

**PHYSICAL DISABILITIES AMONG ADULTS WITH
HIV/AIDS BEING MANAGED BY THE MAKENI HOME-
BASED CARERS IN LUSAKA, ZAMBIA.**

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A mini theses submitted in partial fulfillment of the requirement for the degree of Master of Science in Physiotherapy in the Faculty of Community and Health Sciences in the Department of Physiotherapy at the University of Western Cape

Date:

November 2004

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ABSTRACT

The human immuno deficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) is now being considered as a chronic disease. As people live longer the possibility of physical disability increases. A cross sectional survey using questionnaires was utilized to investigate the nature of physical disability among adults with HIV/AIDS being managed by the Makeni home-based care givers in Lusaka, Zambia. A convenient sample of 209 adults with HIV/AIDS participated in the survey. The statistical package for social sciences (SPSS) was used to analyze the data. The study revealed that 51.7% of the participants experienced mild impairments in the legs whilst 16.3% encountered moderate impairments of the arms. The participants presented with the least activity limitations and participation restrictions in self care activities; the mean was .2033 on a scale of 0-3. Most of the participants encountered more activity limitations and participation restriction in life activities. Thirty seven percent and 25.9% of the participants presented with moderate difficulty in household chores and in performing previous roles respectively.

This study demonstrated that mostly mild impairments and mild to moderate activity limitations and participation restrictions exist among people living with HIV/AIDS in the Makeni home-based care programme in Zambia. Therefore, physiotherapists and other health professionals will have to be more involved in the community home-based programs that are suited for people living with HIV/AIDS so that they are also provided with clinical assessments and rehabilitation services.

DECLARATION

I hereby declare that “Physical disability among adults with HIV/AIDS being managed by the Makeni home-based care givers in Lusaka, Zambia” is my own work, and that I have not submitted or any part of it for a degree at any other university. All the sources I have used or quoted have been indicated by means of complete references.

Mumba Mumba

March 2005



ACKNOWLEDGEMENTS

First and foremost, I want to thank God for his guidance through out this venture.

My heartfelt appreciation goes to Mrs. Anthea Rhoda whose consistent support guided me through out this undertaking. Thank you for your patience and persistence.

Secondly my sincerest gratitude goes to my husband Musonda who believed in me and encouraged me wholeheartedly. I further extend my warmest thanks to our daughter Mulenga who was so understanding when mama sat for long hours writing. Thanks to my dear sister Chiseke for her support when I needed it the most.



Sincere appreciation goes to Mr. Victor Heh for his expertise and assistance with the statistical analysis.

I extend my thanks to Dr Michael O' Dell for his assistance with the literature.

Thanks to the Director of the Community Home-Based Care of the Archdioceses of Lusaka and the Makeni Home Based Care supporting staff.


Last but not the least I extend my gratitude to the staff and colleagues in the department of Physiotherapy at the University of Western Cape.

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LIST OF ABBREVIATIONS

ADLS: Activities of Daily Living.

AIDS: (Acquired immune deficiency virus syndrome), a deficiency of cellular immunity induced by infection with the human immunodeficiency virus and characterized by opportunistic infections.

CNS: Central Nervous System.

DNA: Dioxy Ribonucleic Acid



CDC: Center for Disease Control.

CHBC: Community Home-Based Care.

HIV: (The human immunodeficiency virus). The virus that causes AIDS (Stedman's, 1995).

I-ADLS: Instrumental Activities of Daily Living

ICF: International Classification of Function, Disability and Health.

NIAID: National Institute of Allergy and Infectious Diseases.

PLWHA: People Living with HIV/AIDS.

PNS: Peripheral Nervous System.

RNA: Ribo Nucleic Acid.

UNAIDS: The Joint United Nation's Programme on HIV/AIDS.

WHODAS: World Health Organisation Disability Assessment Schedule.

WHO: The World Health Organization.



CHAPTER 1

INTRODUCTION

1.0 INTRODUCTION

Chapter one provides the general background of the study, followed by the research question, the aim of the study, the objectives, the significance of the study, definition of terms and summary of the chapter.



1.1 BACKGROUND

The Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (HIV/AIDS) now entering its third decade, is recognized as one of the world's most serious public health problems (UNAIDS/WHO 2002). The global impact of this HIV/AIDS epidemic is undeniable. UNAIDS/WHO (2002) estimated that 42 million people world wide were living with HIV/AIDS at the end of 2001 and that the worst affected region with the epidemic is Sub-Saharan Africa with 29.4 million adults and children affected. Zambia, a country in Southern Africa has not been spared by this epidemic; with a population of 10.6 million, 21.5% of the adult population between 15-49 years was living with the HIV/AIDS infection at the end of 2001 (UNAIDS/WHO, 2002).

HIV/AIDS is a disease with progressive and debilitating effects (Lubeck and Fries, 1992). It is known to cause medical complications, which affect the respiratory, cardiac,

neurological, and other organ systems (Galantino, 1992; De Vita, 1994). Notable complications in the central nervous system are meningitis, encephalitis, brain and spinal cord tumors, stroke, and AIDS dementia complex (NIAD, 1994). Peripheral nervous system complications include neuropathies, sensory deficits, distal muscle weakness, diminished position and vibratory sense and problems with urination in cauda equina infections (Gabuzda and Hirsh, 1987; Lange et al., 1988; Levy and Berger, 1991). Silwa and Smith (1991) indicated that complications in the central nervous system can lead to significant functional impairments.

People living with HIV/AIDS are therefore, increasingly being recognized as constituents of the disabled community as their physical functioning is being adversely affected by the opportunistic infections, which ultimately results in disability (Sardi, 2003). Butler (1994) further indicated that due to the escalating pandemic in developing countries HIV/AIDS will soon become the most prevalent disabling condition in the world.

Developing and developed countries have universal guidelines of managing HIV/AIDS. Postnote (2003) reported that preventive strategies which include sexual health education, condom use, treatment of STIs and prevention of mother to child transmission are being emphasized. Other initiatives involve the reduction of the HIV viral load by using antiretroviral drugs (Bodiang, 2001). WHO/UNAIDS (2000) also recommended a comprehensive care package that ideally includes voluntary counseling and testing, social and psychological support as well as home-based care. Unfortunately, most people in developing countries have no access to these proven preventive interventions (The Global HIV Prevention Working Group, 2003). Furthermore, due to the financial constraints of

most developing countries, antiretroviral medications are out of reach for many (Bodiang, 2001).

Zambia has adopted measures of managing HIV/AIDS, which includes home-based care. Home-based care or community home-based care is the “provision of health services in the home or in the community by formal or informal care givers in order to promote, restore and maximize a person’s level of comfort and function, which include care towards a dignified death” (WHO, 2002).

In Zambia, community home based care provides varied support services to people living with HIV/AIDS that addresses their nutritional, medical, psychological, social, and spiritual needs (Panos, 1996). People living with HIV/AIDS (PLWHA) could present with a host of opportunistic infections by the time they are in the home-based care programme. At this stage they are usually in need of medical, nutritional, and psychosocial support services. The services are provided by trained care givers who live in the same communities as those living with HIV/AIDS. The care givers are trained in basic counseling skills, nursing skills and practical advice about nutrition, hygiene as well as preventive health care (Outlook, 2000). When required, the care givers act as liaison between PLWHA and health care centers. The community home-based care programme has no available information on the physical disabilities that could occur in PLWHA nor are the care givers equipped with basic rehabilitation skills that could address these disabilities.

1.2 RESEARCH QUESTION

What is the nature of physical disability among HIV/AIDS adults managed by the Makeni home-based care givers in Lusaka, Zambia?

1.3 AIM OF THE STUDY

The aim of the study is to determine the reported presence of physical disability (impairments, activity limitations, and participation restrictions) among HIV/AIDS adults managed by the Makeni home-based care givers in Lusaka, Zambia.



1.4 OBJECTIVES OF THE STUDY

- 1) To determine the socio-demographic characteristics of adults with HIV/AIDS managed by Makeni home based care givers.
- 2) To identify the reported impairments among adults with HIV/AIDS managed by the Makeni home based care givers.
- 3) To determine the reported activity limitations and participation restrictions of adults with HIV/AIDS managed by the Makeni home-based care givers.

4) To determine the reported environmental factors (e.g. attitudes from family members, physical structures around the house) that affect adults with HIV/AIDS, managed by the Makeni home-based care givers.

5) To determine the socio-demographic characteristics (e.g. age, and gender) and the environmental factors that are associated with the activity limitations or participation restrictions of adults living with HIV/AIDS managed by the Makeni home-based care givers.



1.5 SIGNIFICANCE OF THE STUDY

Although the HIV/AIDS prevalence is 21.5% in Zambia, the presence of physical disability among people living with HIV/AIDS has not been documented in this country. Information gained in the study could assist in the expansion of services provided by the community home-based care givers to include basic rehabilitation services if the need arises. The physiotherapists working in Lusaka, Zambia would also be provided with information that could assist them in planning physiotherapy services for people living with HIV/AIDS in home-based care.

1.6 DEFINITION OF TERMS

The following segment describes some of the terms used in the study.

Ataxia: An inability to coordinate muscle activity during voluntary movement, so that a smooth movement could occur (Stedman, 1995).

Cerebral Toxoplasmosis: A disease caused by the protozoan parasite toxoplasma gondii, which affects the brain, causing a variety of syndromes in humans (Stedman, 1995).

Disability: Is an umbrella term used for impairments, activity limitations and participation restrictions (WHO, 2001).

Function: The special action or physiologic property of an organ to perform its' special work (Stedman, 1995).



HIV/AIDS Wasting Syndrome: This is the involuntary loss of more than 10% of the body weight plus more than 30 days of diarrhea, weakness or fever that is not derived from another cause (Watstein & Stratton, 2003). Furthermore, it is also linked to HIV/AIDS disease progression and death.

Lymphadenopathy: Is the chronic enlargement of the lymph nodes and glands due to infections or cancer (Stedman, 1995). Lymphadenopathy is some times seen as an early sign of AIDS (Watstein & Stratton, 2003).

Multi focal Leuko Encephalopathy: Encephalitis arising from many foci restricted to the white matter (Stedman, 1995). Patients present with symptoms such as dementia, cranial neuropathies, aphasia among others (Fahey & Flemminng, 1996).

Myelopathy: This is a general term that denotes any pathological condition of the spinal cord or bone marrow (Watstein & Stratton, 2003). Symptoms may include weakness, clumsiness in arms or legs, bladder and bowel incontinence (Watstein & Stratton, 2003).

Neurology: A branch of medical science concerned with the various nervous systems (central, peripheral, and autonomic, neuromuscular junction and muscle) and its' disorder (Stedman, 1995).

Paraparesis: Weakness affecting the lower extremities (Stedman, 1995).

Physical: Relating to the body as distinguished from the mind (Stedman 1995).



Rheumatological: The medical specialty concerned with the study; diagnosis, and treatment of rheumatic conditions (Stedman 1995).

1.7 SUMMARY


Chapter one provided the background of the study, following this was the research question, the aim of the study, the objectives, the significance of the study, and lastly the definition of terms. The following chapter two will discuss the literature review.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

In this chapter, the review of literature expands on the rationale for the study in investigating the nature of physical disability among HIV/AIDS adults being cared for by the Makeni home-based care givers, in Lusaka, Zambia. The literature review is expounded under the following main headings:

- 
- i) Prevalence and incidence of HIV/AIDS
 - ii) Transformation of HIV/AIDS into Physical Disability
 - ii) Conceptual Framework for Disability Resulting from HIV/AIDS
 - iv) Impairments in HIV/AIDS
 - v) Activity Limitations and Participation Restrictions in HIV/AIDS
 - vi) Effects of Contextual Factors on Disability
 - vii) Environmental Factors
 - viii) Conclusion

2.2 PREVALENCE AND INCIDENCE OF HIV/AIDS

UNAIDS/WHO (2002) indicated that worldwide the prevalence of HIV/AIDS in adults between 15-49 years at the end of 2002 was estimated at 38.6 million of which 4.2 million adults were newly infected. From this number 2.5 million adult deaths occurred. UNICEF/UNAIDS (2004) states that 60% of the HIV infection in the Sub-Sahara occurs among the youth between 15-24 years. Furthermore, young women in this group were twice as likely to be infected than young men (UNAIDS, 2004). The childhood (under 15 years) HIV infection rate on the other hand, was estimated at 3.2 million (UNAIDS/WHO, 2002). In Zambia, the prevalence of adults living with HIV/AIDS was estimated at 1.2 million at the end of 2001 (UNAIDS/WHO, 2002). Zambia's adult prevalence is the sixth highest in the world following that of Botswana (38.8%), Swaziland (33.4%), Lesotho (31.0%) and Namibia (22.5%) (UNAIDS/WHO, 2002). It can thus be concluded that Zambia is experiencing a serious HIV/AIDS epidemic. Quinn (1998) illustrated that although the HIV/AIDS prevalence was high in developing countries particularly in Sub-Sahara, indications of stabilization in the HIV/AIDS infection rate was evident in the United States and Western Europe. This was due in part, to the accessibility to health care that PLWHA are receiving in these parts of the world. On the contrary however, the majority of Africa faces the challenge of providing affordable anti-retroviral treatment due to the lack of resources (UNAIDS/WHO, 2002).

The World Bank (1999) further stated that HIV/AIDS affects people in their prime age, usually when they are in their reproductive years and nearing their income earning

potential. It is obvious that if a massively expanded prevention programme is not in place the AIDS toll will continue to rise.

2.3 TRANSFORMATION OF HIV/AIDS INTO PHYSICAL DISABILITY

The human immune deficiency virus (HIV) has undergone several changes in the past two decades. With improvements in medical care, the current treatment options are slowing its' progression to acquired immune deficiency syndrome (AIDS) (O' Dell, Hubert, Lubeck, O'Driscoll, 1996., Lubeck and Fries, 1997). People living with HIV/AIDS (PLWHA) are living longer from the time of the HIV infection to the development of AIDS and survival after an AIDS defining illness in developing countries (Graham, Zeger, Park, 1992). HIV/AIDS has therefore been transformed from a "near death sentence" to a chronic disease that may be managed particularly in industrialized countries (Cunningham et al, 1998). This has led to stressing the importance of minimization of symptoms and maximization of the functional status among PLWHA (Stewart et al, 1989, Wu & Rubin, 1992). HIV/AIDS, however, remains a progressive and permanent disease with specific manifestations, which includes neurological impairments (O'Dell, 1993).

Although physical disability has been identified among PLWHA, it remains an area that has not yet been well researched. Most studies relating to disability among PLWHA were performed in the 1980s and 1990s. These focused on the general quality of life of these people with physical disability being seen as an important determinant of quality of life in

PLWHA (Wachtel et al, 1992; Cleary, Fowler, Weissman, Massagli, Wilson, Seage, Gatsonis and Epstein, 1993). O'Dell (1993) observed that most of the studies have not provided the details of types of functional deficits among PLWHA.

2.4 CONCEPTUAL FRAMEWORK FOR DISABILITY RESULTING FROM HIV/AIDS

The WHO (2001) developed a framework; the International Classification of Functioning, Disability and Health (ICF) which is based on the “bio-psychosocial model of understanding disability, it synthesizes the medical model and social model”. WHO (2001) asserts that, “the medical model views disability as a problem caused by disease, trauma or health condition and aims to finding a solution through medical intervention”. The social model on the other hand views disability as having been caused by societal factors and hence, aims to rectify disability by socially integrating the affected individual through social action by environmental modification. In this instance the ICF provides a coherent view of disability by integrating the biological, individual and societal factors (WHO; 2001).

The WHO (2001) indicates that “the ICF provides a standard language to describe and measure health and health related states”. The different domains considered in this framework are body functions, body structures, life areas (tasks and actions), external and internal influences on functioning and disability. These different domains are systematically grouped by the ICF according to the person’s health condition. It would

therefore provide information on what a person with a health condition “can or cannot do”. In the ICF *functioning* encompasses all body functions, activities and participation; on the contrary *disability* encompasses impairments, activity limitations or participation restrictions. Impairments are described as “problems in body functions or structures” (WHO, 2001). Activity limitations are “difficulties an individual may have in executing a task”. Participation restrictions are “problems an individual may experience in involvement in life situations” (WHO, 2001). Therefore, physical disability will be discussed from this angle of the ICF.



2.5 IMPAIRMENTS IN HIV/AIDS

Impairments in HIV/AIDS occur when there has been a successful transmission of the virus; the virus then initiates a transient development of high viremia (Daar et al, 1991, Clark et al., 1991). Before the virus can cause any infection, Fauci (1993) indicates that the HIV virus targets a particular combination of receptors located in the host cell; specifically the CD4 + T lymphocytes and the macrophages. When this occurs, the virus then penetrates the host cell. Ultimately, this leads to the deterioration of the immune system by bringing about a diverse array of opportunistic infections (Cole & Nadler, 2001). This deterioration thus causes changes to the structure and functioning of the organ therefore leading to the occurrence of impairments.

In discussing impairments in HIV/AIDS the focus will be on central neurological and neuromuscular impairments found among PLWHA. These are the conditions that mainly

result in physical disability and are mainly encountered by the rehabilitation professionals (Galantino, 1992, O'Dell & Dillon, 1992).

Analysing impairments in HIV/AIDS clarifies the type of physical disability an individual may present (O'Dell et al, 1994).

The WHO (2001) illustrates that impairments may be temporary or permanent, progressive or static, intermittent or continuous. In this instance impairments represent deviation from certain accepted standards in the biomedical status of the body and its' functions. Thus, impairments are not pathology but are manifestations of that pathology in this case, the symptoms seen in AIDS.



There are many classifications of the HIV disease stages; one of these is by the centre for disease control (CDC, 1989). It classifies the HIV infection according to symptoms, group I being the acute infection stage; group II the asymptomatic stage; group III characterized by persistent generalized lymphadenopathy (symptomatic with having a major opportunistic infection); group IV has other disease manifestations. It must be highlighted however, that HIV does not occur in stages but occurs along a continuum (Hoover et al., 1993). An observation, however, of overlaps between asymptomatic clinical manifestations and symptomatic HIV have been noted (O'Dell et al, 1998).

In group III and IV of the CDC classification, PLWHA will usually present with more impairments. Wachtel et al (1992) indicates that these impairments determine the quality of life and physical disability of an individual. Constitutional symptoms (night sweats, fevers, diarrhoea, fatigue) followed by neurological symptoms are known to affect

physical disability (Wachtel et al, 1992, Cunningham et al, 1998). Single impairments are unusual as most of them occur in a combination. It must be pointed out that complications of HIV/AIDS are several; they coexist with neurological, cardiac, pulmonary or rheumatological impairments particularly in the late stages of HIV infection (Mukand, 1991, De Vita, 1994).

2.5.1 Neurological Impairments

2.5.1.1 Central Nervous System Impairments



Impairments of the central nervous system (CNS) and the peripheral nervous system (PNS) are extremely common either from the HIV itself or from several secondary pathogens common in HIV infection (Levy & Berger, 1991, O'Dell & Dillon, 1992). It is stated that 40% of persons with AIDS will have a neurological complication particularly in-group III and IV of the CDC classification of the disease stages (O'Dell & Dillon, 1992). There are indications of the HIV virus having a propensity for infecting the nervous system and medications such as Vincristin for some cancers, Isoniazid, rifampicin for tuberculosis and dopsone have all been implicated in CNS and PNS complications (Simpson & Wolfe, 1991).

HIV-related CNS impairments present in three ways: namely by diffuse processes, focal brain processes or by myelopathy. The commonest of the diffuse CNS processes is the AIDS dementia complex, a condition that affects the cognitive and motor functions of the brain (Guiloff, 1991, Levinson & Merrit, 1993, Berger & Levy, 1993, Brew, 1993 & O

'Dell, 1996). Cognitive dysfunction is presented by decreased attention, mood disorders, and memory retrieval problems. Motor dysfunction on the other hand, brings about lower extremity weakness, ataxia, cogwheel rigidity and tremor (O'Dell, 1996).

Focal CNS impairments include cerebral toxoplasmosis, cerebral vascular accident, primary lymphoma and progressive multifocal leuko encephalopathy (Levinson & Merritt, 1993, Berger & Levy, 1993). Patients also exhibit symptoms such as fever, fatigue, and progressive hemiparesis (Brew, 1993).

Lastly spinal cord complications have been observed in autopsy of over 20 % in PLWHA as the cause of death (Berger & Levy, 1993). Levinson and Merritt (1993) assert that myelopathy affects the dorsal portion of the thoracic spinal cord, which presents itself as ataxia and spastic paraparesis.

2.5.1.2 Peripheral Nervous System Impairments

McGuire (2003) noted that a wide range of peripheral nervous system (PNS) complications occur in PLWHA. In a study conducted by Lange et al (1988) a peripheral neuropathy was noticed in 50-90% of PLWHA. The presentation was in an acute form of inflammatory demyelinating neuropathies, which rapidly progressed to flaccid paralysis with sensory loss and areflexia (Cornblath et al, 1987). Another form is the chronic inflammatory demyelinating neuropathy, which was slowly progressive with a few sensory complaints (Gabuzda & Hirsh, 1987, So et al, 1988, Lange et al, 1988). In a few isolated cases mono neuropathies were observed usually manifesting in the form of foot

drop. The consequence of these neurological complications is an increasing source of physical disability among PLWHA (Silwa & Smith, 1991).

2.6 ACTIVITY LIMITATIONS AND PARTICIPATION RESTRICTIONS IN HIV/AIDS

Most of the HIV related disability studies were described by assessing activities of daily living (ADLs), instrumental activities of daily living (I-ADLs) and mobility. Some times all three areas were assessed and in others only ADLS were examined. Spector (1990) defined ADLs as activities used in self-care e.g. bathing, grooming, and dressing. While I-ADLS are activities used to function in the immediate environment, they include, shopping, running errands and doing housework. ADLs, I-ADLs and mobility would thus fall into the activity limitations and participation restrictions categories of the ICF. The participation category of the ICF however, seems to be more inclusive of more social roles such as going to school, being involved in the community, basic economic transactions, religious and recreational activities (WHO, 2001).

Disability studies in HIV/AIDS were initially inclined to examining disability in people who had AIDS (after an AIDS defining illness). An earlier HIV related retrospective disability study by Kapantaise and Powell-Griner (1989) examined disability among HIV/AIDS patients in their last year of life by comparing them to non-AIDS patients also in their last year of life. It was noted that 40-60% of the HIV/AIDS group required assistance in ADLs specifically in bathing, eating, toileting, dressing and walking. The

findings were not significantly different from the non-AIDS group, however; the HIV/AIDS group was younger than 55 years of age in comparison to the non AIDS group, which was above 55 years. In this study I-ADLs were not examined. O'Dell (1989) also evaluated disability among AIDS patients (N=37) with CDC group IV HIV classification, at the time of discharge. The findings revealed that 60% of this sample required some assistance in one area of function as was measured by the functional independence measure questionnaire (FIM). The most frequent and severe functional deficits were in stair climbing, 51% and 38% had problems with ambulation; Other ADLs that required assistance were for bathing (29.3%); feeding (27.6%) and dressing had the least frequently occurring deficit of 18% in the upper limb dressing and 21.6% in lower extremity dressing. Although disability is evident among PLWHA in the two hospital based studies, "Impairments" and "activity limitations" were not identified to have been used in the assessment of disability. If they were, the researchers did not provide any indication of what effect they had on the overall disability in this population.

O'Dell, Hubert, Lubeck & O' Driscoll (1996) aimed to investigate the type, frequency, severity and correlates of physical disability among the persons with AIDS (after an AIDS defining illness) in a community based group (N=546). The sample consisted of mainly well-educated, homosexual and bisexual males. Females were excluded, as they were too few. The HIV Health Assessment Questionnaire (HAQ) was used to measure disability. The areas of disability that were assessed were, ADLs in the area of hygiene, dressing, or grooming and I-ADLS that were included were reach and grip. The mobility aspect included, walking and arising. The findings indicated mild to moderate physical dysfunction among the cohort in the areas of I-ADLs, 17% had difficulty in grip, 29% in

reach, 52 % in activities such as shopping, doing errands, and house chores . The author noted that severe disability among PLWHA in the community was unusual. From this study only 3.8% consulted the services of a physiotherapist, showing a low utilization of these services. This study demonstrated strong correlation between the number of symptoms and disability. Social function and employment were not as strongly correlated. These findings highlight the authors' demonstration in examining the effects of impairments and an item of participation (employment) on disability in people with AIDS.

HIV related disability studies have not only been inclined to people with symptoms of AIDS, studies have been extended to those with asymptomatic HIV infection in the pre-AIDS asymptomatic stage. Physical disability in people with HIV has also been compared to the general population. O'Dell, Hubert, Lubeck, & O'Driscoll (1998) assessed disability in an asymptomatic HIV group (N=531) before an AIDS defining illness. The sample was also white homosexual or bisexual males who were well educated. The HIV Health Assessment Measure was used as a self-administered questionnaire. Besides ADLs, I-ADLs and mobility, employment status, health status and HIV related symptoms were measured. Low levels of disability were present in this pre-AIDS cohort in comparison to the general public. The deficits observed tended to be concentrated in the areas of I-ADLs. Evidence of low-level disability among the pre-AIDS group has been demonstrated by Stanton, Wu, & Moore (1994) and Whalen et al, (1991). In this investigation the Stanton group observed that 10% -15% of their HIV sample reported non-independence in I-ADLS while 1%-3% in both I-ADLs and ADLs. The Whalen study found non-independence in 7% of the I-ADLs/ADLs and only 5% in

the I-ADLs of their HIV sample. Although the percentages seem small the results confirm that some degree of physical disability among people with the HIV infection in the asymptomatic phase exists.

Crystal et al (2000) found that activity limitations (such as bathing, dressing, walking, climbing stairs) and participation restrictions (such as working around the house, working at a job, going to school) varied widely among PLWHA. Indications of activities affecting participation was assessed in a Canadian study by Rusch, et al (2003). In their study, certain activities particularly household chores, vigorous activities were associated with some social participation roles of being a student or employee, or involvement in cultural, religious or community involvement among PLWHA in British Columbia, Canada.

The studies on physical disability in HIV/AIDS all demonstrate some commonality concerning the presence of disability, more so among the I-ADLs. The difference is that the degree to which the I-ADLs occur varies with the stage of the HIV/AIDS disease. One notable difference is that different instruments are used in examining the presence of disability, thus there is a variation as to what is being included in the investigation. In addition some of the studies have very few females making it difficult to observe how women are affected. Lastly the similarity that is drawn from the studies is that the more advanced the group is in the HIV disease stage the more likely the group will be in having more limitations in activity and participations (ADLs and I-ADLs).

2.7 EFFECTS OF CONTEXTUAL FACTORS ON PHYSICAL DISABILITY

The WHO (2001) illustrates that environmental and personal factors (contextual factors) complete the background of an “individual’s life and living”. In addition, WHO (2001) illustrates that environmental factors and personal factors are known to impact on the health condition of an individual thus social, attitudinal and physical factors fall in the environmental category. Personal factors include a wide range of personal characteristics, and include age, gender, income, education, and health condition among others.

The WHO (2001) further points out that environmental factors are usually external and may have a positive or a negative impact on one’s health, hence affecting how that individual functions. It is with in this perspective that the ICF characterises disability as an outcome of complex interactions of the individual’s health condition. Similarly, PLWHA could be affected by these complex interactions that stem from either the environment or from within the person. The study thus explored how specific personal and environmental factors impact on physical disability among people living with HIV/AIDS.

2.8 ENVIRONMENTAL FACTORS

2.8.1 Personal Factors

Personal factors have also been implicated in impacting on physical disability. Cunningham, et al (1995) indicated that lower income, public insurance and older age

were associated with poor health related quality of life of which disability is part. Okeefe & Wood (1996) in a South African study of HIV out-patients found that those in the mixed race had poorer physical function than the whites or the blacks. This finding was inconsistent with a study in the US, which reported physical limitation among the HIV infected blacks and the Hispanics as compared to their white counterparts (Fleishman & Crystal, 1998). It must be pointed out that personal factors can vary widely between cultures and different groups of people.

2.8.2 Social Support



Social support is seen as an important factor in psychologically adapting to living with the HIV infection (Green, 1993). This type of support promotes a sense of emotional well being (Kalichman, Dimarco, Austin, Luke, and Difonzo, 2003). The role of the community is vital, particularly if it involves PLWHA as it enhances social solidarity to PLWHA and their families (UN, 2001). Martin (1998) noted that although some people with HIV/AIDS have strong family support systems many do not. Fear of contracting HIV/AIDS due to lack of knowledge of HIV transmission are reasons given. Russel & Schneider (2000) observed that PLWHA some times opt not to seek or access support or treatment as they have fear of being rejected. However those who decide to participate clearly benefit by overcoming isolation and despair.

Lastly, Takai et al (1998) found that when PLWHA are receiving support and care services, “captive environments” for prevention of HIV/AIDS are initiated and supported over a long period of time in that community.

2.8.3 Attitudes

Since the beginning of the HIV epidemic PLWHA have encountered negative attitudes from society such as stigmatization (Herek & Capitano 1993; Mann, Tarantola, & Netter, 1992). Stigma has manifested itself in the form of anger and other forms of negative feelings towards PLWHA (Blendon, Donelan & Knox, 1992). Price and Hsue (1992) indicated that ideas of quarantine of PLWHA or public identification were some of the ways in which people expressed their negative attitudes towards PLWHA. It has been noted that stigmatizing attitudes have led to ineffective AIDS prevention and have caused hardship on PLHA, their loved ones, their caregivers and on their communities (Herek et al, 1998). PLWHA most often encounter stigma and discrimination through their entire experience with HIV/AIDS (De Bruyn, 1999). Therefore, negative attitudes should be addressed in any effort that intends to provide support in order to facilitate their functional abilities.

2.8.4 Physical factors

Pizzi (1992) pointed out that people living with HIV/AIDS may encounter difficulties in adapting to or in negotiating their physical environments. The author indicated that impairments such as fatigue, shortness of breath, CNS and PNS damage could affect their mobility in the community, work place and in the home. In this case structural changes may have to be indicated, so that PLWHA can effectively function within their environment (McDowell, 1992). It was stated that rehabilitation workers may assess the patient's environment by inspecting the obstructive hazards and barriers so that appropriate changes can be made (De Lisa, et al, 1993).

2.9 CONCLUSION

The studies on disability among people living with HIV/AIDS provide an indication that some form of disability exists in the population. Although different instruments have been used in measuring disability among PLWHA the studies also pointed out that ADLs, I-ADLs and mobility were items mostly used to document disability. It is clear from the studies that disability varied depending on the HIV disease stage. The effect impairments have on disability has been emphasized by indicating its importance in disability evaluation. A thorough picture of disability that captures the effects of contextual factors on disability has not been demonstrated in some of these studies. The planned study intends to make a difference in that, it will assess the nature of impairments, activity limitations and participation restrictions and how specific contextual factors influence physical disability among PLHA in home based care, in a Zambian setting, as most of the studies were done in the United States and Canada.

CHAPTER 3

METHODOLOGY

3.1 INTRODUCTION

Chapter 3 describes the methodology of the study. It is described under the following headings: the research setting, the study design, the background on Makeni home-based care programme, the study population, the instrument used, the procedure, the pilot study, the data analysis, and finally the chapter is concluded by the ethical consideration.



3.2 RESEARCH SETTING

The study was based in Lusaka, the capital city of Zambia, a country located in the southern part of Africa. Lusaka has a population of 1.2 million (The World Gazetteer, 2004). The commonly spoken languages in Lusaka are Nyanga and Bemba. The health sector in Zambia has very limited involvement in community home-based care programmes due to its health care system being overburdened with providing hospital care for PLWHA (Zambia National HIV/AIDS/STD/TB council, 2001). Community home-based care has therefore, mostly been initiated by religious organizations such as the Catholic Church. The health sector provides support by seconding mainly nurses to work in these home based care programmes (Zambia National HIV/AIDS/STD/TB Council, 2001).

In Lusaka, specifically, the home-based care services are provided by a non-governmental organisation (NGO), under the Catholic Church organization, the Community Home-Based Care programme of the Archdiocese of Lusaka (CHBC). CHBC has several home-based programmes in Lusaka and outside the city, and among them is the Makeni home-based care programme, which provides services to PLWHA in particular southern townships and one informal settlement. The two townships, situated in the south of Lusaka and informal settlement where the study was undertaken are called Makeni, Bonaventure and John Laing respectively. The first two areas, Makeni and Bonaventure are large townships, which have some small scale farming activities running. They have a regular supply of water and electricity. John Laing, on the other hand, is an informal settlement whose housing structure is made of brick, and is either incomplete or poorly constructed. Water supply in this area is inadequate and poorly distributed; electricity is erratic with some houses not receiving any power.

A coordinator who supervises the activities of the caregivers manages the Makeni home-based care programme. It also has a qualified nurse whose role is to examine, offer treatment, prescribe medication and refer patients that require urgent medical attention to a medical facility.

The Makeni home-based programme has approximately twenty caregivers. The caregivers volunteer their services without any form of payment. These services include monitoring of intake of medication, nutritional advice, bathing and cooking for the very ill and psychosocial advice as well as spiritual support.

PLWHA are admitted to the programme based on the WHO staging system for HIV infection or disease (WHO, 1990). The system has four clinical stages. The clinical stage one involves acute retroviral infection and persistent generalized lymphadenopathy (asymptomatic, normal activity). The second clinical stage involves weight loss (<10% of body weight); minor mucocutaneous infections; herpes zoster; and recurrent upper respiratory tract infections (symptomatic, normal activity). The third clinical stage involves weight loss (>10 of body weight); unexplained chronic diarrhea (>1 month) unexplained prolonged fever (> 1 month); oral candidiasis; vulvo- vaginal candidiasis; pulmonary tuberculosis (within past year); severe bacterial infections and being bedridden <50 % of the day in the last month. The fourth clinical stage involves HIV wasting syndrome; Herpes simplex infection; candidiasis of the oesophagus, trachea, bronchi or lungs; lymphoma, Kaposi's sarcoma and being bedridden >50% of the day during the last month. The admission of patients is not strict as long as the patients have any of the symptoms described by the WHO staging system.

3.3 STUDY DESIGN

A cross- sectional descriptive study was employed in the study. Thyer (2001) indicated that descriptive studies summarize the relationships between or among two or more variables aiming at quantifying the extent of the problem (Katzeenellenbogen, et al, 1991). The cross-sectional design of the study involved examining the responses of different groups of participants at one point in time, therefore having the advantage of collecting information in a shorter time frame (Mertens & McLaughlin, 2004). The study

was quantitative in nature, it hence involved procedures of objectivity seeking in data collection and analysis that are replicable and can be confirmed or disconfirmed (Cage, 1994). It was therefore an appropriate study design for the present study as it aimed to determine the presence and extent of physical disability among adults with HIV/AIDS managed by the Makeni home based care givers in Lusaka, Zambia at a given point in time.

3.4 STUDY POPULATION



The Makeni home-based care programme was chosen as a sample of convenience out of all the NGOs that provide home based care services to PLWHA in Lusaka, Zambia. Convenient sampling is used when a researcher chooses a sample that is readily available and is easily accessible to the researcher (Densicombe, 1998). The Makeni home-based care programme was easily accessible to the researcher in terms of public transportation availability making it cost effective for the researcher. Furthermore, the diagnosis based on the WHO staging system was done by a qualified nurse at Makeni home-based programme. Therefore, there was a possibility that non-HIV infected patients could have been admitted.

The study population comprised of all the registered adults with HIV/AIDS above 15 years of age managed by the Makeni home-based care givers. There were a total number of 270 patients under the care of the Makeni home-based care programme at the time of the study. The researcher aimed to interview 250 clients. However thirty-five (35) of

these were children under 15 years, and were therefore excluded from the study. Twenty-four of these were not interested in participating. Two clients passed away at the time the study was being conducted. The final study sample therefore consisted of 209 participants.

3.5 INSTRUMENTATION

An interview questionnaire adapted from the world health organization disability assessment schedule (WHODAS II) and the international classification of functioning, disability and health (ICF), was used in the present study.

WHODAS II was developed by WHO to provide a profile across six activity domains, which include understanding and communicating, getting around, self care, getting along with people, life activities and participation in society. It is used in research to identify needs, and match patients to interventions, trace functioning over time and measure clinical outcomes and treatment effectiveness (WHO, 2000). The ICF check list is a practical tool used to record functioning and disability (WHO, 2001). Included from the ICF checklist were questions relating to impairments of body functions and structures, and environmental factors. Questions determining limitations in daily activities e.g. washing and dressing, and restrictions in participating in previous activities such as taking care of house hold chores were adapted from the WHODAS.

The questionnaire had four sections. Section A of the questionnaire requested information relating to socio-economic data namely sex, age, area of residence, employment status, marital status, income and education. Section B was adapted from the ICF, the collected

data related to the impairments of the legs, arms, feeling a full bladder, hearing and seeing.

No impairment	0	Normal function
Mild impairment	1	Able to function but not as normally as before, required no form of assistance.
Moderate impairment	2	Function affected to the point where participant required assistance or some form of aid.
Severe impairment	3	Function severely affected; unable to perform function without assistance or aids; required assistance at all time

Table 2.1: Rating of Impairments

Section C of the questionnaire collected data relating to the activity limitations and participation restrictions of the population. This section was adapted from the WHODAS questionnaire and included the section on activity limitations and participation restrictions; they contained sub-sections on mobility, self care and life activities. Table 2. Illustrates the rating of the activity limitations and participation restrictions.

No difficulty	0	Performs activity normally
Mild difficulty	1	Not able to perform activity as before but does not require any assistance.
Moderate difficulty	2	Sometimes requires assistance to perform the activity
Severe difficulty	3	Is dependant on assistance, to perform activity at all time.

Table 2.2: Rating of Activity Limitations and participation Restrictions

Section D of the questionnaire lastly collected data relating to the environmental factors, which impacted on these patients. This section was also adapted from the ICF and included questions that covered support and relationships; attitude; and services/systems/policies.

Two different translators translated the questionnaires to Bemba and Nyanja languages. The questionnaires were translated back to English by the researcher to ensure face validity. The Nyanja translator encountered difficulty in translating the titles of impairments, activity limitations and participation restrictions and environmental factors to Nyanja therefore the headings were maintained in the English language while the contents were translated to Nyanja successfully. The Bemba questionnaire was translated well with only minor spelling mistakes which were corrected. The WHODAS II underwent reliability and validity tests in 16 centers and 14 countries in 1999 and 2000. However, the test results have not yet been made public (WHO, 2001).

3.6 PROCEDURE

Permission to conduct the study was obtained from the Director of community home-based care (CHBC). The research study and its' importance was explained to the coordinator of Makeni home-based care and to the care givers. The names of the HIV/AIDS adults, registered with Makeni home-based care programme were obtained from a register kept by the programme. The participants were contacted and the aim of the study explained to them. If they agreed to partake in the study they were interviewed

in their homes. The HIV/AIDS status of the clients was not discussed at any time during the research. A research team comprising of the researcher and two trained research assistants for each area collected the data. The researcher performed the interviews, while the research assistants located the homes of the participants.

3.7 PILOT STUDY

A pilot study was carried out among adults with HIV/AIDS managed by the Fatima home based carers, in Kaunda Square, Lusaka, Zambia. A total of 10 adults living with HIV/AIDS were interviewed for the pilot study after verbal permission was obtained. The pilot study was carried out in one day, with the assistance of one caregiver. Balnaves & Caputi (2001) indicated that performing a pilot study assists in the identification of problems and benefits associated with the questionnaire design. A question from the section on impairments was changed from “Do you have difficulty with toileting” to “Do you have difficulty with feeling a full bladder? The intention was to assess incontinence, and the question.

3.8 DATA ANALYSIS

The interview questionnaires were coded before data was collected. After all the data was collected information was captured into Excel and cleaned. The frequencies of the following variables were calculated in Excel, social demographic factors; impairments;

activity limitations and participation restrictions and environmental factors. Descriptive statistics in SPSS were also run on all impairments, activity limitations, participation restrictions and environmental factors. Comparing means analysis were tabulated in SPSS to find out by how much gender, age and environmental factors differ on activity limitations and participation restrictions. Sweet (1999) illustrated that univariate analysis involves the exploration of the characteristics of any single variable.

Significance testing was performed using the t test on all variables, a statistical difference was only noted on physical environment.



3.9 ETHICAL CONSIDERATIONS

Permission to conduct the study was obtained from the Higher Degrees Committee of the University of the Western Cape and the Director of the Community Home Based Care Programme of the Archdiocese of Lusaka (CHBC). The participants were informed of the study and that they could withdraw from participation at any time. Informed consent was obtained from the participants. They were reassured of confidentiality and anonymity. Counseling services from the caregivers was available to the participants, if required. The results of the study will be made available to the Director of community home based care, the caregivers, and the physiotherapists working in Lusaka, on request.

CHAPTER 4

RESULTS

4.1 INTRODUCTION

This chapter presents the findings of the study. The first section outlines the social demographic characteristics of the sample. This is followed by section B which presents the findings on impairments, activity limitations and environmental factors.

SECTION A

4.2 SOCIO-DEMOGRAPHIC CHARACTERISTICS OF THE STUDY SAMPLE

4.2.1 Gender versus Age



A total of 209 interview questionnaires were administered to people living with HIV/AIDS (PLWHA) in Makeni home-based care. The study sample consisted of more males than females, 59.33% and 40.67% respectively; with the ages ranging from 16 years to 66 years. The mean age was 33.75 years and the standard deviation was 9.003. The majority of the sample fell into the age range of 25-35 years. Table 4.1 illustrates the age ranges according to gender.

Age Range	Male (N)	Female (N)	Total
15-25	14	22	36
25-35	30	60	90
35-45	29	28	57
45-55	10	14	24
55-65	1	0	0
65-75	1	0	0
Total	85	124	209

Table 4.1: Age versus Gender

4.2.2 Area of Residence

Information regarding the area of residence indicated that 48 (23.0%) people lived in Makeni, 7 (3.3%) lived in Bonaventure; and 154 (73.7%) lived in John Laing.

4.2.3 Employment Status

In the present sample, the majority of the sample 55.98% (117) were unemployed while 19.14% (40) were formally employed and thirty nine (18.66%) were self employed. Eight (3.83%) of the subjects were still in secondary school students. Those who fell in the others category considered themselves as seasonal workers.

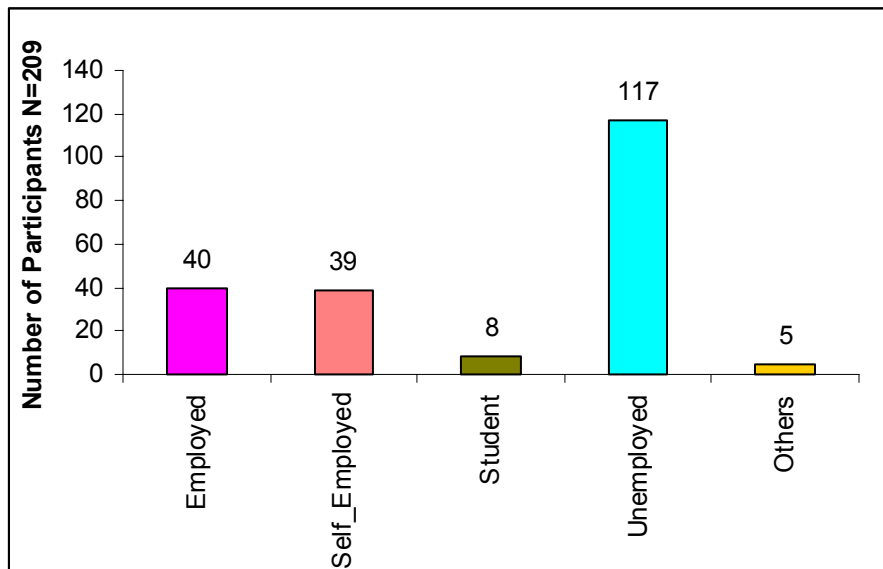


Figure 1: Employment Status of the Respondents

4.2.4 Marital Status of the Respondents:

Marital status information showed that most of the respondents were married and widowed, that is 87 (41.6%) and 61 (29.2%) respectively. Figure 2 below shows further detail.

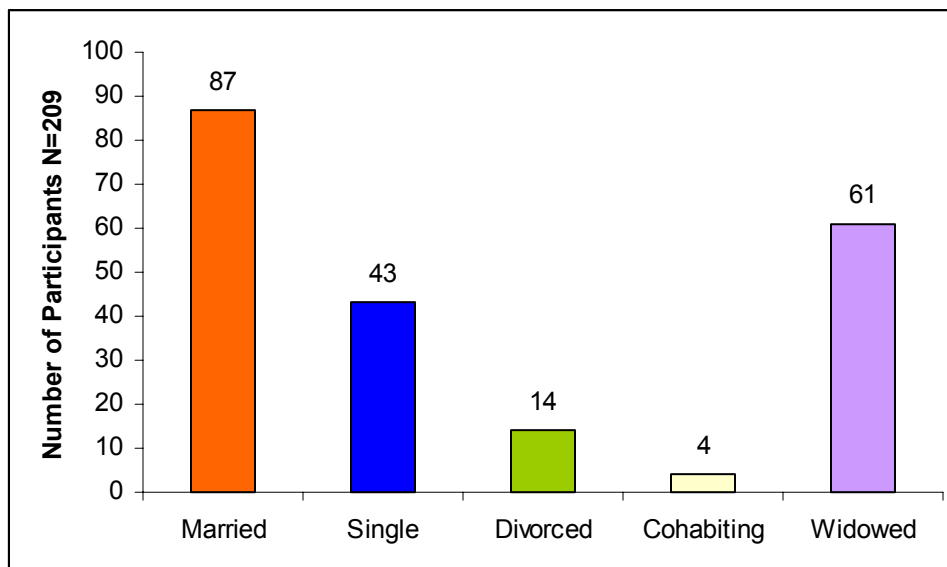


Figure 2: Marital Status of the Respondents

4.2.5 Comparison of Gender, Income and Educational Level

There were more people in the low income bracket with expected earnings under 250,000 Zambian Kwacha which is equivalent to R328.50 South African Rand. This group was followed by those with no income 72 (34.45%). According to the full universal currency converter (2004), 500,000 Kwacha is equivalent to R657.00 South African Rand; 700,000 Kwacha is equivalent to R919.80.

Table 4.2 indicates that most of the respondents, 58 persons with a primary education, had earnings under 250,000 Kwacha, (equivalent to R328.50). There were more females (36) with a primary education than males in this category. Similarly, in the same category more females (25) had no income compared to males. Most of the respondents 109 (52.2%) only had a primary education, followed by those with a secondary education 72 (34.4%). None of the respondents had a college or university education.

Educational Level	Gender	Income Range					
		Under 250 K	251K-500K	501K-700K	Above 700K	No income	Total
Primary Education	Male	22	7	0	0	10	39
	Female	36	8	1	0	25	70
	Total	58	15	1	0	35	109
Secondary Education	Male	17	7	1	1	11	37
	Female	18	4	0	0	13	35
	Total	35	11	1	1	24	72
No Education	Male	3	2	2	1	3	9
	Female	9	0	0	0	10	19
	Total	12	2	2	2	13	28

Table 4.2: Gender, Earnings and Educational Level

SECTION B

4.3 IMPAIRMENTS OF THE RESPONDENTS

The majority of the participants indicated that they had some problems moving their legs and arms. One hundred and eight (51.7%) indicated that they had mild impairments with their legs, while 44 (16.3%) had moderate impairments of the arms. Fewer impairments are noted regarding the functions of seeing, hearing and bladder involvement. Further detail can be viewed in figure 3. When means were tabulated on impairments for the overall sample (N=209) they scored 0.5703 on a scale of 0-3. The standard deviation was

0.41888 indicating that the sample was not nearing 1 (mild impairment) but was generally very mildly impaired.

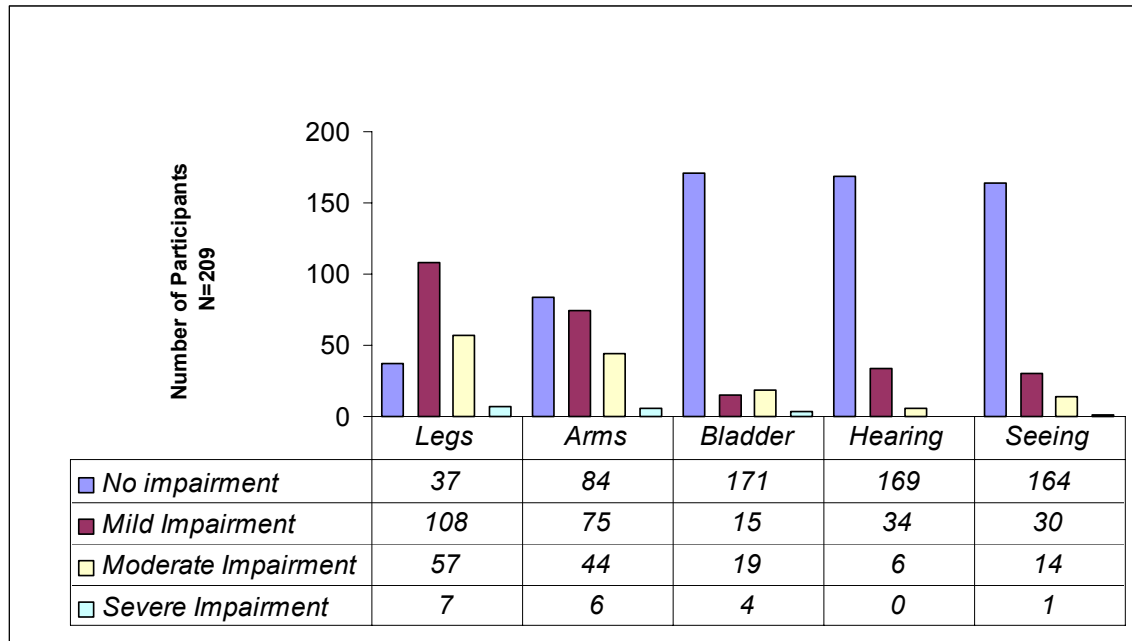


Figure 3: Impairments of the Respondents

4.4 ACTIVITY LIMITATIONS AND PARTICIPATION RESTRICTIONS

4.4.1 Activity Limitations & Participation Restrictions Pertaining to Mobility

Most of the participants 77 (36.8%) encountered mild difficulty in standing for 30 minutes followed by standing from sitting (33.0%). The least difficult activity was observed in walking inside the house with a high number of respondents scoring no difficulty (85%). Means for mobility for the overall sample (N=209) indicated there were generally mild difficulty in mobility activities with a mean of 0.7093 and a standard deviation of 0.69044. Refer to figure 4.

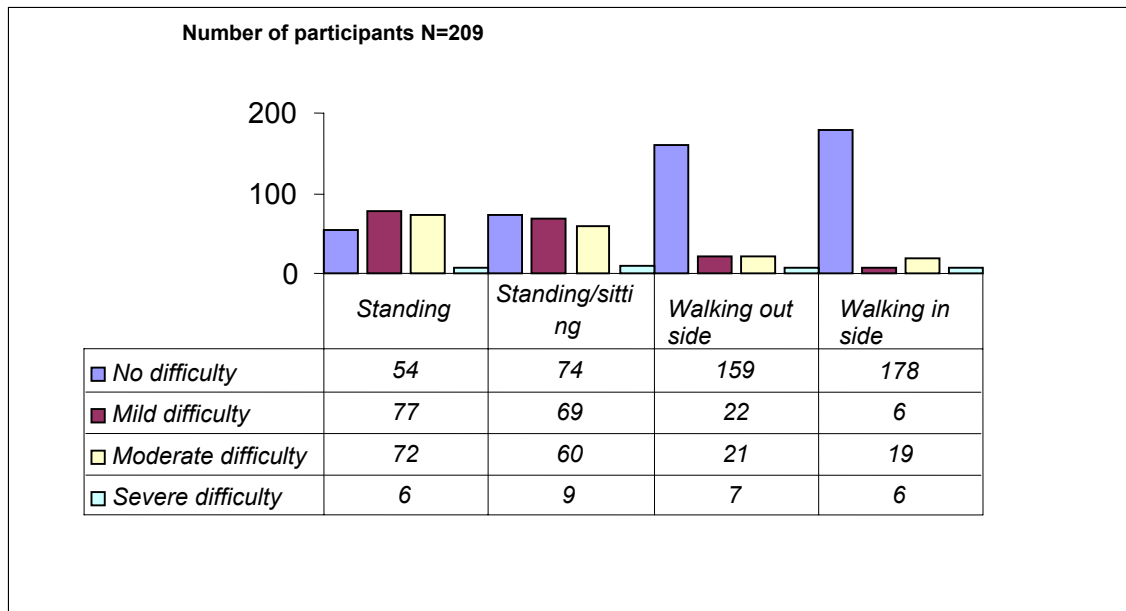


Figure 4: Activity Limitations & Participation Restrictions Pertaining to Mobility

4.4.2 Activity Limitations and Participation Restrictions Pertaining to Self Care

Figure 5 illustrates self care activities. On observation self care activities were the least problematic among the activity limitations & participation restriction activities as most respondents indicated no difficulty in all the four areas of self care. The most difficult activity reported was in washing one self with 6.2% respondents indicating moderate difficulty. Twelve (5.7%) participants encountered moderate difficulty in walking to the toilet. Generally the sample had no difficulty in self care activities and the mean score was much lower than 1. The calculated mean score for this item was 0.2033 and a standard deviation of 0.58777.

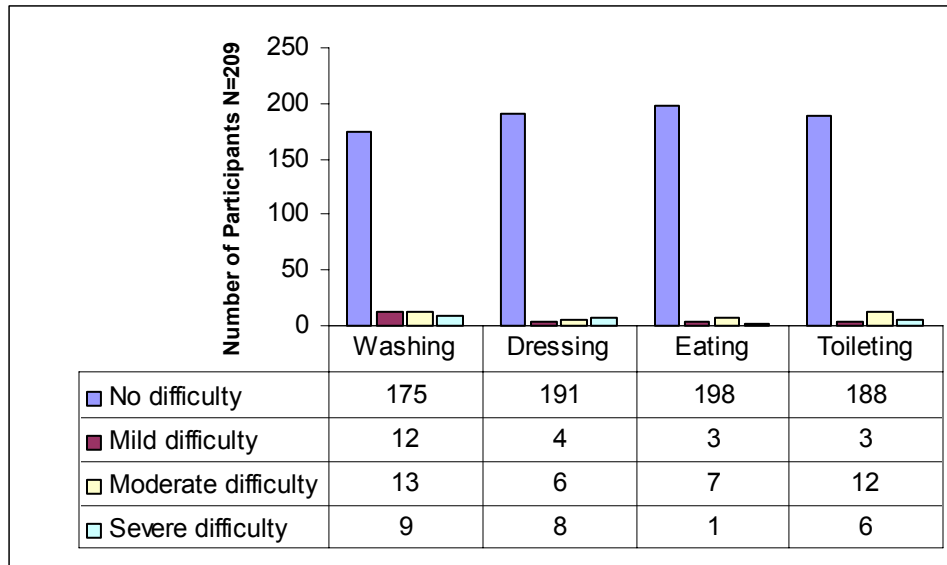


Figure 5: Activity Limitations & Participation Restriction Pertaining to Self Care



4.4.3 Activity Limitations & Participation Restrictions pertaining to Life Activities

A large number of the participants, 35.9% encountered moderate difficulty in performing household chores and in performing previous roles 25.8%. Thirty six (17.2%) participants indicated moderate difficulty in carrying out a job. Similarly thirty six (17.2%) participants experienced severe difficulty in both previous roles and carrying out a job.

The overall mean of 1.0120 indicates that the sample experienced mild difficulty in life activities with a standard deviation of .92015. Refer to figure 6

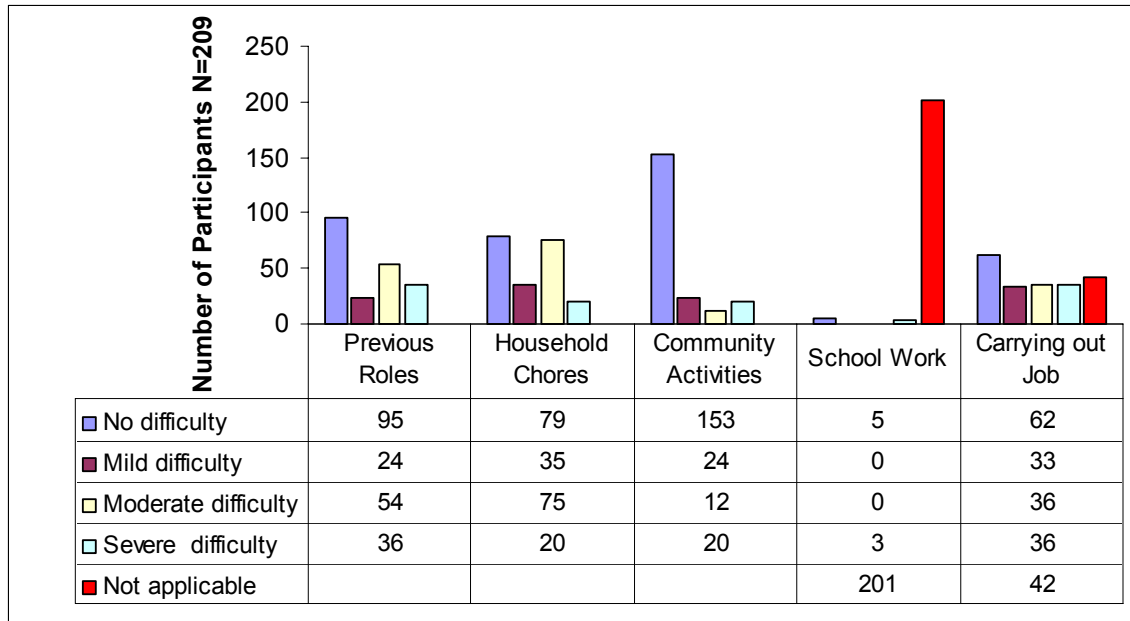


Figure 6: Activity Limitations & Participation Restrictions pertaining to Life Activities

4.5 ENVIRONMENTAL FACTORS

Questions on environmental factors focused on support and relationships attitude and physical geography.

4.5.1 Support & Relationships

The majority of respondents 87.6% indicated they had support from health professionals. Support of personal providers was reported by 84.7% respondents. The least reported support appeared to be from family with only 38.3% respondents indicating that their family was supportive. Refer to figure 7.

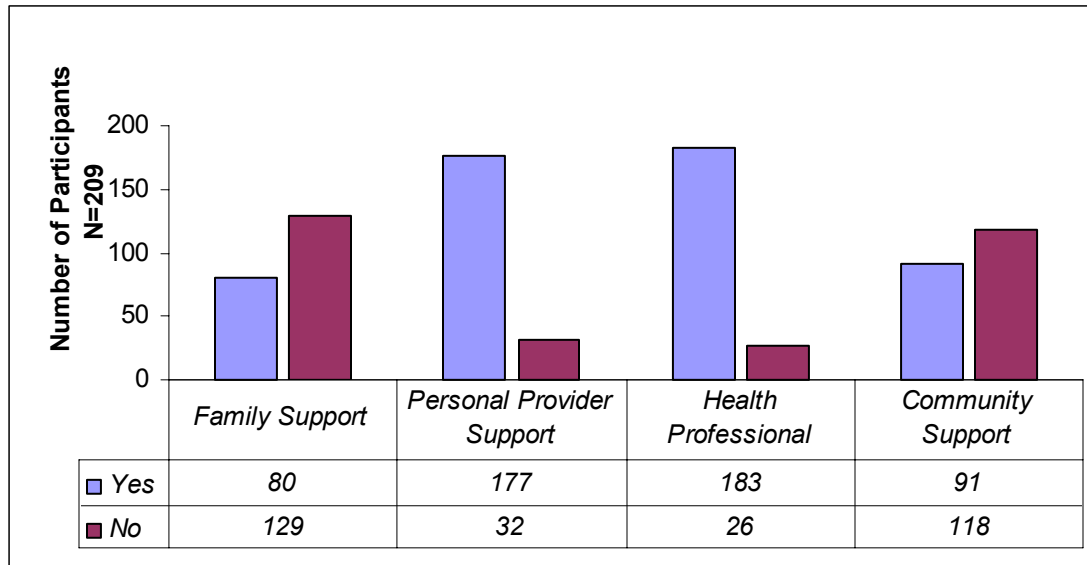


Figure 7: Environmental Factors Related to Support & Relationships of the Respondents



4.5.2 Attitude

The majority of the participants 52.6% reported that the family attitude towards them was not positive. On the contrary 89.0% respondents found the attitude of the personal providers to be more positive. Eighty seven percent also found the attitude of health professionals to be more positive.

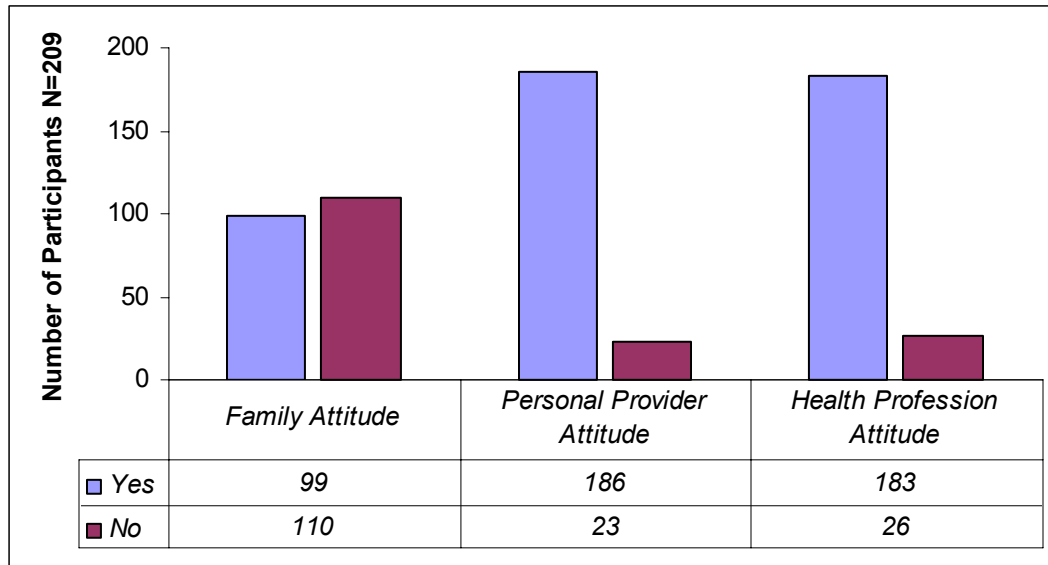


Figure 8: Environmental Factors Related to Attitude towards Respondents



4.5.3 Physical Environment

An equal number 87 (41.6%) of respondents indicated that they either found the physical environment around the house helpful or not. There was a significant difference of $t(117.3) = -6.19, p < .001$ between those who indicated the physical environment around the house was helpful, their mean was 0.3769; $SD = 0.30116$ and those who indicated it was not helpful their mean was 0.8787; $SD = 0.6936$

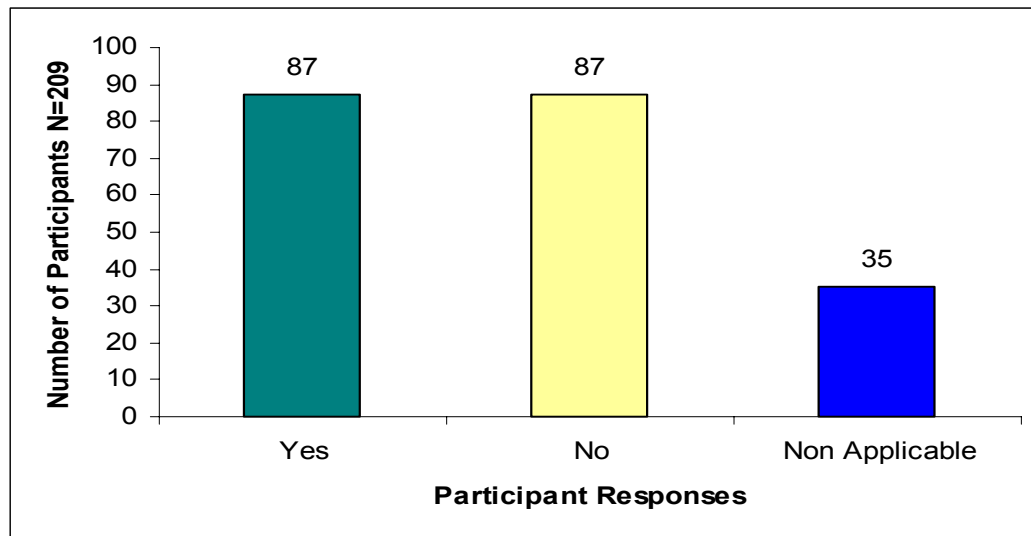


Figure 9: Physical Environment



4.6 AGE AND ACTIVITY LIMITATIONS AND PARTICIPATION RESTRICTIONS

Table 4.3 indicates that participants in the 15-40 years age group presented with fewer activity limitations & participation restrictions (mean = 0.5730). Those in the 41-70 years age group however, presented with more activity limitations & participation restrictions (with a mean of 0.6743). Both groups experienced more activity limitations in the areas of mobility. Nonetheless there was no statistically significant difference between age and activity limitations and participation restrictions.

Age Group	Mobility Mean (std deviation)	Self Care Mean (std deviation)	Life Activities Mean (std deviation)	Activity Limitations Mean (std deviation)
15-40	0.6871 (0.65930)	0.3755 (0.58363)	0.6564 (0.63104)	0.5730 (0.564100)
41-70	0.7880 (0.79402)	0.4522 (0.71359)	0.7826 (0.70239)	0.6743 (0.67074)
Total	0.7093 (0.69044)	0.3923 (0.61358)	0.6842 (0.64779)	0.5953 (0.58901)

Table 4.3: The Effect of Age on Activity Limitations & Participation Restrictions

4.7 GENDER AND ACTIVITY LIMITATIONS AND PARTICIPATION RESTRICTIONS

Information on the relationship between gender and activity limitations & participation restrictions showed that males had more activity limitations than females with a mean of 0.6767 and 0.5395 respectively. The males were most affected in mobility with a mean of 0.8382 and a standard deviation of 0.78841. However, there was no statistically significant difference between gender and activity limitations and participation restrictions. Refer to table 4.4.

GENDER	Mobility Mean (Std deviation)	Self- Care Mean (Std deviation)	Life Activities Mean (Std deviation)	Activity Limitations Mean (Std deviation)
Male	0.8382 (0.78841)	0.5035 (0.75505)	0.6882 (0.72365)	0.6767 (0.70453)
Females	0.6210 (0.60190)	0.3161 (0.48261)	0.6815 (0.59327)	0.5395 (0.48989)
Total	0.7093 (0.69044)	0.3923 (0.61358)	0.6842 (0.64779)	0.5953 (0.58901)

Table 4.4: Relationship between Gender and Activity Limitation & Participation Restrictions

4.8 THE EFFECT OF SOCIAL SUPPORT ON ACTIVITY LIMITATIONS AND PARTICIPATION RESTRICTIONS

In table 4.5 those who admitted to having family support had more activity limitations with a mean of 0.6552 as compared to those who did not; their mean was 0.5581. The ones who admitted to having family support were most affected in mobility with a mean of 0.8125.

	Family Support		Personal Provider Assistance		Health Professionals Support		Community Support	
	Mean (Std deviation)		Mean (Std deviation)		Mean (Std deviation)		Mean (Std deviation)	
	Yes	No	Yes	No	Yes	No	Yes	No
Mobility	0.8125 (0.72968)	0.6453 (0.65974)	0.6893 (0.66212)	0.8203 (0.83336)	0.6694 (0.63332)	0.9904 (0.97591)	0.7060 (0.67556)	0.7119 (0.70455)
Self-care	0.4500 (0.72671)	0.3566 (0.53148)	0.3819 (0.59516)	0.4500 (0.71482)	0.3443 (0.53097)	0.7308 (0.97150)	0.4440 (0.61305)	0.3525 (0.61362)
Life Activities	0.7031 (0.72051)	0.6725 (0.60094)	0.6638 (0.62952)	0.7969 (0.74172)	0.6489 (0.62406)	0.9327 (0.76341)	0.7527 (0.66196)	0.6314 (0.63441)
Activity Limitations	0.6552 (0.6679)	0.5581 (0.53364)	0.5783 (0.56976)	0.6891 (0.68852)	0.5542 (0.53099)	0.8846 (0.85704)	0.6342 (0.59126)	0.5653 (0.58802)

Table 4.5: The Effect of Support & Relationships on Activity Limitations and Participation Restrictions

4.9 THE EFFECT OF ATTITUDE ON ACTIVITY LIMITATIONS AND PARTICIPATION RESTRICTIONS

The highest numbers of activity limitations were observed among the participants who indicated that the attitude of the health care personnel was not supportive. Their mean was 0.7244 and a standard deviation of 0.67309. This was particularly observed in activity limitations related to mobility, which presented with a mean of 0.9327.

	Family attitude: Mean (Std Deviation)		Personal attitude Mean (Std Deviation)		provider Health care attitude Mean (Std Deviation)	
	Yes	No	Yes	No	Yes	No
Mobility	0.7601 (0.74993)	0.6636 (0.63213)	0.6868 (0.68555)	0.8913 (0.71837)	0.6776 (0.65875)	0.9327 (0.86475)
Self Care	0.4121 (0.68382)	0.3745 (0.54528)	0.3860 (0.61020)	0.4435 (0.65215)	0.3880 (0.59528)	0.4231 (0.74259)
Life Activities	0.6591 (0.67900)	0.7068 (0.62061)	0.6788 (0.64407)	0.7283 (0.69049)	0.6653 (0.64965)	0.8173 (0.63070)
Activity Limitations	0.6104 (0.65270)	0.5817 (0.52784)	0.5839 (0.58550)	0.6877 (0.62240)	0.5770 (0.57580)	0.7244 (0.67309)

Table 4.6: The Effect of Attitude on Activity Limitations and Participation Restrictions

4.10 SUMMARY OF RESULTS

Chapter four reported the findings of the study through tables and graphs. The results of the data related to socio-demographic characteristics, the impairments, activity limitations and participation restrictions and environmental factors were indicated. Lastly the findings on the relationship between age, gender, social support, and attitude with activity limitations and participation restrictions were presented. Chapter five will follow with the explanations on the findings of the study.

CHAPTER 5

DISCUSSION

5.1 INTRODUCTION

The purpose of the study was to investigate the nature of physical disability among adults with HIV/AIDS managed by the Makeni home-based caregivers in Lusaka, Zambia. This chapter therefore addresses relevant explanations for the findings of the study. The socio-demographic status of adults living with HIV/AIDS, managed by the Makeni home-based care givers are firstly discussed. This is followed by a discussion of the identified impairments, activity limitations and participation restrictions as well as the environmental factors influencing these.

5.2 SOCIO-DEMOGRAPHIC STATUS OF THE RESPONDENTS

5.2.1 Gender versus Age

The present study showed that there were more female participants than male, the HIV infection rate among females has steadily increased exceeding the rate of males (UN, 2001). A study on the heterogeneity of HIV showed that HIV infection was six times more prevalent in women than in men (Population Council Epidemiology, 2002). Behavioral factors did not explain the susceptibility of these women to HIV infection as it was mostly attributed to the presence of STIs. The ulcerating effect of STIs accounted for the increase in HIV transmission among the women with other reasons not being

discounted (Population Council Epidemiology, 2002). The study also provides a picture of disability among women as other studies have either had very few female subjects or excluded them. In Sub-Saharan it is estimated that 60% of those infected are women (Morton, 2003). The UN (2001) highlights that this increase is attributed to the vulnerabilities of women and girls. In particular cultural practices such as polygamy, sexual coercion and gender violence heighten their risk to HIV/AIDS infection. In addition, social norms that deny women sexual health knowledge and practices to control their bodies (e.g. the choice to use condoms) and which offer limited access to economic opportunities, all enhance their vulnerability (UN, 2001).

Although HIV/AIDS affects all age groups, those in the reproductive age seem to be most vulnerable. A study group (Population Council Epidemiology, 2002) on the heterogeneity of HIV indicated that the prevalence of HIV infection was more widespread in both men and women in the 25-49 year age group, a finding that is similar to the results of the present study. In the present study the highest number of respondents was in the 25-35 years age group followed by the 35-45 years age group. In Zambia, the HIV/AIDS prevalence increases with age from about 11% among the 15-24 year old to 25 % among those in the 30-45 age group and decreases from 45 years onwards (The Millennium Development Goals Progress Report, 2003). Several causes can explain the reasons for the susceptibility of this age group, the aspect of gender inequality in sexual negotiation, men marrying younger girls when they have had several sexual partners and cultural perceptions of sex include reasons why this group is at a greater risk for being infected with HIV. (Garbus, 2003).

5.2.2 Area of Residence

The study revealed that 73.7% of the respondents live in John Laing, an informal settlement. This is due to the densely populated nature of the informal settlements in Lusaka, Zambia. The World Bank (2002) confirms that, out of 1.2 million inhabitants of Lusaka, 800,000 live in informal settlements. An explanation for this phenomenon is that people are living in poverty and tend to prefer cheaper housing options, which are found in the informal settlements.

It can thus be stated that poverty and disability are closely intertwined, poverty increases people's vulnerability to HIV/AIDS, and other infectious diseases. Poverty can contribute to the exacerbation of disability among PLWHA as it affects nutrition, access to medical care and the ability to live in safe environments, factors that can all impact on impairments, activity limitations and participation restrictions.

5.2.3 Marital Status

The study revealed that 87 (41.6%) of the participants were married and 61 (29.2%) were widowed. The reason explaining this occurrence is that because of the high mortality among people with HIV/AIDS their spouses may be dying due to AIDS. Lawrence (2004) indicated that marriage in itself does not protect partners from HIV/AIDS infection. Moreover, an observation was noted in Zambia of younger brides contracting HIV infection within the marriage, as they tended to marry older men. Hence, they were unlikely to use condoms to protect themselves within the marriage, because cultural marriage practices do not publicly advocate for condom use within marriages. Other

reasons that perpetuate HIV/AIDS infection in marriage in Zambia are traditional practices of widow inheritance and sexual cleansing (Kapambwe, 2004). In addition it can be stated by the researcher that widowed participants and their families were likely to encounter hardship when they became ill due to lack of support.

5.2.4 Employment Status, Educational Status, and Income

The three factors of employment, education and income are interconnected in some way and can not be disassociated from each other. As will be observed, when people have less education, their employment status can be affected, ultimately affecting their incomes. This has its own implications when people are living with HIV/AIDS. When people have AIDS, depending on the stage, they may have difficulty keeping a job because of the recurrence of opportunistic infections. These opportunistic infections may at times require hospitalization for extended periods of time, which may jeopardize the ability to hold a job, particularly low income employment. This could eventually lead to unemployment and no income or benefits for survival for PLWHA.

The World Fact book (2004) illustrates that the economic decline in Zambia has brought about severe unemployment, which is currently estimated at 50%. This may explain the high unemployment rate of 56% among the participants of this study.

Given this scenario, those who manage to find employment usually earn low incomes which are insufficient to sustain them. It is believed that almost three quarters of Zambia's population live below the poverty line of US\$1.00 a day (The Millennium Development Goals Report, 2003). This means that there is widespread poverty as can be observed in the majority of the participants of whom 105 (50.2%) fell in the low income group with earnings under R 328.50 South Africa Rand equivalent, while 72 (34.4%)

participants had no income. Hays et al (2000) further confirms that low income among PLWHA has also been associated with poor physical function because they are then unable to afford good nutrition, housing and medical care, among others.

The Makeni home-based care programme has on occasion initiated some income generation programmes for eligible clients. These initiatives assists a few participants, of their clients increase their income earning potential.

Education is vital in building people's skills and ability to process information for livelihood choices including issues related to HIV/AIDS prevention (The Millennium Development Goals Report, 2003). The low level of education among the participants may equally lead to low employment rates among this group. Most of the respondents in the study (52 %) only attained a primary school education, followed by 72 (34%) participants with a secondary school education. The high illiteracy level in Zambia, which is currently at 60% (Mpundu & Schaeffers, 2002) and the lack of expansion in the education sector in the wake of high population growth, may contribute to the stagnation of Zambia's economic growth (Siaciwena, 2000). Hence high levels of poverty and an increase in the incidence of diseases has surfaced, among them is HIV/AIDS (Siaciwena, 2000).

In this study there were no college or university graduates among the participants. The finding is contrary to a study done by O'Dell et al (1996) in which 20% of the participants had attained a college or university education, with another 14% having attained graduate or professional education. Crystal et al (2000) further asserted that those "who were more educated were likely to get better jobs, which could afford them

better health care therefore remaining economically productive well into their HIV disease process”.

SECTION B

5.3 IMPAIRMENTS OF THE RESPONDENTS

Most of the participants noticeably reported mild impairments in the legs and in the arms (52% and 36% respectively) followed by moderate impairment in the legs and arms (27% and 21% respectively). The impairments occurred due to a variety of reasons. One of the reasons could be the fact that PLWHA present with a legion of symptoms, some of which are constitutional symptoms (night sweats, fevers, diarrhea, and fatigue) as well as neurological symptoms, which could contribute to the occurrence of impairments (Cunningham et al, 1998). The mild degree of impairments reported by the sample may have occurred because most of the participants were not in the advanced HIV/AIDS disease stage.

Secondly given this situation of the existence of more than one symptom in HIV/AIDS which negatively affects the body systems, it was not surprising to observe mild and even moderate impairments of the legs and arms as assumed by the researcher because of their frequent functional involvement in various activities (e.g. in walking and doing house chores). The likelihood of early signs of motor deficits, or sensory deficits or malaise from the systemic effects of the HIV/AIDS illness could also have contributed to the mild and moderate impairments.

Because this was a community based sample, it is probable that they may not have been presenting with acute symptoms as a hospital based HIV/AIDS group would, i.e. in the acute disease stages to present with severe impairments. In one of the earliest studies of disability by O'Dell (1989) disability was noted among a hospital based sample. This could explain the low impairment rate among this community based sample who generally reported only mild impairments. In addition, a strong relationship between symptoms and increased disability has been documented (O'Dell, 1993).

Since HIV/AIDS is often characterized by unpredictable cycles of good health and poor health, (Canadian AIDS Society & Canadian Working Group on HIV and Rehabilitation (2003), a cross sectional study such as this may not have been able to capture the whole picture of impairments among the participants. Therefore an individual body may be critically overwhelmed with the symptoms of HIV/AIDS such that they may be incapacitated, but would after a few months or so experience good health and be able to function normally.

In contrast with the present study a study by Rush et al (2004) in British Columbia demonstrated high levels of impairments among PLWHA in a cross sectional study. Specifically, sensory impairments and neuromuscular impairments were documented as impairments that affected the upper and lower limbs (71.9% and 49.5% respectively). In the same study however, the researchers found systemic impairments to be even more prevalent (81.0%) than the two previously mentioned impairments again confirming a strong relationship between symptoms and increased disability (O'Dell, 1993).

5.3.1 ACTIVITY LIMITATIONS & PARTICIPATION RESTRICTIONS

In examining activity limitations and participation restrictions three aspects were covered, these being; mobility, self care and life activities. The findings on activity limitations relating to mobility demonstrated that the majority of the participants 74% (154) encountered mild to moderate difficulty in mobility activities. Sixty two percent (129) experienced mild to moderate difficulty in standing up from sitting. The finding is supported by O'Dell et al (1996) who indicated that deficits in mobility usually occurred in activities that required more endurance and were labour intensive. More than 83% of the sample experienced mild difficulty in mobility activities, implying that they were able to perform mobility activities but felt that their performance had deteriorated.

Regarding self care activity limitations, the sample did not show any major limitations in this area, and presented with mild to moderate difficulty among a few participants overall. Only a few participants (6.2%) reported moderate difficulty in the area of washing one self. Moderate difficulty in walking to the toilet was experienced among 12 (5.7%) of the participants. The participants did not have significant difficulty in dressing, or eating by themselves. The few who required assistance in washing themselves may have encountered difficulty in collecting and lifting water for bathing as most of their homes had no running water indoors particularly in John Laing township. Six participants required assistance in walking to the toilet (pit latrine) as they were located out side and they had steep stairs leading up to the toilet. This finding was not surprising as there have been few activity limitations in self care activities observed among PLWHA, most of them have been observed in instrumental activities of daily living and mobility activities

(O' Dell et al, 1996). On the other hand, however, Kapantaise & Powell Griner in an earlier study found 40%-60% of PLWHA (in their last year of life) required assistance in self care activities. Self care deficits appear to be more prominent in advanced HIV/AIDS disease. It is therefore likely that the sample may not have been in an advanced HIV/AIDS disease stage to exhibit more self care limitations.

The third aspect of activity limitations investigated was related to life activities. The sample reported the most limitations in this area. Seventy five (35.9%) respondents experienced moderate difficulty in performing household chores. Household chores involved activities such as those related to collecting water, cleaning the house and cutting grass among others. Moderate difficulty in performing previous roles was reported among 54 (25.8%) respondents. Previous roles, for instance were activities such as visiting friends and family and activities related to parenting. Carrying out a job was also reported as presenting with moderate difficulty among 36 (17.2%) respondents, while thirty six (17.2%) others experienced severe difficulty in carrying out a job. Of all the categories investigated, life activities presented with the most participants (55%) experiencing severe limitations. Carrying out a job and performing previous roles were the two activities that presented with relatively high numbers of respondents encountering severe difficulty, as can be observed among 17.2% of them in each category. This was followed by severe difficulty among 20 (9.6%) participants in both household chores and community activities. The findings of the study are consistent with the study by Crystal et al (2000) in which more than half of the PLWHA demonstrated limitations in carrying out work, previous roles or household chores. It was further observed that PLWHA had difficulty performing multiple tasks in a sequence as is

expected in performing these roles. Sabesta & La Plante (1996) also asserted that persons with advanced HIV/AIDS disease tended to experience difficulty in the stated roles. The authors reiterated that difficulty in carrying out a job particularly was not only restricted to work intensity but that the progression of one's health condition (HIV/AIDS) necessitated a challenge in carrying out a job (Sabesta & La Plante, 1996). Unfortunately the sample used in the present study, as evidenced by the low level of education are likely to engage in manual jobs, thus making it all the more difficult to carry out any form of employment.



5.4 ENVIRONMENTAL FACTORS

5.4.1 Support & Relationships

The study revealed that the majority of the respondents 183 (87.6%) felt they had the support of health professionals followed by personal provider support among 84.7% respondents. The least reported support appeared to be from family members, with only 80 (38.3%) participants indicating that they received family support. Makeni home-based care programme provides a clinic every once a week and personal providers (care givers) visit their clients regularly. The participants found this service supportive. This finding is similar to an earlier study by Kapantaise & Powell Griner (1989) in which it was observed that 38% of PLWHA in their study were being cared for by either a friend or a neighbour (personal providers) which was not the case among those who had a non AIDS infection. A family member cared for ninety percent of the latter group.

Takai (1998) asserts that if PLWHA receive support and care services they improve their chances of being cared for longer than those not receiving any form of support. On the other hand, literature indicates that many PLWHA do not have strong family support (Martin, 1998). This is because family members may still have a fear of contracting HIV infection as they have poor knowledge of its transmission.

5.4.2 Attitude

Attitudes towards PLWHA could be manifested as negative or positive and could stem from family members, health care professionals, personal providers and the community. In this instance, the present study showed that 110 (52.6%) of the participants experienced their family attitude as unsupportive. On the other hand 186 (89.0%) and 183 (87.6%) participants reported that they experienced the attitude of health professionals and personal providers as supportive. A study by Inoue et al (2004) in a Japanese study, illustrated that PLWHA encountered negative attitudes from parents, spouses, partners and friends and that these difficulties were not easily identifiable, as they are not as apparent as impairments. On the contrary, however, even though PLWHA expressed anxiety over negative attitudes they still limited their social networks to themselves and their families and health professionals (Pakenham, 1998). This finding concurs with De Bruyn (1999) who observed that PLWHA experienced stigma and discrimination, to counter this negative attribute PLWHA tend to isolate themselves. The author advised that efforts that encourage support for PLWHA are required so that their functional ability is facilitated.

5.4.3 Physical Barriers

People living with HIV/AIDS may experience barriers or facilitators that may negatively or positively influence their disability (WHO, 2001). One of these environmental factors is the aspect of physical geography. In this particular instance rehabilitation professionals may prevent disability by altering an impeding environment by using adaptive equipment or modifying the environment (DeLisa, et al 1993). This service is not available in Zambia due to lack of trained personnel.

The results of the present study indicated that 87 (41.6%) respondents found that the physical geography around the house was helpful while 87 (41.6%) others did not find that physical geography around their houses helpful. The complaint related to the physical geography not being helpful may be attributed to the rocky terrain that was particularly visible in John Laing (Informal settlement), where rocks are visible and the participants encounter them every day. The other reason that the participants may have found the physical geography around the house being unhelpful, could be due to poorly constructed steps on the entrance of their homes and some of their toilets (pit latrines). The researcher observed that these steep steps in particular made climbing difficult. Therefore, the physical geography proved to be a barrier instead of a facilitator.

Furthermore, the results revealed that statistically there was a significant difference between the two levels of physical geography (i.e. between those who reported that physical geography around the house was helpful and those who indicated otherwise) against activity limitations & participation restrictions. This implied that there was a

relationship between physical geography and activity limitations & participation restrictions in the sample.

5.5 AGE & ACTIVITY LIMITATIONS & PARTICIPATION RESTRCITIONS

The study found that those who were younger and between 15-40 years had fewer activity limitations, than those who were older and in the 41- 70 years age group. Crystal et al (2003) observed that older patients experienced more physical limitations; a finding that was also noted by Hays et al (2000) in which older age was associated with poor physical function.



Both age groups were most affected in mobility activities. This finding was consistent with O' Dell's (1989) earlier study of a hospital based sample in which mobility deficits were common and present. Particular mobility limitations in this sample were observed in stair climbing and ambulation. This sample, however, was in the CDC group IV of the AIDS classification where more impairments are expected to be present. Kapantaise and Powell Griner (1989) in the first disability study among PLWHA in the last year of life equally observed that PLWHA experienced difficulty in walking.

It was surprising that the age groups in the present study reported difficulty in mobility, since the participants generally reported mild impairments.

5.6 GENDER & ACTIVITY LIMITATIONS & PARTICIPATIONS RESTRICTIONS

In the present study HIV/AIDS affected both gender in respect of activity limitations. It was demonstrated that males presented with more activity limitations & participation restrictions than their female counterparts. This occurrence is inconsistent with the studies by which more women than males were observed to present with functional deficits (Crystal & Sambamoorthi 1996; Sabesta & La Plante; 1996). In their studies they attributed this finding to the fact that women were usually the care givers of their family members even when they were experiencing poor health. Health. On the contrary in Zambia it may be assumed that because women are expected to take on the caring role of taking care of the family, they may be forced to be in a situation in which they appear to be stronger even when their health may be failing, whereas the males are not pressured to this societal expectation and so they may appear to be most affected in respect of their activity limitations and participation restrictions.

5.7 THE EFFECT OF SOCIAL SUPPORT ON ACTIVITY LIMITATIONS & PARTICIPATION RESTRICTIONS

The present study further tried to determine the association between social support and activity limitations. Among the categories in social support were family support; personal provider support; health professional support and community support.

Those who indicated having family support appeared to have more mobility limitations unlike those who indicated otherwise. This could be expected because family members are likely to support and help the family member with HIV/AIDS when they are experiencing difficulties in activity limitations and participation restrictions. This is a possible explanation as Zambians believe in supporting the extended family value system. When the extended family decides to take care of the individual living with HIV/AIDS it is generally expected that they will tend to the needs of the HIV/AIDS affected person under their care. However, this may not always be the situation. A study by Panos Institute (2001) indicated that in Zambia people were willing to take care of a family member with HIV/AIDS, these families preferred however to keep the HIV status of that family member a secret. In addition it was stated that the highest rate of discrimination and stigma towards PLWHA is encountered in the home and at health care professionals.

On the other hand those who indicated that they had no assistance or support from personal providers and health professionals demonstrated more activity limitations in the area of mobility. PLWHA can experience anxiety over their status and therefore may restrict themselves to avoid them being identified with the HIV/AIDS disease by seeking treatment at clinics or centers where people they are familiar to, may notice them (Inoue et al, 2004). Similarly some of the PLWHA in the Makeni home-based care programme may not have wanted the association of the nurses or the care givers as their neighbours would associate them with having HIV/AIDS. The resultant effect of this behaviour is that if they develop impairments that require immediate medical attention they may not

do so therefore putting their health at risk as this would not be brought to the attention of the medical personnel.

5.8 THE EFFECT OF ATTITUDE ON ACTIVITY LIMITATIONS AND PARTICIPATION RESTRICTIONS

The study further assessed the effect of attitude on activity limitations and participation restrictions. In the study the participants with the most activity limitations and participation restrictions indicated that the attitude of the health care workers was unsupportive. These participants experienced the most limitations in mobility related activities. This attitude could have affected the participants to accessing any medical care as they felt that they were perceived negatively. Panos Institute (2001) indicated that extremes form of stigma towards PLWHA had been observed among health care workers. According to Panos Institute (2001) the reasons for this negative attitude towards PLWHA by health care workers was reported to be because of the difficulty encountered due to their multiple infections, “hysteria” and “attention seeking” among people with HIV/AIDS. Furthermore in the same study it was reported that PLWHA were not given the same services as they were believed they were going to die hence less time was spent on PLWHA. The reasons for the participant’s perceived negative attitude could be due to experience encountered with health care workers or may due to their own self perception and how they think they are viewed.

5.9 SUMMARY

This chapter has expounded on the findings of the study on “physical disability among HIV/AIDS adults cared for by the Makeni home-based care givers in Lusaka, Zambia”. In particular the socio-demographic data of the participants, the impairments, the activity limitations and participations restrictions and the environmental factors as well as how the environmental factors affect activity limitations and participation restrictions were discussed.



CHAPTER 6

SUMMARY, CONCLUSION, RECOMMENDATIONS AND STUDY

LIMITATIONS

6.1 SUMMARY

The study aimed to investigate the nature of physical disability among HIV/AIDS adults cared for by the Makeni home-based carers in Lusaka, Zambia. Disability was measured based on the WHO International Classification of Functioning, Disability and Health. The study identified that the sample reported mild to moderate impairment particularly in respect of the legs (51.7%) and the arms (16.3%). Minimal impairments were reported relating to the functions of seeing, hearing and bladder control. The study found that the participants also reported mild to moderate difficulty in activity limitations and participation restrictions. However, when the activity limitations were investigated independently the most limitations were reported to be in the area of mobility activities and the least reported among the self care activities. Activity limitations pertaining to life activities revealed that participants reported experiencing moderate difficulty in performing household chores (35.9%) followed by moderate difficulty in the assuming previous roles (17.2%). Fifty five percent of the participants reported experiencing severe difficulty in the area of Life activities. Regarding environmental factors, the majority 89% and 87.6% of the participants reported that they had support from their personal providers, followed by health care personnel respectively. But on the contrary, the participant's attitude from their family members was reported as unsupportive among 52.6% participants. Concerning the environmental factor relating to physical geography half of the participants found physical geography around the house helpful while the other half found it unhelpful, a significant difference ($p < .001$) was found

between the two levels of physical geography (between those who specified that physical geography was helpful in comparison to those who indicated otherwise). This was particularly applicable to the participants living in John Laing township.

The study further showed that the younger participants reported fewer activity limitations than those who were older and in the 41-70 age group. Information relating to the effect of gender on activity limitations and participation restrictions demonstrated that males were more affected in their activity limitations than the females. When investigating the effects of social support on activity limitations and participation restrictions the respondents reported that those with family support reported more activity limitations probably because they became dependant on the available family support. On the other hand those with those who reported an unsupportive attitude from the health care workers demonstrated having the most activity limitations and participation restrictions.

6.2 CONCLUSION

The results of this study indicate that the majority of the PLWA managed by the Makeni home based carers have minimal impairments in the legs and arms. They also reported having mild to moderate difficulty in the area activity limitations and participations restrictions, which included mobility, self care and life activities. The participants experienced the most limitations in the area of life. This area included activities such as household chores, performing previous roles and carrying out a job. In addition the majority of the respondents reported that they received the most support from health professionals and that they found the attitude of family members unsupportive.

6.3 RECOMMENDATIONS

The following recommendations are made on the basis of the findings in this study.

Some recommendations from the present study could facilitate more efficient rehabilitation services if the following recommendations are considered.

- i) HIV/AIDS counseling and testing should be available and for all people being cared for by community home based care programmes. Services could then be targeted specifically at PLWHA, who have been scientifically tested instead of relying on WHO staging system.



- ii) Physiotherapists could play a role in the evaluation and management of PLWHA in the Makeni home-based care programme. Particularly of benefit could be advice and education on energy conservation methods for PLWHA that are experiencing severe difficulty in life activities. This could be achieved by educating caregivers or the individual participants themselves. Assessment and management of neurological impairments experienced by PLWHA could be beneficial as this could improve their function and prevent disability.
- iii) Further research using a random sample and a valid instrument, which captures observed levels of function, is recommended to further document the activity limitations and participation restrictions of people living with HIV/AIDS in Zambia.

6.4 LIMITATIONS OF THE STUDY

- i) The study was based on a convenient sample, therefore bias may have affected the results of the study.
- ii) The participants were admitted to the Makeni home based care programme based on the WHO staging system. The accuracy of this assessment can be questioned and may have influenced the outcome of the results particularly in impairments, activity limitations and participation restrictions. Participants that may not have been HIV positive could have been part of the research subjects.
- iii) The inability to classify the participants HIV/AIDS stages weakened the study. This was an unforeseen problem as it could have provided the researcher with the level of HIV disease stage of the patient, which could have influenced their impairment levels therefore the results of the study.
- iv) A qualitative research design may have conveyed more in-depth information especially regarding the environmental factors and how they affect physical disability among PLWHA.

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