

**THE BUDDY SYSTEM OF CARE AND SUPPORT  
FOR AND BY WOMEN LIVING WITH HIV/AIDS IN BOTSWANA**

by

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**DECLARATION BY THE CANDIDATE**

I declare that **THE BUDDY SYSTEM OF CARE AND SUPPORT FOR AND BY WOMEN LIVING WITH HIV/AIDS IN BOTSWANA** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

**14 February 2004**

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SIGNATURE

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DATE

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## SUMMARY

A needs assessment during 2000 guided the design of a buddy system in Botswana. Implementation of this care and support system for and by 39 HIV+ve female buddy-client pairs started in 2002. During April and November 2002, levels of disclosure, self-care, support and quality of life of buddy-client pairs and the controls (n = 38) were compared. Orem's self-care theory, Maslow's hierarchy of needs and Cohen and Syme's conceptualisation of social support formed the theoretical framework. By November 2002, clients' disclosure levels, self-care for TB, and antiretroviral therapy adherence had improved. Higher income, higher education and older age predicted higher levels of self-care for antiretroviral therapy. The social support survey reported satisfaction with types of support available in November 2002 (N = 112). Clients' scores for self-care for TB, antiretroviral therapy and social support improved more than those of controls over the study period. The personal resource questionnaire measured perceptions of support: buddies' scores increased more than those of clients. Women on antiretroviral therapy completed the adherence attitudes inventory in April and November 2002 and reported a downward trend in adherence. Findings of the quality of life (SF 36) instrument showed that during the six-month study period, physical and mental health component summary scores improved but remained low (N = 112). During 2003 Botswana's community-based buddy-support programme was adopted by four other countries in Southern Africa in an attempt to enhance the quality of life of HIV+ve women in these countries.

The following key words form the core of this study:

Buddy system for HIV+ve women; Community-based care; Disclosure of HIV+ve status; HIV/AIDS in Botswana; Maslow's hierarchy of needs; Orem's self-care theory; Quality of life of PLWH/A; Situational analysis: HIV/AIDS in Botswana; Social support theory; Women living with HIV and AIDS

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**KEY CONCEPTS**

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- **Buddy system for HIV+ve women**
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- **HIV/AIDS in Botswana**
- **Maslow's hierarchy of needs**
- **Orem's self-care theory**
- **Quality of life of PLWH/A**
- **Situational analysis: HIV/AIDS in Botswana**
- **Social support theory**
- **Women living with HIV and AIDS**

## ABBREVIATIONS

AAI	Adherence Attitude Inventory
AIDS	Acquired Immuno-Deficiency Syndrome
ANOVA	Analysis of Variance
ARV	Antiretroviral
ARVs	Antiretroviral Drugs
AZT	Zidovudine
Batswana	Citizens of Botswana (Plural)
BIDPA	Botswana Institute for Development Policy Analysis
BMIS	Botswana Multi Indicator Survey
BOTUSA	Botswana-United States of America Project
BWP	Botswana Pula
CCM	Country Coordinating Mechanism
CD4	Membrane Protein or Receptor of T-Helper Lymphocytes
COCEPWA	Coping Centre for People Living with HIV/AIDS
CSO	Central Statistics Office
DF	Degrees of Freedom
DOTS	Direct Observed Treatment Strategy
GDP	Gross Domestic Product
GOB	Government of Botswana
HBC	Home-Based Care
HIS/MOS	Health Insurance Study Experiment/Medical Outcomes Study
HIV	Human Immune-Deficiency Virus
HIV+ve	Human Immune-Deficiency Virus-Positive
HIV-ve	Human Immune-Deficiency Virus-Negative
INH	Isoniazid
IPT	Isoniazid Preventive Treatment
MASA	“New Dawn” (in language of Botswana) - National Antiretroviral Treatment Programme
MCS	Mental Health Component Summary

MLHA	Ministry of Labour and Home Affairs
MOH	Ministry of Health
Motswana	Citizen of Botswana (Singular)
MOS	Medical Outcomes Study
NACA	National AIDS Coordinating Agency
NGO	Non-Governmental Organisation
NNRTI	Non-Nucleoside Reverse Transcriptase Inhibitor
NRTI	Nucleoside Reverse Transcriptase Inhibitor
OI(s)	Opportunistic Infection(s)
ORS	Oral Rehydration Solution
PCS	Physical Health Component Summary
PI	Protease Inhibitor
PID	Pelvic Inflammatory Disease
PLWA/H	Person Living with AIDS or HIV
PLWA/Hs	People Living with AIDS or HIV
PMTCT	Prevention of Mother-to-Child Transmission of HIV
PRQ-II	Personal Resource Questionnaire Part II
QOL	Quality of Life
QWB	Quality of Well-Being
SD	Standard Deviation
SF-36	Short Form 36
SPSS	The Statistics Package for Social Sciences
SSS	Social Support Survey
STD	Sexually Transmitted Disease
TB	Tuberculosis
UK	United Kingdom
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNISA	University of South Africa
USA	United States of America
USD	United States Dollars

VCT Voluntary Counselling and Testing  
WWW World Wide Web  
WHO World Health Organization

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## **CHAPTER 1**

### **ORIENTATION TO THE STUDY**

#### **1.1 INTRODUCTION**

In Botswana, the country with the highest recorded Human Immune-Deficiency Virus (HIV) prevalence in the world, nobody escapes the impact of this devastating epidemic (NACA 2002:49; UNDP 2000b:7). The citizens of Botswana are either affected by or infected with HIV or Acquired Immuno-Deficiency Syndrome (AIDS). However, not all is lost and efforts are being made to keep the next generation free of HIV infection; adults are being educated about the importance of knowing their serostatus, and people living with AIDS or HIV (PLWA/Hs) are encouraged to prevent the transmission of HIV.

This first chapter of this study provides background information about Botswana and highlights the unique challenges and opportunities presented by the war against AIDS in this country. There is tremendous pressure on the health-care system, with professional caregivers afforded little time to provide all the care and support that most of the PLWA/Hs need. This chapter describes the services that the government and voluntary organisations have developed in response to the AIDS epidemic. However, as this first chapter explains, the commendable efforts of the Botswana government to expand the health infrastructure and the provision of free curative services have not broken down some other barriers to the accessing of health care and support. More specifically, it is explained that the stigma of the condition, denial and a perceived lack of social support might have a negative impact on the coping and self-care abilities of many PLWA/Hs in Botswana.

The aim of the present study was to investigate whether increased social interaction as a result of a new “buddy programme,” that offers peer support and care, has resulted in higher levels of self-care, positive interaction and improved quality of life among women living with HIV in Botswana.

## 1.2 BACKGROUND TO THE STUDY

Botswana extends over 600 375 km<sup>2</sup> landlocked country (more or less equal in area to France) located in the centre of southern Africa. Botswana shares borders with South Africa, Namibia and Zimbabwe. It has a population of nearly 1.7 million people, 40% of whom are under 18 years of age. About two-thirds of Botswana, west of the cities, is taken up by the Kalahari desert; for this reason most of the people live in the Limpopo River valley, where water resources are more reliable. The concentration of people in this relatively small arable area creates a population density crisis that belies Botswana's land-to-population ratio of 3 persons per km<sup>2</sup> (Tlou 1996:27).

The official language is English, but most people speak the national language, Setswana. Ethnic groups are the Tswana (79%), Kalanga (11%), European (6%), Basarwa (generally known as Bushman or San) 3% and 1% other groups. The largest city is Gaborone, with a population of 223 000; it is one of the fastest-growing cities in the world. Christian beliefs are held by 50% of the population, while 50% follow indigenous beliefs. Many local churches combine traditional beliefs with those of Western Christianity; the largest is the Zion Christian Church. Botswana has a unitary government. Nine district councils and five town councils administer local government. District Commissioners have executive authority and are appointed by central government (Tlou 1996:27). Despite these assignments, Botswana has achieved only limited success in the decentralisation and devolution of authority to the local level. This is partly because the central government controls the finances and there is a scarcity of qualified personnel at local level across professional disciplines; it is this scarcity that also plagues the health-care system. The last elections were held in 1999, when the Botswana Democratic Party won 33 of the 40 contested National Assembly seats. The opposition's performance was dismal, largely due to internal factions. The next elections will be held in October 2004. The current Chief of State and head of government is His Excellency the President Festus Gontebanye Mogae. When the president came to power in April 1998, he inherited a stable democratic political system, coupled with 30 years of continued growth. Compared to other countries on the African continent (or even most

developing countries), this is a remarkable achievement. Since independence in 1966, elections have been contested freely and fairly, and political differences have been managed within the democratic framework (BIDPA 2000a:20; UNDP 2000a:10).

### ***1.2.1 Challenges in Botswana***

When the country gained independence in 1966, Botswana's economy was based largely on agriculture and migrant labour, and it was among the poorest in the world. However, with the discovery of diamonds in the early 1970s, Botswana has shown a dramatic economic growth rate of per-capita income and enjoys healthy fiscal and balance of payment surpluses. By the late 1980s Botswana was the largest diamond producer in the world. To avoid dependence on the diamond market, the Botswana leadership aims to diversify the economy and thereby reducing the vulnerability of relying on one product. The country has channelled the gains from its economic growth to finance the country's infrastructure, including a primary health-care system with clinics and hospitals near to where people live, and has provided employment. Nevertheless, one of the challenges faced by the Mogae administration is poverty. Although the country has some 7 billion USD (United States Dollars) in foreign reserves and a per-capita income of USD2600, the proportion of households below the poverty datum line was 22% and 35% of the labour force was reportedly unemployed (Republic of Botswana 2003:17). As a result the society is divided into the Botswana elite; the urban poor, who benefit little from the country's wealth; and the rural population, whose low incomes are supplemented by income in kind. More than 60% of the nation's cattle, a traditional measure of wealth, are owned by less than 10% of the population. The top 20% of the population enjoy 59% of the national income, while in contrast the poorest 20% of the population share 12% of the national income. The government has set programmes in motion aimed at reducing poverty by half by 2012. The fact that the Botswana economy is growing at a rate of 6.6% is helping the government in this endeavour. However, concerns have been expressed about the negative effects of the HIV/AIDS epidemic, which currently affects 38.8% of the economically active population. Botswana is the worst HIV/AIDS affected country in the world, with an estimated 258 000 Botswana (citizens of Botswana) aged 15-49 years being infected with HIV, out of a population of 1.7 million. The prevalence

of HIV among pregnant women aged 15-49 years was, in 2000, found to be 35.4%. The highest age-specific rate was among women aged 25-29 years. About 85 people are infected with HIV every day, and one out of eight babies is infected with HIV at birth (NACA 2002:49; UNDP 2000a:7).

### ***1.2.2 The AIDS epidemic in sub-Saharan Africa***

As of December 2002, an estimated 42 million people worldwide were living with HIV/AIDS. These include 3.2 million children under fifteen years of age and 19.2 million women. Current estimates from the Joint United Nations Programme on HIV/AIDS (UNAIDS) are that 29.4 million of these 42 million PLWA/Hs are living in sub-Saharan Africa. A total of 5 million people are thought to have been newly infected with HIV during 2002. Ninety-five percent of the new infections were in the developing world. The total number of AIDS deaths in 2002 were estimated at 3.1 million; since the beginning of the epidemic more than 21 million people worldwide have died of AIDS, many of them of diseases such as Tuberculosis (TB) in addition to AIDS (UNAIDS & WHO 2001:3).

In the early 1990s no one realised the extent to which HIV could become a problem in sub-Saharan Africa. While some countries, notably Uganda and Senegal, and more recently Zambia, have been credited with achievements in limiting and reversing the spread of HIV, other countries such as Botswana have seen a rise to levels that were previously thought to be extremely unlikely. Mortality across all age groups is on the rise and life expectancy has declined (Republic of Botswana 2003:16).

As the numbers of PLWA/Hs rise and sexual risk-taking remains constant, the likelihood of acquiring HIV becomes greater, simply because the pool of people with HIV is larger and the chance of meeting an HIV-infected partner in countries such as Botswana is one in three for adult men and women between 15-49 years of age (NACA 2001:ix). As in other African countries, rates of infection among young women in Botswana are three times higher than those found among young men. Young women are much more likely to have sex with, or be coerced into sex by, older men with more sexual experience and are

thus placed at risk. Women are less likely to be able to negotiate condom use because of the power imbalance between the sexes (Republic of Botswana 2003:16). The worst of the epidemic's impact in sub-Saharan Africa remains to be felt. Although the epidemic might not have reached its peak, the situation has already been of great concern since the 1990s. The recorded deaths in hospitals increased by 20% from 1998 to 1999 (Central Statistics Office 1999:56). Not only is Botswana faced with increasing morbidity and mortality from both TB and AIDS, but in many districts patients are turned away or discharged early due to the incapacity of health institutions to cope with the large influx of patients. Staff shortages have resulted in the forced closure of some wards in hospitals since the first quarter of 2001. This has increased the pressure on already overburdened staff at the remaining clinics and hospitals (UNDP & GOB 2000:20). The estimated cost of Botswana's national response for HIV/AIDS during the 2003-2009 strategic planning period is Botswana Pula (BWP) 12.6 billion of which BWP1.9 billion (15%) of the budget is dedicated to the costs associated with the provision of antiretroviral drugs (ARVs) (Republic of Botswana 2003:95).

### ***1.2.3 Home-based care programme***

During 1996, BWP50 million was allocated by the Ministry of Health (MOH) of Botswana for the development and strengthening of a community-based network of lay carers who were trained to provide home-based care (HBC) for terminally ill AIDS patients (Fidzani & Attah 1996:3). This community-based care network was to be a supplementary source of care, and retired nurses were asked to re-enter the workforce to coordinate the programme. The lay carers or HBC volunteers were paid a token amount of BWP100 per month to cover their transport costs. Over 5000 terminally ill AIDS patients were discharged from hospitals into the community in 1999, and the government is reported to have spent BWP45 million for HBC in that same year (CCM 2002:6). The major burden of care in the community falls on middle-aged and older women who have been largely marginalised by inappropriate health education messages targeting youth, and have as a result limited knowledge about HIV/AIDS (Tlou 1996:29). Without adequate knowledge and resources such as gloves and disinfectants, these women were at risk of disease transmission including HIV and TB, and might contribute to the increasing

numbers of PLWA/Hs. In an earlier review of the HBC services by a team of doctors and nurses of Botswana in 1994, barriers to HBC were identified as

- (1) client migration
- (2) refusal of counselling
- (3) concerns about confidentiality, and
- (4) fear of stigma (Buwalda, Kruijthoff, de Bruyn & Hogewoning 1994:158).

This accords with the findings of the needs assessment by Zuyderduin (2000:54), which proposed making peer support available in homes to redress the stigma and discrimination surrounding HIV in Botswana.

#### ***1.2.4 Prevention of mother-to-child transmission of HIV***

To address the problem of HIV transmission from infected mothers to their unborn children, the Government of Botswana established, in April 1999, a national prevention programme to reduce the number of babies acquiring HIV infection from their mothers. The programme included a number of interventions integrated within existing Maternal and Child Health Services: access to voluntary testing and counselling by all pregnant women; availability of the ARV drug Zidovudine (AZT) to HIV-infected mothers from 34 weeks of pregnancy and to the baby for four weeks; advice on avoiding breastfeeding; and access to infant formula for HIV-infected women. The prevention of mother-to-child transmission of HIV (PMTCT) programme was rolled out from the initial two sites, Gaborone and Francistown, to the whole country by 2002. Despite full government support and funding from various sources, the programme has had a mixed reported success. After 18 months, 22% (N = 18 526) of pregnant women had agreed to be tested, and of those tested, 45% (N = 3 986) were Human Immune-Deficiency Virus-positive (HIV+ve). Only 40% of these (N = 1 582) received AZT. In total 8% (N = 18 526) of eligible mother-infant pairs received the planned ARV intervention. Possible reasons cited for this low enrolment were high levels of stigma, lack of involvement of the partners of the pregnant women, and fear of disclosure because when a woman was not breastfeeding the baby (breastfeeding being the norm in Botswana), the community concluded the reason to be AIDS (MOH 2001:9). The uptake had increased to 38 000

mothers in all districts during 2002, a 3% increase in enrolment (CCM 2002:6). As with the HBC programmes, unwillingness to disclose one's HIV+ve status to others remained an important barrier to accessing care and support. The community has been sensitised about the PMTCT programme, and family members, neighbours and others conclude that the mother must have "AIDS" as soon as they see that a newborn baby is not breastfed. Many HIV+ve women need support from the people close to them to continue with exclusive formula-feeding to protect their babies from being infected through breastfeeding, despite pressure from mothers-in-law or other influential persons in their lives to breastfeed their babies.

### ***1.2.5 Introduction of antiretroviral drug therapies in Botswana***

In Botswana's war against HIV and AIDS it was decided in 2002 to extend the PMTCT programme and make the full spectrum of ARV therapy available at four sites in the country to 19 000 AIDS patients. ARV therapy suppresses replication of HIV that causes AIDS, increases production of CD4 cells that bolster the immune system, reduces morbidity, and prolong survival among PLWA/Hs worldwide (Copson 2001:1; Li, Tubiana, Katlama, Clavez, Alt & Autran 1998:1682). The rationale underlying the decision by the leaders of Botswana to introduce ARV therapy was not only the devastation caused by the AIDS epidemic but also the reported positive experiences of other developing and developed countries that had taken this step. In the United States of America (USA), ARV therapy had resulted in a 47% decrease in HIV/AIDS deaths from 1996 to 1997, while Brazil, which had produced generic copies of essential ARVs in the mid 1990s, had achieved a 54% reduction in number of AIDS deaths from 1995 to 1999 (Schuklenk & Ashcroft 2002:180). The impact of ARV therapy in all countries that introduced ARVs included

- (1) reduced mortality
- (2) reduced morbidity
- (3) fewer hospitalisations
- (4) cost savings on reduced absenteeism in the workplace (BIDPA 2000b:55; Schuklenk & Ashcroft 2002:180; UNDP & GOB 2000:15-25).

### ***1.2.6 MASA: a new dawn - the national antiretroviral programme in Botswana***

In 2001, Botswana was the first country in sub-Saharan Africa to publicly announce its intentions to make ARVs available free of charge with nationwide extension to all AIDS patients by 2005 (NACA 2002:5). The Botswana government called the national ARV treatment plan 'MASA', the meaning of MASA in the local language Setswana, is 'new dawn'. By February 2003, a little over one year after the launch date of January 2002, 5201 patients were enrolled, and of the enrolled number 3983 patients were on ARV therapy, while 319 persons had died, a 6% death rate. To manage the demand for ARV therapy and some of the accompanying challenges, only patients with CD4 cell counts lower than 200 cells/mm<sup>3</sup> and/or an AIDS-defining illness were eligible for ARV therapy. Four priority groups identified as first patients were

- All HIV-infected children older than 6 months of age who were inpatients
- All HIV+ve TB patients with CD4 cell counts lower than 200 cells/mm<sup>3</sup>
- All adult inpatients with CD4 cell counts lower than 200 cells/mm<sup>3</sup> and or AIDS defining illnesses
- Pregnant women and with CD4 cell counts lower than 200 cells/mm<sup>3</sup> and/or AIDS defining illnesses and qualifying partners who fulfilled the same criteria (Anabwani & Jimbo 2002:12-21; Darkoh 2003:4). (See Annexure V for Botswana guidelines on anti-retroviral treatment - 2002 version.)

Treatment of AIDS has in the past decade become more effective but also more costly, with the recent development of ARV therapies that no longer use monotherapy but a combination of two to three classes of ARVs: protease inhibitors (PIs), nucleoside reverse transcriptase inhibitors (NRTIs) and non-nucleoside reverse transcriptase inhibitors (NNRTIs) (Li et al. 1998:1682). The cost of providing ARVs in Botswana, based on negotiated prices for 2002, were reported as USD1150 per patient per year for first-line treatment and USD3813 per patient per year for second-line treatment (CCM 2002:5).

The high cost of these ARVs prevents most developing countries from making them available to their AIDS patients. Not only are the drugs expensive, ARV therapy requires supply channels that can make the drugs constantly available. Provision of regular monitoring of patients is vital to detect and manage side-effects. Patients need to go through a thorough screening process of their physical health status. They receive treatment for any other infection they might suffer from and, if eligible and started on ARV therapy, to be seen by a doctor monthly for the first three months and every three months thereafter. These frequent doctor visits are important to deal with adverse side-effects, if any, and to adjust medications if drug resistances or other complications emerge. Concern is raised internationally about making ARVs available in resource-poor countries, since ARV therapy controls the progression of the disease but does not cure AIDS, is expensive and requires lifelong compliance with a complicated regime involving three different drugs. Experts maintain that providing ARVs to larger numbers of people in Africa will require major improvements in the region's health infrastructure (Amoroso, Davis & Redfield 2002:335; Republic of Botswana 2003:18-19).

Many people fear that if the ARVs are taken irregularly, resistant strains will emerge that could cause untreatable infections. The risks of providing ARV therapy to AIDS patients in Botswana, if the patients do not adhere to the regime, include damage to the individual patient and the danger of releasing drug-resistant strains of HIV into the wider population. Concurrent with ARVs being made available in Botswana, AIDS patients need to learn new self-care skills in a system that is facing serious staff shortages; is staffed by personnel who first need to be trained themselves; and which forces the AIDS patient to disclose the condition to at least one other person. One condition the AIDS patient in Botswana has to comply with is that he or she has to bring a family member to the clinic; this person is then trained to monitor the patient and remind the patient about taking the ARVs. In a society with high levels of stigma and discrimination, AIDS patients have been refused ARV treatment even after they explained to health care providers that upon disclosure they were abused and rejected by their family and that they had nobody who volunteered to come along (Zuyderduin 2000:62). No formal data are

available on the extent to which this requirement presents a barrier for certain AIDS patients.

### ***1.2.7 Non-governmental organisations***

To enhance the health-care and social-support system offered by government, voluntary associations, charities and community initiatives to address the HIV/AIDS epidemic have arisen. These are organisations that are not mainly financed by government and not under the control of government. Activities in which these non-governmental organisations (NGOs) are involved, include: service provision; research activities; provision of support services; policy advocacy; fund-raising; and co-ordination (Green & Matthias 1997:1). The voluntary counselling and testing (VCT) centres called Tebelopele and the Coping Centre for People Living with HIV/AIDS (COCEPWA) are two such recent initiatives relevant to the present study.

#### ***1.2.7.1 Voluntary counselling and testing centres***

In 2000, the Botswana-United States of America project (BOTUSA), in collaboration with the MOH, launched the nationwide network of “Tebelepele” VCT centres in support of Botswana’s “Know your status” campaign. In 2000, a pilot TB prevention programme for PLWA/Hs was launched in collaboration with BOTUSA as well, and nationwide implementation is being planned. In April 2000, BOTUSA opened the first anonymous VCT centres in Gaborone and Francistown. By the first quarter of 2003, 15 free-standing VCT centres had been opened in various parts of the country. The primary goals were to contribute to the prevention of HIV transmission, to reduce the impact of HIV and AIDS and the reduction of stigma associated with HIV and AIDS. From their inception to early 2003, over 50 000 clients have received VCT free of charge. These newly diagnosed HIV+ve persons were in need of longer-term supportive counselling and support services, services that were not available to most. The few counsellors that provided this follow-up support were mainly working for voluntary organisations and/or religious groups. To alleviate this unsatisfactory situation, PLWA/Hs have decided to start helping each other and self- support groups have started nationwide.

### *1.2.7.2 Coping centre for people living with HIV/AIDS*

With the highest reported HIV prevalence rates in the world, Botswana is experiencing the epidemic as devastating, resulting in a traumatised nation of infected and affected people. The launching in November 1999 of COCEPWA by a woman living with HIV, Helen Mhone, was in direct response to the increasing number of newly diagnosed HIV+ve men and women who had nowhere to go for care and support in Gaborone, Botswana. COCEPWA offered a safe place for PLWA/Hs to break the isolation, to support each other and to learn from AIDS activists how to challenge discrimination and demand care and support. Since its inception, staff members and volunteers who might be HIV positive or negative run COCEPWA.

To make maximum use of minimal resources within COCEPWA, it was decided during 2000 to carry out a survey asking a sample of PLWA/Hs in Botswana what their needs were, how they coped with living with HIV and if they felt discriminated against due to their HIV+ve status. Despite the fact that only 12 PLWA/Hs went public about their HIV+ve status at the time, and that COCEPWA had less than 20 members, 116 PLWA/Hs were interviewed by their peers. The recommendations made in the needs assessment report highlighted the need for a nationwide expansion of the coping centre concept. HIV+ve persons indicated that they preferred to help themselves and/or to be helped by other HIV+ve persons. Secondly, the report identified the importance of providing a community-based social support network for the HIV+ve community in Botswana to improve the quality and continuity of care (Zuyderduin 2000:54). The HIV+ve members of COCEPWA identified a lack of psychosocial support after a HIV+ve diagnosis and the need for emotional and informational support from peers.

These HIV+ve clients realised that they were still too healthy for the HBC services offered to the AIDS patients by the government. One of the findings of the COCEPWA needs assessment was that over 80% of the respondents reportedly liked to receive support from another HIV+ve person who could visit them at home and support them. In the needs assessment, data were collected on their interest in starting a “buddy system”; this was identified as an initiative in which 47% (N = 116) of the respondents of the

needs assessment would like to participate. Another 43% (N = 116) wanted to know more about the buddy system before deciding whether they wanted to be trained as buddies (Zuyderduin 2000:22).

### *The buddy system*

A draft paper to solicit funds for the proposed buddy programme in Botswana was developed by COCEPWA and a sister organisation in the USA, the AIDS Action Committee in Boston, which had been running its buddy programme since the mid 1980s (Williams 1988:38). Funding was received and the one-year pilot programme was started in October 2001. At the core of the COCEPWA peer support model was an adaptation of the American programme, which largely targeted well-educated, relatively wealthy homosexual white men. The only other sub-Saharan buddy programme, one in South Africa, was reportedly important in rendering social support, such as: instrumental support (shopping, homemaking); emotive support (consoling, compassion); and to a lesser extent informational support (Motsepe & Perry 2000:1; Williams 1988:38). The adapted Botswana buddy programme focused on buddy support to low-income, heterosexual black HIV+ve women on an one-to-one basis in their homes. In the Botswana buddy programme, only women, all HIV+ve members of COCEPWA, were trained as buddies by a team of local trainers. After successful completion of their training, they were paired up with an HIV+ve client by the Botswana buddy programme coordinator. The buddies were expected to commit from four to six hours per week to the programme and to provide information, care and support to their HIV+ve client, also a member of COCEPWA. All buddies received a stipend of BWP250 (approximately USD45) per month. The present study reports on what types of social support were rendered by the buddies and on the impact these buddies' support might have had on the quality of HIV+ve women's lives in Botswana.

### **1.3 STATEMENT OF THE PROBLEM**

In Botswana, HIV has spread rapidly since the mid 1980s, and in 2003 the epidemic continues to spread at an alarming rate, with rapid dissemination to rural areas. This poses an enormous social and economic problem. However, no official figures exist

about how many of the estimated 258 000 HIV+ve persons actually know their status. In 2002 the Botswana government estimated that it had in its care 23 000 PLWA/Hs (CCM 2002:21).

Medical professionals predicted that making ARV therapy available would break the silence and normalise the perception of HIV and AIDS. This assumption has been contradicted by lower than expected enrolment in both the mother-to-child transmission prevention programmes that offered HIV+ve pregnant women monotherapy to protect the baby from infection and the new ARV programme that offers combination therapy to patients with CD4 counts consistently below 200 cells/mm<sup>3</sup> blood (Darkoh 2003:4). In effect, it has proved difficult to reach the estimated 23 000 HIV+ve men and women, yet their health-care practices and coping skills are crucial to addressing the spread of the virus. Since this is largely a disease contracted through heterosexual transmission in Botswana, it is only the HIV+ve men and women who are in the position to commit to the slogan: “HIV stops with me!” Living up to this slogan is, however, problematic in that:

- Most Batswana *don't want to know* if they are living with HIV or not.
- Once they do know that they are HIV+ve (approximately 23 000 persons), *stigma is a barrier to care and social support.*
- If AIDS patients with CD4 levels below 200 cells/mm<sup>3</sup> are admitted to hospital with opportunistic infections (OIs) or present themselves for assessment and are started on ARV therapy, there are *no follow-up systems in the community to support adherence* beyond that offered by a patient-selected family member. Non-intentional reasons for non-adherence could be a lack of food when needed, the need to conceal the medications to avoid stigma or exposure of HIV status, or intolerable adverse side-effects - issues that a family member might find overwhelming and not be able to deal with on his or her own.

These are three of the many challenges Botswana faces in its war against HIV and AIDS: denial, stigma and a lack of community-based adherence support. The buddy programme was designed with these three challenges in mind. The underlying assumption was that

the Botswana buddy programme, providing one-to-one support to a woman living with HIV by another woman living with HIV on their own terms, would be a small step towards breaking the silence surrounding the AIDS epidemic and increasing access to the available care and support systems in Botswana.

## **1.4 PURPOSE OF THE STUDY**

The present study theorised three pathways through which the buddy system could increase the quality of life of PLWA/Hs.

### ***1.4.1 Self-care support***

The first pathway envisaged was the giving of support by the buddy to the client to encourage positive living. Having a buddy who encouraged and believed in the ability of the client to engage in self-care was expected to result in an increase in the client's self-care abilities and in general and mental health. More specifically, the present study investigated whether

- there was an increase in the number of clients who went to the clinic and requested a blood test for CD4 quantification to monitor their immune system
- the HIV+ve women started ARV therapy when they were told by the doctor that they needed it
- the HIV+ve women started or completed TB prevention therapy.

This was aimed in a broader sense at decreasing the levels of stigma, increasing the HIV+ve women's sense of control over their health and boosting their self-esteem to the extent that they were ready to tell others about their HIV+ve condition. It was postulated that in situations such as that in Botswana where there are critical staff shortages in the overwhelmed health and social support services, there might be a role for buddies. HIV+ve persons often have problems in accessing the traditional sources of support because they fear disclosing their status to their family members and friends (Zuyderduin 2000:62). It was hypothesised that adequate levels of peer support would improve the disclosure levels of the clients because they would have acquired the knowledge, skills

and self confidence to talk to their close relatives and friends about what it means to be HIV+ve, and explain to them that they were not at risk of catching the disease by living with PLWA/Hs.

#### ***1.4.2 Informational support***

The second pathway was informational support. The buddies were trained in HIV/AIDS basics, buddy skills and adherence support. After their training, the buddies were expected to teach their clients about HIV/AIDS in general, the importance and benefits of disclosure and the benefits of the ARVs, emphasising specifically the consequences of non-adherence. Measuring the attitudes-towards-adherence scores in the buddy/client pair through self-assessment reports would be useful in drawing up a model for addressing adherence problems. International reports characterise adherence as behaviour by four key components: cognitive functioning; good patient provider communication; commitment; and self-efficacy (Chesney, Morin & Sherr 2000:1599).

#### ***1.4.3 Social and emotional support***

The third pathway was in the area of emotional support and positive social interaction. Buddies were expected to give support to their clients who had received an HIV+ve diagnosis and experienced loneliness, fears and concerns about living with a disease for which there is no cure (Misovich, Fisher & Fisher 1997:95). The present study explored whether having a buddy would improve the mental health of the HIV+ve clients and assessed whether their emotional distress was reduced. Lack of social interaction, be it self-imposed or due to illness, is a stressor leading to ill health (Burgoyne & Saunders 2000:643). In summary, the study focused on the caring connections between the buddies and their clients, whether these relationships were leading to a better quality of life and what factors influenced and motivated the HIV+ve women to engage in self-care.

## **1.5 THEORETICAL ORIENTATION**

In Botswana, AIDS will shift from being the current incurable acute illness to a manageable chronic disease once an increasing number of AIDS patients are doing well on ARV therapy. The health-care practices of the PLWA/Hs and their coping skills are two important determinants of health promotion. The World Health Organization (WHO) has defined health promotion as the process of enabling people to increase control over their health and to improve it (WHO 1986:245). In the developed world in the late 1980s, self-care was proposed as one of the three key mechanisms in the health-promotion framework aimed at achieving health for all. In addition to self-care, mutual aid and the creation of healthy environments were advanced as mechanisms to meet the three major health challenges: reducing inequities; increasing prevention; and enhancing people's capacity to cope with chronic conditions. To determine predictors of self-care, Orem's model of self-care was used.

### ***1.5.1 Orem's self-care deficit theory of nursing***

Orem's self-care deficit theory of nursing describes the purpose of taking care of oneself, the capacity for taking such action and for being able to act on behalf of others (Orem 1995:153). Without knowledge about the self-care behaviours of PLWA/Hs in Botswana, it remains difficult to target interventions for the estimated 258 000 people that are HIV+ve. The present study theorised that to promote the health of the women living with HIV in Botswana, there was a need to support and guide the HIV+ve women to take actions and decisions in the best interest of their own health. Peer support was selected by the participants of a previous study as the most appropriate method of support (Zuyderduin 2000:65). The present study would be important in discovering the predictors of self-care in women living with HIV.

### ***1.5.2 Maslow's hierarchy of needs theory***

What motivates the HIV+ve women is only partly explained by Orem's theory. Although many needs were identified through a study conducted during 2000 on the needs of 116 PLWA/Hs by COCEPWA (See Chapter 3.), the question remained whether meeting

every need was *equally* important for the women living with HIV. The American theorist, Abraham Maslow, pointed out in the 1950s that there is a hierarchy of needs and that lower needs need to be satisfied first and dominate other feelings until they are satisfied (Maslow 1999:65). If, for example, an HIV+ve woman is hungry that hunger need has to be satisfied before she can consider taking care of her other needs such as belonging and self-esteem. The hierarchy of human needs progresses from lower to higher level needs as follows: physiological requirements are the rock bottom survival needs for air, food, shelter, sleep and sex. The second level comprises safety and security needs. The third level includes love and belongingness needs, the human need for warm interpersonal sharing, love, affection and affiliation. The fourth level emphasises the needs for self-esteem and esteem by others, the human need for a sense of confidence and competence, achievement, independence and freedom. At the tip of the pyramid are self-actualisation needs, the individual's need for growth, development, utilisation of potential, the need to become more and more what he/she is capable of becoming/achieving (Hoffman 1996:10; Maslow 1999:33).

Understanding motivation was important in the present study. For instance, a person who is resigned to helplessness and who does not seek the advice of others when help is needed will probably receive less actual social support than a person who copes actively by seeking advice, information, or simply someone to talk to about his/her problems. The end goal of the buddy programme was defined within the context of Maslow's theory, as aspiring to maximum personal growth and that the women living with HIV should be able to live their lives to their fullest potential.

### ***1.5.3 The concept of social support***

A lack of social support has a negative impact on health and well-being, yet it is not easy to define social support. The concept of social support has been studied in many disciplines such as social work, sociology, anthropology and medicine, and as a result many different definitions of social support have been offered. Cohen and Syme (1985:3) conducted a comprehensive review of the literature and research relative to the concept of social support. Together with the theories of Orem and Maslow, Cohen and Syme's

conceptualisation of social support guided the present study. These authors (Cohen and Syme 1985:4) succinctly defined social support as '*the resources provided by other persons*'. The importance of the above three concepts: self-care; needs; and social support, in exploring the helping connections between the women living with HIV will be further examined in the following chapters. Chapter 2 will provide an in-depth explanation and integration of these theoretical structures.

## **1.6 OBJECTIVES OF THE STUDY**

Four objectives were sought to be attained during the present research.

### ***Objective 1***

To establish whether peer support in the form of a buddy was effective towards higher levels of self-care; perceived levels and types of social support; and improved adherence attitudes between the clients (with buddies) and the control group (without buddies).

### ***Objective 2***

To describe the impact, if any, of the buddy-client relationship on reducing levels of stigma, measured on the continuum of steps towards full disclosure by both buddy and client over a six-month period in 2002.

### ***Objective 3***

To list the basic conditioning factors, if any, that are potential predictors of self-care in HIV+ve women.

### ***Objective 4***

To describe the quality of life, in terms of both physical and mental health indicators, of the buddies and their clients in the present study prior to the commencement of the relationship and six-months into the buddy-client relationship.

## 1.7 RESEARCH QUESTIONS

In attempting to establish the impact of the buddies on the quality of life of their clients, the following seven research questions guided the present study:

Research question 1: To how many persons have the clients **disclosed** their HIV+ve status at baseline and is there an increase six-months into the buddy-client relationship?

Research question 2: How did **self-care activities** develop in the buddy and the client six-months into the buddy-relationship?

Research question 3 If on ARV therapy prior to starting their buddy-client relationship, what are the **attitudes-towards-adherence** scores of both the buddy and the client and is there a difference six-months into the relationship?

Research question 4: What are the **levels of perceived support** prior to engaging with a buddy and how have these changed, if at all, six-months into the buddy-client relationship?

Research question 5: What **types of social** support are available to the buddies and the clients six-months into the buddy-client relationship?

Research question 6 What is the **quality of life**, in terms of both physical and mental health, of the HIV+ve buddies and their clients in the present study prior to and six-months into the buddy-client relationship?

Research question 7 What is the relation of the medical outcomes study short form 36 Physical Health Component Summary (PCS) and the medical outcomes study short form 36 Mental Health Component Summary (MCS) scores to the demographic variables, to the levels of self-care, social support and attitudes toward adherence among respondents six-months into the buddy system?

## **1.8 SIGNIFICANCE OF THE PRESENT STUDY**

The present study is considered significant for three reasons:

- 1 The literature reviewed did not reveal the existence of any prior research into the needs, hopes and perceptions of health by the PLWA/Hs in Botswana. This indicates that there is a gap in the existing body of knowledge about how health-care professionals in government and the voluntary organisations can support and care for HIV+ve individuals and their families. This descriptive study aimed to investigate the effectiveness and acceptability of a system of care and support which would build on the strengths of the HIV+ve community. Africa, including Botswana, is seeking acceptable, low-cost models of care that will ascertain high quality health care for the millions of PLWA/Hs.
- 2 Identifying the opportunities for and barriers to collaboration between informal caregivers such as the buddies and care professionals should lead to recommendations for addressing the critical shortages of caregivers, including nurses. The buddies are not social workers, counsellors or nurses and the buddies were trained to seek collaboration with health care professionals. This is critical. Buddies can connect the HIV+ve women with services and were expected to encourage the clients to seek early treatment for OIs, monitor their immune system and take ARV therapies when needed. These referrals to and from the buddies could result in improved communication between the HIV+ve members of COCEPWA and health care providers and as a result lead to increased and sustained high levels of self-care in HIV+ve women.
- 3 Botswana is in the unique position of offering free ARVs for people with AIDS. Full therapeutic benefit requires near-perfect adherence to prescribed regimes. The degree to which these PLWA/Hs follow their drug schedules will impact on the health of the individual client, the country as a whole and globally, since intentional and non-intentional non-adherence by individual patients can easily

result in the spread of multi-drug resistant strains of HIV. Buddies might be a community-based asset for long-term adherence support, and research into their effectiveness is therefore of value. This issue is of critical importance as ARVs do not cure AIDS, but merely control the symptoms and progress of the disease. Therefore ARV therapy involves lifelong therapy.

## **1.9 LIMITATIONS OF THE STUDY**

The limitations of the present study are that the findings in the present study of a non-random sample of 116 women living with HIV cannot be generalised to all PLWA/Hs in Botswana. The prevailing levels of stigma determined the selection of the research methods, and with increased openness a following study might use qualitative methods and explore the views of the HIV+ve women in-depth through face-to-face interviews and/or focus group interviews. The present study provided some insight into the quality-of-life of these 116 women living with HIV and reported their general and physical health scores, perceived levels of support, types of social support and attitudes towards adherence. Within all the limitations of quantitative methodology that are explained in the research methodology Chapter 5 significant findings were, however, reported.

## **1.10 DEFINITION OF TERMS**

**ADHERENCE:** The degree to which a patient follows drug schedules; a synonym for compliance; implies a steady propensity to stick to a prescribed therapeutic regimen (Murphy & Canales 2001:176).

**ANTI-RETROVIRAL DRUGS:** Drugs that treat retroviral infections.

**BATSWANA:** Citizens of Botswana (plural).

**BOTHO PRINCIPLE:** Setswana word for respect, good manners.

**BUDDY:** A close friend or companion.

**COMBINATION THERAPY:** Combined administration of drugs that are effective at different stages of the HIV viral cycle or that affect different elements of the virus.

**CD4:** A membrane protein or receptor of T-helper lymphocytes and some other cells; is the attachment site for HIV; T-helper cells are infected and killed by HIV causing the HIV+ve person to progress to AIDS when CD4 counts are below 200cells/mm<sup>3</sup> (Kalichman 1995:359).

**CLIENT:** A regular seeker of services (Orem 2001:30).

**HIERARCHY OF NEEDS:** Humans have certain needs that must be fulfilled for healthy living. These needs motivate people to act the way they do, and in particular, in ways that satisfy the needs that are not yet fulfilled. Needs are not all equally important, but exist in a hierarchy with the most important, basic needs at the bottom (Maslow 1999:33).

**HIV:** The AIDS virus; a retrovirus of the lentivirus class that produces disease with a greatly delayed onset and protracted course (Kalichman 1995:363).

**IMMUNE DEFICIENCY:** A breakdown in or inability of certain parts of the immune system to function; increases susceptibility to certain diseases , especially TB (Kalichman 1995:362).

**MASA:** Setswana word for “new dawn”, name of the government programme that provides antiretroviral drugs and specialised AIDS treatment and care to nationals of Botswana.

**MONOTHERAPY:** A therapy which uses only one drug or therapy.

**NEEDS:** States of deprivation that motivates living things to act and regain homeostasis.

**PATIENT:** An individual who is under the care of nurses, physicians, or other direct health care providers (Orem 2001:70).

**PEER SUPPORT:** One-to-one contact and support between people who share, or have shared, a common experience.

**PEOPLE LIVING WITH HIV OR AIDS:** Individuals who are infected with the human immunodeficiency virus.

**REVERSE TRANSCRIPTASE:** A complex enzyme characteristic of retroviruses; not found in non-HIV infected human cells (Kalichman 1995:367).

**SELF-CARE:** The practice of activities that maturing and mature persons initiate and perform, within timeframes, on their own behalf in the interests of maintaining life, healthful functioning, continuing personal development and well-being, through meeting known requisites for functional and developmental regulation (Orem 2001:522).

**SOCIAL SUPPORT:** The resources provided by other persons (Cohen & Syme 1985:4).

**SUPPORT GROUP:** Groups of professionals or both professionals and peers that provide emotional, educational, and psychological support and interventions (Spirig 1998:43).

**QUALITY OF LIFE:** Perception [by individuals] of their position in life in the context of the culture and value system in which they live in relation to their goals, expectations, standards and concerns (WHO 1995:1405).

## **1.11 RESEARCH METHODOLOGY**

Through snowball sampling, 116 participants were identified with the assistance of COCEPWA. After learning about the objectives of the present study participants consented to be part of the present study. All participants were HIV+ve women older than 18 years of age and registered as members of COCEPWA. In April 2002, the 116 women were divided into three groups: 39 women were trained as buddies by COCEPWA, 39 members of COCEPWA were the clients of these 39 buddies and 38 COCEPWA members were assigned to a control group. The 39 buddies were trained in April 2002 and paired up with their clients. All 116 women completed the demographic form, the medical outcomes study - Quality of Life short form 36 (MOS-QOL SF-36) questionnaire, the medical outcomes study - Social Support Survey (MOS SSS), the Personal Resource questionnaire part II (PRQ-II) and the Adherence Attitude Inventory (AAI) in April/May 2002. The data collection tools were selected based on the theoretical underpinnings, the review of other studies of PLWA/Hs and the researcher's judgement that these instruments would assist in answering the questions guiding the present research. The data collection process was repeated six months later in October/November 2002. Data were analysed by a professor (emeritus) in Statistics at the University of South Africa (UNISA) in the first quarter of 2003. The non-random sampling techniques used directed the choice of non-parametric tests to establish whether the buddy programme made a significant impact on levels of self-care, social support and the quality of life of the HIV+ve women involved in the present study.

## **1.12 ORGANISATION OF THE REPORT**

In the next chapter, **Chapter 2**, the theoretical underpinnings of the present study are described, followed in **Chapter 3** by a summary and discussion of the main findings of a survey of needs of 116 PLWA/Hs that was carried out during 2000. This survey report contains data that explained the needs and concerns of a section of the PLWA/H community in Botswana during 2000 and informed the buddy programme design that started in 2001.

**Chapter 4** reviews literature pertaining to the challenges in Botswana's war against HIV/AIDS: denial and stigma, self-care, social support of HIV+ve women and the mechanisms for support such as the buddy programmes. This review is important in explaining why, although international research studies of HIV+ve women have been done over recent years, there was a need for the present study.

**Chapter 5** discusses the ethical considerations involved in studying a stigmatised population and describes various methods used to research the buddies and their clients. It also highlights the reasons for including a comparison group, why it was felt important to have the participants complete the data collection tools in an anonymous manner and how the privacy of the participants was safeguarded for the duration of the study so that their contributions would not be identifiable to one specific person. The data that were collected in the demographic form, the MOS-QOL SF-36, the MOS SSS, the PRQ-II and the AAI at the start of the study and again six months later, were analysed and the findings are presented and discussed in **Chapter 6**. This chapter links the findings of the present study with the findings of studies that were reviewed in Chapter 4 and compares the observations of the present study with the conclusions previously reached by other researchers. The theoretical framework and the methodological considerations that guided the present study also contextualised discussions of the research findings.

**Chapter 7**, the final chapter, contains the conclusions and the recommendations for further study and is followed by the bibliography.

### **1.13 SUMMARY**

Botswana is faced with the devastating impact of an AIDS epidemic. The political will to direct some of its wealth to alleviate the suffering caused by AIDS is strong and the Botswana government has put a variety of measures into place in the area of HIV prevention and treatment of AIDS patients. Voluntary organisations are also responding to the crisis and supporting the government's efforts by developing complementary services to enhance the response and alleviate the pressure on the overburdened health-

care system. COCEPWA's buddy programme was designed by PLWA/Hs for PLWA/Hs. It was the first programme in Botswana that was based on an actual assessment (in 2000) of the needs and recommendations of a section of the HIV+ve community. The present study was guided by Orem's theory of self-care, Maslow's hierarchy of needs theory and the conceptualisation of social support by Cohen and Syme. The goal of the present study was to learn more about culturally appropriate and sustainable ways of meeting the health needs of PLWA/Hs in Botswana.

In Chapter 2, the theoretical framework of the present study will be described.

## CHAPTER 2

### THEORETICAL FRAMEWORK

#### 2.1 INTRODUCTION

The theoretical perspectives guiding the present study of the buddy system are described in this chapter. These consist of two theories, Orem's self-care theory of nursing and Maslow's hierarchy of needs theory, and one conceptual framework, namely Cohen and Syme's conceptualisation of social support. These three theoretical structures are unique in their focus but concur in the assertion that adults desire to feel needed *and* need one another. This interdependence possibly enhances the lives of people and might promote health and was in the present study explored within the buddy-client relationships.

Conceptually the three theoretical constructs have various aspects in common. All three have elements of developmental theory, or at least of change - changing the individual's health (or well-being) status for the better – optimising whatever resources are available. Nurse-scholar Orem's theory posits three nursing systems that form a continuum for personal and assisted health care towards creating, and maintaining, optimal self-care. Orem implies both institutionalised and non-institutionalised (lay) involvement in this, an aspect that immediately relates to the present research, as the buddy system involves such a dual organisational structure. As for motivation to involve oneself in self-care and assisting others in doing so, and ultimately in maintaining optimal self-care, Maslow's hierarchy of human needs is relevant. Social support provides the theoretical point of departure of this research, with a collective (cultural), institutionalised and non-institutionalised dimension in fields *other* than health services *proper*. The derived theoretical framework thus projects the dimensions of institutionalisation versus non-institutionalisation; individual versus dyad (and larger groups); the intra-personal, interpersonal (and by implication) the extra-personal dimensions of life and living; a more atomistic versus a holistic view of health and well-being; and a lay versus professional care dimension. In addition, all aspects of the theoretical framework apply to

both the buddy and the client equally. Social support theory in fact projects the possibility of role reversal between buddy and client.

## **2.2 OREM'S SELF-CARE THEORY**

### **2.2.1 *Orientation***

Orem's theory about the potential predictors of self-care was selected in the present study for its philosophical perspective that persons express solidarity with each other, possess free will and are experiencing beings in the process of becoming (Young, Taylor & Renpenning 2001:73). To understand the theory of self-care, one needs to understand the related theories of nursing systems and of self-care deficit (Coldwell Foster & Bennett 2002:126). In addition to these, one also needs to reflect on Orem's conceptualisation of the four meta-theoretical structures in nursing theorising, namely: the human being, health, the environment and nursing per se. The original conceptualisations of this earliest and most established theoretical framework on self-care have been utilised extensively by Orem and other nurse scholars (Orem 1988:75; Orem 2001:141; Young et al. 2001:71). As a result, in the early 2000s, 40 years after its first presentation, Orem's self-care premise is as relevant as it has ever been (Young et al. 2001:6).

### **2.2.2 *Orem and the four meta-theoretical concepts***

As indicated previously, the four meta-theoretical concepts traditionally addressed by nursing theories are the individual; health; the environment; and nursing. The way in which Orem defines health, the individual and nursing is particularly important to the present study.

#### **2.2.2.1 *Health***

In Orem's conceptualisation of health, the concepts of wholeness, soundness and well-being are closely integrated.

**Health** as defined by Orem includes the psychological, interpersonal and social aspects of living as well as the commonly emphasised physical aspects. Orem stated that the

concept of health has general utility, and defined the concept as “a descriptor of living things with respect to their structural and functional **wholeness** and **soundness**” (Orem 1995:96).

**Wholeness** is equated in Orem’s theory with a state of human integrity, and **being sound** means being in possession of full vigour and strength and lacking any signs of morbidity and disease. Ideally, health is the responsibility of a society and its individual members, and not of any formal segment of that society. Orem realises that adversity in the form of ill-health, scarcity of resources, or widespread disaster brings human suffering, but believes that adversity may also bring people increased understanding of themselves and others. The human qualities of courage and willingness to give of oneself to others are often revealed by people who suffer adversity (Orem 1995:96-97). This premise might be helpful in explaining what motivated the 39 HIV+ve women in the present study to be trained as buddies to other HIV+ve women. Orem stresses the importance of deliberate action and making choices; human beings are responsible beings and take care of themselves. These insights, however, do not completely answer the question of what motivates persons to meet their potential and whether all needs, physical and/or psychosocial are equally important (Orem 1995:102). In addition to Orem’s theory, the present study utilised Maslow’s hierarchy of needs theory to explain what motivates a person to engage in self-care.

The notion of *health* as a state of wholeness and sound physical and mental functioning adds to the complexity of Orem’s conceptualisation that health is both an *outcome* of self-care and presented as one of the *conditioning factors* that influences self-care agency and self-care demand (Gast 1996:121). In the present study, self-care motivated by the knowledge that one is living with HIV could result in good health in some respects and poorer health in other spheres. For example, knowing that eating well boosts the immune system might motivate a PLWA/H to choose nutritious food over sugared or fatty food. As a result the PLWA/H could become healthier because of eating less junk food. Nevertheless, at the same time being HIV+ve can lead to poorer mental health. The PLWA/H might have less social support, leading to feelings of depression and isolation.

The end result might be that the PLWA/H experiences somewhat better physical health than before the HIV+ve diagnosis, yet poorer mental health. The improved physical health state might not be expressed as higher levels of well-being. On the other hand, the power to help another HIV+ve person to identify a need for action and perform self-care behaviour could enhance the emotional health of the PLWA/H and lead to improved levels of well-being. Orem's point of view about human beings in action, as persons moving towards maturation and achievement of their human potential, implies that all human beings strive to meet their potential (Orem 1995:102). In the present study, the buddies received training in assessing the client's strengths and weaknesses in all spheres of life (including mental and physical health) with awareness that being HIV+ve is one of the factors influencing self-care ability, but not the only factor.

**Well-being** is associated with *health*. In Orem's theory, the concept of well-being is used in the sense of a state of being, an individual's perceived condition of existence. Orem defines well-being as

'a state characterised by experiences of contentment, pleasure and kinds of happiness, by spiritual experiences, by movement towards fulfilment of one's self-ideals and by continuing personalisation' (Orem 1995:101).

Orem believes that individuals can experience well-being even under conditions of adversity, including being ill (Orem 1995:101). The buddies and clients who participated in the present study attest to this.

Overall, Orem supports the WHO's holistic definition of health as "a state of physical, mental, and social well-being, and not of merely the absence of disease and infirmity (Coldwell Foster & Bennett 1995:133).

#### 2.2.2.2 *The individual*

Orem's conceptualisation of the individual, of the person, is vital to the understanding of the concept of self-care. According to Orem, human beings are distinguished from other living things by their capacity to

- (1) reflect upon themselves and their environment
- (2) symbolise what they experience, and
- (3) use symbolic creations (ideas, words) in thinking, in communicating, and in guiding efforts to do and to make things that are beneficial for themselves and others (Orem 2001:182).

This viewpoint of the individual strongly suggests an existential foundation to Orem's thinking. The existential perspective of the individual involves tenets relating to suffering, choice, meaning in life, responsibility, accountability and the like, all issues vitally important in the immediate situation of the buddy and other PLWA/Hs. However, the way in which the individual addresses these and meets self-care needs is not instinctive, but is learned behaviour (Coldwell Foster & Bennett 1995:133; Gast 1996:117). Adults are expected to be self-reliant and responsible for themselves and the well-being of their dependents (Orem 2001:81). The buddy system is aimed at exactly this type of self-reliance.

“Being normal” in reference to the individual, in terms of Orem's theory, implies that individuals are essentially human, using their talents to meet their potential, and have the power to manage and care for themselves and enjoy satisfying conditions of living in accordance with their genetic and constitutional characteristics (Orem 1995:192).

#### 2.2.2.3 *Nursing*

The domain of nursing is varied, and interaction can take place between a nurse and an individual or families and groups. An assessment is made whether there is a deficit between the demands for self-care and self-care abilities, followed by an attempt to answer the question of why there is a self-care deficit. The nursing offered may be

- in response to a patient's request
- based on an assessment by the nurse as to whether and how the patient can be helped through nursing, or alternatively
- coordination of services by the nurse and the integration of nursing into the patients' activities of daily living (Orem 1995:125).

Both *self-help* and *help to others* are valued by society as desirable activities according to Orem (2001:83). Nursing as a specific type of human service is based on both these values. Nursing is required whenever the maintenance of continuous self-care requires the use of special techniques and the application of scientific knowledge in providing care or in designing it (Orem 2001:81). The needs of the patients are determined, and decisions about role arrangements between caregivers, patients and the family are made in the context of the interpersonal dimensions of practice (Gast 1996:115).

One of the concerns in Botswana expressed by a section of the PLWA/H community, is that nurses do not have enough time to provide supportive counselling, nor to inform the PLWA/Hs how to manage their health. (See Chapters 3 and 4.) This is one of the reasons why COCEPWA proposed the buddy programme of care and support for and by PLWA/Hs.

The buddies in the present study were trained to respond to the requests of their clients and assess how the clients could be helped through peer support. The buddies could also be helpful with referrals, since they were aware of the resources available in the community and were trained to refer the clients to, for example, nurses and social workers for professional services. The buddies enhanced the self-care abilities of the clients based on respect for their autonomy by giving options to the clients to choose from. This strategy was identified in the self-care theory of Orem as an effective method to enhance self-reliance (Orem 2001:81).

#### *2.2.2.4 Environment*

Orem never defines the **environment** explicitly. However, from the definitions of the other three meta-conceptual structures, the environment can be taken as consisting of an intra-personal, an interpersonal and an extra-personal dimension. The environment consists of a wide spectrum of contextual factors that influence the abilities of the person to maintain self-care and the need for self-care (Gast 1996:121). Environmental factors do influence self-care since it is learned behaviour. Prevailing conditions such as cultural elements and the like were first learned in the family as a child and will influence an

adults' established patterns of responding to external stimuli which will affect decisions and actions related to self-care (Orem 1995:226-228). Awareness and acceptance by care givers that environmental and internal stimuli influence deliberate action is a prerequisite for understanding the self-care actions (and lack thereof) and the exercise of self-care agency of adults. In the case of HIV+ve women in Botswana, their commitment to protect their spouse from transmission of HIV during sexual intercourse is negatively influenced if culturally talking about sex is taboo and condom use by married couples unimaginable.

### **2.2.3    *The theory of self-care***

Orem defines **self-care** as an adult's personal continuous contribution to his or her own life, health and well-being (Orem 2001:522). As such, self-care has, since the first presentation of the theory of self-care in the late 1950s, been a concept applicable to the health state of individuals rather than to their state of ill-health (Aggleton & Chalmers 1985:36).

#### **2.2.3.1    *Definition of self-care***

Orem defines self-care as a behaviour that exists in concrete life situations directed by persons to themselves or to the environment to regulate factors that affect their own development and functioning in the interests of life, health or well-being (Orem 1995:104). This theorist suggests that Western society expects adults to be self-reliant and to take responsibility for their dependants, since infants, the aged, the ill and the disabled require assistance with self-care activities (Orem 2001:43). In Botswana self-reliance is valued and also expanded by what is called the *Botho* principle (Setswana word for respect, good manners) that encourages the people of Botswana to care and to allow this caring attitude to permeate every aspect of their lives, like the air they breathe, so that no Motswana (citizen of Botswana) will rest easy knowing that another is in need. Realisation of one's full potential is an individual matter as well as that of the community to which he or she belongs; respect is earned by giving it to others, ensuring social justice for all (Presidential Task Group 1997:2).

Orem's definition of self-care was expanded from the earlier definitions to be defined as

'the practice of activities that maturing and mature persons initiate and perform, within timeframes, on their own behalf in the interests of maintaining life, healthful functioning, continuing personal development and well-being, through meeting known requisites for functional and developmental regulations' (Orem 2001:522).

The involvement of the buddies in the immediacy of their living with HIV/AIDS engaged them in meeting known requisites as contained in Orem's definition of self-care. In addition, these self-care activities were also directed at enhancing self-care in the clients these buddies were assigned to, so that they too could meet "known requisites for functional and developmental regulations". As Orem (2001:43) puts it: "When self-care is effectively performed, it helps to maintain structural integrity and human functioning, and contributes to human development".

#### 2.2.3.2 *Self-care requisites*

Orem identified three categories of self-care requisites, namely: universal self-care; developmental self-care; and health-deviation self-care requisites.

**Universal self-care requisites** are associated with life processes and are common to all human beings during all stages of life, with each affecting the other. They include:

- (1) the maintenance of sufficient intake of water, air and food
- (2) the elimination process
- (3) maintenance of balance between activity and rest
- (4) maintenance of balance between solitude and social interaction
- (5) prevention of hazards to human life, functioning and well-being,
- (6) the promotion of human functioning and development within social groups in accord with human potential limitations, and
- (7) the desire to be normal (Orem 1995:191).

The universal, and consequently basic, nature of these requisites makes them the entry point of the buddy in the lives of clients assigned to them. As indicated in the background to the present study, there exists an acute deficiency of some universal requisites in the lives of both buddies and clients. This is profoundly experienced as regards a sufficient intake of food and water, balance between solitude and social interaction, prevention of hazards to human life (being reinfected, contracting TB, developing full-blown AIDS, and the like), functioning and well-being, socialisation, the desire to be “normal” - using one’s talents to meet one’s potential, and having the power to manage and care for oneself and enjoy satisfying conditions of living in accordance with one’s genetic and constitutional characteristics (Orem 1995:192).

**Developmental self-care requisites** are either specialised expressions of universal self-care requisites that have been particularised for developmental processes, or they are new requisites derived from a condition. Commonly recognised life-cycle stages are the intrauterine stage of life, birth, infancy, the developmental stages of children and adults and pregnancy in either childhood or adulthood (Orem 1995:197). For example, during pregnancy the expectant mother will adjust her food intake and balance between rest and activity in accordance with her condition. With reference to the present study, it is argued that becoming aware of one’s HIV+ve status, without being symptomatic, marks the point from which “particularised new requisites” need to be met in the continuing development of the individual. The buddy is in many ways instrumental in this process.

**Health deviation self-care requisites** exist in conditions of illness, injury or disease but may also result from medical measures required to diagnose and correct a certain condition. The individual will have to seek and secure appropriate medical assistance, and be aware of and attend to the effects and results of pathological conditions and states. In addition to seeking medical assistance, the person has to effectively carry out medically prescribed diagnostics and rehabilitative and therapeutic measures. Awareness of and attendance to the discomforting effects of prescribed medical care measures could result in the modification of the self-concept and self-image in accepting oneself as being in a particular state of health and in need of specific forms of health care (Coldwell Foster

& Bennett 1995:102; Orem 1995:201-202; Orem 2001:48). With regard to the present study these issues are evident in aspects discussed earlier, such as disclosure through not breastfeeding a baby, the strict regimen that needs to be followed during ARV therapy and the like.

Learning to live with the effects of pathological conditions such as being infected with HIV, and the effects of medical diagnostic and treatment measures in a lifestyle that promotes continued personal development, could pose lifelong challenges to PLWA/Hs. Different self-care actions will be needed to promote their health and well-being. In the context of the present study, the 116 HIV+ve women, buddy-client pairs and controls, needed to access health services and, for example, ask for blood tests to monitor their immune system through CD4 quantification. They also needed to obtain ARV therapy if their immune function was depleted by HIV to such an extent that their CD4 counts were below 200 cells/mm<sup>3</sup> blood. How these *health-deviating self-care requisites* to control and manage HIV infection were influenced by basic conditioning factors was also explored during the present study (Orem 1995:203). The buddies aimed at the promotion of health and well-being of their clients. Some of the factors that influenced the outcomes were internal (age, gender, sociocultural orientation) or external (health-care system factors, family system factors, resource availability) to the HIV+ve women. (See Chapter 6.)

#### 2.2.3.3 Agency

Orem's self-care theory of nursing was developed to provide a theoretical framework to direct nurses in their thinking about the work of nursing and the relationship between nurses and patients. Any self-care requirement which cannot be met by the individual is the legitimate responsibility of a helping person and/or caregiver. The caregiver may be either a lay carer (mother, friend or relative), or a professional carer (nurse or social worker). Orem refers to carers as people who fulfil certain roles and defines caregivers as "persons who are in a position of responsibility to take care of other persons" (Orem 2001:25).

Of interest to the present study of buddy care and support was how Orem's theoretical integration of lay care by lay-care and professional care. Orem stated that in specialised health services, nurses care for a special group of persons who are unable to care for themselves (Orem 1995:9). As such both the nurse and the buddy are both caregivers/care agents for the HIV+ clients, each applying their special skills, experiences and life situations.

Orem identifies common features in care and holds that all human beings do care for others. However, Orem cautions that human beings can be *helped* or *harmed* by factors in care situations. Care is interpersonal, based on the objective needs of the recipient of care and respecting and accepting the freedom of this recipient to decide upon a course of action. Care requires that care agents have sufficient knowledge, both theoretical and experiential, to provide care (Orem 2001:27).

In the Botswana buddy programme it was stressed that buddies must understand the source of their right to be there and to serve their clients. The duration of the responsibilities was spelled out, as well as the fact that their responsibilities did not extend to all life situations. Having the desire to help another does not mean that a person has the ability to help. It was emphasised that the buddies should not cross lines of other helping services; they needed to call upon other care agents, such as nurses and social workers with specialised knowledge and experience, to deal with issues falling beyond the scope of the buddies (Orem 2001:29).

Most of the buddies were aware that they did not have the technical competence, knowledge or insight of nurses or other health professionals to make certain health care decisions and the buddies could refer the HIV+ve women to COCEPWA or other health professionals, if necessary. The buddies' strength lay in expressing care and concern for other women living with HIV. The buddy and the client bonded with each other as persons with much in common. The buddy programme stresses the aspect of care and support *for* and *by* women living with HIV. In terms of Orem's theory, it follows that in

the present study the buddies are regarded as *care agents* within a helping situation between two HIV+ve women.

Orem held that four aspects are critical for self-care and helping others

- (1) care
- (2) responsibility
- (3) respect
- (4) knowledge (Orem 1995:26).

As such, a care agent lacking concern or respect for a HIV+ve woman could cause harm. It is of primary importance to the recipient of care that she should be able to trust the caregiver. It needs to be emphasised that even a buddy who does not refer a client for professional treatment when this is indicated but “helps” in areas for which she is not qualified could harm her client. For care to be consummated, respect, commitment and emotional bonds between the care agent and the recipient of care are vital (Haile, Landrum, Kotarba & Trimble 2002:74-80; Kitson 1987:164; Orem 2001:61).

During the present study, the actions of the buddies and the clients were considered in relation to others and this interrelationship was interpreted in terms of Orem’s theory of self-care. The role of buddies as lay carers is likely to assume ever greater importance in providing home- and community-based care for PLWA/Hs in Botswana. This is because the numbers of PLWA/Hs are likely to increase, while the numbers of registered nurses and other health care workers are expected to decline as a result of HIV and AIDS.

Caregiver strain was identified as a risk factor in caring for others. A study by Baker (1997:7) explored the relationship between self-care agency and caregiver strain as perceived by 131 female family caregivers to their elderly parents, and discussed the findings in terms of Orem’s theory. These caregivers perceived less strain when they also focused on attending to their own needs, as opposed to focusing only on the needs of the parent (Baker 1997:7-11). An awareness of the importance of alleviating the self-care deficit implied in perceived caregiver strain in the present study led to the buddies being

encouraged to fulfil their potential for self-care agency. Orem's basic premise is that when they are able, individuals do care for themselves. This *taking action* is termed **agency**. However, it is accepted that self-care ability differs from individual to individual (Chinn & Kramer 1995:44).

In terms of Orem's theory all of the 116 HIV+ve women in the present study were regarded as *self-care agents*, capable of deliberate action. The buddies and clients had met self-care requirements in varying degrees. This is evident from the findings that some buddies or clients went to the hospital for laboratory tests such as CD4 quantification and were screened for TB upon a HIV+ve diagnosis, while others would wait for several years or would not go to clinics or hospitals for any preventative health services. The length of time of being aware of the diagnosis varied, as did the self-care abilities. (See Chapter 6.)

Orem's theory further indicates that a person's self-care repertoire or the "*quality of the agency*" is determined by

- what they *have learned* to do and what they *do consistently*
- what they *can* and *can't do* now or in the future (what their limitations are), and
- whether what they have *learned to do* and *can do* now is equal to meeting all current and projected demands now or at some future time (Orem 2001:466).

The present study is also illuminated by tenets of Orem's theory which hold that people can learn new self-care skills and/or deepen the knowledge that they already have. In the context of the present study these were reflected in the training of the buddies by COCEPWA before they were linked up with their clients.

The buddies were expected to share what they had learned with their clients. The responsibilities of the buddies included encouraging higher levels of disclosure and boosting the self-care actions and capabilities of their clients. The fact that the buddies

were trained by COCEPWA and had basic knowledge about HIV and AIDS empowered them to give social and emotional support to their clients. Being HIV+ve themselves enabled the buddies to empathise with clients. Their presence in the homes of their clients for up to six hours a week facilitated the sharing of information and rendering of tangible support such as going shopping together or sharing other domestic responsibilities. The buddies were told repeatedly during their training and during supervision meetings with the project coordinator of COCEPWA that they were neither nurses nor social workers and that they had to refer their clients to, and/or seek support from, these health care providers when necessary.

The power to act was deliberately exercised by the HIV+ve women in the present study in the form of care of self and care of others, in identifying needs of self and others, and in making the required inputs. Since self-care is a learned behaviour, the HIV+ve clients were assisted by the buddies to expand their self-care repertoire and developed skills to cope with being HIV+ve. Basic conditioning factors in Orem's theory were shown to impact on the therapeutic self-care demands (Deatrick, Angst & Madden 1999:65; Denyes 1988:13).

#### *2.3.3.4 Therapeutic self-care demand*

**Therapeutic self-care demand** refers to the amount and kind of self-care that persons should perform or have performed for them in their time-place localisations (Orem 1995:187). The therapeutic self-care demand is modelled on deliberate, purposeful action, since performing a self-care measure involves making a choice. Throughout life a person faces choices of personal and culturally acceptable actions. The process of deliberate action forms the basis for understanding self-care and care agency. One of the self-care agency structures that relates directly to the present study is a set of *power components* that permit the performance of self-care (Orem 1995:221).

In the present study, the HIV+ve women's capabilities that determined their ability to participate in therapeutic self-care actions included their ability to maintain attention and exercise vigilance with respect to themselves and their internal condition. Living with

HIV calls for active management of health, since OIs or adverse side-effects of medication need to be treated without delay to prevent further depletion of the immune system. Self-care actions require an ability to reason within a self-care frame of reference, motivation and the ability to make self-care decisions. Within the buddy-client dyad, information exchange was ongoing and performance of self-care depended on the ability to learn the technical aspects of self-care and the repertoire of skills adapted to the performance of self-care operations, such as remembering how and when to take ARVs, understanding the difference between HIV and AIDS and knowing how to use condoms. The buddy system is further concerned with the ability of all HIV+ve women to consistently perform self-care, since there is no cure for AIDS, so being HIV+ve requires a lifelong commitment to preventing re-infection and preventing transmission of HIV to other people. All the abilities mentioned above are based on the notion of deliberate action.

According to Orem the demand to attend to oneself needs a practical response (action); if one is *disinclined* the demand can be ignored (inaction), but the awareness of the demand may remain even when it is ignored (Orem 2001:53).

It was explained in the present study that the AIDS epidemic in Botswana results in a critically overburdened health care system. (See Chapter 4.) The fact that there are limited number of doctors and nurses to serve large numbers of patients within a developing health care infrastructure to manage HIV-related treatment and care might hamper the self-care abilities of PLWA/Hs in Botswana. The PLWA/Hs in Botswana have to have the inner strength and the motivation to ensure that they obtain the resources to maintain health and well-being. A qualitative study by Haile et al. (2002:73-80) of 19 women living with HIV/AIDS in the USA examined the phenomenon of inner strength as a resource that these women use to cope with and manage their lives. A conceptual definition of inner strength was arrived at:

‘Inner strength refers to the different ways women with serious illnesses experience and talk about the deepest and existential resources available

to and used by them to manage, in a holistic sense, risk to self-integrity' (Haile et al. 2002:77).

The buddy system was designed to assist those whose power to provide their own self-care was not equal to knowing or meeting their self-care demand. If, for example, a client was ill, the buddy might offer to wait in line for many hours at the busy pharmacy on behalf of her client. In return the client might offer to talk to a relative of the buddy who seemed jealous of the frequency of the buddy-client visits and explain to this relative how she appreciated being helped by her buddy; this praise might boost the self-esteem of the buddy. The mutual care and peer support mechanism as explained in the previous example aims to promote the well-being of buddy and client and allows for role reversal between the helper and the person in need of help.

#### 2.3.3.5 *Basic conditioning factors*

The individual's ability to engage in self-care is further affected by internal or external factors called *basic conditioning factors*. The basic conditioning factors describing individuals are: age, gender, years of education and developmental state. Factors that locate a person within the family and sociocultural groups are the sociocultural orientation and the family system factors. Factors that describe individuals in their worlds of existence include the health state, health care system factors, patterns of living, environmental factors and resource adequacy and availability (Orem 1995:203).

Understanding the basic conditioning factors relating to self-care is important because each person who seeks and receives care is an individual who at the same time is also a member of a family and the community. Considering factors such as age and developmental state helps to identify obstacles that must be overcome as well as methods needed for meeting self-care requisites (Orem 2001:328).

Learning which factors predict self-care has been of interest in studies in the USA that have applied Orem's self-care theory. The relationship between having basic human needs fulfilled and engaging in health-promoting self-care behaviour was studied by

Acton and Malathum (2000:799). The researchers pointed out that employed persons that were of higher social class and income and who had more education tended to engage in more health-promoting self-care behaviours. This confirmed earlier research by Dodd (1997:987), who established that performance status, social support, anxiety and education were predictors of self-care. Of further interest to the present study are the recommendations of Deatruck et al., (1999:70-71), who explored ways of promoting the health of adolescents. Their conclusions were that two ways of promoting self-care in adolescents were: to make the taking up of responsibilities a gradual process; and to foster the confidence of the adolescents in their capability to control outcomes through their own management. In terms of the present study this might mean that one should give HIV+ve women adequate time to learn how to cope with their HIV+ve diagnosis, rather than rushing the disclosure, and give the women control over the management of their care, including adequate time to consider the implications of committing to lifelong ARV therapy.

It is not known whether or not demographic aspects do influence HIV+ve women's health care behaviour in Botswana. Therefore the research instruments attempted to identify such factors and correlate these with (health) self-care activities practised by the 116 HIV+ve women.

#### **2.2.4 Theory of self-care deficit**

This theory explains the situations and conditions when (nursing) care is needed to assist individuals in the provision of self-care.

##### *2.2.4.1 Orientation*

Understanding the self as imperfect, that is, as subject to limitations in knowledge, judgement, decision making and instituting appropriate self-care action, constitutes the basis for understanding the theory of self-care deficit. In terms of Orem's theory the buddies and the clients were defined as *self-care agents*, the performers or providers of care. They had regular, sustained, direct contact with each other and gave each other assistance in this peer helping relationship. Only when a person is unable to provide self-

care should another care agent (nurse or buddy) be approached to provide the assistance needed. Both the buddy and the client could approach nurses and ask for their support. Nursing is defined as “the giving of direct assistance to a person because of specific inabilities for self-care” (Orem 1995:8-9). For Orem, self-care is the answer to the question: “What is the proper object of nursing?” The proper object is not health, or disease or care. The object or focus of nursing is human beings with health-derived or health-associated self-care deficits (Gast 1996:114). In any society or social group there will always be persons whose lives or health and well-being are endangered because they cannot provide their own self-care. In Botswana, the buddy system provided an additional resource to meet the therapeutic self-care demand of PLWA/Hs.

#### 2.2.4.2 *Self-care deficits*

Self-care deficits are *action limitations* related to gaps between self-care agencies and therapeutic demands (Orem 1995:240). A deficit thus stands for the relationship between the action demand and the capabilities of the self-care agent and is neither a human disorder nor an illness. Nursing (like the buddy system) is a response to these deficits in the capabilities of people. Living with HIV can result in a need for support with aspects of universal self-care, such as the maintenance of a balance between solitude and social interaction. Developmental self-care requisites could be, for instance, a need for support with dealing with the loss of friends and relatives, or pregnancy. Seeking and securing appropriate medical assistance is health-deviation self-care. In this regard, five methods of helping were identified that could be adapted by both the nurse and the buddy:

- (1) acting or doing for another person
- (2) guiding and directing
- (3) providing physical or psychological support
- (4) providing and maintaining an environment that supports personal development
- (5) teaching (Orem 2001:56).

As previously indicated, all these feature in the buddy system, which was investigated during the current research.

### 2.2.5 *The theory of nursing systems*

This theory outlines how self-care needs will be met once an individual engages a caregiver. Depending on the individual's lack of ability to administer self-care, and the self-care needs required for maintaining optimal functioning, direct assistance will be given by a nurse or another care agent because of these inabilities, until the individual is able to meet his or her needs. As such, this theory subsumes the theory of self-care deficit and with it the theory of self-care.

As outlined previously, nursing or the buddy system are helping systems, and can promote or impede self-care actions, depending on the selection of the ways of helping and decisions made about role allocation. A selection out of the five methods of helping, for example the *provision of psychological support* and *teaching*, can be made depending on the need (Coldwell Foster & Bennett 1995:129). The helping methods will demand various roles of both the buddy and client. The buddy has to be proficient in her role as listener and competent in switching to the teaching role as well. For her part the client must be willing to confront and live through difficult situations as well as capable of taking on the role of learner engaged in developing the knowledge and skills required for continuous self-care.

Ultimately, the results sought through nursing or the buddy system can be expressed as forms of care that ideally and ultimately result in movement towards positive health and well-being. This goal of promoting the well-being of the HIV+ve client is what the nurses and the buddies have in common. The challenge for nurses in Botswana is that many PLWA/Hs do not consider themselves as patients or unhealthy people in need of care or support from medical personnel. Upon diagnosis, most PLWA/Hs are either not referred from the voluntary testing centres to the clinic, or refuse to assume the patient role implied in going to the local clinic to consult a nurse. Denial is a commonly observed first reaction after being diagnosed HIV+ve. However, the present study outlines potential self-care deficits in addition to stress-buffering coping mechanisms such as denial. Deficits thus stand for the relationship between action that PLWA/Hs *should* take

and their action capabilities for self-care. Deficit in this context should be interpreted as an inter and intra-personal disharmony between “ought” and “could” and not as a human disorder (Orem 1995:177).

In the buddy system, the comparative advantage of the buddies over the nurses is that, to the clients, the buddies are their peers. The buddy and client take responsibility for their health-deviating self-care actions related to HIV/AIDS, each in their own way, and they can share those experiences. The trained buddy has developed certain social support skills and have the latest information about HIV-related care. The buddy’s willingness to help others distinguishes her from her clients. The buddy and the client have a lot in common, yet because of their different life experiences, they are not the same. Nevertheless, the HIV+ve client might have more faith in being accepted by a HIV+ve buddy than by a health care provider. Once a relationship of trust is established and the HIV+ve diagnosis accepted, the buddy can encourage her client to seek nursing care. The buddy could offer to go with the client to the clinic and introduce the client to nurses who associate with the buddies in the buddy programme. This support by the buddy might facilitate a helping relationship between the nurse and the patient. As such, the buddy and client’s self-care agency is complemented by the buddy system in which they help each other. However, the self-care capabilities of the buddy, because of her training, will probably exceed those of the client, who might be limited by having fewer resources, limited knowledge of the meaning of the AIDS condition and lack of information on which to base decisions. In these areas the nurse, with four years or more professional training, will have more skills to assist both buddy and client and is a resource for health and well-being to both.

#### *2.2.5.1 Nursing agency*

**Nursing agency** is a theoretical concept and described as the power that enables nursing interventions. (See section 2.2.3.3 *Agency*.) It is a property or attribute of people educated and trained as nurses that enables them to act, to know, and to help others meet their therapeutic self-care demands by exercising or developing their self-care agency. Nursing

agency is directed to others and self-care agency is directed to oneself (Orem 2001:133). In the present study nursing and the buddy system are both other-directed.

In the buddy system, both the buddy and the client can be defined as *self-care agents* in terms of Orem's theory. The buddies' intersecting roles as care agents are similar to those of nursing in that the buddy system empowers the buddies so that they can act, know and help the clients meet therapeutic self-care demands. Women with HIV or AIDS need to be competent in managing self-care and they must be helped to apply relevant knowledge to their own care.

In the present research, buddies could be seen as agency enabling the clients to meet their self-care demands. Being involved in the Botswana buddy programme and other skills-building programmes of COCEPWA might have encouraged positive living with HIV/AIDS by both buddy and client. Orem points out that *caring* is not unique to nursing and it is thus not caring that distinguishes nursing from other helping professions (Orem 1995:25). The specialised skills of nurses and other health care providers made them resource persons for the buddies, in addition to the project coordinator of COCEPWA who taught and supervised the buddies. As has been said, one of the most important instructions during the buddy training and during their meetings at COCEPWA was that they needed to acknowledge their limitations and refer matters falling beyond their capabilities to professional health care services. For example, matters such as CD4 quantification were referred to the clinic, and if adverse effects of ARVs were noticed the buddy or the client was advised to see her doctor. If suicidal ideation or (sexual) abuse were to be reported. The buddies and clients were told that these matters had to be referred to the relevant professionals through the buddy project coordinator.

#### 2.2.5.2 *Nursing systems*

The nursing systems designed to meet the patient's needs may be wholly compensatory, partly compensatory or educative-supportive. These components of Orem's theory found special application in the present research, as the buddy system is envisioned to guide HIV+ve women along this continuum towards a point of educative support for as long as

possible. However, the system also alerts the buddy to the possibility of taking on a more directive role, as the client's condition might deteriorate at any time. Naturally this continuum applies equally to the buddy.

The **wholly compensatory system** refers to instances where the nurse performs all self-care actions for the patient. The nurse compensates for the patient's inability to engage in self-care and the nurse has to support and protect the patient. The buddy might under exceptional circumstances be faced with a crisis situation where she had to take on a wholly compensatory role. If the buddy were to go to the home of the client and find that the client was severely ill, dehydrated and unable to speak coherently, she would have to act for the client. The buddy would alert the family on the client's behalf and advise them that they needed to rush the client to the hospital. If there were no relatives close by, the buddy would have to make the arrangements herself. The buddy would stay with the client until she was admitted to hospital and left in the care of the doctor and nurses.

In the **partly compensatory** nursing system the nurse assists patients as required. In the above example, the dehydrated patient might, after a few days in hospital, be able to perform some self-care actions and make an effort to take the prescribed treatment on time. The buddy might have a role in encouraging the client to accept the care and assistance from the nurses.

In the **supportive-educative** system the patient accomplishes self-care but the nurse promotes self-care by helping with decision making, behaviour control and acquiring of knowledge and skills (Coldwell Foster & Bennett 1995:106; Orem 1995:305). Sometimes patients only need reassurance; the consultative role of the nurse is most suitable for the patient who is able to perform the actions necessary for self-care and who can learn to adapt to new situations (Cavanagh 1991:27). However, the nurse could decide to teach the patient how to prepare oral rehydration solution (ORS) and explain the importance of drinking this ORS mixture if the patient were to have severe diarrhoea again. The buddy could assist the client by making sure that upon discharge the client had all the

ingredients for preparing ORS, and knew precisely how to prepare ORS, as well as how and when to take it.

### 2.2.6 *Summary*

To summarise, the buddies were expected to respect and try to understand the reasons behind the self-care actions of the clients and vice versa. It was up to the buddies and the clients to decide how and when to initiate and perform activities for maintaining life, health and well-being. Orem's theory states that at times, even though the need for self-care exists, individuals may ignore the need and take no action. The theory holds that the ability to act (agency), could be influenced by age, health values and goals. The 116 HIV+ve women who participated in the present study were studied within a resource-constrained health care environment due to the AIDS epidemic in Botswana. To redress the shortages of specialised care, more specifically professional nursing, the women living with HIV came up with a mutual peer support mechanism, the buddy system: a care and support system aimed at boosting their self-care abilities. The buddy system motivated the HIV+ve women in the present study to help each other towards increased health and higher levels of well-being. Both the buddy and the client were *self-care agents* but the buddies were different from the clients in that they were specialised carers for others as well as themselves. The buddies were trained by COCEPWA and acquired new skills such as guiding and directing, providing support and stimulating the personal development of their clients.

In the present study the buddies were, in their (*nursing*) *agency* role, expected to take action and develop and transmit ways and means to the clients that would assist in identifying the needs of the client and to render input to the client. The methods of helping in terms of Orem's theory, such as supportive-educative roles, could be applied both to professional nursing and the buddy system. The buddies and the clients interacted from four to six hours every week, and valued nurses as a resource because of the wider range of skills and knowledge about addressing the self-care requisites of the HIV+ve women. Despite the (perceived) barriers on the part of the clients to accessing nursing care due to stigma or scarcity, it was emphasised that the buddy system could be harmful

if professional carers were not consulted. The buddies and the clients agreed with the buddy programme coordinator to refer to professional health care providers when matters arose that the buddies were not qualified to deal with and/or when the buddies or clients needed professional care.

In theory, within a health promotion context that views health as a resource for daily living, self-care is seen as empowering. The buddy system translated theory into practice in view of the fact that through the acquisition of additional self-care skills, the HIV+ve women were able to participate more actively in creating their own health and in shaping the conditions that influenced their health. One or more of the three types of nursing systems may be produced for one HIV+ve client over the duration of a period of care, but involvement of the clients in their own care was encouraged at all times. The buddy can complement the *partly compensatory* and *supportive-educative* nursing efforts of the professional health care providers, but was not trained to take on a *wholly compensatory* role for the client. The buddy could assist with referral of the client to the local clinic and request HBC nurses and HBC volunteers to assist if the client were terminally ill but not admitted to hospital.

All self-care implies a process or series of actions. When faced with a new reality such as being diagnosed with HIV infection, attention must be given to new and emerging self-care requisites. Buddies, being women living with HIV and belonging to the same community as the clients, were knowledgeable about the challenges of this decision-making process and examined the self-care actions of the clients within the context of their daily lives.

The theoretical construct by Orem stresses the importance of mutual respect in helping relationships and encourages care agents (nurses/buddies) to have a holistic view and gain an understanding of what self-care is and what results are sought through self-care by the individual before deciding upon methods of helping. The buddy system provided a connection between the informal ongoing self-care efforts of the buddies and clients (lay carers) and the formal professional care institutions.

## 2.3 MASLOW'S HIERARCHY OF NEEDS THEORY

The question remains as to what *motivates* both the buddy and the client to take on their developmental roles as these relate to the three nursing systems within the Orem theoretical construct, namely wholly compensatory, partly compensatory and educative-supportive. Although the answer may be found partly in different motivation theories, Maslow's hierarchy of human needs, seen within the social setting of HIV+ve women in Botswana, seemed an appropriate choice by which to further explain the activities implied within Orem's theory. Naturally, Maslow's hierarchy of human needs applies to both buddy and client. This should always be kept in mind even if not directly stated or discussed.

### 2.3.1 *Orientation*

Maslow expressed his dissatisfaction with the highly esteemed First- and Second-Force psychological theories of his time and refocused attention on the natural goodness of people. Maslow saw deficiency needs as essentially survival needs; even love and esteem are needed for the maintenance of health. All people have a need for self-respect and the esteem of others; gratification of self-esteem needs leads to feelings of confidence, worth, strengths, capabilities and a sense of being needed in this world.

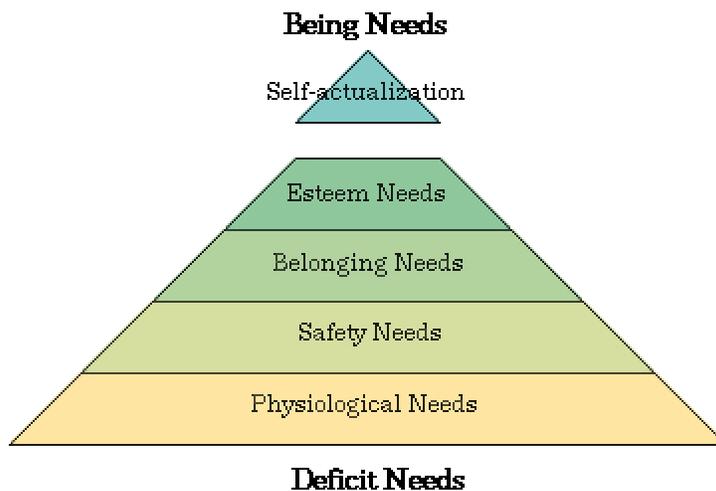
#### 2.3.1.1 *Humanistic psychology*

Maslow believed that human beings can be impressive in their own human and biological nature (Maslow 1996i:84), however, he did not deny a duality of human nature. Maslow's Third-Force (Humanistic) psychology opposed almost every basic tenet of First-Force (Freudianism) and Second-Force (Behaviourism) psychology, namely, that only self-interest, sexuality and aggression are innate motivators for survival and reproduction of the human species (Hoffman 1996:6). The core of human nature was basic goodness and decency asserted Maslow and when people appear to be something other than good, it is because they are reacting to the deprivation of basic human needs. Aggressiveness is only a reaction to the circumstances of one's particular human situation. Maslow's distinct contribution as a Third-Force psychologist was that he came

up with a compelling theory of human motivation; his vision of a hierarchical arrangement of human needs gave a tenable basis for explaining how a person's desire for kindness could be as basic as the need for water (Lowry in Maslow 1999:v-ix). Reflecting on the HIV+ve woman's sociocultural position in Botswana, as set out in the background to this study, one can begin to form an understanding of these individuals' overwhelming need for humanity and humaneness, reflected in both concrete external and interpersonal activities and relationships.

### 2.3.2 Hierarchical structure of motivation

Maslow's theory states that the basic driving force or basic motive of human beings arises from a hierarchy of needs (Hoffman 1996:9; Maslow 1999:168-169). When needs of the lower hierarchy are met, the needs at the next level become the basic motivating need/force. This is illustrated in Figure 2.1



**Figure 2.1** Deficit and being needs in terms of Maslow's hierarchy of needs theory (Maslow 1996d:93; Maslow 1999:33).

The hierarchy of human needs progresses from lower to higher level needs as follows: physiological requirements are the rock-bottom survival needs for air, food, shelter, sleep and sex. The second level comprises safety and security needs. The third level relates to love and belongingness needs: the human need for warm interpersonal sharing, love,

affection and affiliation. The fourth level emphasises the need for self-esteem and esteem by others: the human need for a sense of confidence and competence, achievement, independence and freedom. At the tip of the pyramid are self-actualisation needs: the individual's need for growth, development, fulfilment of potential, the need to become more and more what he or she is capable of becoming and achieving (Hoffman 1996:10; Maslow 1999:33).

The strongest needs are at the bottom and the weakest needs are at the top. Maslow believed that as the lower deficiency-needs are met, the higher being-needs emerge in the realm he called "*metamotivation*" that exists beyond the realm of basic needs (Maslow 1996d:93; Maslow 1999:33). Needs can be met out of order, although they are typically met following a pattern similar to Maslow's hierarchy. Maslow pointed out that, for example, as long as a person is hungry he or she cannot be concerned about other needs because he or she is dominated by the hunger for food (not the hunger for love). This dominance of one more basic need over a lesser basic need Maslow termed "*prepotency*" (Hoffman 1996:201). Unmet needs result in a state of tension or anxiety, and as the deficit increases so does the tension, which ultimately leads to a state of perceived deprivation (Acton & Malathum 2000:806).

The first four levels of needs, termed *deficit needs* by Maslow, are said to occur when human beings experience deficiencies. For example, if the hunger caused by lack of food can be met, then the hunger need is dissipated. Once the need for food is met, it ceases to be a motivating force. If this need is not met, it is regarded as a deficiency in the organism. Maslow equated deficiency needs with "empty holes that must be filled up for health's sake" (Maslow 1999:28). It must be remembered that these deficiency needs must be filled from *without*, by a human being other than the subject. In contrast, *being needs* are not informed by deficits, according to Maslow. Being needs do not cease to be motivating once met, but are motivated by growth. They become stronger as the person "feeds" them from *within*. Examples are the need for truth, uniqueness, justice and meaningfulness. Being-needs drive people and involve the continuous desire to fulfil further potential (Maslow 1999:93).

For example, an HIV+ve woman in need of food for herself and her children but who fears disclosure of her HIV+ve status in her community is faced with a distressing dilemma. In order for her to access food aid from the government, social workers have to assess her situation, and disclosure of her AIDS condition to the social worker would entitle her to get support directed to PLWA/Hs. In terms of Maslow's theory the most basic needs will have to be met first, so this HIV+ve woman has to find a way to provide for herself and her children since they have to eat. However, the woman might even resort to illegal means of obtaining money to buy food if she feels she is not ready to disclose her HIV+ve status.

Maslow held that human beings are capable of knowing right from wrong and desire to behave in accordance with a belief in ultimate values such as truth and love (Maslow 1987:249). Engaging in illegal activities would make the HIV+ve women in this example anxious and dissatisfied, or, in terms of Maslow's theory, make her deprived/unhealthy. The fear for her own safety due to her guilt about her illegal activities could motivate her to consider approaching somebody she could trust. Together with this trusted person she could explore how she could be provided with food or find a job legally. Suppose this HIV+ woman decided that the best way to promote her well-being would be to join a support group for PLWA/Hs. In the company of other HIV+ve people she could share her concerns and possibly come up with strategies to deal with her problems. If as a result of these self-care actions her survival needs were met, she would no longer be solely motivated by her own need and concerns but possible able to concentrate on more social goals. Deciding to help other HIV+ve women could be a possible option and would enable her to give something back to the support group.

If this HIV+ve woman was given the opportunity to be trained as a buddy it could assist her in changing her life. The stipend paid to her as a buddy would enable her to feed her family and she would not have to fear for her safety any more. The motivation to be a buddy would come from within herself, an inner drive to help others because she did not want them to suffer the way she suffered. Being a buddy might help her to find meaning in living with HIV.

### 2.3.3 *Self-actualisation*

Maslow's definition of self-actualisation was amended over the years but retained a solid core of agreement. All definitions of self-actualisation accept or imply the following:

- acceptance and expression of the inner core or self
- the full use and exploitation of talent, capacities and potentialities
- minimal presence of ill health, neurosis, psychosis, or loss or diminution of the basic human and personal capacities (Maslow 1999:218).

Maslow perceived such qualities in people like Einstein and Schweitzer, people concerned with issues of great relevance to humanity. What all these people had in common was that they in their own way were concerned with social goals; they focused on the needs of other people, trying to better their lives.

The buddies in the present study were not overwhelmed by feelings of deprivation and were physically and mentally able to help other HIV+ve women. The HIV+ve women that were prepared to help others were not rich in monetary terms, but had accommodated the illness within their being. It did not dominate their thoughts and actions, but they had accepted the fact that being HIV+ve was for life or until such time as a cure was discovered. This "accepted chronicity" allowed for the development of coping mechanisms and active pursuit of well-being under adverse conditions.

According to Maslow, it is the duty of human beings to be all they can be; to do less would make people discontented and unable to help others. All things being equal, Maslow believed that a person who is safe and who belongs and is loved is healthier than a person who is safe and who belongs but who is rejected and despised (Maslow 1987:38).

Within the buddy-client relationship the HIV+ve women agreed to reach out to each other, talk and share experiences of living with HIV. As they were peers, their acceptance and recognition of one another's suffering was likely to alleviate some of the pain associated with rejection. Appreciation of the regular visits and phone calls by both

buddy and client during the buddy-client interaction was evidence that they needed each other and that they were needed. Maslow stated that in order to discover what people need, it is necessary to set up conditions that foster expressions of these needs, and nurture capacities that encourage and make it possible to meet these needs. If the persons involved within this *permissive atmosphere* are free to choose whatever is best for them, self-actualisation or health is fostered (Maslow 1987:120). If trust was developed within the helping relationship in the buddy-client dyad this could be described as such a *permissive atmosphere*.

It was Maslow's contention that human beings can learn about other human beings by studying exceptionally healthy, mature people, the growing top of humanity. Healthy people have gratified their basic needs for safety, belongingness, love, respect and self-esteem to the extent that they are motivated by being-needs (Maslow 1999:215). In terms of Maslow's theory, healthy people are characterised by

- a superior perception of reality
- increased acceptance of self, others and nature
- changed interpersonal relationships
- greatly increased creativeness
- higher frequency of peak experiences, and
- certain changes in the value system (Maslow 1999:32).

As far as the buddy is concerned, it would be impossible for her to help others to accept a HIV+ve diagnosis if the buddy herself is in denial. Being HIV+ve can lead to a greater appreciation of things in life that other people might not even take time to observe. Having peak experiences requires reflection, taking the time to be awed by the beauty of nature and experiences in one's surroundings. Creative ways must be found to integrate the change of lifestyle that is required, including doing away with things that do not really matter, because the HIV+ve person knows that life is too short to be wasted. HIV+ve people could be healthier, in terms of Maslow's theory, than some others who have not had to face their own mortality by being diagnosed with a life threatening illness for which there is no cure.

An important aspect in Maslow's theory that is applicable to the present study is the recognition that people have needs beyond physiological needs (Stanhope & Lancaster 1992:138). Being diagnosed with AIDS can initially overwhelm the HIV-infected person. Next, he or she has to decide who to tell. Fear among those in society who would like to keep away from HIV and AIDS in general may be caused by a lack of understanding about modes of transmission within the community, and may result in negative reactions towards those living with HIV. The anticipation of a very negative reaction to the disclosure that they are infected with HIV might lead PLWA/Hs to decide to keep the diagnosis a secret and disclose it to only a few people whom they believe they can trust. This decision might be based on real-life experiences or on what they imagine would happen if they disclosed their diagnosis. The PLWA/H is faced with a dilemma: disclosure might lead to rejection by parents, partners or friends and even being evicted from the house. However, non-disclosure forces the PLWA/Hs to lie and pretend to the people they love and others, and this might lead to withdrawal from social interactions. Both alternatives, disclosure and non-disclosure, might result in regression to lower-level needs and ill-health.

In terms of Maslow's argument, these PLWA/Hs would be deprived of love/belonging needs. They may feel alone and isolated, unable to seek assistance and support that might facilitate better health-related decision making. The reverse is also true; if PLWA/Hs do disclose the HIV+ve diagnosis and receive support (connection with others), either from the family or an organisation, their health will be enhanced. This strengthens the conclusion that dialogue and interaction with other people (as in telling them about one's HIV+ve status, but also in more general situations) can either harm or promote well-being. Maslow states that meeting deficiency needs is dependent on interaction, whereas being-needs, such as finding meaning, can be satisfied to a larger extent from within the individual (Maslow 1999:244).

#### **2.3.4 *Peak experiences and meaning in life***

A related concept to Maslow's self-actualisation concept is that of *peak experiences*. These experiences represent moments when individuals feel at their best: moments of

great awe, intense happiness, bliss and ecstasy. Maslow sees having *peak experiences* or *moments of self-actualisation* as optimum health, in that persons having peak experiences typically feel better and stronger (Maslow 1996c:39-40; Maslow 1999:106). Peak experiences and mystic experiences in religion are very similar. These observations by Maslow set the stage for later expressions of transpersonal psychology or Fourth-Force psychology (Gillilan 1993:1).

For Maslow, meaning is experienced by self-actualised, growth-motivated persons who delight in using their creative powers *for their own sakes*, and who affirm themselves and simultaneously transcend themselves through peak experiences. Maslow stated, however, that until the lower needs are satisfied, values and meaning have little impact on human motivation. Yet meaning in life is a being-need that requires fulfilment for healthy functioning and produces illness when unfulfilled. Maslow did not believe in an intrinsic meaningfulness of life waiting to be discovered, but argued that it is a developmental process in which self-actualisation and the creation of meaning are central. Total fulfilment of one's meaning or purpose is not possible, because meaning in life is found in ideals, and ideals cannot be perfected. Individuals are free to choose meanings, but according to Maslow they will be healthier if they choose meanings that help them to fulfil their inner nature. The healthiest outcomes occur if chosen activities match the intrinsic values of those persons as closely as possible. Basically, Maslow was convinced that a healthy person needs a philosophy of life to the same extent that he or she needs sunlight or love (Maslow 1996g:73-77). The HIV+ve women that chose to be trained as buddies believed that helping others was the right thing to do. As such, the health promoting potential of being a buddy as well as having a buddy was acknowledged in the present study.

Friedman (1992:15-16) notes a paradox in Maslow's valuing both autonomy and altruism. Self-actualisation has generally been described in a manner that could easily appear to advocate or condone an individualistic, self-seeking approach to life and a concern with purely personal gratification. In such an interpretation, the concept becomes not only ethically dubious, but also restrictive and misleading in that it directs attention away from our responsibilities to other people and away from communal endeavours

(Daniels 1988:7-38). Perhaps the central issue here is whether self-actualisation is a goal to be sought directly, or whether it emerges as an unsought "by-product" of living. Friedman (1992:15-34) has skillfully exposed the paradox and dangers involved in attempts to achieve self-actualisation by directly aiming at the self, and recognises that the exercise of the virtues is not simply a method for achieving the good life, but is itself central to what we mean by the good life; the relationship between means and ends is *internal*. Such a conception encourages us to focus upon the *way* of living rather than upon its supposed rewards. Rewards, if they come at all, do so as an internal by-product of living the good life (Friedman 1992:16-17). In the case of the buddies who help others to cope with the challenges of living with HIV, the end goal is to improve the quality of life of their clients. If being a buddy improves their own well-being as well, it is a by-product or the reward of altruistic behaviour, it should not be the reason why they decided to help others.

Bearing in mind this criticism of self-actualisation by Friedman, who, after the death of Maslow, went beyond the humanistic psychology of the 1970s by including the importance of dialogue and the human image, it seems possible that Maslow might have agreed with Friedman's theoretical work. It was after all Maslow who argued that growth "requires courage, will, choice, and strength in the individual, as well as protection, permission and encouragement from the environment" (Maslow 1999:225).

In terms of Maslow's theory it was held possible for buddies to role-model positive actions to the client and vice versa. The final decisions and choices rested with the individual. Although the buddy played a supporting role, "filling the empty holes", the client retained the basic responsibility for his or her own life and would always be the most powerful figure in it (Maslow 1987:251).

Maslow's theory was applied in the present study because the theory gives hope; it supports the notion of self-realisation through community involvement and vice versa. Maslow explained human motivation and why most people do not give up when faced with adversity but strive to fulfil their potential, have courage and use inner strength as a resource. Society should be set up, Maslow held, to maximise synergy between the better person and society since they are causes and effects of each other:

An increase in intrapsychic synergy in one person is at the same time a move in the direction of increased synergy in others, the organisation and the society (Maslow 1996b:31; Maslow 1996h:117; Maslow 1999:243).

Maslow's theory was helpful in considering how empowering the buddies with *skills* and *a belief* that they could help others would improve the health of the buddies as well as the health of the clients.

### **2.3.5 Summary**

Maslow's hierarchy of human needs, seen within the social setting of HIV+ve women in Botswana (as set out in the background to this research) seemed an appropriate choice through which to further expand on the activities implied within Orem's theory.

Maslow's beliefs were that people are interdependent, needs are satisfied through others by support, reassurance, acceptance, protection, willingness to listen and kindness. This was noted in Orem's self-care theory that emphasised the support role of caregivers to help the client to select beneficial self-care actions (Orem 1995:228). Taking care of their own deficiency- and being-needs could lead to improved health of the clients and possibly also of the buddies. Maslow wanted to develop a psychology that would deal with the best and highest potential in human nature and emphasised belongingness, love, affection respect for others and the building of self-respect (Maslow 1999:34).

Being part of the buddy programme was believed to give the HIV+ve women a forum for considering existential issues, finding meaning and developing a positive attitude towards life. These positive feelings might be inspired by feeling good about oneself, a by-product of the decision to start helping others. The belief that relevant life outcomes are largely dependent on one's own actions can be empowering, because they are not dependent on others but come from within the person. Faced with a life-threatening illness, the HIV+ve women in the present study might contemplate aspects such as receiving respect from others, but possibly realise that finding meaning in their illness

comes from within. Inner strength is influenced by, but not dependent on, what others think and do.

Maslow's hierarchy of human needs substantiates individual development up and down the nursing systems continuum described by Orem. The entire model rests on the assumption that individuals want to live and grow, become happier, improve in general and move toward the ideal of perfection, even though they never expect to fully reach that point. In terms of Maslow's theory the often-used term "positive living with HIV" might be just that, in that it speaks to PLWA/Hs who find life worthwhile (Maslow 1996b:26). In addition, both Orem and Maslow imply social support in their theories but focus on different aspects important to health. The need for humanity in external and interpersonal activities were considered in the context of disclosing a HIV+ve diagnosis. Maslow's theory of human needs was helpful in understanding that both disclosure and non-disclosure could cause regression to lower level needs and ill-health if outer and inner resources available to the PLWA/H were not helpful in coping with the HIV+ve diagnosis leading to poor self-respect, fear and rejection. It was explained how the buddy-client relationships could promote self-worth and acceptance by offering a permissive atmosphere in which to explore positive self-care actions. These interactions between the buddies and the clients formed the core of these helping relationships. Other people, in this case peers, were inspirational resources in finding meaning and as such the relationships boosted the powers "within". Peer helping relationships were the resources "outside" the HIV+ve women as well by offering protection and encouragement to be courageous and challenging societal levels of stigma and discrimination. In the next section, social support will be discussed in greater detail.

## **2.4 SOCIAL SUPPORT THEORY**

The foundational assertion of the present research is that living with HIV or AIDS involves a dynamic ebb and flow of the PLWA/Hs' physiological and psychosocial tide. Being diagnosed with a life threatening illness for which there is no cure will need profound adjustment of current lifestyles and expectations. The mechanisms to cope with

the fact that life is not and will never be the same again need to be developed over time. In addition to Orem's and Maslow's theories that hold that each person can deliberately engage in need-fulfilling actions, one additional conceptual model was utilised during the present study to add a more social and less institutionalised; more collective and less individual and smaller (elite) group dimension to the study. This reflects the lived environment of the PLWA in totality. *Social support* is a valuable resource for PLWA/Hs, yet they might actually experience a loss of support, as indicated in the background to this study. The concept of social support will be defined to achieve greater precision in the present investigation of the quality of life of the 116 HIV+ve women.

#### **2.4.1 Orientation**

Exclusive focus on individual risk reduction in HIV/AIDS prevention strategies contributed to negative perceptions towards PLWA/Hs at the start of the epidemic during the early 1980s. Public information campaigns about AIDS sought to inform and often explicitly frighten people into at least knowing that AIDS existed. Uncertainty and urgency combined throughout the first period of HIV-prevention efforts that began with the discovery of AIDS in 1981 and continued through 1984 in the developed world. HIV/AIDS illness was contradictory to what was defined as health by society and as a result the threat of a pandemic, and more specifically the presence of PLWA/Hs in the community, threatened the perceived social order.

During the second HIV prevention period, from approximately 1985 to 1988, public health continued to focus on individual risk reduction, often warning against having multiple sex partners, using commercial sex workers, gay and bisexual men as examples of promiscuous people (Mann 1999:217-218). Fear of discrimination affected information management by newly diagnosed people, who feared being labelled a prostitute or homosexual. Individuals became wary of disclosing their HIV+ve status to others. PLWA/Hs shunned their doctor because telling the doctor or even being seen by other patients in the doctor's waiting room potentially exposed them to stigma (Taylor 2001:792).

Finally, in the third period, beginning in the context of a steadily expanding and intensifying global epidemic in 1988, increasing efforts emerged to add a societal dimension to the previous individually centred, risk-reduction approach. By 2003, vulnerability to HIV reflects the extent to which people are, or are not, capable of making and effecting free and informed decisions about their health. HIV/AIDS is *not* a problem of individuals but of *societies* (Mann 1999:217-218).

Nevertheless, reduced levels of social support in society had a negative impact on the health and well-being of individuals, though it is not easy to define social support. A person who is either self-reliant or resigned to helplessness (not seeking the advice of others when help is needed) will probably receive less actual social support than a person who copes actively by seeking advice, information, or simply someone to talk to about a problem.

The concept of social support has been studied by many disciplines such as social work, sociology, anthropology and medicine, and many different definitions of social support are available. Cohen and Syme (1985:3) conducted a comprehensive review of literature and research relative to the concept “social support”. It is their conceptualisations of the positive and negative impacts of social support on health, together with those of Orem and Maslow (as presented in the previous sections), which guided the present study.

#### ***2.4.2 Definition of social support***

Cohen and Syme (1985:4) assert that when social support is viewed as a resource, it can have negative or positive effects on health and well-being. These authors succinctly define social support as “resources provided by other persons” (Cohen & Syme 1985:4).

Their position is based on the earlier work of Cassel and Cobb. In medicine, Cassel (1974:1041) articulated the connection between social support and health and health outcomes (Cassel 1974:1041). Two years later, Cobb determined that social support had stress-buffering properties. Cobb conceived social support as information belonging to one of three classes:

- information leading the subject to believe he or she is cared for and loved
- information leading the subject to believe he or she is esteemed and valued
- information that he or she belongs to a network of communication and mutual obligation (Cobb 1976:300-314).

In Maslow's hierarchy of needs, all these needs were defined as deficiency-needs that are fulfilled by other human beings at the third and fourth level in the needs hierarchy (Maslow 1999:28).

Cobb further postulates that goods and services do not constitute social support. Providing social support does, however, also encompass informational support, and encourage independent behaviour and not dependency. Here social support or the request to participate is explored as having a positive effect on self-esteem and as such results in improved coping and adaptation to stressful situations (Cobb 1976:312). The fact that social support encourages independent behaviour directly relates to Orem's quest for self-care via the three nursing systems of wholly compensatory, partially compensatory and educative supportive roles (Orem 1995:307).

In subsequent studies, social support has been found to promote health in various ways. A strong social support network was found to be important in reducing mortality rates, improving rates of recovery from serious illness such as stroke and cancer and in the success of interventions such as smoking cessation and cancer screening. The seminal work in this area was a large-scale study in the USA during 1979, which found that people with the lowest levels of social contact had mortality rates that ranged from two to four-and-a-half times higher than those of persons with strong social networks. In other words, people who socialise live longer than people who do not (Berkman & Syme 1979:186). In the present study, it was of interest to explore if levels of disclosure of the HIV+ve status to people of choice showed a relationship with available social support and quality of life.

Through the buddy system of care and support, the buddy and the client spent four to six hours per week with each other. Peer support within the buddy-client dyad aimed at encouraging each other to cope with the challenges of living with HIV and alleviating some of the feelings of loneliness and depression. Because of the close links of the buddy with COCEPWA, clients were made aware of upcoming social events or COCEPWA member meetings. The buddy and client could agree to meet there and thus encourage each other to attend; this facilitated entry into a larger support group of PLWA/Hs because they both knew that they would know at least one other person once they went to COCEPWA. The buddy also played a role in introducing the client to other care agents such as nurses and social workers, and because they also met at the home of the client the buddy interacted with the family of the client as well. The buddy system promoted social interaction of the individual buddy and client and their families, and referral to other sources of support in the community aimed at the expansion of their social support network.

#### ***2.4.3 Social support and HIV/AIDS***

Living with HIV/AIDS has been identified as a significant stressor, and social support has been identified as one factor that can attenuate or decrease the stress associated with this illness (Murphy, Koranyi, Crim & Whited 1999:111). From the inception of the epidemic in the 1980s, HIV+ve persons in the USA, mainly white homosexual men, sought the support of other HIV+ve persons and met with people who were going through similar experiences. Gay and bisexual men often experienced an erosion of support from family members or friends because of adverse culturally-based judgments of their sexual practices and their increased health risk (Fontaine, McKenna & Cheskin 1997:249-250). Some of the positive effects of forming these self-support groups included greater social resources, increased knowledge about the shared condition and enhanced skills for coping with their situation. Other benefits that were identified included a greater ability to meet the demands associated with living with HIV, greater self-confidence, decreased fear, a sense of being cared for, emotional release and reduced helplessness (Coward 1994:334; Fontaine et al. 1997:249).

Social support is also believed to be positively associated with adherence to medication regimens (Paterson, Swindells, Mohr, Brester, Vergis, Squier, Wagener & Singh 2000:21). This might have been beneficial to the participants in the present study because the buddy was trained to give adherence support to the client on ARVs and explain the importance of adherence. Moreover, they could help each other as well in that they could ensure that they had a pillbox and set out their daily dose of medication for the week, agree to go for medication resupply together and remind each other that they were due for a medical check-up. If only one of the two in the buddy-client dyad was on ARVs, learning would be facilitated and the advantages and disadvantages of taking ARVs discussed, enabling informed decision making by the other partner prior to starting ARVs.

#### **2.4.4 *Internal determinants of social support***

The internal determinants of social support are coping strategies, which may occur at behavioural, cognitive or physiological levels. Although cognitive coping skills may affect perceptions of social support, it is the *behaviour* of individuals in the form of social coping skills, which affects the availability of social support. In Botswana, more HIV+ve women than HIV+ve men join support groups. A qualitative study by Coward (1994:331) in the USA, which reported on 10 HIV+ve men and 10 HIV+ve women who were asked about their experiences since their HIV+ve diagnosis, found that men and women responded differently once they were informed about their HIV+ve status. Women appeared more experienced in reaching out to others and using others as role models. The women focused on caring for their children and helping other women living with HIV. Men expressed the importance of taking care of themselves and accepting help. The men regarded volunteer work or participating in clinical drug trials as part of creating a legacy or as something that would carry on beyond their life. Both men and women experienced fear and aloneness, having hope and connecting with others (Coward 1994:333). In the present study of 116 HIV+ve women there was a preparedness to care for other women and women had a stronger preference for same-gender support, as compared to men, who did not mind getting support from men as well as women. (See Chapter 3.)

Another study in the late 1990s in the USA by DeMarco, Miller, Patsdaughter, Chisholm and Grindel (1998:539), which looked at women and HIV specifically, reported that women often maintained behaviours that supported the silencing of their voices. This study of 20 women living with HIV/AIDS reported, however, that *for some women*, an HIV+ve diagnosis ignited them to speak for themselves and to shape their own lives based on their feelings and needs. For others, peer or professional support, or both, were the catalysts for the transition from silence into action. Findings suggested interventions that would assist HIV+ve women to judge themselves by internal versus external standards, put their own needs before the perceived needs of others, express themselves toward action rather than avoidance, and feel comfortable about expressing their anger (DeMarco, Miller, Patsdaughter, Chisholm & Grindel 1998:539-552).

Stressful events force people to make cognitive and behavioural efforts towards effective management. These efforts have to change constantly in order to adequately manage the external and/or internal demands appraised as taxing or exceeding the resources of the person. A person who is told his or her HIV+ve diagnosis and understands that it is a disease for which there is no cure has to find ways to cope. Two forms of coping have been identified: *problem-focused coping*: managing or altering the problem that is causing distress, and *emotion-focused coping*: regulating one's emotional responses to the problem (Lazarus 1993:324). A study of coping reported that 264 HIV+ve women were interviewed at eight HIV/AIDS treatment sites in the USA to explore the relationship between coping strategies and both the physical symptoms of HIV/AIDS and the perceived emotional distress. Findings suggested that using active coping strategies that are focused on managing the illness, seeking social support and joining spiritual activities may lower the perceived levels of emotional distress (Linn, Anema, Hodess, Sharpe & Cain 1996:43).

#### **2.4.5 Social support and health**

Two possible models for the role of social support are the *direct-effect* hypothesis and the *buffering* hypothesis. The chief premise of the **direct-effect** hypothesis is that support

enhances health and well-being regardless of levels of stress. Cohen and Syme (1985:6) propose that this **direct benefit** occurs

- as a result of the perception that aid will be provided in the case of stressful events, or
- as a result of membership of a social network.

It is argued that the perception that others are willing to provide assistance could result in overall positive affect and a sense of stability and control over the environment (Cohen & Syme 1985:6). This is in agreement with Maslow's classification of love and belonging as a deficiency need that needs to be met before the individual can move towards self-esteem and feeling confident within oneself. Third-level need fulfilment depends on support coming from outside the individual. Knowledge or faith that support from without will be available when needed contributes to the health and well-being of the individual. Concern that support may not be forthcoming would make the person anxious, and regression to a lower-level need, such as greater concern for safety, could be expected (Acton & Malathum 2000:797).

Likewise, this perception could influence susceptibility to physical illness via effects on neuro-endocrine or immune system functioning. The positive influence of being therapies such as yoga, meditation and massage have been mentioned as having positive influences on immune system functioning, bolstering CD4 counts and perceived levels of well-being (Chidwick & Borrill 1996:271; Strauman, Lemieux & Coe 1993:1042).

To test the direct effect hypothesis, structural support measurement can be utilised, which measures the sources of support. Sources of support imply both the interconnections among social ties such as marital status and the number of people one can call upon when facing a challenging situation (Cohen, Underwood & Gottlieb 2000:11-12).

The **buffering** hypothesis proposes that the beneficial effects of support lie in its protecting people from the pathogenic effects of stress. The result may occur in two ways. Firstly, support may prevent or attenuate a stress response by intervening between the stressful event (or expectation of the event) and the response. In other words, in terms

of the definition of social support by Cohen and Syme, “the resources provided by others” may redefine and reduce potential for harm posed by a situation and bolster the ability to cope with imposed demands. For this reason having social support might prevent the appraisal of a situation as being stressful (Cohen & Syme 1985:4). Secondly, support may reduce or eliminate the stress experience or directly influence illness behaviours or physiological processes by intervening between the experience of stress and the onset of pathological outcomes. In other words, social support may be helpful when stress is increased and neutral when stress is low (Cohen et al. 2000:13).

Cohen and Syme’s (1985:4) conceptualisation of social support contributes to the examination of phenomena impacting on or affecting the health of the 116 HIV+ve women in the present study. In this study the *buffering* hypothesis, functional support, was measured in particular with regard to the tangible, appraisal, self-esteem and belonging aspects of support, all deficiency-needs in Maslow’s terminology (Maslow 1999:33). In terms of Orem’s theory, seeking social support is a universal self-care requisite (Orem 1995:131). Seeking and giving social support is a social endeavour and the HIV+ve women were taking self-care beyond the institutionalised care measures as offered by the health care and social welfare system. This was because not only there were barriers to access for the HIV+ve women and a shortage of professional care agency, but was inspired by the desire of the HIV+ve women to help others. Their HIV+ve diagnosis helped them to reprioritise what was important, gave meaning to their suffering and translated into altruistic behaviour. The present study considered the AIDS epidemic more as a problem of society and less as an individual problem.

Social support theory upholds the notion that human beings can be a positive resource for health. In order to be healthy, people need each other and want to feel needed. This perspective was a valuable addition to the tenets of Orem on self-care and Maslow on the hierarchy of needs, which implied the importance of interpersonal relationships but did not make this as explicit as Cohen and Syme.

#### **2.4.6 Summary**

The present study considered how buddies supported their clients and vice versa. The researcher assumed that the perception of that social support reflected their reality and that it was possible to measure the perceptions of both buddy and client. Theory was useful in providing an inclusive framework within which to examine and describe the support that buddies provided to other HIV+ve women, but also stressed the fact that social support can be either beneficial or deleterious to PLWA/Hs. Decreased social contact and social isolation has been associated with AIDS (Coward 1994:331). A greater probability of social isolation is said to exist when a PLWA/H is experiencing an unstable downward trajectory; although PLWA/Hs actually have a greater than average need for social support, they might encounter great difficulty in obtaining it. The design of the buddy programme was informed by the needs expressed by the PLWA/Hs during the needs assessment in 2000, which reported their need and preference for peer support. (See Chapter 3.)

## **2.5 CONCLUSION**

Orem theorised that adults take care of themselves and make a continuous contribution to their own lives as responsible adults. This is to maintain life and to meet known requisites for functional regulation. Care is provided in the quest for self-care via the systems of wholly compensatory, partial compensatory and educative supportive care. The Botswana buddy programme takes the form of giving psychosocial support *by* women living with HIV, buddies, *to* women living with HIV, the clients. This was believed to boost the HIV+ve women's power components for self-care. The buddies were expected to role-model positive living, be proactive and give guidance, support and coaching and reinforcement of the universal, developmental and health-deviation self-care actions of their clients. Orem's theory provided a basis for examining the balance between the needs, capabilities and limitations in exercising self-care via the continuum provided by the three systems to enhance the quality of life of the HIV+ve women in the present study.

Orem's positive view about the self-care abilities of adults, both clients and buddies, was augmented by Maslow's motivation theory that explained the prepotency of survival needs over being needs. Maslow challenged other scholars in the field of psychology when he argued during the 1960s that the highest possibilities of human beings have practically always been underestimated and that in his opinion all human beings have an innate tendency to move toward higher levels of health, creativity and self-actualisation. Maslow added valuable insights about the importance of finding meaning in life and how being driven by deficiency needs only, could prevent the attaining of higher levels of functioning. Orem and Maslow concurred on the importance of solidarity and helping others. Both theorists regarded caring for others as need fulfilling and a sign of maturity in a person's development. Orem's and Maslow's definitions of well-being reinforced the notion that even when faced with adversity, such as an HIV+ve diagnosis, health is possible. Maslow contended that self-actualisation or health is a matter of degree and of frequency rather than an all-or-nothing affair.

Cohen and Syme's (1987:4) conceptualisation of social support further assisted in explaining that the degree of social support an HIV+ve woman receives has important consequences in terms of her health status. The buddy system by its very nature represents a social support system. Isolation causes the HIV+ve women to be cut off from much-needed social support, a condition the Botswana buddy programme sought to amend. The present research investigated how the Botswana buddy programme affected the quality of life of the 116 HIV+ve women. More specifically, the theories directed the study of the self-care actions (Orem), needs fulfilment (Maslow), and perceived levels and availability of types of social support (Cohen and Syme) at the start of the present study in April 2002 and the change in these areas of interest six months later in November 2002.

The next chapter, Chapter 3, will present and discuss the significant findings of the 2000 survey of the needs of 116 HIV+ve men and women, which provided background information for the present study. The survey was conceptualised by the researcher of the present study during 2000, six months after the founding of COCEPWA by a woman

living with HIV, Ms Helen Mhone, in November 1999. The 2000 survey was unique in that it was the first study in Botswana that had its origin within an organisation by and for PLWA/Hs. HIV+ve research assistants reached out and gained the trust of HIV+ve men and women who, despite low levels of disclosure of their HIV+ve status, chose to participate. The survey gave PLWA/Hs an occasion to unite and express their needs and experiences of being HIV positive in Botswana. The findings of the survey informed the strategic direction of COCEPWA during 2000 and resulted in the scaling up of COCEPWA to six branches nationwide. This expansion of COCEPWA programmes and activities included the design and implementation of the buddy programme.

## **CHAPTER 3**

### **NEEDS ASSESSMENT**

#### **3.1 INTRODUCTION**

In general, there is a growing appreciation of the importance of how health-service recipients feel and how satisfied they are with their care and/or treatment in addition to the traditional focus on health outcomes. However, the self-imposed and societal levels of stigma surrounding HIV and AIDS have forced many PLWA/Hs into silence and denial of their HIV+ve diagnosis.

This secrecy about being HIV+ve has largely prevented contributions by the PLWA/Hs to the definition of quality of life in the context of living with a life-threatening illness. This lack of information about their needs, core functioning and well-being as HIV+ve people influences the development of quality health care and support, since the care providers resort to offering services based on what *they* think is right, without initial input and continuous feedback from the PLWA/Hs involved.

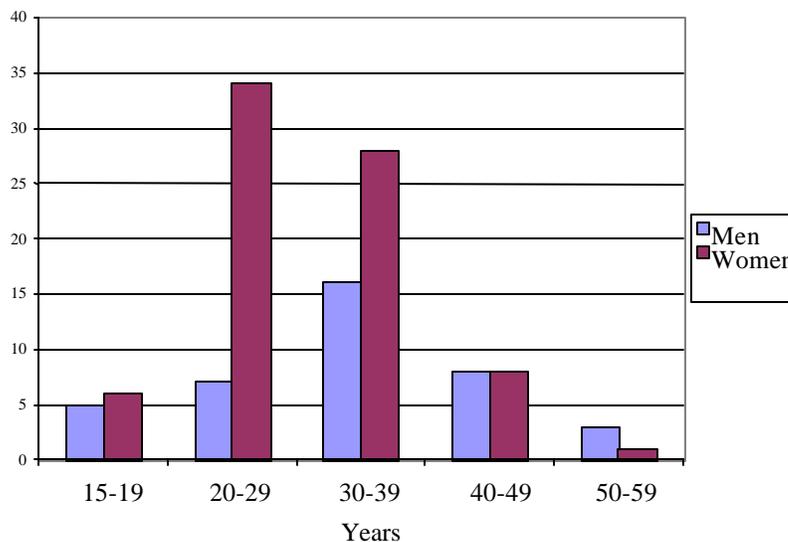
The findings of the survey conducted during 2000 described the PLWA/Hs of Botswana through a review of their backgrounds, self-care actions and a description of needs. The survey findings informed the strategic direction of COCEPWA and over 1000 copies of the report were made available nationally and internationally by COCEPWA to other service providers to PLWA/Hs.

#### **3.2 BACKGROUND INFORMATION**

For every two women that participated in the needs assessment, one man participated. This was not representative of the overall ratio of male to female HIV and AIDS cases in Botswana, which is roughly 1:1. The pattern of both men and women being infected with HIV is indicative of a predominantly heterosexual mode of transmission in Botswana (McFadden 1998:30-32; Piot, Bartos, Ghys, Walker & Schwartlander 2001:968-975;

UNDP & GOB 2000:26). The pattern, nevertheless, conceals deep-seated unequal gender relations and disparities in HIV prevalence rates between *younger* men and women. According to the 2000 Botswana Human Development Report by the UNDP (2000:26), the risk of infection is higher for young women in the age group 15-29 years. Three cases of 15-19-year-old HIV+ve females were reported for every one HIV+ve male case in the same age group (UNDP & GOB 2000:26).

This 3:1 ratio as reported by the UNDP was confirmed in this non-random sample of 116 PLWA/Hs, with 40 women and 12 men infected in the 15-29 year age group. Women were infected with HIV at a much younger age than men, and other studies have suggested that HIV in Botswana is transmitted from older men to younger girls, who in turn infect boys their own age (Tlou 2002:659; Tlou, Rantona & Phaladze 2001:65; UNDP & GOB 2000:26-28). (See Figure 3.1.)



**Figure 3.1 Age and gender of the study participants (N = 116)**

Maslow identified education as a path to self-actualisation, since he believed curiosity and the need to know and understand to be an important element in reaching self-actualisation (Maslow 1996b:29). In the survey, low levels of education were reported. Not all the respondents had attended school but 52 PLWA/Hs (45%) had attended up to primary school level. Only 14 PLWA/Hs (12%) had completed their secondary

education. Fewer than 10% of the study participants had enjoyed tertiary education. Level of education correlated with employment, and low levels of full-time employment were reported; 42 PLWA/Hs (36%) were employed full time.

Monthly income of less than BWP200 or approximately USD40 during the preceding month was reported by 62 PLWA/Hs (53%; N = 116) of which 42 were women (68%; n = 62). Being HIV+ve further depletes incomes. The immediate monetary cost of HIV and AIDS to the household includes increased expenditures on health, such as travel to the government clinics or hospitals, where citizens of Botswana pay a fee of BWP2.00 or USD0.40 for health care services. Patients or their relatives might also incur considerable costs when they opt to pay for second opinions about their own or their relative's illness from traditional health care providers and/or private health care practitioners. Households might draw from their savings, dispose of assets and incur debt to finance expenditures due to rising health care costs. In addition to these direct health care related costs, incomes might dwindle due to early retirement of sick breadwinners and having to make contributions to finance the funerals of relatives (MOH 1997:22; UNDP & GOB 2000:18).

Another factor that further depletes financial resources could be identified; 15% of the survey participants reported that they looked after children of relatives or friends. This is possibly directly related to the increasing number of adults in the 20 to 40 years of age group dying and leaving children behind. Model projections indicate that by 2010 the number of children under 18 years of age who have lost one or both parents in Botswana could rise to between 159 000 and 214 000 children; this will constitute 20% of all children in Botswana (UNDP & GOB 2000:18-19). The government of Botswana makes an effort to ameliorate some of the hardships through social welfare measures, and had provided food and school uniforms to vulnerable children in their community, according to 90 PLWA/Hs (78%) in the survey. However, the persistence of income inequality and poverty among its citizens, in particular the women, remains an area of concern for the Government of Botswana. Female-headed households constitute about 47% of all households having to survive on the lowest household incomes (MLHA 1995:6).

Lack of understanding of what it means to be HIV+ve was reported by 37% of the PLWA/Hs. This was not specific to PLWA/Hs with low incomes, although 42% of those who earned less than BWP200 reported that they did not really understand what HIV and AIDS meant. Analysis by gender revealed that more men (49%) had a poor understanding than women (31%). Most PLWA/Hs tried to educate themselves about HIV and AIDS in the place where they lived, but 26% reported that they had no access to information relevant to living with HIV and AIDS. Maslow held that in order to meet their potential, people need adequate conditions for making choices, which necessitates full access to all information. Maslow cautioned that useful information must not be hidden, so that people can choose without fear or social pressure (Maslow 1996b:29). The survey indicated that information was needed very urgently about HIV treatment (mentioned by 114 PLWA/Hs); welfare (mentioned by 53 PLWA/Hs); and counselling services (mentioned by 42 PLWA/Hs).

### **3.3 METHODS**

#### **3.3.1 Questionnaire**

A 73-item questionnaire was administered to survey the needs of a non-random convenience sample of 39 male and 77 female PLWA/Hs in Botswana. Questions 1-31 asked about demographic variables, HIV testing and disclosure patterns. Questions 32-49 related to coping mechanisms, and questions 50-69 to support. The last four items, 70-73, were questions about how the participants had generally felt during the month preceding the survey. In Section 4 of the questionnaire participants could record comments, suggestions and thoughts they might have had during or after answering the 73 questions (Zuyderduin 2000:59-70). (See Annexure II for questionnaire with answers.)

The 116 participants were identified by two female HIV+ve research assistants who asked other PLWA/Hs they knew to complete the questionnaire. This choice of sampling methodology was informed by a review of previous studies of PLWA/Hs. All those studies used non-random sampling methods (Bunting 1996:64; Erlen & Mellors 1999:75-84; Ingram & Hutchinson 1999:93; Jirapaet 2000:34; Kvitiz, Crittenden, Madura &

Warnecke 1994:191; Metcalfe, Langstaff, Evans, Paterson & Reid 1998:30; Murphy et al. 1999:111). Snowball sampling techniques were used in these quantitative and qualitative studies, since truly representative samples were impossible to obtain due to the fact that this is a hidden population, which made it impossible to compile a census (Flaskerud, Lesser, Dixon, Anderson, Conde, Kim, Koniak- Griffin, Strehlow, Tullmann & Verzemnieks 2002:74-85). Since it is unlikely that marginalised groups such as the PLWA/Hs will reveal themselves, one is generally unable to rely on probability samples, even if the whole population of a country could be identified (Platzer & James 1997:626).

Data were collected using a questionnaire in preference to face-to-face interviewing to protect the privacy of the PLWA/Hs. It was perceived to be less threatening to complete questionnaires than to be tape-recorded during an interview or participate in a group discussion with other participants. One advantage of this method was that a confidential study of hidden populations who were otherwise not identifiable was possible. The PLWA/Hs would have been unlikely to participate in a study that failed to guarantee their anonymity. The research assistants (members of COCEPWA), would not have looked for other PLWA/Hs to encourage them to participate in any study that would not have guaranteed total anonymity.

The survey method was low-cost and was conducted over a time period of four months during 2000. Each PLWA/H completed the questionnaire and mailed or handed in the completed questionnaires to the research assistants. Through this survey, 116 PLWA/Hs were approached to complete questionnaires; all participants (100%) returned questionnaires that were at least 90% complete and all these were included in the survey.

### ***3.3.2 Theoretical background***

Underpinning the presentation of the findings of the 2000 survey is the hierarchy of needs theory of Maslow, which theorised that lower needs must be satisfied before higher needs emerge. As explained in Chapter 2, lower needs are dependent on actions by other people; Maslow labelled these needs for food, safety, belonging and esteem, deficiency

needs (Maslow 1999:168-169). However, people's needs extend far beyond the material problems and the accumulation of objects.

Higher needs, according to Maslow, are not dependent on other people but are met from within a person and are considered "being" needs (Maslow 1999:168-169). These needs for love, social justice, dignity and the like are basic to the growth and development of all people who aim to use all their qualities to reach higher levels of being throughout their lifetime. In the case of the PLWA/Hs, actions such as joining support groups and providing care and support to their peers illustrated their desire to fulfil higher needs.

Reports of rejection and social distancing of PLWA/Hs have been common in Botswana (Bara 2002:1-9; Donnelly 2003:1-3; Tlou 2002:654-663). Pleas for help by President Mogae (2000:13) and the report by Piot et al. (2001:968) about the scope and the devastating impact of the AIDS epidemic in Botswana and the region might discourage people and cause them to lose hope. However, there have been more optimistic studies as well, outside Botswana in the late 1990s, that investigated the link between levels of stigma and levels of motivation of PLWA/Hs to lead positive lives inspired by hope and dreams for the future (Barroso & Powell-Cope 2000:340-353; Nannis, Patterson & Semple 1997:22; Swindells, Mohr, Justis, Berman, Squier, Wagener & Singh 1999:383-391; Tsevat, Solzan, Kuntz, Ragland, Currier, Sell & Weinstein 1996:44-57).

The survey of Zuyderduin (2000:1-70) explored the perceptions of the PLWA/Hs of the quality of their lives, deficiency and being needs and whether the PLWA/Hs pursued higher levels of well-being. The self-care theory of Orem was useful in the interpretation of the findings related to the self-care actions and capabilities of the PLWA/Hs. Orem noted that levels of well-being could be achieved even when faced with adversity and that human beings need other people for healthy functioning (Orem 1995:101-103,453). Taking it a step further, Maslow argued that because of pain and conflict better health was possible (Maslow 1999:9). The motivation for this survey by and for PLWA/Hs was to persuade the HIV+ve people to contribute and voice their needs and concerns.

However, most of all the PLWA/Hs searched firstly for innovative ways to help each other to overcome the suffering caused by HIV and AIDS.

### ***3.3.3 Demographics of the sample***

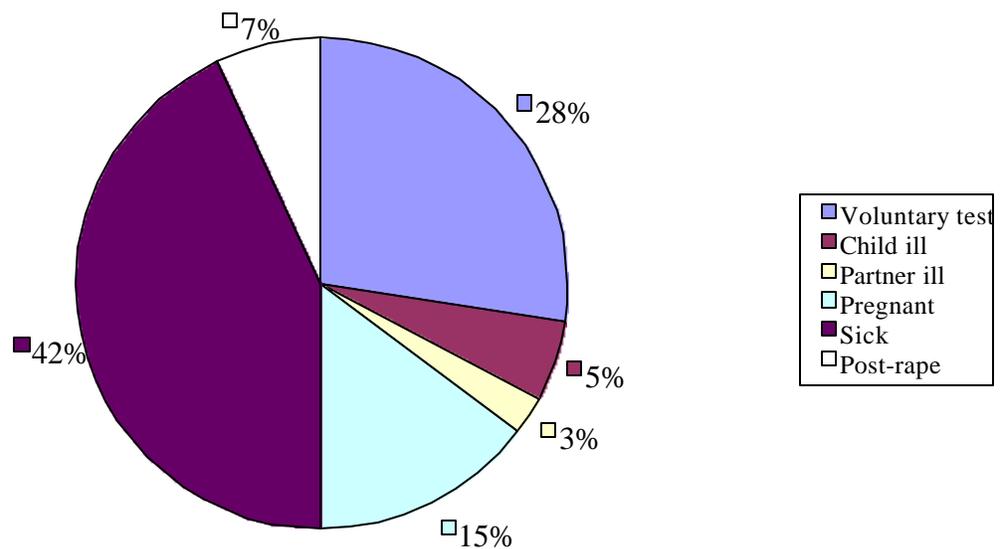
COCEPWA Gaborone was the starting point of the referral chain for this non-random sample. The urban centres of Gaborone and Francistown comprised 65% of the sample. Of the rest of the PLWA/Hs, 26% lived in villages and another 10% lived in remote rural areas. In Botswana PLWA/Hs, when suffering ill-health, often move away from the urban areas and rent out their town houses/rooms to generate income to help them subsist in the rural areas (Zuyderduin 2000:60). This might explain why only 11% of the PLWA/Hs reported themselves to be very worried about their health, as the PLWA/Hs were generally healthy and active members of society while residing in the towns and larger villages targeted for this survey. Different results could be expected if PLWA/Hs living in remote rural areas were targeted.

### ***3.3.4 Reactions of participants***

The participants were asked an open-ended question about the usefulness of the survey to them. Nine PLWA/Hs believed that the needs assessment was a good idea and hoped that their views would be presented to the government. Three people were very sceptical and did not believe it would help them. In addition to this open-ended question, 18 PLWA/Hs commented on the need for a COCEPWA nearby since they desired to have a safe meeting place for PLWA/Hs where they lived, and six PLWA/Hs mentioned the need for supportive counselling. Ten PLWA/Hs expressed a need for support with food, transport and clothing, and five PLWA/Hs urged the authorities to act and make ARVs available to all PLWA/Hs for the sake of their children, who faced becoming orphans if they were not accessing ARV therapy. (See Annexure II for questionnaire with answers.)

### 3.4 TESTING AND DISCLOSURE

None of the respondents of the survey had been tested for HIV as part of pre-employment testing or for insurance purposes. The largest section of the surveyed PLWA/Hs (43%) were tested because they were ill and the doctor wanted to know whether they were HIV+ve. Seventeen PLWA/Hs (15%) were tested during pregnancy. As many as 28% of the 116 PLWA/Hs (10 men and 22 women), went for VCT. Statistics revealed that in the early 2000s about a third of all adults in Botswana lived with HIV, yet only a fraction presented for VCT to discover if they were HIV positive or HIV negative (Donnelly 2003:1-3; UNDP & GOB 2000:37). See Figure 3.2 for reasons for HIV testing among the HIV+ve study participants.



**Figure 3.2 Reasons for HIV testing among study participants (N = 116)**

The data collection process of this survey depended on the participation of PLWA/Hs who had disclosed to at least one or more persons. Many had disclosed their HIV+ve status only to the person who asked them to participate in this survey. The findings reported that 56%

of the surveyed PLWA/Hs were completely “in”, meaning that they had told fewer than five people that they were HIV positive. A smaller proportion (35%) had shared their HIV+ve status with 6 to 30 people, and were “half in/half out”. Only 8 of the PLWA/Hs surveyed stated that they had gone public and had disclosed their HIV+ve status to over 50 people. This low number was not surprising, since even in the late 1990s, in the whole of Botswana only 12 PLWA/Hs had publicly disclosed their HIV+ve status since the first AIDS case was diagnosed in 1985. Some of those PLWA/Hs participated in this survey.

The majority of the PLWA/Hs in this survey were diagnosed as HIV+ve between 1997 and 2000. Re-testing for HIV was common; 62 PLWA/Hs (53.4%) went twice for HIV testing and 22 PLWA/Hs (19%) went three, four or more times. Repeat testing for HIV could be an indicator of denial and/or lack of understanding about the HIV+ve diagnosis. Of the PLWA/Hs, 85% believed that they had become infected with HIV through heterosexual contact, while another 10% had no idea how they became HIV-infected. A plethora of myths about the cause of HIV and AIDS exist, and those misconceptions are believed to have delayed changes in behaviour and aided the spread of HIV infection (Ingstad 1990:28-37; Steen & Mazonde 1999:163-172; UNDP & GOB 2000:32). The misconceptions include beliefs that

- HIV infects only promiscuous people and prostitutes.
- Having sex with a virgin is likened to blood cleansing and will cure AIDS.
- Some traditional doctors can cure AIDS (UNDP & GOB 2000:32).

### **3.5 THE NEED FOR SAFETY, ORDER AND FREEDOM FROM FEAR**

The needs theory of Maslow was helpful in understanding that both keeping the HIV+ve diagnosis a secret and telling other people about a HIV+ve diagnosis were possible sources of tensions and anxieties. Where feelings of safety were affected this possibly prevented higher-level needs from emerging. (See Chapter 2.)

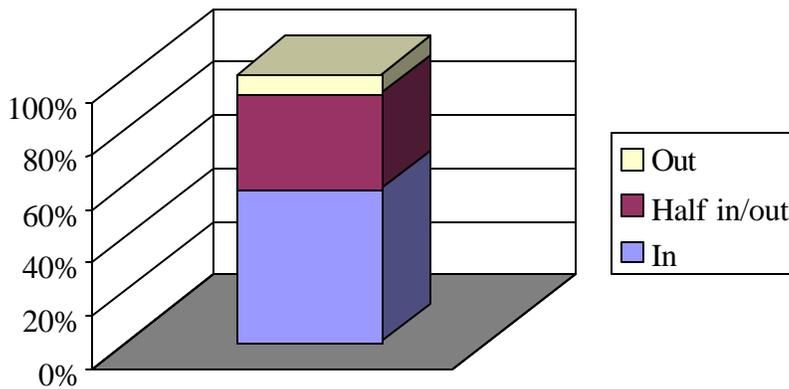
#### **3.5.1 *Risks of disclosure***

Unmet safety needs were expressed as fear of physical and sexual abuses after disclosure and 18 PLWA/Hs (16%) stated that they could not afford a lawyer but required legal assistance in connection with alleged rape/sexual assault cases. Most PLWA/Hs were not talking about their HIV+ve diagnosis; 64 PLWA/Hs (56%; N = 116) did not feel safe and reported that most people, including those who knew them well, were completely unaware of their HIV+ve diagnosis. Their HIV+ve status was their secret. They were “in”. Of these 64 PLWA/Hs who had disclosed to fewer than 5 people, 29% were men and 71% were women.

Maslow expressed his concern about keeping quiet about issues (as in not expressing or releasing all emotions) and encouraged people to discuss the issues that they were disturbed about (Maslow 1996c:41). Cautioning that what is not used will waste away, Maslow warned about physical and emotional “atrophy” due to, for example, unused intelligence or unmet love needs and the like. Maslow argued that people need to express themselves and seek release to prevent abnormalities. Maslow advised people to use all their physical and mental capabilities and achieve total discharge, gratification and perfection (Maslow 1996c:41).

Accepting that not all people have the same need for total expression Maslow posited that “every person finds abeyance - that is, withholding expression - to be more or less troublesome or even intolerable” (Maslow 1996c:41).

Not all PLWA/Hs were secretive about their HIV+ve diagnosis. At the other end of the spectrum, 8 PLWA/Hs (7%; N = 116) reported their HIV+ve status to be public knowledge. They had disclosed to over 30 people and were “out”. On this continuum of disclosure, 40 PLWA/Hs (35%) were in between these two groups, “half in and half out”, and had disclosed to between 6 and 29 people. Four PLWA/Hs did not answer this question. (See Figure 3.3.)



**Figure 3.3 Disclosure of HIV+ve status to other people**

To measure the levels of stigma and discrimination, the PLWA/Hs were asked about violations of their dignity, the number of times they had been insulted because of their HIV+ve status, and whether they had experienced blackmail problems. Of the PLWA/Hs, 15% had experienced both blackmail and insults. Blackmail was a problem for 33% of those PLWA/Hs who had disclosed to fewer than 30 people, but verbal and physical abuse challenged PLWA/Hs who were out with their HIV+ve status as well. Two PLWA/Hs (2%) were beaten once because they were HIV+ve and 17 PLWA/Hs (15%) were threatened with disclosure of their HIV+ve status to people who were unaware of this fact.

Increased openness was a risk factor for verbal and physical abuse and resulted in more frequent incidents of abuse by others. Of the 8 PLWA/Hs (6%; N = 116) who had gone public with their HIV+ve status, 4 PLWA/Hs (50%; n = 8) had been insulted, one PLWA/H (12.5%) had been beaten and one PLWA/H (12.5%) was threatened by disclosure of his HIV+ve status to people who were unaware of this fact. An unfortunate consequence of societal stigma could be the internalisation of the negative views by those who were stigmatised. The result of self-stigma is often self-depreciation and the decision to disclose and to whom becomes more complex because of factors within the PLWA/Hs and factors in the environment (Bunting 1996:64; Flynn, McKeever, Spada & Gordon-Garofalo 2000:60).

Stigma causes the HIV+ve person concerned to suffer but, as Maslow pointed out, the rest of society will suffer as well. Maslow reflected on the phenomenon of ecological balance that exists in nature; such balance benefits not just one group but all species. From this, Maslow deduced that when disturbed conditions, such as abuse, exist between for example family members, they would affect not just the two people in conflict but also everyone involved (Maslow 1996b:31). This insight could be transferred to the understanding of AIDS stigma, in that violations of their human rights harm not only the PLWH/A but damage everyone else involved. Therefore, Maslow argued, the good for other people must be invoked, as well as the good for oneself, since there is synergy between the individual good and the good of society (Maslow 1996b:31-32).

Maslow's theory assisted in understanding the importance of a holistic approach. An exclusive focus on behavioural and attitude changes needed by the HIV+ve people only would assist in decreasing societal stigma but would not be sufficient, as all people in Botswana need to change.

The political climate in Botswana has been conducive to mobilising everybody, both those who know that they are HIV positive *and* the rest of the population. Since his election in 1998, President Mogae has led Botswana's battle against HIV and AIDS, making an effort to break the silence and denial surrounding HIV and AIDS in Botswana (Mogae 2000:13). Supporting the notion that it was important to lead by example and that other people generally mirror one's own personality, Maslow emphasised that "the good world helps to permit the good person to be good" (Maslow 1996b:35).

### ***3.5.2 Rape and HIV transmission***

Unfortunately, not all is well in Botswana. This survey identified eight single women who were tested for HIV and diagnosed HIV+ve after being raped. Reports about rape in Botswana by a local NGO, Women Against Rape in Maun, suggested that - despite a marked increase in the number of reported rape cases - conviction rates have remained extremely low (UNDP & GOB 2000:31). Of the eight HIV+ve raped women, five

indicated that if they were able to get a lawyer free of charge they would use legal assistance in dealing with their situation. Police and court records show that two-fifths of Botswana's rape cases involve girls younger than 16 years, but data on the relationship between abuse and HIV transmission through rape are largely absent (UNDP & GOB 2000:31). None of the raped women were on ARVs. Their families helped four of the women to cope; three of the women were supported by another PLWA/H; and one woman was supported by a nurse. Five of the women had told their parents about their HIV+ve status and had received supportive counselling during the previous three months. All PLWA/Hs (n = 8) would like to be visited at home by another PLWA/H if that were possible. One of the women reported that she went public to tell others what had happened to her.

### ***3.5.3 Need for peer support***

According to Misovich et al. (1997:95-123), successful prevention of HIV transmission is based on three components: information, motivation and behavioural skills. Dialogue with well-informed peers can validate PLWA/Hs' correct information or indeed correct their misinformation, express positive attitudes and norms for behaviour and can provide role models for the development of behavioural skills. These researchers argued that it is likely that AIDS prevention interventions making use of similar (peer) expertise will be more effective than interventions without such leaders (Misovich et al. 1997:95). This was a challenge in Botswana during 2000, since peer support was not available to 16% of the PLWA/Hs. These PLWA/Hs did not know another PLWA/H where they lived, and 20% reported that they could *not* phone another PLWA/H within 24 hours if they had a problem related to their HIV+ve status. Sixty-one PLWA/Hs (53%) reported that they knew between one and five PLWA/Hs, and 22 PLWA/Hs (19%) reported that they knew six or more.

## **3.6 THE NEED FOR LOVE AND BELONGINGNESS**

The PLWA/Hs expressed concerns about loneliness. Love and belongingness were identified as third-level needs in Maslow's hierarchy of needs theory. (See Chapter 2.)

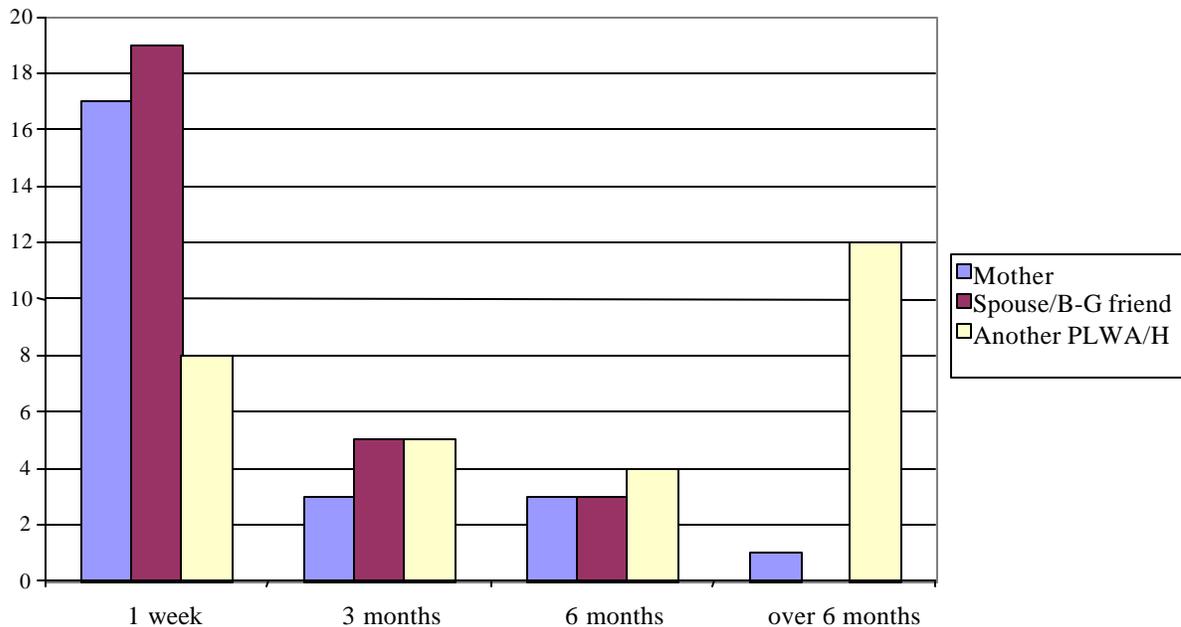
However, nearly 70% of the 116 PLWA/Hs reported that they were not in an intimate relationship. Of those who were, 18 PLWA/Hs (16%) reported that their partners were also HIV+ve.

Nearly a third of the PLWA/Hs had experienced multiple deaths within their families during the year preceding the survey. This might have contributed to additional tensions due to unresolved grieving processes. Supportive counselling was received three months preceding the completion of the questionnaire by 71 PLWA/Hs (61%; N = 116), and 57 PLWA/Hs (47%) had access to a support group. It was very important for the 58 *female* PLWA/Hs (75%; n = 77) across all age groups to be in an all-female support group where they could discuss their problems and concerns with peers. However, despite the availability of peer support, there was evidence that Botswana was indeed experiencing a crisis and that the death toll was rising (Mbogori 1998:2; Mogae 2000:13). Only four PLWA/Hs reported that they had *not* lost close family members. Of the 112 PLWA/Hs who had done so, 27% had lost three or more close family members during the previous year, 1999.

Nearly half of all the PLWA/Hs surveyed (48%) had not told their parents about their HIV+ve status. Seventeen PLWA/Hs (15%) explained that they did not tell their parents because they were frightened of how their elderly parents would react. The reason stated most often was that the PLWA/Hs feared they would be rejected by their family. These PLWA/Hs decided to avoid ostracism or stigmatism, even when they forfeited appropriate psychosocial support as a consequence of these actions.

However, many of the PLWA/Hs who had anticipated negative reactions by those they informed about their status actually found acceptance. The first persons of choice who were told of their HIV+ve status were: another PLWA/H (25%); the spouse or boy/girlfriend (23%) or their mother (21%). When they revealed their HIV+ve diagnosis to another PLWA/H, their partner or their mother, an encouraging 64% reacted to the news in a supportive manner, according to the PLWA/Hs.

Sixty PLWA/Hs (52%; N = 116) informed the first person *within a week* after the HIV+ve diagnosis. Twelve PLWA/Hs (37%; n = 33) took *longer than three months* to disclose and had not told their sex partner (during the last year) that they were HIV+ve. However, 17 PLWA/Hs (15%; N = 116) took *longer than six months* before telling that first person. (See Figure 3.4.)



**Figure 3.4 Time needed to voluntarily disclose HIV+ve status for the first time to person of choice**

Peer support was important in promoting disclosure; of the 17 PLWA/Hs who had not told anybody about the HIV+ve status for more than six months, 70% eventually told other PLWA/Hs about their HIV+ve diagnosis. Thirteen PLWA/Hs (76%; n = 17) who had kept their HIV+ve status a secret for a longer time reported that other PLWA/Hs were the most important people to help them cope with the HIV+ve diagnosis.

The persons most important for helping the PLWA/Hs to cope with the HIV infection were: other PLWA/Hs according to 69 PLWA/Hs (60%; 20 men and 49 women); family

members according to 17 PLWA/Hs (15%; N = 116); and church members according to 10 PLWA/Hs (9%).

### **3.7 THE NEED FOR ESTEEM AND CARE**

Believing that others think well of us enhances self-esteem, and motivational support by caregivers encourages people to take care of themselves (Cohen & Syme 1985:67-68). Since health cannot be defined by PLWA/Hs as the narrow condition of not being ill, PLWA/Hs need support to view health as a resource for living or a resource for power. Maslow thought that people are autonomous, active responsible agents and that fate, biological injustice and the like may set limits but that within those limits a person can either achieve very little, or do a great deal (Maslow 1996a:66). These actions were placed in the realm of free will and self-choice and therefore of responsibility. Maslow believed strongly that one could be all that one is capable of being or be less than one is capable of being, an active agent or a helpless, whining pawn. Being less would, according to Maslow, lead to intrinsic guilt because of having violated or betrayed one's own higher nature (Maslow 1996a:66-67). In these terms, PLWA/Hs would have to accept their fates and become actively involved and retain their underlying sense of self-esteem, self-motivation and self-choice to achieve higher levels of well-being (Maslow 1996a:69).

#### **3.7.1 *Self-care***

People living with HIV and AIDS need to take care, especially with regard to symptoms, diet, exercise, self-development, prevention of OIs and emotional health (Sherman 1999:15). The self-care theory of Orem posited that people can be restricted by both inter- and intra-personal and environmental influences. These inner or outer limitations affect a person's ability to explore, appraise and make decisions and the self-care actions (Orem 1995:461). Failure to be an active agent in self-care in this case might be informed by issues such as denial of the HIV+ve diagnosis and helplessness by the PLWA/H and the like. (See Chapter 2.) This puts the HIV+ve patients at risk as far as self-care actions

such as safer sex are concerned; in the survey 21% of the 116 PLWA/Hs reported that they did not use condoms consistently.

However, denial was also recognised as a defence mechanism in coming to terms with a HIV+ve diagnosis (Kalichman, Sikkema & Somalai 1996:589-599; Lazarus 1993:234-240; Moneyham, Hennessey, Sowell, Demi, Seals & Mizuno 1998:351-362). This coping mechanism serves to allow no more emotional pain than is tolerable and can be recognised as healthy defensiveness for a limited time, but will ultimately lead to ill health if not resolved. (See Chapter 4).

Access to care might be further diminished if PLWA/Hs perceived the attitudes of staff at clinics and hospitals to be negative towards them.

However, both the state of guilt and denial and perceptions of *possible* negative reactions communicate self-stigma. The assessment by the PLWA/Hs of what others *might* do or say is not necessarily a reflection of what is happening in reality. The majority of the PLWA/Hs in this survey, 73 (63%), always told nurses and doctors that they were HIV+ve and received care. Guidance and encouragement from health care providers to engage in health-promoting self-care actions to prevent or treat OIs such as TB and to adopt healthy lifestyles were very important. Self-care requisites of PLWA/Hs included testing for HIV and help with decision making about subsequent disclosure of the HIV+ve diagnosis to family and health care providers. The PLWA/Hs may need time to accept their HIV+ve diagnosis, and the fact that 36 PLWA/Hs (21%) pretended not to be HIV+ve or did not say anything about their HIV+ve status because they did not trust their nurse fully supported this.

Having respect for each other in caring relationships has been identified as a precondition for effectiveness in helping relationships in general. and between caregivers and HIV+ve people in particular (Faugier & Sargeant 1997:222-230; Misovich et al. 1997:95-123; Orem 1995:26; Powell-Cope 1994:324-330; Roberts & Krouse 1990:30-36).

Because HIV is predominantly sexually transmitted, guaranteeing confidentiality has been the foundation of all HIV prevention and health promotion strategies that aimed at lasting behavioural change, but has been subject to debate, since the ethical dilemmas associated with the rights and duties of PLWA/Hs were not always well understood (Gibney, DiClemente & Vermund 1999:88; Hayter 1997:1162-1166). In 1999, Mann (1999:217) postulated that participation in HIV testing and counselling activities increased when HIV testing facilities instituted anonymous testing. However, in Botswana uptake of HIV testing was and still is slow (Bara 2002:1-9; Donnelly 2003:1-3; Talbot, Kenyon, El-Halabi, Moeti, More & Binkin 2000:1156-1163).

Informed consent is the basis for the trusting relationship between health care providers and patients. Studies in the USA and the United Kingdom (UK) during the last part of the 1990s provided examples of the negative effects of forced disclosure: people losing their jobs and their houses and being ostracised by their family and friends (Ingram & Hutchinson 1999:93; Kimberley, Serovich & Greene 1995:316; Mann, Gruskin, Grodin & Annas 1999:17). Forced disclosure was even more dangerous for women, who might have to deal with domestic violence and abandonment by their father or male partner or husband (UNDP & GOB 2000:28). Nevertheless, in Botswana, doctor-patient confidentiality is not absolute and disclosure may be justified in certain circumstances. Botswana applies the principle of “shared confidentiality”. This principle implies that doctors in Botswana shall inform those who need to know of the medical condition of the patient before appropriate health and social welfare care can be provided.

The people who need to know include

- caregivers
- all persons who come into close regular contact, and
- all those living with the HIV+ve person (AIDS/STD Unit 1997:62).

In the Second Medium Term Plan on HIV and AIDS, 1997-2002, a need for clarification of Botswana’s principle of “shared confidentiality” was identified (MOH 1997:62). Not much is known about how doctors in Botswana deal with the demands the shared confidentiality principle places on them and the reality in their daily practice (MOH

1997:62; MOH 1998:12). If patients in Botswana were told about situations in which confidentiality could be breached, the prevailing attitude that the medical profession cannot really be trusted, as reported by 21% of the 116 PLWA/Hs in the 2000 survey, might not occur.

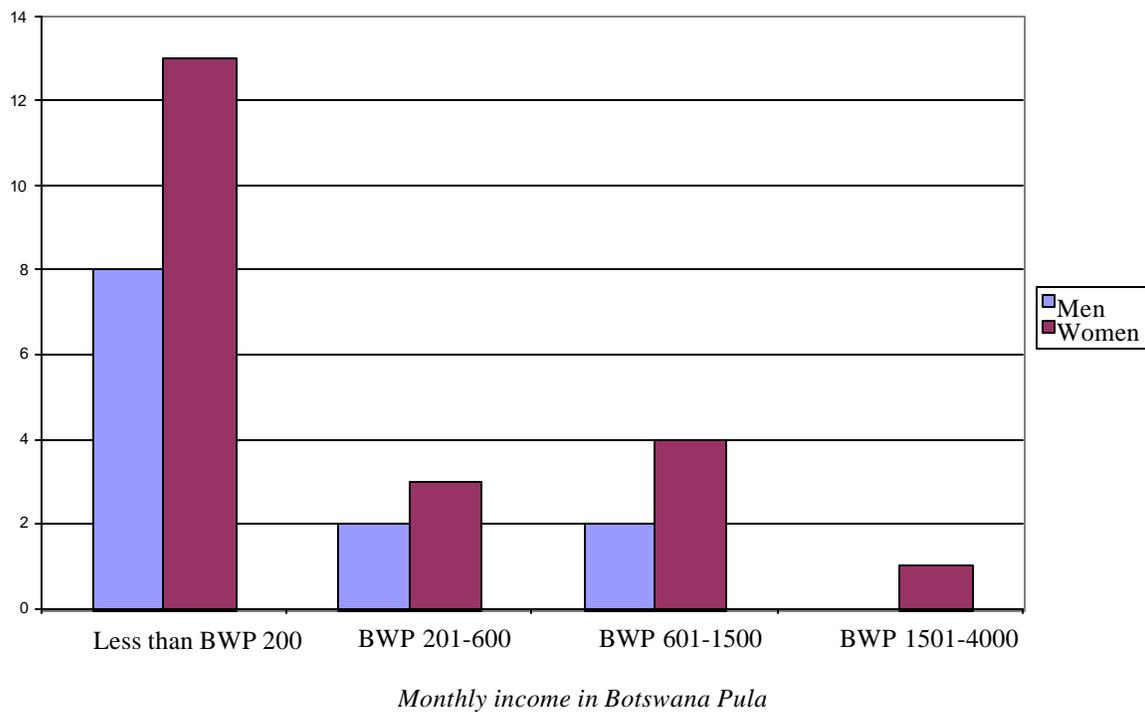
In Botswana, specialised care was offered to HIV+ve women at the local clinics including PMTCT services. (See Chapter 4.) This programme aimed to prevent transmission of HIV from the HIV+ve mother to child during pregnancy, birth or through breastfeeding the baby by giving the HIV+ve mother short-term AZT therapy, one type of ARV (Hankins 2000:57-62). However, 53 PLWA/Hs (46%; N = 116) in the survey, aware of low uptake of this service in Botswana, reportedly thought that few HIV+ve women agreed to participate in the PMTCT programme and take AZT (ARV drug, monotherapy) during pregnancy because the HIV+ve women feared disclosure when not breastfeeding their babies. An alternative reason could be, according to 32 PLWA/Hs (28%), the lack of understanding of prevention of vertical transmission of HIV infection by the pregnant women.

### *3.7.1.1 Tuberculosis*

TB and HIV and AIDS are often referred to as the twin epidemics; a post-mortem study among patients dying of AIDS in 1997/1998 has shown that about 44% of adults dying of AIDS also had evidence of TB disease (Lockma, Sheppard, Braden, Mwasekega, Woodley, Kenyon, Binkin, Steinman, Monthso, Kesupile-Reed, Hirschfield, Notha, Moeti & Tappero 2001:1042-1047). In 1995 it was reported that the true picture of TB/HIV co-infection was not known, but four years later, in 1999, it was estimated that 50-80% of Botswana's TB patients were co-infected with HIV (GOB 1999:20-21; MOH 1995:13). Botswana implemented a TB prevention programme for HIV+ve people, encouraging PLWA/Hs to prevent latent TB from becoming an acute infection when their immune system was weakened by HIV infection, after operational research started in 1999 (BOTUSA 1999:26; Ridzon & Mayanja-Kizza 2002:382). To prevent TB, 21 PLWA/Hs (18%) were on IPT, a course of Isoniazid (INH) tablets that they had to take daily (at home) for six months. The situation is increasingly serious as Botswana in 2002 reported one of the highest TB

infection rates in the world, with about one in every 200 citizens of Botswana having active TB (Talbot, Kenyon, Moeti, Hsin, Doley, El-Halabi & Binkin 2002:311).

Thirty-three PLWA/Hs (29%; 12 men and 21 women) reported that they were suffering from TB and were on Direct Observed Treatment Strategy (DOTS), taking their medications daily (at the clinic) to cure their TB infection. Two-thirds of the PLWA/Hs with active TB were (very) satisfied with the support they received from the government health care system and 60% always told their nurses that they were HIV+ve. An association between poverty, resulting in malnutrition and overcrowding, and TB was identified in the National TB programme of Botswana (MOH 1995:8). In the 2000 survey, incomes and TB were linked, since 64% of the 33 PLWA/Hs with TB belonged to the very low-income group. (See Figure 3.5.)



**Figure 3.5 Monthly income of HIV+ve study participants with TB**

### *3.7.1.2 Antiretroviral treatment*

During the survey period, early 2000, the government of Botswana had not yet included access to ARVs in basic care services to PLWA/Hs. Access to ARVs was confined to the group of persons who could afford medical aid schemes, participated in clinical research trials or paid cash for the ARVs. This survey during 2000, one year prior to the launch of the national ARV programme MASA, found that a small group of five PLWA/Hs - all women - (4%; N = 116) were taking ARVs, whilst 111 PLWA/Hs (96%) were not taking ARVs. This situation changed dramatically in 2002 with the launch of the MASA ARV programme, when thousands of AIDS patients enrolled for ARV treatment free of charge (James 2001:4-8). (See Chapter 4.)

Access to ARVs was in this survey not linked to higher levels of monthly income. Only one PLWA/H on ARVs in this survey reported an income of BWP1500 to BWP4000, approximately USD300 - USD800. The other four women who were on ARVs could not afford to buy the drugs and could have received financial support from other sources or have been participating in clinical research trials. This small section of the PLWA/H community often felt guilty and different from other PLWA/Hs who were not accessing ARVs. One of the women was public about her status and three of them had disclosed to fewer than five people. Four of the five women on treatment did not know any other PLWA/Hs at the places where they lived, but had informed their parents about their HIV+ve diagnosis. Three of the women had received supportive counselling during the previous three months and one woman reportedly felt very depressed. All five women would have liked to get support from other PLWA/Hs through home visits, and three of the women wanted training to set up support groups.

### *3.7.1.3 Depression, tiredness and anxiety about health*

Thirteen PLWA/Hs, four men and nine women, were very worried about their health, felt very depressed, had been very tense and had had no energy during the month preceding the survey (questions 70 through 73).

Out of these 13 PLWA/Hs in poor health, three PLWA/Hs (23%; n = 13) were public with their HIV+ve status and had disclosed to over 30 people. Twelve PLWA/Hs (92%) would have liked to get support through home visits from another PLWA/H, and six PLWA/Hs (46%) identified another PLWA/H as a person who could help them to cope. Three PLWA/Hs (23%) reported that nurses were instrumental in helping them to cope with their HIV+ve diagnosis.

The findings of this survey were in agreement with two other studies. In 1999, 48 low-income women attending HIV clinics in the USA were studied. The researchers listed 349 different needs that could be subdivided as follows: psychosocial needs (32%); physical needs (14%); service and maintenance needs (13%); and financial and legal needs (11%) (Bunting, Bevier & Baker 1999:41). Another USA social work study examined the psychosocial needs of 12 HIV+ve women through in-depth interviews. An analysis of the data indicated a variety of needs, including needs for information and support, assistance from health care professionals, planning for the present and future of their children, financial assistance and adjustment to loss of employment, and finding accommodation (Hobbs Leenerts & Magilvy 2000:58-75).

### **3.8 SELF-ACTUALISATION AND TRANSCENDENCE**

Despite the deficiencies in the fulfilment of safety, belonging and esteem needs, positive attitudes were reported by the majority, over 73%, of the 116 PLWA/Hs. They did not believe the HIV+ve diagnosis was a death sentence and they were optimistic about the future and expressed their will to live. The entire model of humanistic psychology and self-actualisation rests on the assumption that the person wants to live (Maslow 1996b:26). (See Chapter 2.) The traumatic impact of living with AIDS has usually been the focus in studies of PLWA/Hs. However, from 1994 onwards, evidence was beginning to suggest that it was possible that PLWA/Hs could lead meaningful and productive lives (Collins, Kanouse, Gifford, Senterfitt, Schuster, McCaffrey, Shapiro & Wenger 2001:351-360; Coward 1994:331-336; McWilliam, Stewart, Brown-Belle, Desai & Coderre 1996:1-15; Mellors,

Erlen, Coontz & Lucke 2001:235-246; Metcalfe et al. 1998:30-34; Schwartzberg 1994:593-602).

In a qualitative study of five PLWA/Hs, Mellors et al. (2001:236) postulated that through introspection and concern about others and their well-being people can gain understanding about themselves and move out beyond themselves. The process of self-transcendence has the potential to influence the course of HIV and AIDS, and PLWA/Hs might be able to forge rewarding and in some cases life-transforming meaning out of their situation (Mellors et al. 2001:237). Forty-three PLWA/Hs (37%; N = 116) reportedly had experience with overcoming big difficulties in their lives other than their HIV+ve status. Seventy-six PLWA/Hs (66%) were providing support to others who were in difficult situations. The study by Mellors et al. offered insight into how PLWA/Hs transcend the emotional and physical suffering of their illness and how former ways of thinking and being that had limited their ability to integrate the demands of living with HIV and AIDS were transcended (Mellors et al. 2001:237). The attitudes of the participating PLWA/Hs towards being HIV+ve were assessed and 19 PLWA/Hs (16%) reported that they felt ambivalent - sometimes they accepted it; sometimes they denied the HIV+ve diagnosis. However, an encouraging 84% of the PLWA/Hs that participated in the survey reported optimism and positive attitudes towards living with HIV and AIDS. They also needed to plan for the future. When asked if legal services would be required in the year following the present survey, 35 PLWA/Hs (30%) indicated that they needed assistance with planning for the future of their children and 19 PLWA/Hs (16%) needed assistance with issues related to inheritance.

### ***3.8.1 Caring for others***

A good society would encourage desirable traits such as affection, altruism, friendliness and kindness. Maslow believed that basic need gratification must come from interpersonal relations and the wider society (Maslow 1996i:83-84). Despite their own challenges in life, the surveyed PLWA/Hs reported that they took care of others who were ill. Compassion was shown to others and 47% of the PLWA/Hs were caring for a sick family member or neighbour during the month preceding the survey.

Maslow demonstrated that emotionally healthy persons showed that when they behaved unselfishly, this behaviour tended to be a phenomenon of personal abundance stemming from relative basic gratification (Maslow 1996e:113). This might be one possible reason why 35 PLWA/Hs (30%) in the survey reported that they were willing to be trained as buddies. Not all PLWA/Hs were prepared to care for and support others within a buddy system; 19 PLWA/Hs (16%; N = 116) would be buddies if paid, and 50 PLWA/Hs (43%) did not know if they wanted to be trained as buddies.

Selfish behaviour was regarded by Maslow as a phenomenon typical of deprivation, involving threat and insecurity. Maslow did not support the Freudian notion that people are basically selfish, and asserted that unselfish behaviour comes out of inner riches rather than inner poverty (Maslow 1996e:113). (See Chapter 2.)

Maslow argued that as we are born we have an intrinsic need to experience the highest values such beauty, truth justice and so on. These higher needs are biologically rooted just as are our lower needs for food and safety (Maslow 1996d:97). The notion that people have the ability and motivation to improve during their lifetime, and that society is improvable, was important in understanding some of the findings of the survey. Maslow postulated that meeting higher values not only prevents certain forms of illnesses such as neurosis, hopelessness and the like, but motivates people to not merely accept the world as it is but strive to better their world (Maslow 1996d:96-98).

### **3.9 CONCLUSION**

This survey indicated that there were opportunities for sustaining, scaling up and improving HIV and AIDS care and support for PLWA/Hs. Maslow's needs theory was valuable in explaining how higher needs emerge when lower needs are gratified. The theory suggested that it was not only possible to strive for growth and higher values but that doing so would actually help others and yourself. Maslow predicted that efforts to be in this world and

function to one's highest capabilities would have as spin-off deep feelings of inner happiness and fulfilment.

The PLWA/Hs listed a number of desired services, programmes, and interventions that needed to be met by other people. The PLWA/Hs identified the need for access to:

- education about what a HIV+ve diagnosis means
- nutrition advice
- education about basic treatment issues
- access to ARVs
- long-term supportive peer counselling
- TB prevention
- legal assistance.

However, the centre of attention was not only on deficiencies, the surveyed PLWA/Hs had something to offer as well. The PLWA/Hs stated their willingness to be involved in care and support efforts and demonstrated their enthusiasm and motivation to support other PLWA/Hs in Botswana. This 2000 survey was important as background information to the present study because, by 2003, a section of the PLWA/H community had indeed translated words into action and been involved in the design of care and support by and for PLWA/Hs. Members of COCEPWA had during 2001 and 2002 adapted a USA buddy programme into a buddy programme for African PLWA/Hs.

This was a unique survey of needs of people who had up to then been silent about their HIV+ve status and explored how PLWA/Hs understood the meaning of "living with HIV". The PLWA/Hs were asked about possible negative and positive experiences linked to their HIV+ve status. Some of the PLWA/Hs were not yet prepared to disclose their HIV+ve status to more people but were able through an appropriately designed survey to express their need for guidance on how to live well and stated their need for increased access to social support. The PLWA/Hs stated that involvement in matters that affected their own health and well-being was essential.

The next chapter, Chapter 4, describes the literature that was reviewed pertaining to some of the issues raised in the preceding three chapters. More specifically, the chapter reviews literature relevant to the challenges that the AIDS epidemic poses in Botswana. The rationale for community-based care was explored and how social support influences the well-being of PLWA/Hs examined. Some questions relevant to the present study were not completely answered by reviewing literature important to the present study. An overview of the gaps in the literature reviewed concludes Chapter 4.

## **CHAPTER 4**

### **LITERATURE REVIEW**

#### **4.1 INTRODUCTION**

This chapter presents an overview of literature relevant to the present study. Since participation in a buddy programme is considered an intervention that utilises the concepts of self-care, human needs and social support, research results and publications relating to these aspects within the context of HIV/AIDS are presented. Linkages between the variables self-care, human needs and social support, and how these impact on the quality of life of the PLWA/Hs, the major goal of their health care, are discussed. In addition to outlining the three major challenges in Botswana's war against HIV/AIDS: denial; stigma; and developing a follow-up system in the community for PLWA/Hs, this chapter will conclude by identifying the gaps in the literature reviewed and explaining the rationale for the present study.

As discussed in Chapter 2, the three concepts of self-care, human needs and social support were analysed, bearing in mind their philosophical underpinnings of a Western individualist concept of autonomy. The theoretical framework of the present study linked and applied these three concepts, based on the assumption that people need other people *and* that being needed promotes quality of life. Community values and the importance of interrelatedness were considered by expanding upon the importance of self-care actions, human needs and support, and explaining why peer support as provided in the buddy system was believed to be important to the quality of life of the women living with HIV in Botswana in the present study.

#### **4.2 THE WAR AGAINST HIV/AIDS**

Botswana's otherwise buoyant outlook for future economic growth is very much affected by its world-leading HIV/AIDS infection rate (Tlou 1996:27). Since 1987, after the first AIDS patient was diagnosed, Botswana has been involved in campaigns to stop the

spread of HIV infection, promoted condom use and sensitised the nation about HIV/AIDS. By the early 1990s, 80% of the Botswana public had heard about AIDS mainly through the radio (Ingstad 1990:29). This largely successful health education campaign continued during the 1990s, and the 2000 Botswana Multi Indicator Survey (BMIS) established that among women aged 15-49 in Botswana (N = 6488), 95% had by then heard of AIDS. But hearing and talking about AIDS and staying HIV negative are two very different issues. The Botswana government realised that promoting accurate knowledge of how HIV is transmitted and how to prevent HIV infection would prove more difficult than raising general AIDS awareness. This same BMIS study (N = 6488) found that 20% of the women did not know any way to prevent infection and did not know that abstinence and condom use could prevent them from HIV infection. Women with some secondary education were more knowledgeable about ways of preventing HIV transmission than those with less or no education. The survey concluded that, after 15 years of HIV/AIDS campaigning by the government, only 24% of women aged 15-49 had sufficient knowledge about HIV/AIDS transmission (GOB & CSO 2000:54; Tlou 1996:27-30).

In addition to the fact that many have insufficient knowledge, Botswana's unusually high physical and social mobility has apparently further exacerbated the spread and impact of AIDS (Hope 2001:74.). The current life expectancy for men and women is now about 42 years, from a high of 65 years in the 1990s, and could drop to as low as 29 years by 2010 if nothing is done to address the advance of the epidemic (Republic of Botswana 2003:16). Despite Botswana's high birth rate, projections are that the working-age population will actually begin to decline within the next few years and that this will decrease the economic growth rate by 1.5 percentage points below the expected rates for the next 25 years (Dugbately 1999:233).

At the end of that 25-year period, the economy will be 31% smaller than the pre-AIDS epidemic target. These projections do take into account a plethora of new HIV/AIDS related costs, including additional medical care, care for the estimated 35 000 *registered* orphans and the cost of hiring expatriates to address the labour shortages in all sectors due to high mortality rates. Model projections indicated that the orphan population could

rise to between 159 000 and 214 000 children by 2010, which would constitute more than 20% of all children in Botswana (UNDP & GOB 2000:18).

Health expenditure in Botswana for the last two decades has averaged between 5% to 8% of the national budget. On average the country spends 2% of its Gross Domestic Product (GDP) on the health sector, and the government budget for health increased by 32% during 2000/2001, the largest increase in any sector (CCM 2002:8). Botswana has reported continued rises in health care expenditures since the mid 1970s. However, per capita public-health expenditure figures alone are inadequate as a measure of available health care, according to a study in public expenditures and health care in Africa (Dugbately 1999:223-239). Due to higher expenditures, hospital admissions in Botswana rose by 3% per year in the 1980s, but the correlation between rising public expenditures and the quality of delivery of public health care was not clear. Higher health care expenditures in Botswana did not necessarily translate into better health care. It was recommended that to improve the quality of care, governments should recognise and empower some of the grass-roots organisations. By financially assisting and directing NGOs to improve delivery of care, the government could improve health care services at community level (Dugbately 1999:224; Ogbu & Gallagher 1992:615-623).

#### ***4.2.1 Lack of capacity in Botswana's health care system***

In Botswana, the escalating incidence of HIV infection and the rise in numbers of people ill with AIDS increased the strain on health institutions. The health care delivery system depends mainly on its approximately 4000 nurses, who represent 85% of the health manpower. The 210 clinics, 316 health posts and 720 mobile posts are staffed by nurses only. Medical doctors and nurses are available in the 14 primary hospitals, 15 district hospitals and 2 referral hospitals (Akinsola & Ncube 2000:51).

Despite the fact that AIDS is a major disease currently being experienced by the people of Botswana, nurses participated minimally or were excluded from the health care policy processes and resource allocation. This lack of participation was reportedly aggravating the quantity and the quality of service delivery, especially in the rural areas (Akinsola & Ncube 2000:55; Phaladze 2003:32). In several hospitals, 90 to 100% of the patients in

some wards had AIDS-related conditions. In 1999, a total of 1420 patients (18%; N = 80 000) died of AIDS. Another 800 patient deaths (10%; N = 80 000) were due to TB. The three leading causes of death were AIDS (18%), pneumonia (14.8%) and TB (10%) in the hospitals in Botswana in 1999 (Central Statistics Office 1999:56). In 1999, the cause of morbidity of 5188 discharged patients (5.2%; N = 100 730) was TB, and 4113 patients (3.9%; N = 100 730) were discharged with AIDS. At the out-patient departments 29 000 TB patient attendances (0.8%; N = 3.63 million) were recorded (Central Statistics Office 1999:74). More than 200 000 patients (5.5%; N = 3.63 million) required treatment for sexually transmitted infections (STIs), an indication that people continued to have sex without condoms (Central Statistics Office 1999:32).

Despite the overcrowded and understaffed conditions, an effort is being made in the hospitals to educate and involve the family in the palliative care of AIDS patients. This is an important aspect in moving AIDS patients from passive and dependent victim roles towards more active roles. This process of involving both patients and their family members in decision making about present and future care should start during the hospital stay, prior to discharge into community-based HBC. The patients should be encouraged to disclose their HIV+ve status to their caregivers to prevent transmission of HIV to the caregivers. Having the right information and some degree of choice are all aspects of control and it is believed that this reduces the stress of being ill and being dependent on support from other people (Brooking 1989:98).

A Botswana evaluation study of HBC and counselling services during 1994 reported logistical constraints with follow-up of the AIDS patients in their homes. Fear of stigma reportedly resulted in refusal by the AIDS patients to be counselled and/or refusal of disclosure of their HIV+ve status to their relatives (Buwalda et al. 1994:153). A more recent study in 2000 in Botswana reported that knowledge deficit was a common factor among caregivers in the homes, despite efforts initiated to disseminate information about HBC (Ndaba-Mbata & Seloilwe 2000:218). In spite of such endeavours, statistics indicated an alarming rate of readmissions of AIDS patients to hospital with numerous complications, suggesting poor quality of care at home. In addition, there were anecdotal

records of elderly caregivers being diagnosed HIV positive, indicating that transmission might have occurred during the process of care giving. Findings of the study of 15 HBC patients, 10 of whom had AIDS, indicated that families lacked knowledge, especially about AIDS, and lacked the skills for providing appropriate care. They were not aware of the resources that they could access and they lacked professional and material support. The study recommended that a good referral and follow-up system should be in place for effective implementation of HBC, with appropriate procedures for monitoring and evaluation (Ndaba-Mbata & Seloilwe 2000:218).

#### **4.2.2 *Burden of care on women***

Women with HIV infection face multidimensional challenges in dealing with HIV/AIDS, requiring self-care throughout the acute and chronic stages of their illness. They might struggle with their problems alone. In addition to taking care of their own needs they are expected to take care of the needs of others as well. As of 1998, almost 50% of all Botswana households had at least one HIV+ve family member. The cultural perception that women might be the ones bringing AIDS into the home and infecting their children and sexual partners burdened the women with additional stress. These misperceptions were continuing to aggravate the situation of HIV+ve women in Botswana (Baggaley & Van Praag 2000:1036; Greener, Jefferis & Siphambe 2000:888). The HIV+ve women in Botswana might not have support networks in response to the AIDS epidemic nor access to resources like good nutrition, transport and professional support (Page 2001:40-42; Tlou 1996:27; Tlou 2002:659).

Because of the progressive nature of their disease, HIV+ve women are responsible for identifying early symptoms or changes in health status and communicating their observations to doctors or nurses. These health-deviation self-care actions are tantamount to health maintenance and require an ability to advocate for individual requirements based on health-monitoring activities; referrals for resources; support services; and tips for living with the illness (Anastasio, McMahan, Daniles, Nicholas-Kenneally & Paul-Simon 1995:31).

However, culturally society dictates that all others in the family must take precedence over the self-care of a Botswana woman. Therefore HIV+ve women are often not compliant with medical treatment for themselves, and as a result their health suffers, leading to a greater likelihood of OIs and death (Flynn et al. 2000:61; Tlou et al. 2001:68; Williams, Shahryarnejad & Andrews 1997:91).

In Botswana, the marriage institution has been declining with each generation, and according to the 1991 census, 47% of the households were headed by women, the average female-headed household comprising five persons with a monthly income of USD30 per month (MLHA 1995:6). The economic impact of HIV/AIDS in Botswana will be loss of income and higher expenditure in all households, but significantly higher income dependency ratios for the poorer households. Every income earner in this category can expect a further four dependents as a result of HIV and AIDS (UNDP & GOB 2000:18). Female-headed households tended to command fewer economic resources and lower incomes and are therefore more susceptible to poverty. Health risk factors include unprotected sex, alcohol abuse and breastfeeding by potentially HIV-infected mothers (Akinsola & Popovich 2002:761; GOB 1998:8; Greener et al. 2000:888). In studies by Talbot et al. (2002:316) in Botswana and by Quinn (1993:305) in the USA, women were reportedly at greater risk for HIV than men, and gaps in knowledge about women and HIV/AIDS were identified in these two studies.

Studies reframing women's risks agree that social inequalities lie at the heart of risk and HIV infection among women in high- and low-income countries alike (Quinn 1993:306; Stephenson 2003; Zierler & Krieger 1997:401). Globally, in 1990, women constituted 25% of the total number of individuals estimated to be living with HIV. By the year 2000, women accounted for 43% and this proportion continues to grow (Flynn et al. 2000:59).

Women's increasing vulnerability to the disease is not fully understood but it is explained in part by HIV transmission patterns. During heterosexual intercourse, an HIV+ve man is more likely to transmit the infection to his HIV negative partner than is an HIV+ve

woman. From a behavioural standpoint, women lack authority to negotiate sexual relationships, which manifests as the inability to deny a man sex or to negotiate sex with a condom. A further factor is that women in Botswana believe that a man is more likely to marry a woman with proven fertility (Tlou 2002:656).

It is a prevalent attitude on the part of both men and women that men are justified in seeking multiple sexual partners, and have sexual needs that should always be met by women. Men appear to be acting on these cultural norms and are more likely than women to have one-time sexual encounters, simultaneous partners, and be suspected by their partners of such behaviours Talbot et al. (2002:316). Women might discover their HIV+ve status by chance: a spouse or child might be symptomatic or they might be pregnant and be offered testing at the antenatal clinics. The HIV+ve diagnosis could be the first indication that a woman or her spouse has had another sex partner or partners, and disclosure could be traumatic, with women being (wrongfully) accused of having brought AIDS into the home.

Another challenge in HIV/AIDS care in Botswana and the development of programmes aiming at care and support for women is the traditional understanding people have about AIDS. The concept of disease transmission in Tswana thought has been mainly connected with concepts of pollution that originate in the female body. This type of pollution may be transmitted to men via sexual intercourse, and is particularly strongly related to transgression of sexual rules or taboos in society, such as having sexual intercourse with a widow or widower within one year after the spouse has passed away (Ingstad 1990:28-37; Tlou 2002:659).

### **4.3 DENIAL**

Identification of HIV-infected persons requires active HIV counselling and testing programmes *and* public interest in obtaining such services. Both are problematic in Botswana (Donnelly 2003:1-3). Voluntary counselling and testing services, still being implemented, are not yet widely used. Secondly, little is known about the public

motivation to undergo testing and the best models of service delivery in Botswana. In the middle of 2003 there were, in addition to testing facilities at local clinics and hospitals, 15 stand-alone HIV-testing facilities, with staff dedicated to providing services where adults could go for free, rapid HIV testing. To reduce the barriers to access and to decrease the number of people who test but leave before they hear the results, the testing is done on-site and the test results are made available within an hour, to reduce the stress and anxiety associated with a waiting period. This approach emphasises informed consent, pre- and post-test counselling and referral to follow-up services. The goal of VCT is to enable individuals and couples to learn their test results voluntarily in a setting in which confidentiality is strictly maintained. The services aim to empower their clients to take informed decisions about important life events such as partner selection, marriage, pregnancy and family finances and to help clients reduce the risk of HIV transmission (Marum, Campbell, Msowoya, Barnaba & Dillon 2002:527).

In a 1999 study in Botswana, the knowledge, attitudes and beliefs regarding IPT for PLWA/Hs of 278 adult clinic attendees were studied. The majority, 147 attendees (56%; n = 263) reportedly believed that *everyone* should take an HIV test. After testing, 257 attendees (94%; N = 263) believed that a person who tested HIV+ve should tell their family. When asked to offer explanations for the widespread reluctance about HIV testing, fear of stigma was more commonly quoted by those in rural than in urban settings (35% versus 23%,  $P = 0.05$ ). In spite of the conviction that more people should go for HIV testing, only 36 attendees (13%; N = 263) reported that they themselves had undergone testing because they had symptoms consistent with AIDS (36%) or because it was required during blood donation or medical examination (28%). However, only two attendees reported themselves to have tested HIV positive. The investigators warned that this finding of only two HIV+ve persons out of 36 attendees who went for HIV testing might be an underestimate, because the validity of self-reported behaviours and intentions could not be validated (Talbot et al. 2000:1160). As a result of fear of stigma, the majority of the citizens of Botswana are

- not aware of their HIV status

- at risk of transmission of HIV to others if HIV+ve and having sex without condoms or during pregnancy
- not engaging in appropriate self-care to prolong their lives.

#### **4.3.1 Denial as a coping mechanism?**

Denial in Botswana's society is a serious challenge in the lives of HIV+ve women who tested for HIV and disclosed their HIV+ve diagnosis to others. The low level of knowledge about how these HIV+ve women cope is of concern because it could contribute significantly to denial. The psychosocial problems of women living with HIV/AIDS are often under-recognised, as are the economic, personal and social resources necessary to meet their needs. HIV+ve women in Botswana, just like their peers in high-income and other African countries, all need, albeit to various degrees, an overwhelming variety of resources, including access to health care, financial assistance, mental health support, transportation, housing and child care services (Flynn et al. 2000:59 ; McFadden 1998:31; Meursing & Sibindi 1995:56).

Negative social reactions against PLWA/Hs in Botswana include loss of employment, social isolation and rejection by friends and family, but few studies have explored how the needs of the PLWA/Hs can be met. Beliefs about HIV transmission are also rooted in cultural perceptions of disease being a result of witchcraft or the breaking of social norms and taboos (Ingstad 1990:28-37). In Botswana, many older people believe that AIDS is not a new disease but an epidemic resulting from non-compliance with the sexual taboos relating to *boswagadi* or widowhood. *Boswagadi* is a state of widowhood whereby the woman whose spouse has died must undergo ritual cleansing and observe several taboos, the major one being sexual abstinence, for a period of one year. The purpose of these rituals is to dissolve the physical and spiritual unity between the living and the dead spouse that was established at marriage and subsequent births of children. At the end of one year only a traditional healer can perform the purification rituals and declare the widow free to live as a single person. If these rituals are not observed, disease called *boswagadi* will follow; this disease has the same symptoms as AIDS: weight loss, diarrhoea, swollen limbs, and multiple infections. Thus AIDS is seen as an epidemic of

*boswagadi* brought about by young modern people who refuse to observe these taboos. Alternative explanations for AIDS promote denial of the health education messages by the conservative section of the population, who will dismiss them as modern and irrelevant (Ingstad 1990:28-37; Tlou 2002:658).

Coping behaviours can be grouped according to themes or strategies and form a framework for understanding the psychological adjustments that HIV+ve patients have to make. The three themes are: searching for meaning; establishing a sense of control; and enhancing self-esteem (Chidwick & Borrill 1996:271-284; Kalichman 1995:219). To understand the use of coping strategies in adapting to an HIV positive diagnosis, in-depth interviews in a qualitative study were conducted with 18 PLWA/Hs in the USA. Using the constant comparative method of data analysis, it was discovered that PLWA/Hs used the following adaptive strategies: humour, faith, altruism, seeking the support of others, and balance. Specific coping strategies immediately after diagnosis were different from those later employed. Upon first diagnosis the PLWA/H's affective responses were emotion-focused to reduce distress. This period of anger and denial could last for from months to five years, leading to postponement of treatment and inability to confront or to deal with their HIV+ve diagnosis. The connection between positive adaptation and support was underscored in this study (Reeves, Merriam & Courtenay 1999:344). During 1999, a USA study of 58 HIV+ve women sought increased understanding about which psychosocial factors related to positive coping behaviours in HIV+ve women. Predictors of an active, problem-solving style were found to be:

- strong social support
- less loneliness
- lower levels of depression and anger
- conviction that change is part of life (Murphy et al. 1999:111).

When an HIV+ve person did not have supportive counselling or was very depressed, the HIV+ve person coped more often through denial (Murphy et al. 1999:111).

Denial and repression attitudes were negatively associated with the general course of the HIV infection or prognosis, but independent of the functioning of the immune system,

among 100 HIV+ve subjects in a longitudinal study of the psychosocial factors and clinical evolution in HIV-1 infection. At both 6 and 12 months follow-up, an HIV+ve person's full recognition of his or her situation was essential, since CD4 counts alone were found to be only one aspect of disease evolution. Some asymptomatic individuals showed very low counts but reported a fighting spirit. The study concluded, with regard to the prevention of symptom development, that an effort towards attitude modification was justified; it emphasised the importance of the HIV+ve person's subjective capacity to utilise what support was available (Solano, Costa, Salvati, Coda, Aiuti, Mezzaroma & Bertini 1993:49).

This finding was confirmed in an experimental demonstration study of 38 white males in the USA, which reported that negative self-evaluation had immunological consequences. Natural killer-cell activity was lower in distressed patients. Natural killer cells are a type of lymphocyte. To attack cells infected with HIV and AIDS, natural killer cells contain granules filled with potent chemicals, and kill on contact. The killer binds to its target, aims its weapons, and then delivers a lethal burst of chemicals that produces holes in the target cell's membrane. Fluids seep in and leak out, and the cell bursts. They are called "natural" killers because they do not need to recognise a specific antigen before swinging into action. In addition to the fact that natural killer cell activity was lower in distressed patients, the study concluded that positive self-evaluation had a stress-buffering effect (Strauman et al. 1993:1042).

#### ***4.3.2 Denial at global level***

The experiences of the women living with HIV in Botswana and other countries have not always received the attention commensurate with the amount of suffering reported. Global advocacy groups have been criticising the antipathy towards HIV that has emerged in higher-income countries that seem to consider the AIDS epidemic as one of the many catastrophes with which the developing world has to contend. Despite the fact that sub-Saharan Africa is home to 10% of the world's population, it is the poorest and the most severely affected by the HIV/AIDS pandemic, bearing 70% of the global burden. HIV/AIDS has refocused attention on Africa but action has been limited and little has been achieved in slowing the epidemic (Benatar 2002:168).

Since the emergence of ARV therapy in the mid-1990s, HIV has been labelled a chronic illness by policy makers, at least in the developed world, and they have largely become passive towards AIDS, both in their own countries and low-income countries. The effect of this redefinition from "the plague" of the 1980s, warranting an emergency response, to a chronic illness has changed patterns of funding and research and led to the scaling down of prevention and care programmes (Clarke 1994:596; Sherwin 2001:361).

Nevertheless, PLWA/Hs need health education to learn skills to prevent re-infection with different strains of HIV and to maintain lifestyle changes to prevent the transmission of HIV to others. Access to ARVs has been identified as an emergent risk factor, leading firstly to a propensity of HIV+ve people to have unprotected sex, and secondly, because of poor adherence to the medication, to an increase in super-infections with resistant strains of HIV. Speaking from experience, the PLWA/Hs agree that it is time for their greater involvement in matters that concern their well-being. People living with AIDS or HIV want to be trained to fully understand HIV and AIDS, take care of themselves and agitate for the right to access to care, including ARV therapy and support (UNAIDS 1999:3).

For many years, AIDS activists lobbied for care for HIV+ve women. It took the USA ten years after the first woman was identified with AIDS in 1981 before medical practitioners acknowledged that AIDS was not just a gay disease but affected heterosexual women as well. Diseases such as pelvic inflammatory disease (PID) and cervical cancer were only in the 1990s accepted as OIs in HIV+ve women. Infections like TB, PID and herpes zoster are not always AIDS related and might occur in HIV negative (HIV-ve) people as well, but are regarded as symptoms of deficiencies in the immune system when they occur in HIV+ve people. Acknowledgement of PID and cervical cancers as OIs enabled HIV+ve women in the USA to qualify for participation in clinical trials, the advantage being that this gave them access to the latest ARV therapy options (Sherwin 2001:357).

In Botswana, thousands of people do not want to know whether they are living with HIV or not. The political leaders of Botswana have made commendable progress in challenging the public's denial inside the country and have also lobbied globally for

financial support and transfer of skills and resources (Mogae 2000:13). To redress the barriers to accessing care and support, an effort is being made to make services locally available (Anabwani & Jimbo 2002:3-4). This makes Botswana unique and is in contrast with the plight of the vast majority of PLWA/Hs in other developing countries, who lack even the most basic health care and support services (Ford 2000:224).

In the literature reviewed, a bioethical dilemma was identified that it is accepted that everyone living with HIV/AIDS *deserves* access to ARV therapy. Nevertheless, many African countries' per capita health expenditure is less than USD10, and these governments cannot afford to spend thousands of dollars per person per year for HIV-related diseases (Amoroso, Davis & Redfield 2002:322). Questions were asked because there are millions of people who die every year because of the unavailability of relatively cheap medications for malaria or TB (Stephenson 2003:31). In the continuing debate over what is needed, affordable and feasible, the following were identified as basic care services for PLWA/Hs:

- expanded voluntary HIV counselling and testing services
- improved basic health services
- improved clinical management of HIV diseases
- better detection, treatment and control of TB
- strengthened referral networks
- community-based care and support (Lamprey 2000:24-27).

The use of ARV therapy in managing HIV disease was, in 2000, not yet included in the six recommendations for minimum care for resource-constrained settings, since it was deemed too expensive and at the expense of low-cost interventions for tens of millions of PLWA/Hs. However, with the cost of combination therapy coming down, it becomes increasingly higher on the agenda for most countries, since the cost of non-treatment of the millions of PLWA/Hs outweighs the cost of treatment. The costs associated with increased morbidity due to HIV/AIDS are loss of productivity, absenteeism caused by ill-health of employees or of their relatives, and increased costs of health insurance, participation in health care, hospitalisation, funerals, recruitment and training of new

staff. The AIDS epidemic can cause a decline in local markets, drop of growth and productivity, mistrust on the part of foreign investors and tourists, and a reduction of consumption in general (Davies, Carne & Camilleri-Ferante 1999:315-317; Houston 2002:4-6; Lamptey 2000:24-27).

The Botswana national strategic framework for HIV/AIDS 2003-2009 includes the six basic care services as identified above, but additional priority strategies include:

- scaling up of the provision of ARV therapy and IPT in all districts in Botswana
- development of programmes to increase the quality of treatment and care provided by traditional health practitioners
- expansion of family-care services addressing the basic needs of orphans and HIV-affected families by increasing partnerships between government and non-government service providers (Republic of Botswana 2003:23-27).

#### **4.4 STIGMA AND DISCRIMINATION**

An unfortunate consequence of stigma is the internalisation of the negative views by those who are stigmatised; the result is self-depreciation, making the decision whether to disclose and to whom a complex one because of self stigma (Bunting 1996:64; Flynn et al. 2000:60). Stigma in Botswana is real. For example, in a recent report of the BMIS of 2000, 68% (N = 6488) of women aged 15-49 expressed discriminatory attitudes towards HIV+ve people. The women in the study affirmed their beliefs that a teacher with HIV should not be allowed to work and that they would not buy food from a person with HIV/AIDS (GOB & CSO 2000:10). A year earlier, Talbot et al. (2000:1160) interviewed 263 adult clinic attendees in Botswana and identified reasons for other people's reluctance towards HIV testing. The clinic attendees expressed fear of finding out they had a fatal illness (74%); fear of stigma (28%); lack of belief in AIDS or ignorance about its significance (4%); fear of angry partner (0.5%); lack of trust in the confidentiality or validity of the HIV test (9%). However, the meaning of the concept stigma was not further clarified (Talbot et al. 2000:1160). A 2002 survey investigated the myths and misconceptions about HIV/AIDS among 367 field officers (75% women and 25% men)

who were engaged in house-to-house community-based HIV/AIDS education in Botswana, encouraging people to go for an HIV test. Of the field officers, 37% did not know their own status and 22% thought that one could not become infected with HIV if one had unprotected sex with an HIV+ve person only once. Of those surveyed, 12% would take an HIV+ve result to mean that the person was promiscuous, and 10% felt that HIV+ve persons got what they deserved. The majority, 95%, would not, however, mind sharing a house or working next to an HIV+ve person and did not think it was a good idea to isolate an HIV+ve person (Bara 2002:7).

Stigma is a complex phenomenon that is often mentioned but resists simple definition. In 1963, Goffman described stigma theory and defined stigma as the expectation of a stereotypical and discrediting judgement of oneself by others in a particular context (Goffman 1963:7). HIV can evoke a strong stigma response because it is a communicable disease, is fatal, has a mysterious origin and was, when it was first discovered in the 1980s, associated with homosexuals and commercial sex workers, groups of people that were already stigmatised (Kalichman 1995:129). AIDS stigma refers to prejudice, discounting, discrediting and discrimination directed at people perceived to have HIV or AIDS and at the individuals, groups and communities with whom they are associated (Herek, Mitnick, Burris, Chesney, Devine, Fullilove, Fullilove, Gunther, Levi, Michaels, Novick, Pryor, Snyder & Sweeney 1998:36-47). The underlying notion in most studies reporting stigma in sub-Saharan Africa includes the need to address the cultural beliefs and attitudes that affect behaviour, as well as to convey accurate knowledge. It was of concern to note, for example, in the study of the community educators of Botswana, that one-fifth of this group of “HIV-educated” persons put themselves at risk and conveyed the wrong information to the public. One out of every ten field officers was honest enough to report that they expressed discriminatory feelings towards HIV+ve persons; the actual numbers were presumably higher (Bara 2002:4; Blecher, Steinberg, Pick & Hennink 1995:1281).

#### **4.4.1 Disclosure**

Persons living with HIV are exposed to the prejudice of others and are confronted with the negative feelings others might have towards their behaviour. Without just cause women are assumed to be the “guilty” parties in bringing AIDS into the home.

As such, there is a difference between being a man living with HIV and being a woman living with HIV in Botswana. Often when an HIV+ve woman discloses her status, there is more concern with how she became infected than with what type of support she needs. To avoid this, women often do not share their status with anyone, but by maintaining the secret of their diagnosis women suffer a tremendous burden at a time when they most need support. This phenomenon is not confined to Botswana but has been observed in international studies of HIV+ve women (Barroso & Powell-Cope 2000:340-345; Flynn et al. 2000:60). Disclosing to others is risky for men but even more so for women, since it may strain family relationships and friendships, and may lead to rejection from the family home, domestic violence, restriction of career opportunities and loss of employment (Gielen, O'Campo, Faden & Eke 1997:21). The COCEPWA needs assessment stated that 56% (N = 116) of the PLWA/Hs, 21 men and 43 women, indicated that their HIV+ve diagnosis was their secret and they had not told family or friends (Zuyderduin 2000:30). Covering up the illness is a common practice. In a USA study of 18 HIV+ve mothers, the mothers acknowledged that they valued being perceived as normal but acknowledged that normalcy was lost for them because of the stigma of HIV. Consequently, they tried to pass as normal by managing information and manipulating their environment. They attempted to cover up their illness by lying and pretending (Ingram & Hutchinson 1999:93-103).

A stepwise model for disclosure was proposed, based on a qualitative research study narrating the stories of five women living with HIV in the USA. The three researchers were, in 1995, concerned about lacking research concerning women and disclosure in the context of HIV. Two reasons were offered as to why disclosure is important. Firstly, disclosure is necessary for support services to be accessed and, secondly, disclosure is necessary to reduce the perpetuation of this epidemic by women as invisible participants.

The present study agreed with earlier reported findings that disclosure had both costs and benefits. The process of disclosure was summarised into a six step model

1. adjusting to the diagnosis
2. evaluating personal disclosure skills
3. taking inventory
4. evaluating potential recipients' circumstances
5. anticipating the reactions of the recipients
6. motivation for disclosure (Kimberley et al. 1995:320-321).

Women's resistance to disclosure often diminishes when good rapport is established with carers who do not rush the disclosure process (Lipson 1993:44). Women in Botswana who disclosed their HIV+ve status shared their bad news with people who were dealing with the impact of having so many friends and relatives around them who were sick or dying of AIDS. Presently, two groups of people are dealing with the AIDS epidemic in Botswana: the HIV-infected people and the HIV-affected people. The impact of the AIDS epidemic is felt by both groups. HIV-affected people also experience discrimination because it is difficult for them to share the bad news. They have had to come to terms with the fact that a relative or a close friend has HIV alone, because they were told in confidence. Internalisation of HIV-related stigma as observed in Botswana was a phenomenon also discovered in two USA studies which focused on the HIV-affected caregivers. These caregivers based their disclosure decisions on their anticipation of AIDS-related stigma and expectations of rejection and, as a result, often did not tell anybody that they were caring for an HIV+ve person, adding further to their isolation (Jankowski, Videka-Sherman & Laquidara-Dickenson 1996:206-213; Poindexter & Linsk 1999:46-61).

#### **4.5 DEVELOPING COMMUNITY-BASED CARE AND SUPPORT FOR PEOPLE LIVING WITH HIV/AIDS**

The two challenges, denial and stigma have been, and continue to be, barriers to care and support for PLWA/Hs in the community. In Botswana, a serious effort has been made to improve the clinical management of HIV/AIDS since the later 1990s. Better detection, treatment and control of TB, the most common OI in patients with HIV, was made a priority from that point onwards (Talbot et al. 2002:311). However, there appears to be a missing link between Botswana's national HIV prevention programmes and the hospital and HBC services provided to AIDS patients. Both programmes are critical, but apparently fail to meet the needs of newly diagnosed PLWA/Hs. People who, after receiving their HIV+ve test result and thirty minutes post-test counselling, are sent home, might not have psychosocial support systems beyond those of family or friends. And what happens if they cannot tell their family or friends? These newly diagnosed PLWA/Hs might not access care and support. The findings of a USA study in 1997 that measured the resources, stigma and patterns of disclosure in a convenience sample of 262 rural American women with HIV infection selected from AIDS treatment sites confirmed that this phenomenon occurs in other countries as well. Women who were asymptomatic and had not progressed to AIDS had greater difficulty in accessing a number of resources (Sowell, Lowenstein, Moneyham, Demi, Mizuno & Seals 1997:302-312). People in small American towns and rural areas faced the following barriers:

- travelling long distances to medical facilities
- shortages of adequately trained medical and mental health professionals where they lived
- lack of transport
- stigma (Heckman, Somlai, Peters, Walker, Otto-Salaj, Galbadini & Kelly 1998:366).

The present study of the buddies of HIV+ve women in Botswana considered whether community-based care after receiving an HIV+ve diagnosis was indeed an essential component in basic care for PLWA/Hs. The promotion of self-care and perceived levels of support at community level for people who had tested HIV+ve and who were seemingly well, were explored. The 116 HIV+ve women in the present study were all

living with an HIV+ve diagnosis but the majority were neither sick nor terminally ill with AIDS. It is not only in Botswana that there is a need to explore whether such programmes of enhanced care are beneficial. A 1999 study in Tanzania explored whether enhanced levels of care and support were associated with preventive behaviour among people with HIV. A survey examined 154 persons with HIV (102 women and 52 men), using a random control design which assigned the control group to the regular health service and an experimental group to enhanced care and support. Enhanced care consisted of monthly counselling on prevention and problem solving, education of other family members, provision of condoms and when needed referrals for treatment either at the homes of the HIV+ve persons or at counselling centres (MacNeil, Mberesero & Kilonzo 1999:537). Regular health service consisted of access to local health facilities. Data were collected at baseline, at three months and at six months on self-reported sexual risk behaviours, disclosure, reproductive health and psychosocial support. Over the six months, significant risk reduction occurred among both groups, with most of the behaviour change occurring in the first three months after HIV+ve diagnosis. Enhanced care and support did not lead to increased risk reduction among the experimental group, but the study population as a whole changed their behaviour, suggesting that in the short term learning that one has HIV+ve alone has an impact on risk reduction. Disclosure levels went up from 19% at baseline to 84% after six months, but only 26% shared with their spouse and 15.6% with their sexual partner. Parents were told by 50% of the sample. These disclosure data were not separated by gender, nor was it reported who provided the enhanced care, peers or professionals (MacNeil et al. 1999:537).

#### **4.6 SELF-CARE and HIV/AIDS**

During the last decade, only 22% (N = 224) of HIV/AIDS nursing research studies focused on client needs. However, with the rapid changes taking place in HIV/AIDS treatment and the extension of life expectancy among people with HIV, it was accepted that care providers had the opportunity to enhance the quality of life of PLWA/Hs (Goldrick, Baigis, Larsen & Lemert 2000:236; Lovejoy, Moran & Paul 1988:155). In a review of surveys in the social sciences over the past two decades it was concluded that

most research programmes had focused on prevention work and behavioural change, but relatively little research had been done pertaining to the consequences of AIDS in the lives of the HIV-infected, their self-care abilities or how they mobilised resources to build up the hope necessary for living (Pierret 2000:1592). However, it was reported that self-care might be a significant factor in prolonging the asymptomatic stage of HIV infection (Anastasio et al. 1995:34). The present study of the buddies was guided by the self-care theories of Orem, who posited from the early 1960s that self-care is universal learned behaviour and that a person has to acquire new skills throughout life to respond as circumstances change. Thus a person who has received an HIV positive diagnosis after being tested has to meet new challenges and look for ways to enable him or her to cope effectively. In terms of Maslow's hierarchy of needs theory, the end goal of all self-care actions is better health. But what is "better" health?

Defining the concept of health is complex, both from a point of view of the health professionals and the HIV+ve person, and different models exist. In the medical model, health and disease are viewed as opposites; one could not be sick and also experience well-being or health. In the 1970s, research contributions from different disciplines towards changing the medical model succeeded in redefining health. It was argued that health, like power, is a resource differentially distributed in society and that gender influences this relationship. Women-friendly health agendas included issues such as self-determination and the legitimatisation of personal experience. The focus shifted from the medical doctor to the patient (Sheinfeld Gorin & Arnold 1998:10). Contemporary thinking about health emphasises that health is a resource for everyday living. Health for PLWA/Hs is achievable, as an HIV+ve person defines it within the parameters of his or her own being, family and community. This contemporary definition contrasts with the traditional medical model that relies on illness identification. However, AIDS patients who clearly have a variety of significant health problems, such as fatigue and recurrent infections, do not necessarily have the low quality-of-life scores commensurate with their serious health problems or difficulties in performing daily tasks (Carr & Higginson 2001:1357). Evidence is emerging that people with AIDS may also have positive wellness-enhancing experiences and even regard AIDS as an opportunity for self-

actualisation or as a manageable chronic illness (Gloerson, Kendall, Gray, McConnell, Turner & West Lewkowicz 1993:46). Australian professor Kellehaer, director of a palliative care unit, points out that it is a common misunderstanding that health promotion and care for people who live with a chronic life-threatening illness such as AIDS are *opposite* initiatives, when in fact they can and should enjoy a *complementary* relationship (Kellehaer 1999:33). AIDS care should be more than illness management and should enhance a sense of control and support in those living with HIV/AIDS. In this way, the central psychological fact of care is not death but rather the day-to-day quality of life, since the prospect of death is shared by all of us all of the time as well. Kellehaer argues that health promotion is not “death denying” and should not only focus on keeping well, since this may be contributing to the wider problem of stigma, isolation and rejection of those who face life-threatening illness of any sort (Kellehaer 1999:33).

The definition of health is evolving, but concern has been expressed in the health-promotion literature that health care professionals, being more familiar with the medical model, know more about disease, pathology and dysfunction than about assisting PLWA/Hs in their desire to be and to remain healthy (Sheinfeld Gorin & Arnold 1998:4).

Within a health-promotion context that views health as a resource for daily living, giving people self-care options gives them responsibility and control. Through the acquisition of self-care skills, HIV+ve people are able to participate more actively in creating their own health and in shaping the conditions that influence their health.

Critics of Orem’s model have expressed concern about its illness focus. The model being suggestive of the medical model emphasis of the past, and these critics have held that the model may indeed make a substantial and valued difference in the lives of people whose self-care abilities are curtailed due to acute or chronic illness, but that it may not make the same difference in enhancing prevention and promoting well-being. In defence of Orem, Hartweg (1990:35) clarified health-promotion activity in the model and coined the concept “health-promoting self-care”, based on the fact that Orem had included concepts such as wellness and high-level wellness as a major theme, albeit tacit, in general

concepts of the model. Health-promotion behaviour was conceptualised by Orem as one type of self-care activity, and this was implied in the model, though the model has been used primarily in acute and chronic illness settings (Cavanagh 1991:26; Jirovec & Kasno 1990:303). Self-care, like health promotion, was presented as a continuous activity which is self-initiated and deliberately performed towards a specific health goal. Of relevance to the findings of the present study of the buddies was the belief that, for example, the maintenance of a balance between solitude and social interaction, and the fostering of bonds of affection and love and friendship and closeness, are essential for continuing development (Hartweg 1990:40).

#### **4.6.1 Taking control**

In the body of health-promotion and HIV literature, developing personal skills, strengthening community actions, creating supportive environments, reorienting health services (breaking from a medical model and embracing a bio-psychosocial model of care) and building public health policy are recurring themes (Pizzi 1992:1024). The WHO definition emphasises the importance of giving people control over strategies that can be employed to improve their health, which is viewed by the WHO as both a fundamental human right and a sound social investment. The WHO definition assumes people do not have sole control, but allow other people to take responsibility for their choices for health (Stanhope & Lancaster 1992:22; WHO 1986:245-254).

Inspired by Maslow's hierarchy of needs, behavioural strategies to increase the participation by the poorest and least empowered HIV+ve women have been proposed by Flynn et al. (2000:65), who observed different levels of participation, the one mentioned last being the ideal:

- health care services provider taking the more assertive role in the patients' care
- collaboration between the health care provider and the patient
- equal responsibility by the health care provider and the patient
- patient self-determination and client action.

Flynn et al. (2000:59-68) envisage promoting client empowerment in a process where the HIV+ve women can move upwards from dependency and enter the collaborative phase, in which the health services provider and the client share equal responsibility. The next and highest level symbolises client-led categories of client self-determination and client action, wherein the client takes the more assertive role in her own care. It is accepted that the HIV+ve women will move up and down the continuum depending on their needs. If they experience sickness it would be appropriate for the health care provider to take the lead (base level) but in periods of health the client needs less input from the care provider (highest level) (Flynn et al. 2000:66).

Women in Botswana are often portrayed as AIDS victims facing significant stresses such as poverty, gender imbalance, abuse and stress because of their social roles as mothers and caregivers in need of assistance with coping (Awuah Baffour 2002:8). Self-care is not a new concept, but one with roots that go back as far as ancient history, and has always been the responsibility of individuals and families. Various definitions of self-care exist and Levin, one of the initial and foremost proponents of self-care, defined it as “a process whereby a lay person functions on his/her own behalf in health promotion and prevention and in disease detection and treatment at the level of primary health resource in the health care system” (Levin, Katz & Holst 1977:11).

Taking control is a challenge for HIV+ve women. In an American descriptive study, Orem’s theory of self-care guided the study of the self-care burdens of a convenience sample of ten HIV+ve women. Of these ten HIV+ve women, eight women had experienced problems with intravenous drug use in the past, compounding the challenges of living with HIV. The women experienced social isolation, psychological stresses and complex medical problems. Of the health-deviation self-care items, obtaining resources, following special diets and taking daily medications were the most burdensome categories. Universal self-care tasks with the highest burden scores were caring for children, physical activities and work. The women identified feelings of sadness, depression and worry related to the care of their children and their children’s futures. The women reportedly experienced isolation due to the obvious losses in their lives, including

their health, children, death of friends from HIV disease and their futures (Anastasio et al. 1995:41).

Since health cannot be defined by PLWA/Hs in the narrow sense of not being ill, PLWA/Hs need support to view health as a resource for living or a resource for power. People living with HIV/AIDS need to take care of themselves, especially with regard to symptoms, diet, exercise, self-development, prevention of OIs, stress, emotions and adherence to medication therapy including ARVs (Sherman 1999:15). It was noticed that women in some cases were missing more clinic visits and doses of ARV therapy than men, and this difference could be explained by the fact that women had to manage their family and child-care responsibilities. Providing free on-site child care facilities at clinics improved women's adherence to scheduled visits (Chesney et al. 2000:1602).

A USA programme for HIV+ve women consisted of listening to, acknowledging and integrating the social, cultural and historical context of the lives of the women with HIV.

Facilitating wellness in their programmes required

- providing choices and options and allowing choice of life activity and adaptation
- training in adaptive technologies of self-care, work and leisure and communication-skill building
- supporting and developing the power to say no to poverty, homelessness, victimisation and illness
- being sensitive to cultural and gender issues relating to self, others and HIV
- developing community support, support groups and strategies for outreach to women
- developing positive images of self to engender a fighting spirit and to get on with life and living, not death and dying
- creating daily meaning, taking into consideration personal values and choices (Pizzi 1992:1025).

## **4.7 THREE SPECIFIC HEALTH-DEVIATION SELF-CARE REQUISITES**

The present study of the buddy system assessed whether the support of the buddy moved the clients to higher levels of self-care, more specifically whether the HIV+ve women

- (1) started or completed the six-months IPT course for TB
- (2) monitored their immune status by checking their CD4 counts, and
- (3) started ARV therapy if advised to do so by their doctors.

The next section will focus on the prevention of an OI that causes most deaths among HIV+ve patients in Botswana, namely TB. The section explains the process of monitoring the immune system and gives an overview of the challenges of making ARVs available in resource-poor countries.

### ***4.7.1 Prevention of opportunistic infections: TB***

Tuberculosis is the most common OI associated with HIV infection and HIV is one of the most important causes of the global resurgence of TB. Treating latent TB infection in HIV+ve persons reduces the incidence of TB and improves survival rates. In Botswana, which has one of the highest rates of TB in the world at 537/100 000 in 1999, it was recommended that all HIV-infected persons be considered candidates for TB preventative therapy (Ridzon & Mayanja-Kizza 2002:382). The WHO has recommended the use of six months of INH, an anti TB drug, as preventative therapy for HIV-infected persons who have latent TB infection. A precondition is that all HIV+ve persons are screened with skin tuberculin tests and chest radiographs before preventative treatment can be started (Ridzon & Mayanja-Kizza 2002:382).

An education campaign was started in Botswana in the late 1990s to inform the public that preventative treatment might indeed improve the quality and duration of life if they were HIV+ve. It was reported that PLWA/Hs who were asymptomatic derived more benefit from preventative treatment than those with more advanced disease. The

preventative treatment programme was hampered by the same constraints as the prevention of transmission of HIV from mother to child and voluntary testing programmes. Despite stating their willingness to be tested for HIV, few individuals have agreed to undergo actual HIV testing to access this benefit of treatment of latent TB (Talbot et al. 2000:1161). But even those who did go for HIV testing also reported low uptake. A 2000 needs assessment of PLWA/Hs reported that 53% of the PLWA/Hs did not take IPT; 28% had TB and were on DOTS, and only 18% of the 116 PLWA/Hs surveyed were on IPT (Zuyderduin 2000:65).

#### **4.7.2 *Monitoring immune function***

HIV infection, especially in its advanced stages, is associated with profound immunological abnormalities. The most characteristic immunological change is the progressive loss of CD4 cells, which are the primary target cells for HIV infection. The normal range is from 600 cells/mm<sup>3</sup> to 1600 cells/mm<sup>3</sup>. Over time, CD4 cells are destroyed, leading to severe immune depression, the hallmark of AIDS. Immune status monitoring is important in the clinical management of patients and is based upon (among other tests) the quantification of CD4 cells. This assists the clinician in monitoring HIV progression, defines a person's stage of infection and determines when to initiate ARV therapy and how to subsequently monitor responses to ARV therapy. HIV+ve patients with CD4 counts below 200 cells/mm<sup>3</sup> will be referred for viral load assays before they are told that they should be starting ARV therapy (Biberfeld & Lyamuya 2002:186).

With ARV therapy the recovery of CD4 counts is possible, even in severely immunosuppressed patients with, for example, CD4 counts of below 10. Their recovery does not depend on baseline values but on the amplitude and duration of viral load reduction to undetectable levels and the increase in CD4 cells (Li et al. 1998:1682). The early symptomatic stage often occurs after years of infection during which HIV has replicated itself, with more than 10 billion copies being made every day. This stage is characterised by diseases such as herpes zoster, TB, and pneumonia, indicative of defects in cell-mediated immunity. In this stage the CD4 cell counts falls below 500 cells/mm<sup>3</sup>, indicating a risk of disease progression. People living with HIV/AIDS are advised to have

their CD4 counts checked regularly, and preferably before they drop below 200 cells/mm<sup>3</sup> (Sherman 1999:9).

#### **4.7.3 *Antiretroviral therapy in resource-limited settings***

Making ARVs available to nearly 4000 patients by February 2003 in Botswana builds on the experiences of countries that have learned hard lessons about the limitations of ARV therapy over the past 15 years. The three main concerns are

- non adherence
- the spread of drug resistant virus, and
- adverse side-effects (Darkoh 2003:1-7).

In 1986, the initial use of monotherapy with an NRTI, Zidovudine, prolonged disease-free survival, and a few years later, with the discovery of newer NRTIs, mono- and dual therapy rapidly became standards of care. The use of ARV therapy continued to evolve and added new classes of drugs such as NNRTIs, and in 1996 the PIs (Paterson et al. 2000:21).

A combination therapy of three, four, and sometimes five ARVs became the approach in the late 1990s. After the initial euphoria, it was realised that the early patients paid and exacted a heavy price, since these mono- and dual therapies resulted in drug resistance to them in the virus, and other persons were newly infected with these drug-resistant HIV strains. Despite the discovery of newer drugs, the problem did not go away.

HIV in high-income countries is no longer a disease linked with homosexuals; a larger proportion, exceeding 50%, of new HIV diagnoses are occurring among young people as a result of heterosexual intercourse. Yet prevention efforts in those high-income countries have continued to be geared towards men who have sex with men. Between 1998 and 2000, major USA cities detected the fact that 15% of newly infected individuals were infected with drug-resistant virus, and the trend of reduced mortality in AIDS patients has begun to level off since 2000 in high-income countries (UNAIDS 2002:1).

This scenario of rapid growth of treatment failure is at the heart of the problem of the future use of ARVs in Africa. This ARV therapy demands stringent adherence to complex dosing regimes. The rate of virological failure over a six-month period has been demonstrated to be as high as 60% in patients who did not achieve greater than 95% adherence (Amoroso et al. 2002:334; Williams 1999:4). In addition to concerns over emerging drug resistance and adherence, the multiple adverse side-effects such as anaemia, nausea, infections of the liver and others have prompted continued changes in the approach to treatment, and approaches are likely to continue changing as more information is gained on making ARV therapy available in countries such as Botswana.

In the developing world some public health specialists warn against a fourth problem: “ARV therapy optimism”. This optimism is observed because most young people in countries that now afford ARV therapy have *not* experienced the deaths of friends and relatives so common during the 1980s, and these young people know they could access ARV therapy if they were to become HIV positive. One reason offered by a group of men who had sex with men for non-adherence or not practising safer sex was that they perceived the threat of AIDS as being less serious than in the past and reported that they were not afraid of dying or contracting HIV since the advent of multiple treatment options. Attitudes towards risk and treatment were changing in high-income countries (Dilley, Woods, Sabatino, Rinaldi, Lihatsi & McFarland 2003:33; Houston 2002:4).

Youths in Botswana might be subject to these same feelings of false optimism and become less responsive to the continuing HIV prevention campaigns now that MASA, the national ARV programme, has been launched. Botswana is in transition from a situation where, since the first cases were diagnosed in 1985, most AIDS patients’ immune systems were destroyed over time and many died without access to ARV therapy, to a situation in early 2003 whereby the first 4000 AIDS patients have started taking ARV therapy (Darkoh 2003:5).

Botswana’s thousands of AIDS patients who are on ARVs now have to learn how to live with HIV as opposed to preparing for premature death. The nation needs to be educated

that it is not a cure but a lifelong commitment to taking ARV therapy, which is not without its own challenges, in order to prolong life. As such, the nation's health professionals and government leaders try to educate the community to prevent "ARV therapy optimism" by telling the people that it is not a cure, and at every opportunity the importance of adherence is explained.

In contrast, in the rest of the developing world, millions of people continue to die from AIDS without access to basic health care services. People living with HIV/AIDS have no options for prolonging life other than having an optimistic outlook and positive attitudes and seeking early treatment of OIs, eating healthy diets and getting enough rest. Botswana's experiences with making ARV therapy available could provide important lessons for both the developed and the developing world. Prevention of the emergence of multi-drug-resistant HIV variants must be the cornerstone of any implementation policy, including that of the national ARV programme, MASA, in Botswana. The following general points were identified as being crucial to the introduction of ARV therapy in any country:

- (1) long term assurance of an adequate supply of quality manufactured drugs
- (2) sufficient resources to pay for treatment on a long term basis
- (3) funding to train caregivers
- (4) funding to establish reference laboratories for the monitoring of drug toxicities and viral response
- (5) funding to establish an infrastructure for early diagnosis, contact tracing and prevention education (Amoroso et al. 2002:335).

The key challenges for going forward with Botswana's MASA programme were listed as:

- ensuring fairness and equity in prioritising given supply constraints
- lack of project management, technical and implementation skills
- adherence and drug security and lack of a policy to institute controls
- sociocultural factors and stigma, leading to the unwillingness of the public to come forward
- late-stage presentation for care

- unwillingness to participate in the programmes
- interaction between allopathic and traditional/spiritual medicine (Darkoh 2003:5).

It could be argued that the promise or hope that ARV therapies bring is needed to break the silence surrounding HIV/AIDS and the lack of support for PLWA/Hs in communities. While this is an attractive hypothesis, it is supported by few precedents. There are reports suggesting that the perceived availability of ARV therapy may reduce uptake of the prevention messages. The focus nowadays in Botswana is shifting away from care and support for PLWA/Hs, who first of all need the basics such as access to food, counselling and support in addition to ARVs. There is concern that the focus on treatment might distract governments from the commitment to prevention, with the natural tendency for clinical care to trump public health when spending decisions are made. Fears are expressed that HIV prevention messages to the AIDS-free generation will be regarded as a lower priority than making ARV therapy available to PLWA/Hs (Houston 2002:6).

#### *4.7.3.1 Adherence to antiretroviral therapy*

Only PLWA/Hs who fully understand and accept the level of responsibility and long-term commitment necessary to take ARV therapy and to continue taking ARVs consistently should start taking them (Stone 1999:58).

In the various studies reviewed, the terms “adherence” and “compliance” are used, and need in our present study to be defined for greater understanding (Chesney et al. 2000:1599; Cox 2002:425; Erlen & Mellors 1999:75; Holzemer, Corless, Nokes, Turner, Brown, Powell-Cope, Inouye, Henry, Nicholas & Portillo 1999:185; Holzemer, Henry, Portillio & Miramontes 2000:36; Kalichman, Rompa, DiFonzo, Simpson, Austin, Luke, kyomugisha & Buckles 2001:58-67; Kelly 2002:171; McPherson-Baker, Malow, Penedo, Jones, Sneiderman & Klimas 2000:399; Murphy & Canales 2001:173; Paterson et al. 2000:21; Roth, Shoub Nelson, Collins, Emmons, Alderson, Hatcher, Nabrit-Stephens & South 1998:181; Squier 1990:325; Toljamo & Hentinen 2001:618; Williams 1999:13; Wood & Gray 2000:1).

The issue of compliance or conformity can be considered from different perspectives. If considered from a psychological perspective, it can be defined as compliance with a form of social norm to which an individual outwardly conforms to obtain a reward or avoid punishment, though not necessarily believing in the opinions expressed or the behaviours displayed. This is worrying in the context of care, because this blocks meaningful dialogue. The patient will tell the nurse and doctor what he or she thinks they want to hear. Regardless of the definition of compliance, from a nursing perspective the term has historical connotations of authoritarianism and paternalism and contrasts with the assumption that each patient is responsible for his or her individual self-care actions. For example, in the case of AIDS patients it is their informed decision to start ARV therapy, a lifetime commitment, not only because they have been told to do so by the health care providers (Kelly 2002:171).

The terms adherence and compliance are used interchangeably, although there have been calls by nurses who are working actively against the issues of control and power for the rejection of the term “compliance”, a term “denoting the paternalistic requirement to yield to the will of another”, and they prefer “adherence” as the currently more acceptable term “which implies a steady propensity to stick to a prescribed regimen” (Murphy & Canales 2001:176). In the literature, three groups continue to use the terms compliance, non-compliance, adherence and non-adherence. The first group of researchers accept “compliance”; they use the term and keep quiet about the historical controversy (Cox 2002:425; Roth 1998:181). The second group criticises the term and rationalises it but keeps on using the term (Murphy 2001:173). The third group advocates rejection of the term compliance and prefers the term adherence (McPherson-Baker et al. 2000:400 ; Murphy & Canales 2001:177; Stone 1999:58-60; Williams 1999:13-14).

In addition to the other two perspectives, gaining an insight into the patients’ perspectives is one of the objectives of the present study. In the present study the attitudes to adherence were measured assuming that the women with HIV were the only people who could provide information about their compliance with their ARV therapies. Attitudes-

towards-adherence scores were obtained through self reports about whether or when they took their medications (Murphy & Canales 2001:176).

#### *4.7.3.2 Factors promoting adherence*

From 1990-1998, an integrative review of patient medication compliance reviewed 30 research studies. Of these 30 studies, 26 utilised convenience sampling. They concluded that there has not been a golden standard identified for measuring compliance, but that dosage frequency, the patient's confidence in the provider, belief in the efficacy of a drug along with acceptance of the illness showed positive effects on compliance. Education and reminders were very important at the beginning of treatment, also the development of a collaborative relationship between the provider and the patient (Wood & Gray 2000:1-12). A study by the American College of Physicians of 81 AIDS patients who were on combination therapy regimens including PIs reported that AIDS patients who were over 95% adherent suffered no OIs or deaths and spent fewer days in hospital, as compared with patients who were less than 95% adherent. Adherence was measured using a microelectronic monitoring system: a cap on the medication bottles that recorded each opening and listed the date and time and duration of opening. A limitation identified was that this method did not allow the researchers to verify if after opening the bottle the medication was ingested or not (Paterson et al. 2000:21). Another study from the UK provided a model of empathetic understanding and adherence to treatment regimens in practitioner-patient relationships. It was reported that if the practitioner takes responsibility for providing the patient with information and, in addition to the informational-cognitive role, also displays an affective-emotional aspect which is related to the practitioner's capacity to share emotionally in the patients' feelings, empathy is communicated to the patient, which raises the probability of a beneficial outcome (Bennett & DeMayo 1993:47; Squier 1990:335).

Exposure to medication counselling and behavioural interventions increased adherence to combination ARV therapy in 21 non-adherent HIV+ve men who failed to refill their prescriptions on time and were hospitalised with OIs. The men were assisted with weekly medication pill organisers and individual medication counselling and self-management

skills to improve adherence. This confirmed the findings of earlier studies that increased opportunities for supportive patient-provider communication and interaction can enhance adherence (McPherson-Baker et al. 2000:399).

In summary, adherence is a dynamic phenomenon. Any patient can encounter difficulties with the medication regimen. Factors related to adherence include characteristics of the regimen, provider behaviours, social and environmental factors and, most important, strong provider-patient alliances that include explanations of the rationale for treatments and provider availability for follow-ups, along with concerned and caring partners who support daily adherence plans of the patient (Tsasis 2001:113).

#### *4.7.3.3 Reason for starting antiretroviral therapy*

The lack of research into the social aspects of PLWA/Hs in Botswana could explain why by February 2003 only 5201 patients had enrolled in the MASA programme; 3983 patients had decided to start ARV therapy and 6% of the patients had died (Darkoh 2003:4).

Some understanding was gathered from a study of 751 PLWA/Hs in the UK in 1996. The 458 respondents who started ARV therapy gave the following reasons

- My doctor recommended it/told me (68%).
- I decided that the benefits were worth the risk of side-effects (37%).
- I had become ill (29%).
- I was well and wanted to stay that way (26%).
- I had heard/read good reports about it (16%) (Anderson & Weatherburn 1999:204).

## **4.8 PREDICTORS OF SELF-CARE BEHAVIOUR**

In terms of Orem's theory, individuals were expected to take care of themselves to the best of their abilities. Self-care abilities will vary from one person to another, depending on their individual and environmental characteristics, but the will to take action was seen

by Orem as very important (Orem 2001:81). In terms of Maslow's hierarchy of needs theory, unmet needs would cause tension and anxiety and be a barrier to achieving well-being (Maslow 1999:77-78). In both theories *the will to live* was of overriding importance; without it nothing could be achieved.

#### ***4.8.1 Physical and mental health, individual and environmental characteristics***

In 1999, a group of seven nurse researchers from various American universities investigated a convenience sample of 420 PLWA/Hs, of whom 20% were women and 51% were white and had a mean CD4 count of 321 cells/mm<sup>3</sup>. This study examined the relationships between health-related quality-of-life, individual and environmental characteristics, physiological and biological factors, symptom status and three self-reported adherence measures using a descriptive survey design. The three dependent adherence measures were:

- (1) does not adhere to medication
- (2) follows provider advice
- (3) misses appointments (Holzemer et al. 1999:186).

The MOS-QOL SF-36 was used to measure the functional status, general health, social functioning and levels of body pain. The scores on MOS-QOL SF-36 physical functioning were 36.62 (SD = 27.81), MOS-QOL SF-36 role emotional 42.96 (SD = 43.76) and MOS-QOL SF-36 general health: 51.25 (SD = 23.20). There were no significant relationships between age, gender, ethnicity and history of injecting drug use and any of the three adherence measures. Participants with higher symptom scores had higher non-adherence scores, missed more appointments and followed less of the provider's advice; the mean score on body pain was 58.15 (SD = 24.67). The longer one was HIV positive the less likely one was to follow a provider's advice. Higher depression rates related to lower scores on following the provider's advice, missing appointments and being non-adherent. Participants who scored higher on social functioning, MOS-QOL SF-36 score 64.29 (SD = 27.74) and who cherished the environment as in having a meaningful life, feeling comfortable and well cared for and taking time for important

things reported that they were more likely to follow the provider's advice, keep appointments and take their medication. The researchers reported that there may be no golden standard with which to measure adherence. The several strategies available, namely clinician assessment, pill counts, prescription refills, assays, medication event monitoring systems and direct observed therapy all have their strengths and weaknesses. It was recommended that future research continue to struggle with new strategies to capture adherence beyond self-report and that a definition of adherence beyond "to follow closely" or "carry out without deviation" would depend on how the concept was measured, since at present the definition depends on the selected measurement approach (Holzemer et al. 1999:186).

The relationship between perception of engagement with health care provider and demographic characteristics, health status and adherence in persons with HIV/AIDS in this same study was explored and it was reported that the two MOS-QOL SF-36 scales, mental health and general health perceptions were significant but very modest predictors of engagement with health care providers, explaining 4% of the variance. The higher the quality-of-life scores, the more engagement with the provider was reported (Bakken, Holzemer, Brown, Powell-Cope, Turner, Inouye, Nokes & Corless 2000:189).

The findings of Holzemer et al. (1999:194) were subsequently confirmed by another USA study that investigated the purpose in life and depressive symptoms in a convenience sample of 123 PLWA/Hs. This study reported the strong inverse relationship between purpose in life and depressive symptoms for PLWA/Hs. Increased depression was associated with non-adherence to ARVs and increased risk behaviour by PLWA/Hs (Kelly, Murphy, Bahr, Koob, Morgan, Kalichman, Stevenson, Brasfield, Bernstein & St Lawrence 1993:215-219; Lyon & Younger 2001:129).

#### **4.8.2 Value of self-care in context of free health care services**

Orem's nursing model originated in the USA. Before the model was widely introduced in the UK in 1986 a British nurse tutor noted how differently self-care was valued in the UK and the USA. In the USA, control of an individual's health is seen as that person's

responsibility and the person seeking help pays directly or indirectly through insurance premiums. In the UK, more of a welfare-oriented society, people had a different outlook and were relying on the state to provide health services. In this respect Botswana is similar to the UK in that all health care in Botswana is free for children under 18 years of age and those above 60 years of age, all TB and STI patients. All other patients pay BWP2 equivalent to USD0.35. Health care for the majority of the people is provided by the state; private health care is available for those who can afford to pay the much higher fees (Tlou et al. 2001:65).

In the late 1980s self-care as a concept could in the UK only have a chance of success if society was willing to change some of its attitudes, beliefs and values. Feelings of entitlement were further encouraged and reinforced by the British capitalist society. Botswana might face some problems as well in promoting self-care and less dependency on the state (Behi 1986:35). In Botswana, ARVs are provided free of charge in a system that might encourage dependency on medical and nursing procedures since its focus is predominantly on medical procedures, such as

- HIV testing to confirm the medical diagnosis of being HIV+ve
- CD4 quantification to establish if the patient has AIDS
- viral load testing if CD4 is below 200 cells/mm<sup>3</sup>
- starting the patient on ARV therapy

This medical approach has the potential to dehumanise people and to discourage self-care because the person no longer feels in control.

#### ***4.8.3 Definition of quality of life by the individual***

Quality of life can only be expressed by the individuals concerned; their perceptions can be measured as they state what is important in their lives. Ratings of quality of life by the individual, doctors or relatives can be very different. It follows that there is a lack of a widely agreed definition of health-related quality-of-life. Little has emerged from nursing research literature that contributes to quality of life model development. However, following the second world war and the WHO's revised definition of health, research investigations have continued to focus on quality of life issues. The end goal of self-care is improved quality of life, and research by Ragsdale and Morrow (1990:355) supported

the assumption that good levels of physical and mental health influence an HIV+ve person's self-care actions and ability to cope with HIV/AIDS. These authors studied 95 HIV+ve men in the USA in 1990, and indications were that whether they were asymptomatic or symptomatic significantly affected the quality of life of these PLWA/Hs. In the early stages of HIV, people experienced the greatest disruption in their psychosocial aspects of life; as the disease progressed, physical symptoms in addition to psychosocial problems impacted on their quality of life (Ragsdale & Morrow 1990:355).

Although there appears to be no consensus on the definition of quality of life, previous studies suggested that to reach consensus it could be valuable to have the term defined by both professionals or experts and laymen (Farquhar 1995:507). Important to quality of life is a feeling of overall life satisfaction, as determined by the mentally alert individual whose life is being evaluated. People from outside that person's life situation must also agree that the person's living conditions are not life threatening and are adequate to meet the individual's basic needs. Thus quality of life has both objective and subjective components, according to a concept analysis aimed at establishing what "quality of life" means in the health care context (Meeberg 1993:37). The WHO states that the definition depends on how people perceive their position in life in the context of the culture and value system in which they live, and in relation to their goals, expectations, standards and concerns (WHO 1995:1405).

Quality of life can be measured, and depending on the definition of quality of life employed, both quantitative and qualitative research methods have been used over the past two decades. Increased quality of life can give people reason to reflect on their lives. Much of the research on women living with HIV examines the traumatic impact of living with HIV and the negative psychosocial consequences (O'Keefe & Wood 1996:275; Saunders & Burgoyne 2002:683; Schwartzberg 1994:593; Smith, Feldma, Kelly, DeHovitz, Chirgwin & Minkoff 1996:47; Swindells et al. 1999:383). However, some evidence is starting to suggest that PLWA/Hs can lead meaningful and productive lives despite or because of the challenges they are facing (Erlen & Mellors 1999:82). As explained in the theoretical framework of the present study in Chapter 2, both Orem and

Maslow believed in health despite being faced with adversity. A holistic understanding of health permits the broadening of our definition of what being healthy means, and this is believed to give HIV+ve women hope and motivation to strive towards higher levels of well-being.

#### **4.8.4 *Self-care and support***

The interaction between factors related to illness and health is complex, and individualisation of the responsibility for health care should not lead to blaming patients for needing care and support. A qualitative-descriptive study employing grounded theory methods examined personal meanings as well as social interactions that influenced low-income, white HIV+ve women's self-care practices in the USA. A convenience sample of 12 women agreed to participate and the researchers collected data over a period of four years through in-depth interviews and participant observation. The women reported limited support and were struggling to make ends meet due to poverty. Strategies employed were: intervention in the HIV+ve women's isolation from self and others; locating and mobilising resources; feeling emotions and finding meaning. The findings suggested the importance of relationships for stimulating creativity and meaning in the women's lives and talked about a caring connection through life as well as at the time of death (Hobbs Leenerts & Magilvy 2000:58-75).

In addition to the availability of support, higher levels of anxiety and lower performance status were important as predictors of self-care. In 1993, Dodd and Dibble, two professors of physiological nursing in the USA, used Orem's model of self-care to determine predictors of self-care behaviour in a sample of 127 adults with cancer who were to receive their first dose of chemotherapy. Data on physical capabilities, affective state and self-care agency were collected prior to the first chemotherapy cycle and at the beginning of chemotherapy cycles two, three and four. The researcher assessed support and health-promotion lifestyle prior to the first chemotherapy cycle. The researchers measured self-care behaviours at chemotherapy cycle four that were performed when any of the following five side-effects of the chemotherapy were experienced: nausea and vomiting, pain, fatigue, mucositis and hair loss. Significant findings were that side-effects

were a stimulus for self-care, and that patients with smaller support networks performed more self-care. It was also found that having more formal education could be considered a resource for the person. The family system of support was considered an asset; having a smaller support network meant that the options to meet their needs were limited and these patients were then responding to their needs on their own behalf. Age was non-significant as a predictor of self-care. Higher anxiety levels predicted more self-care; the more vigilant state may have been conducive to more self-care by some patients. The researchers concluded that the predictors of greater self-care (lower performance status, lower support and higher anxiety) were amenable to assessment but not to intervention. It was recommended that interventions were indicated with patients with less formal education (Dodd & Dibble 1993:898-900).

This finding was confirmed in a study of 144 patients (101 men and 43 women); one in five dropped out of treatments before completing their intake assessment. Men and those individuals with lower support were most likely to drop out during the intake process after seeing a nurse and before seeing a doctor. Emotional distress was not associated with early drop-out, but elevated levels of anxiety and depression were found across the sample. Those still attending the clinic (N = 114) were then followed for 12 months; free transportation was available to all participants and services were free, but overall 35% of scheduled medical appointments were missed during this period. Higher baseline CD4 counts were predictive of poor appointment adherence; thus healthier patients were less adherent (McClure, Catz & Brantley 1999:157).

The relationship between disease severity, health belief and medication adherence was investigated among 72 AIDS patients in the USA in 2000. The most severely ill patients, as compared with asymptomatic patients, perceived a higher risk of complications if they did not take their medicines as prescribed, and were more adherent. The investigators concluded that experience of illness and having AIDS complications motivated these patients to take their medications as prescribed. It was recommended that experienced patients share their insights about the complications of non-adherence with newer

patients, who could then gain a better understanding of the risks associated with non-adherence (Gao, Nau, Rosenbluth, Scott & Woodward 2000:397).

In a cross-sectional, descriptive study of 101 HIV-infected women living in the USA, factors were identified that influenced adjustment to chronic illness using the cognitive appraisal model of stress and coping. During face-to-face interviews, appraisal of illness, support, and HIV symptom severity were made and adjustment to chronic illness measured. Data were analysed with hierarchical regression, and path analysis and procedures to test for mediation performed. Social support did not directly effect adjustment processes. Adjustment was directly influenced by appraisal of illness and by HIV symptom experience (Bova 2001:217-224).

#### **4.9 THE PHENOMENON OF “DOING WELL” WITH AIDS**

In the previous description of the specific self-care requisites and predictors of self-care, PLWA/Hs’ acceptance of the HIV+ve diagnosis and taking responsibility for their health were recurrent themes. The phenomenon of people “doing well” with HIV/AIDS has fascinated many researchers, since it is believed that increased understanding about these persons might be of value to others.

##### ***4.9.1 HIV/AIDS as an opportunity for self-actualisation***

In the late 1980s, a group of psychiatric nurse clinicians and researchers in the USA shared their feelings and insights concerning the mounting human anguish they were seeing among PLWA/Hs, who were told they were terminally ill and had to be assisted to accept death. Yet many of these persons were doing well despite their illness. These researchers wanted a clearer understanding of the AIDS patients’ concept of “doing well”. It was reported that the 16 participants conceptualised AIDS as a manageable chronic illness and an opportunity for self-actualisation. They perceived having AIDS as becoming through self-reflection, self-accepting and ultimately self-love (Gloerson et al. 1993:46). In another American qualitative study done 10 years later it was reported that three men and two women recruited for the study from a university outpatient clinic

transcended the emotional and physical suffering of their HIV illness. They were asked ten open ended question such as

- Tell me, what is it like for you to be living with AIDS?
- How do you keep a positive attitude?
- How satisfied are you with your life? (Mellors et al. 2001:239-245).

Three main themes: creating meaningful life patterns, connectedness and self-care emerged from the data. The respondents stated that AIDS had turned their life around and had led to some sense of wisdom and personal development. Connectedness was expressed as both receiving and giving support, relationships and altruism as in volunteering and giving something back to others. Self-care included concepts of therapy such as exercise and good diet, survival: beating the odds, and wellness as in seeing themselves as not sick and not giving up. In summary, all five participants gave to the world by helping others, accepted unchangeable situations and were able to achieve satisfaction with life despite living with AIDS. The researchers recommended that potential interventions that might provide PLWA/Hs with an affirmation that their life had value and meaning included encouraging them to participate in support or community groups, resume a hobby, do volunteer work or engage in prayer and reflection to promote spiritual growth (Mellors et al. 2001:239-245).

#### ***4.9.2 Salutogenesis or health creation***

Both the studies of Gloerson et al. (1993:46) and Mellors et al. (2001:239) contributed to a body of knowledge called “salutogenesis”, also defined as “health creation”. A study in the UK revealed how, in the absence of a need for clinical intervention, health visitors appear to assess needs by treating health as a process fuelled by the accumulation and use of “resources for health”. Semi-structured interviews with the main caregiver in 50 families with resident children were analysed using this framework, to provide a lay perspective on how people consider they maintain their health. The analysis demonstrated the usefulness of treating health as a process and of focusing on the development of health-related resources rather than only on problems. The processes of developing

capacity were shown to be more important than the presence or absence of specific resources (Cowley, Billings & Lindstroem 2001:994).

These studies of Cowley et al. (2001:994), Gloerson et al. (1993:46) and Mellors et al. (2001:239) contributed to answering the question of how it was possible that some people in desperate circumstances rapidly succumbed to illnesses and died, whereas others managed to maintain longer-term survival. The development of an orientation that life is purposeful, meaningful and predictable, and gaining a sense of coherence depended on receiving resources from relationships that facilitated successful problem solving. People found meaning while confronting the inevitability of their own mortality. What is of relevance here is that the strategies these PLWA/Hs employed were person controlled:

- accepting
- being positive
- mastering living and relating mind and body
- being active
- being involved in personal health care
- experiencing support (Gloerson et al. 1993:57).

These strategies emphasised how firmly maintenance of well-being was rooted in self-care practices. In settings outside Botswana, patients utilised alternative health interventions such as hypnosis, thermal biofeedback and guided imagery and found that they increased vigour and hardiness in a group of 26 well-coping HIV+ve gay males; significant results ( $P = 0.05$ ) indicated that HIV-related symptoms (fever, fatigue, pain, headache, nausea and insomnia) decreased (Auerbach, Oleson & Solomon 1992:325).

The relationship between hardiness and its components (defined as challenge, commitment and control, perceived support and CD4-counts) was studied among 46 male HIV+ve support group attendees in America. The respondents' relatively high scores on hardiness and support were not significantly related to CD4 counts in this sample, but hardiness was significantly related to support ( $r = 0.38$ ,  $P = 0.02$ ) and the study

concluded that further research on support groups and hardiness was recommended (Byers, Nicholas & Webster 1993:134).

#### **4.10 SOCIAL SUPPORT AND HIV/AIDS**

The social support theory selected in the present study appears to be valuable because it is believed that networks, the context of relationships and the quality of support are as important as the existence, quantity and type of interpersonal relationships. There is still debate as to which dimensions and properties best predict health outcomes. The present study operationalised the concept of social support as “the resources provided by other persons” following the definition of Cohen and Syme (1985:4). When social support is viewed as a resource, it can have negative as well as positive effects on health and well-being, such as reinforcement of poor health behaviours and diminished feelings of self-efficacy. Whereas individuals and families on their own can practise self-care, self-help usually involves more formal group participation. PLWA/Hs seem to value the occasions when they can talk and share their concerns and hopes for the future. This might be happening within their circle of friends, families and/or with peers. Individual support may also be provided by the buddies or be facilitated in self-help groups where peers meet and listen to and learn from each other. PLWA/Hs with low levels of disclosure have as a result fewer people to talk to about issues related to their HIV+ve diagnosis; how this affects their quality of life is discussed.

##### **4.10.1 Orientation**

As stated above, support by buddies to the clients can have negative as well as positive effects on health and well-being, such as reinforcement of poor health behaviours and diminished feelings of self-efficacy. However, research leading to linkages between self-care and support by and to women living with HIV or AIDS could add to current theoretical development and holds potential in identifying relationships between and among variables associated with the quality of life for women living with HIV or AIDS (Stewart & Tilden 1995:539).

#### ***4.10.2 Mitigation of stress and enhancing coping***

Various studies have shown that having support from other PLWA/Hs or family members and friends can mitigate stress and enhance coping among HIV+ve women who often experience a loss of support. Another very important outcome of making support available is the decrease in the length of time HIV+ve women wait to seek care and support (Burgoyne & Saunders 2000:643; Byers et al. 1993:132; Hudson, Lee, Miramontes & Portillio 2001:73; Linn, Poku, Cain, Holzapfel & Crawford 1995:57; Williams et al. 1997:91). In the 1970s and the 1980s the concept of social support was studied, largely among white male participants, and various measuring instruments were developed (Hubbard, Muhlenkamp & Brown 1984:266). Only as a result of political and academic pressure to include women in study populations did women's health become a focus of attention, with the first major study in the USA in 1991, the Women's Health Initiative. Increased understanding evolved that for women and girls, HIV/AIDS prevention and health promotion programmes might be more effective when a support component was included. It was found that components such as group-learning peer role models or buddy programmes, to provide a culturally sensitive built-in connection to others as participants, were successful in modifying behaviour patterns.

If the needs of HIV+ve women in higher-income countries were not well documented, the many studies on African HIV+ve women were characterised by their focus on the poverty and powerlessness of the helpless AIDS victims (Akinsola & Popovich 2002:761; Awuah Baffour 2002:8). This was not acceptable to Campbell (2000:479), who researched women working as commercial sex workers in Africa. Campbell also pointed out that many of the other studies were unduly simplistic and failed to take into account the range of coping strategies and support networks that women constructed to deal with day-to-day life challenges. The sex workers reported strong bonds that served to protect them in times of danger, drinking clubs and friendship circles and rotating credit schemes, which the women linked into on the rare occasions when they had spare money. These existing strategies and networks could serve as potentially strong resources for community-based sexual health promotion and care programmes (Campbell 2000:479-494).

### ***4.10.3 Support and adherence***

Since the 1990s, more attention has been given to adherence issues specific to PLWA/Hs than ever before. Several studies over the last decade have reported that having support correlates with ARV therapy compliance and coping with HIV in PLWA/Hs (Leserman, Perkins & Evans 1992:1514; Linn et al. 1996:43; Peterson, Folkman & Bakeman 1996:461).

An American study of 179 clinical trial study participants revealed that having emotional support and being employed seemed to be predictive of being a good complier; having higher levels of HIV symptoms appeared to be associated with being a poor complier. The study was conceptualised using the theoretical framework of support theory to examine medication compliance ratings. The availability of social support and one's perception of such support depended on one's psychological status and medical condition. (Cox 2002:425).

As compared with HIV+ve women in Botswana, most American HIV+ve women have easier access to a primary care provider specialised in HIV care. However, it was identified that barriers to access in the USA were

- being older
- having difficulty in *remembering* appointments
- having problems with appointment *times*
- the high cost associated with travelling to care (Palacio, Shiboski, Yelin, Hessol & Greenblatt 1999:293).

It was reported in a study of adherence to self-care and social support in another group of chronically ill patients, 213 insulin-treated diabetics, that the respondents who experienced poorer blood glucose levels reported having more peer support. The study reported that adherence to self-care was associated with emotional and instrumental support from both friends and family. Peer support particularly helped those patients who did not achieve good symptom control. Even though peer support did not assist them in getting better metabolic control, it did help them to cope with the fact that they were

having problems with controlling their blood glucose levels. These patients coped better with the complications and poor quality of life. (Toljamo & Hentinen 2001:624).

#### **4.11 MUTUAL SUPPORT MECHANISMS**

The literature reviewed for the present study revealed that social adjustment and support promoted coping, enhanced self-esteem and increased the available coping resources (Hudson 2001:68; Murphy 1999:111). It further explained that self-care was closely related to self-help and both are important health-promotion mechanisms. However, the concept of self-help is ambiguous. Sometimes it means taking responsibility for oneself without support from others, in other cases it means taking responsibility for oneself with support from others, as in self-help groups or mutual aid groups. Self-help groups have been found to assist PLWA/Hs in particular by providing information and coping skills (Stewart & Tilden 1995:10)

##### ***4.11.1 Peer support***

Peer support and comparing notes with others faced with a similar stressful event, such as living with HIV, actually helps with coping (Misovich et al. 1997:95-123). One can look at others who are much sicker and realise that one is in a way fortunate or much better off, and this might help one to cope. Alternatively, if given a chance, one can compare oneself with a person who has been coping with living with HIV successfully, and be inspired to do the same. Similar social comparison with others or with peers also plays an important role in the prevention of transmission of HIV to others. Successful prevention of HIV transmission is based on three components: information, motivation and behavioural skills. Dialogue with well-informed peers can validate HIV+ve persons' correct information or indeed correct their misinformation, express positive attitudes and norms for behaviour and provide role models for the development of behavioural skills. These researchers argue that it is likely that AIDS prevention interventions making use of similar (peer) expertise will be more effective than interventions without such leaders (Misovich et al. 1997:95-123).

In Botswana, in the early 1990s, an innovative AIDS prevention programme was started to meet women's AIDS prevention needs. The programme recognised women as key health promoters for families and communities and stressed self-care and community competency in maintaining basic health. It was recognised that women were major decision makers and health educators on matters pertaining to the health of the family and that strong support from other women might be an important strategy for empowering women to protect themselves and their children from HIV infection. This model used peer education and support groups led by a trained community woman and coordinated by a nurse. The programme recognised that peer support goes beyond mere health education and that it requires a long and at times painful process of change. It was believed at the time that the coming together of women would allow women to develop mutual support mechanisms to maximise their protection from AIDS in the context of their own lives. By 2003, no evidence existed that this innovative project of the early 1990s had ever existed in Botswana, and the 1991 estimate from 20 000 - 45 000 HIV-infected persons reported in that study has now increased to 250 000 or more in 2003 (Norr, McElmurry, Moeti & Tlou 1993:255). Of interest here is that in 2001 one of the authors of that innovative model in the early 1990s, Professor Sheila Tlou, was one of the four women instrumental in formulating the 2001 Botswana buddy system model.

#### ***4.11.2 Brokers: advisors to community members***

In Vietnam, innovative ways were sought to reach TB patients who were reluctant to come forward and be admitted for two months in isolation wards. Swedish researchers interviewed 26 ongoing or recent TB patients and 16 health care providers involved with TB care in Vietnam. These researchers investigated perceptions of TB and the reasons for delay in seeking care. Factors influencing compliance and the low notification of TB by women were explored. TB is, like AIDS, a stigmatised disease in Vietnam, and a harmful reaction related to the stigmatisation of TB was the tendency to conceal the disease, engage in self-medication, and (self) imposed social isolation. Women were reported to be more afraid of enacted stigma than men were. Of interest to the buddy study was that in Vietnam it was reportedly common to consult a neighbour or other person in the community who had had experience with TB. The former TB patient was called "the

broker” because of his or her informal role as an adviser to the community, especially those who had contracted TB. All patients interviewed said that they listened to former patients and trusted what former patients had to say about their experiences of TB and its treatment. In Vietnam, no formal network of brokers seemed to exist, but people in the community were well informed about where to find them. This study reported a need for quality interaction based on transparency and trust among patients, family and provider. Female patients needed support as they received less support from their families than did men and it was recommended to explore the utilisation of the broker structure, since the role of broker was an important link in connecting social network members to one another and to resources outside the network capacity (Johansson & Winkvist 2002:488).

#### ***4.11.3 Buddy programmes***

The buddy system as a model of support is viewed as a stress buffer through the provision of instrumental support, being a culturally appropriate source of information on HIV and AIDS and a source of emotional support from one HIV+ve person to another HIV+ve person. Together with client empowerment and coping strategies, these factors play an important role in the psychological adjustment to HIV infection (Kalichman 1995:240).

The buddy system has been used for conditions other than AIDS. For example, a 1994 study in the USA tested the use and effectiveness of buddy support in a self-help smoking cessation programme with minimal contact. A random sample of 1584 smokers was selected from 9182 smokers who registered for an intervention programme, and the sample was divided into two panels of about equal size. The programme included a manual and complementary televised segments. Engaging a buddy was optional. Measures used were background and psychosocial characteristics of participants, the buddies, programme compliance and smoking behaviour. Standard chi-square statistics were used to compare percentage distribution for categorical variables, and Goodman and Kruskal’s gamma (using one tailed *P*-values) to assess the association between having a buddy and the ordinal participation level variables. No report was given on reliability or validity of the instruments, but the researchers cautioned against overlooking potentially important findings due to the exploratory nature of the analysis of non-experimental data.

Almost one-third, mostly young women, engaged a buddy. Participants whose buddy was a partner or spouse were more likely to quit smoking at the end of programme. The study concluded that buddy support should be promoted and could be improved by guiding the participants in their choice of a buddy (Kvitz et al. 1994:191-195).

Botswana's buddy programme was modelled on an American programme that originated in homosexual communities in the early 1980s in cities such as Boston and New York in the USA. Volunteers in the USA gave emotional and practical support and had more frequent direct, personal contact with the client than any other person at the AIDS service organisation (Williams 1988:38). The Botswana buddy programme defined emotional support as listening to and comforting the client in an empathetic, non-judgemental way. Practical support was defined as helping with cooking, going shopping or assisting with carrying water. The buddies also assisted the client with getting medical appointments, reminding clients to go to medical appointments and arranging transport from COCEPWA if the client was too ill to go by public transport. Buddies also visited their clients during hospitalisation but did not provide medical care. The buddies committed themselves to meeting with their client for a minimum of four to six hours per week for a period of six months. COCEPWA has a project coordinator who supervised the buddy-client activities and organised bi-weekly support group meetings for buddies. Continuing education was provided in workshops for buddies on nutrition and ARV therapy. The buddies signed a written contract outlining their rights and responsibilities. The project coordinator matched the buddy with the client. A two-day formal training was provided which addressed the basics of HIV/AIDS, followed by a two-day buddy training which addressed values clarification, disclosure issues and confidentiality and involved role-playing. This curriculum was much longer than the USA models, which usually involve only one-day formal training. The American buddy programmes also involved non-PLWA/Hs as volunteers; the Botswana buddy programme did not.

No research was identified that studied either the clients who participated in a buddy programme or the relationship between buddy and client satisfaction (Zuyderduin 2003:3). For this study, few previous studies were located that focused on the care

experiences by volunteers or buddies themselves. A qualitative study of 20 AIDS volunteers in Canada who worked at two AIDS service organisations reported that as the volunteers worked with an HIV-infected client, six themes in volunteer caring developed. These themes were: caring, supporting, touching, balancing, benefiting and reflecting. The interactions between the professional staff and other volunteers were important in meeting their support needs. This was regarded as important in order to prevent burnout and to aid coping with the inevitable losses and stress associated with the volunteer work. The volunteers expressed the importance of being trained well and of being given continuous opportunities for further education and receiving support in their work (Katz 1998:13).

Helping behaviours can be as beneficial to the person providing the help as to the recipient. Ten PLWA/Hs in a USA qualitative study described how helping others became an important strategy in helping them live with their HIV+ve diagnosis. This grounded theory study identified and described psychosocial responses to being HIV+ve. The core category that emerged from the data was fighting to survive. Taking care and restructuring one's life were the supporting concepts. Processes involved in taking care were everyday work and illness work. Helping others was one strategy of everyday work the PLWA/Hs found to be helpful in the fight to survive (Gaskins & Brown 1997:35).

One other buddy project in Southern Africa was identified in the literature. To complement the overburdened health care institutions in Gauteng a buddy system of support and care for people infected and affected by HIV/AIDS in Alexandra, Johannesburg was initiated at the Institute of Urban Primary Health Care. In the report on the pilot study, it was stated that 1041 visits were undertaken by the buddies. The buddies provided emotional and instrumental support, and 80% of the visits were at the PLWA/Hs' homes. Attitudes towards the buddies by their own friends were extremely negative and hostile and it was reported that support to the buddies themselves will be prioritised in future programme design. Eleven HIV+ve clients of the buddies were interviewed and it was found that four of the eleven had disclosed their HIV+ve status only to their buddy. These findings corresponded with the 2000 needs survey findings,

where 25% of the respondents (N = 116) disclosed to another PLWA/H first. Barriers to care in the South African buddy project were:

- fear associated with the disease
- the negative social stigma attached to HIV/AIDS
- negative attitudes towards voluntarism (Motsepe & Perry 2000:1; Zuyderduin 2000:29).

#### ***4.11.4 Self-support groups***

In the USA AIDS Action Committee buddy programme on which the Botswana buddy programme was modelled, buddies were expected to meet every other week in support groups to discuss their experiences. In the American programme, non-attendance was regarded as a reason for being discharged from the buddy programme (Williams 1988:38).

Support groups were largely reported as valuable and important strategies in rendering support and care for PLWA/Hs. An integrative review of 15 articles on support groups for PLWA/Hs in the USA in 1996 by Kalichman et al. (1996:589) aimed to provide a scientific base for their usefulness and effectiveness. Support groups have been proposed as a key intervention for PLWA/Hs for more than a decade in the USA, but despite this fact, only a few articles have evaluated and compared outcomes. The conceptual basis for support groups included the fact that living with HIV is a chronic stress factor that can lead increasingly to emotional, physical and social problems (Kalichman et al. 1996:589). It was also suggested by Spirig (1995:27) that support groups empower people and provide social contact, emotional and informational sharing and education and health promotion. Empowerment was believed crucial because it focused on the positive, less fatalistic aspects of the illness (Glajchen & Magen 1995:27; Spirig 1998:45).

The multidimensional concept of quality of life has emerged over the past years and PLWA/Hs use different management styles to improve their quality of life. Quality of life can be conceptualised as the perception by the PLWA/Hs of the effectiveness of their management style in solving problems with their illness. Six management styles used by

PLWA/Hs to maintain control and improve their quality of life were presented in a study of 13 hospitalised AIDS patients in the USA. These management styles were termed: *the loner* (who preferred to sleep and did not want to talk much); *the activist*, (who was active in support and political groups); *the victim* (who managed survival through a posture of dependence); *the mystic* (who managed life by defining it spiritually rather than medically and saw AIDS as a battle between good and evil); *the timekeeper* (who managed life by waiting for things to happen); and *the medics* (who typically referred to AIDS as “their” disease and managed their condition by depending overwhelmingly on medical meanings for the interpretation of AIDS). These styles were often developed or used in support groups that assisted PLWA/Hs to manage the challenges of their illness (Fontaine et al. 1997:252; Ragsdale, Kotarba & Morrow Jr 1992:261).

A need for supportive psychosocial interventions closer to the time of initial HIV+ve diagnosis was recommended in a pilot study of needs, characteristics and experiences of 63 PLWA/Hs in the USA. Of these 63 PLWA/Hs, 34 persons attended an HIV-support group and 29 did not. The PLWA/Hs completed measures of distress, coping and social connectedness, and participated in open-ended interviews concerning their support group experiences. Analysis of variance and analysis of covariance were appropriately utilised to analyse the data. The researchers reported that those who attended support groups knew they were HIV+ve for a longer time, reported less emotional distress, and had more social contact than did the comparison group. The researchers concluded that HIV+ve persons become socially reconnected with time, but individuals with avoidant coping styles experience greater emotional distress and are unlikely to seek support groups (Kalichman et al. 1996:589). The review concluded that support groups are a useful, effective and helpful intervention for the diversity of PLWA/Hs, and that a mixture between educational and psycho-emotional interventions seems to prove successful. Systematic evaluation of the assumed value of support groups, in 1998 still in their infancy, was recommended (Spirig 1998:54).

Support groups for HIV+ve women are being introduced in Asia as well (Jirapaet 2000:34-45). In 1999, participatory action research was utilised as a process for an

empowerment programme in Thailand. To test the empowerment programme's effectiveness, a control group, pre-test/post-test, quasi-experimental design was used. The sample consisted of 94 HIV-infected Thai mothers rearing their own infants, 46 in the six-week experimental group and 48 in the control group. Both groups completed pre- and post-test questionnaires. In addition, an open-ended questionnaire asking about the benefits of the empowerment programme was administered to the intervention group at the end of the programme. The main difference between the two groups was the implementation of the six-week empowerment programme in which the participants met weekly. The empowerment programme components were

- peer group meetings
- professional support on infant rearing
- maternal self-care
- stress management, and
- access to available support (Jirapaet 2000:34-45).

These aspects were critical to improved quality of life in this intervention group of 46 low-income HIV+ve women who lacked basics such as adequate nutrition, shelter facilities for hygiene and health services where needed. The experimental group had significantly higher scores on all mean differences of the dependent variables: coping ability, quality of life and maternal role adaptation, than the control group (Jirapaet 2000:34-45).

In Africa and Asia, as in the USA, little objective evidence existed about the effectiveness of support groups. In Africa, it was commonly assumed that sick people did not need outside support since the extended family provided a safety net for individuals in time of need. The extended family was regarded as a national strength. However, as the AIDS burden grows the system could become overexploited. A study in Uganda in 1993 that explored the extended family and support for 30 AIDS patients found evidence of limited care for 27 out of the 30 patients. Various reasons were given for this by the carers, including lack of food and money for medications and the carers' other family responsibilities. For 17 patients who died during the study period, records of seven cases

showed that other relatives were asked to help with care but refused on the grounds of poverty or other commitments. However, in all but one case the extended family did provide assistance for the funeral. The study concluded that blanket statements about the supportive role of extended families need to be questioned. AIDS wears down family resources and since it is usually the breadwinner who dies, the dependent old and young are left behind who, even if they manage to take care of themselves, do not have the capacity to take on more caring tasks for other relatives. It was recommended that families with one or more HIV+ve family members need moral and practical support in the form of encouragement, reassurance and practical advice. It is unrealistic to expect the extended family to provide these services in all situations (Seeley, Kajura, Bachengana, Okongo, Wagner & Mulder 1993:122).

A study assessing community attitudes toward HIV/AIDS and HBC in Kenya reported in 1999 that the findings indicated that due to inadequate information about the disease and care expectations, people were ambivalent towards the sick, while in some instances outright rejection prevailed. This formed the basis for the families' preference for institutional based care as opposed to HBC. This was further compounded by the economic status of the household/family. Sheer poverty militated against providing adequate home care, even when families might be willing to provide it. The study also confirmed that external observers may perhaps be too taken in by the romanticised idea of unswerving community support. This may further relegate the burden to the primary unit, the family, and especially the women, who ultimately carry the load with limited resources. This study emphasised the need to initially share the issue with the community in order to work out the mechanisms that would lessen the burden of, and facilitate, home care. Training in the care of AIDS patients is crucial, yet lacking at the family and community levels. Whereas care, counselling and support are particularly important prerequisites for HBC, these were conspicuously lacking. Very few caregivers had appropriate training and were worried about their lack of knowledge, and yet they had to care for patients. It was evident that they lacked a framework that would provide the capacity to facilitate home care. Such a framework would bridge the gap between the noble concept of HBC and the realities of such care (Olenja 1999:187).

## **4.12 GAPS IN THE LITERATURE REVIEWED**

Creating new knowledge is one of the expected outcomes of research, or rather the core business of any discipline that wants to remain a legitimate professional discipline. As health professionals borrow theories from other disciplines that may or may not be adequate to guide research or practice, it is important to systematically evaluate whether their adoption should be considered. If there is congruence between the various concepts, health researchers can and should utilise innovations from other disciplines to their advantage (Villarruel, Bishop, Simpson, Jemmott & Fawcett 2001:158). Through crafting the links between research and practice, new ideas are generated. To make this creative process easier to understand, one could compare it to a spinner who prepares wool by combing. The spinner discards debris and aligns the strands of a matted mass in much the same way as the researcher shifts through content to tease out central ideas from extraneous ones. Just as the spinner twirls strands to compose a single thread; the nursing theorist spins central ideas into a synthesised thread for research and practice (Liehr & Smith 1999:81).

### ***4.12.1 Many problems - few solutions***

Denial, stigma and discrimination and the devastation caused by people dying in unprecedented numbers challenge the abilities of the infected and affected people in Botswana and the rest of the world to come up with viable solutions to alleviate the suffering caused by HIV/AIDS. Very few studies out of Africa came up with viable plans to redress the situation, and if they did it was from a technical perspective and without any input from the experience of the PLWA/Hs.

Studies reported on the discrimination against and abuse of women and the poverty of the female-headed households, and how stigma and lack of access to resources and skills hampered progress in HBC. They reported the poor uptake of the PMTCT and the ARV programmes and noted the lack of involvement of nurses in health-care policy development, but solutions offered to address these problems were few and far between and never involved PLWA/Hs as decision makers (Awuah Baffour 2002:8; BIDPA

2000b:2; Buwalda et al. 1994:153; Darkoh 2003:1-7; UNAIDS 2001:2; MLHA 2001:1,122; Ndaba-Mbata & Seloilwe 2000:218; Olenja 1999:187; Phaladze 2003:22; Tlou et al. 2001:22).

#### ***4.12.2 Need for more information on self-care agency of HIV+ve women***

There are gaps in the literature reviewed in that most researchers of the 1980s and the early 1990s in the USA asked homosexual white men in the developed world to participate in their studies. Only in the late 1990s did research on HIV+ve women increase and gender differences in the experiences of living with HIV, and the role of support and self-care become noted. There is a need for more information on the self-care agency of HIV+ve women. In the present study both the buddies and their clients were studied, since little is known about how giving and receiving support influences the domain of quality of life. The beneficial role of support and adherence to complicated lifelong treatment regimes was supported by the literature, but not much information relevant to the present study was located that explained the link between self-care and support. The present study explored what types of support were available to the buddies and the clients six-months into the buddy-client relationship. The study also reported on the levels of the perceived support prior to engaging with a buddy, and what the changes were six-months into the buddy-client relationship.

The research questions and the objectives of the present study are unique to the Botswana context. However, the literature reviewed is largely from outside Africa. Comparison of the findings of the present study with findings of studies on care and support of PLWA/Hs outside Botswana will continue to discover the differences and the similarities in these marginalised sections of the global society. The literature reviewed on the impact of the AIDS epidemic on Botswana as a relatively wealthy nation in sub-Saharan Africa indicated that it is essential to look at the need of those infected with HIV to prolong their lives as well as how best to prioritise their needs to direct the use of limited resources for maximum benefit. An investigation of the relationships and interplay between specific self-care activities and levels of support is justified. Paucity of research investigating initiatives for and by women living with HIV was noted, more specifically insight into

the differences in levels of support and quality-of-life scores between the buddy and the client. Self-care and support received little attention, study or validation, and the buddy programme for and by HIV+ve women is unique in Africa.

#### ***4.12.3 HIV/AIDS as a problem of individuals or as a problem of society?***

One other question was not answered by reviewing the literature. The problem with individual notions of self-care and health promotion and choice is that these are individualistic approaches. Mass epidemics such as the HIV/AIDS epidemic of the 21st century have structural social bases. Action (or inaction) in the developing or the developed nations affects everybody. Effective actions require a move beyond the individual approaches and towards socially responsible health promotion (Benatar 2002:163). Does a buddy system of care offer opportunity for greater involvement by communities? Being diagnosed with a life-threatening illness is traumatic for the individual and his or her family. The volunteer caregiver role may offer HIV+ve people an opportunity to address the trauma of HIV disease by returning to the volunteer a sense of purpose and satisfaction in living. Implications of the present study include consideration of the benefit of volunteer HIV/AIDS service to the larger community.

In the present study concepts from Orem's self-care theories, Maslow's needs theory and Cohen and Syme's social support theory were used and these theories were applied in practice. Building on these foundations and combining them guided the present study of the buddy system. The present study went beyond the Western individualist concepts of the self-care and the hierarchy of needs theories and included the social support dimension, because the interrelatedness of and the connections between the HIV+ve woman's family and friends, peers, (health) professionals and spiritual guidance in society were considered important.

All actions by the HIV+ve woman touch the lives of the people who care for her well-being, while their actions influence her, and it is accepted that interaction can assist with or block self-care actions or personal growth.

The present study describes how self-care, basic needs and support motivate and assist HIV+ve women with coping from the moment they receive their HIV+ve diagnosis.

The theoretical framework of the present study gives a new perspective that goes beyond either individual personal growth through meeting one's basic needs or engaging in self-care actions for improved quality of one's own life. In the present study, these are not regarded as separate individualistic end goals in life. The present study considers the social relationships as in interrelatedness with others and, through encouragement of disclosure by HIV+ve women, reconnection with society and all who care. The HIV+ve woman might adapt to her condition if helped by others to achieve personal growth and engage in higher levels of self-care. All these three actions combined will move her, from the moment she receives the HIV+ve diagnosis which gives her reason to believe that she will die within a foreseeable time, to living positively with HIV. At the time of diagnosis she will need the inner strength and motivation to carry on and expand her self-care agency to look after herself. The present study's theoretical framework articulated the importance of interdependence and explained how coping with HIV, motivation for personal growth and having support were believed to be the building blocks towards achieving adjustment, self-actualisation and higher levels of self-care -- not just for the benefit of the individual but to heal the society as a whole.

#### **4.13 CONCLUSION**

The Botswana buddy system was designed to provide a referral, care and support system for HIV+ve people in situations where there were no support services provided by the public health care system. It is a complementary service in the war against HIV/AIDS, which aims to relieve the pressure on the already overburdened formal institutions such as clinics and hospitals struggling to meet the needs of the thousands of HIV+ve and AIDS patients in Botswana. The burden of care is placed on the women: the wives, the mothers and young girls who are looking after the HIV-infected patients in the hospitals and in the homes, often without any formal support and care for the caregivers and under very difficult circumstances, without the appropriate knowledge and financial resources.

Denial of the problems caused by the AIDS epidemic might act as a buffer against the emotional distress that all people in Botswana have to cope with, but further contributes to misconceptions and the isolation of the HIV-infected at a time when they need support most: at the time of learning their HIV+ve diagnosis and when they need to be taught and supported in behavioural change to prevent re-infection and stop the transmission of HIV to others. The high levels of stigma and cultural beliefs which blame women for bringing AIDS into the home make disclosure a high-risk activity for most HIV+ve women, who if they disclose prefer to tell another HIV+ve person first. In addition to the challenges of denial and stigma, HIV+ve people who are focused on living, not dying, encounter problems in accessing services such as TB prevention to treat latent TB, monitoring their immune status and starting ARV therapy where appropriate.

The commendable effort by the government of Botswana to make ARV therapy available has benefited 4000 AIDS patients during 2002, but the emergence of drug-resistant strains of HIV is a real threat to society. This problem can arise if the AIDS patients are non adherent. Non-adherence is defined as when persons on ARV therapy are less than 95% adherent or, specifically, miss more than two doses of their ARV medications per month (Amoroso et al. 2002:323).

Predictors of self-care behaviours were explored to gain increased understanding of how PLWA/Hs can be encouraged to take control of their health. The literature reviewed indicated that both general and mental health levels and basic conditioning factors such as levels of education and gender influence self-care actions. Despite all the challenges of poverty, abuse, stigma and depression reported, another phenomenon was of interest. Some PLWA/Hs reported that after a period of readjustment they found meaning in AIDS and reported that they were “doing well”. Support was more often than not a key component in the adjustment period when newly diagnosed persons had to learn to deal with their anger and frustration about being diagnosed with a terminal illness. Direct support from other people, especially peers, provided a buffer and assisted them to find balance and meaning in their lives. Mutual support mechanisms such as peer support and

participation in support groups, albeit not always objectively measurable, had largely had the beneficial effects of breaking the isolation and helping them to find understanding among persons who were going through the same experience.

The Botswana buddy programme aimed at challenging the denial and stigma in society by encouraging the HIV+ve women to display a fighting spirit and make themselves visible by disclosing their HIV+ve diagnosis at their own pace. At the heart of any successful intervention with stigmatised groups are trust and respect; the buddy system of care and support by and for women living with HIV added the component of warmth and concern for others going through the same experience. This study explored whether equipping the HIV+ve women with knowledge and resources in addition to their altruistic motives could contribute to their quality of life and, eventually, the healing of a traumatised nation.

Chapter 5 will expand upon the methodological issues already touched upon in the first four chapters. This chapter will explain aspects of the research design in greater detail. The selection of the various research instruments will be explained and a justification for the selection offered through a review of studies that utilised these same instruments in studies with PLWA/Hs.

## **CHAPTER 5**

### **RESEARCH METHODOLOGY**

#### **5.1 INTRODUCTION**

This chapter outlines the methodology used in this quasi-experimental descriptive survey. The study design and the specific research questions that guided the present study are described, followed by a description of the ethical considerations involved in researching HIV+ve women. The sampling method is described. This fifth chapter should enable other researchers to understand how the research questions were addressed, and provide sufficient information to enable others to duplicate or expand upon the present study to evaluate its usefulness. All details about the data collection process and the instruments, the rationale as to why these instruments were selected and the manner in which the data were analysed are therefore described. This chapter is guided by the theories of Orem, Cohen and Syme as well as Maslow, as described in the theoretical framework in Chapter 2. The research experiences gained in conducting the needs assessment (During 2000, as reported in chapter 3 of this thesis.) informed the methodology of the present study. Literature reviewed for the present study summarised past research efforts in relation to the research questions and was used as basis for decision making as well.

#### **5.2 STUDY DESIGN**

The present study was designed to explore how the capacity for self-care of women living with HIV could be developed in a community-based care and support environment within a developing country such as Botswana.

##### **5.2.1 *Orientation***

Most citizens of Botswana (Batswana) did not want to know their HIV status for fear of stigma and the realisation that behavioural changes, irrespective of the outcome of the test, are needed (Donnelly 2003:1-3). Going for VCT was believed to be a measure of self-care in the present study. Answers were sought to the question of whether the HIV+ve women who had taken that first step thereafter reported for laboratory tests for

CD4 counts to assess what damage HIV had caused to their immune system. The present study explored whether social support assisted in meeting specific self-care needs of the HIV+ve women: prevention of OIs such as TB, by taking the six months TB prophylactic treatment course IPT; and the monitoring of their immune systems. Initiation of self-care requires motivation. As Maslow's theory of human needs pointed out, needs are mainly met in an ordered fashion; food and shelter are the basic needs that have to be met before belonging and esteem needs can be addressed. These four deficiency needs can only be fulfilled with help from other people, but as soon as an individual is no longer deprived, other needs, the so-called being needs such as the need for justice or beauty, can be fulfilled or actualised by the individual from within. Self-actualised people, as Maslow explained, are keen to help others and engage in social activities (Maslow 1999:47-49). The theoretical framework of the present study held it as a truth that in order to be healthy, people need other people and that people want to be needed.

The first research question on self-care was phrased as: "How do self-care activities develop in the buddy and the client six-months into the buddy-relationship?" Furthermore, the HIV+ve women in the present study were encouraged to disclose their HIV+ve status to others if they were ready, enabled by the *buffering* and *direct effect* of social support through the buddy system. The specific research question was: "To how many persons have the clients disclosed in April 2002 and is there an increase six-months into the buddy-client relationship?" It was also regarded as important to measure the relationship between levels of engagement in self-care by HIV+ve women, and their perceptions of social support. The findings will be reported and discussed in Chapter 6.

The present study therefore considered whether the buddy system is an opportunity for improving the quality of life of the HIV+ve community. The originators of the buddy system regarded the fact that the buddies, as well as their clients, were HIV-infected themselves as a strength rather than a weakness. The present study linked the variables **social support** and **activities of self-care** for HIV+ve women living with a chronic condition, and of interest here was to find out if there was a relationship between the variables *self-care* and/or *social support* and *quality-of-life* scores: more specifically,

whether the buddy system caused differences in the levels of social support, self-care and disclosure between the clients with buddies and the control group without buddies.

### 5.2.2 *Research questions*

To discover the impact of the buddies on the quality of life of their clients the following seven (7) research questions guided the present study:

Research question 1: To how many persons have the clients **disclosed** at baseline and is there an increase six-months into the buddy-client relationship?

Research question 2: How have **self-care activities** developed in the buddy and the client six-months into the buddy-client relationship?

Research question 3: What are the **attitudes-towards-adherence** scores of both the buddies and the clients if on ARV therapy prior to starting their buddy-client relationship, and is there a difference six-months into the relationship?

Research question 4: What are the **levels of perceived support** prior to engaging with a buddy and what are the changes six-months into the buddy-client relationship?

Research question 5: What **types of social** support are available to the buddies and the clients six-months into the buddy-client relationship?

Research question 6: What is the **quality of life**, both the physical and mental health, of the HIV+ve buddies and their clients in the present study prior to and six-months into the buddy-client relationship?

Research question 7: In this study, what was the relation of the PCS and MCS scores to the demographic variables, to the levels of self-care, social support and attitudes toward adherence?

## 5.3 **ETHICAL CONSIDERATIONS**

The needs assessment survey conducted during 2000 informed the design of the present study.(See Chapter 3.) The initial survey process has assisted in forming a trusting

relationship between the HIV+ve target population, who were all members of COCEPWA, and the researcher (Zuyderduin 2000:54). The positive responses from the HIV+ve community towards the needs assessment during the survey, and upon completion of the study when the report was shared with the study participants and a wider audience, made the PLWA/Hs involved understand the implications of the term *meaningful participation* in research (Gray, Higgs & Pringle 1996:177-200).

The design of the buddy system was a continuation of the participatory needs assessment and programme planning process within COCEPWA during 2000 and 2001. (See Chapter 4.) The preparedness of four HIV+ve persons to assist the researcher with interviewing the buddies and the clients in 2002 as part of the data collection process in the present study further assisted in building trust between the study participants and the researcher.

Forming a relationship of trust and communication with the study participants was important to avoid common problems associated with doing sensitive research on stigmatised groups (Flaskerud & Winslow 1998:69-78; Glesne 1999:128-129). The HIV+ve community could also be defined as a “vulnerable population”. Groups recognised as vulnerable are the poor, persons subjected to discrimination, intolerance and stigma and those who are potentially marginalised and denied human rights. Vulnerable groups typically include women and children, gay men and lesbians, the homeless and the elderly (Flaskerud et al. 2002:75).

Research into health disparities of vulnerable or under-served groups has occupied nursing; nearly eighty studies were carried out and published in a publication called *Nursing Research* between 1952 and 2000, according to Flaskerud et al. (2002:74), who identified areas for future research as:

- community-based studies
- research into health behaviours associated with exercise, nutrition, sleep and rest and use of preventative services
- intervention studies that provided tangible resources

- methodological approaches that involved participants in the research process (Flaskerud et al. 2002:74-83).

The present study investigated how a section of the HIV+ve community in Botswana provided opportunities and resources needed to achieve and maintain health. Nevertheless, the AIDS epidemic is regarded as the responsibility of society as a whole. A narrow focus on individual responsibility for health by considering self-care agency of PLWA/Hs outside the societal context would have the potential to further stigmatise or marginalise the HIV+ve community. The findings of the present study could make it even more difficult for this community to receive the necessary care, find employment and participate in the broader society if certain ethical principles of study design were ignored. Issues of informed consent, maintaining confidentiality and privacy, weighing the risks and benefits of a study and paying attention to issues of fairness had to be considered (Flaskerud & Winslow 1998:75).

### **5.3.1 Dialogue**

Because the majority of the HIV+ve women in the present study had not disclosed their HIV+ve status to many others, it was understood that they feared being identified and subsequently stigmatised if they could be recognised from the findings in the report of the present study. It follows that most PLWA/Hs would normally not agree to participate. However, researchers are as a rule first faced with another problem: difficulty in gaining access to, as well as establishing rapport with, the participants (Platzer & James 1997:626). The literature review revealed that many researchers gained access because they worked with PLWA/Hs in their professional capacity, for example as nurses in AIDS care (Gaskins 2001:15; Laschinger & Fothergill-Bourbonnais 1999:59). It was also common for academics to approach PLWA/Hs in specialised HIV/AIDS health care centres and ask patients (in- and/or out-patients) if they would be willing to participate in their study (Heise & Elias 1995:931; Lubeck & Fries 1992:359). Other researchers would work with and/or contact study participants through self-support groups of PLWA/Hs (Fontaine et al. 1997:249).

Difficulty in gaining access was reportedly not the only challenge. Other issues that needed to be addressed were ethical concerns such as the need to empower the participants to contribute ideas and identify with the goals of the research and stigma contagion (Bowser & Sieber 1993:169; Flaskerud & Winslow 1998:75; Glesne 1999:128-129; Platzer & James 1997:626; Sieber 1993:14).

The ethical issues pertinent to the present study related to whether or not “individuals or communities may be helped or harmed by the conduct, publicity and results of the research” (Sieber 1993:14).

As explained in Chapter 3, a group of 116 male and female PLWA/Hs had shared their experiences and knowledge during the needs assessment of 2000 (Zuyderduin 2000:1-76). The present study of the buddy system was not unfamiliar to the PLWA/Hs, but was one of the issues identified by that section of the PLWA/H community of Botswana in 2000. The present study provided an additional opportunity for a different group of PLWA/Hs, this time consisting of HIV+ve women only, to make a genuine contribution by giving new information as a group about their quality of life, their levels of social support and their self-care agency. The buddies had to disclose their HIV+ve status to such an extent that they were known and regarded as peers by their HIV+ve clients. They had to be willing to share insights, knowledge and experiences during the data collection stage with the researcher about their own experiences and report what type of care and support they were asked to give to their HIV+ve client.

There were no easy solutions such as the strict following of ethical codes to guide the researcher’s behaviour; the ethical quality of the present study was promoted by exchange of ideas and interaction with the participants throughout the study period. In accordance with a recommendation of Glesne (1999:128-129), discussions were held with members of COCEPWA every month during the data collection period in 2002.

### **5.3.2 *Informed consent***

The Botswana buddy programme development can be divided into stages:

- 1 The 2000 needs assessment and prioritisation of programme activities of COCEPWA
- 2 Design of the buddy programme (2001)
- 3 Implementation of the buddy system (2002 onwards)
- 4 Evaluation and redesign of buddy programme (2003)
- 5 Continuation of Botswana buddy programme and replication of the Botswana buddy programme to four other countries in sub-Saharan Africa (September 2003 onwards)

The present study of the buddy system was conducted during the third phase of the buddy programme development. The buddy programme was implemented in late 2001 and the members of COCEPWA anticipated deriving benefits from the present study, since the findings could be considered as part of the internal evaluation process and redesign of the buddy programme that were due in 2003. This benefit to the 116 HIV+ve women involved in the present study could be regarded as a good ethical working rule for obtaining informed consent, because the buddy programme would still be available to the HIV+ve women after the present study was concluded (Annas & Grodin 1998:562).

Communicating respectfully and openly with the members of COCEPWA throughout the present study, and providing a debriefing about the nature, findings and value of the research, were essential requisites for obtaining informed consent (Polit & Hungler 1993:438). The HIV+ve clients, the members of the control group and the buddies all signed a consent form prior to the data collection phase. (See Annexure I.) Furthermore, the participants were made aware of their right to withdraw their consent at any time during the study (Barrett 2000:36).

### **5.3.3 *Right to privacy and dignity***

The right to privacy and dignity covers all aspects of the right to privacy, confidentiality, anonymity and human dignity as well as freedom from exploitation (Rose-Hott & Budin 1999:41). The researcher guaranteed the confidentiality of the information shared, which may or may not have involved personal experiences. The answers given on the structured

questions were not identifiable to persons reading the research report. Due to the sensitive nature of the present study, the data collection process was designed in such a manner that the respondents could not be identified. The questionnaires were administered by the research assistant, who was not aware which respondents were the clients or which were in the control group. The questionnaires were returned to the researcher without bearing any identifying information other than date and number. This anonymous process was selected to guarantee the buddies, the clients and the control group the right to privacy.

#### **5.3.4 Risk-benefit ratio**

In the absence of reliable information about the Botswana buddy programme for care and support by and for PHLW/As, it was believed that the present study would assist in documenting and sharing information about the care and support effort of this non-governmental organisation. The risks to the HIV+ve clients were minimal, since their levels of disclosure were respected and the buddies signed a written agreement about their rights and responsibilities. The COCEPWA project coordinator supervised the buddy-client pairs once they were in the field and organised support group meetings to discuss any issues that the buddies wished to discuss; while a dedicated cellular phone line for the buddy programme was opened to ensure that buddies and clients could access support from the project coordinator at any time. The HIV+ve persons in the control group had normal access to all services offered by COCEPWA, including counselling and peer support.

### **5.4 RESEARCH INSTRUMENT**

For the present study self-completion questionnaires using Likert scales were selected as the research method. A method which was in the past closely associated with objective and positivist research: a science that claimed that it was possible to divide science into theory and observations (Breakwell, Hammond & Fife-Schaw 2000:13). It was accepted in the present study that collecting written responses to close-ended questions, a quantitative method, had its own limitations in that it was not the same as hearing the direct voices of the HIV+ve women. The choice of answers in the self-completion questionnaires restricted the responses and reflected the categories designed by the

researcher. The potential problems with the questionnaires were related to the predetermination of questions and answers (McKie 1996a:32). Generally speaking, qualitative methods of hearing the voices are best obtained through semi-structured or focus groups interviewing (Gray et al. 1996:180).

However, the choice of the quantitative methodology in the present study was made because the participants needed to protect their privacy. The HIV+ve women perceived it to be less threatening to complete the questionnaires, and did not want to be tape-recorded during an interview nor be in a group with other HIV+ve women to whom the participants did not want to disclose. If they had been interviewed in a group and had had to hide their HIV+ve status they could not have responded truthfully when asked certain questions. The selected research method, using all field-tested survey instruments, also had the advantage that all 116 HIV+ve women could contribute to this first study of the buddy programme. The functions of the self-completion questionnaires were to provide

- Information on individual and group characteristics such as gender, age, quality-of-life and attitudes towards adherence
- frequencies, by collating numbers and attributing data to categories such as gender, age bands, quality-of-life
- data for other statistical tests, such as cross-tabulations which measured the strength of a relationship between two or more variables such as social support and quality-of-life (McKie 1996a:32).

## **5.5 RESEARCH POPULATION AND SAMPLE**

All 116 participants in the present study were citizens of Botswana, women who had tested HIV+ve. The participants were adults of 18 years of age or older and could decide for themselves if they wanted to participate in the present study. The 116 participants had told at least one other person about their HIV+ve status and fell into either one of three groups: the buddies, clients or the control group.

### **5.5.1 Population**

The 39 buddies attended training programmes by COCEPWA. After completion of the training the buddies were linked up with their clients through the project coordinator. The 39 clients were members of COCEPWA and were interviewed and given an explanation of the rules before having a buddy assigned to them by the buddy project coordinator. Both buddy and client had to pay their own way when they decided they would go to the movies or any other entertainment; nevertheless the buddies were paid a stipend of BWP250 or US\$50 per month to cover their costs such as telephoning their client and transport costs. The importance of confidentiality was stressed during the training and the support group meetings. The 38 persons in the control group were also members of a COCEPWA branch in the villages Molepolole and Serowe in Botswana, where a buddy programme was not available. Proficiency in basic English and/or fluent Setswana (local language of Botswana) was required from all study participants.

### **5.5.2 Sample**

It was pointed out by Platzer and James (1997:628), that since it is unlikely that marginalised groups such as PLWA/Hs will reveal themselves, one is generally unable to rely on probability samples, even if the whole population of a country could be identified. Previous studies of PLWA/H populations were reviewed for the present study and it was established that for the same reason of “invisibility”, non-random sampling methods should be selected. Snowball sampling techniques were used in both quantitative and qualitative studies, since truly representative samples were impossible to obtain due to the fact this is a hidden population (Bunting et al. 1999:41-52; Call, Klapow, Stewart, Westfall, Mallinger, Demasi, Centor & Saag 2000:977-985; Erlen & Mellors 1999:75-84; Gielen, McDonnell, Wu, O'Campo & Faden 2001:315-322; Ingram & Hutchinson 1999:93-103; Jirapaet 2000:34-45; Metcalfe et al. 1998:30-34; Moneyham et al. 1998:351-362; Nannis et al. 1997:1-22).

Therefore, in consultation with the members of COCEPWA, a non-random convenience sampling was selected for the present study as well. The geographical scope was limited to Gaborone, the capital of Botswana, to ensure supervision of the 39 buddy-client pairs.

During 2001 the buddy programme was designed by employees and a group of HIV+ve members of COCEPWA. For a period of one week in December 2001, the female membership of COCEPWA Gaborone was given an orientation to the buddy programme. At some point in the first quarter of 2002, 39 women subsequently volunteered and were trained as buddies by COCEPWA in April 2002. Those members of COCEPWA Gaborone who were interested in the buddy programme because they needed a buddy themselves could register their names during the first quarter of 2002 as well.

The trained COCEPWA members, in the present study termed “buddies”, were paired up with the COCEPWA members in need of peer support, in the present study termed “clients”, after completion of the buddy training course in April 2002. The control group (n = 38) were selected from the membership list of other branches of COCEPWA (N = 200) outside Gaborone. Due to limited resource availability, COCEPWA Molepolole and Serowe did not have buddy programmes in place during 2002. The control group was created for the client group, comprising 38 participants who were randomly selected from a group of known HIV+ve female (N = 200) COCEPWA members in these two villages Molepolole and Serowe. The HIV+ve women in the control group, all members of COCEPWA, were not disadvantaged in any way as a result of being included in the control group without buddies. The extraneous variables that were controlled for were gender, age and HIV+ve status.

The PLWA/Hs were, during 2002, unlikely to participate in any programme of care and support failing to guarantee their anonymity. The members of COCEPWA would not have applied for training to become buddies nor have encouraged other HIV+ve women to register on the client register if COCEPWA had not guaranteed total anonymity. The buddies consented to complete the research questionnaires prior to being paired up with a client and again six months later, and so did the clients and the HIV+ve women in the control group. As stated above, one advantage of this data collection method was that a confidential study with hidden populations who were not otherwise identifiable was possible. The method was low cost, and the previous experience and trust gained by the

COCEPWA membership during the needs assessment survey of 2000 assisted in the process.

## **5.6 DATA COLLECTION**

The buddy-client pairs and the control group were studied for a six-month period from April to November 2002. The same set of questionnaires was used in April 2002 and again in November 2002 for the buddies, the clients and the control group. Permission for use was sought where applicable and obtained for the use of MOS-QOL SF-36. (See Annexure IV.). The MOS SSS, PRQ-II and the AAI were freely available on the world wide web (WWW) and during 2002 not protected by copyright laws (<http://www.aac.org/aai>; <http://www.montana.edu/cweinert/instruments/PRQ85>; <http://www.rand.org/health/surveys.html>).

### **5.6.1 Collection of demographic information**

The researcher designed a 17-item questionnaire based on literature reviewed for the present study. (See Annexure III.) With the first seven questions relevant demographic data were collected on

- age (question 1)
- marital status (question 2)
- number of children (questions 3 and 4)
- level of education (question 5)
- employment status (question 6)
- monthly income (question 7).

### **5.6.2 Collection of self-care information**

The researcher-designed 17-item questionnaire questions 8-17 further assisted in collecting information on self-care behaviours such as

- When tested for HIV? (question 8)
- Levels of disclosure (question 9)
- TB treatment (questions 10 and 11)

- TB prevention (question 12)
- CD4 quantification (question 13)
- Frequency of CD4 quantification (question 14)
- Whether taking ARVs (question 15 and 17).
- Access to ARVs (question 16).

Levels of openness about the HIV+ve status were assessed through asking all participants how many people they had told that they were HIV+ve at the beginning of the study in April 2002 and again after six months. The participants were given possible answers ranging from: 1-5 people, 10-20, 21-30, 31-50, to more than 50 people (question 9).

After VCT and learning about an HIV+ve diagnosis, individuals are advised to have a laboratory test to measure the number of CD4 cells/mm<sup>3</sup> blood. This is to assess how much the HIV infection has diminished the immune system functioning since first infection. Normal CD4 values range between 800 and 1200 cells/mm<sup>3</sup> blood, and all patients with counts lower than 200 cells/mm<sup>3</sup> blood were at the time of the survey eligible for free ARV therapy in Botswana. As a measure of self-care, it was valuable for the researcher to determine whether PLWA/Hs had accessed these health services from their local clinic. A specific question (question 13) was included in the questionnaire to identify the reasons for failure to do so. All PLWA/Hs without active TB infection were advised to take INH tablets for six months to prevent reactivation of latent TB infection. The PLWA/Hs in the present study were asked if they had completed IPT, were taking INH or had never started IPT (question 12).

### ***5.6.3 Collection of health-related quality of life information***

The MOS-QOL SF-36 was developed at the Rand Corporation in the USA for use in the health insurance study experiment/medical outcomes study (HIS/MOS). The medical outcomes study measures were based on a conceptual model that included two overarching dimensions of health, namely physical and mental health. The MOS-QOL SF-36 is made up of the items which loaded best on factor analyses from 149 items from the longer batteries, based on the results from over 22 000 patients in the HIS/MOS

studies. The authors of the MOS-QOL SF-36 were aiming to develop a short, generic measure of subjective health status that was psychometrically sound, and that could be applied to a wide range of settings. The MOS-QOL SF-36 measures *functioning* and *well-being* and is a concise 36-item health-status questionnaire. Its use across the world has escalated since 1990. Population norms for the USA have been reviewed and published in the handbook of the instrument (Ware, Snow, Kosinski & Gandek 1993:98).

#### 5.6.3.1 *Rationale for selection of the medical outcomes study short form-36 health survey questionnaire*

The MOS-QOL SF-36 was selected in the present study to measure health outcomes during the six-month study period among the 116 HIV+ve women. The MOS-QOL SF-36 is one among several health-related quality-of-life measures currently in use. The instrument evaluates general health status factors that are not specific to any age, disease or treatment group. Emphasis is on social, physical and emotional functioning (Fayers & Machin 2001:19).

Other measures, such as the quality of well-being (QWB) scale, which combines morbidity and mortality outcomes, are often used, but the MOS-QOL SF-36 is perhaps the most common outcomes assessment instrument in contemporary health services research (Ware & Sherbourne 1992:473-483). The QWB scale combines symptoms and problems with three scales of functioning: mobility, physical activity and social activity to produce a point-in-time estimate of well-being on a scale ranging from 0 (for dead) and 1.0 (for asymptomatic with full function) (Anderson, Kaplan, Coons & Schneiderman 1998:756).

In a comparison of the QWB scale and the MOS-QOL SF-36 used with two samples of ill adults, Anderson et al. (1998:755) reported that if the study population included seriously ill AIDS or cancer patients the QWB appeared to be better able to capture outcomes of serious illness over time than the MOS-QOL SF-36. Patients who died during the study period were counted as *outcomes* by the QWB and as *missing data* by the MOS-QOL SF-36. It was observed by the authors that there might be some advantages of morbidity-only

measures such as the MOS-QOL SF-36 in studies where patients on treatment get better over time, even if some of their treated peers die, given that a combined index might miss the treatment effect (Anderson et al. 1998:760). In the present study of 116 HIV+ve women who were not seriously ill, the MOS-QOL SF-36 was selected in view of the fact that the aim of the present study was not to study an illness where mortality is an important outcome. The aim was to assess whether the HIV+ve women experienced increased levels of well-being during the six-months study period.

#### 5.6.3.2 *Content*

The MOS-QOL SF-36 contains 36 items which measure eight dimensions:

1. physical functioning (10 items)
2. social functioning (2 items)
3. role limitations due to physical problems (4 items)
4. role limitations due to emotional problems (3 items)
5. mental health (5 items)
6. energy/vitality (4 items)
7. pain (2 items)
8. general health perceptions of health and changes over the past 12 months (6 items).

The MOS-QOL SF-36 claims to measure positive and negative health; examples of questions are:

*How much does your health limit you in these activities?*

- (b) Climbing several flights of stairs
- (c) Walking more than a kilometre
- (d) Walking half a kilometre
- (f) Bathing and dressing yourself

Possible answers were

- Yes, limited a lot

- Yes, limited a little
- Not limited at all (See Annexure III.)

#### 5.6.3.3 *Scoring*

Each of the eight sub-scales employs its own response format; these varied from dichotomous “yes/no” responses to a six-point scale of “none” to “very severe”. The MOS-QOL SF-36 data were scored in five steps:

- (1) data cleaning
- (2) item recalibration and skip pattern recoding
- (3) reverse scoring of items
- (4) transforming item scores linearly to common metric scores with a possible range of 0-100
- (5) averaging across items in the same scale (Ware & Kosinski 2001:28).

Data cleaning was necessary to make sure that every field with fixed-range (Likert) scales allowed input within that range and the coding of missing answers. The MOS-QOL SF-36 scoring manual stipulated which items needed reverse scoring (Ware & Kosinski 2001:25).

The results were reported for the buddies, the clients and the control group and were analysed to show the effects over time: at baseline in April 2002 and six months later. Item scores for each of the eight dimensions were added up and transformed, using a scoring algorithm, into a scale from 0 per cent (poor health) to 100 per cent (good health). The sub-scales were not added to produce an overall score. The results have conventionally been reported as mean scores for each sub-scale, rather than frequency distribution, despite the well-known tendency of means to distort results by reflecting small numbers of outlying values. Nevertheless, since we were not considering individual scores of the 116 HIV+ve women and wanted to compare the scores with standardised scores in HIV+ve and other populations, the mean scores were reported. The MOS-QOL SF-36 took 5-10 minutes to complete.

#### 5.6.3.4 *Validity*

Validity refers to whether or not the instrument measures what it claims to measure (Breakwell et al. 2000:49). The detailed results of the testing of the longer Rand batteries have been published, together with the history of the development of the MOS-QOL SF-36 from these instruments (Ware et al. 1993:103).

The validity of an instrument can be influenced by *ceiling* and *floor* effects. This refers to the response range and the method of scoring an instrument. Thus an instrument applied to a random sample of the population which was not sensitive to lower levels of ill-health, and which scored from 100 (poor health) to 0 (good health) would be said to manifest a floor effect, as most respondents would score zero. On the other hand, if the instrument was scored from 0 (poor health) to 100 (good health) this would be referred to as a ceiling effects, as most respondents would score 100. Such floor and ceiling effect are more likely to be found in instruments with a small number of items (Breakwell et al. 2000:49; Jenkinson 1994:187).

Floor effects were of some concern in the MOS-QOL SF-36, particularly in the Role Functioning sub-scales in severely ill patients (Ware et al. 1993:29). If patients obtained the lowest score possible, the implication would be that deterioration in condition over time would not be detected by the scale, because there was no score below zero per cent.

#### 5.6.3.5 *Reliability*

Fourteen studies in the USA which analysed the reliability of the MOS-QOL SF-36 were reviewed by the authors of the instrument to establish reliability (Ware & Sherbourne 1992:473). The reliability coefficients ranged from 0.43 to 0.90. The level of reliability achieved by the MOS-QOL SF-36 is lower than that achieved by the full-length versions of the MOS scales it was constructed to reproduce (such as mental health, health perceptions). The minimum reliability standards appeared to have been most consistently met with the physical functioning sub-scale (Ware et al. 1993:25)

#### *5.6.3.6 Permission for use*

The researcher applied for a licence to use the MOS-QOL SF-36 instrument, which is the Intellectual Property of QualityMetric in the USA. Permission for use of 240 survey instruments per year in English, royalty free for the present study was obtained in writing. (See Annexure IV.)

#### **5.6.4 *The adherence attitude inventory tool***

The first version of the AAI of 1999 was the brainchild of a group of three researchers: Dr. Neil Abell, an associate professor at the Florida State University School of Social Work; Dr. Sarah Lewis, an assistant professor of Social Work at Columbia University; and Julie Zimmerman, a registered nurse practitioner. An update was developed by Drs. Abell and Lewis in 2000, in collaboration with Michael Immel, former coordinator of prevention education at the AIDS Action Committee of Boston, Massachusetts. The updated version was used in the present study. (See Annexure III.)

##### *5.6.4.1 Rationale for selection of the adherence attitude inventory*

The AAI tool was administered to gain insight into how the buddies, the clients and the control group who were on ARVs adhered to their medication schedules prior to and six-months into the helping relationship. The measure of adherence to the prescribed regimen was viewed as a direct measure of self-care behaviour (Huss, Salerno & Huss 1991:260).

##### *5.6.4.2 Content*

The four constructs that the tool measured were:

- cognitive functioning (memory)
- patient-provider communication (such as doctor-patient relationship)
- self-efficacy (how well you think you can do something)
- commitment to adherence (how important is it to you).

The AAI included final behaviour questions that acted as pre- and post-questions for any intervention or programme, and measured changes in people's actual adherence within a certain time span. In April 2002 and October 2002 the women on ARVs completed the

AAI to assess adherence behaviour to ARVs of the buddies, the clients and the control group.

#### *5.6.4.3 Scoring*

The AAI was scored by summing all the items on the 7-point Likert scale scores that assessed the attitude towards adherence. The scores ranged from 28 to 196 and were divided by 28, the number of questions, to obtain a total score. High total scores on the AAI, a 6 or 7, indicated that the respondents felt good about their overall ability to take their ARVs as recommended. The results of the AAI were reported for the buddies, the clients and control group who were on ARV therapy and were, where possible, analysed to show the effects over time: at baseline and six months. For those participants who started ARV therapy during the present study, their scores were reported as measured in November 2002 only.

#### *5.6.5 The personal resource questionnaire*

The present study selected the PRQ-II to measure the respondents' level of perceived social support (Brandt & Weinert 1981:277-280; Weinert & Brandt 1987:589-602). (See Annexure III.)

##### *5.6.5.1 Rationale for selection of personal resource questionnaire*

The combined PRQ-II score in itself can be used as a measure of social support. Strong social support has been linked with positive health outcomes in chronically ill persons (Ell 1984:133-149; Leserman et al. 1992:1514-1519; Nunes, Raymond, Nicholas Kenneally, D'Meza Leuner & Webster 1995:174-198). If the PRQ-II score improved over time, this supported the assumption that there were beneficial effects to the buddy system.

##### *5.6.5.2 Content*

The PRQ, a norm-referenced measure of social support, was developed based on relational dimensions (Weiss 1964:36-43). The dimensions included

- (1) provision for attachment/intimacy

- (2) social integration
- (3) opportunity for nurturing behaviour
- (4) reassurance of worth as an individual and in role accomplishments
- (5) the availability of information, emotional, and material help.

The PRQ-II was administered to all HIV+ve women in the present study at baseline in April 2002 and after six months in November 2002 to gain insight into what **sources** of support were available *before* they were paired with a buddy and *after* having been in the buddy-client relationship for six months.

#### 5.6.5.3 Scoring

The PRQ-II was scored by adding up the 25-item, 7-point Likert scale scores that assessed the five relational functions of support. The scores ranged from 25 to 175. A high score in the PRQ-II indicated that the respondents perceived themselves to have a high level of social support.

#### 5.6.5.4 Validity and reliability

The PRQ-II reliability estimates were previously assessed with four data sets. The PRQ-II high internal consistency reliability (coefficient alpha) for the total perceived social support scale ranged from .88 to .90. Moderate correlations were established for the sub-scales: intimacy .66, social integration .59, self-worth .66 to .90 and assistance/guidance .69 to .75. The nurturing sub-scale is independent, with established reliability and validity (Weinert & Brandt 1987:589-602). The authors of the instrument, Brandt and Weinert (1981:277-280), recommended continued evaluation, since construct validation of the instrument accrues from many different studies and there are difficulties in defining the mechanisms of social support.

#### 5.6.5.5 Permission for use

Permission for use of the PRQ-II survey instrument is normally granted royalty free to all academic researchers. The only requirement was to complete a request form online providing a brief abstract of the proposed study, the study population and samples and

which version of the PRQ-II was to be used. This information was subsequently included in the database of Montana University in the USA according to the information on the website (<http://www.montana.edu/cweinert/instruments/PRQ85/requestform.html>).

### **5.6.6 *The medical outcomes study social support survey***

Data collection on *types* of social support available when needed was aided by MOS SSS, a 19-item self-administered questionnaire that asked questions about perceived availability of support if needed. (See Annexure III.)

#### **5.6.6.1 *Rationale for selection of the medical outcomes study social support scale***

The social support survey was developed during the Rand medical outcomes study of 1 402 patients with chronic diseases (Sherbourne & Hays 1990:328-343). The items selected for inclusion were derived from a larger pool of 50 items constructed on the basis of a literature review (Sherbourne & Stewart 1991:705-714). The items deliberately reflected subjective impressions of social support. (See Chapter 2.) The 19-item MOS SSS used in the present study reflected more recent conceptual thoughts on the subjective components of social support, as compared with the earlier 17-item version that was used in the 1990s in the Rand medical outcomes study.

For the present study, social support was operationalised by four multi-item measures of availability, if needed, of four distinct *types* of functional support and an overall social support index termed positive social interaction:

- tangible support, involving the provision of material aid or behavioural assistance
- affectionate support, involving the expression of love and affection
- emotional support, involving the expression of positive affect and empathetic understanding
- informational support, the offering of advice, guidance or feedback
- positive social interaction, involving the availability of persons with whom to do pleasurable things (Sherbourne & Hays 1990:328-343).

### 5.6.6.2 Content

**Types** of social support that were assessed included:

- emotional support
- informational support
- affectionate support
- tangible support
- positive social interaction.

Positive social interaction was judged to be important enough to be included, as this type of support could be beneficial to the health outcomes of people with chronic illnesses. Although a 17-item scale was used initially in the 1990s to represent these dimensions, a 19-item version was subsequently developed which involved dividing the emotional support domain into two dimensions, and thus the scale then contained five, rather than four, dimensions of social support (Sherbourne, Hays, Ordway, DiMatteo & Kravitz 1992:447-468; Sherbourne & Stewart 1991:705-714). In the 19-item version, two single items on the structure of social support were included in order to compensate for the lack of focus on the structure of the network (the number of close friends and relatives, and marital status). The development of the 19-item support scale was based on the same conceptual framework, question type and response format as the 17-item scale. The 19-item scale is the current version used in the present study.

For each item, respondents were asked how often each kind of support was available to them if they needed it. The five-point choice response scale for each item ranged from “none of the time”, “a little of the time”, “some of the time”, “most of the time”, to “all of the time”. Five points were chosen by Sherbourne and Stewart (1990:705-714) on the basis of their review of the research evidence that five to seven response categories were necessary for optional assessment. Examples from the scale are:

*People sometimes look to others for companionship, assistance or other types of support.*

*How often is each of the following kinds of support available to you if you need it?*

- Someone you can count on to listen to you when you need to talk.
- Someone to help you if you were confined to bed.
- Someone who shows you love and affection.
- Someone to have a good time with.
- Someone to do things with to help you get your mind off things.

#### *5.6.6.3 Scoring*

Each response (“none of the time” to “all of the time”) was scored on a scale ranging from 1 to 5, and the scores were added (the higher the score, the greater the level of social support). The MOS SSS consists of four separate social-support sub-scales and an overall functional social support index. Higher scores for an individual scale or for the overall support index indicated more support. To obtain a score for each sub-scale, the average of the scores of each item were calculated. To obtain an overall support index, the average of the scores for all 18 items included in the four sub-scales was calculated, and the score for the one additional item (the last item in the survey) added. The published mean scale scores were transformed to the 0-100 scale using the formula: 100 times the observed score minus the minimum possible score divided by maximum possible score minus the minimum possible score. The sub-scales of the MOS SSS indicated what types of social support were perceived to be available to the buddies, clients and the control group in time of need.

#### *5.6.6.4 Validity and reliability*

Sherbourne and Stewart (1991:705-714) used the scale in a study of the effects of social support and stressful life events on long-term physical functioning and emotional well-being of 1 402 chronically ill people (with hypertension, diabetes, coronary heart disease or depression) participating in the Rand medical outcomes study. This study supported the scale’s construct validity. The authors reported that patients with high levels of social support had better levels of physical functioning and emotional well-being than those with low levels of support, supporting its construct (convergent) validity. In relation to the same sample, the 19 items were reported by Sherbourne and Stewart (1991:705-714) to be correlated weakly to moderately with measures of loneliness, health perceptions,

mental health and measures of family and social functioning. The authors argue that this supports their construct (discriminant) validity. Standardised factor loadings ranged from 0.76 to 0.93 for the tangible support factor, 0.86 to 0.92 for the affectionate support factor, 0.82 to 0.92 for the emotional and the informational support factor, and 0.91 to 0.93 for the positive interaction factor. Results of the principal components factor analysis of the 19 items also supported the construction of the overall index (the first unrotated factor showed high loadings for each of the items, ranging from 0.67 to 0.88). These results support the scale as containing four dimensions and as providing a common measure of overall support.

Sherbourne and Stewart (1991:705-714) reported that the correlations (Pearson's) between the items and the sub-scales were strong. Item-scale correlations ranged from 0.72 to 0.87 for the tangible support scale, 0.80 to 0.86 for the affectionate support scale, 0.82 to 0.90 for the emotional and informational support scale, and 0.87 to 0.88 for the positive interaction scale.

The additional item on number of close friends and relatives correlated low to moderately with each of the functional support items (0.18 to 0.23), indicating its distinct status; marital status was not associated with numbers of close friends or relatives (0.01), but was more highly correlated with the functional support items (0.69 to 0.82).

One advantage of this scale is that it contains more health-specific items than many of the more generic social support scales that have been developed. Most social support scales were developed in the USA and contain culture-specific items which would be unusual in other societies, such as having someone who would loan the respondent a car.

The MOS SSS was developed for use with chronically ill patients in the medical outcomes study. It was recommended that the four sub-scales be used or the total index scores. For psychometric indices the instrument was tested on approximately 3000 patients in three sites. Internal consistency reliability (Cronbach's alpha) was established and fell above

0.91 (each sub-scale and the total scale). Validity tested with multi-trait scaling yielded high convergent and discriminant validity (Frank-Stromborg & Olsen 1997:162).

#### *5.6.6.5 Permission for use*

Permission for use of the MOS SSS instrument was granted for the present study. All of the surveys that appeared on the RAND health site are **public documents, available without charge to all researchers**. An appropriate citation when using the survey had to be provided (<http://www.rand.org/health/surveys.html>).

## **5.7 TIME FRAME**

The data collection phase was completed in eight months, starting 1 April 2002.

## **5.8 RELIABILITY AND VALIDITY**

The present study utilised five different measures to answer the various research questions. The validity or the meaningfulness of the interviews was determined by pretesting the schedules with members of COCEPWA who were asked to provide feedback during this phase.

### *5.8.1 Pretesting of the research instruments*

The literature reviewed pointed out that a questionnaire is the least threatening tool for data collection, since it can be completed in total privacy (Breakwell et al. 2000:161; Polit & Hungler 1993:202; Rose-Hott & Budin 1999:102). In assessing the appropriateness of the English language data collection instruments prior to the present study, the respondents indicated that they preferred having the research assistants nearby to elaborate on the questions and explain some of the questions in Setswana; most HIV/AIDS terms were best understood in English, since Setswana equivalents for some terms did not exist. The research assistants indicated their preference for writing down the answers given by the respondent since the assistants were more familiar with the

layout of the questionnaires and thus quicker, and they ensured that no mistakes were made. The PLWA/Hs commented on

- the wording of the questions
- whether the questions were easily understood
- whether alternatives offered covered the responses the PLWA/Hs wanted to give
- the length of time it took to complete the interview.

The time required to answer all questions was approximately 45 minutes. The participants in the study were assigned unique numbers to be used on their forms. A master list was created by the researcher with codes and full names of the 116 participants for correlation with later results; this was kept under lock and key and was only accessible by the researcher.

## **5.9 DATA PREPARATION AND ANALYSIS**

Data were collected twice during the present study, the first data were collected at baseline during April 2002 before the clients were paired up with their buddies, and the data collection process was repeated with the same instruments six-months into the buddy-client relationship. The responses to all the structured questionnaires yielded a large amount of data that needed to be condensed into a more manageable form. This was done by summarising the data using frequency distributions, graphic presentations and percentages. The statistician, a Professor emeritus of UNISA engaged for the present study, used the statistical package for social scientists (SPSS) software for the data analysis.

### **5.9.1 Data preparation**

The first step was to translate the answers into numerical codes to allow for computer-based analysis. SPSS was used for statistical analysis procedures by the statistician. The nominal data were classified and cross-classified using frequencies. The ordinal data were rank-ordered, and percentages were given to the variables. The variables for the

present study were the scores of the buddies, the clients and the control group on the demographic form, the PRQ-II measuring the perceived levels of support, the MOS SSS assessing types of support, the MOS-QOL SF-36 that measured quality of life and the attitudes-towards-adherence scores were obtained by the AAI.

### **5.9.2 Data analysis**

In the present study, no generalisations were made from the sample to the whole population of PLWA/Hs, since the sample was a small convenience sample (N = 116). Furthermore, the convenience sample was limited to

- adult HIV+ve women;
- PLWA/Hs who had disclosed to at least one other person; and
- members of COCEPWA.

Thus the findings might not be generalisable to HIV+ve adolescents, men, PLWA/Hs who have not told anybody about their HIV+ve diagnosis or who do not associate with support groups for PLWA/Hs. The results of the control group were important in determining whether the changes at six months were unique to the buddy pairs or if the changes were due to chance.

#### *5.9.2.1 Measures of variability*

The present study used bar graphs to represent a frequency distribution of nominal or ordinal data. To show that the data being represented are separate categories, the bars do not touch each other. In another type of graph, histograms, which represent the frequency distributions of variables measured at ordinal, interval or ratio level, the bars touch each other to indicate that data are being represented on a continuum. Mean scores were reported, where applicable, as a measure of central tendency, accompanied by a description of the standard deviation (SD) or how values vary about the mean of the distribution (Campbell & Machin 2000:68).

When a particular value needed to be interpreted in relation to other values in a distribution, z-scores were reported. Z-scores are standard scores that indicate how many

standard deviations from the mean a particular value lies. A z-score is called a standard score because it is interpreted in relation to standard deviation units above or below the mean (Nieswiadomy 1998:251-258).

#### *5.9.2.2 Measures of relationships*

To measure the extent to which values of one variable were related to values of a second variable, correlation techniques were used to study whether relationships existed between variables. A correlation which showed that two variables were related did not mean that one variable caused the other. The correlation coefficient can vary between -1.00 and +1.00. The two numbers represent the extremes of a perfect relationship. A negative number, -1.00, indicates that study participants who scored high on one of the variables tended to score low on the other. Correlation coefficients are frequently symbolised by the letter *r* and are generally calculated on measurements obtained from each study participant on two variables, or two groups of matched study participants. The correlation procedures tests used in the present study were Pearson product-moment correlation for two sets of interval or ratio data, Spearman's rho with two sets of nominal data and the contingency coefficient (Nieswiadomy 1998:260).

Scatter plots provided graphic representations of the relationship between specific variables. From the scatter plot one could determine the magnitude and the direction of the relationships, or the lack thereof when the dots were scattered randomly all over the graph. For nominal or categorical data, relationships could not be depicted in scatter plots. Contingency tables, also called cross-tabulation tables, were used to visually display the relationships between sets of nominal data.

#### *5.9.2.3 Testing hypotheses*

All inferential statistical tests are based on the assumption that no difference or relationship (correlation) exists between, for example, the scores of the clients and the control group on disclosure. If small differences or low correlations were found, chance would be considered the reason. However, if the results of the analysis showed a difference or correlation that was too large to be the result of chance, then the research

hypothesis that having a buddy encouraged disclosure, might be supported. Correlation coefficients typically range from +1.00 (for a perfect direct relationship, through .00 (for no relationship to -1.00 (for a perfect inverse relationship between two variables (Polit & Hungler 1993:434).

Two possible mistakes can be made concerning the null hypothesis; they are termed Type I and Type II errors (Polit & Hungler 1993:448). A Type I error occurs if the null hypothesis is actually true and the researcher rejects it. A Type II error is when the null hypothesis is actually false and the researcher fails to reject it. If, for example, the probability level in the present study is set at .10, the probability of a Type I error is 10%, the risk being that the researcher accepts that something exists when it does not actually exist. The probability of a Type II error can be controlled by using a larger sample size (Nieswiadomy 1998:281; Polit & Hungler 1993:448).

The present study is limited by a possibility of both mistakes, due to the researcher's willingness to report findings at the .10 probability level, and the small sample size. These limitations would prevent the generalisation of the research results to the population of HIV+ve women in Botswana.

The levels of significance can be defined as the probability of rejecting a null hypothesis (a hypothesis that states that no relationship exists between specific variables), when it is true and should not be rejected: the difference found was caused only by chance or sampling error, supporting the null hypothesis (Campbell 2000:98). The letter *P* is used to symbolise the probability level that is set; the most common level of significance that is found in health studies is  $P = 0.05$ , meaning that the researcher is willing to risk being wrong 5% of the time when rejecting the null hypothesis. In the present study a less stringent level of significance such as .10 could be reported, since no great harm would result from rejecting a true null hypothesis. Even if certain findings were not statistically significant, they might still be meaningful in the clinical situation, since these findings add information to the body of knowledge concerning the quality of life of HIV+ve women in Botswana (Nieswiadomy 1998:279). In the interpretation of the statistical tests

the degrees of freedom (df) were reported. The computation of the degree of freedom is usually calculated by subtracting 1 from the total number of participants in a sample. Degrees of freedom for buddy and client groups were  $39-1 = 38$ , and the control group  $38-1 = 37$ ; for the total group of 116 HIV+ve women  $116-1 = 115$  (Brink 1990:119).

Depending on the formulation of the research hypotheses, one-tailed tests of significance were used for directional research hypotheses and two-tailed tests of significance were used for non-directional research hypotheses. The word “tail” was used to indicate the values at each end of the sampling distribution (Nieswiadomy 1998:280).

### *Non-parametric tests*

Non-parametric tests do not make assumptions about the population from which samples were selected. These tests could be used in analysing the present study’s nominal and ordinal data and were suitable for the relatively small sample size. To compare the sets of data that were in the form of frequencies or percentages the chi-square statistic, ( $\chi^2$ ) was used, implying that the frequencies that were obtained or observed were compared to the expected frequencies. Assumptions underlying the chi-square were that

- (1) the data were frequency data
- (2) there was an adequate sample size, since expected frequencies of less than five in a 2 x 2 table would have presented problems
- (3) the measures were independent of each other
- (4) there was some theoretical reason for the categories (Fielding & Gilbert 2000:265; Hazard Munro & Batten Page 1993:89).

In the present study the theoretical framework guided the categorisation; self-care variables were distinguished as well as scores on quality-of-life domains and perceived levels of satisfaction with sources and types of social support. (See Chapter 2.)

Pearson's chi-square test for independence for a contingency table tested the null hypothesis that the row classification factor (cluster of variables) and the column

classification factor (cluster of variables) were independent. This test compared observed and expected frequencies (counts). The expected frequencies were calculated by assuming the null hypothesis was true. The chi-square test statistic is basically the sum of the squares of the differences between the observed and expected frequencies, with each squared difference divided by the corresponding expected frequency. The chi-square statistic is always calculated using the counted *frequencies*. It can *not* be calculated using the observed proportions, unless the total number of subjects (and thus the frequencies) is also known. To determine the significance of the correlations a table of significant values was consulted (Fielding & Gilbert 2000:265; Nieswiadomy 1998:291).

Rank tests that were included in the present study were the Wilcoxon signed rank sum test, alternatively described as the Mann-Whitney rank sum test, and the Kruskal-Wallis test. Rank tests are calculated by replacing the data by their rank values, varying from highest to lowest. Rank tests may also be applied when the only data available are relative rankings. The Mann-Whitney U test was used to compare two independent groups of sampled data. The test statistic for the Mann-Whitney test is U. The U value is compared with a table of critical values for U, based on the sample size of each group. If in this study U exceeded the critical value for U at some significance level (usually 0.05 but 0.10 in the present study), it meant that there was evidence for rejecting the null hypothesis in favour of the alternative hypothesis (Campbell & Machin 2000:90).

The Wilcoxon two-sample paired signed rank test was used to test the null hypothesis that the population median of the paired differences of the two samples was 0. Because the test statistic for the Wilcoxon signed rank test is based only on the ranks of the paired differences, the test can be performed when the only data available are those relative ranks for the paired differences. It was *not* assumed that the two samples were independent of each other. In fact, they *should* be related to each other, such that they create pairs of data points, such as the measurements on two matched people in a case/control study, or before- and after-treatment measurements on the same person (Campbell & Machin 2000:164). This test was applied to measure differences between the following two samples: client and control group samples.

The Kruskal-Wallis test was used to compare three or more independent groups of sampled data (buddies, clients and controls). This test is an alternative to the independent group analysis of variance (ANOVA), when the assumption of normality or equality of variance is not met. This test, like many non-parametric tests, used the ranks of the data rather than their raw values to calculate the statistic. Since this Kruskal-Wallis test does not make a distributional assumption, it is not as powerful as the ANOVA (Hazard Munro & Batten Page 1993:94.95).

## **5.10 LIMITATIONS**

Awareness of certain limitations in the design of the present study enabled the researcher to take these limitations into account in the interpretation of the findings. Non-random sampling methods and the structured data collection instruments have their inherent limitations. However, it has been explained that the guaranteeing of anonymity of the study participants was of the highest priority in the present study.

### ***5.10.1 Limitations of non-random sampling methods***

Having a member of COCEPWA sitting down with the respondents to administer the interview schedule reduced the anonymity aspect, increasing the risk of non-responses to certain questions. Furthermore, the results could have been distorted if some respondents were not perhaps giving completely honest responses. Self-completion questionnaires have a propensity for such corruption by the differences in respondents. It would have been useful to build in a second line of enquiry as check on the results- perhaps holding in-depth discussions with a cross-section of the participants. The researcher had neither the finances nor the time to provide this back-up (Gray et al. 1996:188).

### ***5.10.2 Limitations encountered with the structured data collection instrument***

Tape recording of discussions and allowing other relevant people to be interviewed to validate some of the information provided by the PLWA/Hs would have aggravated the fears of the PLWA/Hs about the risk of involuntary disclosure and could not be used.

## 5.11 CONCLUSION

The methodology used in the present study was presented in this chapter. The study design was informed by the uniqueness of this section of the Botswana population that was studied. The HIV+ve women would only participate if they remained anonymous, and levels of trust between the participants and the researcher had to be developed over time prior to the present study. The ethical considerations were addressed. Demographic data were collected, emphasising measures of self-care. To capture both the types and the sources of support, two different instruments were used. The MOS SSS measured the types of support available six-months into the present study and the PRQ-II captured the levels of satisfaction with the available sources of support. Attitudes-towards-adherence scores were measured among those HIV+ve women who were taking ARVs. The MOS-QOL SF-36 measured the general and mental health scores of the HIV+ve women in April 2002 and again in November 2002. The characteristics of all these instruments were described with a specific focus on their reliability and validity in other studies. It was explained how the large amounts of data were summarised and analysed using descriptive statistics, and which non-parametric tests were selected to analyse the relationships between the variables. The limitations of the design of the present study, including a description of the risk of Type I and II errors and some of the potential weaknesses inherent in quantitative methodology with small samples, were acknowledged. Bearing in mind these provisos about the validity of the data, the research results are summarised and discussed in Chapter 6.

## CHAPTER 6

### FINDINGS AND DISCUSSION

#### 6.1 INTRODUCTION

The findings of the present study are presented by describing the HIV+ve women through a review of the findings generated from the analysis of demographic data, and data relative to the research questions. The present study was conducted at COCEPWA. A convenience sampling method was used to obtain a non-random sample of 116 HIV+ve women. The sample consisted of 39 buddy-client pairs and 38 HIV+ve women in the control group. Of these 39 pairs, all agreed to participate in the study. No participants withdrew from the present study after agreeing to participate; therefore, the rate of participation was 100%. Sadly, four women passed away during the present study. The background information that was collected focused on gaining information about the HIV+ve women's age, marital status, number of children, highest level of education obtained, how they spent their day, monthly income and in what year the women had tested positive for HIV. The self-care variables asked about the number of people the HIV+ve women had disclosed to, TB prevention and care actions, CD4 quantification and actions connected with starting ARVs when advised to do so by their health care providers. The AAI gave additional information about their self-reported ability to stick to their ARV treatment schedules, and the PRQ-II and the MOS SSS gave information on their levels of social support. The MOS-QOL SF-36 questionnaire measured their well-being, more specifically their physical and mental health.

**Please note** that without any intention of being disrespectful or familiar, but in the interests of easier reading of this chapter, the HIV+ve women in the buddy group will be referred to as the “*buddies*”, the HIV+ve women in the control group as the “*controls*” and the group of HIV+ve clients as the “*clients*”.

## **6.2 BACKGROUND INFORMATION**

The first seven questions of the researcher-designed instrument that consisted of 17 questions provided background information about the 116 HIV+ve women in the present study.

### **6.2.1 Findings**

In this survey, 116 HIV+ve women completed the questionnaires. All of these 116 HIV+ve women completed their questionnaires in April 2002. Six months later one HIV+ve woman completed some of the questionnaires but passed away before completion of all instruments. Four women passed away before the second data collection phase in November 2002. Thus a total of 111 women (96%) completed both data collection phases of the present study.

#### *6.2.1.1 Age*

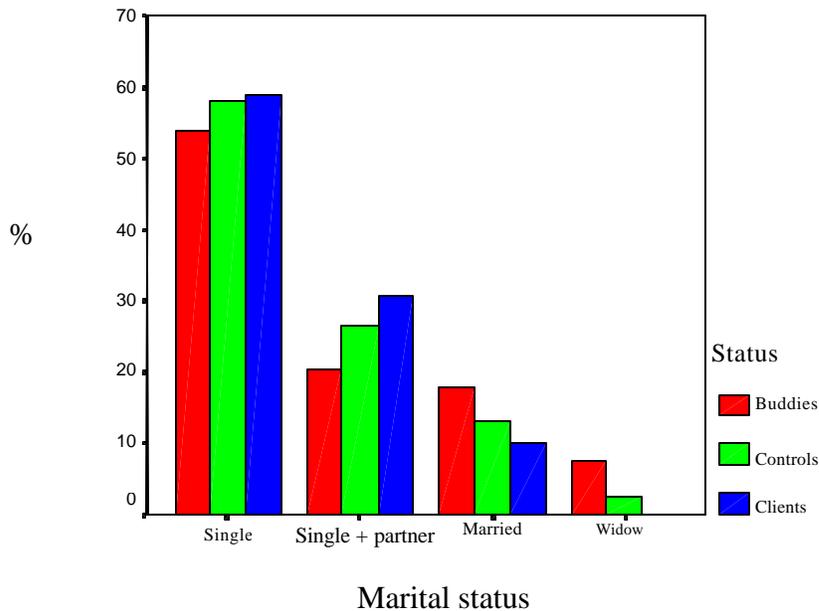
The participants in the present study were all women (100%; N = 116). Their ages varied between 20 and 52 years of age, a mean age of 31.16 years (SD = 7.18) was reported (question 1). The highest concentration was in the 30 to 35 year age range. Very few study participants were older than 40 years of age.

In terms of the three status groups the statistics were as follows. The buddies' minimum age was 22 years and maximum age was 52 years. The mean age was 32.2 years (SD = 6.8). The controls' minimum age was 20 years and maximum age was 49 years. The mean age was 29.8 years (SD = 7.6). The clients' minimum age was 21 years and maximum age was 53 years. The mean age was 31.4 years (SD = 7.1). The buddies had the highest mean age at 32 years; the controls had the lowest mean age at nearly 30 years.

#### *6.2.1.2 Marital status*

Of the 116 HIV+ve women, 66 HIV+ve women (56.9%) were single and 30 HIV+ve women (25.9%) were single but reportedly had a steady partner. Of the whole group, 16 HIV+ve women (13.8%) were married and four HIV+ve women (3.4%) reported that

their husbands had died and they were widows (question 2). The clients had the highest frequencies in the “single” and “single, steady partner” groups and the fewest in the “married” group and none in the “widow” group. (See Figure 6.1.)



**Figure 6.1 Marital status of buddies, clients and the controls in April 2002**

### 6.2.1.3 Number of children

The number of children which the HIV+ve women had varied between 0 and 6 ( $M = 1.85$ ;  $SD = 1.37$ ; question 3). Having two children represented the highest frequency, with having one child almost as frequent. The buddies (being three years older on average) had a slightly higher average number of children at 2.08 ( $SD = 1.49$ ), while the controls (being younger on average) had a slightly lower average number of children at 1.66 ( $SD = 1.28$ ). The clients’ average was 1.82 ( $SD = 1.37$ ). In the case of the buddies, the highest frequency was for having two children; for the other two groups, having one child was most frequent.

### 6.2.1.4 Education

Twenty-six HIV+ve women had attended at least primary school (22.4%;  $N = 116$ ) and 56 HIV+ve women (48.3%) had secondary school education up to Junior Certificate

level, which is in Botswana equivalent to three years of secondary school. Twenty-one HIV+ve women (18.1%) had completed their secondary education up to O-level. Post-secondary education, college or vocational training had been achieved by 11 HIV+ve women (9.5%), and two HIV+ve women (1.7%) had been to university (question 5). There were differences between the three status groups. Of the buddies, 14 (n = 39) fell into the three highest categories (O-level and higher), as against 11 controls (29%; n = 38) and 9 clients (23.2%; n = 39).

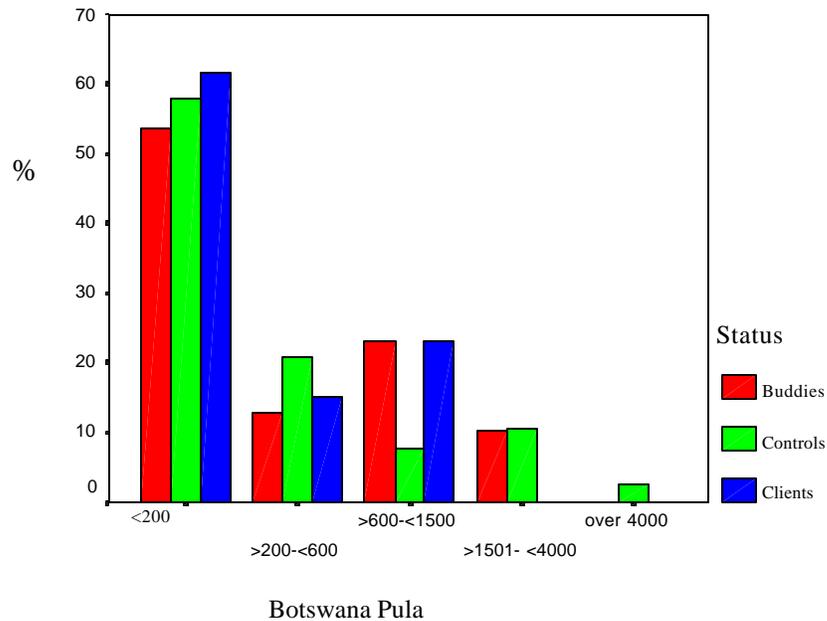
#### *6.2.1.5 Daily activities*

Of the 116 women, 38 (32.8%) were employed full time, one HIV+ve woman, a client, (.9%) was a student and 22 HIV+ve women (19%) were volunteer workers. The majority, 55 HIV+ve women (47.4%), were not working but at home and some were involved in childcare at home. The category “at home/childcare” had the highest frequency, with “full-time employed” second (question 6). The buddies had the largest percentage of “full-time employed” (43.6%; n = 39) and the smallest percentage of “at home/child care” (35.9%). The controls had the largest percentage of “volunteer workers” (26.3%; n = 38) as compared with buddies (20.5%) and clients (10.3%; n = 39). The clients had the smallest percentage of “full-time employed” (23.1%) and the largest percentage of “at home/childcare” (64.1%).

#### *6.2.1.6 Income*

##### *Statistics in April 2002*

In April 2002, 67 HIV+ve women (57.8%; N = 116) earned less than BWP200 per month. Nineteen HIV+ve women (16.4%) earned between BWP201 and BWP600 per month. Twenty HIV+ve women (18.1%) earned between BWP601 and BWP1500, and eight HIV+ve women (6.9%) earned between BWP1501 and BWP4000. Only one HIV+ve woman (.9%) earned over BWP4000 (question 7). Twenty-one buddies (53.8%) and 22 controls (57.9%) earned less than BWP200 a month. Taking into account the status groups, the study found that the clients seemed less well off, with nobody in this group earning more than BWP1500 and more than 24 clients (60%) earning BWP200 or less. (See Figure 6.2.)



**Figure 6.2 Monthly income of buddies, clients and controls in April 2002**

*Statistics in November 2002*

When asked the same question again in November 2002, one HIV+ve woman, a client, did not answer the question. Forty-seven HIV+ve women (42.3%; n = 111) reported themselves to earn less than BWP200 per month. Thirty-six HIV+ve women (32.4%) earned between BWP201 and BWP600. Twenty HIV+ve women (18%) earned between BWP601 and BWP1500. Five HIV+ve women (4.5%) earned between BWP1501 and BWP4000 and two HIV+ve women (1.8%) earned over BWP4000 per month. The income seemed to have advanced somewhat, with fewer HIV+ve participants earning less than BWP200 and more in the BWP201-BWP600 bracket. The buddies seemed to be better off than the others, with the client group slightly worse off than the controls (question 7).

### 6.2.1.7 *Quality of life and demographic variables*

The relationship between the PCS and MCS variables and age, marital status, number of children, education and daily activities was measured by means of rank correlation coefficients.

#### *Age*

The relationship of the PCS and MCS variables to age was measured by means of rank correlation coefficients. The correlations are low, and in none of the cases was statistical significance found. PCS score change April-November 2002 (Spearman's  $Rho = .017$ ;  $P = .862$ , 2-tailed). MCS score change April-November 2002 (Spearman's  $Rho = -.121$ ;  $P = .205$ , 2-tailed).

#### *Number of children*

The correlations are low and not significant. The PCS score change April-November 2002 (Spearman's  $Rho = -.062$ ;  $P = .514$ , 2-tailed). The MCS score change April-November 2002 (Spearman's  $Rho = -.071$ ;  $P = .457$ , 2-tailed).

#### *Income*

Income was recorded in class intervals, and the test of significance was the Kruskal-Wallis non-parametric test. The differences are not significant. PCS score April 2002 ( $P = .285$ ) and the MCS score in April 2002 ( $P = .159$ ). The PCS and MCS values in November 2002 and the changes were related to income in November 2002. None of the differences were significant: PCS ( $P = .698$ ) and MCS ( $P = .490$ ).

#### *Education, daily activities and marital status*

No significant differences were found.

In summary, the correlations were low, and in none of the cases was statistical significance found.

## 6.2.2 *Discussion*

In considering the findings that most of these women were very likely to have been infected with HIV as young adults in their twenties and that the 116 HIV+ve women in

the present study had on average low incomes, one is reminded that HIV and AIDS affect not only the individual. Whole communities are affected by not only deepening poverty but a deteriorating health infrastructure as well, due to the pressure exerted on it by the thousands of people who are falling ill due to AIDS. This is further aggravated by the fact that HIV thrives in bodies weakened by malnutrition and OIs (Piot et al. 2001:968-975). In an AIDS environment, many women's survival strategies have resulted in their destruction. Strategies might have included having sexual relationships in exchange for money or other resources. Alternatively, women stayed in relationships or marriages with men who were suspected of having unsafe sex with multiple partners, for the sake of the well-being of the children. (See Chapter 4.)

In sub-Saharan Africa, transmission of HIV remains predominantly by heterosexual sex, together with a significant level of mother-to-child transmission. By the end of 2000, there were an estimated 1.1 million children under 15 years of age living with HIV in sub-Saharan Africa, over 90% of whom had acquired the infection from their mother. HIV vulnerability and the impact of HIV are proportionally related, as an increasing impact depletes social stability, support and cohesion (Piot et al. 2001:968-972). The relative powerlessness of women, even women with some control over economic resources, makes AIDS a disease of concern, not just to the individual but the whole world. The AIDS epidemic reflects global inequalities of class, gender and ethnicity, as poverty and powerlessness propel the spread of HIV (Bova 2001:217-224; Bujra & Baylies 1999:35-52; Piot et al. 2001:968-975). The buddy system, an initiative by and for HIV+ve women, aimed to redress some of these factors, boost self-care abilities and mobilise support and compassion between PLWA/Hs.

#### *6.2.2.1 Gender and HIV/AIDS*

Globally women represent the fastest-growing proportion of those infected with HIV and AIDS (Dicks 1994:123-143; Te Vaarwerk & Gaal 2001:109). In Botswana, the worst affected country in the world, reported HIV prevalence is 35.4% for the whole 15 to 49 years of age group. However, women are dying in larger numbers than men are. The age-specific death rate for women between 30 and 34 years of age *tripled* from 8.4 to 23.6

deaths per 1000 between the inter-census period in the 1990s, while that of men in the same age group *doubled* (NACA 2003:16; Piot et al. 2001:968).

#### 6.2.2.2 *Poverty*

The 116 HIV+ve women in the present study were mostly single, and nearly 90% had the responsibility of, on average, one or two children. Female-headed households in Botswana are a common phenomenon. These households are on average economically disadvantaged as compared with households where a husband takes care of the family in support of the wife and children (UNDP 2000a:7). In the present study, the clients were and remained the poorest during the six-month survey period in 2002. The majority of the clients (60%) were surviving on BWP200/USD40 and below, the lowest monthly income levels of the three groups studied. The clients had enjoyed fewer years of education and most were not working (77%). The buddies were slightly better off at the start of the programme, had a better educational background, and almost half of the buddies (44%) were employed. Their reported income in November 2002 increased due to the USD45 or BWP250 monthly stipend they received from COCEPWA.

The results of the present study seem to be consistent with the findings of Gielen et al. (2001:320), who identified poverty in women living with HIV and AIDS as a serious concern and asserted that poverty was related to quality of life. This study by Gielen and colleagues followed on earlier studies by Hobbs Leenerts and Magilvy (2000:58-75) in the USA and the study by O'Keefe and Wood (1996:279) in South Africa. These studies also reported a relationship between poverty and poor quality of life and one can extend their findings to the women living with HIV in Botswana that reported quality-of-life domain scores below the 50<sup>th</sup> percentile line on a scale of 0 to 100 (Hobbs Leenerts & Magilvy 2000:58-75; O'Keefe & Wood 1996:279).

#### 6.2.2.3 *Vulnerability and survival strategies*

Vulnerability and survival strategies of women living in a society such as Botswana in which AIDS is having a devastating impact were considered in terms of the theoretical framework of the present study.

Maslow's hierarchy of human needs theory held that the most basic needs, such as providing food for oneself and one's children and having a roof over the family's head, are immediate concerns basic to all human beings (Maslow 1999:39). In the present study, it was acknowledged that women with low incomes in Botswana are engaged in a daily struggle for survival. These same women are likely to hear or read messages about AIDS from the Botswana government, which carries out a public education campaign (as stated in Chapter 4). The public health education messages explain the differences between HIV and AIDS, in that it could take years before HIV diminishes the immune system to such degree that the individual develops AIDS and becomes seriously ill due to OIs. Nevertheless, protecting oneself from HIV infection might not be as immediate a concern as the daily effort to provide food and shelter. In considering the health education messages, the women will have to prioritise needs. The women have to satisfy their own and others' need for food and the like *and* take action to remain HIV negative, or if HIV positive take action to prevent transmission of or reinfection with HIV. In terms of the needs theory, Maslow predicted that human beings address the immediate concerns first. However, as explained earlier, Maslow pointed out that not meeting certain needs would cause anxiety and this could result in "diminished individuals" and ill health (Maslow 1996f:51; Maslow 1999:77-78).

The present study reported that certain basic conditioning factors were risk factors. Basic conditioning factors are those factors, internal or external to people, that affect their ability to engage in self-care, and the amount of self-care required (Orem 1995:203). Background variables such as age, gender, state of health, socio-cultural orientations, resource availability, environmental and family system factors and patterns of living were considered in this section on background variables of the HIV+ve women.

The present chapter details the fact that lower incomes were negatively associated with quality-of-life - vitality domain scores. Women with lower monthly incomes had lower vitality scores than women with higher monthly incomes (quality-of-life - vitality domain scores of 56 points versus 80 points). Lower educational levels were negatively

correlated with self-care capabilities. These were not isolated findings of the present study. A persistent association between HIV vulnerability and lower educational and income levels was reported earlier by Piot et al. (2001:971) and Steen & Mazonde (1999:163-172). Suggestions as to how to address these vulnerabilities were made by Piot and colleagues, who reported that effective responses to HIV and AIDS at community level should

- include people living with HIV as a source both of creativity in devising solutions and of accountability in focusing on the realities of the epidemic
- pursue prevention and care needs in synergy-integrating education, prevention and care
- address stigma associated with HIV, since stigma continues to constitute a major barrier to effective action (Piot et al. 2001:972).

From the literature reviewed, women in the USA as well as in Botswana generally are dependent decision makers not motivated by their own needs only. As mothers and wives, they often allow the needs of others to take on more importance than their own individual needs (Ingstad 1990:28-37; Seidel & Coleman 1999:53-66; Sowell et al. 1997:302-312; Tlou 2002:654-663). Being a mother can be an ambivalent experience, according to a qualitative study by Te Vaarwerk and Gaal (2001:114) of 78 HIV+ve women. This study reported that childcare responsibility was not associated with psychological distress. In most cases, being a mother seemed to be a source of intense sorrow, fear and worry but also a precious gift, a choice for life and a helpful role for structuring daily living.

The social support theory holds that human beings need other people, but warns that it has to be considered that social relationships with other people can at times be *helpful* but may at other times be *barriers* to achieving higher levels of well-being (Ashby Wills 1985:61-78; Cohen & Syme 1985:4; Cohen et al. 2000:316; Hurdle 2001:72-79).

For instance, if concern for the good name of the family prevents an HIV+ve woman from going to the clinic for specialised HIV care, having other people around gets in the

way of better health. In contrast, a supportive mother who offers to take care of the children to enable her HIV+ve daughter to attend support group meetings is helpful. As Ashby Wills in Cohen and Syme (1985:75) pointed out, spouses, friends and family members are a primary avenue of help for distressed persons, and primary functions sought through informal help-seeking are self-esteem maintenance, companionship, and instrumental and possibly motivational support. Sources of tension were reported in a study of HIV+ve women by Coward (1994:331-336); these women feared *being isolated* but regarded *connectedness* as a challenge as well. Furthermore, they struggled with accepting that they had HIV/AIDS in their bodies and were at the same time hoping for a cure.

Being HIV+ve does not have to be equated with giving up or wanting to die; the will to live among PLWA/Hs can be very strong as well (Schirmshaw 2000:543-545; Tsevat, Sherman, McElwee, Mandell, Simbartle, Sonnenberg & Fowler 1999:194). In a study of 51 HIV+ve patients by Tsevat et al. (1999:197), concern or love for children was stated as an important reason for wanting to live longer, even if their health was compromised. In the Botswana survey of the needs of 116 male and female PLWA/Hs by Zuyderduin (2000:32), 75% of the respondents reported that they were optimists, believing that life is worth living; only 15% reported that they believed that HIV infection was a death sentence.

A woman in Botswana might not always be able to take care of her own needs, but these unmet needs do not cease to be motivating or disappear. Maslow pointed out that need fulfilment was not only in the realm of those with plenty of money, high levels of education or other advantages over disadvantaged people. The opposite might be true; to Maslow wealth might be as much a barrier as poverty when it comes to “being all that one can be” (Maslow 1996b:27). People have to strive for growth and fulfilment, even though they never expect to fully reach that point (Maslow 1996b:27-28). The hierarchy of needs theory holds that meeting deficiency needs will always depend on other people around one, but that growth needs, at the highest level of development, come from *within*. As Maslow pointed out, humility and pride need to be integrated, in order, for example,

“to be a self-respecting garbage collector or equally ... to be a truly modest and humble king” (Maslow 1996a:69).

Pursuit of justice and equal rights or helping other people is based on the drive or motivation to help. This drive comes from within, according to Maslow, who stated that unselfish behaviour and psychological health are correlated (Maslow 1996e:113). Unselfish behaviour tends to be a phenomenon of personal abundance, stemming from relative basic gratification, coming out of *inner riches* rather than *inner poverty* (Maslow 1996e:113).

The needs for peer support gave impetus to the design of the buddy system. The HIV+ve women tried to help each other, for instance in discussing and coming up with ideas on how to

- start income generating activities
- maintain healthy relationships with men
- safeguard the futures of their children (Zuyderduin 2000:37-39).

The buddies managed to mobilise resources for social and financial support for the project (Nary 1999:41-44). Once the potential of the project was recognised, this resulted in a one-year grant to COCEPWA to implement the project. The buddies were as a result paid a monthly stipend of BWP250/USD45 for the duration of the project. This redressed some of their monetary problems, but was not the primary reason for coming up with the buddy system. In the present study, exploring the impact of participating in the buddy system looked beyond the meeting of deficiency needs and considered the meeting of growth needs as well.

### **6.2.3 Summary**

A review of the findings of the demographic variables shows that these 116 HIV+ve women in Botswana had faced the fact that they were living with an illness for which there was no known cure or vaccine, in their early thirties. Levels of income were low and nearly all the women had sole responsibility for childcare. Associations between

basic conditioning factors such as income, educational levels and marital status and self-care were identified.

It was important to consider the results of the 116 HIV+ve women in the context of Botswana, the worst affected country in the world. The women live in a society where an estimated 34.5% of the adults are HIV+ve as well (UNDP & GOB 2000:37). The impact is felt in Botswana and the region; the AIDS epidemic is responsible for one in five deaths in sub-Saharan Africa, since an estimated 25 to 28,2 million people are infected with HIV, and 2.2 to 2.4 million will die of AIDS in 2003. Adding to this grim picture is the concern about the thousands of orphans and the fact that this epidemic is depleting social support and cohesion at an alarming rate (Piot et al. 2001:969).

Having a description of the background of the 116 women and gaining an understanding of the context gave insight into the many challenges the women faced. However, this group of women, through their membership of a support organisation for and by PLWA/Hs, were not powerless victims just waiting to be helped but were innovative in the design and implementation of the buddy system. Peer support assisted in the exploration of the meaning of being HIV+ve, what it meant in their lives and the lives of others and how it translated into self-care actions.

The present study explored how the buddy system influenced and utilised the motivation to take care of themselves in the context of being HIV positive, which required special self-care actions such as CD4 quantification, prevention of OIs and persistence in adhering to ARVs. Orem's theory as regards self-care was utilised to distinguish universal, developmental and health-deviating self-care requisites. The self-care theory was further helpful in explaining that it is indeed possible to foster those abilities for self-care (Orem 1995:172). The self-care findings are reported and discussed in the next section.

## SECTION I SELF-CARE

### 6.3 TESTING AND DISCLOSURE OF POSITIVE TEST RESULTS

To explore the self-care levels before the clients were linked up with their buddies and to assess whether levels of self-care improved six-months into the buddy-client relationship, a wide range of questions were asked. The HIV+ve women were asked two specific questions about HIV testing (questions 8 and 9). These questions were posed to find out *when they had gone for an HIV test* and their *disclosure patterns* in April 2002. This same disclosure question was repeated six-months into the buddy-client relationship in November 2002.

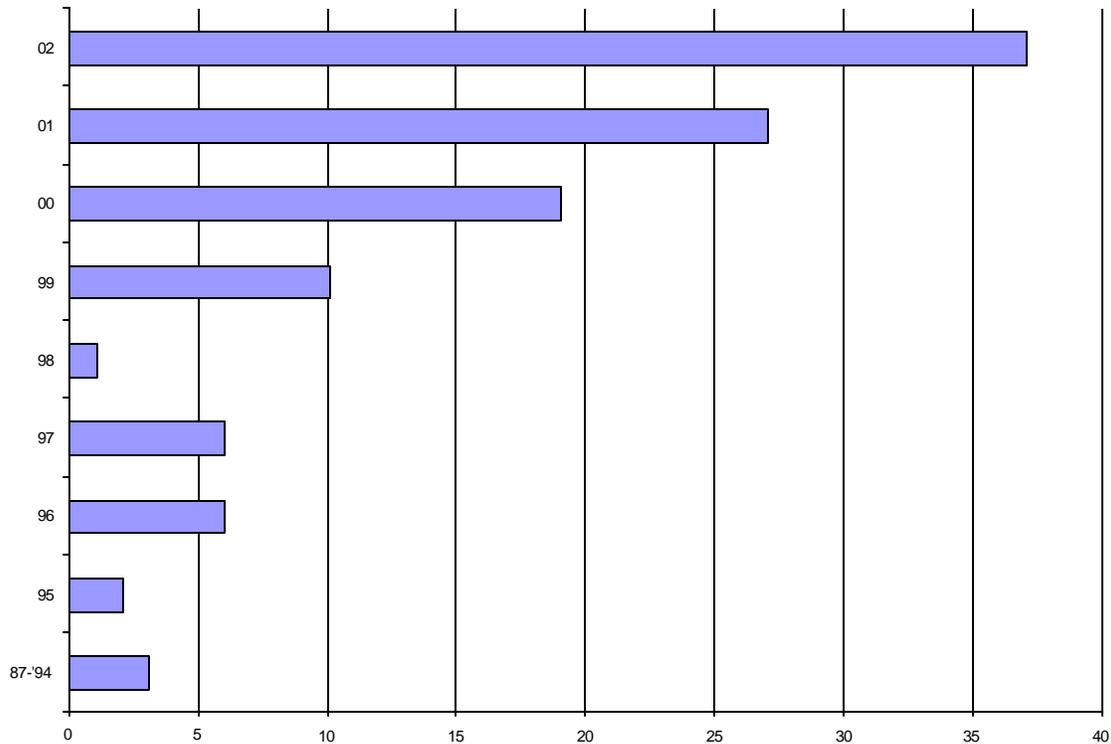
#### 6.3.1 Findings

All women in the present study had been for HIV diagnostic tests. The most commonly reported reasons for going for an HIV test were explored in 2000 among another group of 116 male and female PLWA/Hs in a needs survey, which revealed that they had been tested for HIV because

- they were ill and the doctor wanted to know whether they were HIV-positive or HIV-negative
- they had asked for an HIV test on a voluntary basis, or
- they had undergone a routine HIV test during pregnancy (Zuyderduin 2000:61).

##### 6.3.1.1 HIV testing

The majority of participants had tested positive in 2001 or 2002. The earliest was in 1987, and the frequencies picked up sharply after 1999 (question 8). (See Figure 6.3.)



**Figure 6.3** Year in which the women in the present study were diagnosed HIV+ve

### 6.3.1.2 Disclosure of HIV+ve status

By April 2002, 58 HIV+ve women (50%; N = 116) had disclosed their HIV+ve status to between 1 and 5 people. Eighteen HIV+ve women (15.5%) had disclosed to between 6 and 10 people. Six HIV+ve women (5.2%) had told between 16 and 20 people, and 7 HIV+ve women (6%) had told between 21 and 30 people. Five HIV+ve women (4.3%) had told 31 to 50 people, and 15 HIV+ve women (12.9%) had told over 50 people about being HIV+ve (question 9). Thus, 50% of the participants had disclosed to between 1 and 5 people and 17.2% had disclosed to more than 30 people.

As shown in Table 6.1, a significant number of buddies had disclosed to more people than the other groups. It appeared that fewer of the buddies (28.2%) had disclosed their HIV+ve status to only 1 to 5 people, while 11 buddies (28.2%) had disclosed to more than 30 people. In the control and client groups the majority (68.4% and 53.8% respectively) had disclosed their HIV status to 1 to 5 people, but a few had already disclosed it to more than 30 people (15.8% and 7.7% respectively).

**Table 6.1 Number of people buddies, clients and controls had disclosed their HIV+ve diagnosis to by April 2002**

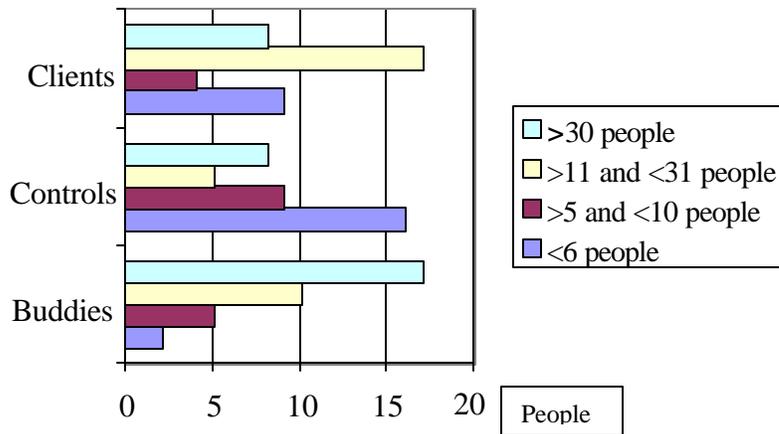
			status			Total
			buddy	control	client	
Number of people disclosed to (04/02)	1-5	Count	11	26	21	58
		% within status	28.2%	68.4%	53.8%	50.0%
	6-10	Count	8	4	6	18
		% within status	20.5%	10.5%	15.4%	15.5%
	11-30	Count	9	2	9	20
		% within status	23.1%	5.3%	23.1%	17.2%
	Over 30	Count	11	6	3	20
		% within status	28.2%	15.8%	7.7%	17.2%
Total	Count	39	38	39	116	
	% within status	100.0%	100.0%	100.0%	100.0%	

A chi-square test was performed in order to compare the three status groups for disclosure. Pearson chi-square (Value 17.168,  $DF = 6$ ,  $P = .009$ , 2-sided). The difference was significant at the 1% level of significance.

*How many people have you disclosed your HIV+ve status to? (November 2002)*

Six months later, in November 2002, 27 HIV+ve women (24.5%;  $n = 110$ ), half of the number six months before, had disclosed to 1 to 5 people. Eighteen HIV+ve women (16.4%) had disclosed to 6 to 10 people, and 11 HIV+ve women (10%) had disclosed to 11 to 15 people. Six HIV+ve women (5.5%) had disclosed to 16 to 20 people, and 15 HIV+ve women (13.6%) had told 21 to 30 people. Thirty-three HIV+ve women (30%) had told over 30 people (question 9).

There appeared to be a definite increase in the number of people to whom the HIV+ve status had been disclosed: the frequency of the lowest category (1 to 5) was now only 24.5%, and the frequency of the highest category (over 30) had increased from 17.2% to 30%. (See Figure 6.4.)



**Figure 6.4** Number of people buddies, clients and controls had disclosed their HIV+ve diagnosis to by November 2002

*Analysis of the variables related to disclosure to other people*

To describe the impact, if any, of the buddy-client relationship on reducing levels of stigma measured on the continuum of steps towards full disclosure of both buddies and clients over a six-month period in 2002, the variables related to disclosure were analysed.

The levels of disclosure were evaluated in the light of:

- being a buddy
- having a buddy, or
- not having a buddy

The relationship between increased levels of disclosure and the status of the HIV+ve women was looked at in November 2002. The chi-square test is as follows. Pearson chi-square (Value 24.779, DF = 6,  $P = 0.001$ , 2-sided). The difference was significant at the 1% level of significance.

The buddies were more open about their HIV+ve status than the controls and the clients in April 2002. Over the period, 17 of the 34 buddies (50%) remained in the same category, but the other 17 buddies (50%) moved to a higher category, meaning that they had disclosed their status to substantially more people by November 2002.

Of the controls, 42.1% (n = 38) had disclosed their HIV+ve status to 1 to 5 people. Twenty-three controls (60.5%) remained in the same category, and 15 (39.5%) moved to a higher category, i.e. had disclosed their HIV+ve status to substantially more people by November 2002.

The clients' disclosure levels also increased. However, 19 of the 38 clients (50%) remained in the same category. In the case of the clients, the largest frequency (23.7%) corresponded to the classes 1 to 5 and 21 to 30 people. Nineteen clients (50%) moved into a higher category, i.e. had disclosed their HIV+ve status to substantially more people by November 2002.

The controls and clients still had more participants in the 1 to 5 group than the buddies, and fewer in the over-30 group. However, the controls seemed least willing to divulge their HIV+ve status. It appeared that the buddies and clients were more open about disclosing their HIV status to other people between the first and second surveys than were the controls, with fewer buddies and clients having told fewer than 6 people as compared to the controls. **Being a buddy** resulted in increased disclosure levels and in addition **having a buddy** resulted in increased levels of disclosure for 50% of the clients. **Not having a buddy** did not stop the controls from disclosing, but they disclosed at a slower pace and more controls remained in the group that had disclosed to fewer than 6 people.

#### *6.3.1.3 Quality of life and disclosure*

No significant relationship was found in April or in November 2002 between the number of people disclosed to by April 2002 and the PCS and MCS scores. (See Table A.VI-1, Annexure VI.)

#### *6.3.1.4 Summary of findings*

Answering the first research question to how many persons the clients had disclosed to in April 2002 and if there was an increase six-months into the buddy-client relationship it

appeared that the clients were more open about disclosing their HIV+ve status between the first and second surveys. The controls seemed least willing to divulge their HIV+ve positive status. The controls moved along the continuum of disclosure but almost half of the group were still keeping their HIV+ve diagnosis to themselves and up to five other people (42% down from 68%).

In April 2002 the majority of the clients (53.8%) had disclosed to 1 to 5 people, but a few had already disclosed to more than 50 people (7.7%). During the six-month survey period, the clients' disclosure levels increased. However, 19 of the 38 clients (50%; n = 38) remained in the same category, having disclosed their HIV+ve status to the same number people. In the case of the clients, the highest frequency (23.7%) corresponds to the classes 1 to 5 and 21 to 30 people. Nineteen clients (50%) moved into a higher category, i.e. disclosed their HIV+ve status to substantially more people; 8 clients (21%) had disclosed their status to over 30 people.

There were noticeable changes. By November 2002, fewer clients (24%, down from 54%) had told fewer than 6 people. There was a marked increase in clients who had opened up to more people, and the number of clients who had told between 1 and 5 people decreased by 50%. The number of clients who had disclosed to more than 30 people tripled.

This results of one of the primary study objectives suggest that participating in the buddy system encouraged disclosure to people of the participant's choice, but did not force the HIV+ve women to disclose if they were not ready to do so. By November 2002, 2 buddies and 9 clients had not increased the number of people they had disclosed to; as in April, they had told 5 people or less.

### **6.3.2 Discussion**

#### *6.3.2.1 Testing for HIV*

The buddies had tested HIV+ve the earliest, and the controls most recently. The finding that the buddies had known their status for a longer time is not surprising, given the fact

that they had over the years accepted their diagnosis to such an extent that they were by 2002 not only meeting the criteria of the Botswana buddy programme but also highly motivated to be trained as buddies to help other HIV+ve women to cope with their illness.

The results of the present study, that buddies had been aware of their HIV+ve diagnosis for a longer period, are consistent with the findings of Kalichman et al. (1996:589) and Metcalfe et al. (1998:30), who report that psychological adjustments have to be made to meet therapeutic self-care demands. Several studies have concurred that upon the first diagnosis of HIV, affective responses are usually emotion-focused to reduce distress. This period of anger and denial could last from months to years before a sense of control and self-esteem is established and the meaning of living with HIV is explored (Kalichman et al. 1996:589-599; Kimberley et al. 1995:316-322; Lipson 1993:43-44,47; Metcalfe et al. 1998:30-34; Schwartzberg 1994:600). Psychosocial quality of life was found to be related to the amount of time that had elapsed since HIV testing, suggesting that women learn to meet the adaptive challenges of illness over time (Te Vaarwerk & Gaal 2001:114).

The fact that the buddies as a rule had been diagnosed earlier than the clients and the controls might have played a role in developing their helping behaviours. In the present study it might also be true that being HIV+ve longer facilitated the development of a sense of control. Over time, self-esteem might have been re-established, despite living in a society with high levels of stigma, and the meaning of living with HIV explored. Stigmatising or chronic resentment of a family member was explained by Orem as evidence that one or more other members of the family had not achieved personal maturity and positive mental health (Orem 1995:27). As such, agreeing to getting tested for HIV was not an individual decision but an action that impacted on the family as well.

#### *6.3.2.2 Disclosure of HIV+ve status to others*

It was reported that the buddies in the present study were more open about their HIV+ve status to others. Being a buddy might have had benefits to themselves. Orem described

people who take care of others or help others within or outside the family unit as benevolent people, as persons who act with love and compassion for others; she identified the giving elements as care, responsibility, respect and knowledge (Orem 1995:27). Altruism as in helping others has been associated with psychological well-being by Maslow (Maslow 1996e:113).

As we have found, during the survey period the levels of disclosure increased for all HIV+ve women but the control group seemed the least willing to divulge their HIV+ve status. The findings of the study suggest that having a buddy who encouraged disclosure was important to the clients, and 50% of the clients moved up one category, for example from the 5 to 10 people category to the 11 to 30 people category, and therefore disclosed to at least twice as many as they had before being part of the buddy system.

In the present study, however, many of the HIV+ve women reportedly did tell fewer than 6 other people that they were living with HIV. It was important to them to keep that piece of information from the people they loved, such as their parents and/or children. This might have been to protect the loved ones from hearing the devastating news as well, or non-disclosure might have been motivated by the need to protect themselves from potential aggressive reactions and being apportioned blame for bringing AIDS into the home (Tlou 2002:654-663).

Nevertheless, the needs assessment reported that when HIV+ve persons wanted to talk about the HIV+ve diagnosis they preferred to disclose to their HIV+ve peers, spouses or boy/girlfriends and mothers (Zuyderduin 2000:30). (See Chapter 3.) The present study results underscored the importance of attending to the psychosocial support needs of the HIV+ve women coming to terms with their HIV+ve diagnosis and having to tell others, for example health care providers about their HIV+ve diagnosis in order to access appropriate care and support. According to Maslow, feeling safe is the foundation for third- and fourth-level needs such as belonging and connectedness. Regression to lower level needs is always a possibility in terms of the needs theory, but the need for love characterises every human being that is born (Maslow 1999:213).

Being informed about one's HIV+ve diagnosis and the realisation that one is suffering from an illness that has no known cure can initially cause some degree of regression or lowered ability to move towards self-actualisation. Maslow asserted that denial of needs such as respect, and frustration in meeting one's goals in life could cause psychopathology or neurosis, but accepted that it is part of the human predicament that as a person we can be both fearful and courageous, and that it is important to think holistically about need fulfilment (Maslow 1996f:51).

Self-actualising or psychologically mature human beings need to gratify their lower needs as well. Maslow termed these choices to meet deficiency needs "healthy" regressive values or coasting values. The needs theory recognised that even healthy or mature people need sleep and rest, seek protection from reality, daydream and the like, but held that ultimately strong and healthy people will seek out growth values over coasting values. Both, however, will always be needed (Maslow 1999:189). Maslow asserted that coasting values, if inactive through gratification, do not exert a regressive pull backward in healthy people but will always be in a dialectical relationship to higher needs, yielding a dynamic equilibrium (Maslow 1999:190-192).

The decision not to talk about an HIV+ve diagnosis might be considered in these terms. Not telling protects the HIV+ve individual for the time being from real and anticipated negative effects, so keeping quiet about the HIV+ve diagnosis could be said to have "healthy regressive or coasting value".

The HIV+ve women in the present study had to weigh the risk of losing their employment or the place where they lived against the relief they would possibly feel when no longer harbouring a secret from those close to them. In the present study, the buddy system encouraged the HIV+ve women to develop a plan of action based on their life goals, and to weigh up what was important to them. Peer support was believed to be of value in providing a sounding board. In the buddy system, the women explored the changes that had to be made as part of coming to terms with the HIV+ve diagnosis.

Whatever the reason for non-disclosure, learning about a HIV+ve diagnosis causes emotional upset. Even when the new fact of life remains hidden, the nature of the illness will eventually compel the PLWA/H to disclose and talk to at least one other person, such as a nurse or doctor, about her HIV+ve diagnosis in order to access appropriate support and care. In the present study, it was assumed that the *will to live* was greater than *the desire to die* of AIDS and that seeking help to improve health comes naturally to a person. Both Orem's and Maslow's theories are based on this premise concerning "the will to live". In Maslow's needs theory the motivation of human beings to do more than eat and sleep was pointed out; humanistic psychology contributed insights that human beings need to grow, to be creative and happy and to love and be loved (Maslow 1996b:27; Maslow 1999:xv). Orem emphasised that individuals require each day to regulate their own functioning and development to sustain life and that these actions are *voluntary* and *deliberately performed* (Orem 1995:95).

The implications of the findings of the current study are:

- Telling others can *help* or *harm* the HIV+ve person, depending on the reactions of the persons being told.
- Availability of peer support and "sharing the secret" fostered emotional bonds, since both buddy and client were vulnerable in that they knew about each other's HIV+ve status and trusted each other to keep that information confidential and remain friends.
- Practising disclosure and/or getting positive reactions within the buddy system might have promoted disclosure beyond the peer relationship by buddies and clients.
- Being able to tell a care agent about the HIV+ve diagnosis was a critical component in meeting therapeutic self-care demands.
- It was possible to participate in the buddy system and not have the HIV+ve diagnosis known by more than 6 people.

### *6.3.2.3 Fostering emotional bonds*

The current study's findings of increased disclosure in the buddy-client relationships might be explained by findings of Lipson (1993:44) who points out that women's resistance to disclosure is often diminished when good rapport is established with carers who do not rush the disclosure process. Subsequently to Lipson's findings in 1994, a USA study found that negotiating of partnerships by health care professionals with the PLWA/Hs *and* their (informal) caregivers, increased the satisfaction of HIV+ve persons with their care; they wanted respect and to be taken seriously (Powell-Cope 1994:329). The findings of the present study are also consistent with the research findings of DeMarco et al. (1998:539), who suggested that the HIV+ve women in their study who experienced peer support perceived such support as the catalyst for the transition from silence to action.

Six months into the buddy system, 50% of the buddies had disclosed to over 30 people, compared with 21% in the other two groups. The number of buddies who were open to over 30 people doubled in the six-month survey period, although the buddies were not "outed" or forced to disclose as a consequence of participating in the buddy system and being a buddy. Of the buddies, 20% had not told and believed that not more than 10 people knew about their HIV+ve status by November 2002. This result is based on self-report and does not reflect what others might have assumed about the buddies' HIV status.

### *6.3.2.4 Levels of social interaction and mental health*

In the present study, keeping secret a diagnosis of a life threatening illness such as HIV and AIDS was expected to affect mental health negatively. Coming to terms with the HIV+ve diagnosis mostly alone, and having fears of being "outed" by the few people who knew about it, were considered as continual stressors.

A study by Nunes et al. (1995:176) identified the apparent mediating effect of disclosure in terms of buffering the potential erosion of well-being of non-disclosure. Nevertheless, no data existed in Botswana to support the buffering effect of disclosure or about the

quality of life of PLWA/Hs who went public about their HIV+ve diagnosis. Significantly, the needs assessment reported incidents of verbal abuse after full disclosure by four of the eight PLWA/Hs that went public with their HIV+ve diagnosis (Zuyderduin 2000:32). (See Chapter 3.) However, it was not known how these negative effects compared with the distress experienced previously because they had not told anyone about being HIV+ve.

The findings in the present study about levels of disclosure point to important implications for the understanding of stigma. Maslow believed that satisfying the four levels of need helped to avoid ill health in its broadest sense. The needs theory postulated that the need for respect has to be met before a person is said to be healthy (Maslow 1999:34-37). Verbally insulting a HIV+ve person is a clear sign of disrespect, and stories about these negative experiences are believed to promote non-disclosure. Despite the high levels of stigma in Botswana reported by Donnelley (2003:1-3), Talbot et al. (2000:1169) and Tlou (2002:659), more HIV+ve women in the present study decided to speak about their experience of living with HIV to people of their choice. Nevertheless, 25% of the 116 HIV+ve women had disclosed to fewer than 5 people by November 2002. This percentage is higher than the findings of Gielen et al. (2001:318), who reported that 12% of the 322 HIV+ve women they studied had no one they could confide in. The findings of the present study extend by two years the results of the needs assessment of 2000, in which 56% of the sample of 116 PLWA/Hs reported that they were completely “in” and that their HIV+ve status was their secret. (See Chapter 3.)

### **6.3.3 Summary**

The findings of the present study indicated a positive trend in number of people disclosed to. The buddy system was instrumental in providing esteem and informational support through

- regular social contact on a weekly basis with another woman living with HIV
- one-on-one (motivational) support and teaching in the home of the client
- information sharing and skills building

- practising disclosure scenarios such as “How would you tell your husband?” and the like
- mutual tangible support (waiting in line with the other to obtain ARV refill prescription; homemaking activities and the like).

These two care strategies, supportive-educative and partly compensatory care, might have contributed to breaking some of the silence surrounding the HIV+ve diagnosis. In the present context of the population of Botswana, which is being sensitised to the need for love of and respect for PLWA/Hs by the government’s public AIDS awareness campaigns and the private sector’s health-education efforts, disclosure should be facilitated both by the accepting attitudes of the community and self-acceptance by the HIV+ve person. (See Chapter 4.)

Further studies are recommended to explore the negative effects and the positive effects of higher levels of disclosure on the quality of life of PLWA/Hs. The present study did not assess whether the reactions of other people after disclosure were helpful or harmful to the HIV+ve women in the study; the possibility of both was assumed in terms of the social support theory that guided the present study.

The next section will present the findings relating to TB, the most common OI in PLWA/Hs in Botswana. Prevention of TB is promoted within the health care system, but uptake of this preventative care measure has reportedly been low, as noted in Chapter 4. This was one of the areas in which the buddy system could benefit the HIV+ve women in the present study. The health-deviating self-care actions were assessed and the findings discussed.

#### **6.4 TUBERCULOSIS**

Botswana has the highest rates of TB in the world and TB is reportedly the most common OI of PLWA/Hs in Botswana, accounting for 30% to 40% of all AIDS related deaths (NACA 2003:44). The present study asked the HIV+ve women if they were suffering

from TB, and if so, whether they were being treated. If the HIV+ve women reportedly were not suffering from TB, the next question was whether they had completed or were taking IPT (questions 10, 11 and 12). Better detection, treatment and control of TB were recommended as an essential element in basic care services for PLWA/Hs, especially in Africa because of the high prevalence of TB (Lamprey 2000:27). Nevertheless, resource constraints were not the only challenge in the treatment and the prevention of TB; stigma was identified as an additional barrier to accessing preventative TB care by PLWA/Hs in Botswana (Talbot et al. 2000:1161).

#### **6.4.1 Findings**

The HIV+ve women were classified into “low levels of self-care” and “high levels of self-care” with respect to TB. If they were taking or had completed a six-month course of INH to prevent latent TB from becoming active TB, or were on treatment for their acute TB infection, they were in terms of the present study displaying “high levels of self-care for TB”. If they were not taking or had never completed a six-month course of INH to prevent latent TB from becoming active TB they were labelled for the present study as displaying “low levels of self-care” for TB.

##### *6.4.1.1 Statistics in April 2002*

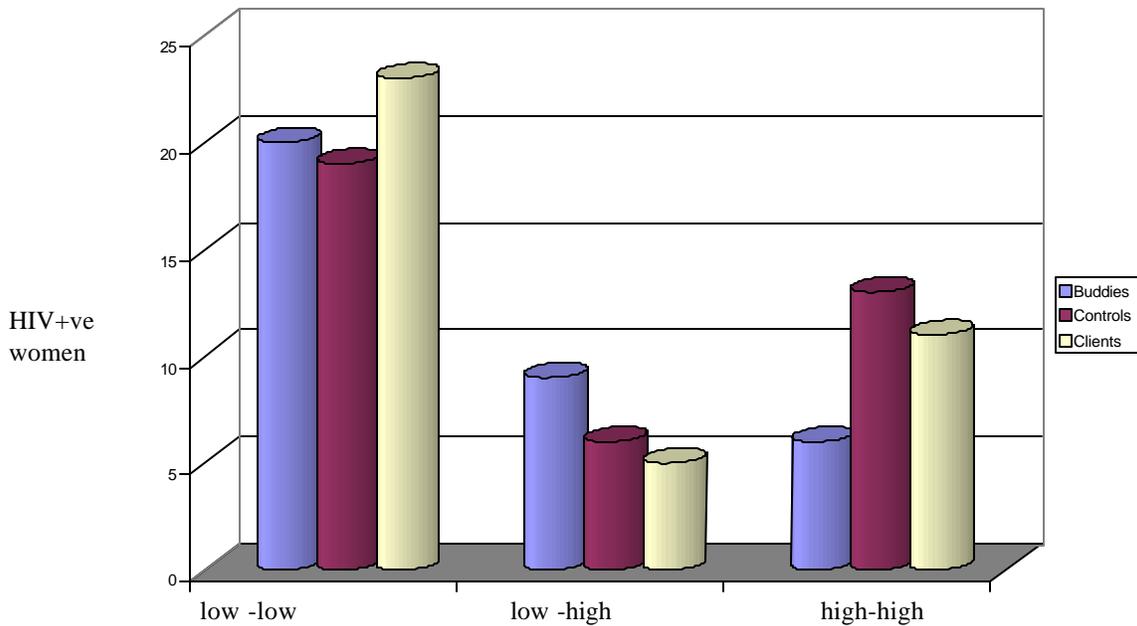
Of the 116 HIV+ve women, 12 women (10.3%) had active TB (question 10). Of these 12 women, 8 were buddies (20.5%; n = 39) and 4 were clients (10.3%; n = 39). All 12 HIV+ve women were on treatment to cure TB and assigned to the “high levels of self-care” group (questions 10 and 11). Seven buddies (18.4%) practised high levels of self-care, compared with 13 controls (34.2%; n = 38) and 11 clients (28.2%). The differences between status group and levels of self-care were not significant at the 5% level of significance ( $P = 0.293$ ).

##### *6.4.1.2 Statistics in November 2002*

Now the number of HIV+ve women who practised high levels of self-care was 15 buddies (42.9%; n = 35), 19 controls (50%; n = 38) and 16 clients (41%; n = 39). The difference was again not significant ( $P = .707$ ).

### 6.4.1.3 Analysis of the variables related to TB and self-care

The change from April to November 2002 with participants maintaining their low level of self-care (low- low), changing from low to high level of self-care (low- high) or maintaining a high level of self-care (high- high) was as follows. Nine buddies (25.7%), 6 controls (15.8%) and 5 clients (12.8%) changed from low to high levels of self-care between the two surveys. These differences were not significant at the 5% level of significance ( $P = .381$ ). (See Figure 6.5.)

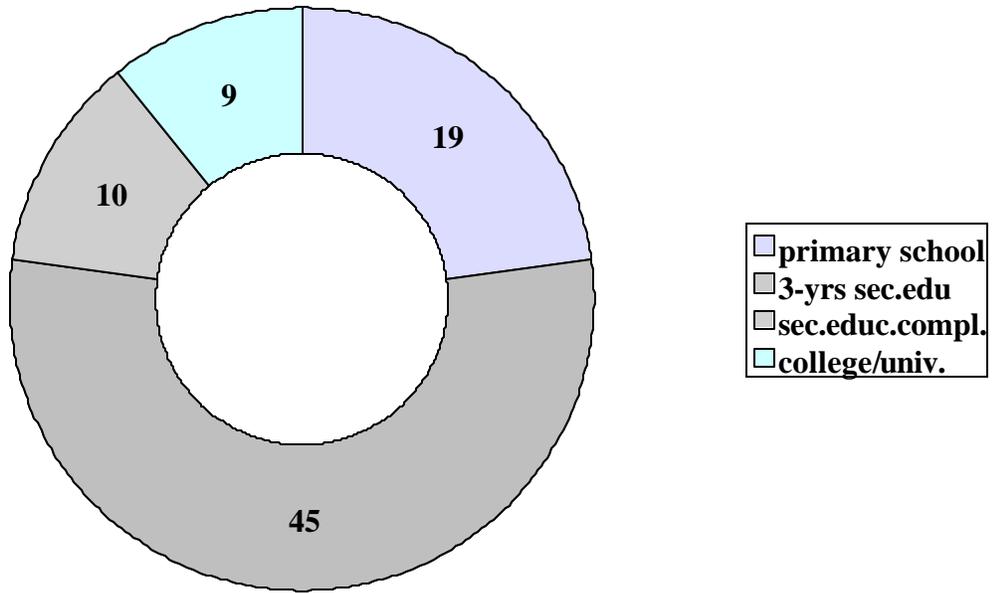


**Figure 6.5 Self-care for TB of buddies, clients and the controls in April 2002 and November 2002**

The level of self-care for TB was affected by education level. This might be partly explained by acceptance of scientific explanations for causes of illness by those women who have enjoyed secondary or higher education (Talbot et al. 2002:311-317).(See Chapter 4.)

HIV+ve women with a low level of education had a higher incidence of low level self-care, and the HIV+ve women with high levels of education had high levels of self-care. This difference is significant at the 5% level of significance ( $P = .049$ ). (See Figure 6.6.)

High levels of self-care for TB (n = 31)  
Low levels for self-care for TB (n = 83)



**Figure 6.6 Relationship between levels of education obtained and levels of self-care for TB in April 2002**

#### 6.4.1.4 Quality of life and levels of self-care for TB

The 31 HIV+ve women who were on drugs to prevent TB had a substantially higher average quality-of-life - role physical score of 69 points (SD = 32.08) than the 84 HIV+ve women who did not, who scored 59 points (SD = 33.92). The Kruskal-Wallis test for significance of differences between the three status groups was significant ( $P = 0.034$ ).

No significant relationship was found between levels of self-care (TB) in April 2002 and PCS ( $P = .223$ ) and MCS ( $P = .564$ ) scores in April 2002. There was a significant relationship between PCS scores in November 2002 and the levels of self-care (TB) in November 2002 ( $P = 0.025$ ). HIV+ve women with high levels of self-care for TB ( $n = 49$ ) had a significantly higher mean PCS score of 46 points (SD = 9.42) than HIV+ve women ( $n = 60$ ) with low levels of self-care, 43 points (SD = 9.68) by November 2002. (See Table 6.2.)

**Table 6.2 Test of significant physical and mental health component summary scores changes by November 2002 and levels of self-care for TB in November 2002**

Test Statistics <sup>a</sup>				
	PCS Score (11/02)	PCS Score Change (11/02-04/02)	MCS Score (11/02)	MCS Score Change (11/02-0402)
Mann-Whitney U	1101.000	1404.000	1377.000	1417.000
Z	-2.248	-.402	-.567	-.323
Asymp. Sig. (2-tailed)	.025	.688	.571	.747

a. Grouping Variable: Self-care (TB) November 2002

#### 6.4.1.5 Summary of the findings on self-care and TB

In summary, to answer the second research question how self-care activities developed in the buddies and the clients between April 2002 and November 2002, the findings showed that in April 2002, 7 buddies and 5 clients practised high levels of health-deviating self-care for TB. The differences between status group and levels of self-care for TB were not significant ( $P = 0.293$ ). Six months later, 9 more buddies did so, bringing the total

number of buddies practising high levels of self-care for TB to 15. The number of clients increased by 11, bringing the total number of clients practising high levels of self-care for TB to 16. The difference between the groups is not significant ( $P = .707$ ). The number of buddies practising high levels of self-care *doubled*, and in the case of the clients *tripled*, which were encouraging results. However, in both groups only 40% reached the desired high levels by November 2002.

HIV+ve women with high levels of self-care had a significantly higher mean PCS score than HIV+ve women with low levels of self-care. Higher levels of education ( $P = 0.049$ ) predicted higher levels of self-care for TB. For the other health variables, such as suffering from TB in April 2002, no significant relationships with PCS and MCS scores were found.

## **6.4.2 Discussion**

### **6.4.2.1 Health-deviating self-care requisites**

The buddy system of care and support encouraged more buddies (+26%) and more clients (+13%) to practise high levels of self-care for TB by November 2002. The controls reported higher levels of self-care than both buddies and clients initially (34%) and 50% reached high levels of self-care (+16%) by November 2002. Having active TB was a health problem for 10% of the HIV+ve women in the present study, more specifically one out of every five buddies had TB. However, it was encouraging to find that all were on DOTS to cure the TB.

The levels of self-care for TB of the 116 HIV+ve women were initially low. The buddies were in need of skills building for TB prevention; 82% reported low levels of self-care for TB initially and this low score was believed to be a barrier towards helping themselves and others as well. The findings of low levels of self-care for TB in this group of HIV+ve women might be explained by the study of Ingram and Hutchinson (1999:93-103), who reported that covering up TB is a common practice because of the *double stigma* of having TB and being HIV+ve. Improvement in measures of health-deviating

self-care for TB supported the positive effect of *having a buddy* and *being a buddy* on self-care agency.

No regression from high to low levels of self-care for TB was reported, implying that all who had started treatment adhered to their course of IPT. The buddies reported the greatest improvement during the research period and by November, 44% of the buddies reported high levels of self-care for TB and the clients 41%. The controls did not progress from low to high levels at the same rate as the buddies and clients, but because more had started or completed IPT initially, in April 2002, the controls scored highest (50%) on self-care for TB by November 2002.

#### 6.4.2.2 *Beliefs about disease origin and self-care for TB*

The present study findings pointed towards a significant positive relationship between the levels of self-care for TB and physical health. A predictor of higher self-care ability for TB was higher *levels of education*. This might be partly explained by the fact that more highly educated women accepted the scientific explanation of the cause of TB being germs and not evil spirits (See Chapter 4). Nevertheless, after six months, overall, 56% of the 116 HIV+ve women in the present study continued to practise low levels of self-care for TB. As compared with the findings of the needs assessment by Zuyderduin (2000:65), the situation was almost the same. At that time, 53% of the 116 HIV+ve men and woman were reporting low levels of self-care for TB.

The buddies were taught specifically about TB and why it was important to prevent latent TB infection from becoming active disease. The fact that during the first data collection phase it was discovered that 20% of the buddies had active TB was shared within the buddy group without mentioning names of the individuals afflicted, and this made all women realise that TB prevention in Botswana was not a luxury for PLWA/Hs but a necessity. This challenging of the denial associated with poor uptake of TB prevention was ongoing, and the topic was repeatedly addressed within support group meetings, at trainings and at other opportunities. It was, however, recognised that denial is a coping mechanism that can assist in the repression of fears and reduce anxiety, but it was argued that this denial could be remedied by becoming more knowledgeable about the disease

and related problems. As Maslow stated, knowledge can have an anxiety-reducing function and add to the feeling of safety based on improved understanding of what was previously feared (Maslow 1999:76). The two authors, Maslow and Orem, concurred that healthy people develop and learn new skills and deepen the knowledge that they already have during their lifetime (Maslow 1999:7; Orem 2001:466).

Greater understanding of the disease and meeting peers with TB might have motivated the 9 buddies, 6 controls and 5 clients to start IPT between April 2002 and November 2002. Some already had started or completed IPT treatment by April 2002. This is in agreement with Orem's proposition that all people display variations in *self-care agency*. Orem (2001:466) holds that people's self-care repertoire is determined by

- what they have learned to do and what they do consistently (*for instance, in the case of the HIV+ve women who had started or completed their IPT*)
- what they can and can't do now or in the future; their limitations (*if their beliefs in myths about the origin of the disease are stronger than scientific explanations, the individuals cannot start IPT until they change their beliefs*)
- whether what they have learned to do and can do now is equal to meeting all current and projected demands now or at some future time (*IPT might not be 100% effective in preventing TB; in case of failure the individual would need to adapt to the new challenges and start TB treatment*)

#### **6.4.3 Summary**

Some of the recommendations of the present study concern further exploration of barriers and opportunities for TB care and prevention. The double stigma associated with TB and HIV/AIDS could be explored in further studies, as well as the supportive-educative care measures needed to address the beliefs about how and why it is important to prevent latent TB from becoming active infection. Self-care for TB translated into significantly improved quality-of-life domain scores; physical health improved as high levels of self-care for TB were achieved.

In the next section the findings relating to ARVs are reported and discussed. In addition to prevention and early treatment of OIs such as TB, the PLWA/Hs in Botswana gained access to ARV therapy through Botswana's MASA programme, as discussed in Chapter 4. However, access depended on the actions and capabilities of the HIV+ve women in the present study. The first step was to go to the clinic and ask for CD4 quantification; then depending on the outcome of the laboratory test results and further examinations by medical doctors, commencement of ARV therapy could be recommended.

## **6.5 ANTIRETROVIRAL THERAPY**

Five questions (questions 13-17) explored self-care and ARV therapy. The HIV+ve women gave details about CD4 quantification (question 13) and the frequency with which participants checked their CD4 counts in April 2002 and in November 2002 was reported (question 14). Are you taking ARVs at present? (question 15) or the reasons why not (question 16) provided insight into ARV uptake. Since ARVs had been available through clinical research programmes and the private medical sector prior to the implementation of MASA, the public ARV programme within Botswana that started early 2002, the duration of taking ARVs for those who reported that they were taking ARVs in April 2002 was enquired about (question 17).

### ***6.5.1 Levels of self-care with respect to antiretroviral therapy***

The HIV+ve women were classified into "low levels of self-care" and "high levels of self-care" with respect to ARV. Checking their CD4 counts *and* taking ARVs when in need of doing so, was termed "high levels of self-care". Checking CD4 counts but not taking ARVs because the CD4 counts were above 200 cells/mm<sup>3</sup> was also labelled "high levels of self-care". If the HIV+ve women did not check their CD4 counts and/or did not take ARVs despite medical advice to do so, it was termed "low levels of self-care".

#### ***6.5.1.1 Statistics in April 2002***

During April 2002, 29 buddies (74.4%; n = 39) maintained high levels of self-care, which was a substantially higher percentage than the 19 controls (50%; n = 38) and the 20

clients (51.3%; n = 39). The difference is significant at the 5% level of significance ( $P = 0.049$ ).

#### *6.5.1.2 Basic conditioning factors in April 2002*

##### *Education*

Education level was related to this variable. The 9 HIV+ve women with higher levels of education (69.2%; n = 13) also maintained, in general, a higher levels of self-care. The relationship is significant at the 10% level of significance ( $P = 0.090$ ).

##### *Income*

Income also played a role. The 8 HIV+ve women in the higher income groups earning over BWP1500 (88.9%; n = 9) generally maintained higher levels of self-care. This relationship is significant at the 1% level of significance ( $P = 0.008$ ).

Age, marital status and number of children did not have a significant relationship with this variable in April 2002

#### *6.5.1.3 Statistics in November 2002*

Thirty buddies (88.2%; n = 34) maintained high levels of self-care and so did 35 clients (89.7%; n = 39), with the percentage much lower for 27 controls (71.1%; n = 38). These differences are not significant at the 5% level of significance, but are significant at the 10% level ( $P = 0.057$ ).

#### *6.5.1.4 Basic conditioning factors in November 2002*

##### *Marital status*

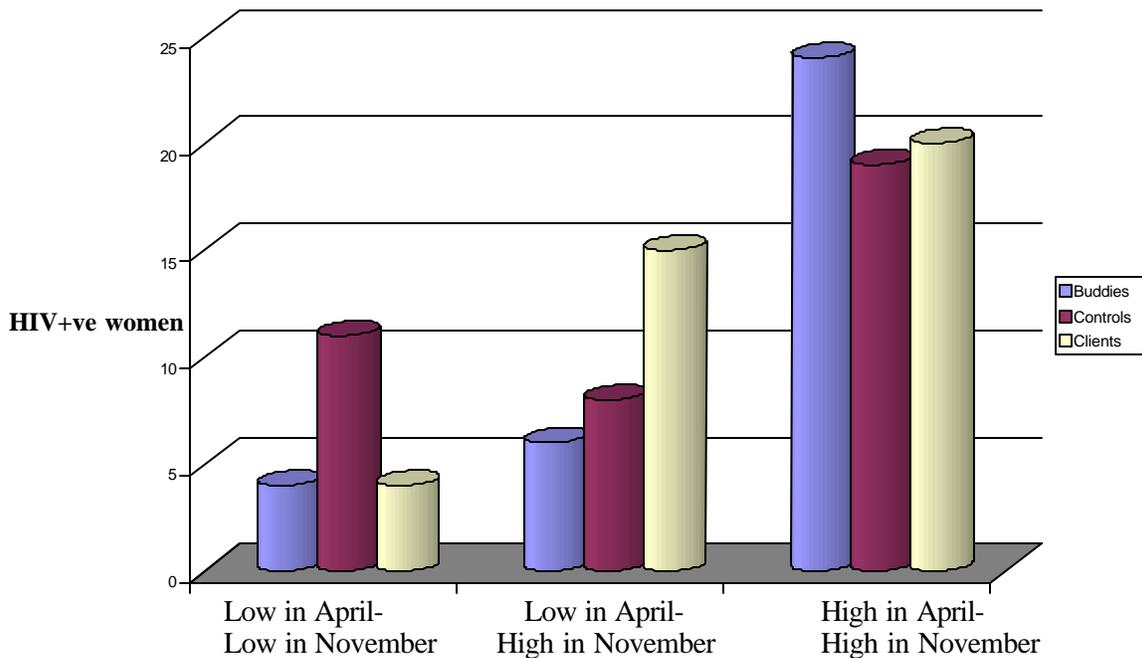
Marital status seemed to have a significant relationship with this variable. It appeared that 7 married women and widows (41.2%; n = 17) maintained low levels of self-care. Low levels of self-care were reported by 8 single HIV+ve women (12.3%; n = 65) and 4 single women who were living with a steady partner (13.8%; n = 29). This relationship is significant at the 5% level of significance ( $P = 0.016$ ).

### *Income*

Monthly income in November 2002 did not have a significant relationship with this variable.

#### *6.5.1.5 Analysis of the variables related to antiretroviral therapy and self-care*

Six buddies (17.6%; n = 34) and 8 controls (21.1%; n = 38) changed from low to high levels of self-care between the first and second surveys. A larger section, 15 clients (38.5%; n = 39) did the same. These differences are significant at the 5% level of significance ( $P = 0.041$ ). (See Figure 6.7).



**Figure 6.7 Self-care for antiretroviral therapy of buddies, clients and the controls in April 2002 and November 2002**

### *6.5.2 CD4 quantification*

There were significant differences between the percentages of buddies, controls and clients that went for CD4 quantification.

#### *6.5.2.1 Statistics in April 2002*

Sixty-six HIV+ve women (56.9%; N = 116) checked their CD4 counts at the start of the present study in April 2002 (question 13). It was noted that 29 buddies (74.4%; n = 39) said 'yes', and so did 18 controls and 19 clients, both just below 50%. This difference was significant at the 5% level of significance ( $P = 0.026$ ). In total 66 women (56.8%) checked their CD4 counts regularly and 50 HIV+ve women (43.1%) did not.

#### *6.5.2.2 Statistics in November 2002*

The replies in November 2002 were analysed to obtain the differences between the status groups. In all three groups, the percentage of 'yes' replies had increased, but the clients now had the highest percentage of 'yes' replies (89.7%), which was substantially higher than the percentage of the controls (71.1%). The percentages in the buddies and clients were about the same. This difference is significant at the 10% level of significance but not quite significant at the 5% level ( $P = 0.057$ ). In total 92 HIV+ve women (82.1%) checked their CD4 counts regularly and 19 HIV+ve women (16.9%) did not.

#### *6.5.2.3 Analysis of the variables related to CD4 quantification*

The 61 HIV+ve women who went for CD4 quantification initially confirmed that they still did so in November 2002. Of the 50 HIV+ve women who had said 'no' initially, 62% had their CD4 counts checked in November 2002. A detailed contingency table compares the replies to the question: "Do you check your CD4 count?" across the two surveys, with the three status groups pooled. (See Table A.VI.2, Annexure VI.) In the case of the buddies, 60% who had previously said that they did not check their CD4 counts reported that they were checking their CD4 counts by November 2002. In the case of the controls, this percentage was only 45%, and in the case of the clients, this percentage was 80%. It thus appeared that the buddy system encouraged more participants to check their CD4 counts.

#### *6.5.2.4 Other factors affecting the replies to the questions*

Other background information (education, income, number of children, education level) did not have a statistically significant effect on the replies in November 2002. However,

marital status did have a significant effect in November 2002 (though not initially). For this analysis, the participants with marital status “widow” were excluded, because this was a very small group of four participants, and no significant statistical results could be drawn for such a small group.

Thirty-nine of the single HIV+ve women (59.1%;  $n = 66$ ) went for CD4 quantification, and so did 17 single HIV+ve women with a steady partner and 8 HIV+ve married women. These differences were not statistically significant ( $P = 0.803$ ). For the November 2002 questionnaire, it appeared that a smaller percentage of married HIV+ve women (64.3%) checked their CD4 than the other two groups (87.7% and 86.2% respectively). This difference was significant at the 10% level of significance, but not at the 5% level ( $P = 0.088$ ).

#### *6.5.2.5 Quality of life and CD4 quantification*

There was a significant relationship between the checking of CD4 counts and quality-of-life domain scores. The participants who by November 2002 checked their CD4 counts ( $n = 90$ ) experienced a mean increase of nearly 5 points ( $SD = 21.08$ ) in the quality-of-life - general health domain, but those who did not check their CD4 counts ( $n = 18$ ) experienced a decrease of 5 points ( $SD = 17.62$ ). The difference between the two groups, measured with a Kruskal-Wallis test of the two means, was significant ( $P = 0.027$ ).

### **6.5.3 Frequency of checking CD4 counts during 2002**

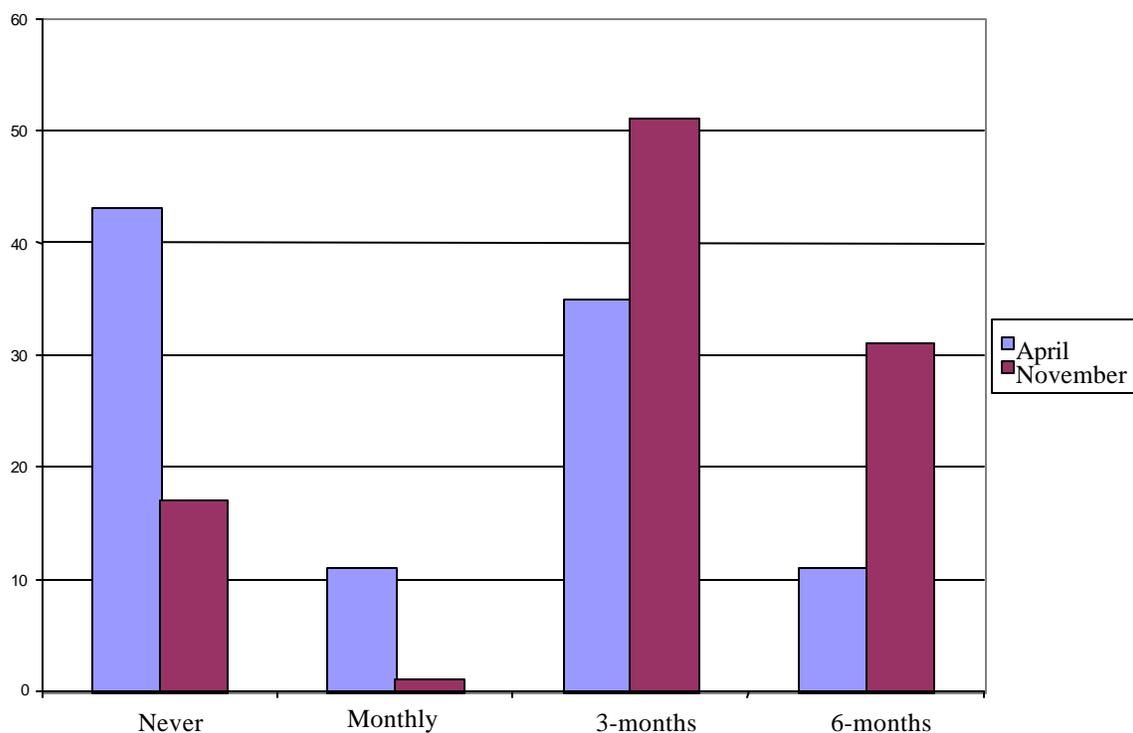
The frequency with which participants checked their CD4 counts initially in April 2002 and in November 2002 was analysed (question 14).

#### *6.5.3.1 Statistics in April 2002*

The situation in April 2002 was as follows: the buddies checked their CD4 counts more regularly than the other two groups. Seventeen buddies (43.6%;  $n = 39$ ) checked every three months and only 10 buddies (25.6%) never checked, whereas more than 20 HIV+ve women (52.6% and 51.3%) in the other two groups never checked. The differences are not statistically significant, but too many low counts prevented the researcher from performing an exact chi-square test.

### 6.5.3.2 Statistics in November 2002

By November 2002, buddies and clients showed a very similar and improved profile. Four HIV+ve women in each group did not check their CD4 counts. The controls were more likely never to check their CD4 counts: 11 controls (28.9%; n = 38) never checked. The first frequency category (“monthly”) was omitted for the chi-square test because of the low frequency (only 1 participant). The chi-square test is not significant at the 5% level of significance ( $P = 0.227$ ). (See Figure 6.8.)



**Figure 6.8** Frequency of checking CD4 counts in April 2002 and November 2002

### 6.5.3.3 Analysis of the variables related to CD4 quantification

By November 2002, 19 HIV+ve women (17%) still did not go to the clinic to have their CD4 counts checked. Having a partner was a risk factor for lower self-care actions and increased the likelihood of not having the CD4 counts checked, since 9 HIV+ve women (47%) who did not have their CD4 counts measured were married or with a steady

partner. Of the whole sample (N = 116), 13% were married and 25% had a steady partner but in this group of HIV+ve women who never tested the married women were over-represented.

#### **6.5.4 Women who were on antiretroviral therapy during 2002**

##### *6.5.4.1 Statistics in April 2002*

A higher percentage of the buddies, 17 buddies (43.6%), took ARVs in April 2002 than the other two groups. Seven controls (18.4%; n = 38) did so. Of the clients, 11 (28.2%; n = 39) took ARVs. This difference is almost significant, chi-square (Value 5.895, DF = 2,  $P = 0.052$ ). In total 35 HIV+ve women (30%) were taking ARVs in April 2002 and 81 HIV+ve women (70%) were not.

##### *6.5.4.2 Statistics in November 2002*

The replies in November 2002 were analysed and the differences between the status groups presented. In both the client and control groups the number of people who had stated taking ARVs had increased: the clients showed an increase from 11 to 19 (to 48.7%); the controls increased only to 36.8%, but the actual number going on ARVs had doubled from 7 to 14 controls. This difference is not significant at the 5% level of significance ( $P = 0.453$ ).

##### *6.5.4.3 Analysis of the variables related to the women who were on antiretroviral therapy and self-care in 2002*

The percentages of “yes” answers in April 2002 and in November 2002 were compared. The 31 participants who had said they were on ARVs initially were all still taking ARVs in November 2002. Of the 80 participants who were not on ARVs initially, 23.8% had started ARV therapy in November 2002. The change in percentage “yes” answers is presented by status group. (See Table A.VI.3, Annexure VI.) In the case of the buddies, 19% who had not started ARV therapy initially said “yes” in November 2002. Of the control group, this percentage was 22.6% and in the case of the clients, this percentage was 28.6%.

The effect of the buddy system thus appears to be less strong than in the case of the CD4 tests; nevertheless the largest increase occurred in the case of the clients.

#### *6.5.4.4 Other factors affecting the replies to the question*

Other background information (education, marital status, number of children, education level) did not have a statistically significant effect on the replies in April 2002 and November 2002. However, age and income did have a significant effect. For this analysis the participants with salaries over BWP4000, a group very small in number, were pooled with those with income BWP1501-P4000 for statistical purposes.

#### *Statistics in April 2002*

##### *Income and taking antiretroviral therapy*

In April 2002, the 5 HIV+ve women in higher income groups showed a higher incidence of yes replies (56%;  $n = 9$ ) to the question whether they were taking ARVs, as compared with 14 HIV+ve women (21%;  $n = 67$ ) in the group with a monthly income below BWP200. These differences are statistically highly significant (Value 13.489, DF = 3,  $P = 0.004$ , 2-tailed.)

#### *Statistics in November 2002*

##### *Income and taking antiretroviral therapy*

For the November 2002 questionnaire, the results were as follows. The 6 HIV+ve women in the higher income groups still had the higher incidence of “yes” replies (46%), but the lower income groups seemed to have caught up somewhat, notably the 20 HIV+ve women in the group with monthly income less than BWP200 (43%;  $n = 47$ ), who now reported that they were taking ARVs. This difference was significant at the 10% level of significance, but not at the 5% level ( $P = 0.081$ ).

##### *Age and taking antiretroviral therapy*

In the case of age, the 35 HIV+ve women group who were on ARVs were somewhat older on average than the 81 HIV+ve women in the group who were not: 32.8 years (SD = 6.46) versus 30.4 years (SD = 7.38) respectively. In both cases (April 2002 and

November 2002) the difference was significant at the 10% level of significance, but not at the 5% level. The difference was tested by means of a Wilcoxon two-sample rank test ( $P = 0.039$  in April 2002 and  $P = 0.069$  in November 2002).

### **6.5.5 Duration of taking antiretroviral therapy**

This question related only to the 35 HIV+ve women who stated in April 2002 that they did take ARVs (question 15).

#### *6.5.5.1 Statistics in April 2002*

The majority of HIV+ve women, 68.6% ( $n = 35$ ) who took ARVs had been doing so for six months or less (question 17). Nine HIV+ve women (25.7%) had been on ARV treatment for 7 to 12 months and two HIV+ve women (5.7%) between 1 and 2 years.

In terms of status groups, the frequencies were that the 17 buddies had been taking ARVs for longer than controls and clients; 94% of the buddies had been taking ARVs for less than a year. Five controls (72%;  $n = 7$ ) had taken ARVs for less than 7 months. The highest frequency of 0 to 6 months was recorded for 9 clients (81.8%;  $n = 11$ ). Only 1 client (9%) and 1 buddy (6%) had taken ARVs for over a year.

#### *6.5.5.2 Statistics in November 2002*

Six months later, there were 51 HIV+ve women (46%;  $n = 111$ ) taking ARVs (question 15). The 7-12 months category had the highest frequency, with 22 HIV+ve women (43.1%;  $n = 51$ ). Nineteen HIV+ve women (37.3%;  $n = 51$ ) had been on ARVs for less than 7 months, and 10 HIV+ve women (19.6%;  $n = 51$ ) for between 1 and 2 years (question 17). The buddies and clients reported the 7 to 12 months category as the highest frequency, but in the controls 0 to 6 months had the highest frequency. The buddies had the highest prevalence of being on ARV for between 1 and 2 years.

#### *6.5.5.3 Quality of life and duration of taking antiretroviral therapy*

The means of the groups who had taken ARVs for different periods were compared by means of the Kruskal-Wallis test.

*PCS and period of taking ARVs in April 2002*

The means are as follows for April 2002. For the 24 HIV+ve women who had taken ARVs for less than 7 months, the mean PCS score was 42 points (SD = 8.14). For the 9 HIV+ve women who had taken ARVs for 7 to 12 months, the mean PCS score was 44 points (SD = 9.22), and for the two HIV+ve women who had taken the ARVs for between 1 and 2 years, the mean PCS was 32 points (SD = 17.97). The group which had taken ARVs for 1 to 2 years had particularly low mean PCS values.

*PCS and period of taking ARVs in November 2002*

For the 19 HIV+ve women who had taken ARVs for less than 7 months, the mean PCS score was 44 points (SD = 6.70). For the 22 HIV+ve women who had taken ARVs for 7 to 12 months, the mean PCS score was 46 points (SD = 9.06), and for the 9 HIV+ve women who had taken the ARVs for between 1 and 2 years, the mean PCS was 43 points (SD = 13.36).

*MCS and period of taking ARV in April 2002*

For the 24 HIV+ve women who had taken ARVs for less than 7 months, the mean MCS score was 44 points (SD = 11.42). For the 9 HIV+ve women who had taken ARVs for 7 to 12 months, the mean MCS score was 47 points (SD = 11.25), and for the two HIV+ve women who had taken the ARVs for between 1 and 2 years, the mean MCS was 44 points (SD = 19.29). The two groups who had taken ARVs for more than 6 months were rather small and no significant difference was found, due perhaps to the very small size of the groups. The Kruskal-Wallis test for significance of differences between length of time of having taken ARVs and the mean PCS was ( $P = .520$ ) and MCS ( $P = .769$ )

*MCS and period of taking ARV in November 2002*

For the 19 HIV+ve women who had taken ARVs for less than 7 months, the mean MCS score was 50 points (SD = 8.11). For the 22 HIV+ve women who had taken ARVs for 7 to 12 months, the mean MCS score was 49 points (SD = 7.81), and for the 9 HIV+ve women who had taken the ARVs for between 1 and 2 years, the mean MCS was 44 points (SD = 12.04). The mean MCS score seemed to go down with the duration of ARV

treatment. The two groups who had taken ARVs for more than 6 months were rather small and no significant difference was found, due perhaps to the very small size of the groups. The Kruskal-Wallis test for significance of differences between length of time of having taken ARVs and the mean PCS was ( $P = .408$ ) and MCS ( $P = .459$ ).

### **6.5.6 Reasons for not taking antiretroviral therapy during 2002**

Of the 116 HIV+ve women, 81 HIV+ve women were not on ARVs. This was expected of the 20 HIV+ve women (24.7%) who reported that their CD4 counts were above 200 cells/mm<sup>3</sup> blood and thus did not qualify for ARV therapy according to the Botswana guidelines. (See Annexure V.)

#### *6.5.6.1 Statistics in April 2002*

Of the 61 HIV+ve women who were not on ARV therapy, the “reason” of the majority, 40 women (49.4%), seemed to be that they had never taken ARVs. Sixteen HIV+ve women (19.8%) claimed they had no access. Two HIV+ve women (2.5%) had been told to stop the ARVs by their doctor, and 3 HIV+ve women (3.7%) had been told to start ARV treatment by their doctor but had not yet agreed to do so (questions 15 and 16). For the status groups the frequencies were reported. (See Table A.VI.4, Annexure VI.) The CD4 count reason seemed to be most prevalent in the buddy group, and the “never taken ARVs” reply was most prevalent among the controls and clients.

#### *6.5.6.2 Statistics in November 2002*

Six months later, the group not taking ARVs had decreased from 81 to 61. The “CD4 count above 200” was now the reply most prevalent for 36 HIV+ve women (59%;  $n = 61$ ), but still 13 HIV+ve women (21.3%) stuck to the “never taken ARVs” reason, and 10 HIV+ve women (16.4%) claimed that they did not have access. One HIV+ve woman (1.6%) had been told to start but had not yet agreed to do so and one HIV+ve woman (1.6%) did not answer the questions (questions 15 and 16). For the status groups, the frequencies are reported. (See Table A.VI.5, Annexure VI.) The “never taken ARVs” reason was most prevalent among the controls and the “CD4 counts above 200” reason was most prevalent in the other two groups.

### 6.5.7 *Summary of findings*

In answering the second research question how the self-care activities developed in the buddy and the client six-months into the helping relationship it was discovered that the level of self-care for ARVs was high to begin with for 29 buddies. The buddies had a higher level of self-care for ARVs than the clients, of whom only 15 had a high level to begin with in April 2002. The difference between the status group was significant ( $P = 0.049$ ). Six months later only one more buddy had been added to the high group, bringing the total to 30 buddies. However, for the clients, 20 changed from low to high levels of self-care, bringing the total to 35 clients. These differences are significant at the 5% level ( $P = 0.041$ ). By November 2002, nearly 90% of both groups had reached the desired high levels. This was a significant improvement and an indication that the buddies had been successful in moving their clients from low to high levels of self-care for ARVs.

#### *Basic conditioning predictors of higher self-care ARV*

Higher income ( $P = 0.008$ ), higher levels of education ( $P = 0.090$ ) and being of a somewhat older age ( $P = 0.069$ ) were predictors of higher levels of self-care for ARVs. Being married was associated with low levels for self-care for ARVs ( $P = 0.016$ ).

The Kruskal-Wallis test for significance of differences between length of time of having taken ARVs and mean PCS was not significant at the 5% level ( $P = .408$ ). By November for the 19 HIV+ve women who had taken ARVs for less than 7 months, the mean MCS score was 50 points (SD = 8.11). For the 22 HIV+ve women who had taken ARVs for 7 to 12 months, the mean MCS score was 49 points (SD = 7.81) and for the 9 HIV+ve women who had taken the ARVs for between 1 and 2 years, the mean MCS was 44 points (SD = 12.04). The mean MCS score seemed to go down with the duration of ARV treatment. The two groups who had taken ARVs for more than 6 months were rather small and no significant difference was found, due perhaps to the very small size of the groups. The Kruskal-Wallis test for significance of differences between length of time of having taken ARVs and mean MCS was not significant at the .05 level ( $P = .459$ ).

### 6.5.8 Discussion

A high level of self-care for ARVs was operationalised in the present study as the HIV+ve women's ability to go to a health care service for CD4 quantification and, if their CD4 counts were found to be below 200 cells/mm<sup>3</sup>, to go for further investigations and start on ARVs when recommended by their doctor. In summary:

- High: Yes to CD4 quantification and yes to ARVs when recommended
- Low: Yes to CD4 quantification and no to ARVs when recommended
- Low: No to CD4 quantification and no to ARVs when recommended

#### 6.5.8.1 Self-care and antiretroviral therapy

The total number of buddies and clients who had checked their CD4 counts and gone onto ARV therapy when they needed to was almost 90% in each group by November 2002. This was an encouraging result that compared favourably with the 70% of the controls who remained at or reached high levels self-care for ARV. The buddy system seemed effective in motivating self-care for ARVs.

#### 6.5.8.2 Frequency of consultations with medical providers

The present study reported on frequency of CD4 quantification because this was taken to represent the minimum frequency with which a medical practitioner examined the HIV+ve women. Results by status groups were encouraging, and by November 2002, 80% of the 116 HIV+ve women were seen by a medical doctor to discuss their CD4 quantification results at three- or six-monthly intervals during 2002. This was a 30% increase from April 2002. These regular doctor visits might have been permitting early detection of other health problems associated with HIV and AIDS, initiation of preventative measures and early treatment of diseases where needed. These results need to be considered within a primary health care system where nurses at clinics and hospital outpatient departments refer patients to doctors only when the nurses cannot treat the presenting problem. Many patients, including PLWA/Hs, were not routinely consulting with or examined by medical doctors in Botswana unless they were seriously ill.

#### *6.5.8.3 Basic conditioning factors as risk factors for low self-care*

The study explored whether basic conditioning factors influenced the association between high or low levels of self-care for ARVs. Having a partner was a risk factor predicting lower self-care actions for ARVs, affecting the remaining 10% of the HIV+ve women in the buddy and client group reporting a low level of self-care. Or put in another way, it was easier for single women to decide to go for a laboratory test and make the lifetime commitment to start ARV therapy, if recommended to do so by the doctor. This did not mean that the other 10% were not motivated to do so as well. The present study discovered an association between being married or having a steady partner and these specific health-deviation self-care deficits. Studies by Tlou (2002:654-663) and a review of the laws of Botswana affecting the status of women reported by the Government of Botswana (1998:42) noted the (legal) dependence of the married woman on the husband and cultural expectations of women in Botswana to take care of others before addressing their own needs. This was a possible explanation for the over-representation of the married women in the group that continued to have this self-care deficit. Further qualitative enquiry into this observed phenomenon beyond the present study might add more insight and discover other possible reasons.

Higher levels of education and higher monthly incomes were two factors that were linked and jointly predictive of self-care agency for ARV at the beginning of the study. However, this effect was less of an influence by November 2002, as women with lower incomes were accessing ARVs as well. These findings are consistent with the intentions of the MASA programme, aiming to give PLWA/Hs access to ARVs irrespective of their income status (Darkoh 2003:1-7). (See Chapter 4.)

#### *6.5.8.4 Methods of helping in the buddy system*

Through the acquisition of self-care skills, the HIV+ve women could actively participate in creating their own health and in shaping the conditions that influenced their health. In the present study, the buddies were paired up with HIV+ve clients and both the buddies and the clients had self-care abilities to various degrees: they had different levels of disclosure; some were on treatment for acute TB infection and others were engaged in

latent TB preventive measures and/or monitoring of their immune function. The buddy system incorporated Orem's three ways of helping:

- guiding and directing
- providing physical and/or psychological support
- providing and maintaining an environment that supports personal development (Orem 2001:56).

The educative/supportive role was performed not only by the buddies but by the clients as well. The buddy system expected the buddies and the clients to contribute to the helping relationship, depending on their self-care skills and abilities and other experiences. The buddies and clients were a source of mutual support. They assisted each other with household chores or running errands when necessary. This reduced the task load of the recipient and this type of support was probably especially relevant for low-income persons, who are often overburdened with instrumental chores, have smaller social networks and are financially unable to buy assistance (Cohen & Syme 1985:71). The perception that one could rely on support being available when needed was believed to have a stress-buffering effect and to promote psychological well-being (Cohen & Syme 1985:72).

It was acknowledged that as far as informational support was concerned, the buddies were trained specifically to ensure that they imparted factually correct information and were a resource as such. However, in situations where the client had disclosed to more people or had started ARVs earlier than the buddy, the client was in the position to help the buddy as well. This approach in the buddy system of care fostered self-esteem, as did the emphasis on guiding and directing rather than doing things for the client that she could do for herself. A point highlighted during the training and in the subsequent support groups was that it was important for the client to avoid over-reliance on the buddy in matters that she was capable of dealing with herself, and vice versa. Yet for those who under ordinary circumstances might be reluctant to seek help, this reluctance might have been reduced within this communal relationship. Thus this approach might have promoted the personal development of both buddies and clients, since they

maintained the boundaries within the helping relationship. Moreover, this was a relationship that was time bound, and would be phased out or extended by a mutually agreed upon time once the first six months of the helping relationship were concluded. Despite the programme's focus on the supportive-educative role, the need for partly compensatory care was frequently observed, since a number of the HIV+ve women reported poor physical health. In particular in the group who had been on ARVs between 1 and 2 years, a particularly low mean PCS of 32 points (SD = 17.97) was observed initially. This improved somewhat to 43 points (SD = 13.36) but was still low by November 2002.

### **6.5.9 Summary**

During the six-month study period the buddy system was beneficial to the participants, resulting in an improvement in self-care abilities both for the prevention of OIs such as TB and accessing HIV-specialised care, through for instance regular visits to clinics and hospitals to consult with health care providers and as a result accessing ARVs when needed.

The present study confirmed Orem's notion that basic conditioning factors predict levels of self-care, as explicated in the theory of self-care. Future interventions could be improved by targeting care and support interventions to low-income, married HIV+ve women with TB infection, knowing that they deal with multiple stressors that predispose them to ill health and lower levels of well-being.

The methods of helping in the buddy system included guiding and teaching and, if physical health was poor, providing partly compensatory care. Collaboration between formal and informal caregivers benefited the HIV+ve women within the buddy system, buffering some of the stressors associated with living with HIV and AIDS. As social support theory states, other people can provide resources and are a resource in themselves. The results of increased levels of disclosure and self-care for TB and ARVs in the present study pointed towards the effectiveness of being a buddy and having a buddy to promote levels of well-being.

## **SECTION II**

### **ADHERENCE**

#### **6.6 ATTITUDES TO ADHERENCE INVENTORY**

In the present study, 61 HIV+ve women (52.7%) could not be considered for ARV treatment because they were not going for CD4 quantification; this was not to say that their CD4 counts were over 200 cells/mm<sup>3</sup> blood. Twenty HIV+ve women (17.2%) had checked their CD4 counts by April 2002 and were told by their doctor that they did not need to take ARVs and were not expected to complete the adherence survey. Subtracting the 61 HIV+ve women who had not gone for CD4 quantification and the 20 women who did not need ARVs, a small group of 35 respondents remained in April 2002.

By November the situation had improved somewhat, since only 26 HIV+ve women (23.2%) - down from the 61 HIV+ve women (52.7%) in April - had not yet checked their CD4 counts, and 51 respondents completed the AAI.

##### **6.6.1 Findings**

The AAI could be completed by the 35 HIV+ve women (30.2%; N = 116) who were actually taking ARVs and were thus able to provide values for the AAI in April 2002. The results of the AAI at baseline and in November 2002 and the differences were reported.

##### *6.6.1.1 Attitude to adherence inventory scores in April 2002*

The mean value of the scores of the 17 buddies was 6.0 (SD = 0.6), with the 7 controls scoring the lowest at 5.7 (SD = 0.4). The 11 clients scored slightly better at 6.1 (SD = 0.4) in April 2002.

### *6.6.1.2 Attitude to adherence inventory scores in November 2002*

Note that by November 2002, 16 additional participants had started ARV therapy, bringing the total to 51 HIV+ve women (45.5%;  $n = 112$ ) that were taking ARVs and provided values for AAI.

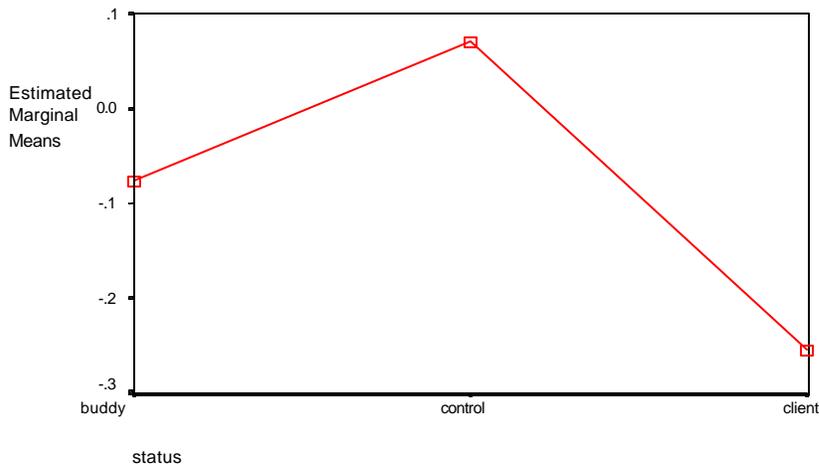
During the six-month survey period 32 more women had checked their CD4 counts, bringing the total to 86 HIV+ve women (76.8%) that had checked their CD4 counts by November 2002. Of those 32 who had checked, 50% did not have to start ARV therapy yet, bringing to 36 the total of HIV+ve women (32.1%) that were told by their doctor that they did not need to take ARVs.

By November the AAI scores had dropped somewhat; the 13 buddies' scores had decreased by 0.1 point since April 2002 to 5.9 (SD = 0.6). The 14 controls had the highest mean of 6.1 (SD = 0.5), with the 19 clients scoring 5.8 (SD = 0.5), the lowest.

### *6.6.1.3 Analysis of the variables related to attitudes towards adherence in April 2002 and November 2002*

The Kruskal-Wallis test for significance was used and the results are as follows. The mean values in April 2002 were not significantly different (Value 4.290, DF = 2,  $P = 0.117$ ). The means in November 2002 were also not significantly different (Value 1.146, DF = 2,  $P = 0.564$ ). The mean changes of the AAI were not significantly different (value .380, DF = 2,  $P = 0.827$ ), and this may in part be due to the small sample sizes.

The means and standard deviations were as follows. The buddy mean difference between scores in April 2002 and November 2002 was down by -.08 points (SD = 0.8;  $n = 13$ ), the controls' score was up by .07 points (SD = 0.17;  $n = 7$ ), and for the clients it was down by -.25 points (SD = 0.72;  $n = 11$ ). The buddies' score showed a slight decrease, the controls showed an average increase and the clients a more substantial decrease between the first and the second survey. This is shown in Figure 6.9.



**Figure 6.9** Estimated marginal mean score differences between scores on adherence attitude inventory in April 2002 and November 2002 of buddies, clients and controls

#### 6.6.1.4 Other factors

The correlation coefficient of number of children with AAI scores in April 2002; (= -.075) and AAI scores change (= .295) are not significant at the 5% level of significance. However, the AAI scores in November 2002 are slightly but significantly correlated with number of children. The correlation coefficient is 0.283 ( $P = 0.046$ ).

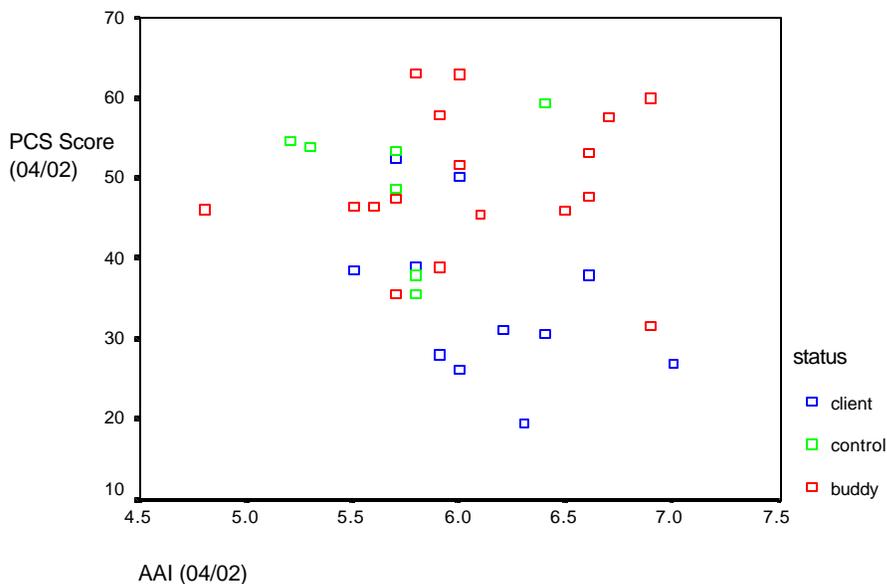
#### 6.6.1.5 Quality of life and adherence

In April 2002, the correlations between PCS and MCS scores and adherence were as follows. The correlation coefficients of the mean PCS score in April 2002 and the AAI mean scores were significant at the 10% level of significance ( $P = .065$ ) The negative correlation seemed to be mainly due to the client group: the higher the AAI score, the lower the PCS score. (See Table 6.3.)

**Table 6.3 Relationship between physical and mental health component summary scores, adherence attitude inventory scores and personal resource questionnaire - part II scores in April 2002**

			Correlations	
			AAI (04/02)	PRQ-2 (04/02)
Spearman's rho	PCS Score (04/02)	Correlation Coefficient	-.315	.154
		Sig. (2-tailed)	.065	.098
		N	35	116
	MCS Score (04/02)	Correlation Coefficient	-.144	.003
		Sig. (2-tailed)	.408	.975
		N	35	116

The negative correlation seemed to be mainly due to the client group: the higher the AAI score, the lower the PCS score. The scatter diagram in Figure 6.10 illustrates the situation.



**Figure 6.10 Physical health component summary scores and adherence attitude inventory scores in April 2002**

#### 6.6.1.6 *Summary of findings*

The third research question was what the attitudes-towards-adherence scores for both the buddies and the clients (if on ARVs) were prior to starting the buddy-client relationship and if there was a difference six-months into the helping relationship. The present study reported that the mean value of the AAI scores for 17 buddies was 6.0 points (SD = 0.6). The 11 clients scored slightly better at 6.1 points (SD = 0.4) in April 2002. Six months later, 8 more clients had started ARV therapy and completed the AAI for the first time. The larger group, now consisting of 19 clients, scored 5.8 points (SD = 0.5) and the 13 buddies' mean score was 5.9 points (SD = 0.6). Four buddies that were on ARVs in April 2002 passed away during the present study. By November, the controls showed an average increase, the buddies a slight decrease and the clients a more substantial decrease between the first and the second survey. The mean AAI scores in November 2002 were correlated with number of children. The correlation coefficient is 0.283 ( $P = 0.046$ ).

#### 6.6.2 *Discussion*

The total scores were encouraging, as they were mostly close to 7 points, which was the maximum score possible. However, the downward trend in both the buddies' and the clients' scores warrants further investigation.

##### 6.6.2.1 *HIV treatment adherence: motivation and skills*

High total scores on the AAI were understood to be an indication that these 51 HIV+ve women felt good about their overall ability to take their ARVs as recommended by their doctor. In the present study, the mean AAI scores were very encouraging in this relatively small section of the 116 HIV+ve women (30%) that were already on ARVs during the first data collection phase in April 2002. The mean AAI scores in the three groups were very similar initially. By November 2002, more participants (up from 30% to 46%) reported AAI scores. The 16 women who had started ARV therapy between May and November completed the AAI for the first time in November 2002. The mean scores of the buddies *decreased* very slightly by 0.1 points, the clients' mean score *decreased* nearly 0.3 points and the controls' score *improved* by 0.7 points.

The AAI scores as reported in the present study have to be appreciated within the context of MASA being a unique initiative on the African continent. In April, the majority of the HIV+ve women on ARV (68%; n = 35) had started ARV therapy very recently. The number of HIV+ve women who had taken ARVs for less than 7 months decreased somewhat but was still high (37%; n = 51) by November 2002. The present study's findings are consistent with the findings of Williams (1999:13) and Holzemer et al. (1999:185), who reported high levels of adherence when patients are symptomatic and/or new to ARV treatment regimes.

All members of COCEPWA had access to four-day HIV and AIDS basics courses. However, the buddies were given additional training by COCEPWA on ARV therapy and why adherence was critical. The buddies were encouraged to share HIV treatment-related information with their clients. Not all buddies were on ARVs themselves at that time, but they received the training as part of their preparation before being linked with a client. Skills were transferred to enable them to assist the PLWA/Hs and give them confidence in organising ARV therapy and communication by teaching them how to

- lay out a weekly supply of ARVs in advance in a pill box/organiser that should be carried everywhere
- encourage somebody to remind them when it was time to go for refills
- take the tablets at the same time each day during routine activities
- communicate with health care providers when questions arose or side-effects were experienced.

The buddies were given in-depth information and were equipped with methods to support their clients in sticking to the prescribed regimens, irrespective of whether they were on ARVs themselves or not. However, role reversal was possible in cases when the clients had been on ARVs for longer and could assist the buddy who started ARV therapy during the survey period. Learning took place between the buddies and clients, with the buddies as resource and linkage to the health care providers when problems with the regimes were identified.

#### *6.6.2.2 Adherence in resource-limited settings*

Some possible explanations for the downward trend of mean AAI scores among buddies and clients, other than this being a larger group of women by November, were explored. The findings of an earlier USA study by Holzemer et al. (1999:186) were considered; in the present study it was also established that HIV+ve women who had been on ARV treatment longer had higher non-adherence scores. Higher non-adherence scores were reported as AAI mean scores around 5 points. The AAI results reported by the present study were also consistent with the findings of Chesney et al. (2000:1602), who reported a negative relationship between adherence and responsibilities for childcare.

The number of HIV+ve women taking ARV treatment increased to 46% by November 2002. However, these results need to be evaluated bearing in mind that not all women (80%) who had had their CD4 quantified by November were eligible for ARV therapy. However, of those who did present for CD4 quantification during the survey period, 50% started ARV therapy. As such, CD4 quantification was for 50% of the HIV+ve women a life-saving measure, since their immune system was depleted to such an extent that they needed ARVs immediately to boost their defences against life-threatening OIs. This might have explained the encouraging AAI scores in this group. The present study found a correlation between the AAI scores and the PCS scores. As in the studies by Williams (1999:13-14), having poor physical health motivated the women with AIDS to be adherent.

Reasons for non-adherence were explored by Kalichman et al. (2001:59) in a convenience sample of 112 women. It was reported in that study that poor adherence to HIV treatments could result from misinformation, forgetting, lack of motivation and side-effects. Among the women who were on ARVs, they found that 46% had missed at least one dose of their ARVs in the past week and were at risk of developing resistance to potentially effective treatments. The study reported the critical role of motivation and behavioural skills, including having HIV treatment-related knowledge about treatment adherence, in predicting missed medication doses (Kalichman et al. 2001:56-66).

### 6.6.2.3 *Limitations*

It was difficult and possibly inappropriate to compare the attitudes-towards-adherence scores of the PLWA/Hs in Botswana with adherence attitudes of participants in USA studies. The encouraging adherence scores in this section of the 116 HIV+ve women need to be considered within the Botswana context and the enormous constraints challenging the MASA programme during 2002. Rolling out this new programme at four sites to thousands of AIDS patients with limited resources resulted in increasingly long queues and more limited time for each patient as the year progressed. MASA counsellors provided information about adherence to all their AIDS patients that were started on ARV therapy. The MASA programme included as a precondition for access to ARV treatment that a family member of the patient was included in this skills-building session as well. Bearing in mind the enormous pressures on the doctors and counsellors, of whom there were too few to deal with all the patients within MASA, it could be explored further how much time is actually available for each patient. (Darkoh 2003:1-7). The pressures of an overburdened care system might be negatively associated with the longer-term attitudes towards adherence, since the AAI assessed the levels of satisfaction with the doctors' *informational-cognitive role* and *empathy* in this group of HIV+ve women (Squier 1990:335).

#### *Limitations due to self-report*

Studies in the USA by Kelly (2002:171-186), Murphy and Canales (2001:173-181) as well as Wood and Gray (2000:1-12) which explored the patients' inclination to stick to a prescribed course of therapy also supported the importance of *mutual partnerships between the carers and patients* in a context where the patients felt they could be *honest* about when they took or did not take their ARVs.

### 6.6.3 *Summary*

The challenges to measurement of adherence and even the terminology used were reported in Chapter 4; the present study focused on self-reported measures and the AAI was designed in such a manner that the results would inform the individual on ARVs on how he or she was doing, as well as giving the health care providers an insight into the

attitudes towards adherence. This mutual partnership based on trust was a key ingredient in assisting the PLWA/Hs to stick to the prescribed regimen. The influence of physical health status was noted, in that being symptomatic motivated or “reminded” them to take their medication. Over time, non-adherence became more of a problem, with better health resulting in missed doses and the like. Within the buddy system techniques were transferred to integrate the medication schedules into daily activities to minimise the risk of forgetting to take the ARVs and/or running out of supplies by reminding each other to go for refills.

### **SECTION III**

#### **LEVELS OF SATISFACTION WITH SOCIAL SUPPORT**

##### **6.7 PERCEIVED LEVELS OF SOCIAL SUPPORT**

The PRQ-II provided a measure of general social support and assessed the adequacy of the PLWA/Hs' perceived level of social support. The buddy system was believed to assist with self-care and promote levels of well-being through the provision of resources that helped participants to deal with crisis and change. The present study was interested in the measurement of supportive functions that were perceived to be available if needed. Findings of perceived support measures were presented in this section, Section III. It was important to tap the availability of resources provided through all social relationships (not just the buddy system) that should help the HIV+ve women to cope with acute or chronic stressors, since no previous studies had been carried out in Botswana. However, various studies from other countries reported that social support was often not available at the time of the HIV+ve diagnosis and subsequently, when the women were coming to terms with living positively with HIV (Chidwick & Borrill 1996:271-284; Fontaine et al. 1997:249-252; Zuyderduin 2000:64-65). It was postulated by Cohen and Syme (1985:13) that the buffering effects of social support are more effective in stressful situations if the support offered matches the needs elicited by the stress the person is experiencing. Commonly reported problems by PLWA/Hs in Botswana were unemployment, threats to self-esteem, barriers to accessing care and concern about the future of their children (Zuyderduin 2000:37-40).

##### **6.7.1 Findings**

The PRQ-II provided a measure of general social support, and scores were calculated by adding the scores on a 7-point Likert scale of the 25 statements. The scores ranged from 25 to 175 points, with higher scores reflecting higher levels of perceived support. The instrument was developed to tap five underlying dimensions: intimacy; social integration; nurturance; worth; and assistance (Weinert 1987:273).

### 6.7.1.1 Statistics in April 2002

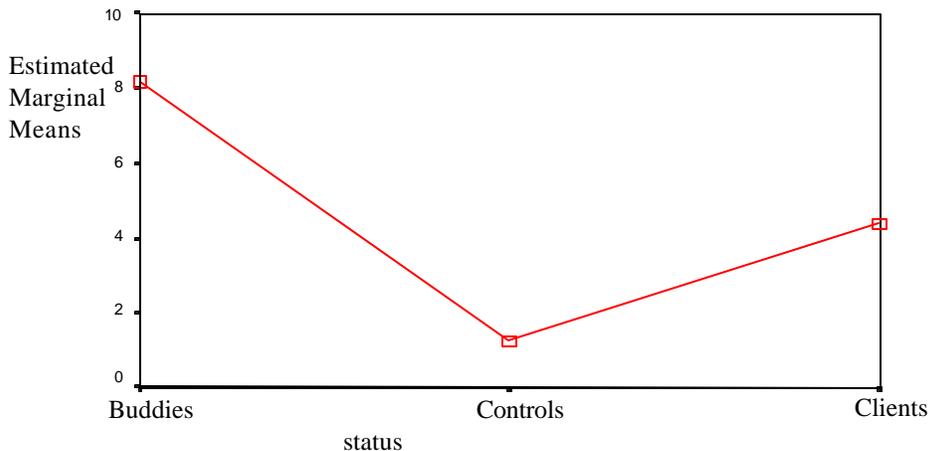
The mean value of the 39 buddies' scores was 143 points (SD = 12.13); this was the highest to begin with. The 38 controls' mean score was 142 points (SD = 17.90). The 39 clients scored 141 points (SD = 12.30), the lowest.

### 6.7.1.2 Statistics in November 2002

The descriptive statistics for November 2002 are as follows. In this case the 35 buddies still had the highest mean, scoring 152 points (SD = 11.35), with the 38 controls scoring 143 points (SD = 19.01), scoring the lowest. The 38 clients scored 146 points (SD = 16.46).

### 6.7.1.3 Analysis of the variables related to perceived levels of social support

The means and standard deviations are as follows. The buddies showed the highest mean increase of 8.2 points (SD = 10.7), and the controls the lowest increase, with 1 point (SD = 12.1). The clients improved by 4 points (SD = 17.9). (See Figure 6.11.)



**Figure 6.11 Estimated marginal means of personal resource questionnaire – part II change between November 2002 and April 2002**

#### *6.7.1.4 Testing for significant differences between the means of the three status groups*

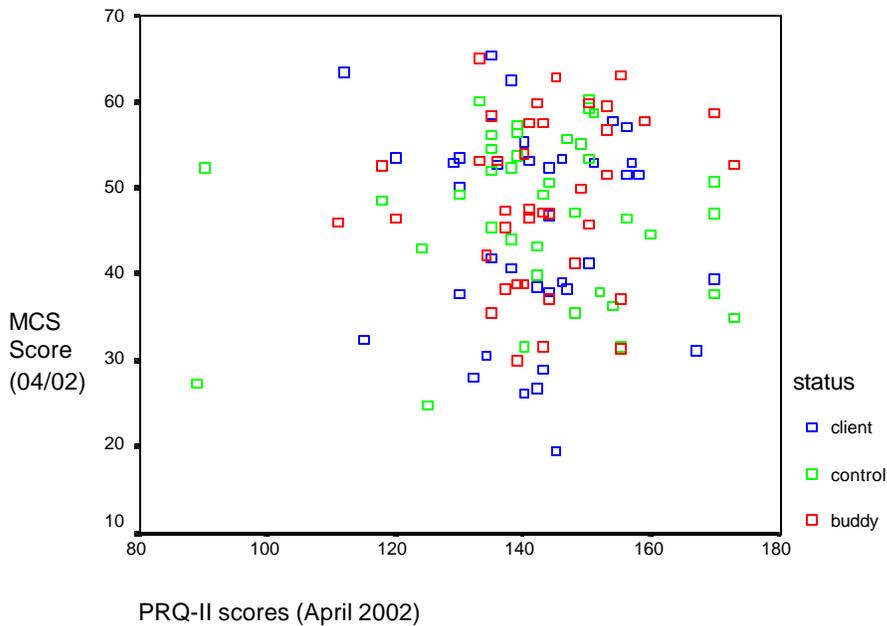
The Kruskal-Wallis non-parametric test was used. The mean values in April 2002 were not significantly different (value .407,  $DF = 2$ ,  $P = 0.816$ ). The means in November 2002 were significantly different at the 10% level of significance, but not at the 5% level (value 4.839,  $DF = 2$ ,  $P = 0.089$ ). The mean changes of the PRQ-II were significantly different at the 5% level of significance (value 6.859,  $DF = 2$ ,  $P = 0.032$ ).

#### *6.7.1.5 Other factors*

None of the factors: marital status, education level, receiving medication for TB, checking CD4 counts, taking ARVs, age, number of children or income, had a significant effect on the PRQ-II values initially, in November 2002, nor on the difference.

#### *6.7.1.6 Quality of life and perceived levels of support*

In April 2002, the correlations between PCS and MCS and perceived levels of social support were as follows. The correlation coefficients of the mean MCS score in April 2002 and the PRQ-II mean scores were significant at the 10% level of significance. The relationship was positive (the higher the PRQ-II score, the higher the MCS score), but the reason did not seem obvious. Even though it was significant at the 10% level of significance, it was not a strong relationship. (See Figure 6.12.)



**Figure 6.12 Mental health component summary scores and personal resource questionnaire - part II scores in April 2002**

*6.7.1.7 Summary of findings*

In summary, answering the fourth research question that asked what the levels of perceived support of the clients prior to engaging with a buddy were and what the changes six- months into the buddy-client relationship were. It was established that the buddies scored 143 points initially, the highest score of the three groups. Six months later the buddies showed improvement and scored 152 points. The buddies showed the highest mean increase of 8.2 points (SD = 10.70). The controls scored 142 points initially. Six months later the controls showed improvement of 1 point and scored 143 points; (SD = 12.09), the controls reported the lowest increase. The clients scored 141 points initially, the lowest score of the three groups. Six months later, the clients showed improvement and scored 146 points. The clients improved by 4 points (SD = 17.88). The mean changes of the PRQ-II were significantly different ( $P = 0.032$ ).

None of the factors marital status, education level, receiving medication for TB, checking CD4 counts, taking ARVs, age, number of children or income had a significant effect on the perceived support levels initially, in November 2002.

## **6.7.2 Discussion**

### *6.7.2.1 Perceived support*

Since perceived support is reported to be of considerable significance for health, it is encouraging to report that during the six-months' survey period the PRQ-II scores improved for all 112 HIV+ve women in the present study (Cohen et al. 2000:87). However, the perceived support for the buddies and the clients progressed faster than that of the controls. The controls reported somewhat lower support scores initially and experienced the lowest mean increase (+1 point).

The buddy system might have contributed to the higher perceived levels of available support. The clients scored the lowest of the three groups initially, but six months later the clients showed an improvement (+5 points) in levels of perceived support. The mean score of the buddies was slightly higher initially and showed the highest mean increase (+8 points). Their scores compare favourably with the PRQ-II scores of American PLWA/Hs. In the present study the PRQ-II scores were higher than those reported in studies by Nunes et al. (1995:174) and Byers et al. (1993:132-136), who also used the PRQ-II with an HIV+ve study sample.

In the study by Byers et al. (1993:134) of the hardiness and social support of 46 HIV+ve men, their PRQ-II scores were 126 points ( $SD = 9.9$ ). The study reported that these PRQ-II scores were not significantly related to CD4 counts. The HIV+ve men with higher perceived support did not report higher CD4 counts. In the study by Nunes et al. (1995:174) of 50 PLWA/Hs, which looked at the relationships between social support, quality of life, immune function and health, the PRQ-II was also used for data collection. That study reported a mean score of 135 points ( $SD = 27.4$ ) and found that social support was significantly related to quality-of-life but not to CD4 counts and perceived health status (Nunes et al. 1995:174-198).

The PRQ-II provided insight into the perceptions of support, and the favourable scores of above 140 points initially for the three status groups and the improvement over time were encouraging. However, buffering effects were not observed since there was no correlation between the PRQ-II and mean PCS scores. The correlation coefficients of the mean MCS score in April 2002 and PRQ-II mean scores were significant at the 10% level of significance. The relationship was positive (the higher the PRQ-II score, the higher the MCS score), but the reason did not seem obvious. The quality-of-life scores of the 116 HIV+ve women in the present study were below the 50<sup>th</sup> percentile line of a scale from 0 to 100, with 100 being the maximum score for optimal well-being. A buffering effect of the buddy system was not supported by the quality-of-life findings, and this might be attributed to small sample size issues presenting as a limiting factor in understanding the significance of the results (Cohen et al. 2000:94). (See Chapter 5.)

#### 6.7.2.2 *Support and mental health*

The experience of social isolation has often been reported in recent studies of HIV+ve men and women in the USA (Anastasio et al. 1995:31-42; Bunting et al. 1999:41-52; Mellors et al. 2001:235-246). Social isolation in PLWA/Hs worsened by the experience of multiple losses, including grieving for loss of their own health, the death of friends and relatives due to AIDS and their changed futures because of the HIV+ve diagnosis, which necessitates profound changes in behaviour. The needs survey by Zuyderduin (2000:65) reported social isolation as well so these experiences in PLWA/Hs in the USA seemed to be expected for the HIV+ve women in the present study as well.

Multiple losses can lead to feelings of hopelessness, apathy and cynicism. These negative sentiments were termed *value-illnesses* by Maslow, who asserted that people need a philosophy of life (Maslow 1999:226).

Although HIV+ve women often acknowledge the negative experiences of their illness, a qualitative study of 54 HIV+ve women by Schirmshaw (2000:343-345) reported that most women admitted that having HIV and AIDS had changed their lives in some positive ways as well. Six forms of stress-related growth were identified:

- 1) positive behavioural changes
- 2) religious/spiritual growth
- 3) growth in relationships
- 4) positive self-changes
- 5) changes in the perception of the value of life
- 6) positive goal-related changes (Schirmshaw 2000:343-345)

In terms of Maslow's theory, finding meaning in illness was of paramount importance and could contribute to the further development of a philosophy of life, integrating the reality of being HIV+ve in this outlook on life and the possibility of premature death. This philosophy could assist in determining what was important to the individual and the issues that needed to be resolved to promote well-being. Maslow stressed the importance of looking into the future, and stated that having distant and even unattainable goals is growth motivating (Maslow 1999:37).

In a qualitative study of PLWA/Hs, it was noted that the awareness or appreciation of time by PLWA/Hs changes; they develop a much more *here and now* focus and this then becomes more of an impetus to:

- accomplish goals
  - partake in activities that would otherwise be delayed
  - treasure everything that is happening now
  - be more compassionate and empathise with the plight of others
- (Schwartzberg 1994:599).

Social isolation upsets the balance between solitude and social interaction that was identified as a universal self-care demand in Orem's theory of self-care. Through the bonds of affection that were fostered in the buddy and client relationships, levels of self-care of all the HIV+ve women in the present study improved over time. The findings of increased disclosure indicated that the women were able to identify people with whom they wanted to share their secret. Perceptions of other people as close friends, or having belonging and self-esteem needs met, as Maslow defined the third- and fourth-level

deficiency needs, might have encouraged this continuing development of self-care actions. (See Chapter 2.)

Reaching outward beyond personal concern or inward towards increased understanding and being there for other people has repeatedly been shown to contribute to the well-being of HIV+ve persons. In a qualitative study by Coward (1994:332-335) among PLWA/Hs, the women identified the following as important in finding meaning in having HIV infection:

- using others as role models
- reaching out to give and receive
- making a difference
- having a purpose (Coward 1994:331-336).

In the present study, there was a positive relationship between perceived support and the mental health (MCS) scores of the MOS-QOL SF-36, but the reasons did not seem obvious. The mental health of the HIV+ve women in the present study was reported separately but its importance viewed holistically. Maslow held that the state of being without values is psychopathogenic. People need to feel needed and be respected by others *and* have the inner motivation to move towards their own growth, based on their own wishes and plans (Maslow 1999:66,226).

### 6.7.2.3 *Gender differences*

Studying the relationship between social support and self-care among senior citizens in the USA, Hubbard et al. (1984:266-270) found that women had a significantly higher score on both social support and health practices than did men. This was found to be consistent with the American cultural norm that encourages women to be more emotionally engaged in relationships than men. In contrast, a recent study among HIV+ve women asserted that quality of life instrument scores that include dimensions of social support in women were found to be lower than those of men (Gielen et al. 2001:316).

The studies by Gielen et al. (2001:315-322) and Hubbard et al. (1984:266-270) affirmed the importance of social support as a variable in health-related behaviour and recommended continuing exploration of the ways in which social support could contribute to women's well-being.

### **6.7.3 Summary**

The finding of meaning in life by HIV+ve women in Botswana is one area in which further qualitative studies could add useful insights, such as how participation in the buddy system contributed to the improved perceptions of social support. The buddy system provided resources to cope with stressful experiences such as disclosure to health care providers in order to access specialised HIV and AIDS care and support. Favourable PRQ-II scores initially in April 2002 and the improvement of these scores over time compared well with findings of PLWA/H samples outside of Botswana. Further studies with HIV+ve men could assist in determining whether gender differences in perceived levels of social support do exist in the Botswana context.

## SECTION IV

### TYPES OF SOCIAL SUPPORT

#### 6.8 TYPES OF SOCIAL SUPPORT

By November 2002, the social support functions that were reported as having been recently provided were assessed through the MOS SSS instrument. Findings of the types of social support were reported and discussed in this section. Measured on a scale of 0 to 100, with 100 being optimal social support levels, the support received was measured in terms of the following constructs: affectionate support; emotional support; positive social interaction; tangible support; and total social support. The underlying rationale for assessing types of support was to describe which dimensions contributed significantly to preventing illnesses or enhanced the adjustment of the HIV+ve women in the present study. Furthermore it was of interest to document the support needs, if any, of the PLWA/Hs in the present study.

##### 6.8.1 Findings

The findings in this section complement the insights gained about the perceived availability of social support by the HIV+ve women as they were reported in the previous section. The MOS SSS instrument measured actual received support. Four distinct types of functional support were measured:

- *affectionate support*, involving expression of love and affection
- *emotional/informational support*, involving the expression of positive affect, empathetic understanding, and the offering of advice, guidance or feedback
- *positive social interaction*, involving the availability of other persons to do pleasurable things with
- *tangible support*, involving the provision of material aid or behavioural assistance

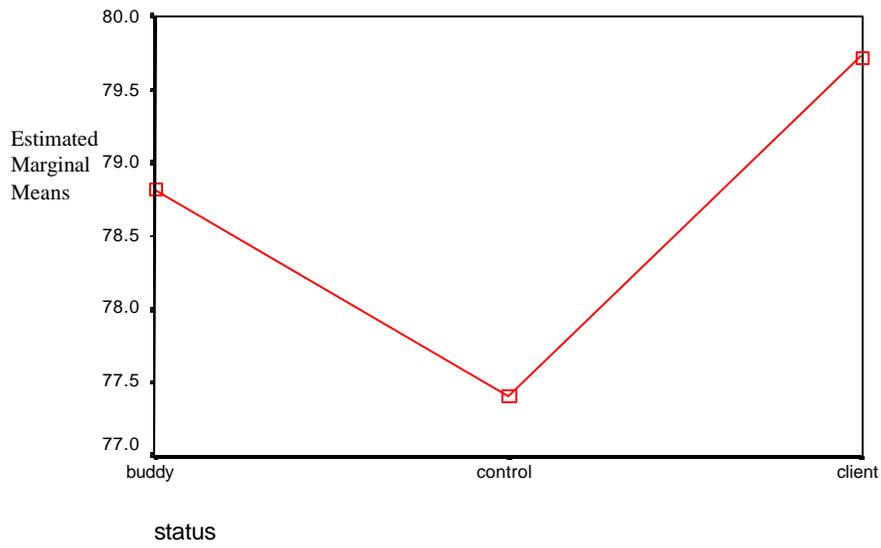
Higher scores for an individual scale or for the overall support index indicated more support. The mean scale scores were transformed to the 0-100 scale, with 100 being the highest level of social support.

*6.8.1.1 Statistics in November 2002*

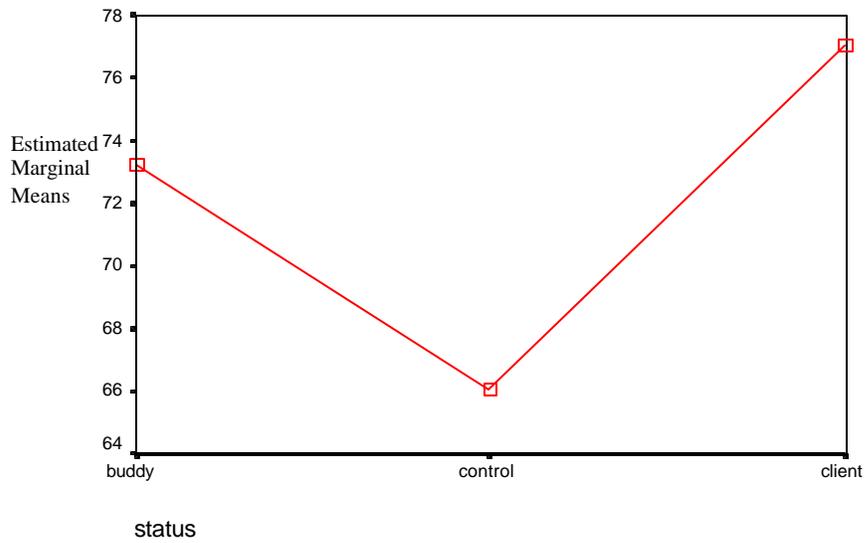
The scores ranged from 72 to 82 points; all social support scores were near to or in the upper 75<sup>th</sup> percentile line on a scale of 0-100, with 100 being the best, indicating that the HIV+ve women were satisfied with the support they received. The relationship between the status of the participants (buddies, controls or clients) and the support received on the five variables was reported as mean scores for the sample:

	<b>All</b>	<b>Buddies</b>	<b>Clients</b>
(1) Emotional Support	79	79	80
(2) Tangible Support	72	73	77
(3) Affectionate Support	80	82	79
(4) Positive Social Interaction	73	77	75
(5) Total Social Support	78	78	78

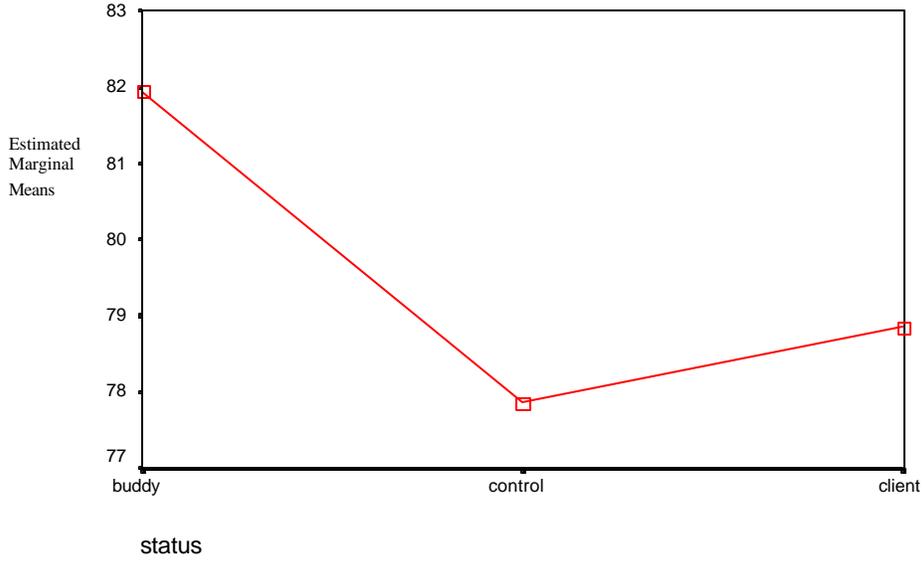
In the cases of tangible support ( $P = 0.073$ ) and total social support ( $P = 0.065$ ) the differences were significant at the 10% level of significance. In the other cases the differences were not significant. The mean values of the five variables for the three groups separately were reported. (See Table A.VI.6, Annexure VI.) Profile plots of the means highlight the differences of the mean value in the three groups with the controls reporting the lowest mean scores in all of the five support dimensions. (See Figures 6.13-6.17.)



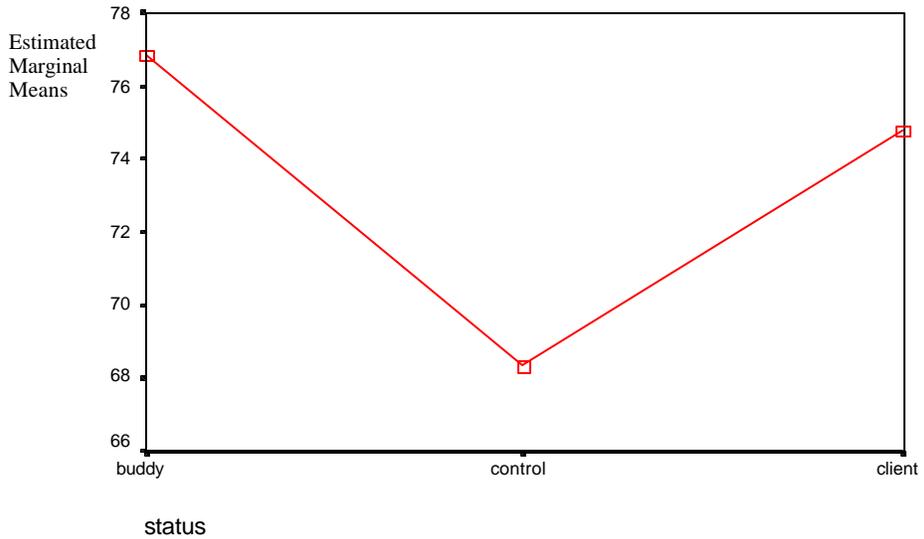
**Figure 6.13 Profile plot of the means of emotional support for buddies, clients and the controls**



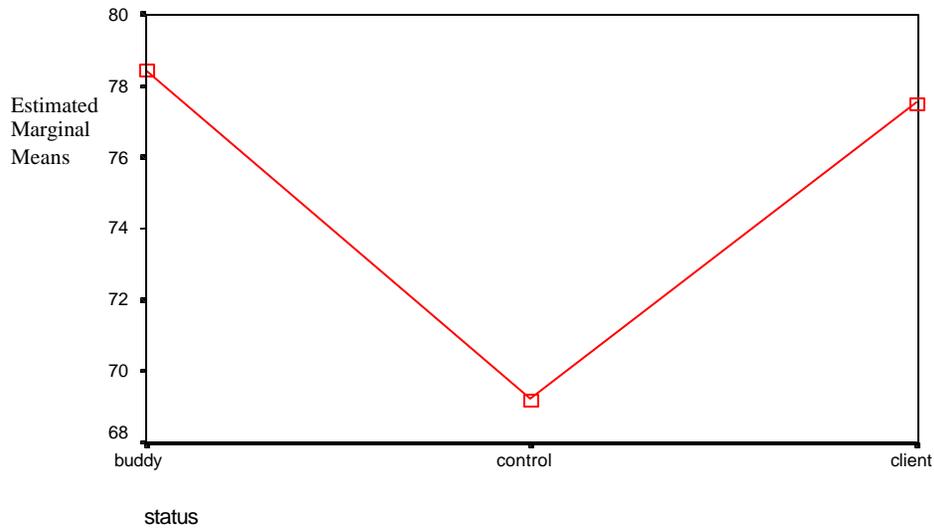
**Figure 6.14 Profile plot of the means of tangible support for buddies, clients and the controls**



**Figure 6.15** Profile plot of the means of affectionate support for buddies, clients and the controls



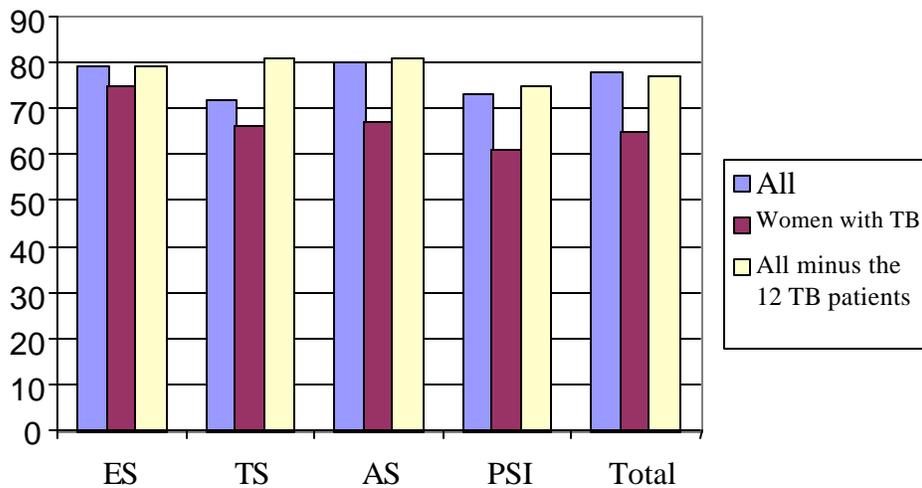
**Figure 6.16** Profile plot of the means of positive social interaction for buddies, clients and the controls



**Figure 6.17 Profile plot of the means of total social support for buddies, clients and the controls**

#### 6.8.1.2 Social support in HIV+ve women with active TB

It was noticed that taking TB treatment in November 2002 was related to the social support variables. In each case, the support received by the participants who were on treatment to cure TB was lower than that received by the others. (See Figure 6.18.)



**Figure 6.18 Social support for all 112 study participants and social support to HIV+ve women with TB (n = 12) and without TB (n = 100) in November 2002**

A non-parametric Wilcoxon (Mann-Whitney) test was performed to test whether these differences were statistically significant. The results were that in the cases of affectionate support ( $P = 0.064$ ) and social interaction ( $P = 0.096$ ) the differences were significant at the 10% level of significance but not at the 5% level of significance. (See Table A.VI.7, Annexure VI.)

### 6.8.1.3 Relationship between status group and receiving treatment for TB.

There was a strong relationship between *status group* and *receiving treatment for TB*. It turned out that the 12 HIV+ve women (10.3%; N = 116) who were receiving treatment to cure TB and who were also, according to the previous step, receiving less support, were all in the buddy group (8 HIV+ve women, 21%) or in the client group (4 HIV+ve women, 10%) but none in the control group. An unbalanced mix of an identifiable lower-support group was observed, which promised to make the differences even more significant if this group of 12 women was omitted from the analysis. The 12 HIV+ve women who were receiving treatment to cure TB were omitted and the three status groups compared again. The means are reported. (See Table A.VI.8, Annexure VI.)

The differences were now more marked, and the Kruskal-Wallis test was again applied to the means. The differences were now more significant. In the case of emotional support there did not seem to be a difference, but in the other variables it seemed that the mean values for the buddies and clients were higher than those of the controls. (See Table 6.4.)

**Table 6.4 Kruskal-Wallis test for significance of differences between types of social support available to buddies, clients and controls with the HIV+ve women who were receiving treatment for TB omitted**

**Test Statistics<sup>a,b</sup>**

	Chi-Square	df	Asymp. Sig.
Emotional Support	.414	2	.813
Tangible Support	6.192	2	.045
Affectionate Support	3.774	2	.152
Positive Social Interaction	6.430	2	.040
Total Social Support	8.604	2	.014

a. Kruskal Wallis Test

b. Grouping Variable: status

#### 6.8.1.4 *Quality of life and types of social support*

The only significant correlations are those between emotional support and the PCS (Spearman's rho = .218,  $P = 0.022$ ) and MCS scores (Spearman's rho = .274,  $P = 0.004$ ) in November 2002 and the change from April 2002 to November 2002. PCS (Spearman's rho = .190,  $P = .047$ ) and MCS (Spearman's rho = .175,  $P = 0.067$ ). See Table A.VI.9 in Annexure VI for the correlation coefficients of the relation of PCS and MCS scores in April 2002 and November 2002 to social support variables in November 2002.

#### 6.8.1.5 *Summary of the findings*

The fifth research question related to what types of social support were available to the buddies and the clients six-months into the buddy-client relationship. The findings pointed out that in November 2002 the buddies and the clients enjoyed high levels of emotional support. The buddies scored 79 and the clients 80 on a scale of 0 to 100. The buddies themselves reported a slightly lower level of tangible support at 73, and the clients scored a bit higher at 77. The buddies fared somewhat better on affectionate support and scored 82; the clients were close with a score of 79. On positive social interaction, the buddies were slightly better off. The buddies scored 77 and the clients 75.

The total social support score was 78, the same for both buddies and clients. It turned out that the mean value of the controls was the lowest in each case. In the cases of tangible support ( $P = 0.073$ ) and total social support ( $P = 0.065$ ) the differences were significant at the 10% level of significance. In the other cases, the differences were not significant.

In each case, the support received by the participants who were on treatment to cure TB was lower than that received by the others. It turned out that the 12 HIV+ve women (10.3%;  $N = 116$ ) who were receiving treatment to cure TB, and who were also receiving less support, were all in the buddy group (8 HIV+ve women, 21%), or in the client group (4 HIV+ve women, 10%), but none in the control group. A non-parametric Wilcoxon (Mann-Whitney) test was performed to test whether these differences were statistically significant. The results were that in the cases of affectionate support ( $P = 0.064$ ) and social interaction ( $P = 0.096$ ), the differences were significant at the 10% level of significance but not at the 5% level of significance.

#### 6.8.2 *Discussion*

The study findings implied a strong relationship between having active TB and being on treatment to cure it and receiving less support from others. Stigma related to TB has been reported in a study by Thorson and Diwan (2001:165-169), which found stigma related to having active TB to be of special importance to women and asserted that it might create a reluctance by the TB patients to get involved with other people. The need for the patient

to attend the clinic for DOTS daily may add to the stigma experienced, because the TB diagnosis is then likely to be evident to other people in the community (Thorson & Diwan 2001:165-169).

#### *6.8.2.1 Social support for HIV+ve women with TB*

The women with active TB had less support at a time when they probably needed it most. Emotional and informational support could have addressed the concerns raised in a study by Steen and Mazonde (1999:163-172) that researched the health-seeking behaviour of patients in Botswana with pulmonary TB. One of the findings was that few patients had a thorough understanding of TB from a biomedical point of view. Even if they had, and understood *how* they had become infected, they considered treatment by a traditional healer necessary, because their questions as to the *ultimate cause* (or the *Why me?* question) needed to be answered; only then could the real cause of the disease be treated and traditional medicine brings a lasting cure. Interesting in the context of the present study is the finding that half of the 212 patients that they studied did not put forward any cause of their disease; either because they were ignorant about infection theories or risk factors or because they had not yet consulted traditional healers (Steen & Mazonde 1999:976-172).

In the present study, when this group who were being treated for TB were excluded from the analysis, there seemed to be a difference and the mean values were higher for the buddies and the clients (except in the case of emotional support) than for the controls. All scores were near or above the 75<sup>th</sup> percentile line on a scale of 0-100, with 100 being the best rating. The findings in the present study of a total support score of 78 for buddies and clients compared favourably with a previous study in the USA that reported a mean score of 66 points for newly registered HIV and/or AIDS clinic outpatients (Burgoyne & Saunders 2000:634).

Informational support was identified as a measure of functional social support (Cohen et al. 2000:90; Cox 2002:425-460; Haile et al. 2002:74-80). Informational support seems to be more relevant if problems cannot be resolved easily and quickly and people need to

search for information, knowledge about resources relevant to the problems and guidance about courses of action. Actual help-giving interactions, self-esteem enhancing behaviours and advice-giving occur together, so esteem support and informational support derive to some extent from the same sources. Provision of advice may be perceived by the person who seeks help as an expression of caring and concern, which would tend to be interpreted as esteem support by the person seeking help (Cederfjall, Langius- Eklof, Lidman & Wredling 2001:31-39; Cohen & Syme 1985:70).

However, Orem pointed out that self-care is both a voluntary and a deliberate action, implying that non-action, even when all information on “what to do” is available, can be expected as well (Orem 1995:95). This was evidenced in the group of 55 HIV+ve women in the present study who were advised to start IPT but did not, and the 20 HIV+ve women who maintained low levels of self-care for ARVs. In terms of Maslow’s theory, two types of knowing were distinguished: *safety* and *growth* knowledge. Maslow stated that all the psychological and social factors that increase fear will cut out the impulse to know. All psychosocial factors that permit courage, freedom and boldness will thereby also free the need to know. Anxiety kills curiosity and the need to explore and get to understand more. If people can be creative and learn new things, then knowledge has a forward-growing function. However, if new things are learned to avoid pain and to become less afraid, knowledge has an anxiety-reducing function, but will not motivate people beyond the basic survival needs (Maslow 1999:76-78).

The mean values of all types of social support of the controls were the lowest in each case. Overall the clients showed more progress towards meeting known health-deviating self-care requisites such as CD4 quantification and self-care for TB and ARVs.

The findings of positive correlation between emotional support, a subscale of the MOS SSS and the PCS and MCS scores in the present study agreed with findings of two studies of HIV+ve women, one by Cederfjall et al. (2001:36) in Sweden and another study by Gielen et al. (2001:319) in the USA. The most significant correlation with these two studies was between the social support score and mental health, suggesting that

social support may have more impact on mental health. The findings of a positive correlation between social support and PCS and MCS scores confirm research findings by Saunders and Burgoyne (2002:689) and Linn et al. (1995:43) and extend the findings to an HIV+ve population in Botswana.

The findings of the present study support Cohen and Syme's (1985:5) premise that social support enhances health and well-being. In the present study, the buddies provided social companionship and encouraged the clients to engage in leisure and social activities. This might have enabled them to access more support or make them feel better about themselves. Companionship might have led to reduction of anxiety levels and motivated clients to be free to explore and gain a greater understanding about living positively with HIV and take self-care actions accordingly. The buddy system provided esteem support, advice and instrumental support and these factors combined correlated with reports of positive mental health and physical well-being.

### **6.8.3 Summary**

In summary, the results of the present study documented satisfactory perceived and functional social support scores by November 2002. Socially healthy persons are believed to be able to cope with day-to-day challenges and to be more likely to engage in family and community activities. Having TB, a communicable disease, resulted in lower levels of support at a time the women needed it most, because having TB and HIV was recognised as a double stigma, limiting social activities and companionship possibly because other people feared transmission of the infections. One out of five buddies had TB and HIV, and despite or because of their own lower levels of support, wanted to support other HIV+ve women. Further exploration of this phenomenon is recommended in future studies.

The buddy system provided motivation enhancement, encouraging the PLWA/Hs to persist in their effort to *live* with HIV and AIDS and communicating their belief that being HIV+ve was not a death sentence. This combination of motivational and esteem-enhancing support buffered some of the stress associated with living with an illness that

has no known cure or vaccine. The buddy system can be termed a protective factor especially effective in times of high stress. These concepts of motivational and esteem-enhancing support were explored within the theoretical framework of the present study. Maslow held that human beings have a responsibility for helping others and being active. His needs theory postulated that non-action has negative effects not only on others but also for the person failing to take action, because he or she must surely feel guilty for the non-action (Maslow 1999:132). In the present study, the association between the practice of self-care and mental/physical health was explored, with the buddy system suggesting new opportunities to improve the quality of life for buddies and clients. Responses to the quality of life questionnaire are reported and discussed in Section V, the next section.

## SECTION V

### QUALITY OF LIFE

#### 6.9 MEDICAL OUTCOMES STUDY - QUALITY OF LIFE

Multiple definitions of “quality of life” exist, according to a study by Ferrans and Powers (1985:15-16), these authors suggested that life satisfaction was the most important dimension to include in any new definition or measurement of the concept. There has been a proliferation of health-related quality-of-life instruments since the late 1980s, since quality of life has been increasingly recognised as an important outcome in and of itself, according to Hays and Shapiro (1992:96). These two researchers were engaged in health care policy and research issues and presented an overview of generic health-related quality-of-life measures for HIV research. They reported that the MOS-QOL SF-36 had distinguished itself as perhaps the most popular generic tool by the early 1990s (Hays & Shapiro 1992:91-97). In the present study an effort was made to determine how the MOS-QOL SF-36 scores produced in Botswana compared with the quality-of-life scores reported in other studies that used the same instrument to understand the differences and the similarities between the results of samples of HIV+ve populations in various countries.

##### ***6.9.1 Findings of the medical outcomes study- quality of life short form-36 domains according to the eight normed variables***

The MOS-QOL SF-36 measures three major health attributes: functional status; well-being; and overall evaluation of health, as well as psychosocial measures. Since there is no consensus definition of quality of life, it was considered important to include both health-related quality-of-life measures and mental health measures (Farquhar 1995:506-507; Ferrans & Powers 1985). For each of the eight health status dimensions, the items were coded, summed and transformed to a scale from 0 to 100, where 100 is the best possible rating (Bult, Hunink, Tsevat & Weinstein 1998:524). (See Chapter 5.)

The scores related initially to all 116 HIV+ve women in the present study. In April 2002, the scores were reported for the 39 buddies, the 38 controls and the 39 clients. By

November 2002, four women had passed away and scores were reported for the remaining 112 HIV+ve women: 36 buddies, 37 controls and 39 clients.

#### *6.9.1.1 Quality of life - general health*

##### *Statistics in April 2002*

The buddies' score was the highest at 66.28 points (SD = 18.84); the controls' mean score was 55.16 points (SD = 18.77), and the clients scored lowest, with 54.49 points (SD = 22.44). The difference between the means of the three status groups initially was significant at the 5% level of significance. The Kruskal-Wallis test of the differences between the three groups was significant at the 5% level of significance (Chi-square value 6.99, DF = 2,  $P = 0.030$ ).

##### *Statistics in November 2002*

The buddies' score was the highest at 67.64 points (SD = 19.48); the controls' mean score was 57.03 points (SD = 24.11) and the clients scored 60.38 points (SD = 23.07). In the case of the November 2002 measurements the difference between the three groups was not significant ( $P = 0.181$ ).

##### *Changes over time*

The buddies (which had been high to begin with) showed the lowest increase, of less than 1 point. The controls' mean scores increased by 2.3 points. The clients showed the highest increase, their mean score increasing by 6 points. The difference between the November 2002 measurements and the initial measurement in April 2002 between the status groups was not significant ( $P = 0.992$ ).

##### *Other factors*

There was a significant relationship with the checking of the CD4 counts. The participants who by November 2002 had checked their CD4 counts ( $n = 90$ ) experienced a mean increase of nearly 5 points (SD = 21.08) in quality-of-life - general health, while those who had not checked their CD4 counts ( $n = 18$ ) experienced a decrease of 5 points (SD = 17.62). The difference between them measured with a Kruskal-Wallis test of the

two means was significant at the 5% level of significance (Chi-square value 4.900, DF = 1,  $P = 0.027$ ). (See Table A.VI.10 in Annexure VI.)

None of the factors marital status, education level, receiving medication for TB, taking ARVs, age, number of children or income had a significant influence on the quality-of-life - general health domain initially, in November 2002 nor on the difference.



#### *6.9.1.2 Quality of life - physical functioning*

##### *Statistics in April 2002*

The mean of the scores of the buddies was 59.36 points (SD = 32.59); the controls' mean score was 64.47 points (SD = 28.35) and the clients scored 67.95 points (SD = 25.41). None of the differences between the means of the status groups were significant ( $P = 0.586$ ).

##### *Statistics in November 2002*

The score of the buddies was 69.44 points (SD = 28.66), the controls' mean score was 67.97 points (SD = 32.82) and the clients scored 75.26 points (SD = 25.55). None of the differences between the means of the status groups were significant ( $P = 0.612$ ).

##### *Change over time*

The buddies' score (which had been high to begin with) showed an increase of just under 10 points. The controls' mean scores increased by 3.5 points. The client group also showed an increase, their mean score increasing by 7 points. The Kruskal-Wallis test for significance of differences between the three status groups was not significant ( $P = 0.623$ ).

None of the factors marital status, education level, receiving medication for TB, checking CD4 counts, taking ARVs, age, number of children or income had a significant effect on the quality-of-life - physical functioning initially, in November 2002 nor on the difference.

### 6.9.1.3 Quality of life - vitality

#### Statistics in April 2002

The buddies scored 61.67 points (SD = 16.20); the controls' mean score was 58.36 points (SD = 21.10) and the clients scored 53.97 points (SD = 25.14). None of the differences between the means of the status groups were significant ( $P = 0.639$ ).

#### Statistics in November 2002

The buddies' mean score was 64.86 points (SD = 17.30), the controls' mean score was 61.62 points (SD = 22.95) and the clients scored 62.18 points (SD = 19.96). None of the differences between the means of the status groups were significant ( $P = 0.985$ ).

#### Change over time

The buddies' scores increased by 3.5 points (SD = 23.59). The controls showed the lowest increase, with 3 points (SD = 15.75). The clients showed the highest increase, with 8.2 points (SD = 17.56). None of the differences between the means of the status groups were significant ( $P = 0.363$ ).

The only significant relationship found was between Vitality in April 2002 and Monthly Income in April 2002. The mean Vitality score of the low-income group was 56 points and the highest income group was 80 points. (See Table 6.5.) The Kruskal-Wallis test of the difference between the means of the income groups was significant (chi-square value 8.204, DF = 3,  $P = 0.042$ ).

**Table 6.5 The difference between mean monthly income and quality-of-life - vitality domain scores**

**Descriptive Statistics**

Dependent Variable: Quality of Life - Vitality

Monthly income- 04/02	Mean	Std. Deviation	N
less than BWP200	55.93	18.778	67
BWP201-BWP600	67.11	19.388	19
BWP601-BWP1500	50.48	27.199	21
BWP1501-BWP4000	70.63	16.784	8
over BWP4000	80.00	.	1

None of the factors marital status, education level, receiving medication for TB, checking CD4 counts, taking ARVs, age, or number of children had a significant effect on the quality-of-life - vitality domain initially, in November 2002 nor on the difference.

#### *6.9.1.4 Quality of life - bodily pain*

##### *Statistics in April 2002*

The means and standard deviations were as follows. The means score of the buddies was 64.95 points (SD = 20.33); the controls' mean score was 60.38 points (SD = 24.58) and the clients scored 55.84 points (SD = 28.55). None of the differences between the means of the status groups was significant ( $P = 0.534$ ).

##### *Statistics in November 2002*

The means score of the buddies was 67.59 points (SD = 22.75); the controls' mean score was 64.26 points (SD = 27.86) and the clients scored 64.39 points (SD = 27.12). None of the differences between the means of the status groups was significant ( $P = 0.959$ ).

##### *Change over time*

The buddies' score (which had been high to begin with) recorded the lowest increase of nearly 2 points (SD = 26.35). The controls recorded a nearly 5 points increase (SD = 32.11). The clients showed the highest increase of 9 points (SD = 26.05). None of the differences between the means of the status groups was significant ( $P = 0.311$ ).

None of the factors marital status, education level, receiving medication for TB, checking CD4 counts, taking ARVs, age, or number of children or income had a significant effect on the quality-of-life - bodily pain domain, initially, in November 2002 nor on the difference.

#### *6.9.1.5 Quality of life - mental health*

##### *Statistics in April 2002*

The means and standard deviations were as follows. The mean score of the buddies was 70.67 points (SD = 17.52); the controls scored 68.16 points (SD = 18.58), and the clients scored 64.10 points (SD = 22.17). The mean score of 71 points of the buddies was the highest to begin with, with the clients scoring 64 points, the lowest. None of the differences between the means of the status groups were significant ( $P = 0.443$ ).

##### *Statistics in November 2002*

The means score of the buddies was 73.44 points (SD = 13.99); the controls scored 69.08 points (SD = 18.03), and the clients scored 71.18 points (SD = 18.68). None of the differences between the means of the status groups was significant ( $P = 0.604$ ).

##### *Change over time*

The means and standard deviations are as follows: In this case, the buddies still had the highest mean, adding 2 points (SD = 31.45); despite a slight increase the controls had the lowest mean of 69 points. The clients improved by 7 points (SD = 30.55) and went up from 64 to 71 points. The three groups experienced an increase in their quality-of-life - mental health domain scores, but none of the differences between the means of the status groups was significant ( $P = 0.245$ ).

None of the factors marital status, education level, receiving medication for TB, checking CD4 counts, taking ARVs, age, number of children or income had a significant effect on the quality-of-life - mental health domain scores initially, in November 2002 nor on the difference.

#### *6.9.1.6 Quality of life - social functioning*

##### *Statistics in April 2002*

The means and standard deviations were as follows. The means score of the buddies was 72.09 points (SD = 24.82), the controls' mean score was 62.51 points (SD = 25.73) and the clients scored 58.69 points (SD = 31.52). The mean value of the buddies, 72 points,

was the highest to begin with, with the clients' score of 59 points being the lowest. None of the differences between the means of the status groups was significant ( $P = 0.122$ ).

#### *Statistics in November 2002*

The means and standard deviations were as follows. The means score of the buddies was 73.15 points (SD = 24.25); the controls' mean score was 73.57 points (SD = 23.91), and the clients scored 72.08 points (SD = 23.89). In this case, the controls had the highest mean of 73.6 points with the clients the lowest at 72 points, while the buddies with 73.1 points scored in the middle. None of the differences between the means of the status groups was significant ( $P = 0.919$ ).

#### *Change over time*

The three means were very close together. The buddies, whose score was high to begin with, showed the lowest increase. The control groups scored an 11-point increase. The clients showed the highest increase with 16 points. None of the differences between the means of the status groups was significant ( $P = 0.175$ ).

None of the factors marital status, education level, receiving medication for TB, checking CD4 counts, taking ARVs, age, number of children or income had a significant effect on the quality-of-life - social functioning domain scores initially, in November 2002 nor on the difference.

#### *6.9.1.7 Quality of life - role emotional*

##### *Statistics in April 2002*

The mean score of buddies was 64.10 points (SD = 40.74); the controls' mean score was 67.10 points (SD = 32.09), and the clients scored 65.81 (SD = 39.36). The buddies scored the lowest at 64 points. The mean value of the controls at 67 points was the highest to begin with. The clients' scores were between those of the buddies and the controls' averages. None of the differences between the means of the status groups was significant ( $P = 0.978$ ).

### *Statistics in November 2002*

The mean score of the buddies was 80.56 points (SD = 34.16); the controls' mean score was 69.37 points (SD = 36.33), and the clients scored 68.38 (SD = 35.01). None of the differences between the means of the status groups was significant ( $P = 0.296$ ).

### *Change over time*

The buddies appeared to have experienced a huge increase of 19 points (SD = 40.19), compared with the controls, who scored an additional 2 points (SD = 39.70). The clients scored 3 points more (SD = 46.12). None of the differences between the means of the status groups was significant ( $P = 0.393$ ).

None of the factors marital status, education level, receiving medication for TB, checking CD4 counts, taking ARVs, age, number of children or income had a significant effect on the quality-of-life - role emotional domain scores initially, in November 2002 nor on the difference.

### *6.9.1.8 Quality of life - role physical*

#### *Statistics in April 2002*

The score of the buddies was 62.05 points (SD = 35.72), the controls' mean score was 58.55 points (SD = 35.01) and the clients scored 56.41 points (SD = 31.79). The mean value of the buddies was the highest at 62 points to begin with, with the clients at 56 points the lowest. None of the differences between the means of the status groups was significant ( $P = 0.713$ ).

#### *Statistics in November 2002*

The means and standard deviations were as follows. The mean score of the buddies was 68.75 points (SD = 35.04), the controls' mean score was 58.11 points (SD = 36.82) and the clients scored 65.38 points (SD = 31.21). In this case, the buddies still had the highest mean with the controls scoring the lowest. None of the differences between the means of the status groups was significant ( $P = 0.429$ ).

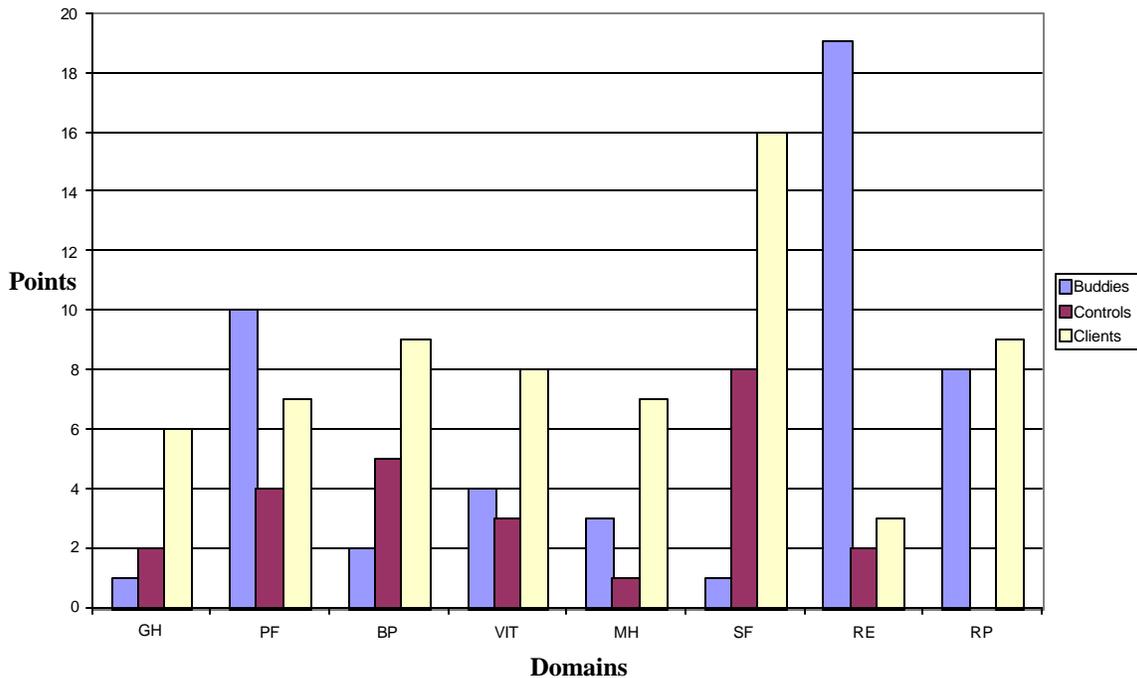
The buddies showed the highest increase with 9 points (SD = 41.81), but the controls showed no increase (SD = 44.48). The clients' increase was almost as high as the buddies' at 8 points (SD = 30.06). None of the differences between the means of the status groups was significant ( $P = 0.594$ ).

The only significant influence was that of receiving medication for TB initially on the quality-of-life - role physical domain scores in April 2002. The Kruskal-Wallis test for significance of differences between the three status groups was significant at the 5% level of significance (chi-square value 4.501, DF = 1,  $P = 0.034$ ). The 31 HIV+ve women who were on drugs to prevent TB had a substantially higher average quality-of-life - role physical domain score of 69 points (SD = 32.08) than the 84 HIV+ve women who did not, scoring 59 points (SD = 33.92).

None of the factors marital status, education, checking CD4 counts, taking ARVs, age, number of children or income had a significant effect on the quality-of-life - role physical domain score initially, in November 2002 nor on the difference.

#### *6.9.1.9 Summary of the findings of the eight domains*

The quality-of-life domain scores of all three status groups changed for the better. The buddies did better than the clients only in the physical functioning domain, and made a very large improvement in the quality-of-life - role emotional domain. The controls also improved, except in the quality-of-life - role physical domain, where they remained at the same level as in April 2002. The clients scored better in six out of the eight quality-of-life domains as compared with the buddies. The biggest improvement was in the quality-of-life - social functioning domain. (See Figure 6.19.)



**Figure 6.19 Increase in mean quality-of-life scores from April 2002 to November 2002**

### 6.9.2 Construction of physical and mental health summary scales

The eight measures of physical and mental health were combined into two measures: one for physical health and one for mental health. This was done in the way suggested in “SF-36 physical and mental health summary scales: a manual for users of Version 1” by John E Ware and Mark Kosinski (Ware & Kosinski 2001).

By combining the mean scores of the following four quality-of-life sub-scales, the PCS was constructed:

- general health perceptions
- physical functioning
- limitation in role-function due to physical problems, and
- bodily pain.

The MCS was constructed by combining the quality-of-life sub-scales relating to:

- limitations in role-function due to emotional problems
- social functioning
- mental health, and
- vitality.

The correlation coefficients among the eight quality-of-life components for April 2002 and November 2002 (See Tables A.VI.11 and A.VI.12 in Annexure VI) were obtained. It was not quite clear, as one might have expected, that these correlation matrices fell into two separate groups of variables, one group for physical health and one group for mental health. Firstly, the sample size was small, and secondly the data referred to three groups of PLWA/Hs. Therefore, the method of standardisation could not logically be based on these data.

Another problem was that standardisation required accurate estimates of the means and standard deviations of these variables based on a large survey of healthy people from the particular population, in this case the people of Botswana. This would require a large survey involving many thousands of people. This has not been recorded.

The best possible course was to use the means and standard deviations from another country. In the present study the available values from the USA were used, which enabled the researcher to compare these HIV+ve women from Botswana with healthy and diseased people from the USA. Unfortunately, data were not available for HIV+ve patients from the USA; therefore, another selection was made for comparison.

#### *6.9.2.1 Descriptive statistics of the eight normed variables for April 2002*

The means, standard deviations, minima and maxima for the April 2002 quality-of-life scores, all HIV+ve women combined (buddies, control and clients), were below 50 points, which was to be expected since the women are HIV+ve and it is not evident what the corresponding mean scores of the healthy population in Botswana would be. (See Table 6.6.) For the three groups, the descriptive statistics were reported. (See Table A.VI.13 in Annexure VI.)

**Table 6.6 Descriptive statistics of the eight normed variables for April 2002 for all HIV+ve women (N = 116)**

Descriptive Statistics					
	N	Minimum	Maximum	Mean	Std. Deviation
Normed PF Score (April 02)	116	13.08	56.76	41.0017	12.62560
Normed RP Score (April 02)	116	25.97	55.56	43.4343	10.05699
Normed BP Score (April 02)	116	17.96	60.40	43.5892	10.52200
Normed GH Score (April 02)	116	16.68	63.78	43.2866	10.24160
Normed VT Score (April 02)	116	20.74	68.66	48.5343	10.15149
Normed SF Score (April 02)	116	12.64	57.33	41.4422	12.45858
Normed RE Score (April 02)	116	25.39	55.66	45.2664	11.29945
Normed MH Score (April 02)	116	17.33	63.97	46.0003	10.85437

*6.9.2.2 Descriptive statistics of the eight normed variables for November 2002*

The means, standard deviations, minima and maxima for the November 2002 quality-of-life domain scores, all participants combined (buddies, control and clients), were generally higher than in April 2002, but still mostly below 50 points, except for the quality-of-life - vitality score (See Table 6.7). For the three groups separately, the descriptive statistics are displayed. (See Table A.VI.14, Annexure VI.)

**Table 6.7 Descriptive statistics of the eight normed variables for November 2002 for all HIV+ve women (N = 116)**

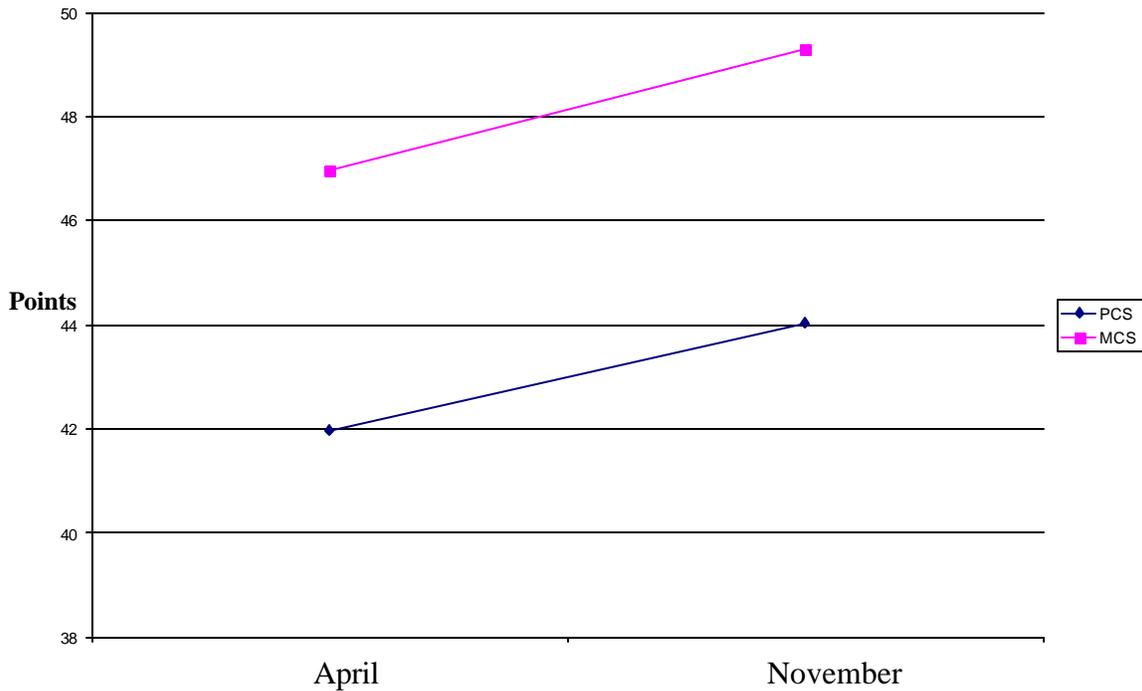
Descriptive Statistics					
	N	Minimum	Maximum	Mean	Std. Deviation
Normed PF Score (11/02)	112	13.08	56.76	44.0852	12.67275
Normed RP Score (11/02)	112	25.97	55.56	44.9296	10.16374
Normed BP Score (11/02)	112	17.96	60.40	45.7065	10.97887
Normed GH Score (11/02)	112	16.68	63.78	44.7416	11.19175
Normed VT Score (11/02)	112	20.74	68.66	50.8638	9.62494
Normed SF Score (11/02)	112	17.61	57.33	45.2267	10.63908
Normed RE Score (11/02)	112	25.39	75.85	47.3732	10.68577
Normed MH Score (11/02)	112	21.77	63.97	47.9859	9.44936

6.9.2.3 *Comparison of the physical and mental health components summary scores*

The mean PCS scores in April were 41.98 points (SD = 8.54) and changed to 44.04 points (SD = 9.62) by November 2002; all scores were below 50 points, but the mean scores increased from April 2002 to November 2002. The PCS scores ranged from 19.14 points to 63.54 points in April 2002. By November 2002, the PCS scores ranged from 14.59 points to 58.89 points.

The mean MCS scores in April were 46.97 points (SD = 10.60) and changed to 49.28 points (SD = 9.25) by November; all scores were below 50 points, but increased from April 2002 to November 2002. The MCS scores ranged from 19.49 points to 65.59 points in April 2002. By November 2002, the MCS scores ranged from 28.11 to 76.12 points. The descriptive statistics for individual groups were reported. (See Table A.VI.15, Annexure VI.)

The descriptive statistics for the mean PCS and MCS scores for April 2002 (N = 116) and November 2002 (N = 112) are given in Figure 6.20.



**Figure 6.20 Physical health component summary scores and mental health component summary scores for April 2002 (N = 116) and November 2002 (N = 112)**

*Analysis of the physical health component summary score variables by status group*  
*Statistics in April 2002*

The means and standard deviations were as follows. The mean PCS score of the buddies was 42.75 points (SD = 7.98). The controls' mean PCS score was 41.46 points (SD = 9.18) and the clients' mean PCS score was 41.71 points (SD = 8.62).

*Statistics in November 2002*

The means and standard deviations are as follows. The mean PCS score of the buddies was 44.48 points (SD = 9.44). The controls' mean PCS score was 42.58 points (SD = 11.07) and the clients' mean PCS score was 44.93 points (SD = 8.34).

### *Change over time*

The buddies improved by 1.8 points (SD = 10.65) and the controls improved slightly with 1.2 points (SD = 12.88). The clients showed the largest mean improvement in PCS scores of 3.2 points (SD = 6.55) from April 2002 to November 2002. (See Figure 6.21.)

### *Analysis of the mental health component summary score variables by status group*

#### *Statistics in April 2002*

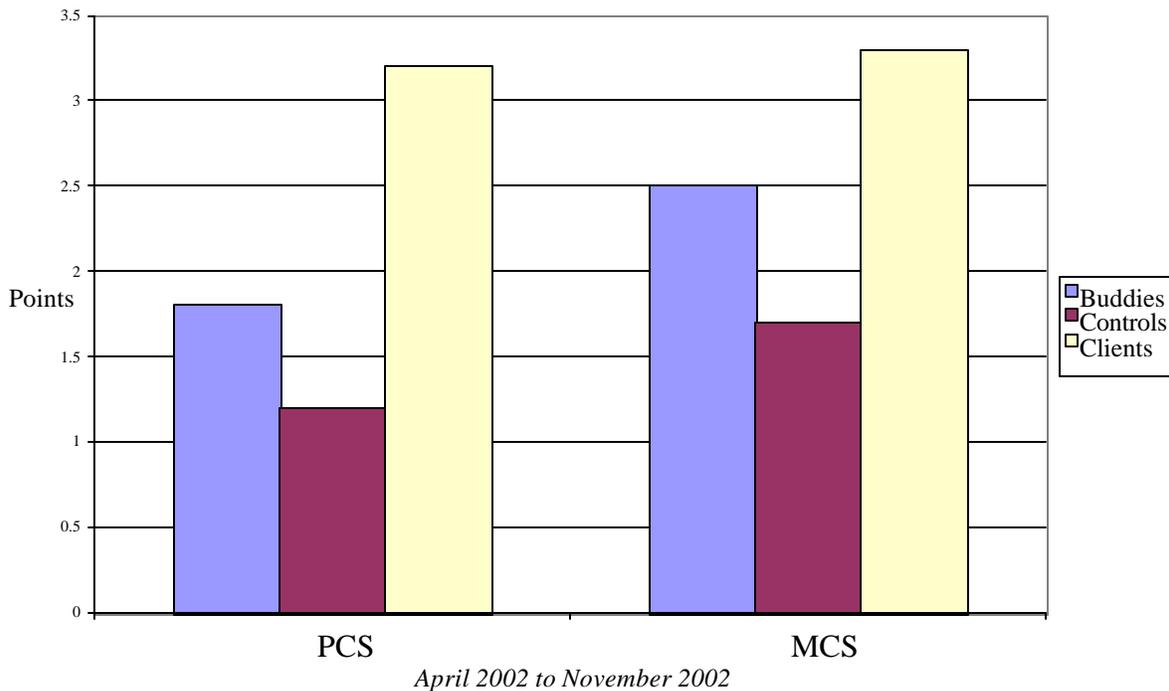
The means and standard deviations are as follows. The mean MCS score of the buddies was 49.00 points (SD = 9.57). The controls' mean MCS score was 47.09 points (SD = 9.52) and the clients' mean MCS score was 44.78 points (SD = 12.32).

#### *November 2002*

The means and standard deviations are as follows. The mean MCS score of the buddies was 51.03 points (SD = 9.16). The controls' MCS mean score was 48.82 points (SD = 9.50) and the clients' mean MCS score was 48.12 points (SD = 9.10).

### *Change over time*

The buddies scores improved by 2.5 points (SD = 10.30) and the controls' scores increased by 1.7 points (SD = 8.66). Once again the clients showed the largest mean MCS score improvement of 3.3 points (SD = 12.02) from April 2002 to November 2002. (See Figure 6.21.)



**Figure 6.21 Physical and mental health component summary mean scores changes from April 2002 to November 2002 (N = 112)**

Non-parametric tests were performed to test whether the differences between the three groups were statistically significant. In none of the cases was statistical significance found (all the significance values larger than 0.05).

#### 6.9.2.4 Summary

The following summary provides answers to the six<sup>th</sup> research question of the quality of life of the HIV+ve buddies and their clients in the present study prior to and six-months into the buddy-client relationship:

### **Eight domains of quality-of-life**

1. **General health** The participants who by November 2002 had checked their CD4 counts ( $n = 90$ ) experienced a mean increase of nearly 5 points ( $SD = 21.08$ ) in quality-of-life - general health domain scores, but those who did not check their CD4 counts ( $n = 18$ ) experienced a decrease of 5 points ( $SD = 17.62$ ). The Kruskal-Wallis test of the two means was significant ( $P = 0.027$ ).

2. **Vitality** A significant relationship found was between quality-of-life - vitality domain scores in April 2002 and monthly income April in 2002. The mean quality-of-life - vitality domain score of the low-income group was 56 points and of the highest income group 80 points. The Kruskal-Wallis test of the difference between the means of the income groups was significant ( $P = 0.042$ ).

3. **Physical Functioning** None of the differences between the means of the status groups was significant ( $P = 0.623$ ).

4. **Body Pain** None of the differences between the means of the status groups was significant ( $P = 0.311$ ).

5. **Mental Health** The three groups experienced an increase in their quality-of-life - mental health domain scores but none of the differences between the means of the status groups was significant ( $P = 0.245$ ).

6. **Social Functioning** The three means were very close together. The clients showed the highest increase, with 16 points. None of the differences between the means of the status groups was significant ( $P = 0.175$ ).

7. **Role limitations due to emotional problems** The buddies appeared to have experienced a huge increase of 19 points ( $SD = 40.19$ ). None of the differences between the means of the status groups was significant ( $P = 0.393$ ).

**8. Role limitations due to physical problems** The only significant influence was the negative correlation of receiving medication for TB with the quality-of-life - role limitations due to physical problems domain scores in April 2002. The Kruskal-Wallis test for significance of differences between the three status groups was significant ( $P = 0.034$ ).

*Summary of Physical and Mental Health Component Summary scores*

The means and standard deviations all HIV+ve women combined were generally higher six-months into the buddy programme, but still mostly below 50 points, except for the quality-of-life - vitality domain score. However, the clients showed the largest mean improvement in PCS scores of 3.2 points from April 2002 to November 2002. The PCS score rose from 41.7 to 45 points by November 2002. The buddies improved 1.8 point to a PCS score of 44 points. In the MCS scores, once again the clients showed the largest mean improvement of 3.3 points, to a total MCS score of 48 points up from 44.7 points by November 2002. The buddies improved their MCS score by 2.5 points to a total of 51 points. In none of the cases was statistical significance found.

The relation of the PCS and MCS scores to the demographic variables and the levels of self-care, social support and attitudes toward adherence were explored to answer the last research question. The MOS-QOL SF-36 results were considered in the context of Botswana and the background information, attitudes towards adherence, perceived and received social support scores were correlated with the eight quality-of-life domain scores and/or the PCS and MCS scores. The results of these correlations were reported and discussed in the section describing and discussing the demographic variables and within the relevant sections I to IV in this Chapter 6.

**6.9.3 Discussion**

Quality of life encompasses multiple aspects of life satisfaction, such as self-esteem, respect, a sense of control over resources, being part of a family and a sense of appreciation and pleasure. Functional health and supportive relationships are important dimensions of quality of life.

### 6.9.3.1 *Quality of life, stigma and coherence*

Looking at the quality of life of the 116 HIV+ve women in the present study included their own assessment in terms of life expectancy and of quality of life remaining. All aspects of quality of life are affected in PLWA/Hs. The early impact of being diagnosed with HIV infection is for the most part an emotional and psychological one. The previous Chapters 3 and 4 of the present study described the coping mechanisms after receiving a HIV+ve diagnosis, the societal levels of stigma and how men often blame women for bringing AIDS into the home. In a qualitative study of women and the PMTCT programmes in Zambia and Botswana, a young, pregnant woman in Botswana aptly described the injustice of facing community stigma:

“When you get AIDS you are ridiculed by society, they laugh at you; they do not regard it as just an illness. You are ill treated, you are no longer related to like before. People think you have been careless, promiscuous. They don’t know that AIDS can just come to you at home.” (Nyblade & Field 2000:20)

The buddy system was designed by and for HIV+ve women who were not unfamiliar with the experiences expressed by this young pregnant woman. Both notions, being stigmatised “*they laugh at you*”, and self-stigma “*people think you have been careless*” had an effect on how PLWA/Hs perceived their quality of life. (See Chapter 4.)

Influencing the results of the MOS-QOL SF-36 of the present study was the self-perceived wellness of the HIV+ve women. Nearly 50% of the 116 women reported advanced stages of HIV infection and needing ARV therapy, their reports of perceived wellness being not only based on physical health or lack thereof but by perceived coherence as well. Perceived coherence is the extent to which persons derive meaning and purpose from their situation, that is, the feeling that they are in control (Berk, Baigis-Smith & Nanda 1995:665). A sense of self-worth and having a positive outlook have been documented as important personality variables relevant to coping with HIV and perceived well-being (Anderson 2000:263; Recvicki, Wu & Murray 1995:173-182).

Destigmatisation of HIV and AIDS requires (self) respect and a change in behaviour in both the HIV-infected and HIV-affected (HIV-ve or HIV status unknown) sections of the population of Botswana. In the light of the misery caused by the AIDS epidemic, all citizens of Botswana have to take action to remain HIV-negative, or if already infected with HIV, prevent HIV transmission. Amidst the estimated hundreds of thousands of PLWA/Hs in Botswana or the millions in the sub-Saharan region, it might be easy to lose sight of the fact that HIV infection is a *preventable* disease. Underpinning all preventative efforts is the notion that people need to take action, do something. In the case of prevention of transmission of HIV, they need to use condoms during sexual intercourse or abstain. The theoretical framework of the present study outlined how Orem emphasised that self-care activities are voluntary and deliberate actions - or inactions (Orem 1995:95). Understanding the self as imperfect, that is, as subject to limitations in knowledge, judgement, decision-making and action is the basis for understanding the theory of self-care underpinning the present study. Nevertheless, Orem was optimistic about people's ability to learn and improve their levels of well-being, even when faced with adversity (Orem 1995:101-103).

Maslow and Orem concurred that it is in the nature of human beings to show intrinsic activity rather than passivity and strive for survival and growth (Maslow 1999:37; Orem 1995:114). Throughout life, people appraise and select from the alternatives available to them and proceed with action. These choices influence quality of life in a positive or a negative manner, depending on the choices made. As social theory explains, other people assert influence on those choices, and these relationships can be helpful or obstructive towards achieving higher levels of well-being. Especially in the case of women in Botswana, the present study reported that they were not always in the position to choose what was best for *them*. (See Chapter 4.)

Maslow explained that human beings depend on other people to meet basic needs, but that to meet growth needs inner resources are tapped. (See Chapter 2.) It was important in the present study to assess these factors "without" the HIV+ve women and collect data on perceived and received support. On both accounts, the HIV+ve women reported social

support scores on a par with or higher than PLWA/Hs in developed countries. Most of the 116 HIV+ve women reported limited disclosure and steered clear of probable stigmatisation. This might have contributed to higher social support. Those who had disclosed to more people seemed to value peer support as well as family support in helping them cope with HIV and AIDS.

The present study reported that emotional/informational support correlated with higher quality-of-life - mental health domain scores. The buddy system was beneficial to perceived levels of support of the clients, who reported higher PRQ-II scores six-months into the buddy-client relationship as compared with the controls. Being a buddy might have been as beneficial to the buddies, for the reason that during the study period they reportedly overcame limitations previously caused by emotional problems. Interviewing PLWA/Hs to find out what kind of emotional problems were experienced, as part of further studies on the health of PLWA/Hs in Botswana might be useful in explaining the marked improvement in this quality-of-life domain during the present study.

The buddy system was designed as a reciprocal relationship (buddies and clients both gave and received). The buddy system assisted in the development of the self-care capabilities for TB and ARVs in buddies and clients. Having peer support was regarded as a resource for better living or quality of life. (See Chapter 3.) Nevertheless, the reported normed quality-of-life (PCS and MCS) scores and mean quality-of-life domain scores were low. Being married, low socio-economic status, being treated for TB and lack of CD4 quantification negatively influenced the reported levels of well-being of the 116 HIV+ve women. This was not an isolated finding of the present study. Researchers such as Deatrack et al. (1999:65) and also Denyes (1988:13) reported that basic conditioning factors in Orem's theory such as income, level of education, and being married were shown to impact on the therapeutic self-care demand. Quality-of-life scores as measured by the MOS-QOL SF-36 in the present study showed that the HIV+ve women's scores on the eight subscales were initially around the 50<sup>th</sup> percentile line on a scale of 0 to 100.

#### 6.9.3.2 Comparison of medical outcomes study- quality of life short form 36 results

The findings in the present study are somewhat *lower* than the findings of two other studies of PLWA/Hs (Bult et al. 1998:523-532; Lamping 1994:31-49). The MOS-QOL SF-36 scores reported by Lamping (1994:40), whose study sample were 81 PLWA/Hs in outpatients' clinics in Canada with CD4 counts below 500 cells/mm<sup>3</sup> and on ARV monotherapy (AZT only) were higher. The mean quality-of-life - physical functioning domain score was 84.51 (SD = 18.28).

Similarity was found to a study by Revicki et al. (1995:177), who studied changes in clinical status and health outcomes of 160 PLWA/Hs in the USA. They administered the MOS-HIV instrument (a related measure to the MOS-QOL SF-36), and reported the following for mean quality-of-life - physical functioning domain scores: 86.5 points for asymptomatic patients, 69.9 points for symptomatic patients and 61.5 points for AIDS patients (Revicki et al. 1995:173-182). This compares with the quality-of-life – physical functioning domain scores of the buddies of 69.4 points, the controls of 67.8 points and the clients of 75.3 points (mean 71 points for three status groups combined) by November 2002. In the present study, 46% of the sample were on ARVs and could be classified as AIDS patients since their CD4 counts were below 200 cells/mm<sup>3</sup>. Nevertheless, the findings in the present study of 71 points were higher than those in a study of the impact of HIV on the quality of life in a multiracial South African population by O'Keefe and Wood (1996:277). Only the reported mean quality-of-life - physical functioning domain score was similar; the other scores of the present study were higher.

In the present study, the clients' scores on the quality-of-life - general health and quality-of-life - vitality domains were particularly low initially. Six months later, these scores improved. However, the clients' highest increase (+16 points) was in the quality-of-life - social functioning domain (ability to visit friends or close relatives). In the quality-of-life - social functioning domain, the clients' score improved to 72 points between April 2002 and November 2002. In comparison, the buddies (+1) and the controls (+12) improved as well, but not as much as the clients (+16 points). Compared with 44 PLWA/Hs in South Africa with CD4 counts of between 200 and 400 cells/mm<sup>3</sup>, the clients' scores were

initially lower at 56 points but increased to 72 points during the study period. The final score in November 2002 of the clients was considerably better than that of the South African PLWA/Hs, who scored 63 points (O'Keefe & Wood 1996:277).

The buddies' greatest improvement (+19 points) during the study period evidenced the fact that they experienced fewer role limitations due to emotional problems. The buddies' score of 81 points and that of the clients, 68 points, on quality-of-life - role limitations due to emotional problems compared favourably with the 47 points of the PLWA/Hs in the study by O'Keefe and Wood (2000:277). The buddies and the clients in the present study reported significantly higher quality-of-life scores on all eight domains as compared with these 32 PLWA/Hs in South Africa. The most significant difference was the higher score (by 35 points) in the role limitations due to emotional problems domain in the buddy group.

The present study's results contrast with pre-ARVs longitudinal studies, in which deterioration in all areas of quality of life occurred over time. Physical function showed a more linear decline with disease progression before ARVs were available to AIDS patients (Lubeck & Fries 1992:359; O'Keefe & Wood 1996:279; Tsevat et al. 1996:44). The present study's results provide additional evidence and extend to a population in Botswana the findings of Saunders and Burgoyne (2002:688) that the introduction of ARV therapy might have had an overall positive impact on the quality-of-life domains for the 52 HIV+ve women that were on ARV therapy by November 2002. This was based on the findings of an overall improvement, not a decline, in quality-of-life scores over the study period, and the better quality-of-life scores among those who engaged in self-care for TB and ARVs as compared with those HIV+ve women who did not.

#### *6.9.3.3 Quality of life summary scales and gender*

In the few studies that have compared PLWA/Hs on quality-of-life indicators, women have generally been found to score lower than men, even after controlling for disease stage (Linn et al. 1996:43; O'Keefe & Wood 1996:277; Wachtel, Piette, Mor, Stein, Fleishman & Carpenter 1992:129). No data were available in Botswana pertaining to men

or other groups of women (HIV-ve or HIV+ve) on quality-of-life PCS and MCS normed scales scores, so no comparison of the quality-of-life scores of the HIV+ve women reported in the present study could be made.

However, study results from samples in other countries were compared. The mean PCS score of 44.04 (SD = 9.62) and the MCS score of 49.28 (SD = 9.25) reported in November 2002 in the present study corresponded with the findings of Call et al. (2000:980). The mean PCS scores in the present study were slightly lower (-1.08) than those of 16 participants with an undetectable viral load (45.15; SD = 13.15) in the study by Call and colleagues. The MCS scores of the HIV+ve women in the present study were significantly higher (+8.30) than those found in these 16 American patients (40.98; SD = 11.87). Call and colleagues concluded that lower viral loads were achieved through a period of effective ARV treatment and that this positively influenced the quality of life of HIV+ve patients (Call et al. 2000:980). The 52 HIV+ve women in the present study were mostly new to ARV treatment and a proportion of them might not have achieved the lower/undetectable viral loads by November 2002 that were given as a possible explanation for the improved PCS and MCS scores in the study by Call et al. It was mainly due to the higher quality-of-life - vitality and quality-of-life - social functioning domain scores of the HIV+ve women in the present study that higher scores were reported.

Orem and Maslow asserted that individuals can achieve well-being even when faced with adversity, and in the present study having peer support was a helpful resource towards achieving higher levels of well-being. Within the supportive relationship, motivational and esteem support were exchanged, and self-care capabilities developed and strengthened. (See Chapter 2.)

#### **6.9.4 Summary**

To summarise, the quality of life of the 116 HIV+ve women in the present study was less than optimal. Quality of life was recognised as a concept representing individual responses to the physical, mental and social effects of HIV and AIDS on daily living,

which influenced the extent to which personal satisfaction with life circumstances was achieved. As a result, the PCS and MCS scores included more than information on health-related quality of life by including perceptions of well-being, self-worth and self-esteem (Bowling 1998:51). The MOS-QOL SF-36 data obtained before and after the implementation of the buddy system were useful in evaluating quality-of-life scores and the effectiveness of the buddy system. Similarities were found with the MOS-QOL SF-36 results of 32 PLWA/Hs in South Africa on quality-of-life - physical functioning, but scores of the 116 HIV+ve women were higher on the other seven quality-of-life domains, particularly in the role limitations due to emotional problems domain. The findings of normed quality-of-life domain scores of below the 50<sup>th</sup> percentile line on a scale of 0 to 100 in the present study are consistent with quality-of-life scores in studies of PLWA/Hs in the USA and extend these to an HIV+ve population in Botswana (Call et al. 2000:980; Te Vaarwerk & Gaal 2001:109-115).

## **6.10 CONCLUSION**

There is no other disease in the 21<sup>st</sup> century that carries as much social stigma and negative social implications as HIV/AIDS. The 116 HIV+ve women in the present study are coping with their illness and the findings of the study showed an overall increase in their self-care actions for TB and ARV. This contributed to the prevention of the most common OI in HIV+ve people in Botswana and provided the women with ARV treatment benefits. Nevertheless, the findings indicated that there was a need for continued support of the HIV+ve women in meeting their known requisites for functional and developmental regulations. The findings of a negative trend in the attitudes towards adherence, especially in the women who had been on treatment longer, were of concern. The risk of the development of resistant strains of HIV was reported in the developed world and is of major concern in Botswana as well. Income, levels of education and marital status were identified as basic conditioning factors predicting self-care abilities in this group of HIV+ve women. The women were enabled to share their HIV+ve diagnosis with more people; the majority of the HIV+ve women were in November open about being HIV+ve to twice as many people as they had been before April 2002.

An overall improvement of quality of life was reported, the increased access to ARVs and prevention of TB infection making a positive contribution to the women's functional health. Nevertheless, the perceived quality of life is less than optimal. Meeting their deficiency needs was not easy for these 116 HIV+ve women and these difficulties were presented as low quality-of-life scores in the physical and mental health domains.

In the interest of healthful functioning, pairing the clients with the buddies was reportedly of some benefit to both buddies and clients. Perceived and received social support contributed positively to levels of well-being and motivated the HIV+ve women to adjust to living with HIV.

The underpinnings of both Maslow's and Orem's theories were instrumental in the discussion of the findings. The fact that both theorists in their different disciplines expressed their belief that it is indeed possible to experience well-being in adversity, provided people are not isolated, confirmed the value of including social support theory that asserted that being in supportive relationships is critical for well-being. The buddy system provided a mechanism for linking formal and informal caregivers, with the buddies fulfilling mainly supportive/guiding roles and partly compensatory roles, and referred the clients to HBC services of formal health care institutions for wholly compensatory care when physical health deteriorated.

The power to act was deliberately exercised by the 116 HIV+ve women in the present study in the form of care of self and others, in identifying needs of self and others, and in making the needed input. Since self-care is learned behaviour, the buddy system allowed for expansion of self-care repertoires and coping mechanisms.

In the last chapter of this thesis, tentative conclusions to the present study will be presented and recommendations for further research provided.

**CHAPTER 7**  
**CONCLUSIONS AND LIMITATIONS OF THE RESEARCH:**  
**RECOMMENDATIONS FOR FUTURE RESEARCH**

**7.1 INTRODUCTION**

Bearing in mind the study limitations, several conclusions were nevertheless reached at the end of the present study. These conclusions and recommendations for further research will be presented in this chapter. An insight gained from the present study was that when poorer and less educated HIV+ve women come together as a group they may be able to collectively discover options that allow them to overcome many obstacles.

In Botswana, the government, HIV/AIDS policy makers, health care professionals and other concerned sections of society have recognised the problem of widespread denial of the impact of HIV on society. Innovative strategies are required to sensitise the people of Botswana to the fact that all citizens are either infected by or affected by HIV. The devastating impact of the AIDS epidemic has to be faced and the citizens of Botswana need to participate and come up with culturally appropriate solutions to the multiple challenges posed by AIDS. A local non-governmental organisation of PLWA/Hs showed initiative and came up with a unique programme resulting in an African buddy system providing care and support. This programme seeks to break the silence surrounding women living with HIV and AIDS and encourages HIV+ve women to access care and support.

**7.2 CONCLUSIONS**

Although firm conclusions would need additional studies, the following conclusions were reached on the basis of the data gathered and analysed in the present study.

It was concluded that the buddy system was helpful in overriding the HIV+ve women's socially acquired bias towards care for others and their tendency to ignore their own needs. The findings of the present study revealed that the buddy system encouraged the HIV+ve women to take care of themselves as well as their families. The present study's findings relating to the health-deviating self-care actions for TB and ARVs demonstrated that the buddies had the expertise and behavioural skill-building techniques to encourage their clients to be more active in meeting their self-care requisites. By seeking social support, preventing opportunistic infections such as TB and going on ARVs when needed, the HIV+ve women achieved higher levels of well-being.

Having TB and HIV was shown to be of special importance to health outcomes. The present study revealed that HIV+ve women with TB needed special attention and support to cope with the double stigma associated with having TB and HIV/AIDS, but the women reported that they perceived the levels of support available to them to be low.

The findings of the present study showed that the buddy system contributed to higher levels of disclosure; the clients were more open, in comparison with the controls, and after the six-month study period more buddies had told over 30 people of their HIV status. Increased levels of disclosure during the study period might be an indication that the buddy system was to some extent effective in decreasing levels of self-stigma on the part of the HIV+ve women. The ongoing public health education campaigns sensitising the public to the needs of HIV+ve people might also have contributed to acceptance of HIV+ve members within the family. The buddy system provided one-on-one peer support, encouraged PLWA/Hs to accept themselves and motivated the PLWA/Hs to engage in social activities. This is believed to have expanded the number of people they could call upon when they needed care and support. The study furthermore reported a positive relationship between emotional support and mental health, bearing in mind that the changes in the overall group do not necessarily reflect the unique outcomes for each HIV+ve woman.

The findings of the present study indicated that peer support by and for women living with HIV was effective in increasing the number of people the buddies and clients could talk to about their experience of living with HIV. Increased openness and ability to talk about being HIV+ve is the first step towards accessing appropriate health care and support. The buddy system contributed to making HIV a real issue within families, not something people had heard about on the radio. Stigmatising and discriminatory behaviour in some individuals might cease with the knowledge that their mother, sister or daughter was also HIV+ve. Increased openness by women living with HIV and the distribution of correct information about HIV and AIDS at community level might have added a different and possibly much needed perspective. The buddies were there for their clients in their homes, encouraging dialogue and positive coping within the families. This buffer function was important to the woman disclosing and possibly cushioned the impact of the first reactions to the news to family members that their relative was living with HIV. Through their training and application of the learned skills, the buddies contributed to improved levels of well-being over the six-month study period.

The findings of the present study contributed to the understanding of informational and emotional support for clinical outcomes related to ARV therapy. Overall attitudes towards adherence involved emotional and social components; in the present study, the results were good but showed a negative trend during the six-month study period, especially in those women who had been on ARV therapy for a longer time. Without intervention, these women might be at risk for developing resistance to potentially effective treatments. This finding is important for purposes of service delivery of skills and knowledge required by people living with HIV and AIDS, in order for them to participate fully in their care plans and to adjust to the realities of sustaining lifelong commitment to ARV therapy.

Being a role model was found to be an important motivational factor in the buddy system. Altruistic behaviour by the buddies might have contributed to the buddies' mental health and have assisted in giving meaning to their living with HIV. Being needed and appreciated by others might have contributed to the reported higher levels of well-being

of the buddies. Self-actualising behaviour in all the HIV+ve women in the present study, through for example mastery of self-care behaviour, is believed to have contributed to quality of life and optimal well-being. Nevertheless, the finding that the mean quality-of-life scores of the 116 HIV+ve women were low was not surprising, given the consistently strong negative relationship between quality of life and HIV/AIDS reflected in research reports (Akinsola & Popovich 2002:761-772; Anastasio et al. 1995:31-42; Call et al. 2000:977; Murdaugh 1998:59).

The present study reported on both deficiency and being needs, and these mixed findings were in agreement with the premises of both Orem and Maslow that all human beings make a continuous contribution to their own life and strive towards needs fulfilment.

In addition to the efforts of their clients, the buddies were able to boost the power components and the motivation of their clients. Basic conditioning factors such as income, marital status and education predicted self-care ability and were an important factor in the recognition that lower-level deficiency needs such as lack of food and shelter caused by poverty hamper the meeting of health-deviating self-care requisites.

The challenges posed by living with HIV might have negatively influenced the quality-of-life scores in this group of HIV+ve women. Nevertheless, the 116 HIV+ve women reported satisfaction with their social support and a degree of well-being under adverse circumstances such as stigma, undesired side-effects of their ARV therapy and OIs.

The insights of the two theorists, Orem and Maslow, were valuable in understanding that well-being is a matter of degree and of frequency rather than an all-or-nothing affair. Maslow believed that encouragement of personal growth is a real possibility, and asserted that healthy people are made by a healthy culture, but that it is just as true that sick people make their culture sicker and that healthy people make their culture healthier. Maslow held that improving individual health was one approach to making a better world (Maslow 1999:7).



## 7.3 LIMITATIONS OF THE PRESENT STUDY

### 7.3.1 *Participation of HIV+ve women*

All the women in the present study were registered members of COCEPWA. A group of HIV+ve women had been given the opportunity to contribute their ideas on how to adapt the *American* buddy programme into an *African* buddy programme prior to the start of the present study. The majority of these pioneers had by April 2002 been trained as buddies.

The researcher faced two challenges concerning the participation of the HIV+ve women. Firstly, the present study was unique in the sense that after the needs assessment by Zuyderduin (2000:1-70), it was the first local study which *involved* women living with HIV and AIDS in Botswana in

- deciding upon some of the objectives of the present study, and
- evaluating the effectiveness of the buddy system.

Secondly, the design of the present study was informed by the challenges of doing a study with women who were extremely cautious and valued the privacy of information relating to their HIV+ve status. The study participants had disclosed their HIV+ve status to one or two peers within COCEPWA, but possibly not to their “significant others” such as their partner, parents or children.

The meaningful participation by the buddies in the present study motivated the other HIV+ve women who were not eligible to be trained as buddies and who were randomly assigned to either the client or the comparison group to participate as well. The researcher was known to the study participants and based within COCEPWA, and this might explain the high completion rate for all the questionnaires, initially in April 2002 and six months later in November 2002. This awareness by the buddies of the objectives of the buddy programme might have been a limitation in that it could have influenced some of their responses to the questions posed. The possibility of introducing bias was acknowledged

and conscious efforts were made throughout the present study to document all findings objectively.

### ***7.3.2 Role of the researcher***

The researcher was not coordinating the buddy programme but was based within the organisation during the study period. Great care was taken to be objective and report the findings of the study objectively. Without this relationship between the researcher and the HIV+ve women, the research would very probably have been impossible. The HIV+ve women had never participated in any official research project prior to the present study. The involvement of the researcher with COCEPWA from early 2000, a period during which trust was established prior to the study, was an essential factor in the study. All research findings were reported objectively.

### ***7.3.3 Design of the study***

This study would have greatly benefited from a more flexible design, using open-ended questions and an ability to add and change questions. However, at the initial stages of the design of the present study, the HIV+ve women would not have been comfortable with more direct contact, tape recording of interviews or group discussions.

The data collection of the present study was based on self-reports by the HIV+ve women. As mentioned in the literature review section, Chapter 4, and as shown in the present study's results in Chapter 6, the women living with HIV and AIDS have a slightly lowered psychological condition. This comprehensive survey, with its multiple questionnaires, may have been a burden to them and may have compromised the answers to some degree. In order to study predictors of quality of life among PLWA/Hs, a large number of variables had to be tested, because quality of life is believed to be under the influence of many factors, from demographic characteristics to clinical conditions. For these reasons the current findings should be considered preliminary and in need of independent replication.

### **7.3.4 Sampling**

Before any inferences and suggestions can be generalised from the present study to a population, for example, all women living with HIV and AIDS in Botswana, several characteristics of the sample should be addressed. All the 116 HIV+ve women were members of COCEPWA and had had access to basic knowledge and training in HIV and AIDS and supportive counselling by peer counsellors from COCEPWA before the data were collected in April 2002. The resultant data might be prejudiced in unknown ways, insofar as information was obtained from willing participants only in the present study. This survey is not perfectly representative of the all women living with HIV because of the non-random sampling method.

### **7.3.5 Data analysis**

The conclusions drawn can only refer to the sample of 116 HIV+ve women, a relatively small sample. The HIV+ve women were all members of COCEPWA and they might have influenced one another's responses to the test. This might have caused the results of the statistical tests (such as correlations or *P*-values) to be inaccurate. One way this was avoided was by aggregating individual cases to the higher level, using the three status groups as the unit of analysis, rather than the individual HIV+ve women. Unfortunately this required sacrificing some statistical power, making a Type II error more likely.

## **7.4 RECOMMENDATIONS**

Certain recommendations can be considered in this setting, based on the findings obtained in the present study.

- Because social support and self-care are dynamic factors that are embedded in a social environment that is always changing, *longitudinal study design* with both male and female study participants would be a powerful tool for examining the relationship between self-care, social support and quality of life over a number of years.

- The present study was designed in 2001; shortly thereafter the MASA programme took off. Early in 2002, CD4 quantification and viral load testing were only done in Botswana, Gaborone, in clinical research settings, and most women had never had access to such services and as a result did not know their laboratory markers. Since then, considerably more AIDS patients could access specialised care, as compared with the situation in Botswana in early 2002. Future studies could benefit from reliable *validation of medical markers* such as CD4 counts and viral load.
- Future HIV-related quality of life research studies extending over longer periods could be done to determine the impact on well-being afforded by ARV therapy. *The positive and negative impact of the ARVs on well-being* is of interest, since ARV therapy can retard disease progression and extend length of life, but also poses unpleasant side-effects that could potentially erode the quality of life.
- It could be useful to include measures related to *finding meaning in adversity* in future studies that examine the relationship between social support and quality of life among HIV+ve people.
- Quantitative methodology was selected and judged as an appropriate investigative tool by the study participants, partly because the women concerned feared disclosure of their HIV+ve diagnosis. Nevertheless, the present study reported that more HIV+ve women had disclosed to over 30 people by November 2002, and qualitative research methodology is recommended for future studies in order to gain deeper understanding of the positive and negative effects of disclosure on social support, self-care and quality of life issues.
- The theoretical framework of the present study integrated Orem's theory of self-care, Maslow's hierarchy of needs theory and aspects of the social support theory. The effectiveness of the helping relationships within the buddy system hinged on the notion that support from without, and motivational and self-esteem support

between peers who share the experience of being HIV+ve, would boost the power within individuals to strive for self-actualisation. This theoretical framework could in future be applied to and tested with other stigmatised or vulnerable populations.

## **7.5 THE WAY FORWARD**

Botswana's vision for the future is carefully optimistic, intensifying the local efforts to ensure a complete turnaround of the AIDS epidemic. The next few years will be very challenging. The impact of the AIDS epidemic is distressing, but within Botswana a tremendous effort is being made to win the war against HIV/AIDS. The main national challenges will be coordination and funding of this effort. Implementation of the HIV/AIDS programmes is time-consuming and shortages of human resources hamper progress. High levels of HIV-related stigmatising of PLWA/Hs are evidenced in rejection, denial, discrediting and social distancing, and frequently lead to discrimination and violation of human rights.

While the challenges are great, the buddy system of care and support for and by women living with HIV or AIDS has a future in a resource-limited country searching for culturally appropriate ways to reach the community with informational and emotional support. After successful evaluation in March 2003, the Botswana buddy programme will from mid-2003 onwards be replicated. The Botswana buddy programme will be adapted to the prevailing realities in the southern African region, function as the community-based care, and support component in four new comprehensive pilot ARV programmes in Lesotho, Namibia, South Africa and Swaziland. Close to 1500 buddies will have to be trained in these four countries combined by 2005.

The buddies, as members of their communities, are role models of positive living and have the skills to motivate their peers to be self-reliant and access specialised HIV care services when needed. Research involving PLWA/Hs should be stepped up in order to

contribute effective inputs into future policy developments and the design of future health care delivery systems acceptable and accessible to PLWA/Hs.

This quantitative study of women living with HIV in Botswana succeeded in uncovering predictors of self-care, provided insight into levels and types of social support available to the women and into how being HIV+ve impacts on levels of well-being. Keeping one's HIV+ve diagnosis a secret causes mental anguish and loneliness and presents a formidable barrier to accessing available care and support. The HIV+ve women coming up with this unique buddy programme knew what they needed. The first duty was not *to do* but *to be* in the buddy-client relationship. Poem 1391, written in about 1877 by Emily Dickinson (1961:597), expresses this simple but profound undertaking of *being there*, and the dilemma of how to resolve the tension between isolation and connectedness that was foundational to all progress made in the present study:

*They might not need me - yet they might -  
I'll let my Heart be just in sight -  
A smile so small as mine might be  
Precisely their necessity - (Dickinson 1961:597).*

