored social relief services are not generally available in Nigeria. HIV programming in Nigeria has not been primarily social protection focused (Samuels et al 2012)

However some community based organizations includes a Household Economic Strengthening program on the basis that a financially strong household is better placed to provide uninterrupted and complete services to the children in its care.. HIV often exacerbates existing vulnerabilities in our health and social system. For example poverty is intensified in HIV affected families: medical bills drain resources and illness interferes with income generating work (Kuo and Operario 2010). Elderly caregivers are not in the workforce and thus may require cash transfers to help them meet their HIV caregiving responsibilities. While transfers are relevant for the general population, such protections are of even greater importance in HIV affected communities and should be prioritized in endemic contexts (Kuo and Operario 2010). There is good evidence that cash transfers improve child nutrition, health and education in the short term in poor families including HIV-affected families (Miller et al 2010, Robertson 2013). Unemployment benefits can help ensure that hard won gains are not quickly wiped away during an economic downturn. Nigeria does not offer comprehensive government sponsored unemployment benefits. The labour law though requires that employers provide severance pay. Pensions are a critical mechanism for ensuring economic security particularly for elderly caregivers (Hofmann et al 2008). However pension disbursement in Nigeria is unstable with many pensioners being owed several months. Pensions are predominantly provided through a contributory system which excludes workers in the informal economy.

Micro-lending projects should be encouraged for affected caregivers to help them launch a small business or enterprise from the home. Small employment creation projects could

also be facilitated. For example, in Khayelitsha in Cape Town, the Wola Nani project has been very successful in providing a small income for women living with HIV/AIDS. They have started a beadwork and craft workshop where people learn skills. Many of the women can do the work at home and then the project sells and markets it for them. Wola Nani sells many of their products overseas. Gender equitable access to employment opportunities is critical for caregivers who are disproportionately women (Govender et al 2011, Messer et al 2010).

Caregivers personal factors

Caregivers personal factors are shown in prior research to impact the caregiving context. These characteristics of caregivers have been recognized as contributing to outcome measures.

(i) Caregiver's highest level of education

Several studies have reported education levels among caregivers. Hansell et al (1998) found significant differences between HIV negative and HIV positive caregivers' education level. Though not statistically significant, Black et al. (1994) found that HIV negative caregivers in both of their studies had higher levels of education. Although there have been mixed results, some studies have demonstrated that education may play a role in medication adherence due to the often complex drug treatment regime (Cupsa et al 2000, Marhefka et al 2006) . A review of adherence research, found that demographic characteristics such as race/ethnicity, sex, occupation and income are poor predictors of treatment adherence. One study indicated a significant relationship between low education levels and lower adherence rates. Mastering the administration of medicines for the child can be a very complex task. The cognitive ability of the caregiver plays an important role in successfully implementing the intervention. Missed doses reduce the efficacy of the medication, thereby allowing drug-resistant mutations to develop; this places the infected child at greater risk (UNICEF, 2016).

(ii) Another Ill Child

HIV infected mothers are often affected by numerous oppressive factors including poverty. As such, this condition may negatively affect the growth and development of all their children. Thus, in addition to the HIV positive child, it is possible that the individual is caring for more than one ill child, this will subsequently add to the caregiver's

perceived burden. Therefore, even if the child may be HIV negative, he/she may be characterized by many of the same challenges such as low birth weight, delayed psycho-motor development, poor language development, etc. (Knight et al 2000, Noyce et al, 2006).

(iii) Socio-economic status

Child health is strongly related to family income (Schor et al 2003). Poverty has the potential to impact negatively on early childhood development (Linver et al 2002, Schor et al 2003, Lima et al 2004). Emerson (2004) noted that even in developed countries poverty was associated with poor parental health and well being and consequently poorer parenting practices and that the experience of poverty is often associated with poor child health and well being. The care of children affected by HIV/AIDS in developing countries is falling on poorer people within communities, especially women. In Kenya, most families that agreed to take in foster children were living below poverty line, whereas wealthier relatives tended to maintain minimal links with orphans (Mathambo and Gibbs 2009).

Signs and symptoms of caregiver stress

Caregiver stress can take many forms (Pinquart 2018). These may include the following:

Feeling frustrated and angry one minute and helpless in the next minute (Mosch 2006)

Making mistakes when giving medicines (UNICEF 2016)

Turning to unhealthy behaviours like obsessive eating, drinking too much alcohol or smoking (Sinha 2001), feeling alone, isolated or deserted by others (Cruces 2014), sleeping too much or too little (Drake et al 2014), gaining or losing a lot of weight (Block et al 2009), feeling worried or sad often (Mclaughlin and Hatzenbeuhler 2009).

Resilience

Coping and resilience both have a strong history in and connotations to Western psychological sciences, rooted in a focus on individual capabilities, traits and strategies. Taylor (2011) suggests that people facing hardship cope through the perception of others' availability to provide support in times of hardship, and not necessarily through the actual support. A consequence of this individualistic focus is that coping skills can be taught (such as positive thinking and appraisal) Moskowitz (2011). While coping and resilience are interconnected and both pertain to adapting successfully to hardship, Rutter (2012)

clarifies that the two are not synonymous because coping is essentially an individual feature, and moreover one that implies overt action. In particular it ignores the social context and social influences, both of which can be very influential. Although researchers look to identify the conditions that enable resilience, primarily through the interface between risk and protective factors, processes and social ecologies (Ungar 2012), there is a knowledge gap of how resilience is an outcome of people's engagement with a coping-enabling environment.

Resilience is a stress-resistant construct in human capacity that is difficult to measure and define (Karairmak 2010). Although there are some measures to quantify resilience in children and adolescents, there are only a few measures to assess resilience in adults. Fig 2.2 below shows the mapping of the resilience concept.

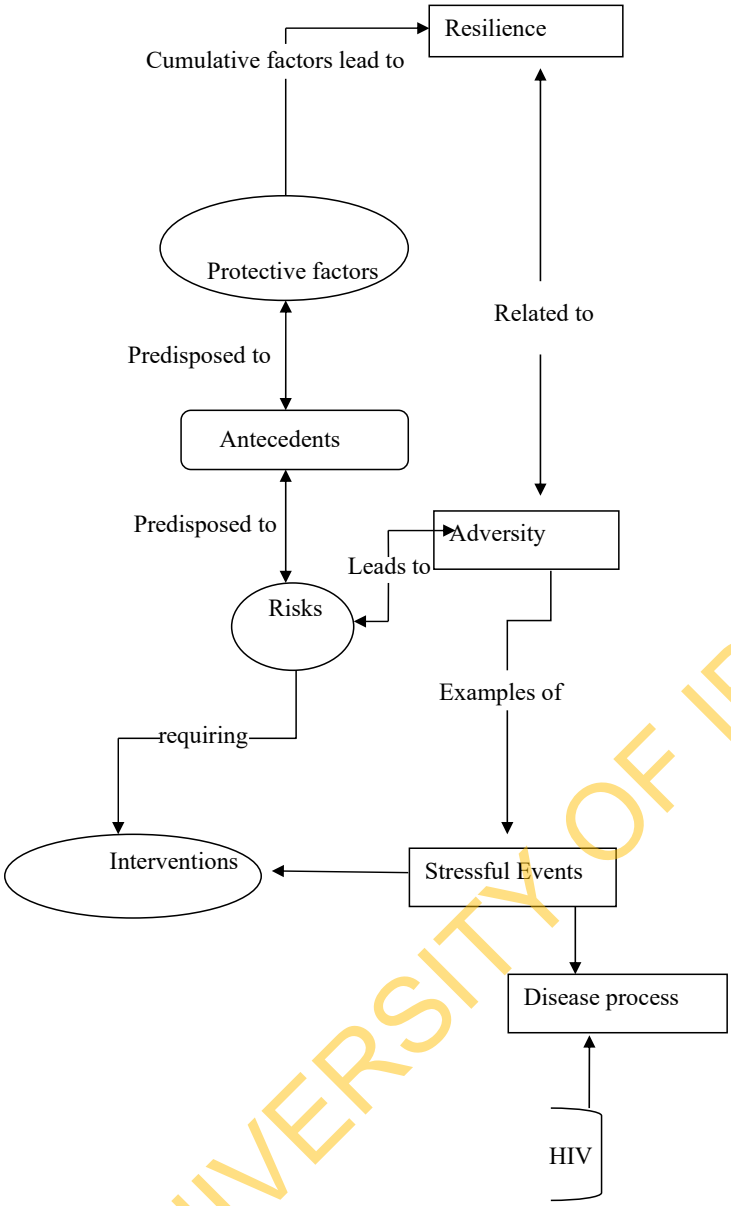

Fig.2.2: Mapping of the resilience process (Source: Garcia-Dia et al 2013)

The central concept of this framework is that the existence of stressors, such as HIV/AIDS in a young child, serves as a source of stress to the caregiver. Within this

framework the independent variables, or stressors, impact the dependent variable of perceived stress. This model also provides for the inclusion of conditioning variables, which can affect the various processes.

Yu et al (2014) conducted a pilot theory based intervention to improve resilience, psychosocial well-being and quality of life among people living with HIV in rural China and findings evidenced higher resilience, social support and quality of life. There was also reductions in depression, anxiety and stress.

Further, for many HIV negative caregivers the task of caring for an infected child is a new experience requiring substantial role redefinition and adjustment (Hansell et al. 1999). In addition, within this framework, the ill child's symptomatology has an effect on the caregiver, which in turn leads to the outcomes of stress and coping. These illness management tasks, which may include multiple hospitalizations and continuing follow up out-patient visits, were listed as a major caregiver stressor (Richardson et al, 2008). This was especially burdensome for caregivers of children placed with foster families, who, as a group, were much sicker than children still living with their biological mothers (Cohen et al., 1995).

Conceptual Framework

The fundamental process of coping is the same for everyone, although people differ in age, gender, culture and socio-economic situation. The Ecological theory explains the dynamics of the various factors that influence the coping behaviour of people.

Ecological model

The stress and coping strategies of caregivers of HIV positive children can also be explained according to the ecological model. In the eco-systemic perspective (Donald, Lazarus and Lolwana, 1997), coping is framed as a process of interaction between an individual and an environment, each with its own set of resources, vulnerabilities, potential and needs. While coping and resilience are interconnected and both pertain to the active process of adapting successfully to hardship, Rutter, 2012 clarifies that the two are not synonymous because coping is essentially an individual feature, and moreover one that implies some overt action. In particular, it ignores the social context and social influences, both of which can be very influential. The ecological model theory situates coping within environment which influences the coping response of an individual and

such that the individual can become resilient and possess abilities to successfully engage in actions and processes that help them overcome a problem or difficulty through participation or engagement with the environment.

Table 2.2: Illustrates the 'protective factors' in an ecological model.

Individual (caregiver)	Family	Community Factors (indigenous networks	Community Level Factors (externally facilitated support)	Political Economy
Perceived locus of control	Family structure; monogamy or polygamy	Involvement in the community	Knowledge skills and training	Access to Antiretroviral therapy and healthcare services
Self efficacy	Intimate partner relationship	Livelihood support from community members	Space for reflection and transformation (provision of respite care, facilitate support group meetings	Access to child welfare services
Parenting skills	Family bonds and cohesion	Peer social capital/acceptance	Home visits and support from community health and adherence support worker	Access to educational services
Health, temperament, belief systems Religion	Social support/network			Cash transfer programs

CHAPTER THREE
METHODOLOGY

Research Design

The goal of the research was to identify the stress factors and coping strategies of women caregivers of HIV positive children at Massey Street Children's Hospital, Lagos.

The study was a descriptive cross-sectional survey using both qualitative and quantitative methods. The qualitative method was by In-depth interviews. The qualitative method was to support the development of a questionnaire. The quantitative method utilized the developed questionnaire.

Study location

The study area was Lagos. Lagos State has an estimated population of about 21 million which represents about 11.7% of the national population of 180 million (National Population Commission, 2016). Lagos is situated in the south western part of Nigeria, and the boundaries of this area are defined by the Atlantic coastline in the south, the Republic of Benin in the west, while the north and east boundaries are shared with Ogun state. The dominant presence of Lagos metropolis as the former Federal Capital Territory, the commercial centre as well as her strategic location on the Atlantic, indicate the uniqueness of the state.

The study site was a children's hospital - Massey Street Children Hospital Lagos. Massey Street Children's Hospital (MSCH) is primarily a children's hospital but offers family centered antiretroviral treatment and palliative care services for mothers of infected children and as well their spouses/ partners. The hospital is a state government health facility managed by the Lagos State Health Services Commission which serves about 50,000 – 100,000 children annually. The population served by the hospital is varied, and a mix of people from different backgrounds and ethnic groups utilize the hospital. The hospital is located within Lagos Island in a highly populated area where basic amenities are inadequate. There is poor water supply, poor electricity supply, and poor accessibility by road. The hospital itself is constrained by lack of space which has limited its expansion and service to the public. Massey Street Children's Hospital serves as primary care and referral facility for the people of the Lagos Island Local Government, one of the 20 Local Government Areas (LGAs) which make up Lagos State. The hospital also has patients

from the other 19 LGAs. The 20 LGAs in the state are divided into three categories. The Urban LGAs are Ikeja, Lagos Island, Lagos Mainland, Mushin, Oshodi Isolo, Somolu, Surulere, Eti-Osa, Apapa, Amuwo Odofin, Ajeromi-Ifelodun, and Agege. The semi-urban LGAs are Alimosho, Ojo, Badagry, Ifako-Ijaiye, Ikorodu and Kosofe. Only two LGAs, Epe and Ibeju Lekki are categorized as rural (MOEP, 1999). The indigenous peoples of Lagos State are the Awori group of the Yoruba people. Yorubas are the dominant ethnic group in Lagos. Lagos is a cultural melting pot that has attracted a cross-section of Nigerians from all over the Federation as well as foreigners from other African countries and the rest of the world.

Study population

The study population is made up of women caring for HIV positive children who have accessed the services of Massey Street Children's Hospital for antiretroviral HIV/AIDS care for their wards for at least 3 months.

Study variables

The independent variables selected for the study were the

(i) Socio demographic characteristics of the caregivers.

(ii) Socio demographic characteristic of HIV positive child

The dependent variables include

(i) Child related stress factors

(ii) Hospital stress factors

(iii) Emotional stress factors

(iv) Financial stress factors

(v) Coping strategies

Sample size determination

A total sample of all caregivers of HIV positive children on ARV treatment for at least 3 month in Massey Street Children Hospital who were available over a 2 month period at the time of the study (July – September 2009) was taken.

The sample size determination of minimum sample size was

$N = \frac{z^2pq}{d^2}$

n = the desired sample size

z = standard normal deviate usually set at 1.96 which corresponds to the 95% confidence interval

p = the proportion of study population receiving drugs at the hospital

q = 1- p = 1- 0.5 = 0.5

d = degree of accuracy desired being 0.05

n therefore $= \frac{1.96^2 \times 0.50 \times 0.5}{(0.05)^2}$

$= \frac{3.8416 \times 0.25}{0.0025}$

$= \frac{0.9604}{0.025}$

$= 384$

However, because availability of mothers was dependent on time of scheduled doctor's appointment and drug refill, only 200 women were available to participate over a 2 month period.

Data Collection Process

Sampling procedure

Two research assistants were recruited and participated in the data collection using the interview guide and questionnaire. They were recruited to assist the researcher in the qualitative and quantitative data collection. They were given orientation on the objectives and importance of the study, sampling processes and how to secure respondents' informed consent. The researcher and a research assistant conducted the in-depth interview with a purposively selected sample based on availability (invitation was extended with the assistance of the support group coordinator) of 2 caregivers at Massey Street Children's Hospital, Lagos and 5 caregivers at Ikorodu General Hospital.

Likewise, for the quantitative data collection the researcher and a research assistant also worked together in order to administer questionnaires to the caregivers waiting to consult with the doctors and to obtain drugs at the pharmacy in the shortest possible time to avoid further delays to the respondent. The questionnaires were given to caregivers who met the

criteria and consented to participate when the purpose of the study was explained. Caregivers who consented to participate were taken through the questionnaire. Where the number of waiting caregivers increased the respondents were allowed to complete the questionnaire by self administration in other to approach other qualified respondents before they leave the hospital premise. The sample frame of all the children currently receiving antiretroviral drug treatment in the hospital was used. A purposive sampling of caregivers at the ART clinic as they await appointment with the doctor or pharmacist with their children was done; with particular note of those already interviewed so as not to duplicate interviews with the same respondent. The caregivers with children with at least 3 months on antiretroviral drugs were identified by questioning.

Instrument for data collection

The data for this study was collected using both quantitative and qualitative data collection methods. The instrument used for the quantitative data were interviewer administered in part and self administered in part. The qualitative data was collected by use of an in-depth interview guide.

The qualitative tool comprised of the introduction, which included introduction of the researcher and the purpose of the interview. Interviews were conducted on 7 persons. They were recruited from women with HIV positive children in the study hospital and one other state government hospital offering similar services in Ikorodu. The interviews were conducted by the researcher and a research assistant using an interview guide developed to direct the course of the discussion. The guide contained questions which focus on the challenges of caregivers of the children with HIV. The questions comprise potentially stressful aspects of the diagnosis of HIV, disclosure, stigmatization, relationships and role in the family and society, socioeconomic status, personal issues and concerns. The sample was purposively selected. Women who were interviewed were invited by the health facility counsellor/support group coordinator. Women who made themselves available on the appointed day were interviewed. Each tape recorded session lasted about 35 min. The tapes were transcribed and subsequently reviewed to produce the final list of stressors. Qualitative data generated was used to formulate the questionnaire.

The quantitative method utilized the developed questionnaire. The data collection instrument was developed from review of relevant literature and the contribution of health

education experts, peer review and the information obtained from analysis of the in-depth interview. The developed questionnaire was pilot tested on pediatric caregivers who met the inclusion criteria selected at other ART clinics at General Hospitals within the state – at Isolo, Ikorodu, and Badagry.. The questionnaire has three sections. The first section is the socio-demographic section and the second section a stress factor section with listed life events common to women living with HIV. The respondents were required to indicate how stressful these factors were to them on a five point (5) level scale. The scores ranged from 0 for stress factor does not apply to 4 for very stressful. Maximum stress score for the scale was 88.0. Caregivers with stress scores ≥40 were vey stressed, 24 – 39 were moderately stressed, and stress scores ≤ 23 were mildly stressed. The degrees of stress were explained to the respondents on the questionnaire and also reiterated by the researcher and research assistant. The third section deals with coping styles. The respondents were asked to indicate which coping styles they usually use in dealing with each of the listed stressors. The coping styles which the mothers were asked to choose from include confrontation, avoidance, anger, complaint and acceptance. Explanations on these coping styles were given on the questionnaire. The pretested questionnaires were administered among the targeted sample population.

Validity and reliability of instrument

Validity and reliability of instrument was ensured by pretesting of questionnaire by review of peers and contribution of health education experts. The questionnaire was also pretested in other ART clinics at General Hospital Isolo, General Hospital Badagry and General Hospital Ikorodu within the Lagos metropolis on caregivers of children receiving antiretroviral treatment for HIV. The conditions during administration were similar to those in the final study. Based on the results, relevant corrections were carried out and then a retest of the pre-test was again carried out as before. The instrument was subjected to measures of internal consistency with the use of Cronbach's alpha coefficient analysis to confirm its reliability. This is a model of internal consistency, based on the average inter-item correlation. In this approach, result showing correlation coefficient greater than 0.5 is said to be reliable. The result showed a correlation coefficient 0.897 which proved that the questionnaire was reliable.

Data management, analysis and presentation

The steps involved in the analysis of the In-depth interview data included the following: The tape-recorded In-depth interviews were transcribed verbatim. Review of the transcribed script was done for identification of themes. The themes informed the development of the questionnaire used in the survey. The stress factors that were determined as appropriate for the target sample were scored on a five point Likert –type scale (A score of 4 = highly stressful, a score of 3 = moderately stressful, 2 = don't know, 1 = not stressful, 0 score = stress factor does not apply). Thus scores could be computed for each woman that reflected general level of stress. Higher scores reflected greater overall stress. The potential range of scores was therefore between 0 - 88.

The quantitative survey was analysed with the following steps. The data was checked and cleaned. The coded questionnaire was double entered into a computer using the Statistical Package of the Social Sciences (SPSS). All discordant entries were checked against original data collection instrument and corrected. Data was analyzed descriptively for mean and for inferential statistical application.

Ethical consideration

Permission for the study was obtained from the management of the Health Services Commission, Lagos State and the hospital. Only consenting caregivers were included. Informed consent was sought in order to protect the rights of study participants. Confidentiality was ensured during and after conduct of the interviews.

Study limitation

The attempt to develop a psychological instrument measuring HIV related stress and making it adaptable to our socio cultural environment created some challenges. However the qualitative survey sought to reduce this challenge by consideration of the experience of women caregivers of HIV positive children within the socio cultural environment as identified by the analysis of the in-depth interview. The study of the sample population in only one centre may be a limitation. In future a multi centre study may yield a larger and more generalised sample of caregivers with HIV positive children. This limitation was however reduced by the choice of a referral centre with the highest number of children being treated for HIV in the state. Further, the study was limited by the focus on caregivers who were already accessing antiretroviral treatment for the HIV positive children in their care. This limitation is based on the assumption that antiretroviral

therapy impacts on the perception of burden experienced by the caregiver. Future studies could consider identification of stress factors experienced by caregivers before the initiation of antiretroviral treatment for the HIV positive child.

CHAPTER FOUR
RESULTS

The results of qualitative and quantitative (survey) data collection are presented in this chapter.

Section A: Qualitative Findings

Diagnosis of HIV

Two women reported that they got to know of their HIV status during pregnancy at the antenatal clinic. One of them reported that she had rejected the test result and was in denial. She refused to obtain treatment for herself and the baby during pregnancy. After delivery her baby later became sick and was admitted to the hospital. Many tests were conducted and her baby was confirmed HIV positive.

Ikorodu Interviewee 1

"Yes I went for ANC, I was told but I did not agree. I said how come that such will be inside my body, not knowing that the virus is inside my body"

The other woman reported that she tested HIV positive during pregnancy of her baby. On the day she was told she informed her husband and he said no problem. The following day they went to the laboratory together and he did his test. He was negative.

Ikorodu Interviwee 2

"So I thought he would feel somehow, but he even encouraged me that tihis was not the end of life; that we shouldn't tell anybody and since then I don't have problem with him. If they tell me to buy this drug or multivitamin that we will give – there is no problem."

However, her baby tested positive after delivery despite the intervention of PMTCT that she had received and her decision not to breastfeed her baby.

"The time I had delivered – he was so small. He was crying, he was crying. It was in the night. I was feeling that I should breastfeed – that day I wept."

Another woman reported attending ANC at a private hospital where they gave general health talk – they did not talk about HIV. She later accessed a public health facility where

she was informed. She obtained information and treatment for herself and her baby. She got to know about PMTCT and Early Infant diagnosis

Ikorodu Interviewee 3

"I'm not breastfeeding my baby. The baby got PMTCT drugs. I'm praying for the baby. Nothing happened to my baby. I requested for the test so that one will know early"

One woman reported that she was sick and her baby's situation was worse before they both later tested positive for HIV.

Massey Interviewee 1

"Before I got to know I was HIV positive – I was coughing, coughing for more than 3 months. Child was sick. Fear is in me."

Availability of Social Support

The women reported spousal, parental and family support as well as support from friends, church and clinic support group members. A woman whose husband tested HIV negative, reported suprising support from her husband.

Who do you turn to for support?

Ikorodu Interviewee 1

"My husband. God and my husband"

Ikorodu Interviewee 2

"My husband and my parents – my parents are aware of it".

An interviewee in Massey Street Hospital reported that her mother ostracized her. She was living with her mother but her mother pursued her out with her daughter. She was afraid, *"thinking and thinking"*. She sought shelter in a church and reported support from her clinic support group members who counseled her not to worry.

Two women reported not disclosing to family or friends.

Ikorodu Interviewee 4

"No I don't discuss anything with anybody. I don't discuss with anybody. I put myself on God"

The second woman's decision was made in agreement with her husband.

At Massey Street Hospital, one woman reported her sister confiding in her and she later decided to take her sister's HIV positive child to live with her family to care for him better though she did not disclose his status to her spouse or children.

Coping strategies

Ikorodu Interviewee 1

"I have been praying to God and I also come to the hospital and meet a doctor who will tell me what to do. I'm just praying that God will give us a miracle. I just put myself in the hands of God. I cannot kill myself." This respondent had stated that she wished to die when she was first diagnosed as HIV positive. However on accessing treatment in the hospital she made the discovery that she was not alone:

"*At first I wanted to kill myself but when I came out and saw it was not only me – small children and adult; I took it as I saw it."*

Section B: Quantitative Findings

Socio-demographic characteristics

Most women caregivers of HIV positive children sampled at the Massey Street Children's Hospital were Christian (68.5%), living with husband (78.5%), age 31 – 40 years (54.5%), (mean age 32.9 ± 10.6 years), had secondary school as highest level of education (53.0%) and were traders (53.5%) as shown in table 4.1

Table 4.1: Socio-demographic characteristics of respondents

Socio-demographic Variables	N=200 (%)
Age (Years)	
<20	2 (1.0)
20-30	66 (33.0)
31-40	109 (54.5)
41-50	19 (9.5)
>50	4(2.0)
Religion	
Christianity	137 (68.5)
Moslem	61 (30.5)
Others	2 (1.0)
Marital Status	
Living with partner	2 (1.0)
Living with husband	157 (78.5)
Separated from husband	8 (4.0)
Widowed	27 (13.5)
Divorced	3 (1.5)
Single	3 (1.5)
Highest Level of Education	
None	9 (4.5)
Quaranic	4 (2.0)
Primary	47 (23.5)
Secondary	106 (53.0)
Tertiary	34 (17.0)
Occupation	
Professional	24 (12.0)
Trader	107 (53.5)
Skilled	35 (17.5)
Non skilled	10 (5.0)
Unemployed	24(12.0)

Source: Survey at Massey Street Children's Hospital, Lagos

Respondents' monthly income

The monthly income of majority of caregivers (39.0%) was between N5000 – N10000 monthly. A significant number of caregivers (12.0%) had monthly income less than N5000. There were those who reported having no income at all (23.6%) and 22.5% did not report on their income. Monthly income of respondents is as shown in Table 4.2*

Table 4.2 Monthly income of caregivers

Monthly income (Naira)	N=200 (%)
<N5000	24(12.0)
N5000 –N10 000	78(39.0)
N11000 – N30 000	39(19.5)
N31 000 – N50 000	10(5.0)
N51 000 – N100 000	4(2.0)
No income	(23.6)

* Forty-five (22.5%) women did not indicate their income

Number and age distribution of children being cared for

The age of children being cared for by women caregivers ranged from six months to 14 years. The distribution amongst these were children 6-10years old (29.5%), children from 2-3years old (24.0%). For 56% of the respondents the number of children being cared for in their family was either 1 or 2. Some respondents (38.5%) had children numbering 3-5 in their family unit.

Stress factors

Table 4.4 shows the prevalence for each of the stress factors, grouped into categories; these are disease factors, hospital factors, child factors, emotional factors and financial factors.

Stress factors considered by women caregivers as very stressful included HIV positive status of child (73.0%), waiting to know baby's HIV status (50.5%) and admission of child to hospital (38.0%). The prevalence of other factors is shown in the table. The stressors perceived as moderately stressful included: Accessing the hospital for treatment of the child (24.5%), waiting for doctors/hospital staff (22.5%) and keeping hospital appointments for treatment (21.0%). The prevalence of other stressors are indicated in Table 4.4. The most prevalent factors considered not stressful at all were: adhering to HIV drug regimen for treatment of the child (70.5%), cost of good food (67.5%), cost of health care for the child (63.5%). Other stressors considered not stressful at all and their prevalence are as shown in table 4.4.

Table 4.34 Prevalence of respondents perception of stressors on the stress scale

	Frequency (N) Very Stressful	Prevalence %	Frequency (N) Moderately Stressful	Prevalence %	Frequency (N) Not stressful at all	Prevalence (%)
DISEASE FACTORS						
Child being HIV positive	146	73.0	24	12.0	26	13.0
HOSPITAL FACTORS						
Admission of child to hospital	76	38.0	17	8.5	14	7.0
Accessing the hospital for treatment for the child	54	27.0	49	24.5	94	47.0
Keeping hospital appointments for treatment	46	23.0	42	21.0	107	53.5
Attitude of hospital staff	14	7.0	32	16.0	64	32.0
Waiting for doctors/hospital staff	36	18.0	45	22.5	109	54.5
Handling stigmatization from health care workers	11	5.5	12	6.0	13	6.5
CHILD FACTORS						
Waiting to know baby's HIV status	101	50.5	24	12.0	37	18.5
Deciding best feeding option for the child	19	9.5	16	8.0	51	25.5
Adhering to HIV drug regimen for treatment of the child	20	10.0	24	12.0	141	70.5

Table 4.34 continued. Prevalence of respondents perception of stressors on the stress scale

	Frequency (N) Very Stressful	Prevalence %	Frequency (N) Moderately Stressful	Prevalence %	Frequency (N) Not stressful at all	Prevalence (%)
EMOTIONAL FACTORS						
Disclosure of HIV status of child to family	18	6.0	7	3.5	49	24.5
Disclosure of HIV status of child to friends	9	4.5	1	0.5	12	6.0
Handling stigmatization from family	8	4.0	6	3.0	4	2.0
Handling stigmatization from friends	8	4.0	3	1.5	26	13.0
Thought of a life of continuous HIV drug use for child	53	21.5	32	16.0	103	51.5
Thought of possible lack of free HIV drugs to use for child	38	19.0	31	15.5	40	20.0
FINANCIAL FACTORS						
Cost of health care for the child	33	16.5	35	17.5	127	63.5
Cost of good food/nutrition	25	12.5	27	13.5	135	67.5
Cost of milk formula for alternative feeding option	14	7.0	18	9.0	39	18.5
No means of livelihood/ no job or trade to do to provide income to care for the child	8	4.0	11	5.5	10	5.0
Transportation cost for clinic appointments	39	19.5	41	20.5	102	51.0
Lack of home or shelter	9	4.5	3	1.5	10	5.0

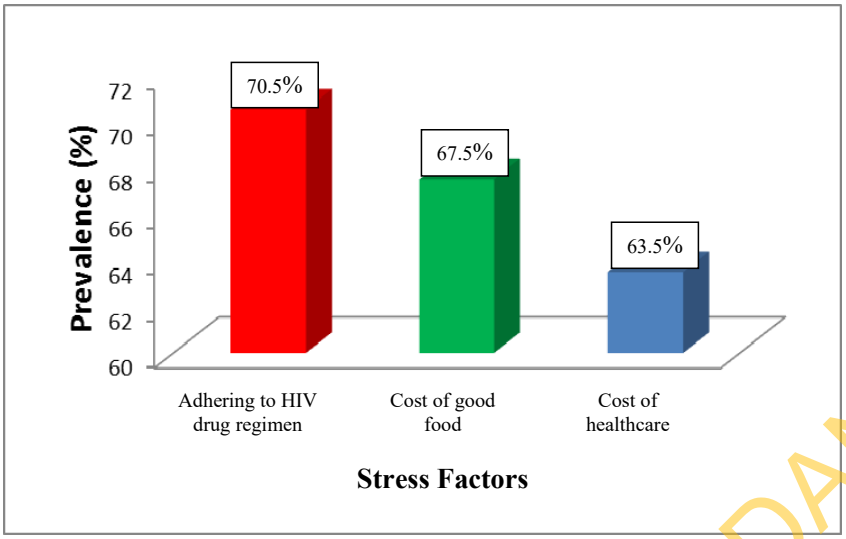

Fig 4.1 Factors considered not stressful at all by respondents

Respondents (71%) who scored greater than or equal to 40 on the total stress score were considered as very stressed. Respondents with total scores in the range of 24 to 39 (16%) were considered moderately stressed and those with scores less than or equal to 23 (1326%) were mildly stressed as shown in table 4.45 below

Table 4.45. Stress score analysis

	Frequency	Percent
Very stressed [40 - 70]	142	71.0
Moderately stressed [24 - 39]	32	16.0
Mildly stressed [14 - 23]	26	13.0
Total	200	100.0

COPING STRATEGIES

Caregivers adopted multiple coping strategies as multiple concurrent stressors required different coping strategies. However, the commonly adopted coping strategy was acceptance. Caregivers' most prevalent coping strategy was acceptance when: HIV positive status of children was discovered (80%), Keeping hospital appointments (94%), adhering to drug regimen for child (92%), and waiting for doctors/hospital staff (87%). The second most prevalent coping strategy adopted across the stressors was to confront the problem/issues: on admission of child (19.5%), waiting to know baby's HIV status (17.5%), and deciding best feeding option (15%). Anger as a coping strategy was utilized across all the stressors except in handling stigmatization from friends (0%) though with lower prevalence. Complaint was not utilized at all (0%) in certain situations: handling stigmatization from family, disclosure of HIV status to friends, attitude of hospital staff, keeping hospital appointments, cost of milk formular, no means of livelihood/no job. The comparison of coping strategies across specific stressors is shown in table 4.57

Table 4.56: Comparison of stressors with prevalence of coping strategies adopted by caregivers

STRESSORS	COPING STRATEGIES Frequency N (%) Acceptance	Complain	Anger	Avoid	Confront	Don't Know	Not Applicable	Stress Score
DISEASE FACTORS								
Child being HIV positive	160 (80.0)	2 (1.0)	20 (10.0)	2 (1.0)	12 (6.0)	4 (2.0)	0 (0.0)	3.45
HOSPITAL FACTORS								
Admission of child to hospital	44 (22.0)	2 (1.0)	24 (12.0)	0 (0.0)	39 (19.5)	3 (1.5)	88 (44.0)	1.87
Accessing the hospital for treatment for the child	185 (60.5)	1 (0.5)	4 (2.0)	1 (0.5)	8 (4.0)	1 (0.5)	0 (0.0)	2.30
Keeping hospital appointments for treatment	188 (94.0)	0 (0.0)	4 (2.0)	1 (0.5)	3 (1.5)	0 (0.0)	4 (2.0)	2.09
Attitude of hospital staff	87 (43.5)	0 (0.0)	4 (2.0)	0 (0.0)	7 (3.5)	1 (0.5)	101 (50.5)	1.10
Waiting for doctors/hospital staff	175 (87.5)	3 (1.5)	6 (3.0)	0 (0.0)	5 (2.5)	2 (1.0)	9 (4.5)	1.94
Handling stigmatization from health care workers	20 (10.0)	1 (0.5)	3 (1.5)	0 (0.0)	6 (3.0)	0 (0.0)	170 (85.0)	0.50
CHILD FACTORS								
Waiting to know baby's HIV status	115 (57.5)	3 (1.5)	14 (7.0)	0 (0.0)	35 (17.5)	5 (2.5)	28 (14.0)	2.62
Deciding best feeding option for the child	47 (23.5)	1 (0.5)	3 (1.5)	1 (0.5)	30 (15.0)	4 (2.0)	114 (57.0)	0.89
Adhering to HIV drug regimen for treatment of the child	184 (92.0)	1 (0.5)	4 (2.0)	1 (0.5)	1 (0.5)	1 (0.5)	8 (4.0)	1.14
EMOTIONAL FACTORS								
Disclosure of HIV status to family	57 (26.5)	1 (0.5)	3 (1.5)	18 (9.0)	13 (6.5)	1 (0.5)	107 (53.5)	0.75
Disclosure of HIV status to friends	6 (3.0)	0 (0.0)	1 (0.5)	27 (13.5)	3 (1.5)	0 (0.0)	163 (81.5)	0.25
Handling stigmatization from family	14 (7.0)	0 (0)	3 (1.5)	4 (2.0)	4 (2.0)	0 (0.0)	175 (87.5)	0.30

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Table 4.5 continued: Comparison of stressors with prevalence of coping strategies adopted by caregivers

	COPING STRATEGIES Frequency N (%)						
	Acceptance	Complain	Anger	Avoid	Confront	Don't Know	Not Applicable
STRESSORS							
Handling stigmatization from friends	12 (6.0)	1 (0.5)	0 (0.0)	2 (1.0)	5 (2.5)	2 (1.0)	178 (89.0)
Thought of a life of continuous HIV drug use for the child	165 (82.5)	1 (0.5)	13 (6.5)	0 (0.0)	9 (4.5)	8 (4.0)	4 (2.0)
Thought of possible lack of free HIV drugs to use for the child	55 (27.5)	7 (3.5)	26 (13.0)	2 (1.0)	20 (10.0)	86 (43.0)	9 (4.5)
FINANCIAL FACTORS							
Cost of health care for self and child	170 (85.0)	3 (1.5)	5 (2.5)	0 (0.0)	9 (4.5)	4 (2.0)	9 (4.5)
Cost of good food/ nutrition	128 (64.0)	2 (1.0)	4 (2.0)	0 (0.0)	6 (3.0)	54 (27.0)	6 (3.0)
Cost of milk formula for alternative feeding option	55 (27.5)	0 (0.0)	3 (1.5)	1 (0.5)	19 (9.5)	3 (1.5)	119 (59.5)
No means of livelihood/ no job or trade to do to provide income to care for the child	7 (3.5)	0 (0.0)	3 (1.5)	1 (0.5)	6 (3.0)	2 (1.0)	181 (90.5)
Transportation cost for clinic appointment	175 (87.5)	2 (1.0)	3 (1.5)	1 (0.5)	8 (4.0)	2 (1.0)	9 (4.5)

Comparison of stress score and age set of caregivers

Women younger than 20 years had the highest mean stress score (47.0), women age 31-40 had stress score (35.4) and women older than 50 had the least stress with mean stress score (24.3) as shown in table 4.6

Table 4.67 Age set of caregivers and mean stress score

Age (years)	N	Mean Stress Score	Std. Deviation
<20	2	47.0	1.41
20 – 30	66	31.9	10.96
31 – 40	109	31.7	10.47
41 – 50	19	35.4	14.04
>5	4	24.3	3.77
Total	200	32.1	11.02

ANOVA

	Sum of square	df	Means square	F	Sig.
Between Groups	915.28	4	228.80	1.91	0.11
Within Groups	23252.60	195	119.24		
Toal	24167.88	199			

~~4.8~~ Comparison of stress score and marital status of caregivers

Caregivers living with partner had the highest stress score (52.5), followed by single women with stress score (43.0), while least stress was experienced by women living with husband (31.2) as shown in table 4.7

Table 4.~~9~~ 7 Marital status of caregivers and mean stress scores

Marital Status	N (Frequency)	Mean Stress Scores	Std. Deviation
Living with partner	2	52.5	10.60
Living with husband	157	31.2	10.27
Separated from husband	8	36.6	12.60
Widowed	27	32.6	13.29
Divorced	3	37.3	7.37
Single	3	43.0	10.58
Total	200	32.1	11.02

ANOVA

	Sum of square	df	Means square	F	Sig.
Between Groups	1555.00	5	311.00	2.667.078	0.02
Within Groups	22612.87	194	116.56		
Toal	24167.88	199			

Comparison of stress score and religion of caregivers

Moslems had the lowest mean stress score (30.1) and Christianity mean stress was 32.9. Other religion adherents had the highest stress score as shown in table 4.8.

Table 4.8 Religion of caregivers and mean stress score

Religion	N (Frequency)	Mean Stress Score	Std. Deviation
Christianity	137	32.9	11.36
Moslem	61	30.1	10.06
Others	2	40.0	7.07
Total	200	32.1	11.02

ANOVA

	Sum of square	df	Means square	F	Sig.
Between Groups	470.87	2	235.434	1.96	0.14
Within Groups	23697.01	197	120.289		
Total	24167.88	199			

Comparison of stress score and educational level of caregivers

Caregivers with tertiary education had the highest mean stress core 39.9. Those with quaranic education also had high stress score (34.8). Those who had no education had the least stress level (27.4). The comparison of all educational levels is shown in table 4.9.

Table 4.9 Educational level of caregivers and mean stress score

Educational level	N	Mean	Std. Deviation
None	9	27.4	7.95
Quaranic	4	34.8	10.08
Primary	47	30.2	9.57
Secondary	108	30.8	9.93
Tertiary	34	39.9	13.69
Total	200	32.1	11.02

ANOVA

	Sum of square	df	Means square	F	Sig.
Between Groups	2612.13	4	653.03	5.91	0.00
Within Groups	21555.75	195	110.54		
Total	24167.88	199			

~~4.12~~ Comparison of stress score and occupation of caregivers

Caregivers who were professionals in their occupation had the highest stress level (39.3). Those who were in skilled work employment had the least stress score (28.9). Those who were unemployed had high level of stress (36.8) though not as high as those in professional job positions. The comparison is as shown in table 4.10.

Table 4.1~~02~~ Occupation of caregivers and mean stress score

Occupation	N	Mean	Std. Deviation
Professional	24	39.3	12.20
Trader	107	30.8	10.08
Skilled worker	35	28.9	10.38
Non skilled worker	10	29.1	10.29
No job	24	36.8	11.33
Total	200	32.1	11.02

ANOVA

	Sum of square	df	Means square	F	Sig.
Between Groups	2399.52	4	599.88	5.37	0.00
Within Groups	21768.36	195	111.63		
Total	24167.87	199			

TEST OF HYPOTHESIS

Test of hypothesis of association between stress and other variables

Table 4.113 shows the ANOVA table of the association between stress and other variables: age, marital status, religion, educational level and occupation. The mean stress scores according to the variables are shown in table 4.13. There is no significant association between stress and age ($p>0.05$), There is no significant association between stress and religion ($p>0.05$). There is significant association between stress and marital status ($p<0.05$). There is significant association between stress and educational level ($p<0.05$) and there is significant association between stress and occupation of caregivers. Null hypotheses that there are no significant association between Stress and age and stress and religion are accepted. Null hypotheses that there are no significant associations between stress and marital status, educational level and occupation are not accepted.

Table 4.113: ANOVA table showing significant difference of stress scores by age, marital status, educational status and occupation.

Socio-demographic variables	Total	Total Mean (SD)	F statistics	p-value
Age	200	32.1(11.0)	1.91	0.11
Marital status	200	32.1(11.0)	2.67	0.02
Religion	200	32.1(11.0)	1.96	0.14
Educational level	200	32.1(11.0)	5.91	0.00
Occupation	200	32.1(11.0)	5.37	0.00

CHAPTER FIVE
DISCUSSION, CONCLUSION AND RECOMMENDATIONS

In this chapter, the implications of the study are discussed. The results are compared with results obtained in similar studies. Factors that cause stress in the sample population are considered. The relationship between the stress factors and the coping strategies are examined. The conclusions gathered from this study shall form the basis for recommendations for effective health promotion and education programs for prevention and management of stress among women caring for HIV positive children.

5.1 Socio-demographic characteristics

This study was an all women sample as it considered the stress factors and levels of stress encountered by women caregivers with HIV positive children in Massey Street Children Hospital, Lagos. In Uganda, Kagotho and Ssewamala (2012) reported on a quantitative baseline survey of 297 caregivers and found most caregivers of HIV affected children to be female. Future studies may want to consider male caregivers stress factors and coping strategies, for comparison and identification of gender issues related to stress and coping strategies of caregivers. Women caregivers of HIV infected children are usually a mother, aunt, or grandmother (Richter, Foster and Sherr 2006, Ekaete et al. 2013)

The age of the women ranged from less than 20 to over 50. The majority (54.5%) were in the age range 31 – 40. Those in 20 -30 age bracket were 33.0%. This result differs to that obtained in the study conducted by Ekaete et al (2013) where women age 41 – 50 years were the majority that participated in caregiving. It can be seen from this that many young women in their reproductive years are being affected by HIV either as patients themselves or as caregivers to infected HIV positive children (Talley and Crews 2007). As rates of HIV infection in women of child bearing age continue to grow and advances as treatment lengthen women's survival, greater numbers of women with children are coping with HIV and AIDS as a chronic health condition (Schuster et al 2000). Many children acquire HIV through mother-to-child transmission (UNAIDS/UNICEF/WHO, 2015). In Rwanda and Zambia, the majority of new infections estimated between 60% and 95%, occur between stable cohabiting partners who are likely to be parents (Dunkle, Stephenson and Kanta 2008) as well as between parent and children through vertical transmission (De-

Cock et al 2008). Labour migration entailing the separation of spouses has facilitated the spread of the virus (Brummer, 2002). In this study marital status of women showed that 78.5% of these women were married and living with their husbands. Almost universally, families provide the bulk of care and support for persons living with HIV/AIDS (UNAIDS, 2004). HIV poses a unique threat to family and well being (Akintola, 2003).

The result of this study is contrary to that of studies conducted by Armistead et al (1999) which found that mothers with HIV/AIDS tend to be single. The difference in results may be due to the difference in environmental context in which the studies were conducted. Family life is highly regarded in African and Nigerian culture, most women get married and remain married; separation, divorce and single status are not the expected norm in African culture. The difference in result could also lead us to believe that many of the caregivers of these children may not be the biological mothers of the children but are either their aunts or grandmothers. This study did not consider the relationship between the caregiver and the child. This may be an area other studies may choose to explore. Many respondents in this study were traders (53.5%) and many (>51.0%) earned monthly income below minimum wage (N18000). Stable, well paying jobs reduce financial stress and improve family functioning. Prior studies have shown that social support and higher socio-economic status are protective for elevated stress levels (Adler 2002, Szanton, Gill and Allen 2005).

Studies in high income countries report a lack of significant influence of HIV exposure on child cognitive, motor and language functioning, while studies from resource poor setting indicate a stronger impact of maternal HIV status on child developmental outcomes (La Doare et al, 2012). Data correlating child cognitive, motor and language with HIV status in Nigeria is limited. However nutritional status of children exposed to HIV has been documented to be poor as a result of poverty both in high income countries as well in low income countries. Increased skills and training in income generation can provide people with flexibility and more available options to effectively deal with problems. These factors increased an individual's chances of obtaining and maintaining stable employment and income (Jackson et al 2000). Few women in our sample were educated beyond secondary school and lacked the skills and training to be engaged in a stable high income paying employment. Many (68.0%) of the women caregivers reported to be Christians.

This may be as result of many factors one of which in a study by Alemu et al 2013, stated that caregivers' religious beliefs is associated with disclosure of children HIV positive status; orthodox Christians were 4 times more likely to disclose their children's HIV positive status relative to their counterparts in other religion. Moore and Williamson 2011 similarly reported that caregiver's recourse to religious ministers for spiritual support and counsel. Also, Protestant caregivers were 18.2 times more likely to disclose their child's HIV serostatus for spiritual help relative to their counterparts with a traditional religion.

Though this study relates religion specifically to openness in disclosure of HIV status, the same reason may extend towards the health service seeking behaviour of the religious adherents. On the other hand, it may be that Christians were not as careful to prevent the HIV infection of their children. In this study however 81.5% did not disclose HIV positive status to friends and 53.5% did not disclose to family. This is indicative that these caregivers are selective of who disclosure of HIV positive status of their children is made.

5.2 Stress levels in women caregivers

The presence of a chronic medical condition in a child is a factor that has been related to increased maternal stress and psychological difficulties (Thompson and Gustafson, 1996). Those caring for children with HIV infection can experience stressors in their role as caregivers that are unique to this disease. These stressors can be made worse when the caregivers have fewer social supports, more marital problems, and more concurrent stress such as found in developing countries which are resource constrained and have low socio-economic standard of living. The caregiver's well being may depend more on internal resources rather than on external resources which are generally lacking.

The most stressful factor identified in this study is the nature of the disease itself. This is different from the study reported by Commodari (2010) that actual hospitalization of children is a stressful event for caregivers, even if hospitalization is for middle and transient pathologies. Hospitalisation in this study though associated with stress; stress from this factor was secondary to the stress from being infected with the disease. Many (45.5%) of respondents in this study did not experience hospitalization of their children. Hospitalizations often results in relationship changes with less contact with friends and

relatives who could provide social and emotional support in caring for the sick child. The mean stress score for child being HIV positive was 3.45 on a scale of 4 being very stressful and 0 – not applicable, while mean stress score for admission to hospital was 1.87. The overall stress score calculated from the listed 22 stress factors ranged from 0 – 88 as such 44 would be the expected 50% average score. The actual mean score of 32.13 which is less than 50% indicates that stress levels experienced by the women are not as high as presumed, or that these women are coping better than expected. Women less than 20 years experienced more stress than the average and actual mean with a stress score of 47. Women 41 - 50 years also experienced stress with stress score of 35.36 which is higher than the actual mean score of 32.13. The higher stress scores in women less than 20 may be attributable to anxiety and fear due to inexperience from age, marital status, inadequate economic resources and social status (Armistead et al 1999). The lower stress levels and younger age (20 - 40) of women has been explained by (Pearlin et al 1981). They suggested that younger women have higher levels of energy that enable them to seek extra social and recreational activities, thus providing them with a greater reserve of coping mechanism than older women.

Young unmarried women below 20 could be experiencing more stress because they lacked social and financial support from a husband and his relatives. These women would therefore more than likely be solely responsible for their own as well as the upkeep of their baby. Women 41- 50 years may experience more stress as a result of increasing family and workplace responsibilities, as well as other role demands. It may be that as a result of maturity in age they were not considered as requiring social support in caregiving for their older children, unlike young mothers who are culturally provided support in caring for their new born and young children. Many of the respondents were traders. In South western Nigeria many of these women have the responsibility for their own welfare and that of their children particularly women from polygamous families. Women with no jobs understandably experienced more stress because of the anxiety that the unemployment status creates in terms of financial and economic insecurity. Professional women however experienced more stress than unemployed women perhaps because of other role demands connected to the jobs they are employed on and from repeated required absence from work to keep hospital appointments. This stress may also be related to their educational level and perceived social status. Women with tertiary level

education exhibited more stress than all the other women who had lower or no education at all. Women with higher income levels also showed more stress than women with lower levels of income. HIV is considered a disease of poverty. The role of education and monthly income on stress level can be explained by the fact that education is associated with economic status, such that more highly educated women would have greater access to financial resources. However, the attainment of high level education and financial resources by these women has increased their stress level rather than reducing it. The stress being experienced by these women may also be as a result of the secrecy surrounding the HIV status of their children and fear of exposure or disclosure. It may be due to the hospital environment and being in the midst of people of lower educational and socio-economic status. It may well be as a result of a keener understanding of the realities of the HIV positive status of their children. It will therefore be necessary to counsel and educate these women on the use of social and emotional supports in coping better with the care of their HIV positive children.

Accessing the hospital for treatment was another stress factor with higher frequency rating with a mean stress score of 2.30. The mean difference between groups however was not significant. It was noted in this study that women who lived close to the hospital and spent less than 10 minutes to get there experienced more stress than those who spent greater than 10 minutes to get there. The mean difference though was not statistically significant; this result can be compared to the result reported by Uzochukwu et al, 2009 that being male and living more than 20km from the treatment centre was positively and significantly associated with adherence to ART. It could be that women who live near the hospital would have preferred to have their child treated in a much further location where their children and they themselves could remain relatively unknown for fear of being stigmatised by neighbours.

The thought of lack of free HIV drugs for treatment of child was another stress factor with high frequency rating with mean stress score of 2.28. Other studies have observed similar anxieties in mothers about the future of their children. Qualitative data collected by Andrews, Williams and Neil, (1993) with a sample of 72 mothers indicated that mothers reported increased levels of anxiety in relation to their children. In a prospective study by Manopaiboon et al, (1998); 129 mothers were interviewed after giving birth to a

child; 19.4% of children later tested positive to HIV. In addition, on a measure of HIV related worries three items were consistently rated as things they worried about a lot; their child's health, uncertainty about the future, and concern about their child growing up without a mother. The thought of lack of free drugs for use in the future falls into the category of worries about the uncertainty of the future. The worry indicates a lack of confidence in the capacity and quality of the public health system in the nation. Presently the provision of free antiretroviral drugs is being heavily funded by foreign governments and international donor organizations. The withdrawal of donor funding may be disastrous in the future if concerted government efforts are not made to ensure the security of our public health system. On an individual level caregivers need to be counselled to take on a health insurance policy to guarantee availability of sustained treatment for their children and themselves in the case of this eventuality. On the other hand, there is need to counsel the women on the futility of worrying but rather to engage in positive thinking.

The mean difference in stress score was not significant with the age of the child. However, it was observed that stress was higher for caregivers of children 6-23 months. Stress reduced as age of child increased. This may be explained by the anxiety the mother experiences in the stages of care of an HIV positive child. Dorsey et al (1999) reported that HIV infected mothers reported lower levels of parenting self efficacy than mothers who were not infected. The stress observed may be due to a variety of reasons such as lack of perceived self efficacy, accessing medical services, ensuring survival and wellbeing of child and complicated drug regimen. The reduction in stress with age increase of child may be due to increased confidence and self efficacy, increased social support and network and improved coping strategies. However, stress level increased for women with children age 10-14 years. This may not be directly related to the health of the child but may be as a result of need to disclose the HIV diagnosis to the child. The older child may wonder aloud and ask questions on the reason for continuous visit to the hospital and use of medications particularly when he/she observes that other siblings who may be HIV negative are not similarly affected. In West Africa the disclosure rate of HIV status to adolescents was 28.8% (Arrive et al 2012). A study in Ghana reported a disclosure rate of 21% (Kallem et al 2011). There is little data regarding disclosure of HIV status of adolescents to them in Nigeria. Generally, disclosure by caregivers or

parents ranges from being complete, partial or not done at all. Several factors affect disclosure of HIV status by caregivers to adolescents. These factors include fear of social exclusion or stigmatisation (Waugh 2003). Our study both in the in depth interview and survey also confirms this; as generally disclosures were not made to friends or family members with very few exceptions. In the survey 53.5% did not disclose to family and 81.5% did not disclose to friends the status of their HIV positive children.

Health status of child was not related significantly with difference in mean stress score. The classification of the health status of child was as reported by the women. More precise information e.g. CD4 count, viral load and DNA PCR levels, growth monitoring records, could have provided an objective assessment of the child's health status.

The diagnosis of the child was the most stressful factor experienced by the women caregivers. Other tasks and strategies in the management of the health of the child were perceived in varying degrees of stress but no task or strategy matched or exceeded the stress brought on by the HIV diagnosis. This suggests that when caregivers are supported through the specific activities and tasks related to the care and management of a HIV positive child their ability to cope is improve

Coping Strategies

The results of this study showed that most women at the study site used acceptance coping more than other methods of coping. Acceptance is an active method of coping. Active coping consists of eight coping strategies namely: acceptance, direct action, positive reframing, religion, emotional support, instrumental support, helping others and information seeking. The qualitative and quantitative data collected is indicative of the fact that quite a number of women in this study utilize a combination of coping strategies to adjust to the stress of caring for an HIV positive child. Acceptance of the HIV diagnosis, the direct action of seeking antiretroviral treatment for their HIV positive child and the decision to adhere to antiretroviral drug therapy are some of the active coping strategies utilized by these women. Positive reframing by believing that all will be well despite the diagnosis of HIV came out clearly in some of the statements made by the women in the in-depth interview- an example *"People with HIV are even better than people with other diseases that are even more 'powerful' than HIV. The only thing is the earlier you know the better for you, because if you don't know you will be causing more*

problems in your body because by the time you know things may have gotten out of hand. So, the earlier the better." Religion played a part as well as mentioned by the women in the in-depth interview with statements such as *"I put all my hope in God", "I have been praying to God."* The other coping strategies included in the survey tool were avoidance, complain, anger and confront. Avoidant coping consists of seven coping strategies namely: distraction, escape, denial, emotional venting, out-of-control, self blame and substance use. In this study other than acceptance, anger and confrontation were coping strategies with high frequency of use across the stress factors experienced by the women. Complaining and avoidance were less utilised.

However, in the IDI one of the respondent avoidant coping strategy of denial proved maladaptive she said "*Yes I went for ANC. I was told but I did not agree. They told me but I did not agree. I said how come that such will be inside my body. Not knowing that the thing is inside my body."* she had rejected the test result and was in denial. She refused to obtain treatment for herself and for the baby during pregnancy. After delivery her baby later became sick and was admitted to the hospital. Many tests were conducted and her baby was confirmed HIV positive. A study by Chalfin et al, (2005) reported coping strategies of religion, acceptance and positive reinterpretation commonly utilised across 3 groups of caregivers raising young children with HIV infection. In a study by Baskin, Forehand and Saylor, (1986) adjustment was found to be better with the use of emotion focused coping strategies and decreased use of palliative coping methods. The current study grouped possible coping mechanisms into five mechanisms for the purpose of planning educational interventions, other researchers have considered as many as 20 possible approaches to stress (Manke and Curklis, 1998). For example, various aspects of avoidance, such as escape, drinking excessively and use of drugs have been considered separately.

The fact that most women in this study used an active accepting mode in response to these stressors may be as a result of their appraisal of the circumstances surrounding them and their forming the conclusion that other mode of coping would have no benefit or advantage over simple acceptance of their peculiar circumstances. The belief system, religion and spirituality of the caregiver may have influence on the choice of coping strategy (Phillips 2006)

The Federal and State governments and health workers need to improve the quality of services they provide to children with HIV and their caregivers by making the prevention and treatment of antiretroviral therapy as patient and caregiver friendly as possible. Provision of prompt services, information, health education, and empathetic counselling by health workers is required. Health worker – patient ratios at hospitals can be increased by employment of more health workers and increasing the number of health facilities providing ART services.

For financial factors stressors the women were more inclined to confront their problems. Though this study did not probe further to determine what specific actions caregivers undertook in confronting their financial problems. In a study Olley (1993) found that caregivers of children with sickle cell anaemia confront their financial stressors by specific actions of earning income, borrowing, obtaining financial resources from their husband or a relative. Higher stress levels in economically and educationally advantaged women indicate a need for emotional and social support. Caregiver's adjustment was found to be worse when they had fewer social supports, more marital problems, less family communication and more concurrent stress particularly financial stress (Pakenham and Bursnall 2006, Kaplan 2010, Pinquart and Teubert 2010). Richter et al 2009 found that mother's adaptation was found to be related to family and social supports. This was supported by the results of this study.

Implications for Health Promotion and Education

This study is relevant for the purpose of creating awareness of the need of caregivers of HIV positive children for health promotion and education interventions. One of the first steps to reduce the burden of caregiving and promote health among caregivers is to develop effective practices to identify those in need. Frontline health professionals who come in contact with these caregivers are in a position to recognize caregivers at risk or in need and guide them to appropriate care and resources (Lund 2014, Kakuma et al. 2011). Therefore, comprehensive intervention should focus on educating health professionals regarding the risks of caregiving and information related to health promotion as well as direct training and engagement in behaviours that can help maintain health and prevent disease. Clearly health professionals are well suited to engage caregivers in such a

dialogue. Unfortunately, evidence suggests that health professionals often fail to encourage mental health promotion among caregivers (Jackson and Cleary 1995). Significant shortcomings exist in the level of education and training available to family caregivers regarding the relationship between health and caregiving. In other climes evidence suggests that family caregivers often report feeling unprepared for their caregiving duties (Family Caregiving and Public Policy 2003). Toseland and Smith (2001) identify a variety of ways to educate and train family caregivers, including single session community workshops and forums, lecture series and discussions, support groups, psychoeducational and skill building group, family counselling, care coordination/management, and technology based interventions. While a variety of these models are currently being utilized, research literature fails to definitively identify the most effective methods of educating and training caregivers. Health professionals from a variety of disciplines often lack the education and training to appropriately identify, treat and refer women caregivers with physical and mental health needs.

Conclusion

This study was aimed at determining the stress levels, identifying stress factors and coping strategies utilised by women caregivers of HIV positive Children at Massey Street Children's Hospital, Lagos. The instrument used in the conduct of the research was a modified version of Life Event Inventory Scale and the HIV stress Scale. Twenty-two stress factors were identified and grouped into five categories: disease, hospital, child, emotional and financial stress factors.

The results of the research showed that overall level of stress was moderate. Women in the study sample experienced stress most in the disease, hospital, child and emotional factor categories. The singular disease factor stressor: the condition of child being HIV positive was the most stressful. Hospital factors stressors were six – the most stressful was admission of child to the hospital followed by accessing the hospital for treatment. The most stressful child factor out of three was the waiting to know baby's HIV status. The emotional factor causing the most stress was the thought of no free HIV drugs for the treatment of the child.

Some independent variables were found to have significant association with mean stress scores. Analysis of variance (F-test) between independent variables and mean stress showed that marital status of women was significantly associated with mean stress scores. Single women and women living with a partner had the highest mean stress scores. Educational level of women was significantly associated with mean stress scores. The higher the educational level of the women the more the mean stress score. Women with tertiary level education had higher mean stress scores and women with no education had lower mean stress scores. The occupation the women engaged in was significantly related with mean stress scores. Professional women and women with no jobs experienced higher levels of stress than women in other occupations.

In coping with the stress experienced, generally the women were found to use acceptance as a coping strategy. Few women complained: they were more likely to express anger or confront the situation.

The moderate level of stress among the women in the study sample could indicate that women in the South western area of Nigeria caring for children who are HIV positive are resilient and have adjusted to the unique stressors of caring for children with HIV. More adaptational interventions which generate appropriate patterns of coping for specific stressors need to be provided formally in all medical institutions where caregivers of children being treated for HIV can access them.

Possible interventions aimed at increasing the resources for these women with HIV positive could be explored by other studies. This study was an all women sample future studies could focus on stress factors and coping strategies of caregivers (male and female) of HIV positive children.

Recommendations

The findings in this study indicate the need for the following:

1. Development of a standardized national HIV stress assessment tool to measure HIV related stress and to identify caregivers requiring intervention.
2. Efforts must be made to educate and train the health care workforce to meet the physical and mental health needs of caregivers. Such education and training opportunities should be available to those currently training in the health professions, as well as those already in the workforce, through continuing professional education opportunities.
3. There is need for improvement of quality of services obtainable at the hospitals by caregivers. Additional services that could be offered are links to psychological interventions, social services that offer financial support and skills acquisition training for the unemployed and unskilled thereby making it possible for the women to be better economically empowered. Economic empowerment results in a better standard of living.
4. Concerted government efforts are required to ensure commodity security in our public health system to ensure sustainability of free antiretroviral drug supply. The National Health Insurance Scheme should be strengthened and made accessible to all. This will go a long way in allaying the fears and anxiety of the women about the future of their children.
5. Support to improve caregiver's ability to cope through preparatory training on specific activities and tasks related to care and management of a HIV positive child. Referrals to health education and emotional support services that teach effective coping strategies like behavioural modification, recreation therapy, art therapy, mind and body relaxation techniques are required. There is need for long term capacity building for family carers.
6. Support for the disclosure process of HIV positive status of child to older children age 10 – 14 by the caregivers through counselling and communication skills training will further reduce the stress burden experienced by the caregivers resulting from secrecy and non disclosure to the child.
7. Religious institutions and leaders have a key role to play in support of caregivers and families of HIV positive children. The findings of this study is suggestive that non christian religions need to create awareness and open communication

channels with adherents of their religion on support available to individuals and families affected by HIV.

8. Male involvement in the role of caregivers of HIV positive children will reduce the burden of care on women caregivers which arise from the multitude of caregiving tasks which they grapple with alone.
9. The development of community based home care programs to include home visits, in-home assistance to monitor health status, provide physical, emotional, financial support, medication, food and supplies delivery, counseling and education regarding proper care.

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APPENDICES

APPENDIX I

INDEPTH INTERVIEW GUIDE

STRESS FACTORS AND COPING STRATEGIES OF WOMEN WITH HIV POSITIVE CHILDREN IN MASSEY STREET CHILDREN'S HOSPITAL, LAGOS

INTERVIEWEES: MOTHERS OF HIV POSITIVE CHILDREN

I. PURPOSE:

To learn about the stress factors and coping strategies of mothers of positive children.

II. INTRODUCTION:

You are welcome. Thank you for your audience and time. My name is _____ and I am working on a Master's degree in Public Health research Project titled Stress Factors and Coping Strategies of Women with HIV positive Children.

During our discussion we'll be talking about several issues. I'd like to get your opinions during the discussion. There is no right or wrong answer and I'd like to hear all your ideas.

Let's begin introductions –may I know your name, what you do and anything else you'd like to share about yourself, i.e., hobbies, what work you do

Q/N	MAIN QUESTION	PROBE QUESTION
1	What is your understanding of HIV and how has your understanding changed • Your previous knowledge of HIV/AIDS • Your present knowledge of HIV/AIDS	How did you get this knowledge • From radio, TV, newspaper, information leaflets/booklets • From family members, friends, neighbours, colleagues at work, church and mosque • Information obtained during hospital visit/doctor consultation [Probe for knowledge of ways of transmission, knowledge of prevention of infection. Knowledge of mother to child

		transmission of HIV and its prevention
2 [a]	Under what circumstances did you get to know that your child was HIV positive?	
[b]	Do you know how your child got infected?	
[c]	How do you think the infection could have been prevented?	
[d]	How old is your infected child.	
[e]	Do you have other children? Are they also infected?	
3. [a]	What were your feelings/emotions at the point of discovery of the infection? For each feeling/emotion can you describe in detail how you actually felt	
[b]	Do you still have the same feelings and emotions that you had then	
4	What decisions /conclusions did you make at the point of discovery of the HIV status of your child?	
	For each decision/conclusion that you made can you list the factors that influenced each particular decision/conclusion.	Probe for fears, anxiety, spouse, and other family members influence
5.	As mothers taking care of children who are HIV positive you are probably going through some experiences that bothers you and that you are concerned about. What are these experiences?	

COPING STRATEGIES

6. What are the problems/challenges that you have in taking care of your child/children who are HIV +ve? [probe for treatment, economic, required long term specialized child care]

7. How do you cope with taking care of child/children who are HIV +ve [probe for coping strategies. For each one listed probe for how it helps them cope]
8. Who do you turn to for support?(For every person mentioned probe for reason why).
9. Have you been able to discuss with family and friends the health condition of the child? And what was the outcome of the disclosure.
10. What do you think will help you to better adjust to the required demands of taking care of your child?

We've been talking today about the stress factors associated with women taking care of HIV positive children and how they are able to manage and adjust to this situation. Let's summarize key points. Is there anything else you'd like to share with us? I thank you all for agreeing to take part in the discussion.

ATONA IWADI-IJINLE FUN IFOROWEROPO

AWON OKUNFA LAALA ATI AKOJOPO AWON ONA IFARADA TIAWON OBINRIN TI OMO WON NI ARUN-KOGBOOGUN NI ILE-IWOSAN OMODE TI MASSEY NI IPINLE EKO

Awon oluforowa-lenuwo: Awon momo ti awon omo won ni arun-kogboogun.

I. Idi iwadi:

Latimo nipa awon okunfa laala ati akojopo awon ona ifarada ti awon momo ti omo won ni

NOOMBA	AWON IBEERE NI TARATARA	AWON IBEERE FUN IWADI NI NHISE
1	Kinni awon nkan ti e mo nipa arun-kogboogun ati bawo ni oye yin nipa re se kun rere: • Kinni imo yin lati ehin wa nipa arun-kogboogun? • Kinni imo yin bayi nipa arun-kogboogun?	Bawo ni ese ni oye yi: Lati ori Redio, Manomano/ Telifisan, iwe iroyin ojojumo, awon iwe-iroyin ti onilewo. • Lati owo awon ebi mi, awon ore, alabagbe, awon alabasisepo, olubasinpo ni Soosi/Mosalasi. • Awon nkan ti agbo nigba ti a lo ri Ile-iwosan/lo ri Dokita [Sewadi fun awon ona ti won fi mo ngbo, ni imo lati dena nipa kiko arun-kogboogun yi. Imo momo si ki omo ko ko arun-kogboogun ati ona idena re.
2 [a] [b] [d]	Nipa ona wo gan ni ese mo pe omo yin ni arun-kogboogun? Nje e mo bi omo yin se ko arun yi? Kinni ona ti ero pe o ye ki won ti fi dena kiko arun-kogboogun yi se yin?	

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[e]	Omo yin toni arun yi tito omo odun melo bayi?	
[e]	Nje eni awon omo miran? Nje won ni arun yi kan naa?	
3. [a]	Bawo gan ni o se seyin si/gbeyin lokan soke si ni ibi ti eti kokogbo nipa kiko arun-kogboogun yi? Si bi o se seyin si/gbeyin lokan soke si ni e le sapejuwe re ni ekun-rere bi o se ri ni ara yin gan.	
[b]	Nje o si nse yin bi ti ibere/gbeyin lokan soke bee bi eyi ti e ni ni ibere?	
4	Kinni awon ipinnu/erongba yin ti e se ni igba ati ni ibi ti eti mo pe omo yin ni ipenija arun-kogboogun yi?	
	Lori ipinnu/erongba kookan ti ese, nje e le so awon okunfa okookan fun awon ipinnu/erongba naa.	Sewadi fun awon ifoya/iberu, iporuru-okan ti oko mi ati awon ara ebi mi yoku.
5.	Bi awon momo se ntoju awon omo ti won lugbadi arun-kogboogun ti e si nla awon ifarada ipenija kan to kanyin gbongbon koja. Kinni awon ipenija ifarada yi?	

Ii. Ifaara:

E kaabo fun iforowero yi. A o dupe ifarabale yin lati kopa ati fun asiko yin pelu. Oruko mi ni _____. Atipe mo nsise lori iwadi igboye-keji ni Ilera-gbogbogbo, ti afojusun yi si da lori awon okunfa laala ati akojopo awon ona ifarada awon omo ti awon omo won ni arun-kogboogun.

Nigba iforowani-lenuwo yi, a o ma soro lori awon nkan toromo afojusun iwadi yi. A o si fe lati gba awon ero yin lekunrere nigba iforowere naa. Ti ko si ni si idahun ti ko tona atipe a o si gba gbogbo ero yin ni ekun rere.

E je ka bere ifini-moni ni san an – nje mo le mo oruko yin bi, nkan ti e nse ati awon nkankan ti e ki fe ki eni kankan mo nipa yin, bi apeere, nkan ti eferan lati ma se, iru ise ti e nse ati bee bee lo.

AKOJOPO AWON ONA IFARADA

11. Kinni awon ipenija/ifooro-okan ti eni nipa itoju ni sise fun omo/awon omo yin ti wonni arun-kogboogun yi? [Sewadi fun itoju, inawo, pipesi iru itoju gan ti omo naa nilo].
12. Bawo ni e se nfarada itoju ni si se fun omo/awon omo ti wonni arun-kogboogun. [Sewadi fun akojopo awon ona ifarada, lori okookan awon ona yi ti wonsolati farada].
13. Tani e ma nwoju fun iranlowo? (Fun eni kookan ti won ba daruko, se iwadi fun idi naa)
14. Nje eti ni ajosopo pelu ebi ati awon ore yin nipa ippo ilera omo yin yi bi? Atipe kinni abajade ifitoni-leti yi?
15. Kinni e ro pe o le ran yin lowo lati tun sawari awon ona tose gbogi fun agbende nipa sisetoju pipe fun omo yin yi?

A ti nforojomitoro oro nipa awon okunfa toromo awon momo fun itoju awon omo won toni arun-kogboogun ati awon ona ti won fi nfaradaa ati atun-gbaramun fun itoju ni asiko naa. Ki a se akojo awon koko ero wonyi papo. Nje esi tun ni nkan miran ti e ko ti so, sugbon ti e si fe so funwa bi? Ti koba si. Mo dupe pupo lowo gbogbo yin lapapo fun kikopa yin ninu iforowaro yi.

APPENDIX II

QUESTIONNAIRE

STRESS FACTORS AND COPING STRATEGIES OF WOMEN WITH HIV POSITIVE CHILDREN

DEPARTMENT OF HEALTH PROMOTION AND EDUCATION

FACULTY OF PUBLIC HEALTH

UNIVERSITY OF IBADAN

My name is Olukemi Sekoni and I am a Master's in Public Health degree research student in the Department of Health Promotion and Education, Faculty of Public Health, University of Ibadan. The purpose of this questionnaire is to identify some of the stress factors impacting on the lives of women with HIV positive children and how they attempt to cope with them. This is for research purpose only and therefore there is no wrong answer. Because names are not included anonymity is guaranteed and all response will be treated confidentially. Therefore please give complete answers and to the best of your knowledge.

SECTION A

Please fill in the appropriate response in the space provided or circle the relevant response

1. Mother's age as at last birthday……..
A. Less than 20 B. 20 – 30 C. 31 – 40 D. 41 – 50 E. Above 50

2. Marital status
A. Living with partner B. Living with husband C. Separated from husband
D. Widowed E. Divorced F. Single

3. Religion
A. Christianity B. Moslem C. Traditional Religion D. Other [Specify]_____

4. Highest Educational level
A. None B. Quaranic C. Primary D. Secondary E. Tertiary

5. Occupation [means of livelihood]
A. Professional [specify e.g Teacher, Nurse etc] _____ B. Trader C. Skilled [Specify e.g fashion designer, hairdresser, caterer etc] _____ D. Non skilled_____ E. No job

6. What is your monthly income?
A. 5,000 – 10,000 B.11, 000 – 30,000 C. 31,000 – 50,000 D. 51,000 – 100,000 E greater than 100,000

7. Which part of town is your home located.

8. How long does it take you to get to the hospital from your home?
A. Less than 10 min B.10 – 30min C. 31 min – 1 hr D. 1 – 2 hrs E. over 2 hrs

9. How many years since child tested positive?
A. Less than 1 year B. 1 - 2 years C. 3 – 5 years D. more than 5 years E. More than 10 years

10. Current age of child
A. 6 – 23 months B. 2 – 3 years C. 4 – 5 years D. 6 – 10years E. 11 – 14 years

11. How would you assess/describe the general state of health and well being of your child?
A. Good B. Fair C. Poor

12. Number of children in family
A. 1 – 2 B. 3 – 5 C. 6 and more

13. Number other children also HIV positive
A. 1 B. 2. C. None D. All

SECTION B

STRESS FACTORS

Below is a list of experiences and challenges you do encounter or are likely to encounter as a woman with a HIV +ve child. Indicate with a check (√) to what extent these challenges and experiences stress you. Insert your (√) at the appropriate column.

Key

Very stressful – The situation bothers you a lot
It annoys you a lot
You think about it most of the time

Moderately stressful – The situation worries you sometimes
It makes you give a serious thought about how to cope with it

Not stressful - You have become used to the situation OR it does not bother you at all

Not Applicable - The situation does not occur for you

Don't know - You are uncertain whether the situation is stressful or not

	STRESSORS	Very Stressful	Moderately Stressful	Not stressful at all	Don't Know	Not Applicable
	DISEASE FACTORS					
14	Child being HIV positive					
	HOSPITAL FACTORS					
15	Admission of child to hospital					
16	Accessing the hospital for treatment for the child					
17	Keeping hospital appointments for treatment					
18	Attitude of hospital staff					
19	Waiting for doctors/hospital staff					
20	Handling stigmatization from health care workers					
	CHILD FACTORS					
21	Waiting to know baby's HIV status					
22	Deciding best feeding option for the child					
23	Adhering to HIV drug regimen for treatment of the child					
	EMOTIONAL FACTORS					
24	Disclosure of HIV status of child to family					
25	Disclosure of HIV status of child to friends					
26	Handling stigmatization from family					
27	Handling stigmatization from friends					
28	Thought of a life of continuous HIV drug use for child					
29	Thought of possible lack of free HIV drugs to use for child					
	FINANCIAL FACTORS					
30	Cost of health care for the					

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	child					
31	Cost of good food/nutrition					
32	Cost of milk formula for alternative feeding option					
33	No means of livelihood/ no job or trade to do to provide income to care for the child					
34	Transportation cost for clinic appointments					
35	Lack of home or shelter					
36	Other financial problems [specify in space provided below] _____ _____					

~~36 Other financial problems[specify in space provided below]~~
~~_____~~
~~_____~~

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SECTION C

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COPING STRATEGIES

For each stress factors mentioned in Section B indicate which coping method you usually use or will use to deal with the situation. You are required to choose between acceptance, Complain, Anger, Avoid, Confront, Not applicable and I don't know. Indicate with a check (√) at the appropriate column.

KEY

Acceptance – accept the situation as it is, that there is nothing you can do about it.

Complain - You tell friends, family and others about the problems often.

Anger - You become easily annoyed over the situation.

You abuse others or even break or damage things.

Avoid - You look for other ways out of the situation e.g. if you are being stigmatized you stay away from such people.

Confront - You try to solve the problem directly.

Not applicable – Situation does not occur for you.

I don't know - You are not certain how you will respond.

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	STRESSORS	COPING STRATEGIES						
		Acceptance	Complain	Anger	Avoid	Confront	Don't Know	Not Applicable
	DISEASE FACTORS							
37	Child being HIV positive							
	HOSPITAL FACTORS							
38	Admission of child to hospital							
39	Accessing the hospital for treatment for the child							
40	Keeping hospital appointments for treatment							
41	Attitude of hospital staff							
42	Waiting for doctors/hospital staff							
43	Handling stigmatization from health care workers							
	CHILD FACTORS							
44	Waiting to know baby's HIV status							
45	Deciding best feeding option for the child							
46	Adhering to HIV drug regimen for treatment of the child							
	EMOTIONAL FACTORS							
47	Disclosure of HIV status to family							
48	Disclosure of HIV status to friends							
49	Handling stigmatization from family							
50	Handling stigmatization from friends							
51	Thought of a life of continuous HIV drug use for the child							
52	Thought of possible lack of free HIV drugs to use for the child							

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	~~FINANCIAL FACTORS~~							
~~53~~	~~Cost of health care for self and child~~							
~~54~~	~~Cost of good food/ nutrition~~							
~~55~~	~~Cost of milk formula for alternative feeding option~~							
~~56~~	~~No means of livelihood/ no job or trade to do to provide income to care for the child~~							
~~57~~	~~Transportation cost for clinic appointment~~							
~~58~~	~~Other financial problems[specify in space below]~~ _____ _____							
		COPING STRATEGIES						
		Acceptance	**Complain**	**Anger**	**Avoid**	**Confront**	**Don't Know**	**Not Applicable**
	DISEASE FACTORS							
37	Child being HIV positive							
	HOSPITAL FACTORS							
38	Admission of child to hospital							
39	Accessing the hospital for treatment for the child							
40	Keeping hospital appointments for treatment							

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41	Attitude of hospital staff							
42	Waiting for doctors/hospital staff							
43	Handling stigmatization from health care workers							
	CHILD FACTORS							
44	Waiting to know baby's HIV status							
45	Deciding best feeding option for the child							
46	Adhering to HIV drug regimen for treatment of the child							
	EMOTIONAL FACTORS							
47	Disclosure of HIV status to family							
48	Disclosure of HIV status to friends							
49	Handling stigmatization from family							
50	Handling stigmatization from friends							
51	Thought of a life of continuous HIV drug use for the child							
52	Thought of possible lack of free HIV drugs to use for the child							
	FINANCIAL FACTORS							
53	Cost of health care for self and child							
54	Cost of good food/ nutrition							
55	Cost of milk formula for alternative feeding option							
56	No means of livelihood/ no job or trade to do to provide income to care for the child							
57	Transportation cost for clinic							

	appointment							
58	Other financial problems[specify in space below] _____ _____							

EKA IGBEGA ATI EKO IMO ILERA TI EKUN ILERA GBOGBOGBO EDA NI FASITI ILU IBADAN

IWE-IBEERE LORI AWON ONA TO MA NMUN LAALAA SISE WA ATI AWON ONA ABAYO TI AWON OBIRIN TI OMO WON NI ARUN-KOGBOOGUN

Oruko mi ni Olukemi Sekoni, mo je akeko ni imo ilera ti gbogbogbo eda, gegebi akeko oluwadi ijinle lati Eka igbega ati eko imo ilera ti Ekun ilera gbogbogbo eda ni Fasiti ilu Ibadan. Erongba awon ibeere nipa iwadi yi, ni lati mo die ninu awon isoro ti awon obirin ti omo won ni arun-kogboogun nla koja ati bi wonse nfarada. Eyi si wa fun iwadi nikan, nitori naa, si mo daju pe ko si si idahun kankan to lodi si otiti iwadi yi. Fun idi eyi, a ko fe ki e da oruko yin ni ona kankan ninu idahun awon ibeere isale gbogbo yi, ti a si nfi dayin loju pe gbogbo ero yin ti e ba fuunwa ni yio si wa ni ida konko. Fun idi eyi, a si nro yin pe ki e je ki awon idahun yin wa ni ekun rere si imo yin lori awon ibeere naa.

IPIN A

Jowo, fi idahun to to abi ikamonra si okokan awon ibeere to wa ni isale wonyi.

1. Ojo ori momo omo yi ni ojo-ibi to esetan/rekoja?_____

a) Kere si Ogun-dun b) Laarin Ogun-odun si Ogbon-odun d) Laarin Ogbon-odun lekan si Ogoji-odun e) Laarin Ogoji-odun lekan si Aadota-odun e) Ju Aadota odun lo

2. Ibagbepo si eda?

a) Ngbepapo pelu ore b) Ngbe pelu oko d) Ti tuka lodo oko e) Je opo e) Ti kora sile f) Je apon

3. Esin?

a) Omo lehin Kristi b) Musulumi d) Elesin abalaye e) Omiran (se alaye)_____

4. Ile-iwe togaju ti e lo?

a) Nkolo ile-iwe b) Ile-Keu d) Ile-iwe Alakobere e) Ile-iwe Girama e) Ile-iwe Giga

5. Ise ti e nse (nkan ti e nse lati jeun)?

a) Ise ti e yan laayo (se apeere, bi Oluko, Noosi ati bee bee lo_____b) Onisowo d) Onise owo (se apeere, bi Aranso, Aserun-loso, Oluta-onje ati bee bee lo)_____ e) Kokose_____ e) Nkosise_____

6. Oto bi eelo/owo oya re ti e ma nri ni osu-kan?

a) Edegbeta si Egbarun b) Edegbefa si Egbedogun d) Edegbedogun-le-legberun kan si Egberun-laadota e) Egberun-laadota-le-legberun kan si Egberun-lona-ogorun

7. Ni ogangan ibo ni inu Ilu ni ibugbe yin wa?
8. Bawo ni ibugbe yin yi se jina si ile iwosan si?

a) Kere si irin iseju mewa b) Irin iseju mewa si ogbon iseju d) Irin mokanlelogbon si wakati kan e) Irin wakati kan si wakati meji e) Ọ ju irin wakati meji lo.

9. O ti to odun melo bayi ti ati se ayewo fun omo na pe o ni arun yi lara?

a) Kere si odun kan b) Laarin odun kan si odun meji d) Odun meta si odun marun e) Ti ju odun marun lo e) Ti ju odun mewa lo

10. Ojo ori omo naa to bayi?

a) Osu mefa si osu metalelogun b) Odun meji si odun meta d) Odun mefa si odun mewa e) Odun mokanla si odun merinla

11. Bawo ni e se le salaye iru ipo ti ilera omo yin ye wa ni akoko yi?

a) O dara gidi b) O san die c) O buru jai

12. Awon omo ninu ebi yin to melo gan?

a) Omo kan si meji b) Omo meta si marun d) Omo ju mefa lo

13. Iye awon omo to ni arun-ko-gboogun yi to?

a) Omo kan b) Omo meji d) Ko si omo kankan e) Gbogbo awon omo ni

IPIN B

AWON OKUNFA IDAAMU

Awon nkan wonyi je oniruru iriri ati awon ipenija to le je idojuko abi to se se idojuko awon momo pelu omo to ni arun HIV. Fi eyi han gege bi awon eyi se damun ati iriri ti ona yin. Fi maaki (∨) nipa mun eyi tio ye ju ni isale yi.

Kokoro/Atoka

Ni idaamu nla - Ipo naa mun ifooro wa pupo
Mun inu bibi wa gidigidi
Nro nipa re ni opo igba

Ni idamun niwon ba - Igba yi nmun idaamun ni awon igba kan
Eyi ma nmun ipooro okan wa si bi wonse ma le fara da

Ko mu idaamu kankan wa rara - Eyi ti ba ara wa mun abi ko tu irun kankan ni lara wa.

Ko ni nkan se - igba yi ko sele fun iwo.

Nkomo - Eko ni idaniloju boya ipo yi ni laalaa ninu abi ko ni.

	Awon orisirisi okunfa Idaamun/Laala	Ni idaamu nla	Ni idamun niwon ba	Ko mu idaamu kankan wa	Ko ni nkan se	Nkomo
	Awon okunfa idaamun nipa arun-kogboogun					
14	Omo to ni arun-kogboogun					
	Awon okunfa idaamun ni ile-iwosan					
15	Dida omo duro/gunle fun itoju ni ile-iwosan					
16	Lilo si ile-iwosan fun itoju omo naa					
17	Pipa ojo itoju fifuni ni itoju ni ile-iwosan mo					
18	Ihuwasi awon osise ile-iwosan/eleto-ilera					
19	Diduro de awon Dokita/Eleto-ilera					
20	Igbmora ideyesi/ipegan lati odo awon osise eleto-ilera					
	Awon okunfa idaamun lati odo omo					
21	Diduro omo latimo ipo ilera arun-kogboogun re					
22	Sise odiwon/itosona nkan jije to dara julo toye fun omo naa					
23	Ipamo ilana lilo oogun fun isetoju arun-kogboogun ti omo					
	Awon okunfa idaamun nipa ero-okan					
24	Siso ipo idamo ilera kokoro arun-kogboogun ti omo fun ebi re					
25	Siso ipo idamo ilera kokoro arun-kogboogun ti omo fun awon ore re					
26	Sise igbamora itiju/abuko si nini arun-kogboogun lati odo awon ebi					
27	Sise igbamora itiju/abuko si nini arun-kogboogun lati odo awon ore					

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28	Ero nipa lilo oogun arun-kogboogun fun omo titi aye					
29	Ero nipa pe anfani riri oogun ofe lo fun omo na ni orekore lee dase					
	Awon okunfa idaamun nipa inanwo					
30	Iye owo gbigba itoju eto ilera fun omo naa					
31	Iye owo sise eto fun ounje daradara/ti yio se ara-loore fun omo naa					
32	Iye owo sise fun pipese miliki mimun miran yato si jije awon ounje miran					
33	Ko si ise sise fun ounje oojo pipese/ko si ise tabi owo lati se ipese itoju fun omo					
34	Inawo fun oko wiwo lati lo fun awon asiko gbigba itoju ni ile-iwosan					
35	Aini ile abi ibugbe					
36	Awon isoro miran nipa inawo [se alaye re si aye ti apese si isale yi] _____ _____					

IPIN D

AWON ONA TI WONFI NKOJU IPENIJA

Fun okokan awon orisi okunfa idaamun/laala ti a ko si isale yi, se alaye ona ti e ma nlo abi ti e le lo lati dojuko ipenija idaamun yi. A si royin lati mun okan ninu "Mogba nkan ti ode bami", "Sisaroye ntodebami", "Inu-bibi", "Yiyerafun/Madasi", "Ma dojuko", "Kojemo" ati "Nkomo". Se idamo nipa mimaaki iho to wa ni iwaju okookan ni isale yi.

Kokoro/Atoka

Mo gba nkan ti ode bami: Mo gba bi nkan gbogbo ti ri, ti ko si si nkan ti mo le se.

Sisaroye ntodebami: Siso fun ore, ebi ati awon miran nipa gbogbo ipenija mi.

Inu-bibi: Inu ma nbi mi nipa nkan to nsele.

Yiyerafuun/Madasi: Wiwa awon ona abajade miran kuro ninu ipa yi bi ti won ba da eye si mi/ya mi si oto, mo le kuro ni odo iru awon eniyan be.

Ma dojuko: Nma wa ona abayo/ojutu si isoro ni sungba ni.

Kojemo: Igba naa ko sele nitori ti emi.

Nkomo: Ko damiloju bi ma se dahun.

	Awon orisirisi okunfa Idaamun/Laala	Inu-bibi	Yiyerafuun/ Madasi	Ma dojuko	Kojemo	Nkomo
	Awon okunfa idaamun nipa arun-kogboogun					
37	Omo to ni arun-kogboogun					
	Awon okunfa idaamun ni ile-iwosan					
38	Dida omo duro/gunle fun itoju ni ile-iwosan					
39	Lilo si ile-iwosan fun itoju omo naa					
40	Pipa ojo itoju fifuni ni itoju ni ile-iwosan mo					

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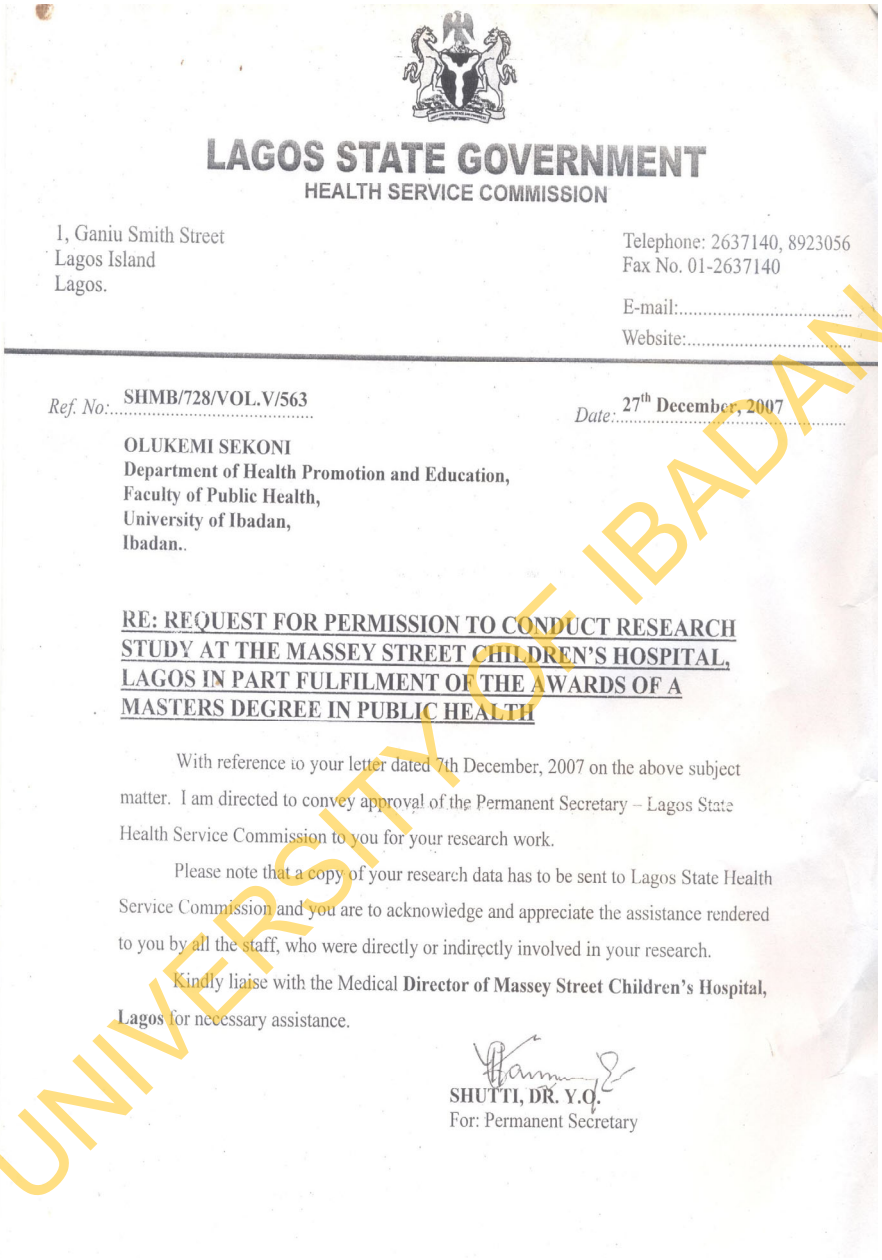
41	Ihuwasi awon osise ile-iwosan/eleto-ilera					
42	Diduro de awon Dokita/Eleto-ilera					
43	Igbmora ideyesi/ipegan lati odo awon osise eleto-ilera					
	Awon okunfa idaamun lati odo omo					
44	Diduro omo latimo ipo ilera arun-kogboogun re					
45	Sise odiwon/itosona nkan jije to dara julo toye fun omo naa					
46	Ipamo ilana lilo oogun fun isetoju arun-kogboogun ti omo					
	Awon okunfa idaamun nipa ero-okan					
47	Siso ipo idamo ilera kokoro arun-kogboogun ti omo fun ebi re					
48	Siso ipo idamo ilera kokoro arun-kogboogun ti omo fun awon ore re					
49	Sise igbamora itiju/abuko si nini arun-kogboogun lati odo awon ebi					
50	Sise igbamora itiju/abuko si nini arun-kogboogun lati odo awon ore					
51	Ero nipa lilo oogun arun-kogboogun fun omo titi aye					

52	Ero nipa pe anfani riri oogun ofe lo fun omo naa ni orekore lee mo si					
	Awon okunfa idaamun nipa inanwo					
53	Iye owo gbigba itoju eto ilera fun omo naa					
54	Iye owo sise eto fun ounje daradara/ti yio se ara-loore fun omo naa					
55	Iye owo sise fun pipese miliki mimun miran yato si jije awon ounje miran					
56	Ko si ise sise fun ounje oojo pipese/ko si ise tabi owo lati se ipese itoju fun omo					
57	Inawo fun oko wiwo lati lo fun awon asiko gbigba itoju ni ile-iwosan					
58	Aini ile abi ibugbe					
59	Awon isoro miran nipa inawo [se alaye re si aye ti apese si isale yi] _____ _____ _____ _____					

APPENDIX III

ETHICAL APPROVAL LETTER



LAGOS STATE GOVERNMENT
HEALTH SERVICE COMMISSION

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Ref. No: SHMB/728/VOL.V/563

Date: 27th December, 2007

OLUKEMI SEKONI
Department of Health Promotion and Education,
Faculty of Public Health,
University of Ibadan,
Ibadan..

RE: REQUEST FOR PERMISSION TO CONDUCT RESEARCH STUDY AT THE MASSEY STREET CHILDREN'S HOSPITAL, LAGOS IN PART FULFILMENT OF THE AWARDS OF A MASTERS DEGREE IN PUBLIC HEALTH

With reference to your letter dated 7th December, 2007 on the above subject matter. I am directed to convey approval of the Permanent Secretary – Lagos State Health Service Commission to you for your research work.

Please note that a copy of your research data has to be sent to Lagos State Health Service Commission and you are to acknowledge and appreciate the assistance rendered to you by all the staff, who were directly or indirectly involved in your research.

Kindly liaise with the Medical **Director of Massey Street Children's Hospital, Lagos** for necessary assistance.

SHUTTI, DR. Y.O.
For: Permanent Secretary