THE ROLE OF TREATMENT BUDDIES IN THE PUBLIC-SECTOR ANTIRETROVIRAL PROGRAMME IN THE FREE STATE PROVINCE

By

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DECLARATION

I herewith declare that this thesis submitted by me for the Doctor of Philosophy Degree in Development Studies at the University of the Free State is my own independent work and has not previously been submitted to any other university/faculty. I further cede copyright of the thesis in favour of the University of the Free State.

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LIST OF ACRONYMS AND ABBREVIATIONS

HIV	Human immunodeficiency Virus
AIDS	Acquired Immune Deficiency Syn**dr**ome
NDoH	National Department of Health
WHO	World Health Organisation
UNAIDS	Joint United Nations Programme on HIV/AIDS
ASSA	Actuarial Society of South Africa
NGOs	Non-government Organisations
MSF	Medecins Sans Frontieres
PEPFAR	President's Plan for AIDS Relief
ANC	Ante-natal Care
STD	Sexuality Transmitted Diseases
TAC	Treatment Action Campaign
ARV	Antiretroviral
SACBC	South African Catholic Bishops Conference
TB	Tuberculosis
GTB	Global Tuberculosis programme
CHW	Community Health Worker
DOTS	Directly Observed Treatment Short-course
DOT	Directly Observed Therapy
DAART	Directly Administered Antiretroviral Therapy
NCM	Nurse Case Management
DREAM	Drug Resource Enhancement against Aids and Malnutrition
CM	Case Management
HAART	Highly Active Antiretroviral Therapy
COCEPWA	Coping Centre for People living With HIV/AIDS
IMB	Information-Motivation Behavioural
MEMS	Medication Event Monitoring System
MDOT	Modified Directly Observed Therapy
CHaMP	Connecticut HIV Medication Project
ART	Antiretroviral Therapy
SC	Standard of Care group
IG	Intervention Group
CG	Control Group
ANOVA	Analysis Of Variance
FE	Fixed Effect
RE	Random Effect
STI	Sexually Transmitted Illness

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ABSTRACT

Recent advances in antiretroviral treatments have simplified dosing regimens for people living with HIV. Yet, typical regimens still remain far more complex than treatments for other health conditions and adherence continue to concern health care providers. Adherence to antiretroviral therapy still dominates debates as one of the challenges facing HIV positive patients and the health service delivery. Thus, support for people on antiretroviral therapy becomes fundamental. It sis therefore argued that treatment buddies can be critical element in enhancing adherence and in retaining patients in care

Against this background, research was undertaken to assess the role of treatment buddies in the South African public sector antiretroviral treatment programme as implemented in the Free State province. To achieve this aim certain objectives and hypothesis were identified and based on these objectives, five key outcomes for the study were identified. This study used two sources of data: (i) data collected from a longitudinal study conducted among patients enrolled in the public sector antiretroviral treatment programme (patient survey) and (ii) data from once-off individual interviews conducted with treatment buddies of patients interviewed as part of the patient survey (treatment buddy survey). Patients included in the analysis represent the sub-sample of patient respondents in the survey observed at least once in each of the four phases of the treatment career (n=160). Following the completion of the sixth and final round of the patient interviews, telephonic interviews were conducted with treatment buddies (n=55) using a semi-structured interview schedule to supplement information on treatment buddies collected in the patient survey as well as to provide insight into some findings from the patient survey data.

Analyses for the purposes of this study focused on an investigation of treatment support and related outcomes over the treatment career. Various bivariate and multivariate regression analyses were performed separately for point estimates and change outcomes for each of the five main outcomes. Differences and transitions in key explanatory variables were regressed on point estimates of the main outcomes, while point estimates and lagged differences or transitions in key explanatory variables were regressed on differences and transitions in main outcomes respectively to avoid problems of endogeneity and to focus on causal dynamics of cause-and -effect.

The study reveals that throughout the study, access to a treatment buddy declined over the treatment duration. As expected, health related quality of life consistently impacted on access to and transitions in access to a treatment buddy. Patients who had access to a treatment buddy had improved health-related quality of life. The treatment career phase featured as a strong predictor of access to a treatment buddy. Access to treatment buddy declined as months on treatment increased. The study reveals that similar to access to a treatment buddy, access to alternative support mechanisms declined as treatment duration increased. However, a significant decline over the treatment career phase was only observed in access to informal, individualised support such as emotional and physical caregivers. Access to more formal support and to group-based support did not exhibit a similar significant declining trend over the treatment career. The findings revealed that access to a treatment buddy was associated with perfect adherence knowledge. Moreover, the frequency of treatment buddy visits declined over the treatment career. Access to other forms of support increased the frequency of treatment buddy visits. Marital status was strongly associated with access to treatment buddy and other key outcomes.

Clinical adherence varied significantly across the treatment career, increasing as treatment duration increased. The transition results indicate that patients who had been on treatment for six to twelve months and patients who had been on treatment for 18 to 30 months were less likely to transition from clinical adherence to non-adherence. This statement denotes that patients who have been on treatment for a longer period are more likely to maintain clinical adherence.

Overall, the research indicates that treatment buddies represent an important form of informal adherence and psycho-social support in the early phase of the ARV treatment career, particularly among married ART clients. Access to treatment buddies declines later in the treatment career as clients' health-related quality of life improves. Policy makers and programme managers should develop suitable adherence support strategies for single clients as well as suitable longer-term adherence support strategies for clients facing challenges with medication adherence later in the treatment career.

CHAPTER 1

ORIENTATION AND BACKGROUND TO THE STUDY

1.1. Introduction

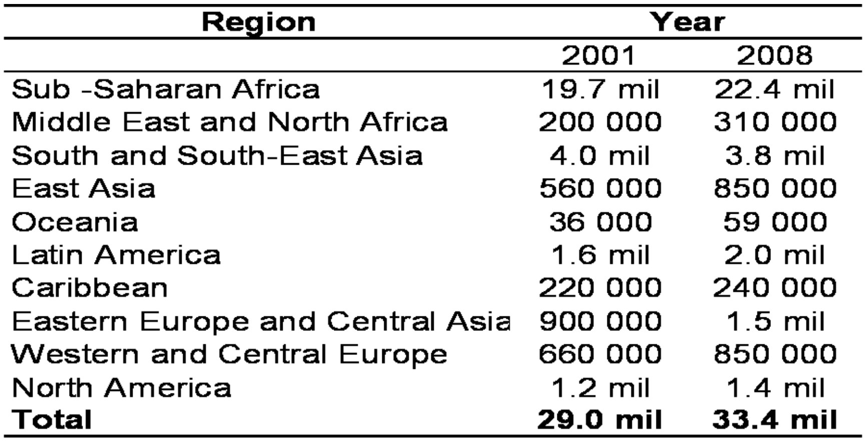
Responding to the devastating impact of the HIV/AIDS epidemic, antiretroviral therapy treatment programmes have been introduced all around the world. It has been acknowledged that effective HIV/AIDS care requires antiretroviral therapy as a treatment option. Furthermore, it is believed that without access to antiretroviral therapy (ART), people living with HIV/AIDS cannot attain the fullest possible physical and mental health and cannot play their fullest role as actors in the fight against the epidemic (WHO, 2006).

In the absence of ART, health care workers will remain disempowered and fail to contribute to the fight against HIV to the fullest of their potential. In addition, children will be orphaned earlier and stigma and discrimination will continue to be fuelled by the perception that HIV infection is a death sentence. Antiretroviral drugs inhibit the replication of HIV. When antiretroviral drugs are given in combination, HIV replication and immune deterioration can be delayed while survival and quality of life can be improved (WHO, 2006). However, to achieve improvement in health-related quality of life, antiretroviral medication has to be taken in a proper manner. For this reason, medication adherence becomes an integral factor in the success of the antiretroviral therapy (García & Côté, 2003).

1.2. The nature and scale of the HIV epidemic

UNAIDS (2006), argues that global HIV prevalence has levelled off due to changes in incidence together with rising AIDS mortality. However, the number of people living with HIV has continued to rise due to among other factors, population growth and the availability of antiretroviral therapy. The number of people living with HIV/AIDS increased over the years in all regions except South and South-East Asia (Table 1.1). According to UNAIDS, an estimated 33.4 million people were living with the virus in 2008 and 2.7 million people are estimated to have acquired HIV. An estimated 2 million people died of HIV/AIDS in 2008 (UNAIDS, 2009).

Table 1.1: Number of people living with HIV/AIDS, by region



Region	Year	
	2001	2008
Sub -Saharan Africa	19.7 mil	22.4 mil
Middle East and North Africa	200 000	310 000
South and South-East Asia	4.0 mil	3.8 mil
East Asia	560 000	850 000
Oceania	36 000	59 000
Latin America	1.6 mil	2.0 mil
Caribbean	220 000	240 000
Eastern Europe and Central Asia	900 000	1.5 mil
Western and Central Europe	660 000	850 000
North America	1.2 mil	1.4 mil
Total	**29.0 mil**	**33.4 mil**

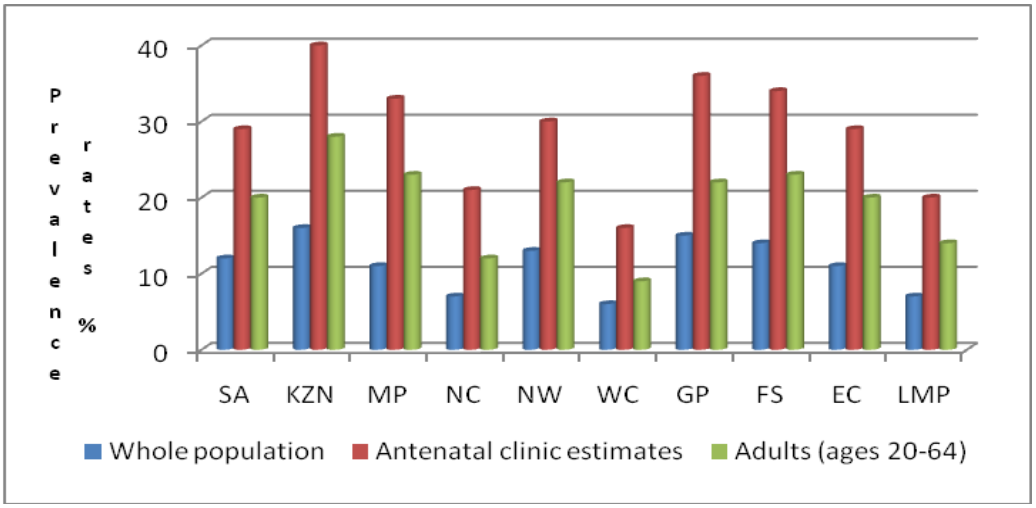
Source: UNAIDS (2009).

Sub-Saharan Africa has just over 10% of the world's population, but it is home to two-thirds of all people living with HIV, therefore remaining the most affected region in the world, with an adult HIV prevalence of 5.2%. In sub-Saharan Africa alone, an estimated 1.9 million were newly infected in 2009, bringing the number of people living with HIV to 22.4 million (UNAIDS, 2009). The HIV/AIDS epidemic in South Africa is referred to as one of the worst in the world as it shows no evidence of decline. In South Africa alone, 5.7 million people were living with HIV in 2009 (UNAIDS, 2009).

It has been 26 years since 'acquired immune deficiency syndrome' or AIDS was first reported in South Africa. Still without a cure more than two decades later, the fatal virus rapidly spread to all the corners of the globe. Current estimates indicate that South Africa has the largest number of people living with HIV/AIDS in the world. The Nelson Mandela study on HIV/AIDS (Shisana *et al.,* 2009) estimates the overall HIV prevalence in the South African population (over the age of two) to be 11.4% . HIV prevalence among those aged 15-49 was 15.6%. According to South Africa's 2008 Antenatal Survey report which was released in July 2009, the overall national HIV prevalence among antenatal women aged 15-49 years was 29.3%. In 2006 and 2007, the HIV prevalence was 29.0% and 29.4% respectively (NDoH, 2008). The findings suggest that HIV prevalence over the last three surveys has stabilized around this level. However, there have been some variations in the HIV prevalence rates in the provinces

In the Free State Province of South Africa, HIV prevalence was 14.9%, the highest prevalence in the country. The HIV prevalence among ANC attendees equals 34%, which is more than the national prevalence figure of 29% (NDoH, 2008). In comparison with figures for 2005, a slight increase in the HIV prevalence was noted in the Free State. The projected population of the Free State is approximately 2.8 million, including 387,770 HIV infected people.

Figure 1.1: Provincial distribution of HIV prevalence in South Africa, 2008



Source: Prepared by Nathea Nicolay, Metropolitan. October 2008.

1.3. A global push for ART

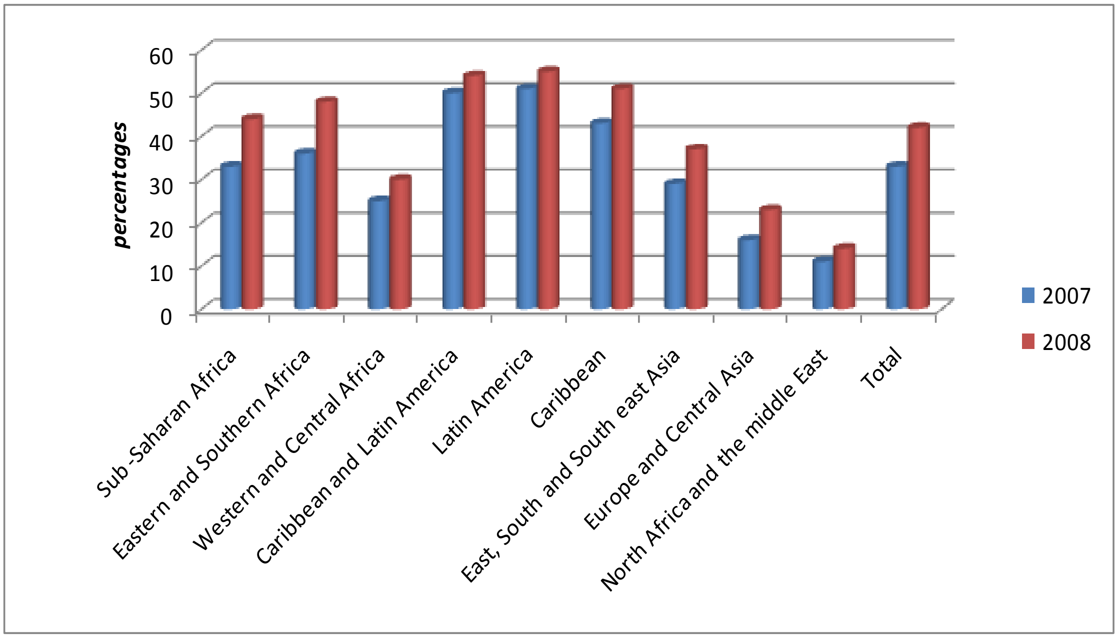
Since the 2000s development assistance for HIV and AIDS has been increasingly provided through partnerships and Global Health Initiatives. Recent international initiatives such as the US President's Emergency Plan for Aids Relief (PEPFAR), the United Nations Global Fund to fight AIDS, Tuberculosis and Malaria and the 3 by 5 strategy, as well as other international initiatives have dramatically increased access to ART in South Africa.

1.3.1. The '3 by 5' strategy

The first, '3 by 5', was launched by the World Health Organization (WHO) in 2003. The goal of the 3 by 5 initiative is for WHO and its partners to make the greatest possible contribution to prolonging the survival and restoring the quality of life of individuals with HIV/AIDS advancing towards the ultimate goal of universal access to ART for those in need of care as a human right and within the context of a comprehensive response to HIV/AIDS (WHO, 2003a).

The aim of was to get 3 million people in lower- and middle-income countries on ARVs by 2005. It was not intended as a final objective, but as a stepping stone to universal access. Though the target was not attained until 2007, it was seen by some as succeeding in a number of ways. Treatment was vastly expanded with coverage tripling from 400,000 people in December 2003 to 1.3 million in December 2005. This included an eight-fold increase in sub-Saharan Africa. Furthermore, treatment infrastructure was expanded with the number of public sector treatment sites increasing from 500 to more than 5,100. At the end of 2008, it was estimate that 4 030 000 people were receiving antiretroviral therapy, more than 1 million more people than at the end of 2007(WHO, 2008).

Figure 1.2: Antiretroviral therapy percentage coverage in low and middle income countries, by region (2007/08)



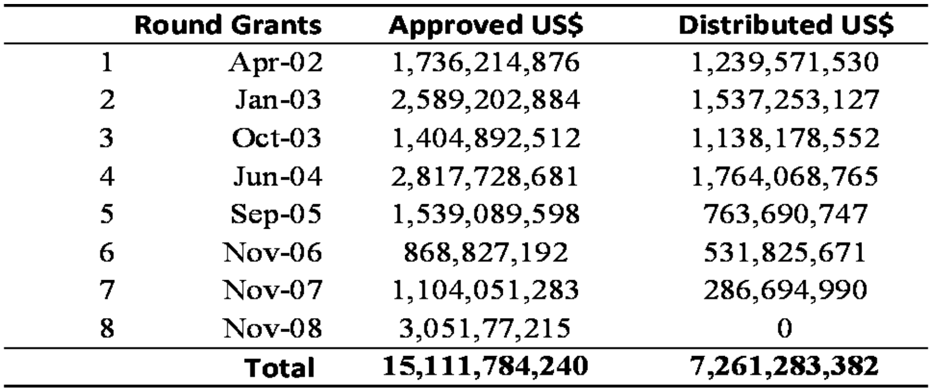
Source: WHO, 2008:12.

Antiretroviral therapy coverage increased in both low and middle income countries (Figure 1.2). The greatest increase in the number of people receiving treatment in 2008 was in sub-Saharan Africa, the region with the greatest need (a regional increase of 39% in 1 year). Progress was substantially higher in Eastern and Southern Africa and in Western and Central Africa. The percentage increase in the number of people receiving treatment (14%) is lower in the Caribbean than in other regions.

1.3.2. The Global Fund

The Global Fund to fight AIDS, Tuberculosis and Malaria was established in 2002 to dramatically increase resources to fight three of the world's most devastating diseases. The purpose of the global fund is to attract, manage and distribute funds to countries, organisations and communities that urgently need financial help to allow them to fight AIDS, tuberculosis (TB) and Malaria (Naimak, 2006). By the end of 2007, programmes supported by the Global Fund delivered AIDS treatment to 1.4 million people (The Global Fund, 2007). The Global Fund is financing programmes in all regions of the world. However, in recognition of the disproportionate impact of these diseases in Africa, 61% of funds are aimed at funding programmes in Sub-Saharan Africa. Nearly two thirds of the funds are for AIDS.

Table 1.2: Global Fund funding: approved and distributed (2002-08)



	Round Grants	Approved US$	Distributed US$
1	Apr-02	1,736,214,876	1,239,571,530
2	Jan-03	2,589,202,884	1,537,253,127
3	Oct-03	1,404,892,512	1,138,178,552
4	Jun-04	2,817,728,681	1,764,068,765
5	Sep-05	1,539,089,598	763,690,747
6	Nov-06	868,827,192	531,825,671
7	Nov-07	1,104,051,283	286,694,990
8	Nov-08	3,051,77,215	0
	Total	**15,111,784,240**	**7,261,283,382**

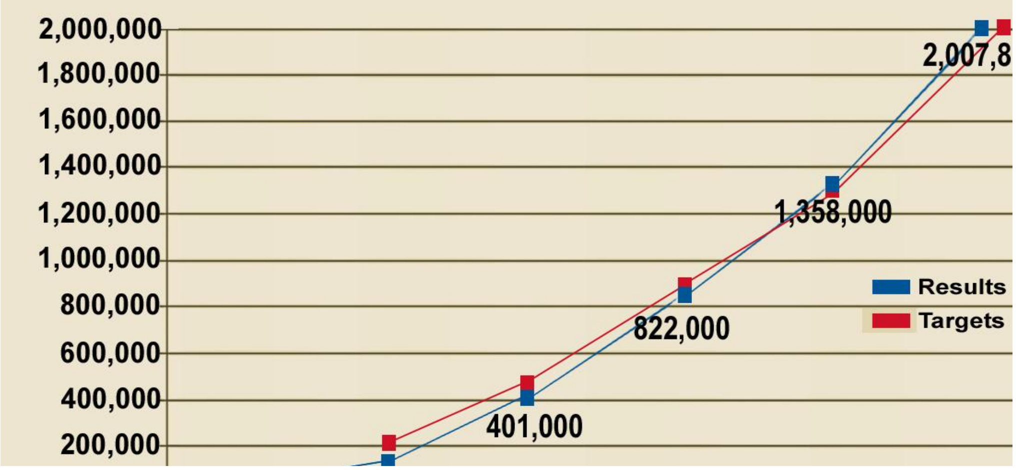
Source: The Global Fund, 2009:27

Table 1.2 shows the grants that have been approved by the Global Fund so far, and the money that have actually been distributed (accurate as of January 31st, 2009)(The Global Fund, 2009). The Global Fund has committed itself to providing US$65 million for HIV and AIDS programmes in South Africa over a six year period. About 55% of this grant had been disbursed between December 2003 and April 2005 (Ijumba & Barron, 2005). Access to performance-based funding from the Global Fund to fight AIDS, has enabled the Western Cape Province in South Africa to race ahead with its antiretroviral rollout. As of 2005, the Global Fund's contribution helped enable the province to provide antiretroviral treatment to 65% of those people who desperately need it.

1.3.3. The President's Emergency Plan for Aids Relief

The President's Emergency Plan for Aids Relief (PEPFAR) is a US five-year $15 billion global initiative to combat the HIV/AIDS epidemic. The President's Emergency Plan was announced in 2004, after acknowledging the global HIV/AIDS pandemic as the greatest challenge facing the world. Globally, PEPFAR supported antiretroviral treatment for an estimated 2.1 million people by 2008. Figure 1.3 shows an upward trend in access to ART, which means that access to ART increased over the years.

Figure 1.3: Number of people receiving ART in 15 PEPFAR focus countries (2003-08)



Source: PEPFAR (2009: 55).

South Africa has been identified as one of the focus countries worldwide to receive substantial resources and increased funding under the President's Emergency Plan. PEPFAR is by far one of the largest donors supporting ART provision in South Africa and the Emergency Plan strongly supports South Africa's comprehensive HIV/AIDS prevention, treatment and care programme (PEPFAR, 2006). PEPFAR allocated US$89 million to South Africa in the 2004/5 financial year (Ijumba & Barron, 2005). An estimated 210,300 people had been receiving antiretroviral treatment supported by PEPFAR by September 2006 as opposed to the 500, 000 targets for 2008. As of September 2009, PEPFAR-supported site level service delivery totalled 589,808 of the public sector patients in South Africa and an additional 57,164 patients at NGO and private sector sites. While exact figures are unknown, an additional 51,633 adults and children were reported on ART in the private sector in 2009;

although this number may be misleading, as 86,000 people were estimated to be on treatment through workplace treatment programmes and Disease Management Providers (UNAIDS 2008).

1.4. HIV/AIDS policy in South Africa

Sustained high HIV-infection rates at a national and provincial level have evoked a renewed urgency to both prevent new infections as well as to address the health care needs of those individuals who are already living with HIV/AIDS. This situation eventually led to the development and implementation of an expanded national comprehensive HIV/AIDS prevention, treatment and care programme, a programme that has been endorsed and supported by the international community. In November 2003, the Cabinet approved the *Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa* prepared by the National Department of Health, and instructed the department to proceed implementing the plan. Among other things, the Operational Plan strategically focuses on the provision of ART by the public health sector to reduce HIV/AIDS-related morbidity and mortality, as part of the government's comprehensive strategy to combat the epidemic (NDoH, 2003).

Two policy frameworks, namely the Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa 2003 and the STD/HIV/AIDS Strategic Plan for South Africa 2007-2011 are the pillars of South Africa's response to the HIV/AIDS epidemic (NDoH, 2003, 2007). These documents focus on treatment, care and support for people living with HIV/AIDS and emphasise the importance of support in ensuring patients' adherence to antiretroviral (ARV) medication. The Operational Plan (NDoH, 2003) envisaged treatment buddies to play an important role in retention and follow-up of patients (see Chapter 3).

The *National Antiretroviral Treatment Guidelines* (NDoH, 2004) were released to guide the implementation of the ART programme. The purpose of these guidelines is to set standards for the use of ART drugs in South Africa. On December 1st, 2009, on World AIDS Day, the President (Jacob Zuma) announced the new key interventions to improve antiretroviral treatment (ART) access to special groups (all HIV-infected infants and pregnant women and people with TB and HIV at CD4 less or equal to 350/mm3), in order to decrease the disease burden, to address maternal and child mortality and to improve life expectancy. The Clinical Guidelines for the Management of HIV & AIDS in adults and adolescents (NDoH, 2010) serves as a new guidance to health practitioners with regard to the comprehensive management of HIV infected adults and adolescents. According to the Clinical Guidelines (NDoH, 2010), the eligibility criteria for ART includes the following: (i) CD4 count < 200 cells/mm^3, irrespective of WHO clinical stage or (ii) WHO Stage IV disease, irrespective of CD4 count (iii) CD4 count <350 cells/mm^3 in patients with TB/HIV and pregnant women and (iv)MDR/XDR-TB, irrespective of CD4 count.

According to the Clinical Guidelines for the management of HIV/AIDS, psychosocial factors that form part of the treatment readiness recommendations for patients who are to initiate ART are as follows: *(1) have attended at least 3 preparation visits on "Drug Readiness Training" at an HIV clinic, (2) have demonstrated no alcohol or substance abuse, (3) have no untreated depression, (4) have disclosed their HIV status to at least one friend or family member or have joined an HIV support group and (5) have accepted their HIV-positive status and have insight into the consequences of HIV infection and the role of antiretroviral therapy before initiating ART* (NDoH*,* 2004).

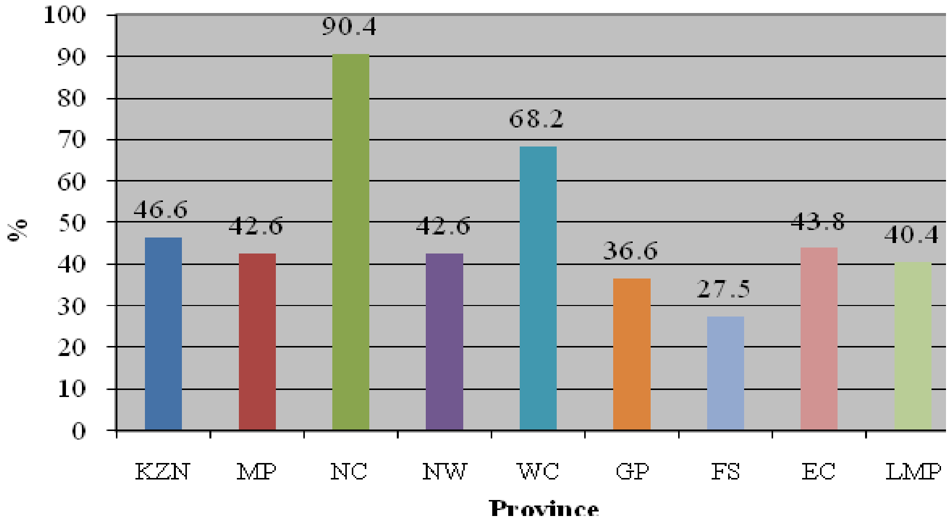
1.5. The South African antiretroviral treatment programme - a new dawn

Antiretroviral drugs have been available since the early 1990's however; the widespread use of ARV drugs exclusively benefited industrialised countries, which only bear 5% of the global burden of HIV/AIDS. Nonetheless, as shown above, there has been a dramatic increase in ART coverage in developing countries over the past years. Most importantly, this process has been aided by the launch of the Global Fund to fight HIV/AIDS, Tuberculosis and Malaria in 2002 and the United States President's Plan for AIDS Relief (PEPFAR) in 2004.

In South Africa, the demand for access to ARVs was most prominently expressed by the Treatment Action Campaign (TAC) from 1998. As a result, ART was made available in 2004. Notwithstanding an increasing demand for ART, current access to ART for individuals utilising the public sector is still extremely limited. This means that AIDS deaths are alarmingly common throughout the country. It is thought that almost half of all deaths in South Africa, and an overwhelming 71% of deaths among those aged between 15 and 49, are caused by AIDS (Dorington *et al.*, 2006). According to the HIV& AIDS and STI National Strategic Plan 2007-2011, 42.8% (roughly 200,000) people in South Africa were enrolled on ART in 2007/8. The Free State has had the lowest access to ART in recent years (27.5%). According to the 2010 Country Progress report on the Declaration of Commitment on HIV/AIDS, the public ARV treatment programme reported approximately 919,923 people on treatment by the end of November 2009, with the private and non-governmental organisation (NGO) sector supporting an additional estimated 51,633 people (NDoH, 2010). In total, 44% of adults in need of treatment accessed it in 2008 and this percentage increased to 55% in 2009 (NDoH, 2010). This may be an indication that uptake in the public sector has been the main source of growth in coverage and expansion in the private and that other programmes have stagnated.

Despite progress in making antiretroviral treatment available in the public health sector, there remains a vast unmet need for treatment. By the end of November 2009, programme data showed that 833,653 adults and 86,270 children (under age 15) were on treatment (NDoH, 2010). This is an increase of about 30% of children enrolled in ART and an increase of about 26% in adult treatment from 2008 to 2009. The South African ART programme reached 81% of children in need of ARVs in 2009 and 55% of adults in need, using STATS SA estimates(NDoH, 2010).

Figure 1.4: Access to ART in South Africa, by province (2007/2008)



Source: Department of Health (2008: 6)
Note: Reporting periods run from mid-year to mid-year

Figure 1.4 above, provides the latest available information on access to antiretroviral therapy by province.

1.5.1. The role of non-governmental organizations in ART

In South Africa, non-governmental organizations (NGOs) such as Medecins Sans Frontieres (MSF), have contributed to the effort to increase access to ART. MSF has been caring for people living with HIV/AIDS in developing countries since the 1990's and began offering ART in its programme in Cameroon, Thailand and South Africa in 2000. In countries where health structures are insufficient or non-existent, MSF collaborates with authorities to provide assistance. MSF HIV/AIDS programmes provide a comprehensive package of care, including prevention efforts (health education, prevention of mother-to-child transmission of HIV, condom distribution), voluntary counselling and testing, nutritional and psychosocial support, treatment and prophylaxis of opportunistic infections and ART, when needed.

1.5.2. The role of faith-based organisations in ART

Many faith-based initiatives have been on the front-line of the epidemic since its devastating effects on the population became apparent in Africa. Faith-based organisations (FBOs) such as Catholic Relief Services in particular have been a source of ART therapy. Nowadays, these faith-based organizations, which often reach the most remote communities, as well as being prominent in large urban centres, are uniquely placed to provide a range of quality HIV-related services (from training of home-based caregivers to provision of antiretroviral therapy) to those in need. The Catholic Church has attempted to coordinate its responses to AIDS in South Africa through the Southern African Catholic Bishops' Conference (SACBC) (Munro, 2005). The sites supported by the SACBC providing antiretroviral therapy aim at complementing government programmes in areas where government-funded antiretroviral therapy is not available, notably in resource-poor communities (UNAIDS 2006).

1.5.3. The role of the private and the corporate sector in ART

The provision of ART has been taking place for some time in the private sector and number of patients accessing ART is increasing. Individual sector initiatives and private doctors provide ART in private for the profit sector. Within the private sector, the funding for ART is taking place largely through employers, medical schemes and private self-funding by HIV-infected employees (NDoH, 2006b).

Faced with increasing absenteeism, disability and deaths related to HIV/AIDS, more and more employers are committing to fund payments of HIV/AIDS treatment for their employees. Companies that provide ART for their infected employees include among others DeBeers, Anglo-American, Daimler Chrysler, Nedcor, Anglo Gold and BMW South Africa. These companies are believed to have pioneered ART provision in South Africa. Approximately 45 000 people were receiving treatment through private sector channels by the end of 2004 (Ijumba & Barron, 2005).

1.6. The importance of antiretroviral therapy

For Southern and South Africa, HIV/AIDS is perhaps the single most important obstacle to social and economic progress. As a result, AIDS is no longer a considered a health problem but a development problem with potentially ominous consequences. The primary goal of ART is to decrease HIV-related morbidity and mortality. The plan is to reduce the detectable viral load of HIV as low as possible, ideally to below the current level of detection of 50 copies/ml. The idea is to maintain this level of suppression for as long as possible. And by so doing, to prevent opportunistic infections occurring and improve the quality of prolonging the life of HIV infected persons. The secondary goal is to decrease the incidence of HIV through (i) an increase in voluntary testing and counselling with more people knowing their status and practicing safer sex, (ii) reducing transmission in discordant couples and (iii) reducing the risks of HIV transmission from mother to child (NDoH, 2004).

ART is believed to have significant effects on the lives of people living with HIV/AIDS. The provision of antiretrovirals has resulted in empty beds in clinics and hospitals, people living with HIV/AIDS returning to their families and jobs and the AIDS-related morbidity and mortality having declined dramatically (Rathbun *et al.*, 2005; Cederfjäll *et al.*, 2002). In many high income countries where antiretroviral drugs have been available and accessible, the medication has helped in maximizing well being and improved quality of life for the majority of people living with HIV/AIDS, thus transforming the disease from a fatal to a manageable chronic illness.

Adedimeji and Odutolu (2004) argue that advantages inherent in providing universal access to ARVs could be equalised by negative challenges in the lives of those living with HIV and AIDS. The absence of care and social support, critical to ensuring adherence to ARV treatment and strengthening prevention efforts, may jeopardize the modest gains achieved in resource poor settings and comprise well-being. Besides providing hope to individual sufferers, the availability of ARV treatment is widely regarded as a pillar for effective HIV/AIDS management at all levels.

ART has demonstrated efficacy in improving the immune system and reducing HIV/AIDS-related mortality and morbidity in many countries. (Arnsten *et al.,* 2001; Rathbun *et al.,* 2005 Cederfjäll *et al.*, 2002; Jia *et al.*, 2004: 594; Yen *et al.,* 2004: 501; O'Connell *et al.,* 2004: 882). However, the treatment also brings significant challenges. ART includes complex regimens that require strict adherence to complicated treatment schedules and treatment-resistant variants of HIV that develop in response to under dosing and irregular use of antiretroviral drugs (Campbell *et al.,* 2005). As a result, adherence has surfaced as one of the fundamental challenges to AIDS clinical care and is the most important factor in the success of HIV treatment (Wong, 2004).

1.7. Contextualising the challenge to make ART work

Antiretroviral therapy improves clinical outcomes and reduces the morbidity and mortality rates related to HIV infection (García & Côté, 2003: 37; Battaglioli-DeNero, 2007). However, the most significant determining factor is the ability of the patient to adhere to treatment. Hence, the provision of support for people living with HIV/AIDS is considered a key element in comprehensive care and support as well as an essential part of the health care package at all levels. Both the Operational Plan (NDoH, 2003) and the National Antiretroviral Treatment Guidelines (NDoH, 2004) highlight the importance of support for people living with HIV/AIDS, especially those on ART. These documents therefore call upon families and communities to play a critical role in providing support and in ensuring patient's adherence to treatment.

Low levels of adherence are associated with increases in viral load, a fall in CD4 count, increased risk of disease progression, increased likelihood of developing viral resistance, the development of clinical complications and shortened survival (Weiss, 1999; Catz, 2000: 128; Roberts 2000: 155; Laws *et al.,* 2000; Turner, 2002: 143; García & Côté 2003: 37; DiMatteo, 2004: 208; Hammami *et al.,* 2004; Carter, 2005: 1; Cederfjäll *et al.*, 2002). Lack of social support may also hinder patients from adhering to treatment, which may eventually impact negatively on their well-being and health-related quality of life Abdool-Karim *et al.* (2004:978). The treatment buddy programme as a form of social support and an adherence strategy was initiated in South Africa with the above mentioned challenges in mind.

1.8. Rationale for the study

Recent advances in antiretroviral treatments have simplified dosing regimens for people living with HIV. Yet, typical regimens still remain far more complex than treatments for other health conditions and adherence continue to concern health care providers. In fact, adherence to ART still dominates debates as one of the challenges facing continued treatment of HIV positive patients and health service delivery (Chesney, 2000; Fogarty *et al.*, 2002; Simoni, *et al.*, 2003; Orrell *et al.*, 2003). Properly taken ARVs have been shown to reduce viral loads, but the requirements for adherence are high, with most studies suggesting that it has to be higher than 90% to avoid the risk of resistance (Singh *et al.*, 1999; WHO, 2005).

Thus, support for people on ART becomes fundamental. Social support is important as it is one of the factors consistently associated with adherence to antiretroviral therapy across a wide variety of studies (Garay-Sevilla *et al.*, 1995; Dybul *et al.,* 2002; Chesney *et al.*, 2003; Blanco *et al.,* 2005; Kumarasamy *et al.,* 2005; Davies *et al.*, 2006; Battaglioli-DeNero, 2007; Simoni *et al.,* 2002: 431; Power *et al.,* 2003; García & Côté 2003: 40; DiMatteo, 2004: 212; Naar-King, 2006: 44; Remien *et al.*, 2006).

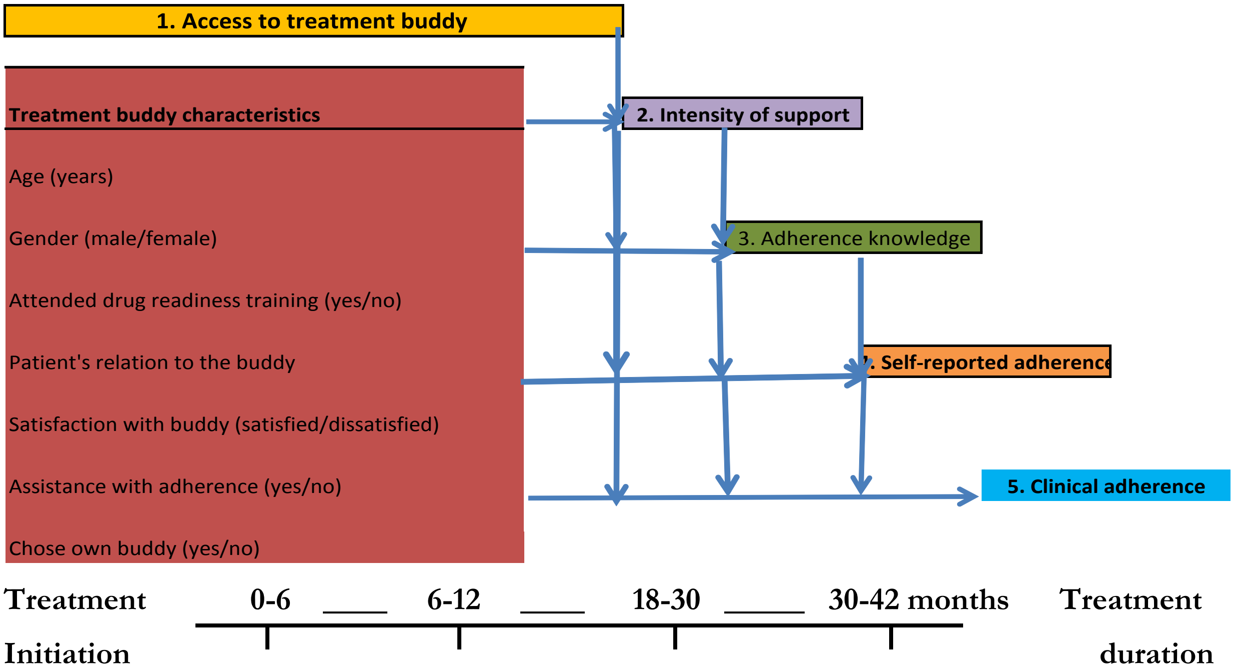
The South African ART programme appreciates the potential of family members and peers for treatment support in two areas. Initially their role was to ensure that the person living with HIV/AIDS continues with therapy, but they are increasingly involved in generating awareness and direct response to HIV/AIDS in the community. The treatment buddy system is also aimed at complementing the overburdened health care institutions by using families and the community to enhance patient's adherence to a lifetime treatment. The assumption was that the buddy programme providing one-on-one support would be a small step towards breaking the silence surrounding the HIV/AIDS epidemic and increasing access to available care and support systems.

The treatment buddy programme uses treatment buddies to assist people in adhering to their treatment. Patients are directly observed swallowing medication, especially through their first months in the programme. It has been shown that treatment buddies can be a critical element in increasing adherence and in retaining patients in care (Lyon *et al.*, 2003; NDoH, 2003). Prior research has also demonstrated that peer support can influence patient's preventative health behaviour and complement the services of health care providers. Informal care-giving and social influence theories suggest that taking advantage of existing supportive relationships may possibly lead to sustained positive changes in adherence behaviour (Nachega *et al.,* 2006). This study will assess how support from treatment buddies relates to biological outcomes health-related quality of life.

1.9. Conceptual framework

This study focuses on an investigation of treatment buddy support and related outcomes over the treatment career. The focus is on the treatment career, because the treatment is life-long and because effectiveness is dependent on optimal long-term adherence (Godin *et al.*, 2005). Ttreatment duration is measured by months on treatment. Midpoints in the treatment career in this case were represented by 3, 12, 24 and 36 months, respectively.

Figure 1.5: The role of treatment buddies in adherence across the treatment career



In addition to determining how each of the five main study outcomes changes across the treatment career phases, each of these main outcomes are investigated independently (Figure 1.5). Moreover, the five key outcomes on the right hand side are interlinked, symbolising that these outcomes may impact on each other. The treatment buddy characteristics listed on the left hand side are also interlinked with each of the four outcomes. The hypothesis is that access to a treatment buddy may or may not impact on each of the key outcomes but certain characteristics of the treatment buddy may be important as these characteristics may impact on each of the outcomes. This section explains how each of the key outcomes is investigated, starting with the first outcome.

First, an attempt is made to understand how many patients have treatment buddies and why they may have treatment buddies. Furthermore, an effort is made to determine how the need for support, represented by health status, may influence access to a treatment buddy. The study also tries to establish whether other sources of treatment support complement or substitute access to a treatment buddy (Burrage & Demi, 2003; Gielen *et al.*, 2001; Bennett, *et al.,* 2001; Manning-Walsh, 2004; Douaity, *et al.*, 2007).

Secondly, the argument here is that access to a treatment buddy on its own may not necessarily make a difference or influence patient's adherence to treatment or related outcomes, but rather the intensity of treatment support or frequency of visitations provided by the treatment buddy.

Thirdly, Figure 1.5 reflects the hypothesis that patients who have a treatment buddy and/or are visited regularly may have better adherence compared to patients without a treatment buddy *(*Simoni *et al.*, 2002; Javanbakht, *et al.*, 2006; Burgoyne, 2005; Catz, *et al.*, 2000; Garay-Sevilla *et al.*, 1995; DiMatteo, 2004.).

Fourthly, increased adherence knowledge (which is used as proxy for the cognitive demands the patient had to be aware of regarding the use of ARVs) is likely to lead to higher levels of self-reported adherence (taking medication as prescribed) (Kalichman *et al.*, 2000; Simoni *et al.*, 2002) which, in the fifth instance, may in turn be reflected in suppressed viral load, a clinical measure of treatment adherence.

The main question, therefore, is how access to a treatment buddy impacts on the intensity of treatment buddy support, adherence or medication knowledge, and self-reported and clinical adherence. In addition, the focus is also on treatment buddy characteristics' impact on each of these four latter study outcomes, the argument being that having a treatment buddy may not predict or may not be associated with any of these key outcomes but rather treatment buddy characteristics.

1.10. Aim of the study

The general aim of this study is to assess the role of treatment buddies in the South African public sector antiretroviral treatment programme as implemented in the Free State province

1.11. Objectives of the study

The study has the following specific objectives:

- To determine how the need for support, represented by health status, may influence access to a treatment buddy and the intensity of treatment buddy support
- To establish whether and how access to alternative support mechanisms may complement or substitute access to a treatment buddy
- To determine how access to a treatment buddy and treatment buddy characteristics impact on the intensity of treatment buddy support
- To determine how access to a treatment buddy and treatment buddy characteristics impact on adherence knowledge
- To determine how access to a treatment buddy and treatment buddy characteristics impact on self-reported adherence
- To determine how access to a treatment buddy and treatment buddy characteristics impact on clinical adherence
- To determine how access to other sources of support impact on the intensity of treatment buddy support, adherence knowledge, and self-reported and clinical adherence
- To determine how the intensity of treatment buddy support impact on self-reported and clinical adherence

1.12. Hypotheses

Below is a summary of the main hypotheses that will be tested as part of the empirical analyses to be conducted as part of this study, based on the conceptual framework outlined in Figure 1.5 above:

- High or improving levels of health status are associated with a decline in access to a treatment buddy
- Support mechanisms are more likely to complement rather than substitute treatment buddy support
- Access to treatment buddy is associated with increased frequency of treatment buddy visits.
- Access to treatment buddy is associated with improved adherence knowledge
- Increased frequency of treatment buddy visits is associated with improved adherence knowledge
- Access to treatment buddy is associated with an improved self-reported adherence and clinical adherence
- Access to other sources of support is associated with increased frequency of treatment buddy visits, improved adherence knowledge and improved self-reported and clinical adherence
- Increased frequency of treatment buddy visits is associated with improved self-reported and clinical adherence

Note that, due to constraints of space, the above hypotheses exclude hypotheses concerning expectations regarding how key study outcomes may vary across the treatment career and the extent to which each of the seven distinct treatment buddy characteristics in Figure 1.5 may impact on each of the four down-stream outcomes of the intensity of treatment buddy support, adherence knowledge, and self-reported and clinical adherence.

1.13. Structure of the thesis

The thesis comprises of the literature review, which has two chapters. Chapter 2 deals with social support in the context of health and health care programmes. There are reasons behind the inclusion of the two literature review chapters. Firstly, the treatment buddy system is viewed as the social support mechanism for patients on the antiretroviral treatment, hence the inclusion of the social support chapter. Secondly, even though the treatment buddy system is perceived as a support mechanism, it is also seen as an adherence strategy aimed at enhancing adherence among patients on antiretroviral therapy, thus the inclusion of the adherence chapter. Chapter 3 attempts to define the concept of adherence and the most commonly used measurements of adherence. In addition, various factors thought to influence patient adherence and adherence strategies in place to address adherence are discussed with reference to the literature. Chapter 4 observes the research design and methods as well as analytical tools employed in the qualitative and quantitative analysis. From Chapter 5 onwards, the findings from the empirical work are discussed, while chapter 10 concludes with a summary of key findings and resultant policy recommendations.

CHAPTER 2
SOCIAL SUPPORT, HEALTH AND HEALTH CARE

In this chapter an attempt is made to define the concept of social support with specific reference to health and health care. The different databases were searched with various combinations of the following keywords; *social support, health, illness, antiretroviral therapy, HIV/AIDS, quality of life, adherence, stigma, disclosure, directly observed therapy, adherence interventions, treatment buddy, treatment support, peer support.* Additional relevant articles were also obtained from bibliographies of already identified papers. The relevant literature obtained in this manner was employed to shed light on the following aspects of this research: social support concepts; types of social support; sources of social support, formal and informal support; HIV/AIDS and social support; adherence and social support; and constraints to optimal functioning of social support.

2.1. Introduction

As a concept, social support has evolved over time, starting with the term 'social ties', as used by Durkheim to refer to a 'social system' as described by Caplan (1974), to what is now commonly called 'social support'. The concept of social support and its potential impact on health has been widely studied in disciplines such as social work, sociology, anthropology and medicine. In addition, social support and its relationship to health have been examined in diverse age groups, populations and for conditions such as cancer, mental illness, pregnancy, heart disease and depression. According to DiMatteo (2004:208), the interest in the concept of social support is accredited to its possible role in the presence of the disease and illness. The theoretical perspective used to guide this section is Cohen and Syme's (1995) conceptualization of social support, which is outlined below.

2.2. Definition of social support

There are many definitions of social support found in the literature. Although different terminology is used in many of them, these definitions have common characteristics. For the purposes of this study, social support refers to those social relationships that provide actual assistance or a feeling of attachment to a person or group that is perceived as caring or loving (Cohen & Syme, 1995). Social support advocates a process that is centred on the mutual exchange of information (Schwarzer *et al* 2003). Shumaker & Czajkowski, (1994: 460) argue that support involves the following beliefs: (i) that one is cared for and loved and has an opportunity for shared intimacy; (ii) that one is esteemed and valued (iii); that one shares mutual obligations, communication and companionship with others; (iv) that one has access to information, advice appraisal and guidance from others and (v) that one has access to material or physical assistance.

2.3. Social support concepts

Social support concepts can be organised into three broad categories, namely social embeddedness, enacted support, and perceived social support (Barrera, 1986).

2.3.1. Social embeddedness

Social embeddedness refers to the connections that individuals have to significant others in their social environments (Hinson-Langford *et al.,* 1997: 96). According to Barrera (1986), being socially connected is an essential element in one's psychological sense of community as it alleviates the feeling of isolation. There are two prevalent approaches to measuring social embeddedness. One approach consists of using broad indicators of the presence of social ties such as marital status, participation in community organisations, presence of older siblings and contact with friends. These indicators are used with the rationale that available social ties could potentially serve as sources of social support and possibly provide support during a crisis. A second approach is reflected in the use of social network analysis. Social network analysis involves structured procedures for identifying individuals who have important relationships with the main subject.

2.3.2. Enacted support

Enacted support is the actual support provided. Behavioural descriptions of support are referred to as "enacted" support to distinguish it from "available" support that is measured by scales of perceived availability. Measures of enacted support assess what individuals actually do when providing support. In such cases, measures of enacted support are relevant in providing assistance when subjects are confronted with a catastrophe (Barrera, 1986). Kaijage (2004) argues that even though it has been shown that healthy individuals who perceive themselves to be socially supported are self assured, loved, accepted, and socially included, it is also true that it is the actual support received or enacted during the times of crises that makes a difference in the life of the person caught in the middle of the crisis.

2.3.3. Perceived support

Perceived social support is an important concept that characterises social support as the cognitive appraisal of being connected to others (Barrera, 1986). Measures of perceived support incorporate two dimensions: perceived availability and adequacy of supportive ties. These measures differ from the measures of social embeddedness in that they do not quantify the number of supporters or the amount of social contact. Instead they capture individual's confidence that adequate support would be available if needed. According to Schaefer *et al.* (1981), perceived social support involves an evaluation or appraisal of whether and to what extent an interaction or relationship is helpful. People who have a strong social network have a reason to believe that support will be forthcoming if they need it, and in many circumstances their perceptions that support is available are probably correct.

2.4. Types of social support

According to Sarason *et al* (1990), a broad range of interpersonal behaviours by members of a person's social network may help him or her to successfully cope with deleterious life events and circumstances. Four types of social support, namely emotional; informational; instrumental and appraisal support are observed recurrently in the social support literature (Parker & Parrot, 1995: 283; Friedland *et al.,* 1996: 16; MacArthur 1998; Benett *et al.,* 2001: 672; Manning-Walsh, 2004: 483; Mauldin 2004; Finfgeld-Connett 2005: 5; Keyes *et al.,* 2005; Kristofferzon, 2005: 40).

2.4.1. Emotional support

Emotional support is viewed as the most important aspect through which support is passed on to others (Hinson-Langford, *et al.,* 1997: 96). Emotional support represents the ability to turn to others for comfort and security during times of stress, leading the person to feel that others care for him or her (Schaefer *et al.,* 1981: 385; Veiel & Baumann, 1992: 43; MacArthur 1998; Westaway *et al.*, 2005: 74; Barry 2006: 185). This type of support comprises of comforting gestures, which are intended to alleviate uncertainty, hopelessness, anxiety and depression. Emotional support is defined as being empathetic and understanding, and encouraging expression of feelings because it is believed that emotional support normalises situations by diverting attention away from the problems at hand (Benett *et al.,* 2001: 674).

Providers of support are thought to be reliably available and willing to provide support during challenging times. Basically, support providers serve as advocates by motivating and empowering recipients to act on their behalf (Sarason, *et al.,* 1990). MacArthur (1998) argues that emotional support in particular impacts both psychological and physical health. Cohen and Syme (1995: 8) argue that feelings of belonging, elevated self-esteem, and security stimulated by social support may directly help in recovery from physical illness.

2.4.2. Instrumental support

Instrumental support includes providing tangible goods such as food, transportation and financial services and is also referred to as tangible support (Schaefer *et al.,* 1981:386; Sarason, *et al.,* 1990: 322; Canney 1993: 19; MacAthur 1998; Benett *et al.,* 2001: 674; Faulkner & Davies, 2005: 39; Barry, 2006: 185). Even though the provision of instrumental support may suggest caring and love for an individual, it is distinguishable from emotional support in that the carer provides concrete assistance, for example, by performing assigned work for others (Hinson-Langford, *et al.,* 1997: 96). Sarason *et al.* (1990: 322) and Walsh and Connelly (1996, in Mauldin, 2004) found that instrumental support is mostly provided by informal community relations. Tangible support may help reduce the ill person's pain, fatigue and worry. It is also believed that, instrumental support can make it physically easier to comply with therapeutic regimens. In a study of patients with diabetes, Westaway *et al.* (2005) found that instrumental support was the most important underlying dimension of social support.

2.4.3. Informational support

Informational support is a term applied to the process through which persons may provide information, advice and guidance (Benett *et al.,* 2001: 674; Westaway *et al.,* 2005: 74). Informational support is basically provided to help the recipient address his/her own problems or providing information on social or health related matters (Schaefer *et al.,* 1981: 386; Sarason, *et al.,* 1990: 322; Canney, 1993: 18; MacArthur, 1998; Faulkner & Davies, 2005: 39; Hough 2005: 16). Even though social support in general is frequently provided by the family, kin and close friends, informational support is often provided by casual acquaintances. According to Canney (1993:19), information provided by close ties is often less helpful because people in the same social network are more likely to have similar information. Therefore, people who are not part of the client or ill person's social networks (e.g. health providers) are considered an important source of information.

2.4.4. Esteem/appraisal support

Appraisal support involves the communication of information which is relevant to self-evaluation or self esteem rather than problem solving. According to Hinson-Langford *et al.* (1997: 97), appraisal support is also referred to as affirmational support. Affirmational support encompasses expressions that affirm the appropriateness of acts or statements made by another. In the course of human existence, people encounter threats to their self-esteem. Esteem support is the provision of constructive feedback, encouragement or other information that will help the recipient to evaluate his/her own sense of self-efficacy or competency. Cheng and Chan (2006) believe that information about the esteem in which a person is held by others may influence motivation to get well and consequently increase adherence with medical regimens and performance of health care behaviours

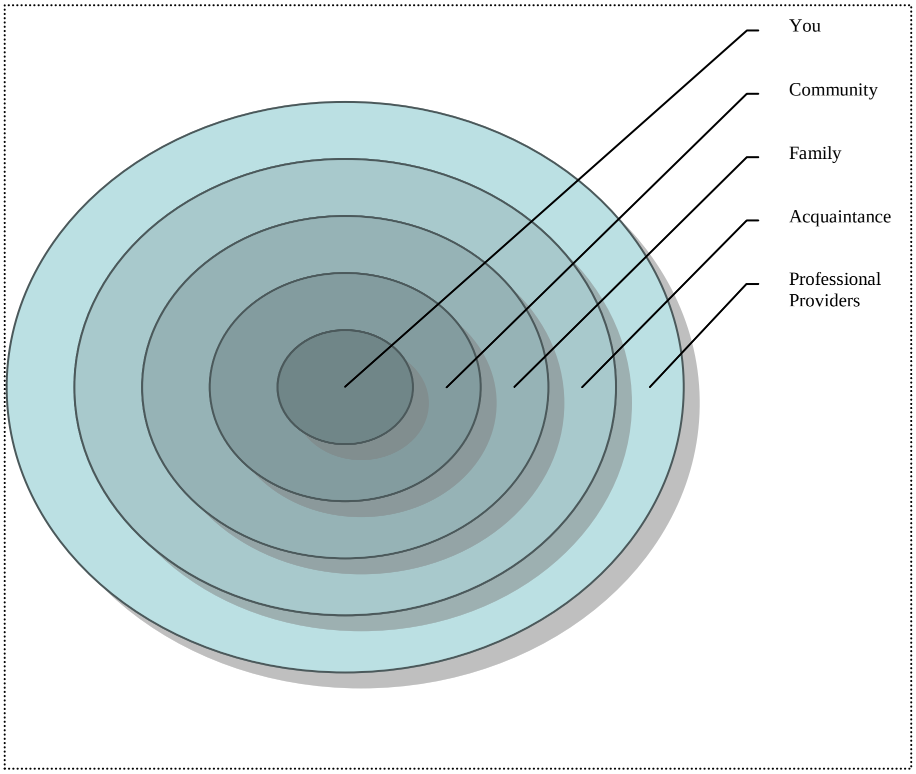
2.5. Sources of Social support

Social support may originate from a variety of sources, including family, friends, support groups, neighbours, health care professionals and fellow members of one's religious congregation (Benett *et al.,* 2001: 674; Manning-Walsh, 2004: 483; Jia *et al.,* 2005: 396). These sources of social support are mainly referred to as social support networks. Such social support networks have been considered an important factor in coping and in recovery from physical illness and in increasing adherence to medication regimens. Various studies have found that not only do social networks facilitate well-being, but the lack of it may also adversely affect health outcomes. Social support networks promote healthy behaviour by providing material services, emotional support, or referral and information about other resources. Alternative sources of social support can also be classified more formally using the convoy model.

2.5.1. The Convoy Model of social support

The Convoy Model of social support was designed to address the issue of continuity and change in social support over the life course. The model developed from the work of Bowlby and other theorists who noted the importance of interpersonal relationships over the entire life course (Sarason & Sarason, 1985). The model seeks to describe and explain the social support phenomenon with emphasis on informal social relationships developed within a life span of a person. The Convoy Model emphasises that the individual grows up and matures for the most part surrounded by people who are close and important to him or her. Beginning with the primary giver, usually the mother, the tone of these interpersonal relationships is set. The recipient is firstly exposed to a select few primary caregivers and then to an ever broadening range of family and friends. These people represent a convoy or protecting shield through which the individual interacts with the world at large (Gallagher & Truglio-Londrigan, 2006).

Figure 2.1: The Convoy Model of social support



Source: Adapted from Gallagher and Truglio-Londrigan (2006; 26).

To emphasise various levels of importance that convoy members might attain, the convoy is presented as five concentric circles with the target person in the middle (Gallagher & Truglio-Londrigan, 2006). The innermost ring consists of the family as the closest and most important providers of social support. The middle ring consists of friends, acquaintances and co-workers, who are important but not the most intimate supporters. The two added outer rings consist of the community and professional providers. The convoy model of social support is designed to provide a broad perspective on the structure and function of social support over the life course. Personal and situational characteristics are considered determinants of the support convoy. The structure and function of the support convoy provide basic information about the network itself and the kinds of support that are exchanged (Sarason & Sarason, 1985).

The terms convoy adequacy and outcomes are used to describe the effects of the support convoy on the individual (Sarason & Sarason, 1985). People may come to think of their network as too demanding or not understanding. In general, people develop a sense of satisfaction or dissatisfaction with their convoy of support. This sense of convoy adequacy is then translated into outcomes, which may include measures of both mental and physical health. Common examples of outcome measures include life satisfaction, well-being, health, negative effects and happiness (Sarason & Sarason, 1985).

Of great concern though, is that the convoy model identifies the importance of the above mentioned informal social support sources, but does not look at the formal community support. The main aim of formal community support is the provision of valuable services. The provision of these services is most important when informal support provided by family, friends and acquaintances may be insufficient or lacking (Gallagher & Truglio-Londrigan, 2006). Therefore, it is logical to propose the addition of a fourth and a fifth outer ring to the Convoy model (as shown in Figure 2.1), one that consists of community support and professional providers.

Persons who provide support may also vary depending on the type of situation and the individual receiving the support. According to Fingeld-Connett (2005: 6), an integrated social network is an antecedent to effective implementation of social support. He further argues that, having specific types of people (e.g. spouse, parents or friends) within the network appears less relevant than the personal attributes of the people who comprise the support system. Close associates, such as family and friends, are frequently acknowledged to be social support providers, in addition to neighbours, church members, support group participants, peers and acquaintances. Health care professionals are looked to for social support only when others cannot provide the support that is required. This situation might occur because of geographic distance, stigma or other circumstances related to a health problem, the need for secrecy or time constraints.

Walsh and Connelly (1996, in Mauldin, 2004) found that the type of social network to which a person belonged was related to the type of support they received. Moreover, emotional support was more frequently received from networks of extended family, whereas families of origin provided the largest amount of material support. The literature further argues that the size of one's social network seems to be less important to health outcomes than its composition. Researchers have reported that families are not viewed as particularly helpful to HIV positive people. In fact, the majority of studies suggest that friends provide more support to HIV infected individuals than their family. Social support for people on ART could be offered by two social networks: formal and informal.

2.5.2. Formal and informal support

Schaefer *et al.* (1981: 383) argues that a social network can be described in terms of its structure. Social support networks often grow out of other groups, but they may also be created deliberately. Due to the functional and structural aspects of one's social support network, many researchers have linked social support with improved psychological well-being and decreased depression and anxiety in people with HIV/AIDS.

2.5.2. (a) Formal support

Formal care is defined as governmentally mandated or sponsored professional services, e.g. government financial assistance, medical social services, home help service, trained volunteers and counsellors etc. (Gottlieb, 1983: 262; Selwyn & Schietinger, 2003). Formal services operate under a system of clear categories for assessing the need of eligibility. Formal support with universal criteria, routine procedures and formalised systems of management offer a way to provide greater equity, reliability and efficiency in the delivery of services.

Technical knowledge or the routine administration of resources can be best handled by formally organised professional services. Formal support network can be structured along a team-based approach to medical care, involving professional nurses, social workers and medical staff who serve as emotional, informational and tangible support specialists. Formal support is also a mutual flow activity; professional helpers cannot force patients into accepting support if patients are not willing to receive it. The provision of formal support services is especially important when informal social support provided by family, friends and acquaintances is insufficient or unavailable (Finfgeld-Connett, 2005: 7). In the South African setting, formal social support is generally provided by NGOs or community health workers.

i. Non-Governmental Organisations

Non-governmental organisations (NGOs) form part of formal support networks. Various NGOs play a critical role in the provision of a multitude of services. The specific services delivered by NGOs include providing care, counselling, support, education and training or awareness programmes, and the provision of other health-related services to people living with HIV/AIDS and the community. Together, these support mechanisms better ensure that persons living with HIV will receive ongoing information, care and support to minimize the risk of transmitting the virus to others and to maintain good health and slow the progression of disease (NDoH, 2003: 59).

ii. Community Health Workers

Community Health Workers (CHWs) in this study comprise of home based carers and lay counsellors. This cadre of volunteers often form part of Community Based Organisations. CHWs are considered a useful tool to assess and support patient adherence to ART and other therapies, including locating and reaching out to patients missing scheduled appointments, promoting continuity of care and adherence to treatment (NDoH, 2003: 28). CHWs promote ongoing care-seeking behaviour in patients, encouragement of treatment adherence, practical support through caring support networks and assistance in education provision. These service providers also play a role in carrying forth prevention messages and providing and reinforcing accurate information to address stigma, fear and discrimination that surround HIV infection. Moreover, CHWs play a critical role in the provision of physical, emotional and informational support. Support mostly provided includes helping with cooking and bathing (NDoH, 2003).

5.2.2 (b) Informal support networks

Research has demonstrated the vital role that informal caregivers play in attending to the physical, emotional and spiritual needs of people living with HIV/AIDS (Knowlton, 2003). Informal supporters perform a variety of roles that help people with HIV/AIDS adhere to treatment regimens, avoid unnecessary hospital admissions, reduce reliance on formal caregivers, remain at home longer and maintain quality of life. Traditionally, family members have served as primary supporters for seriously ill individuals. Informal support is found within social networks, usually on an unorganised or spontaneous basis. Such support is distinguished from formal support by the types of people, what they do and the reasons behind what they do.

Informal support systems include relatives, spouses/partners, family members, friends and acquaintances, who willingly provide care and support, usually on an unpaid basis (Selwyn & Schietinger, 2003; Galagher & Truglio-Londrigan, 2004). These supporters vary in the types of tasks performed, the amount of time devoted to care giving and support and living arrangements. It should be noted that informal support is a mutual flow, involving receipt and provision of help. Informal supporters are integrated into patient's culture and usually share similar values. Informal supporters who are related to the recipient may also share similar interests and problems with patients, especially their spouses and family members. Thus, they are better equipped to identify needs and to provide appropriate services (Gottlieb, 1983: 265).

i. Family and friends

Almost universally, family, relatives and friends provide up to 90% of care and support for people living with HIV/AIDS (UNAIDS, 2004). As the primary psychosocial environment, family tends to serve consistently as helpful support sources that can effectively deal with life's problems. Families have a critical role to play in supporting the chronically ill through different stages of illness and treatment. Studies conducted recently suggest that family involvement in care giving activities for people with HIV/AIDS has become increasingly important. AIDS has become a chronic illness, with infected individuals surviving for longer periods of time at higher levels of health status than ever before. The number of those infected with HIV/AIDS continues to grow and is projected to continue increasing rapidly. Smith and Rapkin (1996) argue that if efforts to promote family involvement in care giving activities for people living with HIV/AIDS are to be successful, the definition of the family in the context of HIV/AIDS needs to be made.

Family membership has traditionally been conceived of in terms of blood or legal ties; however data suggest that many people living with HIV/AIDS interpret family as extending beyond this to include individuals with whom they have significant social affiliations. These individuals form the family choice for people living with HIV/AIDS. Relatively little is known about the structure, composition and functioning of informal support systems for people living with HIVAIDS. Family members mostly provide physical, emotional and instrumental support to people living with HIV/AIDS. However, Smith and Rapkin (1996) are of the opinion that the presence of family members does not guarantee their involvement in support and caring activities. In addition, friends have also been found to be an important source of social support (Hall, 1999: 79.

ii. Support groups

Support groups are also considered an important part of the informal support network. A support group has been identified as a structure or meeting where people with common challenges, concerns and needs come together to support one another in various aspects of daily living and functioning. It is argued that support groups can influence an individual's well-being and provide protection to those in crisis (Burrage & Demi, 2003). These networks help people to live with their conditions. Professionals may be instrumental in establishing and maintaining the network, may be consultants to the support network, or may not be involved at all.

Support groups often provide informational support and material support and broader social network (Whittaker & Garbarino, 1983: 112). Moreover, support groups are a valuable resource for helping with emotional issues that may arise while on therapy. There may be some members of the support group who have been on therapy and can help with strategies on maintaining health and managing side effects while on treatment. Studies have found that participation in support groups reduces feelings of isolation, increases knowledge, and promotes coping efforts. Support groups can also help reduce the stigma associated with HIV/AIDS, foster early detection of illnesses, and improve adherence to treatment.

iii. Treatment supporters/buddies

Treatment supporters or buddies are considered the most crucial part of the informal support network. Such people ensure patient's adherence to treatment (Porter & Ogden, 1997: 121; Strick, 2002; Bednall *et al.,* 1999: 759; Garner, 1999: 1326). Treatment buddies ensure that the patient takes the correct drugs, the correct dose at the right time (Calder, 2001). Treatment supporters currently are mostly used in the tuberculosis DOTS programme; they may be a health worker or a trained and supervised community member. The treatment buddy system of support is viewed as a stress buffer through the provision of support (Burrage & Demi, 2003).

Treatment buddies are different from treatment supporters in a sense that the patient chooses the treatment buddy However, similar to the DOTS programme, in some instances a supporter may be chosen by someone else (e.g., nurse). A treatment buddy is a culturally appropriate source of information on HIV/AIDS and a source of emotional support, but most importantly plays a critical role in ensuring patient's adherence to ARV treatment regimens. The treatment buddy programme is normally considered an informal support because it does not operate under a system of clear categories. No formal communication exists between the treatment buddy programme and the health system (Escott & Walley, 2005).

iv. Faith-Based Organisations

Spiritual belief systems are also important as part of the informal support network. Religious organisations' participation helps in developing social resources. A study by Manning-Walsh (2004), found that individuals with church membership have higher levels of emotional health and larger social networks than do non-members. Therefore, participation in religious organisations may result in better quality of life owing to religious group's promotion of stable and effective social support.

2.6. Benefits of social support

Perceived social support has been found to be associated with adjustment and coping with to HIV and its potentially chronic, disabling influence (Burgoyne & Saunders, 2000: 644; Burgoyne, 2005: 111). Research to date suggests that social support may promote positive physical and psychological health outcomes during serious illness like HIV/AIDS, aid the recovery process and even reduce mortality in adults (Shumaker & Czajkowski, 1994: 73; Chen *et al.,* 2005).

In most studies, social support has been found to promote quality of life and health of people living with HIV/AIDS in various ways. The use of social support as a health intervention has been strengthened by research indicating that people with larger social networks enjoy a variety of health benefits. These include a reduced susceptibility to infectious diseases and depression (Faulkner & Davies, 2005). According to Karademas (2006: 1282), social support is related to subjective well-being and depression. The assumption that social support is always intended to be positive leads people to highlight the existence of social support as a positive influence on health and health behaviours, and its absence as a negative influence. Diminished social support is in part linked to increased loneliness, depression and anxiety, and poorer physical health. Social support is therefore an important contributor to health.

Social support has two sorts of health effects, namely (direct) effects and buffer effects. The direct effect hypothesis argues that social support enhances health and well being, irrespective of the level of stress a person is experiencing. Such direct benefit could occur as a result of the perception that others will provide aid in the event of stressful occurrences or merely as a result of integrated membership in a social network. Recently, there has been a substantial interest in determining whether the positive relationship between social support and health occurs because support enhances health and well-being, irrespective of stress level (direct effect hypothesis), or because support protects people from the pathogenic effects of stressful events (buffering hypothesis).

2.6.1 The direct effects hypothesis

According to Sleutel, (2003), people perceiving high levels of social support report lower levels of depression, higher self-esteem and a greater optimism. Thus, the perception that social support is available when it is needed has important implications for an individual's psychological well-being. Prior research suggests that there are conditions where this does not occur, and these may be precisely the conditions under which support is most needed and desired. During chronic stressful conditions, support is not always as abundant as people believed it would be. This may be in part due to a lack of available social relationships. Early researchers theorised that when a life threatening illness (such as HIV/AIDS) transpires, social networks may not always be responsive. Close relatives and friends may have difficulty providing effective support under stressful conditions. They may feel threatened by the event or uncertain about how to help.

Studies further suggest that patients living with HIV infection and who consistently took ART over a relatively long-term period of time appeared to experience better clinical benefit in terms of virological suppression if they perceived having interpersonal, informational and emotional support available to them (Burgoyne, 2005). Burgoyne and Saunders (2000: 644) pointed out that perceived social support is associated with reliance on friends and partners. Moreover, perceived social support has been shown to be more strongly associated with improved health outcomes than are other measures of social support networks and even actual support received (Sleutel, 2003). Below is the discussion on the direct effects of social support.

i. Reducing the risk of ill health

Physical illness is often accompanied by a host of fears and problems such as severe pain, progressive deterioration, energy loss, dependency on others, changes in self-concept and a number of other potential changes that can be terrifying. To cope with these problems, the physically ill person may have greater than average needs for numerous forms of social support. Social support may be of great importance in reducing the intensity of fear, depression and anger that may result from serious illness. For some illness, physical limitations may lead to a need for instrumental assistance in order to replace or compensate for abilities or assets lost as a result of the illness (Sarason *et al.*, 1990: 322).

Studies on hearing-impaired adults found that emotional support and esteem support were associated with lower levels of anxiety, depression and paranoia. (A person who is no longer able to meet family responsibilities may need outside help with household tasks (tangible support). Sarason *et al.*, 1990: 322). Uncertainties and fears that the ill person is experiencing may intensify needs for clarification of what is happening (informational support) and reassurance that the feelings and fears are normal consequences of the illness. The resultant threat to self-concept may intensify needs for reassurance that others will still love and not abandon the ill person (emotional support). These various forms of support can be especially important for easing the burdens encountered by the seriously ill at a time when they have less emotional and physical strength to deal with these burdens.

ii. Aiding the recovery process

The relationship between social support and recovery from physical illness may be mediated by the effects of social support on health behaviour and/or the mobilisation of the immune system (Whittaker & Garbarino, 1983: 107; DiMatteo, 2004: 207). In the case of health behaviours, information from others about proper health care and coping with illness may influence their perceived and actual ability to influence their health status (Cheng & Chan, 2006). Instrumental help may also have a direct impact on the patient's well-being, while information about the esteem in which a person is held by others may influence their motivation to get well and consequently increase adherence to treatment regimens and performance of other health care behaviours. Cohen and Syme (1995: 8) argue that feelings of belonging, elevated self-esteem, and security, stimulated by social support, may directly help in recovery from physical illness. Support, ability to cope and motivations to get well may similarly help recovery by directly influencing emotional and cognitive states associated with the disorder or by increasing compliance with medical regimens

2.6.2 The buffering hypothesis

Contrary to the direct effect model, the buffering hypothesis proposes that support exercises its beneficial effects in the presence of stress by protecting people from the pathogenic effects of such stress (Shumaker & Czajkowski, 1994: 47; Cohen & Syme, 1995). Under conditions of high stress, individuals with high social support will therefore have significantly better health outcomes than those with low support. In this model, support may play a role at two different points in the causal chain of stress pathology. Firstly, support may intervene between the stressful event and the stress experience by preventing a stress response. Secondly, support may intervene between the experiences of stress by reducing the stress experience. Social support may alleviate the impact of the stress experience in three ways: (1) Support may reduce the importance of the perception that a situation is stressful; (2) may in some way tranquilize the immune systems so that people are less reactive to perceived stress (3) or may facilitate healthful behaviours such as exercising or attending to personal hygiene, proper nutrition and sufficient rest (Whittaker and Garbarino, 1983: 108; Cohen and Syme, 1995: 8).

Studies suggest that while the presence of social support may contribute directly to health outcomes, there has been a greater interest in the idea that social support to protect people in times of stress, i.e. in the indirect effects of social support (Friedland *et al.,* 1996: 16; Benett *et al.,* 2001: 672).

Furthermore, a positive linkage between stress and social support can be interpreted as evidence that exposure to stressful circumstances activates the mobilisation of enacted support (Barrera, 1986: 423). Reviews indicate that people who have socially supportive relationships are less likely to experience a wide range of negative physical and psychological health consequences. Studies indicate that the loss of social and emotional relationships is associated with physical disorders. Turner (2002: 149) and DiMatteo (2004: 208) further argue that support and assistance from friends and family promote patient adherence by encouraging optimism, buffering the stress of being ill, reducing patient depression and giving practical assistance.

2.7. HIV/AIDS and the role of social support

Turner *et al.* (1993) argue that HIV/AIDS has become a serious public health problem with astonishing medical, psychological and social implications. 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. Social support is an important aspect of psychological adjustment for many people living with HIV (Mason *et al.,* 1997: 155). Previous studies suggest that depression negatively impacted on health-related quality of life of people living with HIV/AIDS, either directly or indirectly through mediating variables such as social support (Jia *et al.,* 2005: 396). Similar to other chronic illnesses, social support can buffer stress associated with living with HIV/AIDS and can promote a sense of emotional well-being (DiMatteo 2004: 207; Mawar *et al.,* 2005: 476). Authors such as Mason *et al.* (1997: 155) hypothesise that social support provides a buffer against stressful experiences such as HIV/AIDS and may have positive effects on the immune status of persons with HIV/AIDS, thereby preventing stress-induced illness or other unpleasant physical consequences.

Social support therefore addresses the ongoing psychological and social problems of HIV infected persons. HIV infection affects the physical, psychological, social and spiritual dimensions of a person's life. Social support is known to help people cope better with the different stages of the infection and enhance the quality of life of the infected person. As a result, the provision of social support for people living with HIV/AIDS is considered an important element in comprehensive care and support as well as a crucial part of the care package at all levels (Benett *et al.,* 2001: 671).

Moreover, Bloom (1997: 3) Benett *et al.* (2001: 672) and Hough *et al.,* (2005: 14) argue that social support influences health outcomes in persons with chronic illnesses and is a critical factor in coping with HIV. On the other hand, lack of social support for people living with HIV/AIDS tends to result in gaps in terms of needed practical and emotional resources (Burgoyne, 2005: 111). Karademas (2006: 1282) further suggests that individuals with more supportive families or friends have a better health status and that they recover faster from health problems compared to persons who are less socially integrated. According to Keyes *et al.* (2005), social support promote health by providing persons with positive experiences, socially rewarding roles, or improved ability to cope with stressful events. The authors discovered that emotional support was considered more desirable and was more often used than other forms of support. On the other study, satisfaction with informational support was a strong predictor of better quality of life (Friedland *et al.,* 1996: 29; Douaity & Singh, 2001: 455).

Furthermore, informational support was considered particularly critical for patients experiencing HIV/AIDS-related symptoms (Douaity & Singh, 2001: 455). A study by Jia *et al.* (2004: 600) revealed that social support was significantly associated with quality of life. Douaity and Singh (2001: 455) argue that older patients with HIV infection were less satisfied with their social support resources. Social support for patients with HIV/AIDS has shown a strong potential to influence health-related quality of life (Friedland *et al.,* 1996: 17; Douaity & Singh, 2001: 455; Jia, 2004: 600; Burgoyne & Renwick, 2004: 1354).

2.7.1 Social support and health-related quality of life of PLWHA

Health-related quality of life is defined as the individuals' appraisal of their current health status physical functioning, social and emotional well-being (Ulla-Sisko, 2000; Hudson *et al.,* 2004). Understanding the role of care and social support and its relationship to health-related quality of life is important for several reasons. The first reason is the HIV related stigma and discrimination which makes access to care and support more difficult for people living with HIV/AIDS. Secondly, HIV infected persons face restricted access to treatment due to several socio-economic, structural and other constraints. Finally, we consider the ambivalent attitudes and behaviours from family members, caregivers and friends towards HIV/AIDS (Kumarasamy *et al.*, 2005).

According to Keyes *et al.* (2005), social support promotes health by providing persons with positive experiences, socially rewarding roles or improved ability to cope with stressful events. Further, in a study by Keyes *et al.* (2005), emotional support was considered more desirable and was more often used than other forms. On the other hand, satisfaction with informational support was a strong predictor of better quality of life (Friedland *et al.,* 1996: 29; Douaity & Singh, 2001: 455).

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2.7.2 Social support and adherence to ART

Social support is also believed to be positively associated with adherence to medication regimens. DiMatteo (2004) is of the opinion that patient adherence may well mediate the link between social support and health. Strict adherence to antiretroviral treatment regimens is critical to the effective management of HIV/AIDS. Given the rapid rates of HIV replication and mutation, failure to follow the dosing instructions of prescribed regimens can lead to resistance and incomplete viral suppression.

Turner (2002: 149) and DiMatteo (2004: 208) further argue that support and assistance from friends and family promote patient adherence by encouraging optimism and self esteem and giving practical assistance. Certain patient characteristics such as younger age, ethnicity and lack of high school education have been shown to correlate with non-adherence, while socio-demographic factors such a college education and older age have been associated with taking medications as prescribed. However, (Power *et al.,* 2003: 246) found no significant association between adherence to treatment and socio-demographic variables.

In a study by Power *et al.* (2003), satisfaction with social support among HIV/AIDS infected patients was positively correlated with adherence to antiretroviral medications, and poor quality of social support has been significantly associated with suboptimal adherence rates. He further found that, participants who perceived their partner to provide a more satisfactory support pertaining to their HIV (status?) were significantly less likely to miss doses of medications. A study by Roberts among patients on antiretroviral therapy (2000: 164) revealed that the support from friends and family members was significantly related to adherence.

Simoni *et al.* (2002: 436) found that a need for social support was positively correlated with acknowledged non-adherence to ART. Better social support was further associated with greater likelihood of viral load suppression to undetectable level. In addition, HIV positive adults consistently taking ART appeared to experience better clinical benefit if they perceived informational and emotional support to be available. According to studies conducted by Douaity and Singh (2001: 455) and García and Côté (2003: 40), satisfaction with the social support system significantly increased the likelihood of adherence to ART among HIV-infected people. Isolated patients without support of family loved ones or friends were more likely to have decreased adherence to treatment.

2.8. Constraints to optimal functioning of social support

According to Cohen and Syme (1995: 287), some of the unsupportive negative responses to the ill may occur for reasons specific to a particular disease. The disease of HIV/AIDS for example, can evoke physical hatred and revulsion if others are fearful of catching the disease or if they see previously healthy individuals become radically changed by general deterioration of health. Aside from the physical revulsion and fear that a serious disease can provoke, simply trying to deal with a person who is in pain or feeling depressed can be a stressful experience for potential supporters. Interacting with a seriously ill person may result in feelings of awkwardness, inadequacy and frustrations because there seems to be little that one can say or do. People may also become demoralised if they notice little improvement in the patient after providing support or reassurance.

Moreover, those closest to the patient may feel sadness because the ill person is suffering, as well as anger and resentment that the disease has disrupted their own lives. Even though, supporters of the ill people undoubtedly want to be helpful, their feelings and beliefs may result in behaviours that are unintentionally damaging to the patient. Such behaviours may include avoidance of the patient, avoidance of open discussion about the illness and uncomfortable interactions. Unfortunately, the ill person may interpret these behaviours as evidence of rejection at the very time when support from others is especially important (Sarason *et al.,* 1990).

Furthermore, stressful events often elicit emotional reactions in social network members, such as fear, discomfort, frustration, helplessness and embarrassment. In addition to the negative feelings provoked, providers of support may be unable to extend effective or skilful support because they hold misconceptions about the coping process (Sarason *et al.,* 1990). On the other hand, Gottlieb (1983) argues that social support might be detrimental because it may interfere with adherence. If treatment is acceptable to family members and other close persons, they may help the patient remember his treatment regimen and encourage him/her to follow it. But if the treatment for the patient goes against their values and beliefs, they may subvert the treatment regimen.

It has been shown that perceived available social support and satisfaction with actual social support are relatively stable over years even if those years comprise developmental transition with subsequent changes in network membership (Shumaker & Czajkowski, 1994: 47). Hupcey (1998: 1234) argue that the perception of satisfaction with the support provided and the outcomes of social support may be influenced by the person providing the support. Gottlieb (1983: 136) suggests that the seriousness of the patient's illness is one of the most important variables affecting his or her responses to various forms of social support, as well as his/her ability to adjust to various outcomes. Seriousness of an illness is determined by various factors, including the amount of pain, physical limitation, and difficulty of following the treatment, the likelihood of recovery and the threat of survival.

Moreover, diseases in which stigma is attached, (e.g. HIV/AIDS) may also affect the willingness of agents to offer social support to sick individuals. People with HIV/AIDS are often alienated, both emotionally and geographically, from the natural support group of their own families. In the case of a chronic illness like HIV/AIDS, persons may feel that they are being a burden and so wish to isolate themselves or refrain from requesting help.

2.9. Conditions for the benefits of social support to materialise

Social support is effectively delivered when all parties involved have a common context in which to anticipate, interpret and respond to each other's needs. Because circumstances are context specific, support is enhanced when providers and recipients have shared challenges as well as common demographic, socio-cultural and religious backgrounds. Shared experiences coexist with mutual relationships in which reciprocity is the norm, and giving and receiving support is an active process of both parties. Mutuality and reciprocity are part of the socio-cultural value system, which ideally has a balance between giving and receiving support.

2. 10. Summary

Social support can be conceptualised as actions that others perform when they render assistance or support to the focal person. Social support may be provided in different forms, *i.e.* emotional, instrumental and appraisal support. Social support networks are the vehicles through which social support is provided. Such networks vary depending on the situation: they can be family, friends, community members or support group members. Research to date suggests that social support may promote physical and psychological health outcomes during a serious illness such as HIV/AIDS.

Social support has been found to promote health-related quality of life by providing HIV infected persons with positive experiences or improved ability to cope with their stressful situation. Social support is also positively associated with adherence to medication regimens. Such support can enhance adherence directly by providing reinforcements or reminders or indirectly by enhancing participant motivation or mitigating the negative effects of the stressful event. Even though social support is viewed as an important contributor to individual wellbeing, it has its own limitations. In the event of HIV/AIDS in which stigma is attached, willingness of people to offer social support may be limited. It is also important to note that there might be other constraints to optimal functioning of social support. For example if the treatment goes against the values and beliefs of members of a person’s social support network, their willingness to support the individual might be ineffective or counter-productive.

CHAPTER 3
ADHERENCE TO ANTIRETROVIRAL THERAPY

In this chapter an attempt is made to define the concept of adherence and the most commonly used measurements of adherence. The different databases were searched with various combinations of the following keywords; adherence, compliance *health, antiretroviral therapy, HIV/AIDS, adherence interventions, adherence devices and models of adherence.* Additional relevant articles were also obtained from bibliographies of already identified papers. The relevant literature obtained in this manner was employed to shed the light on the following aspects of this research: definitions of adherence; measures of adherence; determinants of adherence; adherence devices and adherence interventions.

3.1. Introduction

Adherence to treatment regimens is considered the most important factor in the success of antiretroviral therapy for people infected with HIV (Safren *et al.*, 2001; Fisher & Fisher, 2006; Battaglioli-DeNero, 2007; Shah, 2007). Adhering to medication has beneficial consequences since unnecessary limitations in health and excessive hospitalisation is prevented (Coetzee, 2004: 27; Insel & Cole, 2005: 202; Tyndall *et al.*, 2006). Adherence to ART ensures the effectiveness of ARV medication; however, treatment also brings significant challenges. ART requires strict adherence to avoid the development of treatment-resistance resulting from under-dosing and irregular use of antiretroviral drugs (Kalichman *et al.*, 1999: 267; Safren *et al.,* 2001; Podisi, 2005; Battaglioli-DeNero, 2007).

To achieve the maximum benefit from antiretroviral treatment, HIV/AIDS patients are required to adhere to their regimen at least 95% of the time (Cederfjäll *et al.*, 2002; Parsons *et al.,* 2007; Shah, 2007). However, Weiser *et al.* (2003) argues that estimates of average rates of non-adherence with antiretroviral therapy ranges from 50% to 80% in many different social and cultural settings and the risks associated with non-adherence are extensive at both individual and societal levels. Kent *et al.* (2003) argues that 80% adherence to ART may be low especially when virological outcomes are used to determine effectiveness.

3.2. Definitions of antiretroviral treatment adherence

Although there is no universally accepted definition, medication adherence may be defined as the extent to which a patient takes medication in the way intended by a health care provider. The terms adherence and non-adherence are meant to be non-judgmental statements of fact rather than expressions of blame toward the patient or provider. The term '*medication adherence'* in HIV/AIDS care specifically refers to the ability of the person living with HIV/AIDS to be involved in starting, managing, and maintaining a given therapeutic combination medication regimen to control viral (HIV) replication and improve immune function (Gray, 1998; Chesney *et al.,* 2000; Vermeire *et al.,* 2001). The term adherence is preferred over compliance. Compliance is less favoured because of its "*hierarchical, controlling and provider in charge connotation" (*Gray, 1998). Hardon *et al.* (2006) further argue that adherence has a broader meaning than compliance. It is believed that adherence reflects the importance of active patient involvement in making treatment decisions, while at the same time recognising the significance of practitioner relationship skills in strengthening this participation (Chesney *et al.*, 2000; Vermeire *et al.,* 2001).

Adherence to antiretroviral treatment is a difficult responsibility. Even though many individuals believe in the value of the medication and insist that they have taken medication as prescribed, non-adherence to medication remains a persistent challenge (Insel & Cole, 2005). Forms of non-adherence include skipping whole medication doses, taking only part of a dose, delaying doses, and not following special dosing instructions (Catz, 2000: 128; Roberts, 2000: 155; DiMatteo, 2004: 208).

3.3. Measures of adherence

The question of how to measure adherence has vexed many researchers (Lyon, *et al.,* 2003; Cederfjäll *et al.*, 2002). One problem with measuring adherence is the use of different terms to refer to the same issue, namely a patient's ability to follow a treatment plan. No general agreement currently exists on which term (adherence or compliance) is best to use, though adherence has quickly been gaining popularity (Lyon *et al.*, 2003). Moreover, the complexity of the problem of terminology as mentioned above has been the barrier toward development of a gold standard of measurement (Vermeire *et al.,* 2001; Arnsten *et al.*, 2001; Hardon *et al.,* 2006). Battaglioli-DeNero (2007) is of the opinion that patients may overstate their adherence because they fear criticism or disappointing the health care provider. It is further argued that certain interviewing techniques can help the health care worker to more accurately assess the patient's degree of adherence.

There are a number of measures of patient's adherence in taking medication. These measurement methods or approaches to measurement fall into three categories:

3.3.1 Subjective measures of adherence

The most commonly used measure of adherence is the patient self-report (Chesney *et al.,* 2003; Arnsten *et al.*, 2001), where the patient is asked how many doses he/she missed in the last day or two days or two weeks. Most important to note is that the format of the questions varies from study to study, thus resulting in problems of comparability of adherence estimates across studies. Self-reported methods are vulnerable to overestimates of adherence or underestimates of non-adherence (Cederfjäll *et al.*, 2002). In most cases, answers are influenced by the patient's desire to provide a socially acceptable answer, especially when the interviewer is a health worker. Other inaccuracies may result from imprecise or inconsistent questioning or patient forgetfulness. Other subjective measures include reports on adherence by persons other than the patient, such as health care providers.

3.3.2 Objective measures of adherence

These measures of adherence include pill-counts, pharmacy refill records, and electronic monitors of pill or drug use (Lyon *et al.*, 2003). The most commonly measured in this category is "the event-monitoring system". The medication event-monitoring system (MEMs) is inserted into a medication bottle and contains a computer chip that provides both the frequency and time of opening of the medication bottle to be measured (Vermeire *et al.,* 2001). Researchers argue that, MEMs, if used appropriately, can allow a more accurate assessment of adherence. The MEMs record the number of drugs taken, the number of days on which the correct dosage was taken, and the number of doses that were taken within one hour of the prescribed time (Goudge *et al.,* 2004). However, it is argued that the caps only measure bottle opening and not actual medication ingestion (Arnsten *et al.*, 2001). Chesney (2000) argues that despite the limitations of this measure, adherence data are providing convincing insight about the association between drug taking and viral load. Deschamps *et al.* (2004) and Arnsten *et* *al.* (2001) believe that the MEMs should preferably be combined with patient's self-report or pill count in order to measure non-adherence as validly and reliably as possible.

3.3.3 Physiological measures of adherence

These methods or indicators comprise viral load, CD4 count, and plasma essay or lab reports. In this category of adherence measure, the most frequently used methods are viral loads and CD4 counts. Goudge *et al.* (2004) is of the opinion that a patient's viral load can be used to measure adherence. However, there may be a variety of clinical reasons why the patient's viral load is not as low as expected due to the presence of opportunistic infections and other health complications. Authors argue that the viral load is an indirect measure in that it does not offer conclusive evidence of adherence behaviour. Lyon *et al.* (2003) further argues that even though viral loads and CD4 counts are considered the best direct methods for measuring adherence, viral loads and CD4 counts can be costly, time consuming and have limitations. Lyon *et al.* (2003) further argue that even with 100% adherence, patients can experience treatment failure, resistance and limited efficacy.

Some studies used multiple methods of assessment and Kent *et al.* (2003) is convinced that using multiple methods to measure adherence may yield more reliable results. By far the most frequently used was the subjective method. A significant association has been shown between self-reported levels of adherence and viral load (Weidle *et al.,* 1999; Hecht, 1998). Catz *et al.* (2000) conducted a study in Wisconsin on adherence with 72 participants on ART comparing self-reported measures and viral load. The results indicated that nearly one third of patients had missed their medication doses in the past 5 days and 18% had missed doses weekly over the past 3 months. Frequency of missed doses was significantly related to detectable viral loads. On the other hand, Kent *et al.* (2003) points out that self-reporting constantly demonstrates mean adherence rates that are 20% - 40% higher than those observed with pill-counts. Arnsten *et al.* (2001) further argue that self-reports produce higher adherence estimates than electronic monitoring. However, Hardon *et al.* (2006) argue that the use of more than one measure of adherence allows the strengths of one method to compensate for the weakness of the other and to more accurately capture the information needed to determine levels of adherence.

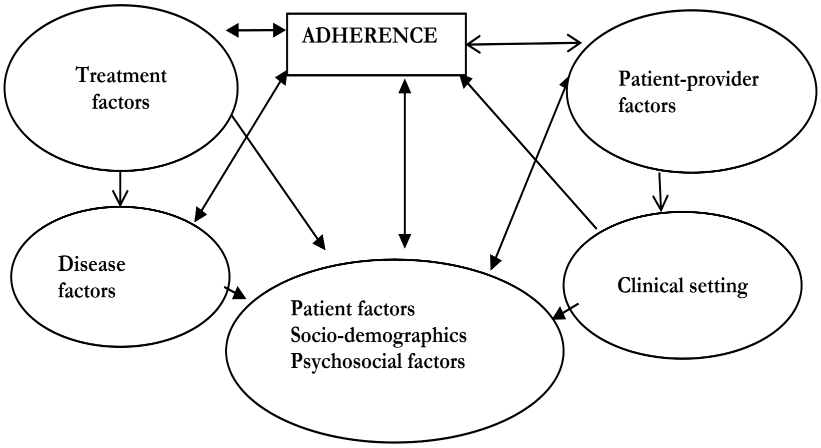
3.4. Determinants of adherence to treatment

Adherence to medication is considered a complex and dynamic behavioural process that is strongly influenced by the patient, his or her supportive environment, and practices of health care providers (Vlasnik *et al.,* 2005; Parsons *et al.,* 2007). Adherence may be related to changes in nutritional status, medical appointments, access to healthcare, pre-existing medical conditions or mental health status (Kennedy, 2000). Therefore, a number of obstacles need to be addressed in order to assist patients to adhere to therapy. These obstacles include restricted treatment access, complicated dosing regimen and pill burden, short term and long term side effects of treatment and stigma related to HIV (Bontempi *et al*., 2004). Safren *et al.* (1999) and Podisi (2005) further argue that a useful framework to ensuring adherence will be to consider the characteristics of the regimen: the disease itself; patient, the clinical setting and the clinician, because all these factors have an important influence on adherence. The information-motivation-behavioural skills (IMB) model presents a more nuanced presentation of patient/individual-level factors that matter for adherence and hence will be discussed below.

Various determinants of adherence as described in the theoretical models above will now be discussed in more detail.Figure 3.2 illustrates determinants of adherence and the interrelationship existing between these determinants.

The following discussion highlights various factors that contribute to increasing or declining adherence. From studying the literature, it is clear that there are factors that increase adherence as well as factors that decrease adherence, both of which need to be considered in assisting people with HIV to start and maintain effective treatment. It is also important to consider that each patient simultaneously deals with several factors that impact his/her ability to adhere to treatment. Although these factors are classified into five main categories, the classification has been done for heuristic purposes only. Many of the individual factors are multidimensional, crossing category boundaries and hence illustrating the complexity of classification.

Figure 3.2: Determinants of adherence



Source: Adapted from Ickovics and Meade (2002: 99)

3.4.1 Treatment and disease factors

Treatment and disease factors are interrelated, therefore are discussed together in this section. Treatment factors relate to characteristics of the treatment 'or the illness' that generate barriers to adherence. The patient's fear of side effects is believed to predict adherence. Adverse effects are one of the examples and the most common reason for HIV infected patients discontinuing their antiretroviral therapy (Weiss, 1999; Ickovics & Merade, 2002; Weiser *et al.,* 2003; Patel & Patel, 2006; Heyer & Ogunbanjo, 2006). Discontinuation of treatment is not just related to serious side effects, but even common side effects, such as nausea, vomiting, diarrhoea and neuropathy. Battaglioli-DeNero (2007) argues that patients who know that the adverse effects they may be experiencing are temporary in nature may be better able to endure them and thus exhibit higher levels of adherence. In their study of adherence among patients on ART, Catz *et al.* (2000) reported that non-adherent patients had significantly greater perceived severity of medication side effects. Several studies revealed that longer time on antiretroviral treatment and not experiencing positive effects of taking medications were consistently related to poor adherence (Mehta *et al.*, 1997; Gordillo *et al.*, 1999; Turner, 2002; Power, 2003).

The complexity of the treatment regimen is also important. The complexity of the treatment regimen includes the number of medications, the number of doses taken each day, and the number of pills taken at each dose (Haynes & Klinger, 2006). Dosing frequency and pill burden are commonly cited as obstacles to patient adherence (Ickovics & Merade, 2002; Rathbun *et al.,* 2005; Battaglioli-DeNero, 2007). In a study conducted by Golin *et al.* (2002), high dose frequency was significantly associated with non-adherence.

3.4.2 Patient factors

Many determinants of adherence have been studies that are referred to as patient factors. These are mostly characteristics of the patient that could be associated with adherence. Various patient factors influence adherence to medication. These factors will be discussed in detail below.

i. Socio-demographic and socio-economic factors

In developed countries like the United States, the most common patient-related factors that influence adherence to antiretrovirals include income and accessibility to health care. For the most part, patients' demographic characteristics (Chesney et al., 2000; Singh, 1996) and socio-economic status may reduce access to health care and treatment (Mehta *et al.*, 1997; Battaglioli-DeNero, 2007; Heyer & Ogunbanjo, 2006). In many developing countries like South Africa, Uganda and Botswana, the patient may not have the financial means (i.e. money for transport) to ensure sustained supply of antiretroviral drugs and therefore may have to resort to an interruption of their medication (Weiser *et al.*, 2003; Mshana *et al.*, 2006). Stout *et al.* (2004) conducted a cross-sectional study on adherence among patients on ART in Costa Rica. In this study, difficulty in finding transport was significantly associated with non-adherence.

According to the literature, the most common reasons for missed doses were predictable and included forgetting, being too busy, being out of town, being asleep, being depressed, being too ill and homelessness (Laws *et al.*, 2000; Cederfjäll *et al.*, 2002; Stout *et al.,* 2004; Reynolds *et al.*, 2004; Podisi, 2005; Parson *et al.*, 2007). In a study by Roberts (2000), forgetfulness was the most commonly mentioned barrier to adherence to the regimens. A study conducted by Fong *et al.* (2003) among

Chinese patients also revealed that forgetfulness and a busy workload were significantly associated with poor adherence. Homelessness and alcoholism were identified as risk factors for non-compliance among TB patients in a study by Burman *et al.,* (2006).

ii. Patient knowledge and belief

Patient's beliefs of HIV/AIDS, their knowledge about the nature of the illness and medication, and their views regarding the efficacy of ART affect their decision to initiate and continue treatment (Mehta *et al.*, 1997; Weiser *et al,,* 2003; García & Côté, 2003: 39; Carter, 2005: 1; Haynes & Klinger, 2006; Patel & Patel, 2006; Heyer & Ogunbanjo, 2006). Results of a prospective study of 140 HIV-infected patients, conducted by Gollin *et al.,* (2002) indicated that 80% of patients felt that ART medication was worth taking and agreed that medications helped people live longer.

Medication knowledge involves the ability to read and comprehend information necessary for appropriate use of medication. A qualitative study conducted by Roberts (2000) in California, San Francisco General Hospital, revealed that patient's inadequate knowledge regarding how to take treatment was a barrier to adherence. Moreover, studies indicate that a positive attitude, generated by the individual's own positive experiences or those of peers, as well as the awareness that the treatment is socially acceptable, promotes adherence (Malcolm *et al.*, 2003; Stone *et al.,* 1998; Heyer & Ogunbanjo, 2006). In their studies, Naar-King *et al.,* (2006) and Kalichman *et al.* (1999) discovered that health literacy was a significant predictor of adherence. Poor health literacy creates barriers to fully understanding one's health illness and treatment.

The literature suggests that interventions should not focus just on boosting a patient's ability to be adherent, but also on boosting the patient's belief in this ability (Naar-King *et al.,* 2006; Malcolm *et al.*, 2003). However, García and Côté, (2003: 39) are of the opinion that overconfidence about the efficacy of the medication may have a negative effect on adherence behaviour. Such overconfidence may result in patients thinking that their illness is less severe or threatening than it really is and underestimating the importance of medication. It is believed that a patient's ability to identify medications and understand the relationship between adherence and medication resistance predict better adherence (Kalichman *et al.*, 1999; Ickovics & Merade, 2002).

Health literacy and medication knowledge affect the patient's ability to absorb knowledge about therapy. Health literacy is the ability to read, understand and act on health information. Vlasnik *et al.* (2005) suggest that poor medication taking knowledge leads to medication errors, impairs the ability to remember and follow treatment recommendations, and reduces effective interaction with the health care system, all of which impairs proper adherence. Motivation affects the patient's ability to adhere to treatment.

iii. Social support

Social support may be important as it is one of the factors consistently associated with improved adherence (Garay-Sevilla *et al.*, 1995; Mehta *et al.*, 1997; Laws *et al.,* 2000; Cederfjäll *et al.*, 2002; Malcolm *et al.*, 2003; Blanco *et al.,* 2005; Kumarasamy *et al.,* 2005; Davies *et al.*, 2006; Battaglioli-DeNero, 2007). The absence of a support network of friends, family or partner may influence adherence. In a study by Catz *et al.* (2000) in Milwaukee, Wisconsin, out of 72 participants on ART, 49% reported that having no one available to provide reminders for medication times was an adherence barrier. Supporters can provide encouragement and alleviate psychological conditions such as depression and anxiety, which affects adherence negatively. The results of a study conducted in the Bronx, New York, by Simoni *et al.* (2002) on mediators of social support and ART among patients on ART, revealed that the need for social support was positively correlated with acknowledged non-adherence. In addition, in a study on adherence to ART in three Spanish prisons, Blanco *et al.* (2005) also found that lack of social support was significantly associated with non-adherence. In his study conducted in Madrid, Spain, Gordillo *et al.* (1999) reported similar findings to Blanco *et al.* (2005).

iv. Social/physical environment

The social/physical environment in which patients take their antiretroviral medication is another important factor in patient's adherence to treatment. The prevailing atmosphere of ignorance, stigmatisation and rejection create additional barriers to adherence to ART (Abdool-Karim *et al.*, 2004). In a qualitative study by Kumarasamy *et al.* (2005), stigma emerged as a major barrier to ART adherence. A study conducted by Weiser *et al.* (2003) in Botswana revealed that because of stigma, 59%

of patients on ART kept their HIV status a secret from their families, therefore did not have adherence support. The findings of the qualitative study on barriers and facilitators of adherence among patients on ART conducted by Roberts (2000) in California, San Francisco General Hospital, showed that being in a public or an unfamiliar environment was an obstacle to taking their antiretroviral medication. Several studies revealed that alcohol, drug abuse (Chesney *et al.*, 2000; Cederfjäll *et al.*, 2002) and younger age were consistently related to poor adherence (Mehta *et al.*, 1997; Weiss, 1999; Gordillo *et al.*, 1999; Turner, 2002; Power *et al*, 2003).

3.4.3 Patient-provider factors

Aspects of the patient-provider relationship that may influence adherence, include among others, patient's perceptions of the provider's competence, affective tone of the relationship, trust, open communication, adequacy of referrals and overall satisfaction (Ickovics & Merade, 2002). A trusting relationship with the health care provider has been shown to increase adherence (Lyon *et al.*, 2003; Kalichman *et al.,* 2000; Singh, *et al.*, 1996; Heyer & Ogunbanjo, 2006). It is further argued that communication difficulties that arise when the patient's attitude about disease and therapy is different from that of the provider's may be a barrier to adherence (Haynes & Klinger, 2006).

Without open and non-judgemental communication from the health care team, patients may not trust or may misunderstand the prescribed regimen. Therefore, a focus on communication with patients, particularly regarding expected side effects and their management will help build a positive and trusting relationship between the patient and the health care provider. A study conducted by Malcolm *et al.* (2003) in hospital-based HIV/AIDS clinics in Rhode Island revealed that patients who had excellent adherence received consistent feedback from clinicians and tended to work as partners with providers who they trusted and respected.

3.4.4 Clinical setting

Aspects of the clinical setting that may influence adherence include access to ongoing primary care, involvement in a dedicated adherence program, availability of transportation and childcare, pleasantness of the clinical environment, convenience in scheduling appointments, perceived confidentiality, and satisfaction with past experiences in the health care system. Chesney (2003) and Machtinger &

Bangsberg (2006) found that dissatisfaction with previous experience in the health care system is associated with non-adherence. Safren *et al.* (1999) and Haynes and Klinger (2006) further argue that characteristics of the clinical setting such as location, flexible clinic hours and privacy influence adherence. Lack of financial and institutional resources, disruptions in the supply of medication, and difficulty in gaining access to health services has been associated with poor adherence (Heyer & Ogunbanjo, 2006; Safren *et al.,* 2005; Forgaty *et al.*, 2002). The section below provides an overview of various adherence devices that may assist in increasing adherence.

3.5. Adherence support devices

A variety of devices that may help patients adhere to their treatment regimens are available. Most of these devices are simple, inexpensive, and easy to integrate into the routine care of patients on ART. Findings of a prospective study of predictors of adherence conducted by Golin *et al.* (2002) in North Carolina revealed that participants using no adherence aids or devices took 68% of doses versus 76% for those using adherence aids. The following are examples of commonly used adherence devices.

- *Medication organisers*: (pill boxes and pill charts): Medication organizers are readily available and come in many different shapes and sizes appropriate to the needs of individual patients. They allow patients to organize their weekly doses of medication in one convenient location instead of carrying multiple pill bottles, and to verify whether they have taken a given dose. Patients taking pill boxes to appointments helps clinicians monitor for recent non-adherence. Pill charts can be especially helpful for individuals who have literacy problems.

- *Electronic devices*: ccommon devices include alarms on watches, beepers, or other electronic items that allow for multiple daily reminders. Calendars, paper or electronic, allow patients to document scheduled doses and note when they have been taken. These devices are useful, however have limitations. Electronic devices should be discreet to help the patient feel that his/her confidentiality is not at risk. Claxton *et al.* (2001) investigated the effectiveness of electronic devices on adherence. In their review, they selected studies using electronic monitoring to measure adherence; adherence declined as the number of daily doses increased.

- *Telephone reminders*: these reminders can help with adherence on a regular or intermittent schedule. However, these reminders can be labour intensive for the staff and of course, require that the person be accessible by the telephone. It is important that the staff ensure that the patient is comfortable with the frequency of calls. The findings of the review by Van Dulmen *et al.* (2007) indicated that reminders are one of the most inexpensive adherence devices and have been successful in improving appointment keeping.

- *Medication diaries*: are journals in which the patient records when he/she takes or skips doses of experiences side effects. Keeping such journals can assist the patient and the provider in identifying patterns and uncovering reasons for missing doses of medication.

- *Incentives*: such as money, telephone cards, movie passes, transportation, food vouchers, as well as other small items (e.g. notebooks) have been found to be effective with some individuals when provided as part of the treatment plan. Giuffrida *et al.* in Van Dulmen *et al.* (2007) reviewed eleven randomised trials in which patients were paid for adherence in cash gifts or vouchers. The results showed improved adherence in ten out of eleven studies (odds ratios>1.0). The sections below focus on interventions that may be used to improve adherence by limiting the above constraints and enhancing the positive facilitating factors.

3.6. Adherence support interventions

Increasing recognition of medication adherence as a crucial factor in treatment outcomes has sparked a number of recent studies investigating methods to support and improve adherence. Researchers, in line with the conceptual models and empirical evidence on determinants of adherence presented in Section 4, argue that interventions to encourage adherence must not only address intra-psychic factors such as knowledge of the regimen and beliefs in benefits of treatment, but also environmental and social factors, such as the interpersonal relationship between the provider and the patient and social support from family members and friends. Adherence interventions generally aim either to inform people about HIV treatment and thus improve adherence or to generate behaviour change through incentives, suggestions or emotional support. The discussion below gives a brief overview of single and multifaceted adherence intervention strategies designed to improve adherence to ART (Kagay *et al.*, 2004).

3.6.1 Singular type interventions

This section provides an overview of various types of singular interventions. These are interventions which make use of a single adherence element or strategy within the intervention.

3.6.1. (a) Clinic-based adherence intervention services

There are different types of clinic-based intervention services and Harman, *et al.* (2005) established a standard of care for ART adherence by evaluating what clinics were actually doing to assess and address patient's adherence needs on a daily basis. The idea was to assess the comprehensiveness and intensity of adherence interventions that are being provided to patients in clinical care settings. In addition, Rathbun *et al.* (2005) conducted a prospective randomised controlled study to examine the impact of the adherence clinic care model. The study revealed that patients who received education and follow-up in an adherence clinic had better adherence to ART and greater viral suppression. Harman *et al.* (2005) identified intervention services to clinic patients and distinguished these services into levels.

- *Low-level adherence services* – these services consisted of *ad hoc* discussions held on a one-on-one basis with a health care provider. Due to time, patient load or other constraints, these low-level adherence services are part of routine clinical care and are provided on an as-needed basis.

- *Low-medium-level adherence services* could also be provided on an ad hoc basis; however there is staff with specific training on adherence issues available at the clinic site. At this level, caregivers recognise the importance of assessing patient adherence on an ongoing basis, but used no formal method to do so. Furthermore, sites in this category provide memory aids such as beepers or pillboxes.

- *Medium-level adherence services* are characterised by sites that have on-site clinical staff specialising in adherence issues, but limited patient reach in that the adherence-support staff to patient ratio is small and only appears to reach patients who are already having adherence problems.

Interventions at this level take a team approach and make use of local resources through referrals to community- based organisations or off-site support groups.

- *Medium-high-level adherence services* provide on-going, on-site support groups, or have visiting nurse programmes to provide care to a limited number of highly-non-adherent patients. Clinic sites provide more intensive services to address adherence issues. Medium-high-level interventions are not however, offered to most patients across the continuum of adherence (e.g. initiation of ART, maintenance of adherence, addressing non-adherence). This level of intervention targeted comprehensive care for the identified non-adherent patient.

- *High-level adherence services are* characterised by clinics that provide not only consistent assessment of adherence and on-going support groups but these services are also provided to patients at all levels of adherence, from initiation to maintenance.

Harman *et al.* (2005) pointed out that, given the behavioural and physical demands of ART adherence, the current standard of care practices for supporting adherence are probably insufficient. It is believed that a single source of support is not sufficiently effective to improve ART adherence or to support the maintenance of adequate ART adherence.

3.6.1. (b) Information-Motivation-Behavioural Skills (IMB) model

The information-motivation-behavioural skills (IMB) model is used to understand, predict and promote adherence to antiretroviral therapy. Grounded in health and social psychology, the model portrays adherence as a health behaviour determined primarily by an individual's (i) knowledge, (ii) attitudes toward taking antiretroviral medication, and (3) ability to perform necessary adherence-related tasks together with a sense of self-efficacy (Ware *et al.,* 2006). The IMB model focuses comprehensively on the information, motivation and behavioural skills factors that are conceptually and empirically linked to adherence and specifies situational and personal factors that may moderate the relation between IMB model constructs and adherence to therapy (Fisher & Fisher, 2006). The IMB model of adherence asserts that adherence-related information, motivation and behavioural skills are fundamental determinants of adherence to antiretroviral therapy among HIV-infected individuals.

i. Information

According to the IMB model of adherence, information that is relevant to adherence to ART is a prerequisite of consistent and correct use of therapy. Information about ART may be accurate and may facilitate adherence. Alternatively information may be inaccurate and may constitute impediments to ART adherence, as in the case of the individual who lacks information about what constitutes adequate adherence and about potential drug interactions or side effects.

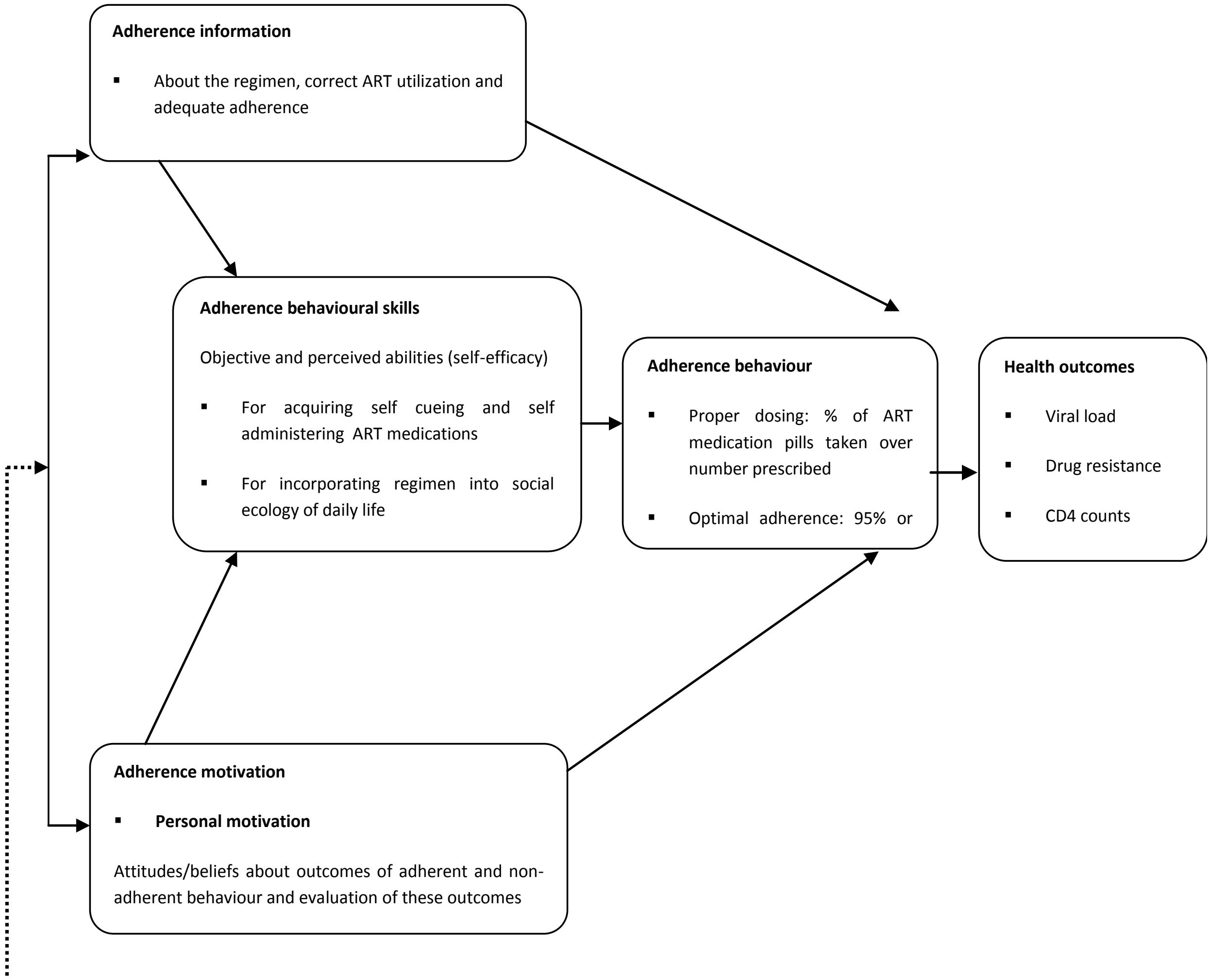
ii. Motivation

Individual's motivation to adhere to treatment is another fundamental determinant of adherence to ART. According to the IMB model of adherence, an individual's motivation to adhere to antiretroviral therapy is based on his or her personal and social motivation to adhere to therapy. Personal motivation to adhere involves an individual's attitudes towards adhering to the regimen and based on an individual's beliefs about the outcomes of ART adherence and evaluation of these outcomes. Social motivation to adhere rests on the individual's perception of social support from significant others for adhering to his or her medication and the individual's motivation to comply with these significant others.

iii. Behavioural skills

The behavioural skills component of the IMB model of adherence consists of an individual's objective abilities as well as his or her perceived self-efficacy concerning the performance of the complex sequence of behaviours that are involved in adhering to ART. The behavioural skills involved in ART adherence can include objective and perceived abilities to self-administer combinations of ART medication according to a prescribed schedule and as directed; to incorporate adherence to therapy into the ecology of daily life; to identify and minimise or cope with ART side effects; to obtain and update ART adherence-related facts and to be able to mobilise social support for ART adherence. The IBM model of adherence to ART also asserts that adherence to therapy is linked with individual health outcomes (Fisher & Fisher, 2006).

Figure 3.1: The IMB model of adherence



Source: Adapted from Fisher & Fisher (2006: 465).

3.6.1. (c) A cognitive-behavioural intervention

Cognitive-behavioural interventions for ART adherence are aimed at increasing self-care, thus leading to longer life and decreasing morbidity (Safren *et al.,* 2004). Cognitive interventions are designed to teach, clarify or instruct (e.g. treatment information); behavioural interventions are designed to shape, reinforce or influence behaviour (e.g. paper system, individual assessment and counselling) and effective interventions are designed to optimise social and emotional support (e.g. peer support). Studies suggest that cognitive-behavioural strategies can be used when mild memory difficulties are present or when the individual feels overwhelmed by the pill-taking challenge. Wagner *et al.* (2006)

conducted a 48-week controlled trial of cognitive-behavioural adherence intervention for patients initiating or changing antiretroviral treatment. The randomisation was to one of three adherence intervention groups: (1) a five session training intervention that combines cognitive-behavioural components and a 2 week practice trial, (2) the same intervention as above, but without the practice trial, and (3) no intervention, but usual clinical care. Results indicated that the intervention helped patients to take at least 90% of prescribed doses and patients sustained a mean adherence level of 90% or more at 24 weeks and the majority throughout the study. Effects of the cognitive–behavioural intervention were modest and transient and no effects were observed on viral load or CD4 cell count. A review by Van Dulmen *et al.* (2007) indicated that behavioural interventions played a role in improving adherence to medication.

3.6.1. (d) The Life-Steps intervention

The Life-Steps intervention is based on techniques and principles of the problem-solving therapy and more general principles of cognitive behavioural therapy (Safren *et al.*, 2001). The intervention assists HIV patients to identify and solve problems with adherence. Safren *et al.* (1999) defines a problem solving therapy as an approach that trains individuals to deal with stressful or apparently overwhelming problems. In the Life-Steps intervention, eleven informational, problem solving and cognitive behavioural steps are targeted: *(1) psycho-education, (2) transportation to appointments, (3) obtaining medication, (4) communicating with providers, (5) coping with side effects, (6) formulating a daily medication schedule, (7) storing medications, (8) cues for pill-taking, (9) guided imagery review of successful adherence in response to daily cues, (10) responses to slips in adherence, and (11) review of procedures* (Safren *et al.*, 1999).

Safren *et al.* (2001) conducted a study utilising Life-Steps intervention as a single session intervention. Fifty-six participants who reported that they had not taken all their prescribed treatment for the past two weeks were part of the intervention. Some patients received Life-Steps intervention and others received a self-monitoring intervention. Patients under the latter intervention received a minimal intervention that utilised a daily diary to be completed and returned at the two-week assessment session and 12-week follow-up appointment. The first part of Life-Steps involved follow-up telephonic reviews, informational and motivational interventions aided by a videotape presentation. The session with the clinician included eleven informational, problem solving and cognitive-behavioural steps for improving adherence. At first patients completed the self-report measures. All participants returned back for the acute outcome assessment and the 12-week follow-up assessment. Patients who received a single-session Life Step intervention exhibited significantly faster improvements in adherence than patients who received the self-monitoring intervention (Safren, 2001).

3.6.1. (e) Motivational interviewing interventions

Motivational interviewing is a therapeutic treatment style that may be used when exploring issues of ambivalence and conflict regarding adherence. Motivational interviewing has successfully enhanced patient adherence to treatment medication (Battaglioli-DeNero, 2007). Through the use of motivational interviewing, the counsellor attempts to stimulate change by identifying discrepancies in the patient's current behaviour and the patient's goals of healthier behaviours. The aim of the intervention is to develop medication self-management skills in the patient. This approach encourages patients to describe their behaviours and develop their own solutions. The principles of motivational interviewing include: (i) e*xpressing empathy, (ii)* s*upporting self-efficacy, (iii) avoiding argumentation and rolling with resistance,* and *(iv)* d*iscovering discrepancies (*Battaglioli-DeNero, 2007).

In a study by Battaglioli-DeNero (2007), 134 HIV positive patients, who were either candidates for initiation of ART or had imperfect viral control, were randomly assigned to receive either motivational interviewing or an HIV information programme. Both groups received educational materials, spent the same amount of time with a health educator and received audiotapes and workbooks but the content varied in accordance with the treatment group. Overall, self-reported adherence increased over time in patients who received motivational interviewing, whereas self-reported adherence decreased in patients who received the control intervention. Adherence was negatively correlated with viral load and the intervention had no significant effect on viral load, suggesting that clinical adherence outcomes did not change, but only subjective outcomes changed.

3.6.1. (f) Nurse-based Intervention

Nurses generally have more contact with HIV-positive patients than do clinicians, which makes them ideally positioned to deliver adherence-boosting interventions. In a study by Battaglioli-DeNero (2007), nurses successfully improved adherence and factors related to adherence such as patient self-efficacy among HIV-positive individuals with low health literacy. The intervention consisted of education about the importance of adherence and motivational enhancement, including personalized feedback on health status and adherence-skills building. All information and educational materials were designed to accommodate the lower level of literacy in the target group and were delivered over two adherence sessions and one booster session.

In a study conducted by Kalichman *et al.* (2005) in Battaglioli-DeNero (2007), thirty HIV positive individuals who scored below 80% on an assessment of health literacy and had an average CD4 count of 315 cells/mm^3 were part of the intervention. At the second and third month of follow-up, the number of missed doses, the number of doses taken off schedule and overall non-adherence significantly decreased as compared to the baseline. Even though there was no control intervention, the results of the study suggested that appropriately tailored nurse-based interventions can improve adherence in patients with low health literacy.

3.6.1. (g) Directly observed therapy

The principle of directly observed therapy (DOT) has its roots in the treatment of tuberculosis (Porter & Ogden, 1997: 121; Calder, 2001; Kironde & Bajunirwe, 2002: 74; Bayer & Wilkinson, 1995; Volmink & Garner, 2006; Noyes & Popay, 2006; Khan *et al.,* 2005: 354; Zwarenstein *et al.,* 1998). DOT as a treatment adherence strategy emerged in response to the recognition of the difficulties in sustaining adherence to complex treatment regimens (Wohl, 2004: 388). DOT refers to the practice that involves taking of medication in the presence of a provider or other responsible third party, either in the health facility or at the patient's home, so that the provider can actually watch the pills being swallowed (Porter & Ogden, 1997: 121; Bednall *et al.*, 1999: 759; Garner, 1999: 1326; Strick, 2002). This ensures that the client takes the correct drug, the correct dose and at the right time (Calder, 2001).

Given the scope of the problem of adherence and its impact on antibacterial resistance and transmission of infection, DOT was seen as a very reasonable approach and one that may be very cost-effective in ART. (Choi, 1998: 212; Atun *et al.,* 2005: 123). DOT seeks to improve adherence of people to treatment through health workers, family members or community members directly observing them taking their treatment (Sumartojo, 1993; Lienhardt & Ogden, 2004: 833; Volmink & Garner, 2006; Nazar-Stewart & Nolan, 1992). This strategy has been shown to improve treatment outcomes (Soares *et al.*, 2006), reduce the burden of drug-resistance infection and decrease the incidence of disease in the community (Maher and Mikulencak, 1999; Lucas *et al.*, 2004: 409; Lucas, 2001; Clarke *et al.,* 2005; Newell, *et al.,* 2006; Strick, 2002; Behforouz, *et al.,* 2004a; Balt *et al.*, 1998). Various forms of DOT supervision and advantages and disadvantages of DOT will be discussed in detail below. This detail is necessary insofar as the treatment buddy system in part is related to DOT-based strategies. Some researchers argue that the treatment buddy is similar to DOT because of the direct observation component present in both strategies.

i. Forms of DOT supervision

The patient needs support and prompting in terms of treatment adherence. However, rigid forms of DOT may be an intolerable burden for the patient. Therefore, four forms of DOT supervision exist to address this challenge.

- *Health facility-based DOT*: The patient comes to the health facility for each drug intake (except during the weekend or non-working days) and takes the drugs in the presence of a health worker.

- *Community-based DOT*: a community health worker or person in the community trained and supervised by the health system observes drug intake of the patient. The community health worker goes to the patient's house or the patient goes to the community health worker's house.

- *Family DOT*: The patient takes the drugs at home and is being supervised by a family member who has officially been tasked to observe the patient's drug intake.

- *Self-administered treatment with once a week DOT in health facility:* the patient goes to the health facility for DOT once per week only and takes the drugs at home on the other days (Von Christian, 2001).

ii. Advantages and disadvantages of DOT

DOT has many advantages and disadvantages (Volmink *et al.,* 2000). When used as a collaborative effort though, with the patient, DOT has many advantages over self-administered therapy:

Table 3.1: Advantages and disadvantages of DOT

Advantages	***Disadvantages***
People are closely monitored and that may ensure that the patient completes an adequate regimen	Is time consuming and labour intensive
It lets the health care worker monitor the patient regularly for side effects and response to therapy	Can imply that the patient is incapable or irresponsible
It helps the health care worker solve problems that might interrupt treatment	Can be perceived as demeaning or punitive
By ensuring the patient takes every dose of medicine, it helps the patient become non-infectious sooner	Moves away from adherence models of communication with cooperation between the patient and the provider back to the traditional medical approach with the patent as the passive recipient of advice and treatment

Source: Volmink *et al.* (2000:12).

iii. Can DOT be adapted to HIV?

Various authors argue that given the success of DOT for tuberculosis, the commonalities between HIV disease and tuberculosis, and the commonalities of their respective multi-drug therapies, it would be appropriate to use DOT for ART (Santos *et al.*, 2006: 808). As a result, there has been a growing interest in the use of DOT as a programmatic strategy for enhancing adherence and clinical outcomes in HIV-infected individuals (Strick, 2000; Stone 2001: 870; Lucas *et al.,* 2002: 527; Santos *et al.*, 2006: 808). Even though TB and HIV infections differ with respect to route of transmission, duration of treatment, complexity of treatment regimen, pill burden and the likelihood of cure, both infections are recognised as threats to international public health result in premature morbidity and mortality if left untreated, and lead to the development of drug resistance if adherence to treatment is inadequate and available drugs used for treatment for both HIV infection and tuberculosis have considerable toxicities (Altice *et al.,* 2004: 377).

Even though DOT is successful in many countries (WHO, 2003b; Moore, 1996; Floyd, 1997; Mangura, *et al.,* 2002; Bharti, 2004; Nachega *et al.*, 2006), some studies yielded different results, suggesting that the effectiveness of the programme may depend on the setting and on the form of direct supervision employed (Santos *et al.*, 2006 ; Volmink, 2000 ; Goicoechea *et al.*, 2006: 236; Khan *et al.,* 2005; Newell *et al.*, 2006; Clarke *et al.*, 2005; Volmink *et al.,* 2000; Khan, 2002; Linhardt & Ogden, 2004). "Direct observation" means that a health worker or other trained person (employer, teacher or volunteer) watches and assists as the patient swallows the anti-TB drugs in his or her presence. The patient thus, does not bear the sole responsibility to adhere to treatment (Page-Shipp *et al.*, 2007). In a certain sense, the strategy may thus shift the responsibility for cure from the patient to the health system. Jaffar *et al.* (2005) argue that DOT has been advocated to increase adherence to tuberculosis therapy, but there is no evidence that DOT improves cure rates and Whalen (2006) suggest that the DOT strategy does not address the number and frequency of contacts.

Table 3.2: Comparison of Directly Observed Therapy for Tuberculosis and HIV

Feature	*Tuberculosis*	*HIV*	*Implications for supervised therapy*
Mode of transmission	Aerosol	Sexual or blood contact	While DOT for tuberculosis is supported and enforced in many areas as a public health mandate, this is unlikely to be the case for DAART.
Duration of therapy	6-12 months	Lifetime	While DOT for tuberculosis is recommended for all diseased patients, DAART will likely to be used only in settings or subsets of HIV-infected individuals.
Dosing requirements	Twice or thrice weekly	Once or twice Daily	While all tuberculosis treatment doses are supervised by healthcare workers in many clinical settings, modified DOT, where some fraction of doses is self-administered, will be required in most DAART strategies.
Dynamics of infection	Long generation time, slow emergence of resistance	Short generation time and error-prone replication with rapid emergence of resistance	The effects of DAART on the development of drug resistance are less clear than in DOT for tuberculosis.

Source: Adapted from Lucas *et al.* (2002: 528).

iv. Directly Observed Therapy for ART

Lucas *et al.* (2004b: 409) and Macalino *et al.* (2004) however argue that significant differences in the treatment of tuberculosis and HIV-infection pose challenges to the development of Directly Observed Therapy for ART (DAART). Furthermore, various settings have been proposed for DAART, including community-based outreach programmes, prisons, long-term care facilities, substance abuse treatment sites and resource-poor countries (Lucas *et al.,* 2002: 527). Unlike DOT for tuberculosis, DAART programmes are relatively new; require some additional consideration because of secrecy and stigma of HIV infection and lack of careful discussion and evaluation of the necessary components. Altice *et al.,* (2004: 477) furthermore points out that similar to DOT programmes, DAART programmes are likely to have the highest yield when provided in conjunction with enhanced services.

v. How effective is DOT for ART? Lessons from developed and developing countries

Several authors concluded that DAART is effective, reduces mortality, lessens AIDS-related stigma, improves medical staff morale, boots interest in HIV testing and counselling, and thus contributes to prevention (Farmer, *et al.*, 2001b; Macalino *et al.*, 2004; Clarke *et al.*, 2002; Lucas *et al.,* 2004a; Sarna *et al.*, 2005). Conway *et al.*, (2004) carried out a prospective observational clinical study which evaluated the safety and efficacy of once daily and twice daily DOT in 54 HIV patients in ART and methadone treatment. ART was dispensed daily as DOT and patients in twice daily ART, self-administered the second dose. At baseline, the median viral load was 111,000 copies/ml and the median CD4 count was 165 cells/mm. After a median of 24 months, 17 0f 29 patients in once daily ART and 18 of 25 in twice daily ART had a viral load of <400copies/ml.

In San Francisco, an observational study to assess the efficacy of DAART provided in conjunction with methadone was conducted by Clarke *et al.* (2002). A cohort of 39 patients was enrolled to receive ART as DOT and was followed for one year. Patients attended the clinic daily and were given morning ARV medication under supervision and were given single dose of their evening medication to take at home. Increased CD4 count over time was achieved. At 48 weeks patients had achieved maximum viral suppression. The DOT programme of co-administered methadone and ART can be implemented with good results, even for patients who continue using cocaine.

In a randomised controlled trial of DAART versus self-administered therapy by Altice *et al.* (2004), adherence was higher for supervised than for unsupervised medication administration. Javanbakht *et al.*, (2006: 143) conducted a randomised intervention trial in California, among 90 HIV positive patients experiencing treatment failure because of non-adherence with medication. Participants were randomly assigned (two groups) to an adherence case management intervention with monetary reinforcement (CM) or to a standard of care group (SC). The CM participants met regularly with a treatment advocate for individualised adherence support. After 48 weeks 55% of those in the CM achieved a drop in viral load as compared to 28% only in the SC group.

Lucas *et al.* (2004a) in turn conducted a non-randomized comparative study in Baltimore to assess the effectiveness of DAART (a methadone clinic delivered DAART). Three groups were compared (DAART group, standard group and adherence support group). DAART patients visited the methadone clinic 7 days per week and ingested 1 dose of ART while observed by a nurse or medical officer. Evening dose was taken on a self-administered basis. At 6 months, RNA levels were significantly lower in the DAART group. DAART was feasible for and acceptable to patients in a methadone clinic setting and the strategy increased rates of viral suppression.

Macalino *et al.* (2004) found similar results in his community-based study of DOT among persons with substance abuse disorder and history of non adherence. Outreach worker delivered and observed once daily ART doses 7 days per week. In this study once daily dosing of ART by DOT proved feasible. The study by Parsons *et al.*, 2006 involved 19 hospitalized patients (children and adolescents) for directly observed antiretroviral therapy from John Hopkins Hospital. Differences in CD4 count and viral load at admission, prior to discharge and 6 months after discharge, were evaluated. Compared to the mean CD4 count at admission (262), the mean CD4 count at discharge (492) and 6 months after discharge (429) were significantly higher ($p<0.01$ respectively). Compared to the mean viral load at admission (log 5.7), the mean viral load at discharge (log 4.7) and 6 months after discharge (log 5) were significantly lower ($p<0.01$ respectively). Hospitalization for DAART with non adherence resulted in the reduction of the viral load and increase in CD4 count.

In Kenya, for example, the ART strategy was developed as a facility-based intervention to promote adherence to antiretroviral therapy. This intervention was designed to provide support to patients, foster responsible treatment-taking behaviour and enable close supervision of the patient during the first few months of taking treatment (Sarna *et al.*, 2005). Clients visited these treatment sites every month for treatment follow-up and to receive formal treatment-related adherence counselling by trained adherence counsellors.

Munyao *et al.* (2005) carried out a facility-based intervention to promote adherence to HAART in Kenya. Patients visited the clinic two days per week and took one dose of medication in the presence of the observer for 24 weeks. Sarna *et al.* (2005:234). One hundred and sixteen patients were randomised to the DAART arm and 118 to the non-DAART arm. DAART patients observed taking treatment twice weekly at specially designed facilities for 24 weeks, followed by monthly follow up for 24 weeks. Non-DAART patients received monthly follow-up for 48 weeks. CHWs traced DAART and non-DAART clients who did not keep follow-up clinic visits. High levels of adherence to HAART were observed for all patients during the first 24 weeks, however, patients exposed to DAART achieved higher adherence levels compared to non-DAART. There was no significant difference in CD4 count and weight between the two groups in first 24 weeks.

Santos *et al.*'s (2006) findings contradicted other studies. Santos *et al.* (2006) implemented a pilot study that examined attitudes toward voluntary enrolment in a community-based DAART programme among HIV-infected inpatients. The majority of patients (83%) preferred self-administered therapy and only 17% elected for DAART. A significant proportion of patients thought the DAART approach was intrusive and very few were willing to meet with providers on a daily basis (Bryant *et al., 2004).*

3.6.2 Multi-faceted interventions

Turner (2002) argues that, because multiple factors affecting adherence may need to be addressed, interventions aimed at improving treatment adherence will require the implementation of a multifaceted approach.

3.6.2. (a) Educational and counselling interventions

Educational interventions are defined as any intervention provided with an intention of improving the person's ability to manage his or her disease. Van Dulmen *et al.* (2007) argue that for educational interventions to be effective, they should be adapted to the situation and needs of the patient. A number of counselling interventions have been found to be more effective than providing knowledge alone. Several theoretical behavioural models have been used to guide educational and counselling interventions. Some common elements of these theory-based counselling approaches include: (i) establishing dialogue and rapport with the client and providing ongoing services, (ii) understanding and addressing client needs, situations, and pressures for sexual and drug-using behaviour, (iii) addressing the client's high-risk behaviour in a step-wise manner, understanding the readiness and motivation for a change in each specific high-risk behaviour and building the client's skills for implementing changes (Van Dulmen *et al.* (2007).

A controlled randomised trial was employed to assess the impact of the educational and counselling intervention on adherence among patients on ART. The study enrolled 244 ART patients who offered three individual sessions by trained nurses over a period of six months (Pradier *et al.*, 2003). The intervention presents a combination of educational and counselling approaches and was founded on the principles of motivational psychology and client-centred therapy, and the use of an empathic therapeutic to enhance participants' self-efficacy and skills. The intervention was delivered through individual counselling by health care professionals (nurses) who were known by the patient to be part of the medical staff in charge of their care.

To address the cognitive components, each individual's motivations, expectations, degree of knowledge, personal beliefs and assumptions about the disease and medications were assessed and explored. To address the emotional components, patients' personal concerns and experiences related to being HIV-infected were acknowledged. A significant reduction of viral load was obtained in patients who benefited from the intervention. To address the behavioural components, nurses developed patients' descriptions of plans for accomplishing adherence to treatment. Patients were assisted to develop self awareness skills to distinguish occasional lapses. To address social components, nurses assessed the degree to which the social stigma associated with HIV/AIDS hindered patients from taking medication in the presence of others. The availability of supportive significant others, local support groups and HIV support hotlines were assessed. Nurses' tasks also included identifying patient's economic concerns and other social potential barriers that may affect patient's willingness and ability to receive treatment.

Pradier *et al. (*2003) conducted a controlled randomised trial in South-Eastern France to assess the impact of the above educational and counselling intervention. The study included two groups of patients on antiretroviral therapy: 123 patients in an intervention group (IG) and 121 in a control group

(CG). Both groups received the usual clinical follow-up at enrolment and at six months. Both groups had a medical consultation every 2 to 3 months on the physician's recommendations. The intervention group was offered three individual sessions every two months, while the control group voluntarily made appointments with health providers. The proportion of adherent patients was similar in both groups at baseline and was significantly higher in the IG group at six months, but only among those who attended all three sessions. Viral load decreased in patients in the IG and decreased among those in the CG, with differences being statistically significant. The intervention was more effective in the subgroup of patients who completed all three planned sessions.

Gray *et al.* (1998) argue that patient education is an important strategy in improving adherence and can be seen as the foundation of most patient-focused interventions. Moreover, Vermeire (2001: 337) argues that educational strategies alone may not significantly improve patient adherence. He is of the opinion that a combination of behavioural and educational strategies has a better effect.

3.6.2. (b) The Connecticut HIV Medication Project (CHaMP)

Dieckhaus and Odesina (2007) designed a multifaceted intervention (CHaMP) for adherence that operated in several HIV clinical sites. Participants known to have imperfect adherence or who have risk factors for poor adherence were referred to an on-site adherence nurse for evaluation, but participation was voluntary. Education was provided by the nurse and based on the initial interview; an individualized adherence plan was devised. Elements of the intervention included a combination of pillboxes, calendars, home visits, reminders and continued education and communication and referral to social support services. A retrospective analysis was performed on 249 patients who were referred to the programme over a 35-month period. Mean adherence by self-report at baseline was 89%. At follow-up, adherence had increased to 96.9%. A significant reduction in viral load was also observed between baseline and follow-up.

Lyon *et al.* (2003) conducted a study to describe a family-approach intervention to improve adherence to ART in HIV-infected youths. Twenty-three youths and their treatment buddies (family members) attended a 12 week programme. The intervention comprised six bi-weekly family and youth education sessions and six bi-weekly youth-only education sessions. The programme also used treatment buddies to observe treatment swallowing by patients. Of the 23 youths, eighteen finished the intervention. By the end of the intervention, there was a 37% decline in the reporting that medication was not taken because patients fell ill. There was a 21% decline in youths reporting not taking doses because they were too sick. Ninety-one percent of youths self-reported an increased adherence after completion of the intervention. In this study, using a family approach to increase adherence was found to represent a useful adherence support intervention.

3.6.2. (c) The case-management intervention

Adherence case-management programmes consist of intensive adherence education and collaborative planning that is multidisciplinary and designed to be maintained over an extended period of time. In practice, case management programmes are designed for patients who have demonstrated, or are at great risk for, inadequate adherence. Case-management programmes can exist separately from or within the primary clinical site. In a prospective study of one such programme, which included weekly medication organization sessions using pillboxes and monthly individualized adherence counselling, 21 non-adherent men on ART were compared with 21 matched controls. After 5 months, compared with the control group, those in the programme exhibited a significant improvement in their medication adherence as measured by pharmacy refill data and also had been hospitalized on fewer occasions (McPherson-Baker *et al.*, 2004).

In a randomised controlled study conducted among HIV infected patients in Los Angeles, California, Javanbakht *et al.* (2006) developed an intensive adherence case management programme aimed at patients experiencing treatment failure as a result of non-adherence. Contingency management strategies were used to encourage and reinforce consistent medication taking behaviour. The adherence programme, which was based on an evaluation of each patient's adherence needs, included an educational programme, individualised planning of regimen, the use of adherence aids and devices, as well as referrals to psychosocial services. Moreover, patients in the programme received monetary incentives for improvements in the viral load. Patients involved in the case management programme met with a trained treatment advocate who conducted a comprehensive review of each patient's adherence needs. The assessment included an evaluation of the patient's medical, psychosocial and environmental needs. Follow-up visits were scheduled where a treatment advocate and the patient met every week or once a month depending on the patient's duration on the programme (Javanbakht *et al.,* 2006).

3.6.2. (d) Patient-centred adherence support interventions

A patient-centred adherence support model has been implemented in Khayelitsha since the beginning of ART provision. The goal of the patient-centred model is to empower ART patients to become responsible for their own health, supported by medical monitoring from the clinic. The model promotes patient's understanding and individual responsibility for their therapy. The first point is to provide training on HIV and recognition of HIV-related conditions, HIV medication and their side effects and on the rights of service users (MSF, 2005). The principal elements of the adherence support model include the following:

i. Individual support

Trained counsellors are available during clinic working hours to assist and support individual patients having difficulties with any aspect of ART. In case of serious adherence problems, a nurse-counsellor performs home visits as needed for more thorough follow-up. Patients are required to undergo a minimum of three counselling sessions for treatment readiness prior to ART initiation. All patients enrolling in the programme are required to identify a *'treatment assistant'*, usually someone living in their household, who could assist with adherence issues (Coetzee *et al.*, 2004).

ii. Peer support

Peer support groups have been established for ART patients and patients attend support groups hosted by the clinic twice a month. Support groups have been segregated given the fact that patients on ART have different needs and aspirations depending on the duration on treatment. Support groups exclusively for ART patients facilitate discussions on factors that enhance or are barriers to adherence, adverse events, disclosure and other psychosocial issues and also served as forums for health promotion and education among ART patients (Coetzee *et al.*, 2004).

iii. Material support

Educational materials are provided to help patients appreciate the risks and benefits of antiretroviral therapy and understand the importance of adherence. People in therapy are provided with pillboxes, drug identification charts, daily schedules, diaries and educational materials explaining the risks and benefits of ART (Coetzee *et al.*, 2004).

Combining simplified regimens with a low pill burden and a comprehensive individual support programme, resulted in the Khayelitsha ART programme showing high levels of adherence to the medication. Research suggests that in Khayelitsha and Lusikisiki, an approach centred on educating and empowering patients to be actively involved in the treatment programme has yielded positive results even for patients who had been on treatment for more than two years (MSF, 2005).

3.6.2. (e) Home-based AIDS care intervention

Uganda implemented a home-based programme that uses weekly visits to promote adherence to antiretroviral therapy. Trained and experienced counsellors made home visits at enrolment, one month after enrolment, and then quarterly to provide adherence support. Home visits were made before starting treatment with the aim of: (i) educating the client, the spouse and a medicine companion who agreed to observe the patient taking at least one dose of ART daily, and (ii) formulating an individual adherence plan, a prerequisite for starting ART (Egwang, 2006). Medication in pill boxes was delivered to patients on a weekly basis by a team of trained field officers, who elicited information about symptoms of possible illness or drug toxicity and self-reported adherence to ART. Daily events such as reminders, support from the medicine companion, weekly visits by field workers, and support from the counsellors were reported most frequently as factors which sustained good adherence. Egwang (2006) asserted that a home-based AIDS care programme in a poor rural setting in Uganda achieved a good adherence and response to ART.

3.6.2. (f) The treatment buddy strategy

The main goal of the treatment buddy programme is to help people living with HIV/AIDS by providing one-on-one support but also to complement the overburdened health care institutions (Burrage & Demi, 2003). For the purpose of the study, this adherence strategy is defined as the programme that provides one-on-one assignment of the buddy to an individual infected with HIV in which the buddy provides mainly adherence support (Burrage & Demi, 2003). In countries such as Botswana and Thailand, support for people living with HIV/AIDS is part of the treatment strategy; hence peer support systems have been established (Wilson *et al.,* 2007). The treatment buddy system, which is a client-centred approach, differs from DOT in that the buddy programme is flexible and patients are given the opportunity to choose the mode of DOT. The treatment supporter plays a supportive rather than policing role. In Swaziland for example, Escott & Walley (2005) found that patients preferred treatment supporters (chosen by patients) to take a more active role than merely observing treatment. The following section provides an overview of different types of treatment buddy programmes that exist in different countries.

i. Overview of treatment buddy programmes

The buddy programme has been used in diverse community settings and in various health programmes to provide social support and to enhance adherence to ART. Some of these treatment buddy programmes are briefly discussed below.

ii. The *Accompagnateur* programme of Haiti and Boston

One example of a successful buddy programme was implemented in rural Haiti for individuals with HIV infection. In Haiti, patients on ART received daily home visits from people called a*ccompagnateurs*, who provide directly observed treatment, respond to patient and family concerns, and offer moral support (Farmer *et al.,* 2001a; Mitty *et al.,* 2002: 989). According to Koenig *et al.* (2004: 25), adherence to ART in Haiti has been very high and as a result, all patients who were studied responded with weight gain and improved functional capacity.

This initiative has served as a model programme for other resource-limited countries, demonstrating that adherence to ART can be exceptionally high if a*ccompagnateurs* are available to assist with adherence to therapy. This programme has been adopted in Boston. Like in Haiti, the Boston a*ccompagnateurs* are drawn from the community and have first-hand knowledge of obstacles faced by patients in their daily lives. These people visit patients in their homes on a daily basis to provide support and encouragement while the patients take their daily doses of antiretroviral therapy. Their activities include accompanying patients to medical appointments, ensuring adherence to treatment, provision of education social support and encouragement (Behforouz *et al.*, 2004b).

iii. The Botswana buddy programme

The Botswana buddy programme for ART was modelled on an American programme that originated in the early 1980's. Volunteers allowed emotional and practical support and more frequent direct, personal contact with the patient. In this case, emotional support was defined as listening and comforting the patient in an empathetic and non-judgmental way. The practical support on the other hand, was defined as helping with cooking, carrying water and going shopping (Zyderduin, 2004). Buddies also arranged transport for very ill patients from Coping Centre for People living with HIV/AIDS (COCEPWA). COCEPWA organized bi-weekly support group meetings for buddies. A two day buddy training which addressed values clarification, disclosure issues and confidentiality was provided. Buddies are expected to commit from four to six hours per week to the programme and provide information, care and support to their HIV positive clients. This programme differs from the South African programme in that the project coordinator matched the buddy with the patient and buddies were all living with HIV/AIDS (Zyderduin, 2004).

iv. The South African treatment buddy programme

The buddy system of support and care for people infected with HIV/AIDS and on antiretroviral treatment was designed to support people, especially in the few months after initiating treatment. The programme further assists people who are having difficulty adhering to treatment. Treatment buddies specifically assist patients in taking treatment on time and reminding patients to go to medical appointments (Zyderduin, 2004). The implementation of the buddy programme indirectly complements overburdened health care institutions. The South African treatment buddy programme is to some extent similar to the Haiti programme discussed above. The South African treatment buddy programme differs from the Botswana programme in that the Botswana buddy programme consisted of women only, all of whom were HIV positive members of COCEPWA.

In South Africa, anyone can be a treatment buddy, a buddy can either be a friend, a family member, a neighbour, a relative, community health worker, or co-worker (May & West, 2000: 416) and the patient is given an opportunity to choose his/her own treatment buddy. Similar to the Boston buddy programme, buddies can either be HIV positive or negative. However, community health workers trained as treatment supporters are assigned to patients in need of, but without treatment buddies. Treatment buddies maintain regular contact and schedule regular visits with clients. When attending the drug-readiness programme[1], patients are required to be accompanied by their treatment buddies. Attendance of drug-readiness training by the treatment buddy is deemed essential so as to be acquainted with treatment requirements and what is expected from the treatment buddy.

Programmes differ in respect of what treatment buddies or supporters are required to do. Peer education and peer counselling is almost like the buddy system, but a buddy usually helps and supports just one person for a long time. The patient chooses the treatment supporter because they trust them. The treatment buddy with specific reference to the South African programme, is expected to perform the following tasks: (i) Give the patient the antiretroviral drugs at each appointment according to the schedule. (ii) Look at the drugs to be sure they are correct. (iii) Watch the patient swallow all the drugs and the pill count is done when visiting patients. (iv) Be aware of possible side effects. (v) Have the patient eat food with the drugs if needed. (vi) Refer patients to the health facility if a patient develops serious side effects; (vii) Encourage the patient to continue with treatment and support the patient to ensure adherence to treatment;.(viii) Provide constant support and encouragement for the patient (Zyderduin, 2004; Burrage & Demi, 2003; Farmer *et al.,* 2001a; Mitty *et al.,* 2002: 989; Behforouz *et al.*, 2004b).

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[1] The drug readiness training consists of three modules aimed at preparing patients for antiretroviral medication [focusing on positive living, healthy lifestyle and antiretroviral medication and adherence].

v. How does the treatment buddy strategy differ from the TB DOT?

A qualitative study conducted in Tanzania revealed that most patients who were treated in the community admitted that they got encouragement and support from other family members (Wandwalo *et al.*, 2006). It was generally felt that patients should be given the choice to decide which DOT option they prefer. Patients preferred a treatment supporter who is caring, not lenient, someone who is not very busy, older than the patient and who can read and write. Family relationship or sex of the treatment supporter was not important consideration in choosing a treatment supporter.

DOT supporters are usually formally trained and form part of the health care systems, hence not known to the patients. Moreover, DOT supporters fall under the umbrella term "Community Health Worker which is described by WHO (2003) as people who are involved in health activities in their communities but not as formal government employees. Treatment buddies do however contact health facilities when experiencing problems with the patients; yet, there is no formal monitoring strategy in place, particularly in South Africa. Treatment buddies differ from DOT supporters in that buddies do not only observe patients taking treatment but provide instrumental support and assist helping them cope psychologically with the disease.

Nachega *et al. (*2006) recommend the use of family and friends to promote adherence. This means that it is important to understand what key elements of treatment support are needed to promote adherence. Therefore, consideration should be given to offering DAART in an individually tailored, patient-centred and flexible manner as an option for clients who would find it helpful.

vi. How effective is the treatment buddy strategy?

A study by Lyon *et al.* (2003) revealed that using treatment buddies to increase adherence to antiretroviral therapy was a useful intervention for many adolescents in the USA. Results of a study conducted by Nachega *et al.* (2006) in South Africa suggested that the characteristics of treatment buddies and various relationship factors may influence patient's adherence to antiretroviral therapy. Furthermore, patients on antiretroviral therapy emphasized the important role of treatment buddies not only in helping them take medication but in helping them cope psychologically with the disease.

A study conducted in Tanzania by Mshana *et al.* (2006) revealed that patients enrolling in the antiretroviral treatment programme are required to identify treatment buddies, but were reluctant to disclose their status due to fear of stigma., and this had an impact on patient's adherence. A pilot study conducted in Gauteng revealed that buddies provided emotional and instrumental support and 80% visited patients at their homes. A qualitative study conducted in the USA revealed that for HIV-positive buddies, helping other HIV positive patients was an important strategy in helping patients live with the HIV-positive diagnosis (Gaskins & Brown, 1997).

A study conducted by Pearsons *et al.* (2007) in Mozambique shows that a peer-delivered, modified directly observed therapy program may be an effective strategy to promote long-term adherence among persons initiating HAART in resource-poor settings. The antiretroviral treatment programme is new in South Africa; this situation makes it tricky to confirm the feasibility and the sustainability of the treatment buddy programme. However, studies conducted in South Africa and Malawi have shown that a patient-nominated buddy system is more effective in providing adherence support and is more feasible (Clarke *et al.,* 2005; Manders *et al.*, 2001; Wilkinson *et al.*, 1996).

3.7. Summary

Supporting patients so that they can adhere to treatment will ensure that the benefit from life saving ARV therapy can be maximised. However, the difficulty in measuring adherence hinders attempts to evaluate methods for enhancing adherence. Many factors have been associated with adherence behaviour. Despite the complexity and multiplicity of the factors that may influence adherence to antiretroviral treatment, it is only through a thorough understanding of these factors that we will be able to propose new strategies for promoting diligence. Moreover, adherence to medical recommendations is a multi-faceted behaviour and requires a multi-factoral response. Therefore, strategies to encourage adherence should not only address factors such as knowledge of the regimen, belief in benefits of treatment and attitude towards medication-taking behaviour, but also environmental and social factors such as the interpersonal relationship between the provider and the patient and social support from family members and friends.

Various adherence interventions have been developed and implemented in different settings with an aim of improving patient's adherence to antiretroviral therapy. These include, among others, DAART and the treatment buddy strategy. There has been a growing interest in the use of DOT as a programmatic strategy for enhancing adherence and clinical outcomes in HIV-infected individuals, given the success of DOT for tuberculosis and the commonalities between the HIV disease and tuberculosis. However some authors argue that differences between the two diseases pose challenges in the development of DAART. One of the challenges is the fact that unlike TB treatment, which is a short-term treatment, antiretroviral treatment is a life-long commitment. Therefore, DOT for tuberculosis cannot be replicated into the HIV/AIDS programme but may be instrumental in the design of DAART programmes.

The DOT has also been criticised for its failure to consider patients' needs. The fact that the patient is directly observed means that the patient does not bear the sole responsibility to adhere to treatment. In a certain sense, the strategy thus shifts the responsibility for cure from the patient to the health system. Buddy programmes are examples of interventions that involve and integrate peers and family members who share a common desire to increase adherence to medication for people with HIV/AIDS. Given the fact that antiretroviral therapy is a long term treatment, countries such as South Africa opted for the treatment buddy system to enhance adherence to antiretroviral treatment. Some authors argue that the buddy support should be promoted and could be improved by giving participants an opportunity to choose their own buddies and by guiding the participants in their choice of a buddy. Some studies have revealed that using treatment buddies increases adherence to antiretroviral therapy and that patients with treatment buddies were more likely to adhere to programmes and demands.

Adherence interventions have shown to be better when combined. Furthermore, several authors argue that multi-faceted interventions are more effective in promoting medication adherence than single focused interventions. However, up to now, there is no evidence that any one intervention or strategy improves adherence better than another. As a result, multifaceted and long-term interventions are recommended and believed to be effective in promoting medication adherence.

CHAPTER 4
RESEARCH METHODS

4.1. Introduction

The strategy *"scientific enquiry"* necessitates a distinct plan that will lead to the production of accurate answers to the research questions under study. This chapter provides a discussion of the research approach and design selected for the study. The purpose of this chapter is to describe and motivate the research methods applied in the study. The research strategy adopted to select the research area and research participants, and collect and analyse the data is discussed in detail. Key socio-demographic characteristics of the patient and treatment buddy study populations are presented. Multinomial regressions are performed to compare socio-demographic characteristics of different sub-samples in the data in order to establish the presence of potential selection or attrition bias. Definitions of key study outcomes and explanatory variables are provided, while a comparison of key outcomes by sub-samples is performed to determine if key study outcomes differ significantly between patients included in the study and patients excluded from the study.

4.2. Study design

The study is explanatory, but also descriptive and exploratory in nature. The study provides an overview of the nature and scope of the treatment buddy system (descriptive), insight and comprehension into the perceived role of treatment buddies in the antiretroviral treatment programme (exploratory) and uses empirical data to test various hypotheses regarding the role of treatment buddies in impacting HIV/AIDS/ART knowledge, improving adherence and thus enhancing treatment outcomes (explanatory). The treatment buddy system in the context of antiretroviral therapy was explored to determine the strengths and weaknesses of this system from the perspective of both the patients and treatment buddies. Explanatory and descriptive studies provide a detailed and a highly accurate picture. In other words, the researcher observes the event and describes what happens (Neuman, 2000). Exploratory studies are valuable and essential when a researcher is breaking new ground and they usually lead to insight and comprehension about the research topic (Babbie & Mouton, 2001: 80).

The empirical study entailed the systematic collection, presentation and analysis of data about the role of social support, and specifically treatment buddies, among patients and treatment buddies in the public sector antiretroviral treatment programme in the Free State. The data collected focused on exploring access to treatment buddies, quantitative and qualitative characteristics of support provided, level of satisfaction with support provided and characteristics of the treatment buddy system in enhancing adherence to antiretroviral therapy.

The study utilises multiple sources of data, a process called triangulation (Cooper & Schindler, 2006; Neuman, 2000: 125). In triangulation, evidence from multiple sources is gathered in order to address the questions at hand from different points of view. In research, there is a need for multiple types of evidence gathered from different sources, often using different data collection methods (Baker, 1994). It is believed that these methodologies complement each other, as one compensates for the weaknesses of the other (Cooper & Schindler, 2006). This study uses two sources of data: (1) data collected from a longitudinal study conducted among patients enrolled in the public sector antiretroviral treatment programme (patient survey) and (2) data from once-off individual interviews conducted with treatment buddies of patients interviewed as part of the patient survey (treatment buddy survey). The patient survey had a broader function and only data from certain sections of the questionnaire were used for the purposes of the current study. The sections included socio-demographic information and data on health-related quality of life, patients' adherence to treatment, patient's knowledge about treatment and social support mechanisms available to patients on ART (home/family/community-based care and support).

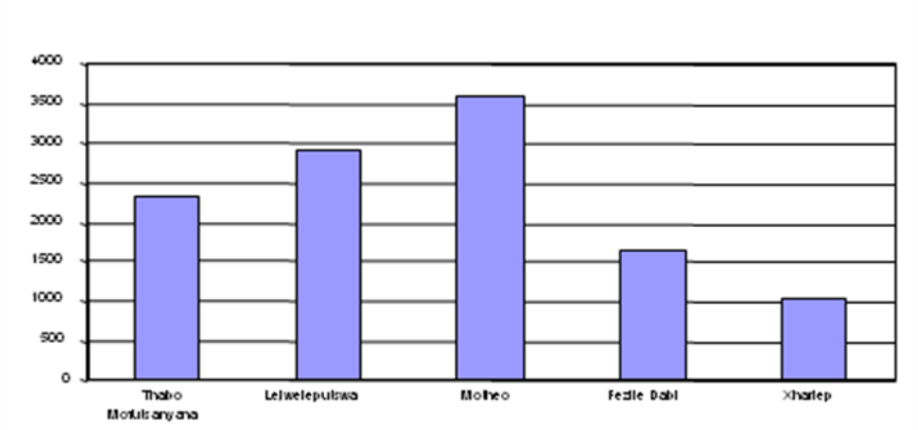
4.3. Research area

Free State province is the third largest (geographically) of the nine provinces in South Africa; it has the second lowest population density. The province is home to approximately 2.8 million people. The Free State is situated in the heart of South Africa. The main languages spoken in the province are Sesotho and Afrikaans. This study forms part of a larger longitudinal study undertaken by the Centre for Health

Systems Research & Development (at the University of the Free State) to monitor and evaluate the public sector antiretroviral treatment programme in the Free State province. The study was conducted in all five health districts (Xhariep, Fezile Dabi, Lejweleputswa, Thabo Mofutsanyana and Motheo) as indicated on the map (figure 1). A total of sixteen initial sites (sites where treatment was made available in 2004/05 when the programme was first launched in the province), antiretroviral treatment sites, were selected for the study.

Figure 4.1: Demarcation of the five health districts of the Free State province

Figure 4.2: Access to ART in the Free State, by district (2007)



Source: Free State Department of Health (2007: 5).

Figure 4.2 illustrates patient enrolment in the public sector ART from inception to 2007, broken down by district. These are the most recently available figures. Access to ART was highest in Motheo and lowest in the Xhariep district. Access to ART is higher in districts that are classified urban as compared to districts that are classified as rural (Thabo Mofutsanyana, Fezile Dabi and Xhariep).

4.4. Sampling design

This section discusses the type of sampling techniques followed to identify the patients and treatment buddies respectively who were interviewed as part of the study.

4.4.1. Patient survey

The patient survey comprised a representative sample of public ART patients in five health districts in the Free State province. Participants were men and women 18 years and older, who were eligible to start antiretroviral therapy in each district in the Free State province during the first two months following the launch of the programme in 2004/05. A random, proportionally stratified sample was used to select respondents. In a simple random sample, every element in the population has an equal probability of being included in the sample and random sampling allows generalisation. Patients were sampled randomly from a list of patients eligible to start with ART in each district in the Free State province, i.e. patients who had CD4 counts below 200 and/or were in WHO stage 4 and were certified by the physician at a treatment site as ready to initiate treatment, proportional to the treatment status of patients in the sampling frame, i.e. the list of patients who were eligible for and ready to commence ART at each of the assessment sites in the province two months subsequent to the launch of the programme in each district. In terms of treatment status, a distinction was drawn between so-called non-treatment and treatment cases respectively, which can be described as follows:

Non-treatment patients represent patients whom had been certified as ready to commence treatment following a medical examination, but had not by the time the sample frame was constructed actually started taking ART. Treatment patients in turn represent patients who by the date the sample frame was constructed had actually commenced treatment. For each district, with exception of Xhariep, eighty patients were randomly sampled from the sampling frame, proportional to the number of treatment and non-treatment patients at each health care facility in the particular district. In the Xhariep district there were fewer than 80 patients in the frame, which resulted in all patients in the frame being selected for recruitment into the study.

The study employed a longitudinal approach where patients were re-interviewed at approximately six- to nine-month intervals over the period 2004-08. Patients lost to follow-up were replaced at subsequent interview rounds by randomly sampling respondents, dependent on treatment status at sampling stage, from the original sampling frame. When the original sample frame was exhausted, no attempts were made any longer to replace patients lost to follow-up with newly recruited patients from the original sample frame.

As explained in Chapter 1, analyses for the purposes of this study are focused on an investigation of treatment support and related outcomes over the treatment career. Treatment duration is measured by months on treatment. Patients included in the analysis represent the sub-sample of patient respondents in the survey observed at least once in each of the four phase of the treatment career (n=160). In cases where we had multiple observations for the same patient in any particular treatment career phase, the observation used in the analysis is the observation closest to the midpoint of the relevant treatment career phase (refer to Figure 1.3).

Table 4.1: Number of patient interviews, by survey round

Survey round	Baseline	1st follow-up	2nd follow-up	3rd follow-up	4th follow-up	5th follow-up	Total
A. Original cohort							
Number of interviews conducted	371	307	268	242	219	202	1,609
Number of patients lost to follow-up		63	38	27	22	19	169
Attrition rate (%)		17.0	10.2	7.3	5.9	5.1	45.6
Median months of follow-up [IQR]							
B. Cohort replacements							
Number of patients recruited		8	29	44	2	0	83
Number of interviews conducted		8	29	73	64	61	235
Number of patients lost to follow-up			1	13	14	5	22
Attrition rate (%)			12.5	18.9	11.1	6.0	26.5
C. Duration of follow-up (total)							
Median months [IQR]		7.0 [5.9-8.2]	7.0 [5.8-8.2]	6.4 [6.0-7.2]	9.1 [7.5-10.0]	5.3 [4.4-6.3]	6.7 [5.6-8.4]

Note: Numbers interviewed and lost to attrition do not add up due to some follow-up interviews, as a result of practical and logistical considerations, being conducted not in the subsequent survey round, but the next round only (e.g. two patients were interviewed at baseline and then again in the third round, but not in round two). Attrition rates are calculated by dividing the number of patients lost to attrition by the number of patients ever interviewed up to and including the previous survey round.

Table 4.1 presents an overview of patients who formed part of the study, including replacements and attritions. In total, 1,844 interviews were conducted with 452 individual patients. Five rounds of follow-up interviews were conducted with patients at intervals of approximately six to nine months, although the actual timing between interviews varies somewhat due to logistic and practical constraints.

Table 4.2: Reasons for loss to follow-up

	Total	
Reason	**N**	**%**
Deceased	72	43.6
Refusal	28	17.0
Untraceable	21	12.7
Transferred	15	9.1
Migration	15	9.1
Withdrawn/defaulted	7	4.2
Health	3	1.8
Other	4	2.4
Total	*165*	*100.0*

Note: Reasons for loss to follow-up are not known for all patients. Percentages may not add up due to rounding.

Table 4.2 provides a breakdown of the main reason for loss to follow up for patients lost to attrition. By follow-up 5 or round 6 of the survey, 189 patients had been lost to follow-up, primarily due to mortality among participants as well as refusal. The aggregate attrition rate is 41.8%.

The following section discusses the type of sampling techniques followed to identify the patients and treatment buddies respectively who were interviewed as part of the study.

Table 4.3: Socio-demographic characteristics of patients in the study (n=160)

	Study cohort	
Variable	**%/mean**	**N**
Age (years)	*Mean=39* *Median=39* *IQR=13*	*939*
Age		
18-24	9%	82
29-39	*44%*	*415*
40-50	*38%*	*357*
>50	*97%*	*85*
Total	***100***	***939***
Gender		
Female	*66%*	*619*
Male	*34%*	*324*
Total	***100***	***943***
Level of education		
No education	*4*	*37*
Primary	*29*	*277*
Some secondary	*51*	*482*
Matric/Std 10	*14*	*130*
Tertiary	*2*	*21*
Total	***100***	***947***
Population group		
Black	*94%*	*890*
Coloured	*4%*	*39*
White	*2%*	*18*
Total	***100***	***947***

According to Table 4.3, most patients were female (66%), with a mean age of 39 years (IQR*13; median=39*) and of black ethnicity (94%). The majority of participants had some secondary education (51%) followed by primary education (29%), while few had no formal or tertiary education (4% and 2%, respectively. On aggregate, therefore, over 80% of patients had less than a matriculation/Std 10 education (84%). The majority of patients in a correlational study of buddy programs for people infected with HIV in three South-eastern states in the United States also had secondary education (Burrage and Demi (2003).

Table 4.4: Treatment buddy characteristics, by treatment career (n=348)

Variable	**Treatment career**					
	0-6 months	***6-12 months***	***18-30 months***	***30-42 months***	***Total***	***p-value***
Age(years)	28	*36*	*33*	*31*	*264*	*0.200*
Gender of buddy						
Male	*22%*	*20%*	*24%*	*13%*	*45*	*0.224*
Female	*78%*	*80%*	*76%*	*87%*	*225*	
Relation with buddy						
Parent	*34%*	*15%*	*12%*	*15%*	*66*	*0.000*
Partner	*12%*	*30%*	*40%*	*31%*	*95*	
Sibling	*12%*	*15%*	*21%*	*17%*	*56*	
Child	*6%*	*25%*	*21%*	*35%*	*85*	
Other	*36%*	*15%*	*6%*	*2%*	*47*	
Satisfaction with buddy						
Satisfied	*98%*	*100%*	*98%*	*98%*	*341*	
Dissatisfied	*2%*	*0%*	*2%*	*2%*	*5*	*0.638*
Chose buddy yourself						
Yes	*86%*	*93%*	*98%*	*89%*	*313*	*0.086*
Buddy attended drug readiness training						
Yes	*43%*	*52%*	*53%*	*37%*	*153*	*0.081*
Buddy assisted with adherence						
Yes	*99%*	*96%*	*92%*	*98%*	*326*	*0.178*

Note: ANOVA and chi2 tests were used to obtain the reported values.

Table 4.4 summarizes treatment buddy characteristics by treatment career, as reported by patients. According to Table 4.4, the mean age and gender of treatment buddies did not vary significantly across treatment career phase. The relationship of the patient with the treatment buddy did differ significantly across the treatment career. At less than 6 months, most patients (36%) had other categories of people as treatment buddies, compared to 2% at more than 30 months. This finding may be attributed to non-disclosure due to stigma attached to HIV/AIDS. Patients starting treatment may prefer to use external support but as time on treatment increases, patients may turn to family members for support.

Overall, patients were highly satisfied with support from treatment buddies. Patients were more likely to choose their treatment buddies, even though choice of buddy varied significantly by treatment duration at 1% level. Patients who have been on treatment for less than 6 months were less likely to choose their own (86%) treatment buddies compared to patients who have been on treatment for longer. The reason for this could be that treatment buddies may have subsequently been assigned rather than chosen by patients themselves. Furthermore, the attendance of drug readiness training by treatment buddy varied significantly across the treatment duration at 1% level.

Treatment buddies of patients who had been on treatment for 30-42 months were less likely to have attended drug readiness training compared to buddies of patients who have been on treatment for a shorter period of time. The reason for this decline in attendance of drug readiness training could be attributed to the change in practice. Early in the programme, patients were encouraged to have treatment buddies and treatment buddies were encouraged to attend drug readiness training. Assistance with adherence did not vary significantly by the treatment duration. The majority of treatment buddies however provided adherence support irrespective of the treatment duration.

4.4.2. Treatment buddy survey

Following the completion of the sixth and final round of patient interviews, telephonic interviews were conducted with treatment buddies using a semi-structured interview schedule to supplement information on treatment buddies collected in the patient survey as well as to provide insight into some findings from the patient survey data.

A non-probability sampling method was used to select participants. Purposive sampling was followed in the identification of treatment buddies since information about treatment buddies was obtained from patients already part of the patient's survey. Purposive sampling is more appropriate when the researchers want to select the sample on the basis of their knowledge of the population and its elements

(Babbie, 1998). Consent to interview the treatment buddy was firstly obtained from the relevant patients. Out of 263 patients interviewed in round six, 90 indicated having a treatment buddy. All patients who had treatment buddies were contacted, but only 73 (81%) patients could be reached and gave verbal consent for the treatment buddies to be interviewed. Out of these 73 patients' treatment buddies, only 55 (75%) could be reached and were interviewed. Of the 18 (33%) outstanding treatment buddies, 11 (61%) could not be reached, 5 (28%) refused to be interviewed, and 2 (11%) had since died.

Table 4.5: Socio-demographic characteristics of treatment buddies (n=55)

Variable	%	N
Age (years)	*36*	*55*
Gender		
Female	*75%*	*41*
Male	*25%*	*14*
Level of education		
No education	*4%*	*2*
Primary	*22%*	*12*
Some secondary	*45%*	*25*
Grade 12	*22%*	*12*
Tertiary	*7%*	*4*
Employment status		
Full-time	*22%*	*12*
Part time	*11%*	*6*
Informal	*2%*	*1*
Self employed	*5%*	*3*
Unemployed	*60%*	*33*

Table 4.5 presents socio-demographic characteristics of treatment buddies interviewed as part of the treatment buddy survey. Most treatment buddies were female (75%, with a mean age of 36 years (S.D = 13.69; range = 11 – 66 years). In a correlational study conducted by Burrage & Demi (2003) in three Southeastern states of the United States, the majority of treatment buddies were also female. The

majority of treatment buddies had some secondary education (51%) followed by primary and a matric/Std 10 (22%) respectively. Over half of treatment buddies were unemployed (60%).

Table 4.6: Treatment buddy characteristics (n=55)

Treatment buddy characteristics	*%*	*N*
Treatment buddy also a lay worker		
Yes	*9%*	*5*
Attended drug readiness training		
Yes	*22%*	*12*
Chose self as buddy		
Yes	*51%*	*28*
Need training		
Yes	*62%*	*34*
On ARVs		
Yes	*20%*	*11*

Table 4.6 presents characteristics of treatment buddies as reported by those treatment buddies interviewed as part of the treatment buddy survey. Very few treatment buddies (9%) were lay or community health workers. Only 22% of interviewed treatment buddies had attended drug readiness training for ART. Approximately half (51%) of treatment buddies volunteered themselves to be treatment buddies, while 42% reported being chosen by patients. Sixty-two percent of buddies reported that they needed training to improve their treatment buddy activities (see Appendix 2). The majority of participants (62%) in the treatment buddy survey visited patients on a regular basis, primarily since the majority of treatment buddies resided with patients. Participants had been working with their current clients for a mean period of 37 months (*S.D = 49.01; median = 44; IQ*R *= 48*). Only 20% of treatment buddies reported being on antiretroviral treatment. Of those treatment buddies not residing with their patients, 86% spent less than an hour travelling to patients.

4.5. Data collection strategy

Face-to-face interviews were conducted with patients using a semi-structured questionnaire. Face-to-face interviews were appropriate in that interviewers could ask all types of questions and use extensive probes. Advantages of the face-to-face interviews include the fact that good cooperation from participants is maintained and illiterate participants can be reached (Cooper & Schindler, 2006). However, interviewer bias is great in face-to-face interviews and the behaviour or the appearance of the interviewer may affect the respondent. Secondly, questions may be altered and participants coached by the interviewers (Neuman, 2000; Cooper & Schindler, 2006). To address these limitations, interviewers were thoroughly trained and were given sufficient practice before the actual data gathering process.

Methods used for identifying the appropriate variables from the patient survey for addressing the research objectives of the present study included: conducting extensive literature searches for familiarization and knowledge acquisition purposes, stating clearly the research objectives of the present study, identifying the questions that address these objectives as they appear in the questionnaire used in the original study and understanding the original dataset to identify the relevant variables for the present study. The current study focused on data from the following sections of the patient questionnaire: (i) The patient's socio-demographic section; (ii) Health-related quality of life (iii) Health/Care seeking behaviour; (iv) Use and effects of ARV medication; (v) Adherence (self-reported and clinical); and (vi) Social support.

Patients were contacted to acquire consent and, conditional on consent, to obtain the treatment buddy's contact details. Treatment buddies were thereafter contacted telephonically and interviewed by trained interviewers. Telephonic interviews in the case of the treatment buddy survey proved to be the best data collection strategy, given the demographic characteristics of treatment buddies (treatment buddies being employed, at school or living in another town), Moreover, telephonic interviews have advantages because with this strategy, researchers can quickly reach people across long distances and the majority of the population can be reached with a response rate that can reach 90% (Neuman, 2000). However, the strategy is not without any disadvantages as it requires a limited interview length and the cost of conducting telephonic interviews is high but lower compared to face-to-face interviews. In addition, respondents without telephones are impossible to reach and lack of motivation makes it easier for the respondent to hang up. In this study, such limitations were countered by providing interviewers with intensive training and practice and ensuring that only questions that were relevant and important for the study were asked and/or explored.

A semi-structured interview schedule was used to interview treatment buddies. Advantages of semi-structured interviews are that they are useful where some quantitative and some qualitative information is needed, and they include a mix of types of questions, some open and some closed (Laws *et al.*, 2003). The interview schedule contained broad topic areas, as well as specific probing questions (see Appendix 1). In addition, it allowed for questions to be added and omitted based on the responses of each interviewee, which guided the interview process.

The treatment buddy questionnaire ascertained demographic information (such as age, marital status, level of education and employment status), the relationship of the treatment buddy to the patient; training received and involvement in the antiretroviral treatment programme. The latter included their main role, the tasks or the activities most frequently performed for or with their patients during visits and the length of time that the treatment buddy had participated in the programme and worked with the particular patient. The regularity and the length of visits, challenges experienced and knowledge of ART were also established during the interview (see Appendix 2).

4.6. Validity and reliability

"Internal validity" refers to the extent to which an empirical measure adequately reflects the real meaning of the concept under study (Babbie and Mouton, 2001). Allowing for the study design and overall methodology, all questions used for the purposes of this study were considered to be a valid measure of the relevant variables. The phrasing of questions used and the number of questions available from the original questionnaire for the purposes of this study were considered satisfactory.

The questionnaire used in the original study was piloted to test for internal validity. As a means of ensuring external validity; the design of the instrument was informed by a literature review and questionnaires employed in other studies of this nature. Prior to finalising the questionnaire and it being translated, the draft instrument was circulated for comment amongst stakeholders from government departments as well as academics. These comments were integrated into the final instrument.

Reliability is concerned with the consistency of the results (Babbie, 1998). In this regard, guiding the fieldwork teams or interviewers during the data collection process was a priority. Data collection was supervised by a fieldwork manager and data editor. The researcher paid regular visits to the area to perform quality control checks and to assist the data editor with the editing of questionnaires. In cases where participants could not be reached or was not at home at the time of the interview, or if questionnaires were returned with missing data, interviewers returned to or re-contacted participants for completion of the questionnaire. However there was still loss to follow ups as a result of participants who could not be located.

4.7. Ethics

The Ethics committee of the Faculty of Humanities at the University of the Free State approved the study protocol. Participants were given a verbal guarantee that any information offered will be kept anonymous and confidential and that participation in the study was voluntary. Anonymity means that subjects or respondents remain anonymous or nameless. Confidentiality on the other hand means that the information may have names attached to it, but the researcher holds it in confidence or keeps it secret from the public (Neuman, 2000: 98-99). Written, informed consent was obtained from all study participants, including consent to access respondents' clinic files and to link data from the health care system to the data from the patient survey. Informed consent was obtained from respondents by the nursing staff at the respective clinics who interact with the client, and by the fieldworker prior to the interview. With regards to treatment buddies, verbal informed consent was obtained telephonically by interviewers.

4.8. Measurement and definition of key outcomes and explanatory variables

In this section, the key study outcome variables are first noted and defined. Secondly explanatory variables to be used in the multivariate analysis are listed and defined. The key outcomes are used in multivariate analysis as dependent variables; with a set of selected explanatory variables being regressed on these to answer certain questions (refer discussion below for details).

4.8.1 Dependent variables

This section firstly identifies and discusses each of the key outcomes as describe in Figure 1.5. The nature of each of the five key outcomes which are also referred to as dependent variables is outlined with specific reference to the manner in which outcomes were measured and constructed. Secondly, explanatory variables (independent variables) are also discussed the same as way as key outcomes

4.8.1 (a) Access to treatment buddy

Access to treatment was measured using a dummy variable *(no=0, yes=1)*, to distinguish between patients that did not have treatment buddies as opposed to those who had (*question 20.1; do you have a treatment buddy?*) (see Appendix 1). This access to the treatment buddy variable (primary outcome) does not, however, represent transitions in access to treatment buddies. Using these cross-sectional variable limits, the ability to determine how access to treatment buddies may actually have changed over the treatment career for the same patients and what variables explain these observed changes, is why transitions in access to treatment buddies were employed to further investigate this particular issue. Transitions focus on how 'states' or patient's experiences have changed over time for the same respondents. Transitions in this case consist of four states (access to buddy in all periods; gained access to buddy; lost access to buddy; no access to buddy in either period). A binary variable reflecting transitions in access to treatment buddy (gained access (0→1) and lost access (state (1→0) was created for this purpose.

4.8.1. (b) Intensity of treatment buddy support

The frequency of visits by the treatment buddy, a proxy for the intensity of adherence support, was measured by using a categorical variable (*0= at irregular intervals, 1= at least once per day)*. This variable was constructed by using question 20.8 in the questionnaire (*How often does this person help you with adherence?*) and creating three categories from the six available response categories (see Appendix 1). To determine how the frequency of visits may actually have changed over the treatment career for the same patients and what variables explain these observed changes, transitions in the frequency of treatment buddy visits were employed to further investigate this particular issue. Transitions focus on how 'states' or patient's experiences have changed over time for the same respondents. A binary variable reflecting transitions in intensity of visits (gained daily visits (0→1) and lost daily visits (state (1→0) 'was created for this purpose.

4.8.1. (c) Adherence knowledge

Adherence knowledge was measured using a Likert scale ranging from 1-5 (definitely true=5, partly true=4, uncertain=3, partly false=2, and totally false=1), summed across four items from the patient questionnaire. The four items are: *1. It is correct to stop ARV treatment when one no longer suffers from opportunistic infections, 2. One can protect other people from HIV by sharing ones ARV medication with them, 3. After a couple of years one can stop taking ARV medication, 4. Missing few doses of ARV medication is acceptable* (see Appendix 1). In the original data set, lower values on the Likert scale represented positive responses and were subsequently recoded so that higher values reflected positive (correct) responses. Firstly, dummy variables out each of the four items that qualified were created where true (positive) responses *=1* and all other responses=*0*. The adherence knowledge variable was thereafter constructed by generating a new dummy variable where 1=true (positive) responses in all four items and 0= for all other values that were set to missing. The objective behind the use of adherence knowledge was to determine if the patient had enough information to help them cope with the ARV regimens and what is expected of them when on ARV treatment. To determine how adherence knowledge may actually have changed over the treatment career for the same patients and what variables explain these observed changes, transitions in adherence knowledge were employed to further investigate this particular issue. A binary variable reflecting transitions in adherence knowledge imperfect to perfect knowledge (0→1) and perfect to imperfect knowledge (1→0) was created and used in the analysis.

4.8.1. (d) Self-reported adherence

As explained in Chapter 3, both subjective and clinical measures of adherence were used in the analyses as that may yield more reliable results in terms of the impact of treatment support on adherence to ART. It is believed that self-reported measures may not be reliable as patients may over report their adherence levels. Therefore, it is considered good practice to also use clinical measures of adherence in an attempt to establish the more reliable measure of adherence, even though both measures are not entirely reliable measures of adherence (Cederfjäll *et al.*, 2002; Battaglioli-DeNero, 2007). In the analysis, a self-reported measure of adherence was employed and compared with a clinical measure of adherence.

Adherence was measured with the aid of a binary variable *(yes=1, no=0)* that distinguishes between patients who reported that they had taken their ARVs as prescribed during the past week, as opposed to patients who reported missing at least one dose during the past week (*q. 17.39: During the past week did you take your ARVs as you have just explained?)* (See Appendix 1). To determine how self-reported adherence may actually have changed over the treatment career for the same patients and what variables explain these observed changes, transitions in self-reported adherence were employed to further investigate this particular issue. A binary variable reflecting transitions in self-reported adherence (non-adherence to adherence (0→1) and adherence to non-adherence (1→0) was created and used in the analysis.

4.8.1. (e) Clinical adherence

A physiological or clinical measure of adherence, namely viral load, was used to measure adherence. This variable (measured within 90 days of interview) was converted into a binary variable: where 0=detectable *(>50ml copies*) and 1=undetectable *(<50ml copies*) viral load (Lazo *et al.*, 2007). To take full advantage of the panel data, the focus was also on how 'states' have changed over time for the same respondents. Therefore, to establish how patient's clinical adherence has changed over time for the same respondents, transitions were used. A binary variable reflecting transitions in clinical adherence, non-adherence to adherence (0→1) and adherence to non-adherence (1→0) was created and used in the analysis.

4.8.2 Explanatory variables

Explanatory variables in the study, as used in the relevant literature include: Age, gender *(male or female)*, level of education *(no education, primary, secondary, matriculation, tertiary)*, marital status *(living with partner, not living with partner and single)*, household size, access to a treatment buddy *(yes/no),* access to community health worker (*yes/no*), access to an emotional caregiver (*yes/no*), access to a physical caregiver *(yes/no),* participation in a support group *(yes/no)*, self-reported level of adherence (*binary (yes/no)*, clinical adherence (*adherence/non-adherence*), adherence knowledge (*perfect/imperfect*), intensity of visits (*at least once per day/irregular intervals*), and health-related quality of life, represented by EQ-5D and EQ-VAS (discussed below); treatment duration and treatment buddy characteristics (age, gender, relation to the patient, attendance of drug readiness training by treatment buddy, choice of treatment buddy, regularity of visits by treatment buddy, assistance with adherence by treatment buddy, satisfaction with support provided by treatment buddies).

EQ-5D is a standardized self-reported instrument. The EQ-5D assesses health status using five 'domains' of self-reported problems: *mobility, self-care, usual activities, pain/discomfort and anxiety/depression*. Each domain is answerable by three statements indicating no problem (1), some/moderate problems (2) or extreme problems (3) Responses to these five items were combined to derive a single weighted index value describing health status using York tariffs. The resulting index can be regarded as societal value of the respondent's health status. The index ranges from -0.181 to 1, with negative values referring to health states valued as worse than death (Wu *et al.*, 2002); and *EQ-VAS;* (*a visual analogue scale*) to rate one's overall health status was used. The EQ-VAS is a vertical, graduated (0–100 points) 20 cm 'thermometer', with 100 at the top representing 'best imaginable health state' and 0 at the bottom representing 'worst imaginable health state'. It is a standardized instrument for use as a measure of health outcome (Wu *et al.*, 2002).

4.9. Data analysis

The software package STATA version 10 was used to analyse the data. *Xtsum* is a generalisation of summaries and reports means and standard deviation for cross-sectional time-series data. The descriptive statistics of the variables included in the models were estimated using the *xtsum* command. These descriptive statistics are reported in Appendix 3. Cross-tabulations of individual variables using the '*tab*' command were used to verify the integrity and nature of the variables in the data set. Variables are not always in the format required for analysis, therefore new variables necessary to perform data analysis for the purposes of answering specific research questions were created using a combination of the 'generate', '*replace*' and/or "*recode*" commands.

Two types of analysis were conducted to inform the answers to the various research questions described in Chapter 1 of the thesis. Firstly, bivariate analysis was performed using the following quantitative tools: Chi2 tests were employed to assess the statistical significance of differences in categorical variables; statistical methods to compare differences in means in averages of continuous variables; analysis of variance (ANOVA) and correlation coefficients were used.

Secondly, multivariate analysis was conducted using each of the key outcomes of the study described in Section 7.2.1 above. Logistic regressions were performed to investigate the determinants of access to treatment buddy; frequency of treatment buddy visits; adherence knowledge; self-reported adherence and clinical adherence. In terms of the multiple logistic regressions, the *Xtlogit* command was used to run regressions for the fixed effects model (FE) and the random effects model (RE) and the *logit* command was used to estimate the simplified pooled model. The Fixed effects model assumes that subjects estimated are fixed and uses only within individual variation while in the Random Effects model the measurements are randomly sampled from a larger population, therefore variance between them is of interest (Allison, 2006). The selection of variables for regression analyses was guided by the results of the bivariate analyses. The Pearson or Hosmer–Lemeshow test and the Likelihood-ratio tests and Hausman specification tests were employed to choose the appropriate estimator. The multiple logistic regressions report odds ratios. Depending on the appropriate test statistic and overall fit of the model, the results of either pooled or random effects models were reported and discussed. To address the problem of small sample sizes in some key outcome variables, the exact logistic regression was performed, since exact logistics regression provides a better coverage than the standard regression.

Table 4.7: Summary of regression models' specifications

	1. Access to buddy		2. Intensity of visits		3. Adherence knowledge		4. Self reported adherence		5. Clinical adherence	
	Level of access (0/1)	Transitions in access (0→1) (1→0)	Frequency of visits (0/1)	Transitions in frequency (0→1) (1→0)	Level of adherence knowledge (0/1)	Transitions in the level of adherence knowledge (0→1) (1→0)	Level of self reported adherence (0/1)	Transitions in the level of self reported adherence (0→1) (1→0)	Level of clinical adherence (0/1)	Transitions in the level of clinical adherence (0→1) (1→0)
Regression model type	**Logistic panel**		**Logistic panel/cross-sectional**		**Logistic panel**		**Logistic panel**		**Logistic panel**	
Variables										
A. Need:										
Health related quality of life	ll and Δ	ll or lΔ	ll and Δ	ll or lΔ						
B. Treatment buddy support:										
(a) Access										
Access to treatment buddy					t	ls (or lt)	t	ls (or lt)	t	ls (or lt)
(b) Treatment buddy characteristics:										
Age			l✻	l	ls	ls	ls	ls	ls	ls
Gender			s✻	s	ls	ls	ls	ls	ls	ls
Attended drug readiness training			s✻	s	ls	ls	ls	ls	ls	ls
Relation to the patient			s✻	s	ls	ls	ls	ls	ls	ls
Satisfaction with buddy			s	s	ls	ls	ls	ls	ls	ls
Buddy assist with adherence			s	s	ls	ls	ls	ls	ls	ls
Chose own buddy/chose self			s✻	s	ls	ls	ls	ls	ls	ls
C. Other treatment support:										
Access to emotional carer	t	ls (or lt)	t	ls (or lt)	t	ls (or lt)	t	ls (or lt)	t	ls (or lt)
Access to physical carer	t	ls (or lt)	t	ls (or lt)	t	ls (or lt)	t	ls (or lt)	t	ls (or lt)
Access to community health worker	t	ls (or lt)	t	ls (or lt)	t	ls (or lt)	t	ls (or lt)	t	ls (or lt)
Participation in support group	t	ls (or lt)	t	ls (or lt)	t	ls (or lt)	t	ls (or lt)	t	ls (or lt)
Household size	ll or Δ	ll or lΔ	ll and lΔ	ll or lΔ						
D. Other variables ✛										
Intensity of visits					t	ls (or lt)	t	ls (or lt)	t	ls (or lt)
Adherence knowledge							t	ls (or lt)	t	ls (or lt)
Self reported adherence										
Clinical adherence										

Note: Individual-level sociodemographic variables (age,age2, gender, marital status, level of education) and the treatment career variable (0-6mnths, 6-12mnths, 18-30mnths, 30-42mnths) are included in each of the above regression models.

Legend:ll = lagged levels; Δ = differences; t = transitions; lΔ = lagged differences; ls = lagged states; lt =lagged transitions

0→1 represent transitions INTO and 1→0 transitions OUT of the particular state

✛ these variables are key outcomes in the regression models but are also explanatory variables

✻ logistic regression using a cross-sectional data from the treatment buddy survey will also be estimated

Table 4.7 above provides an overview of the manner in which the various multivariate analyses will be performed, with a distinction being drawn between dependent and explanatory variables. The dependent variable is defined as "the one which has to be measured to examine whether the participants' at various levels of the independent variable differ in terms of it" (Huysamen, 1997: 24). The variable is thought to be affected by another (independent variable). The dependent variables in the present study are access to treatment buddy; intensity of visits; adherence knowledge and; adherence (self-reported and clinical.. The explanatory variable is defined as "the antecedent treatment, procedure, condition, or status that causes, enables, or leads to a consequence or outcome that is dependent on it" (Meltzoff, 1998: 283).

As noted in Table 4.7, various multivariate regression analyses will be performed separately for point estimates and change outcomes for each of the six main outcomes. Differences and transitions in key explanatory variables are regressed on point estimates of the main outcomes, while point estimates and lagged differences or transitions in key explanatory variables are regressed on differences and transitions in main outcomes respectively to avoid problems of endogeneity and to focus on causal dynamics of cause-and-effect.

Even though the five key outcome variables are considered dependent variables, they may also be explanatory variables in some instances as they may predict each other in multivariate analysis. For example, access to a treatment buddy may be associated with self-reported adherence. As illustrated in the bottom part of Table 4.7, these are included as explanatory variables in the corresponding regression models. Treatment support as explanatory outcome are represented by two separate measures: (a) access to treatment buddy and (b) treatment buddy characteristics respectively. Two types of regression models are estimated to determine how treatment buddy support may impact on the various key study outcomes: one including the access to treatment buddy variable only, the other including the treatment buddy characteristics only as explanatory variables. This approach is followed, because treatment buddy characteristics are only known for patients who actually have treatment buddies. Estimating one model only with both access and characteristics of treatment buddy support would have resulted in the significance of the treatment buddy access variable being dropped from the relevant regression model.

Regressions are performed separately for transitions into a particular state (0→1) and transitions out of a particular state (1→0) in respect of categorical outcomes. In Table 4.7, lagged transitions (or lt) are in brackets, this to indicate that having too few observations, as a result of the use of lagged differences or transitions across four time periods or treatment career phases only, in some cases may not allow for this specific regression model to be estimated.

4.10. Selection and attrition bias

As explained in Section 4.3.1, this study uses only the so-called treatment career cohort sample of 160 patients for the purposes of the empirical analysis, a sub-sample that comprises patients that not only stayed in the programme but also stayed in the study over all six survey rounds and that may differ from other sub-samples in the larger dataset in key respects. A distinction is drawn between the treatment career cohort; study cohort; attritions and replacements.

To establish whether patients included in the analysis are different from those excluded, a multinomial regression model was estimated to compare key socio-demographic characteristics across the different sub-samples. The results are summarised in Table 4.8 below.

Table 4.8: Socio-demographic characteristics of patients by sub-sample

Number of obs	**1752**
LR chi2 (36)	**853.43**
Prob>chi2	**0.0000**
Pseudo R2	**0.1757**

	Study cohort		**Attritions**		**Replacements**	
Variable	**RRR**	**P-value**	**RRR**	**P-value**	**RRR**	**P-value**
Age (years)	*0.94*	***	*0.97*	*	*0.95*	*
Gender						
Male						
Female	*1.39*	**	*0.85*		*0.83*	
Level of education						
No education						
Primary	*0.44*		*1.13*		*0.56*	
Some secondary	*0.42*	***	*0.64*		*0.68*	
Grade 12	*0.45*	**	*1.32*		*1.31*	
Tertiary	*0.66*		*3.28*	**	*1.09*	
Population group						
Black						
Coloured	*0.72*		*0.98*		*0.21*	**
Indian/Asian	*1.24*		*3.77*		*1.12*	
White	*1.06*		*1.61*		*2.61*	

Notes: Treatment career cohort is the base outcome. Significance: **** significant at 1% level; ** significant at 5% level; * significant at 10% level*

- **Study cohort relative to treatment career cohort**

Reported here is a relative risk ratio for a one unit increase in age for being in the study cohort relative to treatment career cohort, given that the other variables in the model are held constant. If age were to increase by one year, the relative risk of being in the study cohort compared to the treatment career cohort would be expected to decrease by a factor of 0.94. In other words, older patients are more likely to be in the treatment career cohort than the study cohort. For females relative to males, the relative risk of being in the study cohort to treatment career cohort would be expected to increase by a factor of 1.39 given that the other variables in the model are held constant. In other words, females are more likely than males to be in the study cohort over the treatment career cohort. In as far as education is concerned; the relative risk of being in a study cohort to treatment career cohort would be expected to decrease by a factor of 0.42 and 0.45 respectively. In other words, patients with some secondary and a grade 12 education, rather than no education, are more likely to be in the treatment career cohort than the study cohort.

- **Attritions relative to treatment career cohort**

Given the other variables in the model are held constant. If age were to increase by one year, the relative risk of being in attritions to treatment career cohort would be expected to decrease by a factor of 0.97. In other words, older patients are more likely to be in the treatment career cohort than the attritions. In as far as education is concerned; the relative risk of being in a study cohort to treatment career cohort would be expected to increase by a factor of 3.28. In other words, patients with tertiary rather than no education are more likely to be in attritions than the treatment career cohort.

- **Replacements relative to treatment career cohort**

The results indicate that, given the other variables in the model are held constant. If age were to increase by one year, the relative risk of being in attritions to treatment career cohort would be expected to decrease by a factor of 0.95. In other words, older patients are more likely to be in the treatment career cohort than the replacements. In as far as race is concerned; the relative risk of being in attritions to treatment career cohort would be expected to decrease by a factor of 0.21. In other words, coloured rather than black patients are more likely to be in the treatment career cohort than the replacements.

Hence, some socio-demographic characteristics differed significantly between sub-samples, suggesting that the results need to be interpreted with care given the presence of selection and attrition bias. To establish whether selection or attrition bias exists, the main study outcomes were compared across patients in the different sub-samples. Table 4.9 summarises the results from these regression analyses.

Table 4.9: Key outcomes by sub-sample

	Subsample				
Outcomes	**Treatment career cohort**	**Study cohort**	**Attritions**	**Replacements**	**P-value**
1. Access to buddy					
Level of access (0/1)	38.6	34.11	36.66	34.83	0.475
Transitions in access (0→1)	12.53	11.88	6.64	9.41	0.009
Transitions in access (1→0)	15.30	12.21	8.47	8.91	0.002
2. Intensity of visits					
Frequency of visits (0/1)	77.78	87.78	83.03	92.42	0.013
Transitions in frequency of visits (0→1)	2.55	1.32	1.60	0.00	0.076
Transitions in frequency of visits (1→0)	1.88	0.66	0.69	0.00	0.051
3. Adherence knowledge					
Level of adherence knowledge (0/1)	89.58	93.07	83.30	86.14	≤0.001
Transitions in the level of adherence knowledge (0→1)	4.99	5.28	6.86	4.95	0.537
Transitions in the level of adherence knowledge (1→0)	6.54	5.28	5.26	6.93	0.696
4. Self reported adherence					
Level of self reported adherence (0/1)	96.94	99.21	97.03	99.29	0.097
Transitions in the level of self reported adherence (0→1)	2.00	0.00	1.60	0.50	0.048
Transitions in the level of self reported adherence (1→0)	2.22	0.66	1.14	0.50	0.099
5. Clinical adherence					
Level of clinical adherence (0/1)	68.83	71.56	61.21	78.07	0.009
Transitions in the level of self reported adherence (0→1)	1.88	1.65	0.69	1.49	0.412
Transitions in the level of clinical adherence (1→0)	9.87	9.57	8.47	1.49	0.002

Legend: 0→1 represent transitions INTO and 1→0 transitions OUT of the particular state

There are no significant differences in access to treatment buddy between patients in the study and patients excluded from the empirical analysis. However, there were significant differences between those in the study and those excluded in terms of those who gained and lost a treatment buddy respectively ($p<0.05$). Patients in the study were more likely to have gained access to a treatment buddy compared to patients in other sub-samples, while patients in the study were also more likely to have lost access to a treatment buddy compared to patients in other sub-samples.

The intensity of treatment buddy support varied significantly by sub-sample. The proportion of patients visited at least once per day was significantly lower among those in the study ($p<0.05$). There were weak but significant differences in transitions in intensity of visits. Patients in the study were more likely to be visited at least once per day compared to patients in other sub-samples ($p<.10$), while patients in the study were also more likely to be visited at irregular intervals compared to patients in other sub-samples ($p<.10$).

The level of adherence knowledge also varied significantly by sub-sample ($p<0.01$). Adherence knowledge was significantly higher among patients in the study cohort compared to other sub-samples ($p<0.01$).

Transitions in adherence knowledge (perfect to imperfect and imperfect to perfect knowledge) did not vary significantly by sub-sample.

The level of self-reported adherence varied significantly by sub-sample. Self-reported adherence was lowest among patients in the study (treatment career cohort) compared to other sub-samples and was more likely to decline or increase among those in the study ($p<.10$). Clinical adherence was lowest among the patients lost to follow-up compared to other sub-samples ($p<0.05$). The proportion of patients who experienced a decline in clinical adherence was significantly higher among those in the study compared to other sub-samples ($p<0.01$).

Most of the main study outcomes therefore did differ significantly between the sub-sample of 160 patients to be included in the analysis and sub-samples of other respondents in the larger dataset, suggesting that the results need to be interpreted with care, given the presence of selection and attrition bias.

4.11 The limitations of the study

Although the study has its own strengths, the study has also has some limitations which are pointed out below;

- Attrition and selection bias- this study uses only the so-called treatment career cohort sample of 160 patients for the purposes of the empirical analysis, a sub-sample that comprises patients that not only stayed in the programme but also stayed in the study over all six survey rounds and that may differ from other sub-samples in the larger dataset in key respects.
- The analyses lacked statistical power due to the lack of variation in the outcome; this may be attributable to a shortcoming of the study, in this case lacking statistical power because of having to use only the subset of the data with clinical markers observed in close enough proximity to the interviews.
- The small number of non-adherent cases, which constrain the analysis in terms of variation in the outcomes is the result in part of the weaknesses of self-reported adherence measures
- The fact that the patient and treatment buddy surveys were collected at different times represent a potential shortcoming or limitation for the study, because it makes the comparability of the results difficult.
- In this study, we could not establish the possibility that a treatment buddy could actually be the same person as the emotional or physical caregiver.

4.12 Summary

The study uses two sources of data: (1) Data collected from a longitudinal study conducted among patients enrolled in the public sector antiretroviral treatment programme (patient survey) and (2) data from individual interviews conducted with treatment buddies. A random proportional stratified sample was used to select patients. The study employed a longitudinal approach where patients were interviewed at approximately six- to nine-month intervals over the period 2004-08. Purposive sampling was followed in the identification of treatment buddies since information about treatment buddies was obtained from patients already part of the patient's survey. Face-to-face, semi-structured interviews were conducted with patients at six consecutive interview rounds, while semi-structured, telephonic interviews were conducted with fifty-five treatment buddies to supplement the patient survey data. Written, informed consent was obtained from all study participants, including consent to access respondents' clinic files and to link data from the health care system to the data from the patient survey. With treatment buddies, verbal consent was obtained telephonically by interviewers.

Bivariate and multiple regression analysis were used to determine how treatment buddy support is associated with and impacts on the main study outcomes, adherence knowledge, self-reported and clinical adherence.. Most of the main study outcomes differed significantly between the sub-sample of 160 patients to be included in the analysis, suggesting that the results need to be interpreted with care, given the presence of selection and attrition bias. The following chapter comprises of presentation and discussion of results, first for access to a treatment buddy and then for other key study outcomes respectively.

CHAPTER 5

ACCESS TO A TREATMENT BUDDY

5.1. Introduction

In this chapter an attempt is made to understand how many patients have treatment buddies and why they may have treatment buddies. Furthermore, an effort is made to determine how the need for support, represented by health status, may influence access to a treatment buddy. The chapter also aims to establish how access to other sources of treatment support may impact on access to a treatment buddy. In this chapter, three different topics are explored, namely (i) current access to a treatment buddy, (ii) losing access to a treatment buddy, and (iii) gaining access to a treatment buddy.

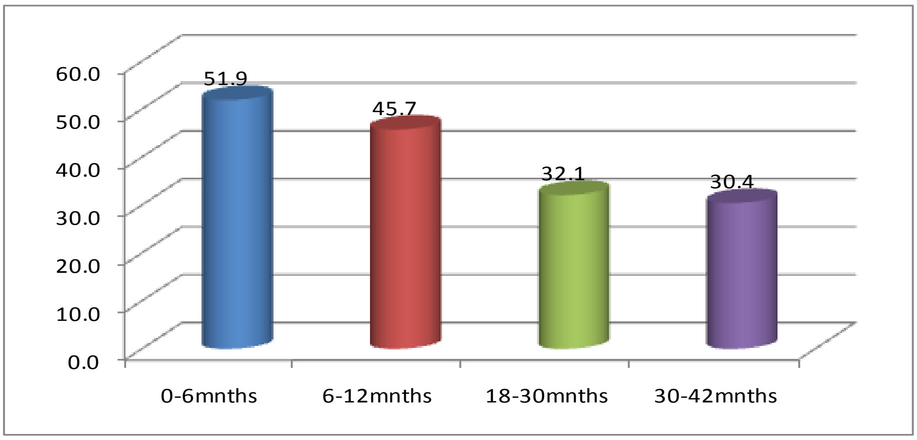
5.2. Current access to a treatment buddy

This sections focuses on (i) how access to other forms of support impact on access to a treatment buddy, (ii) how past levels and past changes in levels of health-related quality of life impact on access to a treatment buddy and lastly, (iii) how household size impacts on access to a treatment buddy.

5.2.1. Access to a treatment buddy and other support

Figure 5.1 demonstrates a clear trend in access to a treatment buddy, indicating a significant decline across the four phases of the treatment career ($p<0.001$). According to Figure 5.1, access to a treatment buddy is highest among those who had been on treatment for six months or less and lowest among those who have been on treatment for 30-42 months. The small percentage of patients with access to a treatment buddy, for those who had been on treatment for longer, could be attributed to various reasons. A decline in access to a treatment buddy could be due to improvements in patients' health status and a reduced need for treatment support or could be due to changing needs of patients on treatment. A decline in access to a treatment buddy over the treatment career could mean the role of a treatment buddy, which is to enhance adherence through the provision of adherence support visits and reminders, is important as patients start treatment, but that the need for such support declines in the long term due to the possibility that patients get used to treatment and establish their own routines with regard to medication taking. This reported decline in access to a treatment buddy is consistent with that of Burgoyne and Renwick's (2004) results of a four-year longitudinal study of support over time, among adults living with HIV in the HAART area in South Africa.

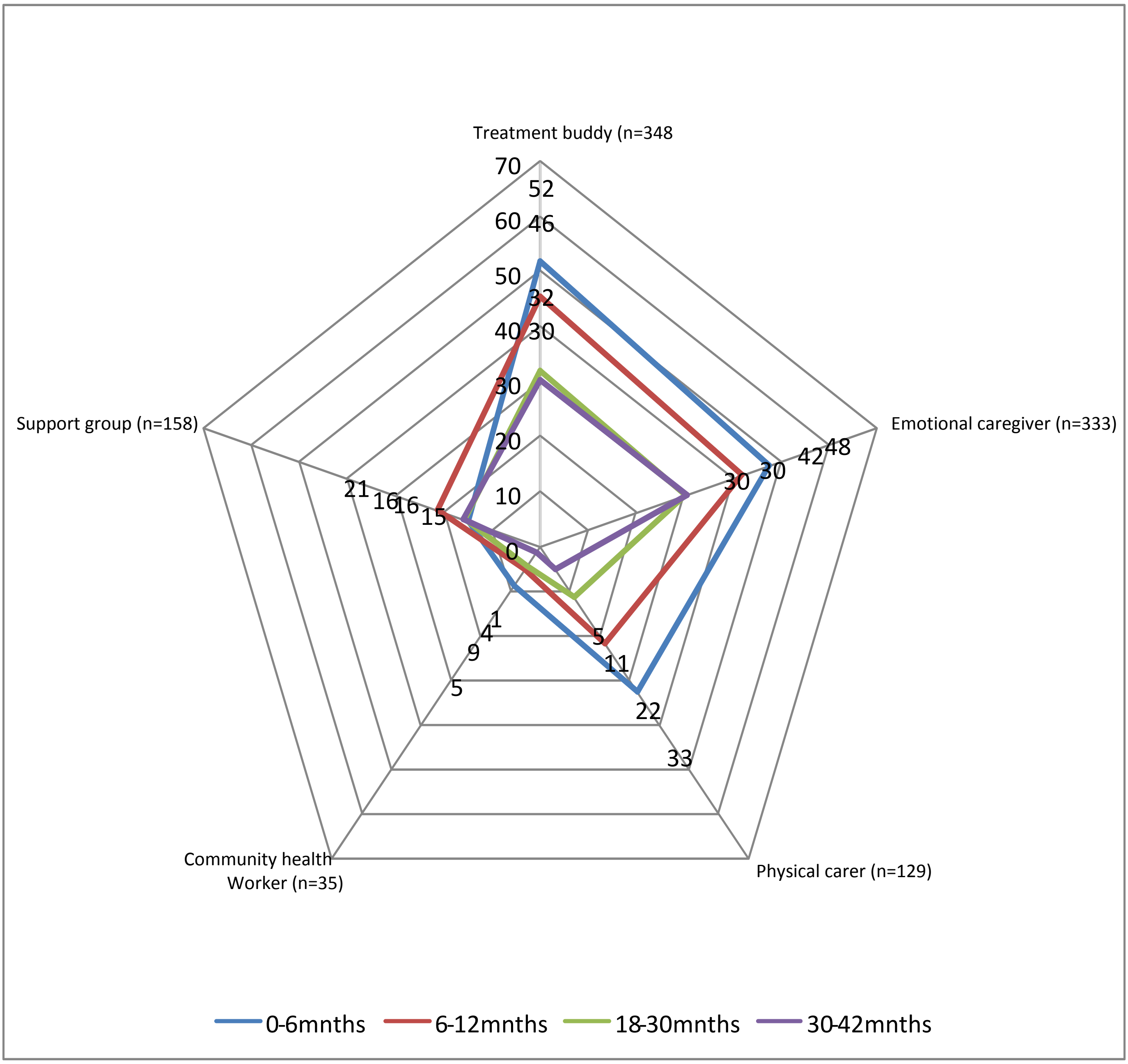
Figure 5.1: Access to a treatment buddy, by treatment career phase (n=944)



Note: Results are statistically significant at the 1% level (chi2= 30.56, p<0.001).

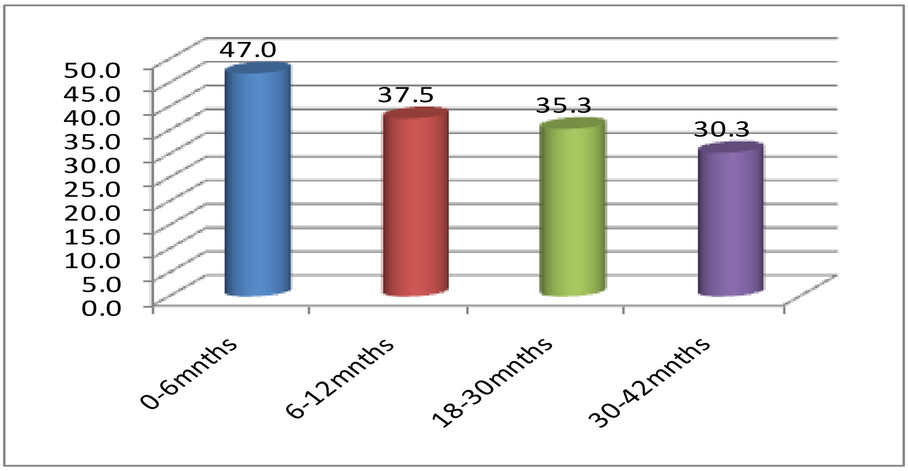
Figure 5.2 reports the proportion of patients with access to different forms of support in the four different phases of the treatment career. On aggregate, access to all forms of support declined as treatment duration increases. Moreover, the proportion of patients who had been visited by a community health worker is generally lower while most patients had access to a treatment buddy and an emotional caregiver. At zero to six months on treatment, a large proportion of patients had access to a treatment buddy (52%), followed by 48% who had an emotional caregiver, 33% to a physical caregiver, 15% to a support group, and 9% only to a community health worker. At 6-18 months on treatment, though, the proportion with access declined for each form of support, except for participation in a support group, which was 21%. At 18-30 months on treatment, most patients had a treatment buddy and an emotional caregiver.

Figure 5.2: Current access to different forms of support, by treatment career phase



At 30-42 months on treatment, the proportion of patients who had a treatment buddy was the same as those with an emotional caregiver (30%). Participation in a support group did not decline further as compared with other forms of support. The large number of patients with access to a treatment buddy, followed by access to an emotional caregiver, may be indicative of the extent to which adherence and emotional support is desired among ART clients.

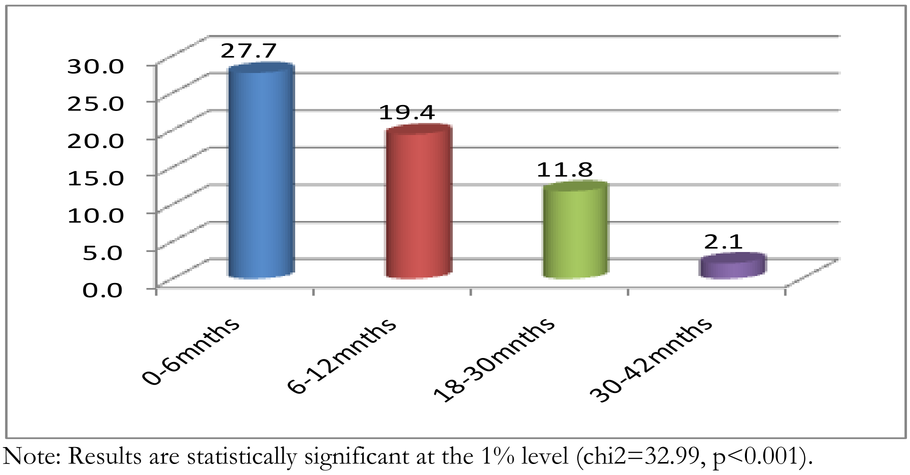
Figure 5.3: Current access to an emotional caregiver among patients with a treatment buddy, by treatment career phase (n=947)



Note: Results are statistically significant at the 10% level (chi2=6.37, p=0.095).

Figure 5.3 indicates that access to an emotional caregiver among patients who had a treatment buddy varied significantly but weakly only across the four phases of the treatment career. Figure 5.3 shows a downward trend in access to an emotional caregiver as the treatment duration increases. At zero to six months on treatment, a large proportion of patients had an emotional caregiver, whereas access to an emotional caregiver was lowest among those who had been on treatment for longer than 30 months One possible explanation for this trend may lie on improvements in patient's health status; one would expect that health status would improve as months on treatment increase, thereby reducing a need for support among patients on treatment. A decline in access to an emotional caregiver could be expected if an emotional carer is the same person as the treatment buddy, because access to treatment buddy also declined over time (see Figure 5.1).

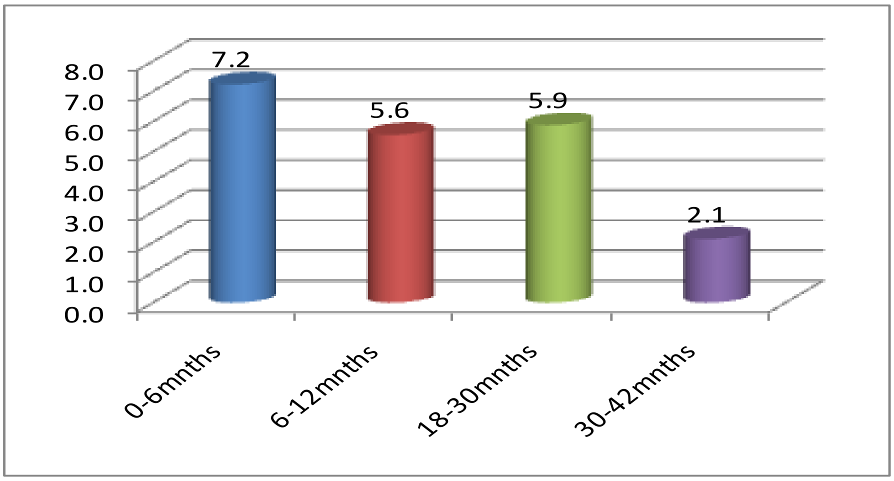
Figure 5.4: Current access to a physical caregiver among patients with a treatment buddy, by treatment career phase (n=947)



Note: Results are statistically significant at the 1% level (chi2=32.99, p<0.001).

Figure 5.4 demonstrates that access to a physical caregiver among patients who had access to a treatment buddy differed significantly by treatment duration (p<0.001*)*. The highest number of patients who had a physical caregiver was those who had been on treatment for six months or less. Furthermore, access to a physical caregiver among patients with access to a treatment buddy declined as treatment duration increased. Very few patients had a physical caregiver by 30 to 42 months on treatment. Improvements in physical functioning may be the reason for a decline in the proportion of patients who have access to a physical caregiver.

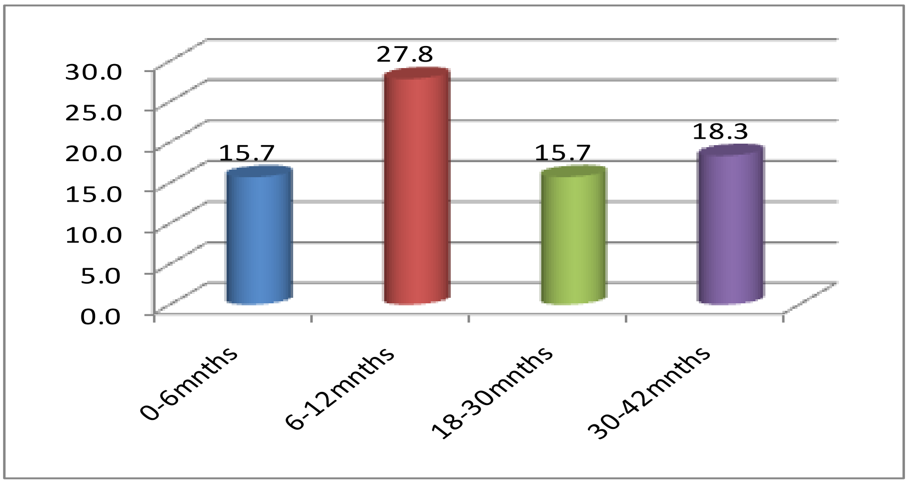
Figure 5.5: Current access to a community health worker among patients with a treatment buddy, by treatment career phase (n=947)



Note: Results are not statistically significant (chi2=3.65, p=0.302).

According to Figure 5.5, access to a community health worker among patients who had a treatment buddy did not differ significantly by treatment career phase. The number of patients with a treatment buddy who were visited by a community health worker declined as treatment duration increased. Most patients who were visited by a community health worker had been on treatment for six months or less. By 30 to 42 months on treatment, only 2% were visited by a community health worker.

Figure 5.6: Current participation in a support group among patients with a treatment buddy, by treatment career phase (n=947)



Note: Results are not statistically significant (chi2=4.55, p=0.208).

As in the case of access to a community health worker, participation in a support group among patients who had treatment buddies did not vary significantly by treatment duration (Figure 5.6). Participation in a support group was low among patients who had been on treatment for less than six months, but increased among patients who had been on treatment for 6 to 12 months (28%), Participation in a support group further declined among patients who had been on treatment for 18-30mnths (16%). However, these differences were not statistically significant.

5.2.2. Need and current access to a treatment buddy

Table 5.1 shows that past levels of health-related quality of life impact significantly on current access to a treatment buddy. This association is statistically significant at the 5% level for both measures of health-related quality of life: EQ-VAS and EQ-5D. Patients with higher health status in the past were more likely to have a treatment buddy in the past period compared to patients reporting worse health status. Patients with treatment buddies had improved health-related quality of life compared to patients who did not have a treatment buddy, which means that patients with better health are better able to access support.

Table 5.1: Past levels of health-related quality of life, by current access to a treatment buddy

Current access to treatment buddy	Summary of past health-related quality of life (EQ-VAS)							
	Mean	*SD*	*p25*	*p75*	*Median*	*Min*	*Max*	*Frequency*
No treatment buddy	68.47	19.93	50	80	70	0	100	**518**
Treatment buddy	72.16	18.85	60	90	70	20	100	**265**
Total	**69.72**	**19.64**	**50**	**90**	**70**	**0**	**100**	**783**

Current access to treatment buddy	Summary of past health-related quality of life (EQ-5D)							
	Mean	*SD*	*p25*	*p75*	*Median*	*Min*	*Max*	*Frequency*
No treatment buddy	0.85	0.24	0.7	1	1	-0.2	1	**595**
Treatment buddy	0.88	0.22	0.8	1	1	0.0	1	**265**
Total	**0.86**	**0.23**	**0.8**	**1**	**1**	**-0.2**	**1**	**784**

Note: EQ-VAS: results are statistically significant at the 5% level (F= 6.26, p=0.012). EQ-5D: results are statistically significant at the 5% level (F= 6.26, p=0.027).

Table 5.2: Changes in the level of health-related quality of life, by current access to a treatment buddy

Current access to treatment buddy	Summary of changes in health-related quality of life (EQ-VAS)							
	Mean	*SD*	*p25*	*p75*	*Median*	*Min*	*Max*	*Frequency*
No treatment buddy	1.05	21.08	-10	10	0	-70	80	517
Treatment buddy	-0.20	20.09	-10	10	0	-70	65	265
Total	**0.63**	**20.75**	**-10**	**10**	**0**	**-70**	**80**	**782**

Current access to treatment buddy	Summary of changes in health-related quality of life (EQ-5D)							
	Mean	*SD*	*p25*	*p75*	*Median*	*Min*	*Max*	*Frequency*
No treatment buddy	0.00	0.20	0	0	0	-1.2	0.9	519
Treatment buddy	-0.01	0.21	0	0	0	-1.2	0.8	265
Total	**-0.00**	**0.20**	**0**	**0**	**0**	**-1.2**	**0.9**	**784**

Note: EQ-VAS: results are not statistically significant (F=0.63, p=0.426). EQ-5D: results are not statistically significant (F=0.96, p=0.328).

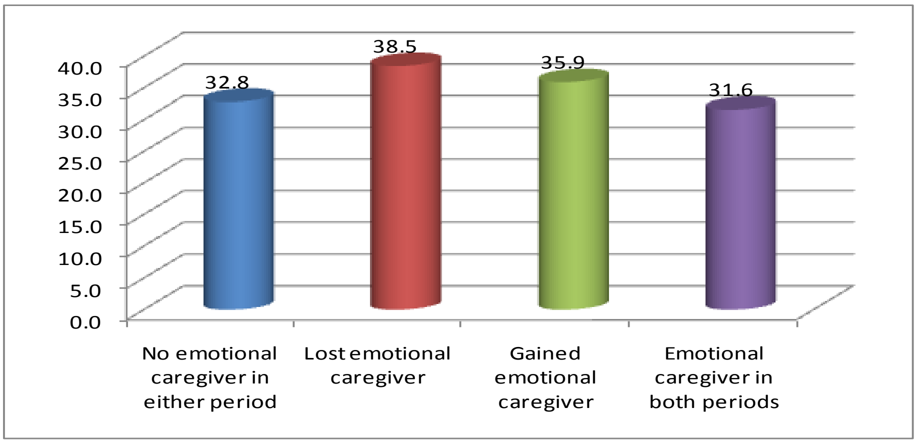
Table 5.2 indicates that changes in the levels of health-related quality of life did not impact significantly on current access to a treatment buddy. The results suggest that access to a treatment buddy in the current period is not influenced by past changes in the level of health-related quality of life. However, the results do reflect the expected higher level of access among those reporting a decline in health status, which implies that need, as proxied here by health-related quality of life, may drive access to treatment buddy support. It is, however, unfortunate that the results are not statistically significant.

5.2.3 Current access to a treatment buddy and changes in access to other support

This section assesses the association between current access to a treatment buddy and changes in access to other forms of social support (emotional caregiver, physical caregiver, community health worker and support group). This section provides an indication of whether the mentioned forms are actually complements or substitutes.

5.2.3. (a) Transitions in access to an emotional caregiver

Figure 5.7: Current access to a treatment buddy, by transitions in access to an emotional caregiver (n=784)



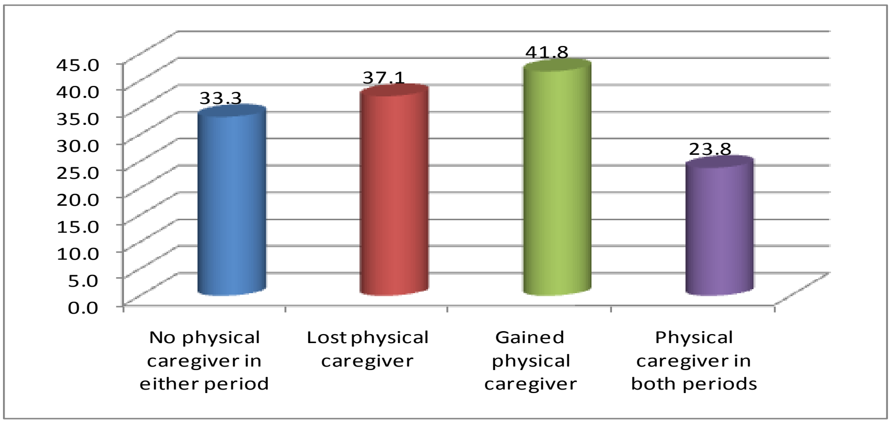
Note: Results are not statistically significant. (ch2=1.79, p=0.617).

The results indicate that there is no association between current access to a treatment buddy and transitions in access to an emotional caregiver. However, current access to a treatment buddy is highest among patients who lost access to an emotional caregiver (39%) and lowest among patients who have an emotional caregiver in both periods (32%). One would expect these results if these sources of support are substitutes. Access to a treatment buddy is also high among patients who gained access to an emotional caregiver, which suggests that these are complements rather than substitutes, which may be the case if the same person acts as both treatment buddy and emotional supporter. The results indicate that access to emotional caregiver was highest irrespective of access to a treatment buddy.

5.2.3. (b) Transitions in access to a physical caregiver

Transitions in access to a physical caregiver did not impact significantly on current access to a treatment buddy. Figure 5.8 indicates that even though there is no association, current access to a treatment buddy is highest (42%) among patients who gained access to a physical caregiver and lowest among patients who had access to a physical caregiver in both periods (24%). Access to a treatment buddy is highest among patients who gained access to physical caregiver, which suggests that these are complements rather than substitutes, which may be the case if the same person acts as both treatment buddy and physical caregiver. Low access to a treatment buddy among patients who had access to physical caregiver in both periods indicates that access to a physical caregiver substituted for access to a treatment buddy.

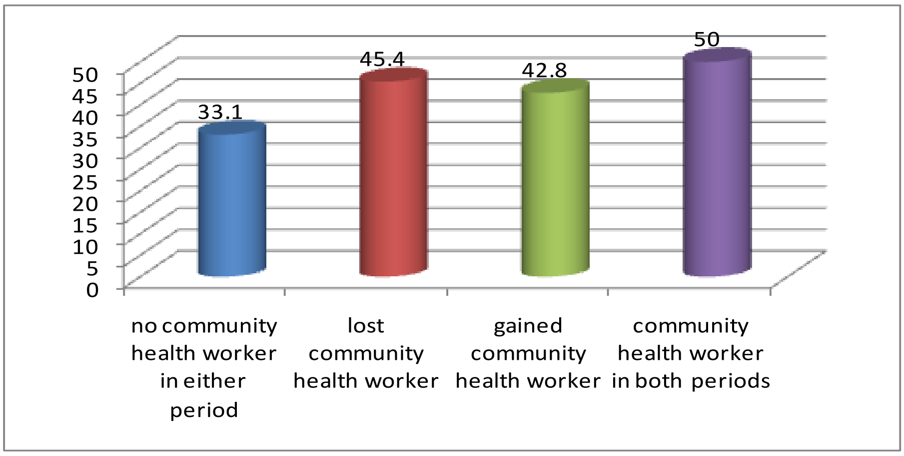
Figure 5.8: Current access to a treatment buddy, by transitions in access to a physical caregiver (n=784)



Note: Results are not statistically significant (chi2=4.36, p=0.224).

5.2.3. (c) Transitions in access to a community health worker

Figure 5.9: Current access to a treatment buddy, by transitions in access to a community health worker (n=784)

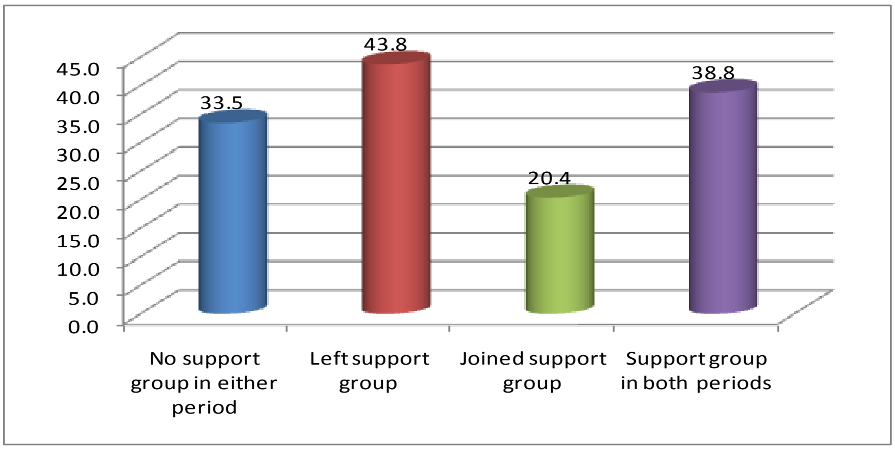


Note: Results are not statistically significant (chi2=2.74, p=0.432).

Recent transitions in access to a community health worker did not significantly impact on current access to a treatment buddy. However, current access to a treatment buddy is highest among those who had community health workers in both periods. Access to a treatment buddy was lowest among those who did not have a community health worker visit in both periods (Figure 5.9). Current access is also high among patients who lost access to a community health worker, which implies that access to treatment buddy may have been used as a substitute for patients who lost support from a community health worker. Access to a treatment buddy among patients who had a community health worker in both periods imply that these forms of support complement rather than substitute each other.

5.2.3 (d) Transitions in participation in a support group

Figure 5.10: Current access to a treatment buddy, by transitions in participation in a support group (n=784)



Note: Results are statistically significant at the 10% level (chi2=7.45, p=0.059).

Figure 5.10 indicates recent transitions in participation in a support group had a weak but significant impact on current access to a treatment buddy. Current access to a treatment buddy was highest among patients who discontinued participation in a support group (44%), suggesting that access to treatment buddy in this case was used as a substitute for the discontinued participation in a support group. Current access to a treatment buddy is also high among those who participated in a support group in both periods (39%). The simultaneous access to both forms of support implies that these forms of support complement each other.

5.2.4. Household size and current access to a treatment buddy

According to Table 5.3, past household size significantly impacted on current access to a treatment buddy, and this association is significant at 1% level ($p<0.01$). Mean differences in Table 5.3 suggest that patients from larger households were more likely to have current access to a treatment buddy. These results make sense because the descriptive findings reported in Chapter 4 reveal that a lot of treatment buddies seem to live with the patients and, therefore, one would expect increases in household size to increase the likelihood of gaining a buddy.

Table 5.3: Past household size, by current access to a treatment buddy

Current access to treatment buddy	**Summary of past household size**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
No treatment buddy	3.87	2.15	2	5	4	1	14	516
Treatment buddy	4.39	2.09	3	6	4	1	14	265
Total	**4.05**	**2.14**	**3**	**5**	**4**	**1**	**14**	**781**

Note: Results are statistically significant at the 1% level (F=10.31, p=0.001).

Table 5.4: Past changes in household size, by current access to a treatment buddy

Current access to treatment buddy	**Summary of changes in household size**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
No treatment buddy	0.00	1.47	0	0	0	-11	11	515
Treatment buddy	-0.05	1.44	0	0	0	-8	8	264
Total	**-0.01**	**1.46**	**0**	**0**	**0**	**-11**	**11**	**779**

Note: Results are not statistically significant (F=0.23, p=0.631).

There is no significant association between past changes in household size and current access to a treatment buddy. The results presented in Table 5.4 suggest that past changes in household size did not impact significantly on current access to a treatment buddy. Furthermore, the results are contradictory insofar as one would expect an increase in household size to be associated with access to a treatment buddy. However, as the reported differences are not, in fact, statistically different, one should not make too much of the implied nature of the association between observed changes in household size and current access to a treatment buddy.

5.2.5. Determinants of current access to a treatment buddy

Table 5.5 reports the determinants of current access to a treatment buddy. Two regressions models were performed using each of the alternative measures of health-related quality of life, one for EQ-VAS and the other for EQ-5D. The aim was to establish whether the regression results will differ based on the measure of health-related quality of life or whether the findings would be consistent across both measures of health-related quality of life. The reported results are for the random effects model (RE) and the overall model performed adequately in terms of goodness-of-fit ($p<0.01$).

Table 5.5: Need and access to support as determinants of current access to a treatment buddy

Independent variables	**Odds ratio**		**Odds ratio**	
	EQ-VAS		**EQ-5D**	
1. Sociodemographic variables				
Age	0.780		0.792	
Age2	1.002		1.002	
Female (*male=0/female=1)*	0.782		0.739	
Marital status				
[comparison group=single]				
Living with partner	4.710	***	3.876	***
Not living with partner	2.834	**	2.370	*
Educational status				
[comparison group=no formal education]				
Primary education	4.054		3.755	
Secondary education	2.466		2.194	
Grade 12	12.017	**	11.98	*
Tertiary education	4.224		4.655	
2. Need variables				
Treatment career				
[comparison group=0-6months]				
6-12months	2.870	***	2.723	***
18-30months	0.757		0.815	
30-42months(omitted)				
Past level of health related quality of life (EQ-VAS)	7.219	**		
Changes in the level of health related quality of life (EQ-VAS)	1.202			
Past level of health related quality of life (EQ-5D)			1.016	*
Changes in the level of health related quality of life (EQ-5D)			0.995	
3. Access to support variables				
Transitions in access to emotional carer				
[comparison group=no emotional carer in either period]				
Lost emotional carer	1.413		1.439	
Gained emotional carer	1.108		1.082	
Had emotional carer in both periods	1.141		1.187	
Transitions in access to physical carer				
[comparison group=no physical carer in either period]				
Lost physical carer	0.868		0.837	
Gained physical carer	1.376		1.328	
Had physical carer in both periods	0.160	***	0.154	***
Transitions in access to community health worker				
[comparison group=no community health worker in either period]				
Lost community health worker	2.731		3.019	
Gained community health worker	2.133		2.410	
Had community health worker in both periods	2.530		2.345	
Transitions in participation in support groups				
[comparison group=no participation in either period]				
Stopped participating	1.824		1.920	
Started participating	0.384		0.415	
Participated in both periods	1.439		1.373	
Past household size	1.108		1.127	
Changes in household size	0.945		0.963	
Sample size	*754 (160)*		*756 (160)*	
Wald chi2 (P)	*55.20 (p=0.001)*		*55.72 (p<0.001)*	
H $_{0:}$ *pooled model vs. Ha: RE (LR test)*	*163.16 (p<0.001)*		*165.39 (p<0.001)*	
Ho: RE vs. Ha: FE (Hausman test)	*15.46 (p=0.948)*		*7.78 (p=0.999*	
Note: Results are for Random Effects regression model.				
**** significant at 1% level; ** significant at 5% level; *significant at 10% level*				

According to Table 5.5 not living with a partner has odds ratios of 2.37 and 2.83 respectively and significant at the 5% and 10% respectively. The results suggest that patients who did not live with partners were 2.3 and 2.8 times more likely to respectively have a treatment buddy compared to patients who are single. Living with a partner has odds ratios of 4.71 and 3.87, respectively and is significant at the 1% level. This finding means that the patients living with their partner are 3.8 and 4.7 times more likely respectively to have a treatment buddy compared to patients who are single. This makes sense because married, unlike single, patients have partners who are more likely to provide support as a treatment buddy. Furthermore, the size effect on cohabitation is larger than on non-cohabitation, meaning that the likelihood for access to treatment buddy is higher among patients living with partner. Grade12 has an odds ratio of 12.01 and 11.98, respectively and is significant at the 5% and 10% level respectively. Therefore, the odds of having access to a treatment buddy are 12 times greater among patients with grade 12 than among patients with no education.

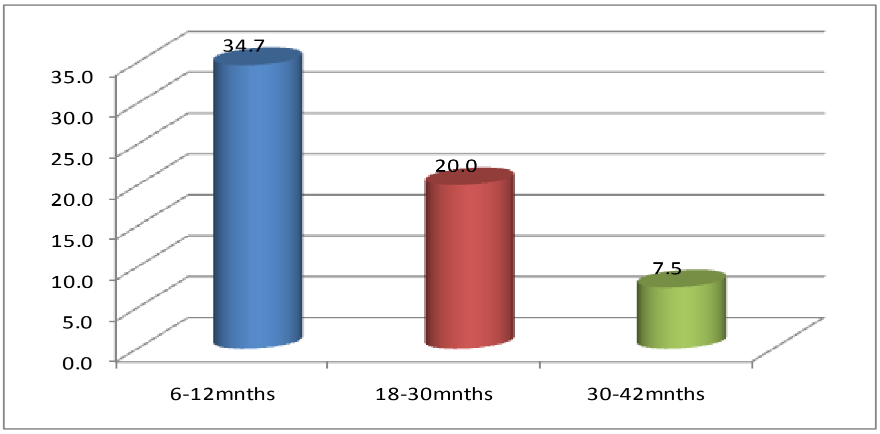
The '6-12months variable' is significant at the 1% level with odds ratios of 2.87 and 2.72, respectively. Therefore, patients who have been on treatment for 6-12 months were 2.9 and 2.7 more likely to access a treatment buddy compared to patients who had been on treatment for 0-6 months only. A small increase in the likelihood of having a treatment buddy makes perfect sense since descriptive results highlighted a decline in access to a treatment buddy over the treatment duration.

Health-related quality of life as measured by EQ-VAS has an odds ratio of 1.01 and is significant at the 10% level in explaining differences in current access to a treatment buddy. For each increase in the health-related quality of life of one percentage point, the odds of having a treatment buddy increases by approximately 1%. Similarly, health-related quality of life, as measured by EQ-5D, has an odds ratio of 7.21 and is significant at the 5% level. For each increase in health-related quality of life by 0.01, the odds of having a treatment buddy increases by 7.2%. Having a physical caregiver in both periods has odds ratios of 0.160 and 0.154 respectively and is significant at the 1% level. This denotes that for patients who had a physical caregiver in both periods, the odds of having a treatment buddy declined by 73% and 71%. This finding could suggest that physical caregivers also perform the duties of a treatment buddy.

5.3. Losing access to a treatment buddy

This section focuses on (i) how access to other forms of support (emotional caregiver, physical caregiver, community health worker and support group) impact on the probability of losing access to a treatment buddy, (ii) how past levels and past changes in levels of health-related quality of life impact on the probability of losing access to a treatment buddy and lastly, (iii) how household size impacts on the probability of losing access to a treatment buddy.

Figure 5.11: Losing access to a treatment buddy, by treatment career phase (n=481)



Note: Results are statistically significant at the 1% level (chi2=40.66, p<0.001).

Figure 5.11 demonstrates loss of access to a treatment buddy across the different phases of the treatment career. Figure 5.11 compares loss of access between different phases, with 0-6 months on treatment automatically excluded because patients in this phase could not have lost access to any support. There is a clear and statistically significant trend in losing access to a treatment buddy over the treatment duration ($p<0.001$). According to Figure 5.11, the proportion of patients with a treatment buddy who subsequently reported not having a treatment buddy, declines as treatment duration increases. The chance of having lost access to a treatment buddy is highest among those who had been on treatment for 6 to 12 months and lowest among those who have been on treatment for more than 30 months. The low number of patients who had lost access to a treatment buddy, for those who had been on treatment for 30 months, could be because access to a treatment buddy is generally low among patients who had been on treatment for a longer duration, thus resulting in fewer patients being at risk of losing a treatment buddy (refer Figure 5.1). The fewer patients being at risk of losing a treatment buddy may be due to declining need and improved health status, a question that is the focus of the analysis reported in the subsequent section.

5.3.1. Need and losing access to a treatment buddy

Past levels of health-related quality of life as measured by EQ-VAS does not impact significantly on losing access to a treatment buddy (p>0.10), but there was a weak association between losing a treatment buddy and past levels of health-related quality of life as measured by EQ-5D. The results suggest that patients who reported higher health-related quality of life in the previous period are more likely to report not having a treatment buddy any longer. This is also true for EQ-5D, the difference being that the result in this case was not statistically significant. The results indicates that need for support declined as patients' past health status improved, which in part explains the observed decline in access to a treatment buddy over the treatment career.

Table 5.6: Past level of health-related quality of life, by losing access to a treatment buddy

Losing access to treatment buddy	**Summary of past health-related quality of life (EQ-VAS)**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
Access to a treatment buddy in both periods	68.23	20.00	50	80	70	0	100	413
Losing acces to a treatment buddy	70.81	19.52	50	90	70	20	100	67
Total	**68.59**	**19.94**	**50**	**85**	**70**	**0**	**100**	**480**

Losing access to treatment buddy	**Summary of past health-related quality of life (EQ-5D)**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
Access to a treatment buddy in both periods	0.84	0.24	0.74	1	1	-0.18	1	414
Losing acces to a treatment buddy	0.89	0.12	0.79	1	1	0.62	1	67
Total	**0.85**	**0.23**	**0.76**	**1**	**1**	**-0.18**	**1**	**481**

Note: EQ-VAS: results are not statistically significant (F=0.96, p=0.327). EQ-5D: results are statistically significant at the 10% level (F=2.88, p=0.090).

Table 5.7: Past changes in the level of health-related quality of life, by losing access to a treatment buddy

Losing access to treatment buddy	**Summary of past changes in health-related quality of life (EQ-VAS)**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
Access to a treatment buddy in both periods	0.20	21.71	-10	10	0	-60	80	363
Losing acces to a treatment buddy	3.83	20.43	-5	20	0	-70	45	41
Total	**0.57**	**21.59**	**-10**	**10**	**0**	**-70**	**80**	**404**
Losing access to treatment buddy	**Summary of past changes in health-related quality of life (EQ-5D)**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
Access to a treatment buddy in both periods	0.00	0.22	0	0	0	-1.18	0.83	365
Losing acces to a treatment buddy	0.07	0.20	0	0.123	0	-0.27	0.85	41
Total	**0.00**	**0.22**	**0**	**0.016**	**0**	**-1.18**	**0.85**	**406**

Note: EQ-VAS: results are not statistically significant (F=1.04, p=0.308). EQ-5D: results are statistically significant at the 5% level (F=3.92, p=0.048).

Past changes in the level of health-related quality of life, as measured by EQ-VAS, does not impact significantly on losing access to a treatment buddy (Table 5.7). However, respondents who lost access to a treatment buddy did, as expected, report greater improvements in health-related quality of life in the previous period compared to respondents who had access to a treatment buddy in both periods. In fact, improvements in the level of health-related quality of life, as measured by EQ-5D, significantly impacted on losing access to a treatment buddy. Therefore, patients who experienced an improvement in health status since the previous period, were more likely to lose access to a treatment buddy compared to patients with a treatment buddy in both periods. As health status improves and need for support declines, one would expect a decline in access to support.

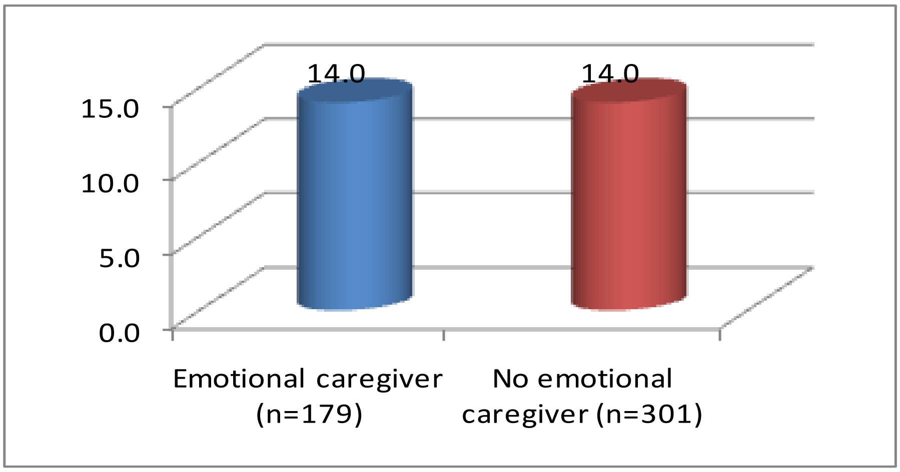
5.3.2 Losing access to a treatment buddy and past access to other support

The focus here is on understanding the nature of potential causal impacts between the relevant variables. This section assesses how previous needs, as proxied by health-related quality of life, past access to other forms of support and previous household size, impact on not having a treatment buddy anymore.

5.3.2. (a) Past access to an emotional caregiver

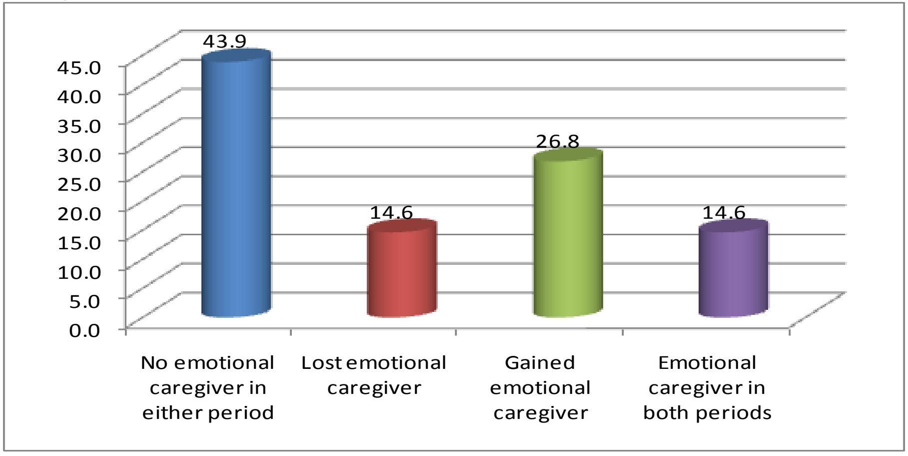
Previous access to an emotional caregiver did not impact significantly on the probability of losing access to a treatment buddy (figure 5.12). Furthermore, 14% of patients who previously had access to an emotional caregiver lost access to a treatment buddy, and 14% of patients who previously did not have access to an emotional caregiver lost access to a treatment buddy.

Figure 5.12: Losing access to a treatment buddy, by past access to an emotional caregiver



Note: Results are not statistically significant (chi2=0.00, p=0.997).

Figure 5.13: Losing access to a treatment buddy, by past transitions in access to an emotional caregiver (n=404)



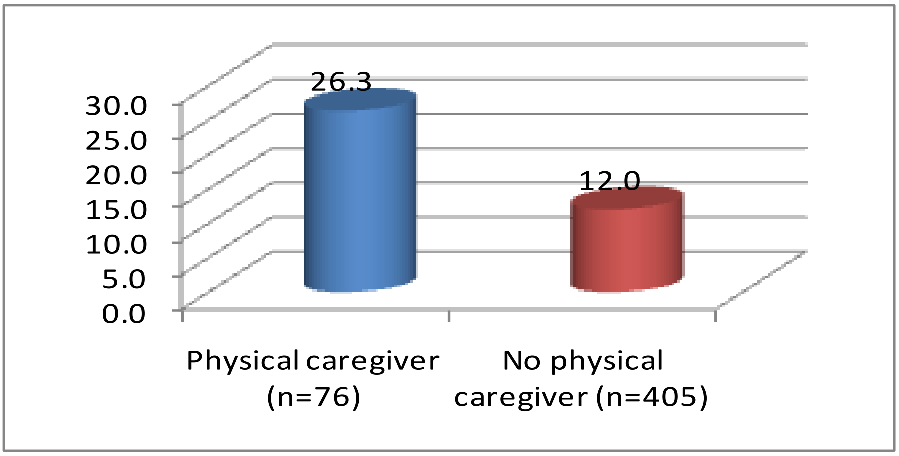
Note: Results are not statistically significant (chi2=3.47, p=0.323).

Past transitions in access to an emotional caregiver did not impact significantly on losing access to a treatment buddy. According to figure 5.13, losing access to a treatment buddy was highest among patients who did not have an emotional caregiver in either period (44%), which may be true if other forms of support are considered substitute. Patients who previously gained access to an emotional caregiver were more likely to lose access to a treatment buddy, which suggests that these are actually complements rather than substitutes, which may be the case if the same person acts as both treatment buddy and emotional supporter. Patients who previously lost an emotional caregiver were least likely to lose access to a treatment buddy, which suggests the use of these forms of support as complements.

5.3.2 (b) Past access to a physical caregiver

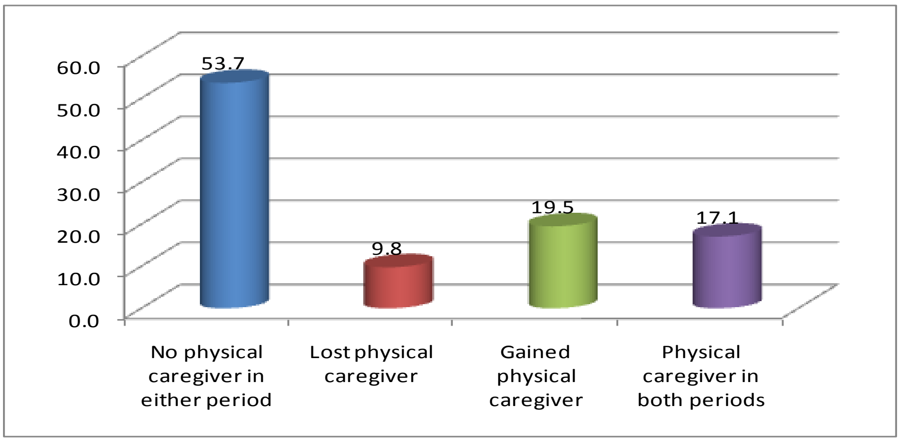
Previous access to a physical caregiver impacted significantly on losing a treatment buddy (p<0.01). Figure 5.14 shows that patients who previously had a physical caregiver were more likely to lose access to a treatment buddy (26%) compared to 12% of patients who did not have a physical caregiver in the past. These results were not expected but could imply that previously having a physical caregiver did not warranty a need for a treatment buddy in a current period. This is especially true when a physical caregiver also performs the duties of a treatment buddy.

Figure 5.14: Losing access to a treatment buddy, by past access to a physical caregiver



Note: Results are statistically significant at the 1% level (chi2=11.55, p=0.001).

Figure 5.15: Losing access to a treatment buddy, by past transitions in access to a physical caregiver (n=406)



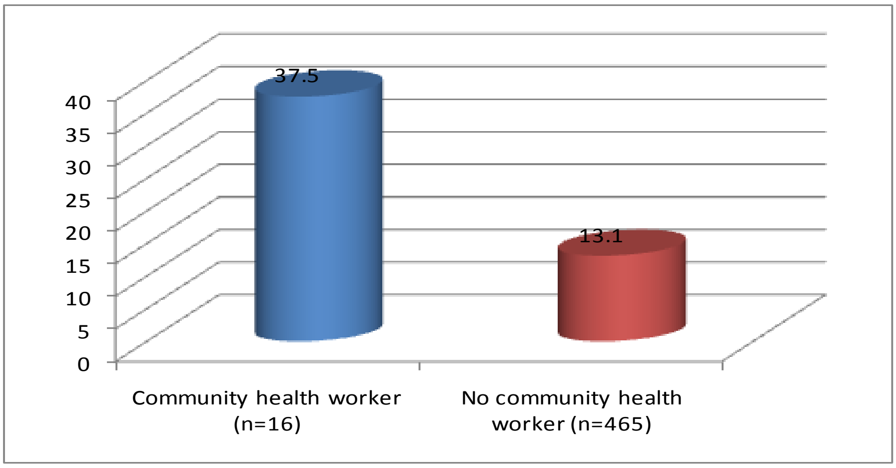
Note: Results are statistically significant at the 1% level (chi2=16.35, p=0.001).

Figure 5.15 indicates past transitions in access to a physical caregiver impacted significantly on losing access to a treatment buddy (p<0.01). A large proportion of patients who lost access to a treatment buddy did not have a physical caregiver in either period (54%). Approximately 20% of patients who in the past gained access to a physical caregiver, had lost access to a treatment buddy, which suggests that improved health status may have reduced the need for support. Patients who did not have a physical caregiver in both periods were more likely to lose access to treatment buddy because of improved health status which reduced the need for support.

5.3.2. (c) Past access to a community health worker

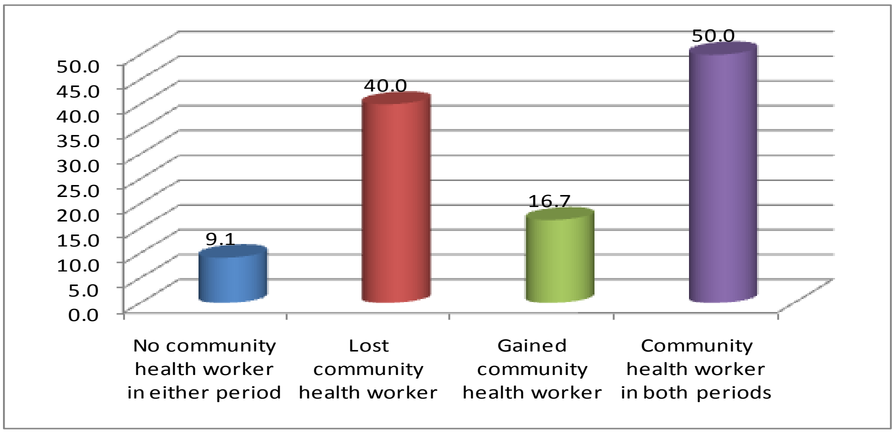
Figure 5.16 indicates that past access to a community health worker impacted significantly on losing access to a treatment buddy and (p<0.01). Patients who previously received visits from a community health worker were more likely to lose access to a treatment buddy. This is expected if a community health worker also provided adherence support. On the other hand, patients who previously did not have a community health worker were less likely to lose access to a treatment buddy, which suggests that these forms of support complement each other.

Figure 5.16: Losing access to a treatment buddy, by past access to a community health worker



Note: Results are statistically significant at the 1% level (chi2=7.66, p=0.006).

Figure 5.17: Losing access to a treatment buddy, by past transitions in access to a community health worker (n=406)



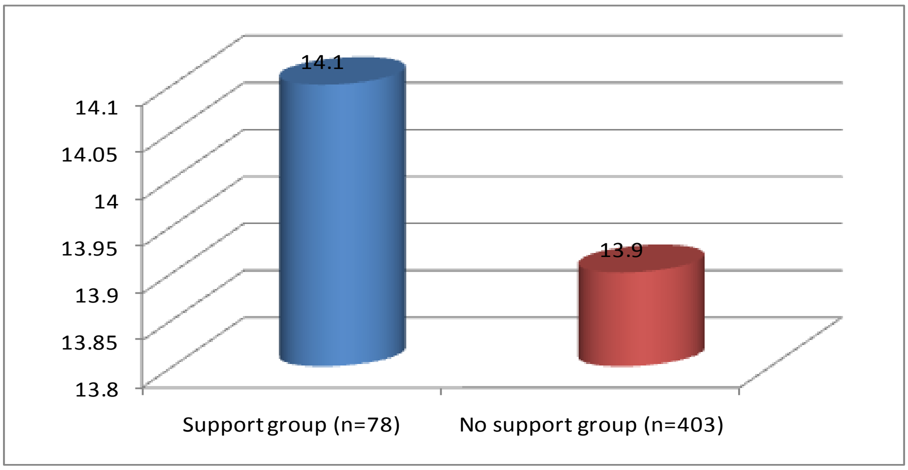
Note: Results are statistically significant at the 1% level (chi2=12.93, p=0.005).

Figure 5.17 indicates that transitions in access to a community health worker significantly impacted on losing access to a treatment buddy (p<0.01). The results reveal that losing a treatment buddy was higher among those who were visited by a community health worker in both periods. This finding is expected given that a community health worker may be performing all other duties including that of a treatment buddy. There is also a possibility that a community health worker is also a treatment buddy. The results indicating that previously losing a community health worker increases the probability of losing a treatment buddy because a same individual might be performing these duties.

5.3.2. (d) Past participation in a support group

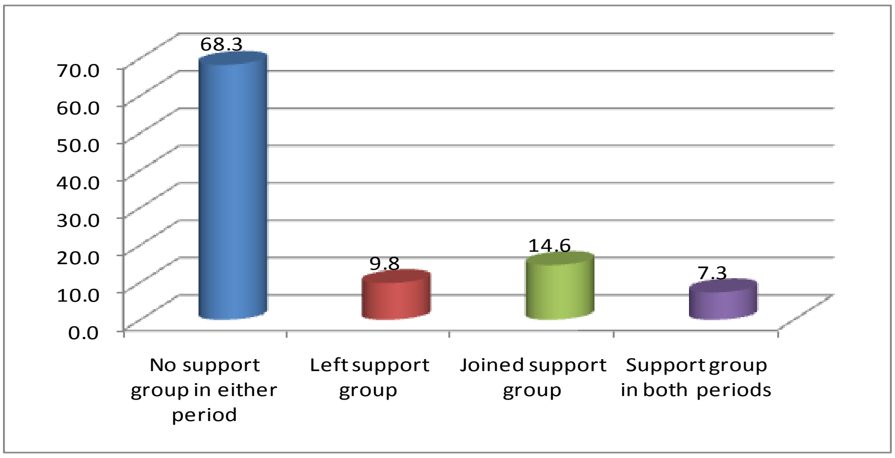
Figure 5.18 shows that past participation in a support group did not significantly impact on losing access to a treatment buddy. Patients who participated in support groups were more likely to lose access to a treatment buddy, which suggests that participation in support group in the past substituted for a treatment buddy because of the nature of support received in a support group. On the other hand, patients who did not have a support group were more likely to substitute for access to a treatment buddy.

Figure 5.18: Losing access to a treatment buddy, by past participation in a support group



Note: Results are not statistically significant (chi2=0.00, p=0.961).

Figure 5.19: Losing access to a treatment buddy, by past transitions in participation in a support group (n=406)



Note: Results are not statistically significant (chi2=3.60, p=0.308, chi2).

Past transitions in participation in a support group did not significantly impact on losing a treatment buddy. Patients who previously did not participate in a support group in either period were more likely to lose access to a treatment buddy, which could imply a reduced need for support due to improvements in health status. However, these results are not statistically significant.

5.3.3. Household size and losing access to a treatment buddy

Table 5.8 shows that there were significant differences in past household size between patient who have lost access to a treatment buddy and those with access to a treatment buddy in both periods ($p<0.05$).Patients who lost treatment buddies come from significantly larger households. On the contrary, patients who lost access to a treatment buddy were expected to come from smaller households and not the other way round.

Improvements in health status may have driven the patients to discontinue accessing support, irrespective of the household size.

Table 5.8: Past household size, by losing access to a treatment buddy

Losing acces to treatment buddy	Summary of past household size							
	Mean	*SD*	*p25*	*p75*	*Median*	*Min*	*Max*	*Frequency*
Access to a treatment buddy in both periods	3.83	2.19	2	5	4	1	13	12
Losing acces to a treatment buddy	4.55	2.55	3	6	4	1	14	67
Total	**3.94**	**2.26**	**2**	**5**	**4**	**1**	**14**	**479**

Note: Results are statistically significant at the 5% level (F=5.87, p=0.015).

Table 5.9: Past changes in household size, by losing access to a treatment buddy

Losing access to treatment buddy	Summary of past changes in household size							
	Mean	*SD*	*p25*	*p75*	*Median*	*Min*	*Max*	*Frequency*
Access to a treatment buddy in both periods	-0.03	1.64	0	0	0	-11	11	362
Losing acces to a treatment buddy	0.39	1.91	0	1	0	-4	8	441
Total	**0.00**	**1.67**	**0**	**0**	**0**	**-11**	**11**	**403**

Note: Results are not statistically significant (F=2.45, p=0.118).

Previously observed changes in household size did not impact significantly on losing access to a treatment buddy in the recent past. On the contrary, these results were not expected; rather the expectation was that patients who lost access to a treatment buddy would be from smaller households. These results are however not statistically significant.

5.3.4. Determinants of losing access to a treatment buddy

Table 5.10 provides regression results of the determinants of losing a treatment buddy. The reported results are for the random effects model and the models performed adequately in terms of overall goodness-of-fit ($p<0.05$). The first column presents results of a regression where EQ-VAS was included in the model as a measure of health-related quality of life, while the next column on the right provides results of the regression, where EQ-5D was used as measure of health-related quality of life.

Table 5.10: Past need and access to support as determinants of losing a treatment buddy

Independent variables	**Odds ratio**		**Odds ratio**	
	EQ-VAS		**EQ-5D**	
1. Sociodemographic variables				
Age	0.662	*	0.663	*
Age2	1.004	*	1.004	*
Female (*male=0/female=1*)	0.959		0.972	
Marital status				
[comparison group=single]				
Living with partner	2.678	*	0.465	
Not living with partner	1.328		0.398	
Educational status				
[comparison group=no formal education]				
Primary education	4.661		5.783	
Secondary education	3.019		3.854	
Grade 12	8.135		11.049	
Tertiary education	15.268		17.300	
2. Need variables				
Treatment career				
[comparison group=0-6months]				
6-12months	6.814	***	6.134	***
18-30months	3.139	**	3.375	**
30-42months(omitted)				
Past level of health related quality of life (EQ-5D)	8.235			
Past level of health related quality of life (EQ-VAS)			1.010	
3. Access to support variables				
Past access to emotional carer	0.390	**	0.386	**
Past access to physical carer	1.637		1.690	
Past access to CHW	7.975	**	9.224	**
Past participation in support groups	0.909		0.859	
Past household size	1.195	*	1.192	*
Sample size	*462 (150)*		*463 (150)*	
Wald chi2 (P)	*31.25 (p=0.018)*		*31.62 (p=0.016)*	
H_0: pooled model vs. Ha: RE (LR test)	*6.05 (p=0.007)*		*6.64 (p=0.005)*	
Note: Results are for Random Effects regression model, FE could not be estimated.				
**** significant at 1% level; ** significant at 5% level; *significant at 10% level*				

Age in years has an odds ratio of 0.66 and is significant at the 10% level. This result denotes that for each increase in age of one year, the odds of losing a treatment buddy decrease by 95%, indicating that older patients were less likely to lose access to treatment buddy. Age square has an odds ratio of 1.004 and is significant at the 10% level. The results moreover suggest that younger patients and older ones are more likely to lose a buddy, while those in the middle are less likely to have reported not having a buddy. Living with a partner was significant at 10% level with the odds ratio of 2.67. This means that patients who cohabited were 2.6 times more likely to lose a treatment buddy than single patients. These results are, however, unexpected, as it would be expected that patients living with partners would be less likely to lose access to treatment buddy.

The 6-12 months variable is significant at the 10% level, with odds ratios of 6.81 and 6.13, respectively. Therefore, patients who had been on treatment for 6-12 months are between 6 and 7 times more likely to lose a treatment buddy compared to those in the first phase of the treatment career. The 18-30 months variable is significant at 5% level with the odds ratios of 3.13 and 3.37; therefore, patients who had been on treatment for 18-30 months are 3 times more likely to lose a treatment buddy compared to those in the first phase of the treatment career. An increase probability of losing a treatment buddy as months on treatment increase is expected, because the general expectation is that health status improves as months on treatment increase.

Past access to an emotional caregiver was significant at the 1% level with an odds ratio of approximately 0.39. The results for patients who previously had access to an emotional caregiver, indicate that the odds of losing access to a treatment buddy decrease by 86%. This finding is true if the person providing emotional support is the same person providing treatment support. Past access to a community health worker was significant at the 5% level with odds ratios of 7.97 and 9.22. This denotes that patients who previously had access to a community health worker are between 8 and 9 times more likely to lose a treatment buddy. This result could be expected if a community health worker performed similar duties to a treatment buddy, which would be expected to increase the odds of losing a treatment buddy. Past household size was significant at 1% level with the odds ratio of 1.19. Hence, for each increase in past household size of 1 member, the odds of losing a treatment buddy increase by approximately 19%. This result on household size is rather unexpected; one would expect the odds of losing a treatment buddy to decrease as household size increases.

Table 5.11: Past changes in need and access to support as determinants of losing a treatment buddy

Independent variables	**Odds ratio**			**Odds ratio**	
	EQ-VAS			**EQ-5D**	
1. Sociodemographic variables					
Age	0.725	**		0.708	**
Age2	1.003	*		1.003	**
Female (*male=0/female=1)*	0.845			0.869	
Marital status					
[comparison group=single]					
Living with partner	1.054			1.051	
Not living with partner	0.999			0.973	
Educational status					
[comparison group=no formal education]					
Primary education	2.200			2.391	
Secondary education	1.639			1.743	
Grade 12	3.319			3.934	
Tertiary education	5.545			5.135	
2. Need variables					
Treatment career					
[comparison group=0-6months]					
6-12months(omitted)					
18-30months	2.184	*		2.529	**
30-42months(omitted)					
Past changes in the level of health related quality of life	8.228	*			
Past changes in the level of health related quality of life (EQ-VAS)				1.005	
3. Access to support variables					
Past transitions in access to emotional carer					
[comparison group=no emotional carer in either period]					
Lost emotional carer	0.682			0.613	
Gained emotional carer	1.262			1.118	
Had emotional carer in both periods	0.237	**		0.181	**
Past transitions in access to physical carer					
[comparison group=no physical carer in either period]					
Lost physical carer	2.135			2.514	
Gained physical carer	2.538	*		2.329	
Had physical carer in both periods	3.870	**		4.285	**
Past transitions in access to community health worker					
[comparison group=no community health worker in either period]					
Lost community health worker	9.966	**		9.394	**
Gained community health worker	1.608			1.843	
Had community health worker in both periods	6.471			7.887	*
Past transitions in participation in support groups					
[comparison group=no participation in either period]					
Stopped participating	1.917			1.806	
Started participating	2.837	*		2.364	
Participated in both periods	0.733			0.873	
Past changes in household size	1.137			1.134	
Sample size	*384*			*386*	
Wald chi2 (p)	*32.09 (p=0.124)*			*16.46 (p=0.870)*	
LR chi2 (p)	*40.79 (p=0.017)*			*46.90 (p=0.003)*	
H_0: pooled model vs. Ha: RE (LR test)	*16.15 (p<0.001)*			*13.88 (p<0.001)*	
Note: FE could not be estimated, results are for Pooled regression model, RE was not appropriate in terms of overall fit.					
**** significant at 1% level; ** significant at 5% level; *significant at 10% level*					

The reported results in Table 5.11, are for the pooled model, which performed adequately in terms of overall fit (p<0.05). Although the random effects model was the better model, the random effects model did not perform adequately in terms of overall goodness-of-fit (p>0.10). In regression models, the first column presents results of a regression, where EQ-VAS was included in the model as the measure of health-related quality of life, whereas the column on the right provides results of the regression, where EQ-5D was used as the measure of health-related quality of life.

Table 5.11 shows the results of socio-demographic variables, past changes in need and past transitions in access to other support as determinants of losing access to a treatment buddy, unlike in Table 5.10, where the focus was on how past levels of household size and access to other support impacted on transitions in access to a treatment buddy. Age has an odds ratio of 0.72 and 0.70 respectively and is significant at the 5% level. The results denote that for each increase in age of one year, the odds of losing a treatment buddy decrease by 90% and 92% respectively, which means that older patients were less likely to lose access to a treatment buddy.

Age square has an odds ratio of 1.003 and is significant at the 10% level. The results moreover suggest, that younger and older patients are more likely to lose a treatment buddy, while those in the middle are less likely to have reported not having a buddy. The 18-30 months variable is significant at the 1% and 5% level respectively, with the odds ratios of 2.18 and .2.52; hence, patients who have been on treatment for 18 to 30 months were between 2 times and 2.5 times more likely to lose access to treatment buddy compared to patients in the first phase of treatment career. An increase probability of losing a treatment buddy as months on treatment increase is expected because the general expectation is that health status improves as months on treatment increase.

Past changes in the level of health-related quality of life, as measured by EQ-5D, were significant at the 5% level, with the odds ratio of 8.22. This denotes that for each increase in health-related quality of life by 0.01, the odds of losing a treatment buddy increases by 8.2%. This result is expected given prior results on the impact of health-related quality of life on access to a treatment buddy.

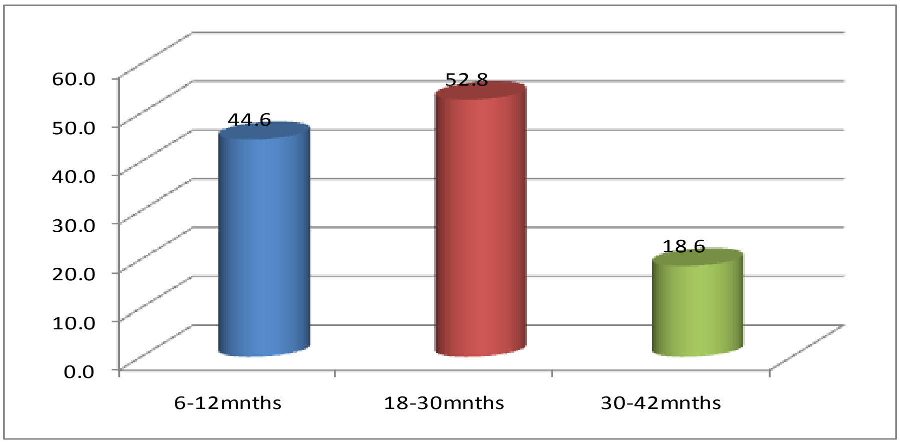
Past transitions in access to an emotional caregiver were significant at the 5% level, in predicting the likelihood of losing a treatment buddy, with odds ratios of 0.23 and 0.18 respectively for the 'past access to an emotional caregiver in both periods' outcome. The odds of losing a treatment buddy decreased by 94% and 97% respectively among patients who previously had access to emotional caregivers in both periods, compared to patients who did not have access to an emotional caregiver in either period. These results are similar to that of earlier analyses. This finding suggests the possibility that an emotional caregiver could have been the same person as treatment buddy. Where EQ-VAS was included in the model, previous access to a physical caregiver was significant at the 10% level. The odds ratio for 'gained access to a physical caregiver' of 2.53 means that patients, who in the past gained access to a physical caregiver, were 2.5 times more likely than those without a physical caregiver in both periods, to have lost access to a treatment buddy. Further, variables "had a physical caregiver in both periods" are significant at the 5% level with odds ratios of 3.87 and 4.28 respectively. Therefore, patients who had physical caregivers in both periods were between 3.8 and 4.2 times more likely to have lost access to a treatment buddy. This may suggest that for these patients, access to physical care may be a priority and therefore physical caregivers are expected to provide physical and adherence support, hence losing access to treatment buddy.

Having lost access to a community health worker was significant at the 5% level, with odds ratios of 9.96 and 9.39 respectively, which means that patients who lost access to a community health worker in the previous period were 9 to 10 times more likely to have lost access to a treatment buddy, compared to patients never visited by a community health worker. This suggests that community health workers may have been treatment buddies as well. Where EQ-5D was included in the regression, having access to a community health worker in both periods was significant at the 10% level, with an odds ratio of 7.88, which means that patients who previously had access to a community health worker in both periods were 7.8 times more likely to have lost access to a treatment buddy, compared to patients never visited by a community health worker. This could be due to the possibility that community health workers may have also provided adherence support, hence reducing the need for a treatment buddy. Joining a support group in a previous period was significant at the 10% level in predicting losing access to a treatment buddy. The odds ratio of 2.83 denotes that patients who joined a support group in the previous period were 2.8 times more likely to lose access to a treatment buddy. This could suggest that the support group was a substitute for a treatment buddy.

5.4. Gaining access to a treatment buddy

Gaining access to a treatment buddy varied significantly by treatment career phase. Figure 5.20 show that a relatively large proportion of patients gained access to a treatment buddy between the first and second phases (44%) and the second and third phases (52%) of the treatment career. Only a small proportion of patients gained access to a treatment buddy between the third and fourth phases of the treatment career (18%). A decline in the number of patients gaining access to a treatment buddy could be an indication of improvements in patient's health status. A small proportion of patients gaining a treatment buddy at the fourth phase is expected, because an increase in the number of months on treatment is associated with a reduced need for treatment buddy support.

Figure 5.20: Gaining access to a treatment buddy, by treatment career phase (n=300)



Note: Results are statistically significant at the 1% level (chi2=30.73, p<0.001).

5.4.1. Need and gaining access to a treatment buddy

Table 5.12 indicates that past levels of health-related quality of life (for both the EQ-VAS and EQ-5D measures) did not impact significantly on gaining access to a treatment buddy. However, in both cases, past levels of health-related quality of life were lower among patients who gained access to a treatment buddy. In other words, patients with a lower health status were more likely to have gained access to a treatment buddy and this makes sense, because low health status implies greater need and hence gaining a buddy is expected.

Table 5.12: Past level of health-related quality of life, by gaining access to a treatment buddy

Gaining access to treatment buddy	**Summary of past health related quality of life (EQ-VAS)**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
No acces to a treatment buddy in either period	72.62	18.65	60	90	70	30	100	198
Gaining acces to a treatment buddy	69.42	19.70	60	80	70	20	100	102
Total	**71.53**	**19.04**	**60**	**90**	**70**	**20**	**100**	**300**
Gaining access to treatment buddy	**Summary of past health related quality of life (EQ-5D)**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
No acces to a treatment buddy in either period	0.87	0.24	0.84	1	1	-0.00	1	198
Gaining acces to a treatment buddy	0.84	0.21	0.76	1	1	-0.18	1	102
Total	**0.86**	**0.23**	**0.79**	**1**	**1**	**-0.18**	**1**	**300**

Note: EQ-VAS: results are not statistically significant (F=1.91, p=0.168). EQ-5D: results are not statistically significant (F=1.54, p=0.215).

Table 5.13: Past changes in the level of health-related quality of life, by gaining access to a treatment buddy

Gaining access to treatment buddy	**Summary of past changes in health-related quality of life (EQ-VAS)**							
	Mean	*SD*	*p25*	*p75*	*Median*	*Min*	*Max*	*Frequency*
No acces to a treatment buddy in either period	1.57	20.01	-10	10	0	-60	65	152
Gaining acces to a treatment buddy	-3.03	21.14	-10	10	0	-60	50	65
Total	**1.89**	**20.41**	**-10**	**10**	**0**	**-60**	**65**	**217**

Gaining access to treatment buddy	**Summary of past changes in health-related quality of life (EQ-5D)**							
	Mean	*SD*	*p25*	*p75*	*Median*	*Min*	*Max*	*Frequency*
No acces to a treatment buddy in either period	0.01	0.21	0	0	0	-0.82	0.80	152
Gaining acces to a treatment buddy	-0.08	0.25	-0.15	0	0	-1.18	0.34	65
Total	**-0.01**	**0.23**	**0**	**0**	**0**	**-1.18**	**0.8**	**217**

Note: EQ-VAS: results are not statistically significant (F=2.32, p=0.128). EQ-5D: results are statistically significant at the 1% level (F=9.14, p=0.002).

Past changes in the level of health-related quality of life (as measured by EQ-5D) impacted significantly on the chances of gaining access to a treatment buddy($p<0.05$). Table 5.13 reports that patients who reported a past decline in health-related quality of life were more likely to gain access to a treatment buddy, compared to those with no access to a treatment buddy in either period. The same was true for comparisons in EQ-VAS, although the differences in health status across patients who gained access to a treatment buddy and those who did not have a treatment buddy in this case, were not statistically significant ($p>0.10$). The results are as expected, because it would be expected that patients whose health status deteriorated would need support and hence gain access to a treatment buddy.

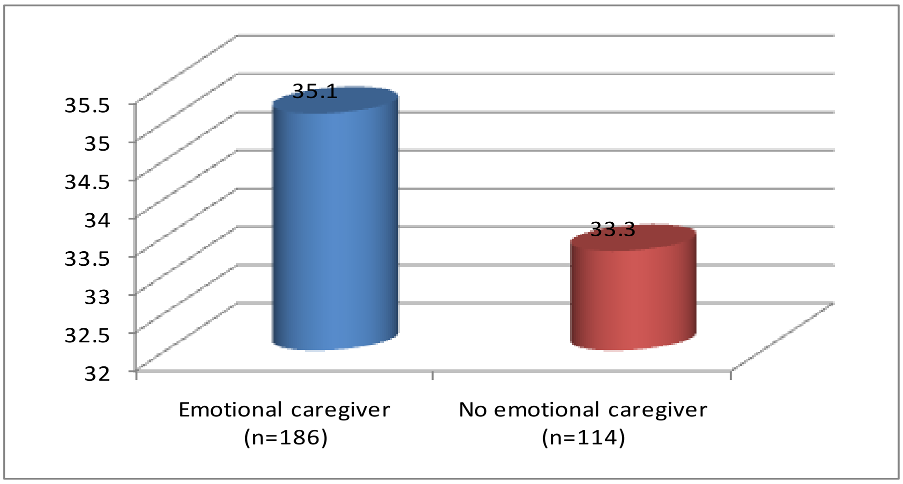
5.4.2. Gaining access to a treatment buddy and past access to other support

This section assesses how previous access to other support impacted on gaining access to a treatment buddy over time: the focus shifts from access to an emotional or physical caregiver, to access to a community health worker or support group, followed by an analysis on how household size, a proxy of the supply of informal support, may impact on transitions in access to a treatment buddy.

5.4.2. (a) Past access to an emotional caregiver

Figure 5.21 indicates that past access to an emotional caregiver did not significantly impact on gaining access to a treatment buddy. Gaining access to a treatment buddy was however, higher among patients who previously had access to an emotional caregiver, which is expected if is the same person is fulfilling the duties as emotional caregiver and treatment buddy. These forms of support are used simultaneously which imply that these forms of support rather complement each other.

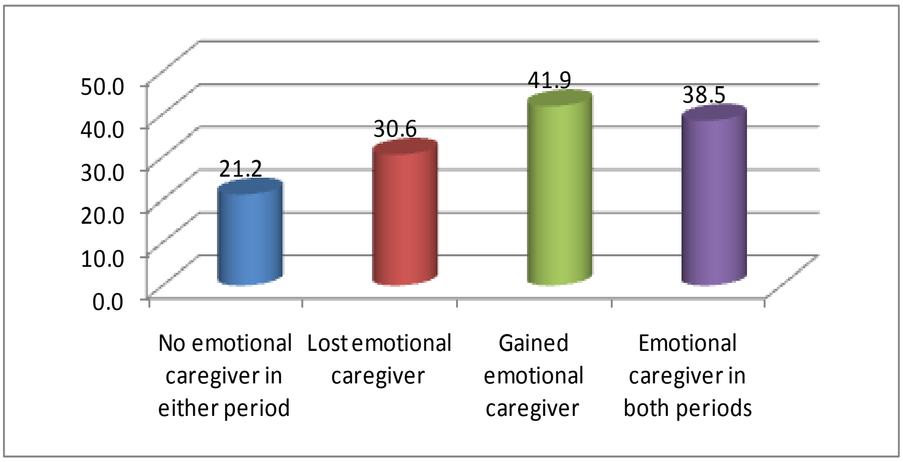
Figure 5.21: Gaining access to a treatment buddy, by past access to an emotional caregiver



Note: Results are not statistically significant (chi2=0.09, p=0.756).

Figure 5.21 indicates that past access to an emotional caregiver did not significantly impact on gaining access to a treatment buddy. Gaining access to a treatment buddy was however, higher among patients who previously had access to an emotional caregiver, which is expected if the same person is fulfilling the duties as emotional caregiver and treatment buddy. These forms of support are used simultaneously which imply that these forms of support rather complement each other.

Figure 5.22: Gaining access to a treatment buddy, by past transitions in access to an emotional caregiver (n=217)



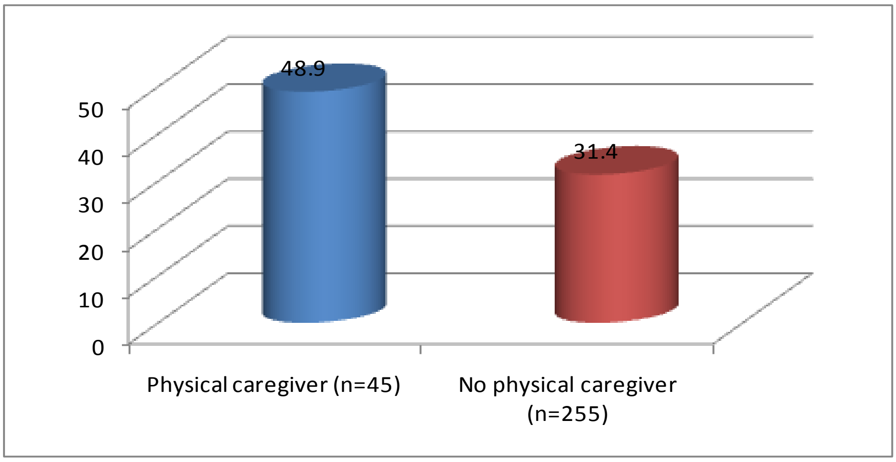
Note: Results are statistically significant at the 5% level (chi2=7.86, p=0.049).

Figure 5.22 reflects an upward trend in the extent to which past transitions in access to an emotional caregiver impacted on the chances of gaining access to a treatment buddy. Gaining access to a treatment buddy was highest among patients who in the past gained access to an emotional caregiver, which may suggest that an emotional caregiver and a treatment buddy, are actually the same person. In addition, patients who previously had an emotional caregiver in both periods were more likely to gain access to a treatment buddy, which suggests that these forms of support complement each other. This may imply that the same person is fulfilling the duties of both the treatment buddy and an emotional caregiver.

5.4.2. (b) Past access to a physical caregiver

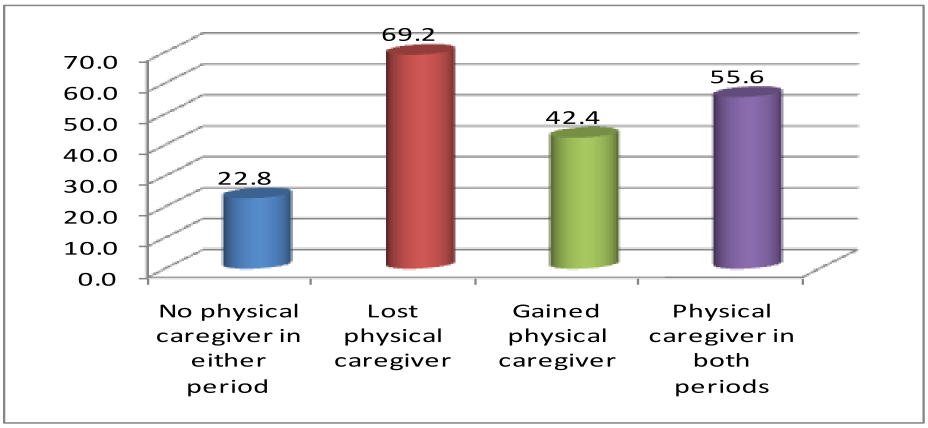
Past access to a physical caregiver significantly impacted on gaining access to a treatment buddy ($p<0.05$). Figure 5.23 reveals that patient who previously had access to a physical caregiver, gained access to a treatment buddy. This finding could also be true if a physical caregiver is the same person as a treatment buddy. Further, patients who previously did not have access to a physical caregiver were less likely to gain access to a treatment buddy.

Figure 5.23: Gaining access to a treatment buddy, by past access to a physical caregiver



Note: Results are statistically significant at 5% level (chi2=5.22, p=0.022).

Figure 5.24: Gaining access to a treatment buddy, by past transitions in access to a physical caregiver (n=217)



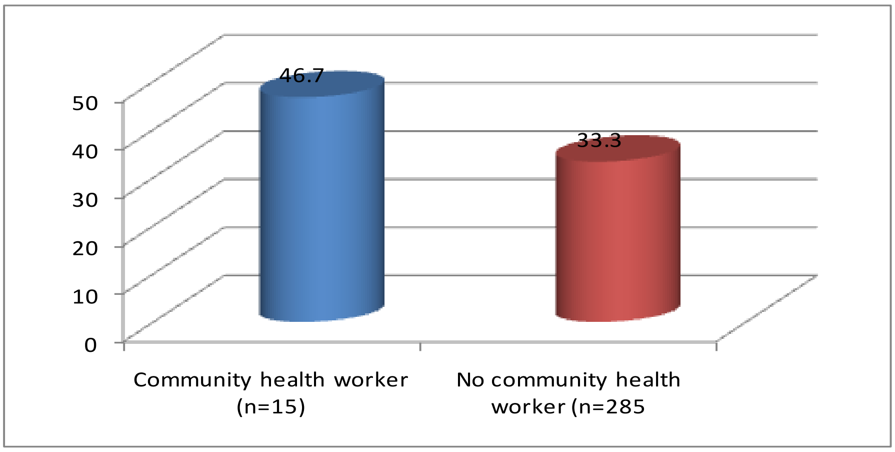
Note: Results are statistically significant at 1% level (chi2=18.72, p<0.001).

Past transitions in access to a physical caregiver impacted significantly on gained access to a treatment buddy (p<0.001). Patients, who previously lost access to a physical caregiver, were more likely to gain access to a treatment buddy, which suggest that these forms of support complement each other. Moreover, patients who previously had a physical caregiver in both periods were also more likely to gain access to a treatment buddy, which is expected when the same person is fulfilling the duties as physical caregiver and a treatment buddy.

5.4.2. (c) Past access to a community health worker

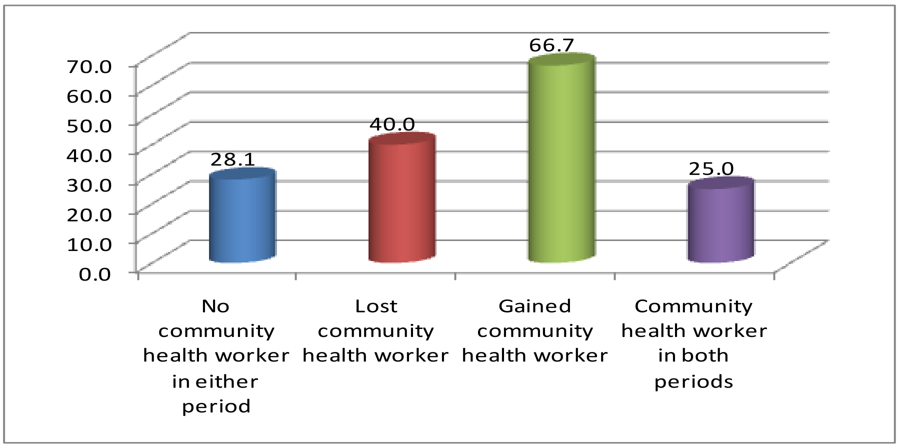
Past access to a community health worker did not significantly impact on subsequent gains in access to a treatment buddy. Gaining access to a treatment buddy was highest among patients who previously had access to a community health worker (Figure 5.25). One possible explanation for this finding is that a community health worker in this case could be the same person as the treatment buddy, suggesting that the two forms of support complement each other.

Figure 5.25: Gaining access to a treatment buddy, by past access to a community health worker



Note: Results are not statistically significant (chi2=1.12, p=0.288).

Figure 5.26: Gaining access to a treatment buddy, by past transitions in access to a community health worker (n=217)



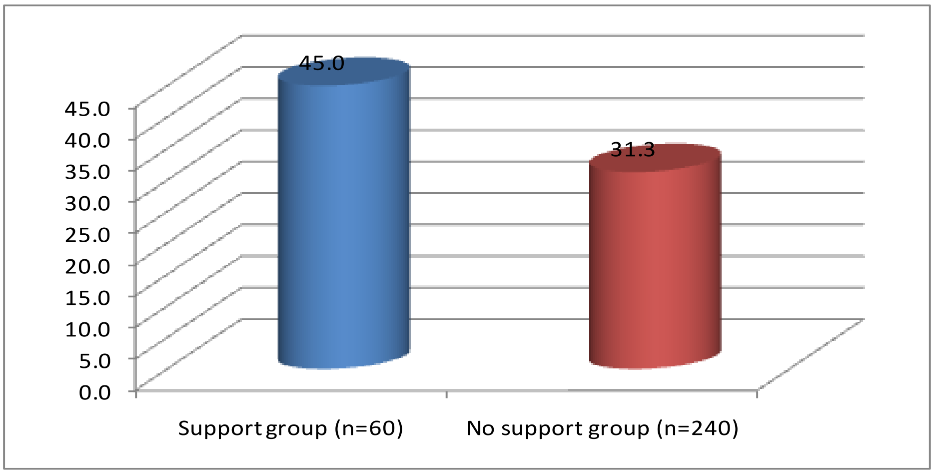
Note: Results are statistically significant at 10% level (chi2=6.38, p=0.094).

Past transitions in access to a community health worker significantly, but weakly impacted on gaining access to a treatment buddy in a current period (p<0.10). Gaining a treatment buddy was highest among patients who previously had gained visits from a community health worker (67%), which implies that having a community health worker in the past, may have been instrumental in increasing the probability of gaining a treatment buddy. Previously losing a community health worker increased the chance of gaining access to a treatment buddy in a current period, which suggests that these forms of support complement each other.

5.4.2. (d) Past participation in a support group

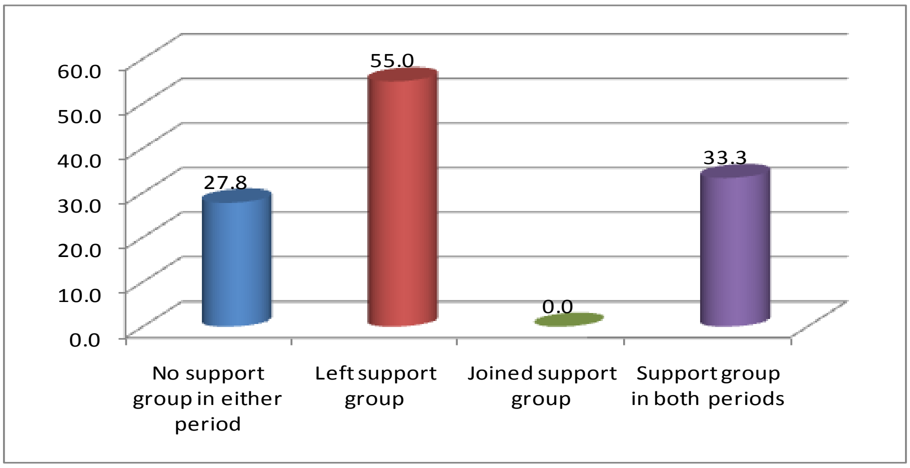
Figure 5.27 indicates that past membership of a support group was significantly associated with subsequent gains in access to a treatment buddy (p<0.05). A large proportion of patients who gained access to a treatment buddy previously participated in a support group. Participating in support groups could have increased access to different forms of support, hence in this case, gaining access to a treatment buddy.

Figure 5.27: Gaining access to a treatment buddy, by past participation in a support group



Note: Results are statistically significant at 5% level (chi2=4.04, p=0.044).

Figure 5.28: Gaining access to treatment buddy, by past transitions in participation in a support group (n=217)



Note: Results are statistically significant at 5% level (chi2=9.91, p=0.019).

Past transitions in participation in a support group had a significant impact on gaining access to a treatment buddy ($p<0.05$). A large proportion of patients who previously discontinued participating in a support group, gained access to a treatment buddy. This result indicates that these two forms of support substitute each other. Patients who previously participated in a support group in both periods, gained access to a treatment buddy, suggesting that these two forms of support complement, rather than substitute, each other. It is also expected that participating in a support group would increase the likelihood of having support, in particular, a treatment buddy through support group members.

5.4.3. Household size and gaining access to a treatment buddy

Table 5.14 indicates that, past levels of household did not significantly impact on gaining access to a treatment buddy. Patients who gained access to a treatment buddy previously had smaller households. On the contrary, patients, who had no access to a treatment buddy in either period, had a larger household size. This result was not expected as one would expect that an increase in household size would increase the likelihood of having a treatment buddy.

Table 5.14: Past household size, by gaining access to a treatment buddy

Gaining acces to treatment buddy	**Summary of past household size**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
No acces to a treatment buddy in either period	4.33	1.92	3	6	4	1	10	198
Gaining acces to a treatment buddy	4.08	1.95	3	5	4	1	14	101
Total	**4.25**	**1.93**	**3**	**5**	**4**	**1**	**14**	**299**

Note: Results are not statistically significant (F=1.16, p=0.281).

Table 5.15 shows that past changes in household size similarly did not impact significantly on gaining access to a treatment buddy. Patients that gained access to a treatment buddy, as expected, were from larger households compared to those with no access to a treatment buddy in either period, as they were from smaller households. This is an expected result, given that buddies often live in the same household as patients, so one would expect increases in household size to increase the likelihood of gaining a treatment buddy.

Table 5.15: Past changes in household size, by gaining access to a treatment buddy

Gaining access to treatment buddy	**Summary of past changes in household size**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
No acces to a treatment buddy in either period	-0.11	1.29	0	0	0	-5	6	152
Gaining acces to a treatment buddy	0.07	2.15	0	1	0	-8	8	64
Total	**-0.06**	**1.59**	**0**	**0**	**0**	**-8**	**8**	**216**

Note: Results are not statistically significant (F=0.69, p=0.407).

5.4.4. Determinants of gaining a treatment buddy

Table 5.16 provides the results of a pooled regression model on the past levels of need and access to other support as determinants of gaining access to a treatment buddy. The model performed adequately in terms of goodness-of-fit (p<0.001). Results are presented separately for two measures of health related quality of life, namely EQ-VAS and EQ-5D.

Table 5.16: Past levels of need and access to support as determinants of gaining a treatment buddy

Independent variables	**Odds ratio**		**Odds ratio**	
	EQ-VAS		**EQ-5D**	
1. Sociodemographic variables				
Age	0.962		0.947	
Age2	1.000		1.000	
Female (*male=0/female=1)*	0.761		0.812	
Marital status				
[comparison group=single]				
Living with partner	0.487		0.520	*
Not living with partner	0.705	*	0.679	
Educational status				
[comparison group=no formal education]				
Primary education	0.365		0.423	
Secondary education	0.757		0.854	
Grade 12	0.186	**	0.198	*
Tertiary education	0.470		0.451	
2. Need variables				
Treatment career				
[comparison group=0-6months]				
6-12months	4.416	***	4.399	***
18-30months	7.007	***	7.004	***
30-42months(omitted)				
Past level of health related quality of life (EQ-VAS)	0.986	*		
Past level of health related quality of life (EQ-5D)			0.498	
3. Access to support variables				
Past access to emotional carer	0.789		0.752	
Past access to physical carer	1.643		1.578	
Past access to CHW	1.683		1.659	
Past participation in support groups	2.227	**	2.111	**
Past household size	0.919		0.910	
Sample size	*293*		*293*	
LR chi2 (p)	*69.18 (<0.001)*		*67.36 (p<0.001)*	
$H_{0:}$ pooled model vs. Ha: RE (LR test)	*3.45 (p=0.498)*		*7.06 (p=0.499)*	
Ho: RE vs. Ha: FE (Hausman test)	*2.60 (p=0.919)*		*2.60 (p=0.974)*	
Note: Results are for Pooled regression model.				
**** significant at 1% level; ** significant at 5% level; *significant at 10% level*				

Living with a partner has an odds ratio of 0.48 and is significant at the 10% level in the model that employed EQ-VAS as measure of health-related quality of life. This means that patients living with their partner are 4.8 times more likely to have gained a treatment buddy compared to single patients.

In the results for the EQ-5D mode, those patients not living with their partner in turn were 3.4 times more likely to have gained a treatment buddy compared to single patients (p<0.10). These findings are expected given that patients with partners would be more likely to gain access to treatment buddy than single patients. These results are similar to the ones discussed earlier where the majority of treatment buddies were patients" partners. When comparing patients with partners, the results indicate that the side effects of cohabitation are weightier than on non-cohabitation, meaning that the odds of gaining a treatment buddy were higher among patients who cohabited with their partners compared to those who did not cohabit, again highlighting the probability that partners are more likely to provide support as treatment buddies.

Having grade12 was significant at the 1% and 5% respectively with odds ratios of 0.18 and 0.19. Hence, patients with grade 12 were 94% and 91% less likely to gain access to a treatment buddy, respectively compared to patients with no formal education. This finding could suggest that patients with no education would be more likely to need adherence support, hence gaining access to treatment buddy, while for patients with grade, 12 the need for adherence support may decrease due to their educational status.

The 18-30months variable is significant at the 1% level, with odds ratios of 0.14 respectively. Therefore, the odds of gaining access to a treatment buddy decreased by 90% for patients who had been on treatment for 18 to 30 months, compared to patients who had been on treatment for 0-6 months correspondingly. This result is expected as earlier analysis also revealed the same decline in access to treatment buddy as treatment duration increases, which is possibly explained by improvements in health status over the treatment career.

Past level of health-related quality of life as measured by EQ-VAS is significant at the 10% level with the odds ratio of 0.98. This means that past increases in the level of health-related quality of life decreased the odds of gaining access to a treatment buddy. This result means that patients who experienced improved health status were less likely to gain access to a treatment buddy, which is expected, especially given earlier results that consistently linked poor health status with increased access to treatment buddy and vice versa.

Past participation in a support group was significant at the 5% level, with odds ratios is 2.11 and 2.22. This means that patients who previously participated in a support group were twice as likely to gain access to a treatment buddy compared to patients who did not participate in a support group in either period. There are two possible explanations for this result. Firstly, this could suggest that members of the support groups become the patient's treatment buddy and secondly, the two forms of support complement rather than substitute each other.

Table 5.17 reports the results of the poled regression model, which performed adequately in terms of overall fit ($p<0.001$). The reported results, unlike in Table 5.16, are for past changes in need and transitions in access to other support as determinants of gaining access to a treatment buddy.

The '18-30 months' variable is significant at the 1% level, with an odds ratio of 6.52 and 6.32, respectively. Hence, patients who have been on treatment for 18-30 months are 6 times more likely to gain access to a treatment buddy. This result is rather unexpected, since the previous analysis indicated the complete opposite. Gaining access to a treatment buddy would be expected to decline among patients who have been on treatment for a longer duration. Past changes in the level of health-related quality of life, as measured by EQ-5D, was significant at the 5% level. The 1.04 odds ratio denotes that a past decline of 0.01 units in health status is associated with an increase in the odds of gaining access to a treatment buddy. A need for support among patients experiencing a decline in health status would drive patients to gain access to a treatment buddy.

Past transitions in access to a physical caregiver was significant at the 10% level in predicting gaining a treatment buddy. The odds ratio of 4.73 means that losing access to a physical caregiver in the previous period increased the odds of subsequently gaining access to a treatment buddy by 4.7 times. An improvement in physical functioning may be the reason for a decline in the proportion of patients who have access to a physical caregiver and the need for adherence could explain increased odds of gaining a treatment buddy. Gaining access to a community health worker in the past similarly increased the odds of subsequently gaining access to a treatment buddy by significant margins. In this case, patients who in the past gained access to a community health worker were 6.2 and 6.4 times more likely, respectively, to gain a treatment buddy. This result would be expected, as community health workers perform similar duties to treatment buddies.

Table 5.17: Past changes in need and access to support as determinants of gaining a treatment buddy

Independent variables	**Odds ratio**		**Odds ratio**	
	EQ-VAS		**EQ-5D**	
1. Sociodemographic variables				
Age	1.079		1.062	
Age2	0.999		0.999	
Female (*male=0/female=1*)	1.558		1.751	
Marital status				
[comparison group=single]				
Living with partner	0.915		1.077	
Not living with partner	0.608		0.627	
Educational status				
[comparison group=no formal education]				
Primary education	0.196		0.237	
Secondary education	0.555		0.775	
Grade 12	0.194		0.247	
Tertiary education	0.195		0.188	
2. Need variables				
Treatment career				
[comparison group=0-6months]				
6-12months(omitted)				
18-30months	6.522	***	6.328	***
30-42months(omitted)				
Past changes in the level of health related quality of life (EQ-VAS)	0.985			
Past changes in the level of health related quality of life (EQ-5D)			0.104	**
3. Access to support variables				
Past transitions in access to emotional carer				
[comparison group=no emotional carer in either period]				
Lost emotional carer	1.240		1.141	
Gained emotional carer	1.870		1.858	
Had emotional carer in both periods	1.614		1.730	
Past transitions in access to physical carer				
[comparison group=no physical carer in either period]				
Lost physical carer	4.736	*	3.814	
Gained physical carer	1.443		1.179	
Had physical carer in both periods	2.662		2.704	
Past transitions in access to community health worker				
[comparison group=no community health worker in either period]				
Lost community health worker	0.258		0.325	
Gained community health worker	6.273	**	6.455	**
Had community health worker in both periods	1.186		1.238	
Past transitions in participation in support groups				
[comparison group=no participation in either period]				
Stopped participating	2.392		2.173	
Started participating(omitted)				
Participated in both periods	1.217		1.245	
Past changes in household size	1.017		1.019	
Sample size	*202*		*202*	
LR chi2 (p)	*66.39 (p<0.001)*		*70.59 (p<0.001)*	
H_0: pooled model vs. Ha: RE (LR test)	*1.105 (p=0.499)*		*7.306 (p=0.499)*	
Note: Results are for the Pooled regression model, FE could not be estimated.				
**** significant at 1% level; ** significant at 5% level; *significant at 10% level*				

5.5. Summary

This chapter reveals that access to a treatment buddy and other forms of support declined as treatment duration increased. However, a significant decline over the treatment career phase was only on access to informal, individualized support (such as a treatment buddy and emotional and physical caregivers). Access to more formal support (community health workers) and group-based support (support groups) did not differ significantly over the treatment career phase. In chapter 2, an argument was put forward to consider the inclusion of community level support when discussing the convoy model of social support. This was based on the argument that the presence of informal support (mostly family members) does not always guarantee access to support, hence highlighting the need for the involvement of informal support mechanisms. Findings in this chapter confirm the argument that informal or individualized support may not always be available.

There are two possible explanations for the decline in access to support over the treatment career phase. Firstly, a decline in access to support, including a treatment buddy, could be due to improvements in patients' health status. This has some implications for a treatment buddy strategy in the long-term (its existence and effectiveness in a long-term). A reduced need for treatment buddy support, over a period of time, is driven by changes in patients' needs, which could necessitate implementation of a strategy to address those needs (e.g. pill fatigue). A decline in access to a treatment buddy over the treatment career could mean the role of a treatment buddy, which is to enhance adherence through the provision of adherence support visits and reminders, is important as a patient starts treatment, but that the need for such support declines in the long term due to the possibility that patients get used to treatment and establish their own routines. Secondly, a change in policy could be responsible for a decline in the number of people with treatment buddies. Initially, (when the public-sector ART programme was first implemented) having a treatment buddy was a qualifying criteria for initiation of treatment but this has since been lifted, yet not abandoned, and as a result more and more patients initiate treatment without having treatment buddies. A decline in access to a treatment buddy over time concurs with the findings of Yoder *et al*, 2009, where patients who had been on ART for a longer period, reported that they did not need support from treatment supporters any longer. A study conducted in Uganda by Foster *et al*, 2010, also found that treatment companions were useful at the start of antiretroviral treatment, but were no longer needed after a few years on treatment.

Need, as measured by health-related quality of life, was significant in all three outcomes, which indicates that past changes in health-related quality of life explained changes in access to a treatment buddy. Past health status explained current access and losing a treatment buddy. This means that patients with improved health status had access treatment buddies and patients who previously experienced improvements in health status lost access to a treatment buddy.

Changes in health status, explained losing and gaining a treatment buddy. Patients who had improved health status in the previous period, lost access to treatment and patients who previously had improved health status were less likely to gain access to a treatment buddy. These findings were consistently significant in bivariate and multivariate analyses. Improvements in health status reduce a need for treatment buddies. This implies that treatment buddies seem to be important at the commencement of antiretroviral medication, at the time when patient's health status is mostly poor.

Access to a physical caregiver and participation in support groups was significant in all three outcomes and access to community health worker as significant in two of the outcomes. Participation in support groups complemented access to a treatment buddy. The results highlight the simultaneous use of these forms of support, in both, bivariate and multivariate analyses. Access to a treatment buddy was high among patients who participated in support groups and patients who participated in support groups were more likely to gain access to a support group. This could imply that participation in support groups may have increased access to treatment buddies, by possibly using support group members as treatment buddies.

Access to a physical caregiver reduced the likelihood of having a treatment buddy. Access to a physical caregiver explained both losing and gaining a treatment buddy. Firstly, patients who had access to a physical caregiver were more likely to lose treatment buddies. This implies that physical limitations could automatically reduce access to a treatment buddy and secondly, patients who had physical caregivers were more likely to gain access to a treatment buddy, suggesting that these forms actually complement rather than substitute each other. Even though not significant throughout, the results indicate that other forms of support are complements rather than substitutes for access to a treatment buddy. Past household size explained current and losing access to treatment buddy. As expected, patients from larger households were more likely to have access to support, hence treatment buddies. The bivariate results indicating that married patients were more likely to have access to treatment buddy concur with the results reported by Yoder *et al,* 2009. In this study, single patients and patients living alone were less likely to have access to a treatment buddy.

CHAPTER 6

INTENSITY OF TREATMENT BUDDY SUPPORT

6.1. Introduction

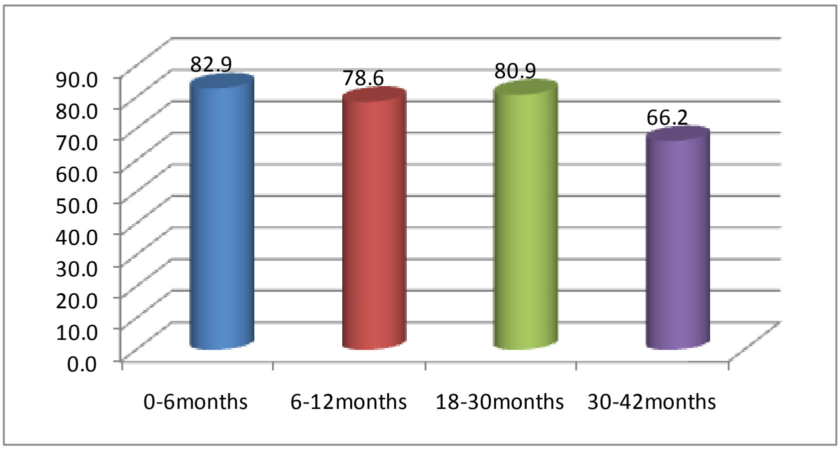
This chapter attempts to establish whether the argument that access to a treatment buddy on its own may not necessarily make a difference to patient's adherence to treatment, but rather the intensity of treatment support or frequency of visits provided by the treatment buddy, is true or not. An effort is made to determine how access to a treatment buddy, treatment buddy characteristics, and access to other support impact on the intensity of support provided by a treatment buddy.

The chapter explores three main outcomes, namely (i) current intensity of support provided by a treatment buddy (ii) transitions in intensity of treatment buddy support from daily visits to irregular intervals and (iii) transitions in intensity of treatment buddy support from irregular intervals to daily visits. (Bivariate analyses on how these self-reported adherence outcomes differ by need for support; access to a treatment buddy and treatment buddy characteristics is performed. This is followed by multiple regression analyses, which explores the role of the former outcomes in predicting intensity of treatment buddy support).

6.2. Current intensity of treatment buddy support

The intensity of treatment buddy support varied significantly across the treatment career ($p<0.05$). Figure 6.1 demonstrates that daily treatment buddy visits declined across the phases of the treatment career, particularly in the final phase. A large proportion of patients who had been on treatment for 0-6 months received daily treatment buddy visits (83%). At 18-30 months on treatment, 81% of patients were visited on a daily basis by their treatment buddy. The proportion of patients who were visited on a daily basis was lowest among patients who had been on treatment for 30-42 months.

Figure 6.1: Daily treatment buddy visits, by treatment career phase (n=317)



Note: Results are statistically significant at the 5% level (chi2=8.99, p=0.029).

Based on the evidence in Figure 6.1, the intensity of treatment buddy support remained around 80% in the first three phases and then only dropped substantially at phase 4. It can be argued that as months on treatment increase, patients get used to treatment and establish their own routines, with regard to taking medication, and improved health status is achieved, thus reducing the need for regular or daily visits by a treatment buddy. However, it may also be explained by treatment buddies becoming 'tired' and actually making fewer visits, i.e. the observed decline in the intensity of support need not be in line with the patient's actual needs, but may be beyond their control and simply the result of a treatment buddy's choice on how often to visit the patient.

6.2.1. Need and current intensity of treatment buddy support

Table 6.1: Past levels of health-related quality of life, by frequency of treatment buddy visits

Current regularity of visits	**Summary of past health-related quality of life (EQ-VAS)**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
Daily	70.65	18.17	34	70	70	30	100	68
Irregular intervals	72.21	19.18	30	80	70	20	100	179
Total	**71.78**	**18.88**	**30**	**80**	**70**	**20**	**100**	**247**

Current regularity of visits	**Summary of past health-related quality of life (EQ-5D)**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
Daily	0.89	0.18	0.8	1	1	0.2	1	**68**
Irregular intervals	0.86	0.23	0.8	1	1	0.0	1	**179**
Total	**0.87**	**0.22**	**0.8**	**1**	**1**	**0.0**	**1**	**247**

Note: EQ-VAS: results are not statistically significant (F=0, 34, p=0.563). EQ-5D: results are not statistically significant (F=0.59, p=0.444).

Table 5.1 shows that past levels of health-related quality of life did not differ significantly by the frequency of treatment buddy visits. However, patients who were visited on a daily basis on average exhibited higher health status as measured by EQ-5D, compared to patients who were visited irregularly, who on average reported lower health status. Furthermore, contrary to the results for EQ-5D, the results for EQ-VAS are the opposite: in this instance, patients who were visited on a daily basis on average exhibited lower health status compared to patients who were visited irregularly, who on average reported higher health status. These results are contradictory, however, and hence it does not matter ultimately that the results are not statistically significant.

Table 6.2: Changes in the level of health-related quality of life, by frequency of treatment buddy visits

Current regularity of visits	**Summary of changes in health-related quality of life (EQ-VAS)**							
	Mean	*SD*	*p25*	*p75*	*Median*	*Min*	*Max*	*Frequency*
Daily	-2.15	20.02	-10	10	0	-60	50	68
Irregular intervals	0.27	19.52	-10	10	0	-70	65	179
Total	**-0.40**	**19.65**	**-10**	**10**	**0**	**-70**	**65**	**247**
Current regularity of visits	**Summary of changes in health-related quality of life (EQ-5D)**							
	Mean	*SD*	*p25*	*p75*	*Median*	*Min*	*Max*	*Frequency*
Daily	-0.02	0.20	0	0	0	-0.85	0.38	68
Irregular intervals	0.00	0.21	0	0	0	-1.18	0.80	179
Total	**-0.01**	**0.21**	**0**	**0**	**0**	**-1.18**	**0.8**	**247**

Note: EQ-VAS: results are not statistically significant (F=0.74, p=0.389). EQ-5D: results are not statistically significant (F=0.52, p=0.470).

Table 6.2 shows that patients visited on a daily basis by their treatment buddy on average had reported a decline in health status in the recent past, compared to patients who were visited irregularly, who on average reported improvements in health status. Although not statistically significant, the results in this case are consistent across the two alternative health status measures. The differences however are not statistically significant. In fact, the reported results are in line with the argument in the Table above. This findings support the hypothesis that changes in need may explain frequency of treatment buddy visits.

6.2.2. Current intensity of treatment buddy support and treatment buddy characteristics

This section focuses on how treatment buddy characteristics may impact on the current intensity of treatment buddy support, using the data reported in the patient and treatment buddy surveys respectively. The results of the relevant analyses are compared across the two datasets for each of the treatment buddy characteristics recorded in both surveys.

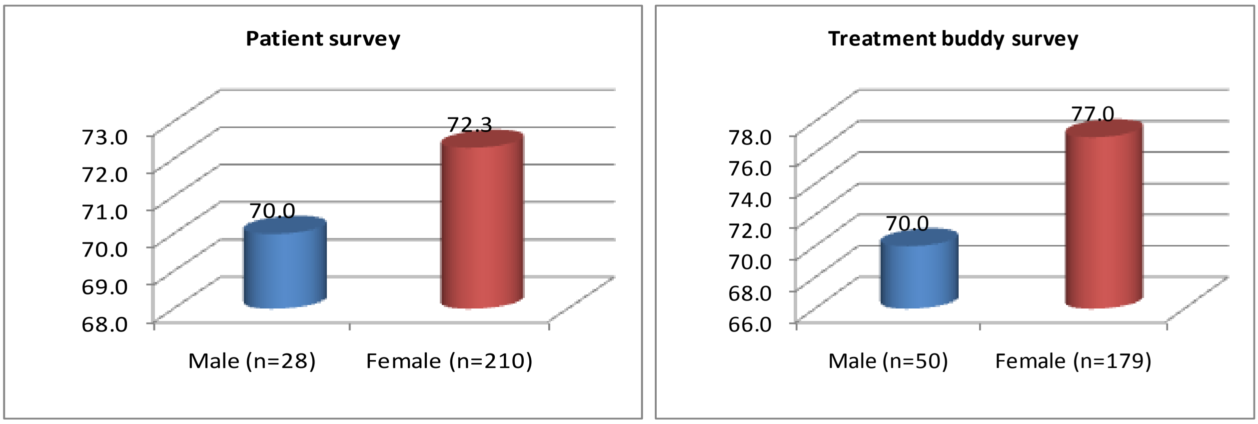
Table 6.3: Age of treatment buddy, by frequency of treatment buddy visits

Current regularity of visits	**Summary of age of treatment buddy (patient survey)**							
	Mean	*SD*	*p25*	*p75*	*Median*	*Min*	*Max*	*Frequency*
Daily	25.88	13.37	13.5	34.5	30	5	68	68
Irregular intervals	35.36	16.13	24	48	33	1	78	175
Total	**32.71**	**15.96**	**21**	**44**	**32**	**1**	**78**	**243**
Current regularity of visits	**Summary of age of treatment buddy (treatment buddy survey)**							
	Mean	*SD*	*p25*	*p75*	*Median*	*Min*	*Max*	*Frequency*
Daily	37.92	13.54	29	46	36	13	80	56
Irregular intervals	33.40	14.31	23	42	31	9	72	173
Total	**34.51**	**14.23**	**25**	**42**	**32**	**9**	**80**	**229**

Note: Results are statistically significant at the 1% level (F=18.52, p<0.001) (patient survey). Results are statistically significant at the 5% level (F=4.33, p<0.038) (treatment buddy survey).

Table 6.3 indicates that age of the treatment buddy impacted significantly on the current regularity of treatment buddy visits (p<0.00 and p<0.05 respectively for the two surveys). The results of the patient survey indicate that younger treatment buddies were more likely to visits their patients on daily basis compared to older treatment buddies. The treatment buddy survey in turn indicates that older treatment buddies were more likely to visit their patients on a daily basis compared to younger treatment buddies. The two results differ completely, perhaps due to the treatment buddy survey and patient survey and being measured at very different times, with the treatment buddy survey having been conducted after the completion of the sixth round of follow-up interviews with patients. In an attempt to explain such contradictory, but highly statistically significant results, a separate analysis of the sub-sample of patients interviewed at a time closer to that of the treatment buddy survey was done. Results indicated that differences in age in the last treatment career phase and the treatment buddy survey are not significantly different, which means that contradictory differences shown in Table 6.3 may be attributed to the asynchronous nature of the two surveys.

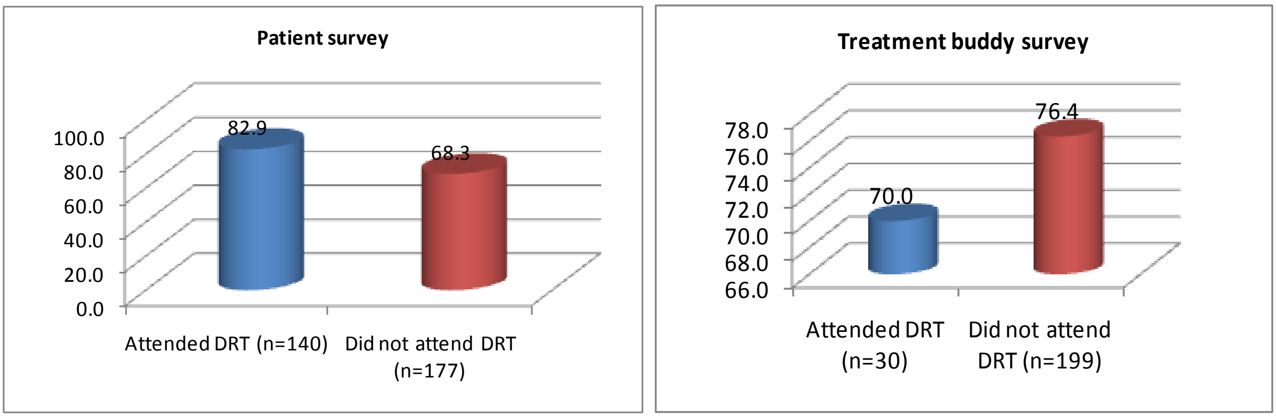
Figure 6.2: Daily treatment buddy visits, by gender of treatment buddy



Note: Results are not statistically significant (chi2=0.09, p=0.759). Note: Results are not statistically significant (chi2=1.06, p=0.302)

Figure 6.2 shows that the frequency of treatment buddy visits did not differ significantly by the gender of the patient's treatment buddy, nor in the patient survey or in the treatment buddy survey. Female treatment buddies were however more likely to visit their patients on a daily basis compared to those who had male treatment buddies. These results are however not significant.

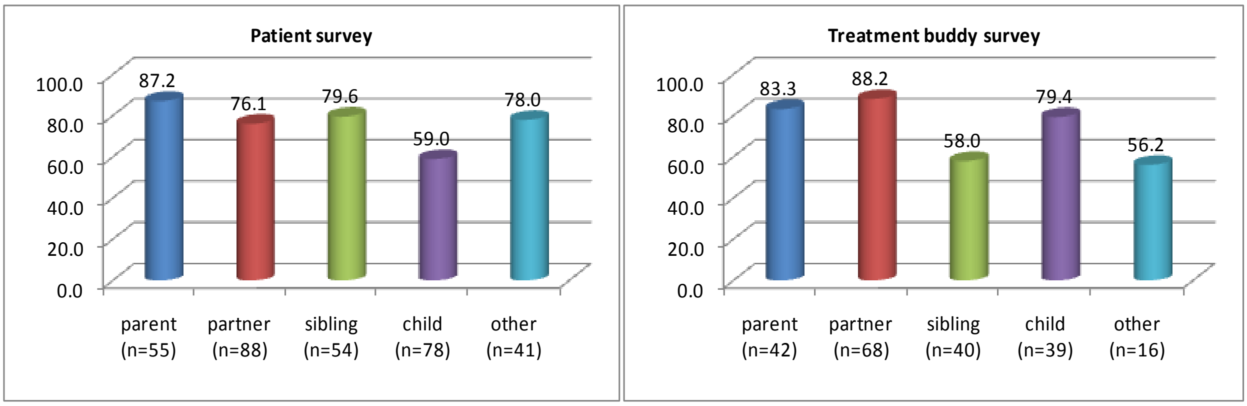
Figure 6.3: Daily treatment buddy visits, by attendance of drug readiness training



Results are statistically significant at the 1% level (chi2=0.09, p=0.003). Results are not statistically significant (chi2=0.09, p=0.448).

Figures 6.3 shows that the attendance of drug readiness training impacted significantly on the frequency of treatment buddy visits, but only for the patient survey ($p<0.05$). According to the patient survey, patients whose treatment buddies attended drug readiness training were more likely to be visited on a daily basis. This finding highlights the importance of treatment buddies attending the drug readiness training provided to patients. On the contrary though, the treatment buddy survey indicates that patients whose treatment buddies did not attend drug readiness training were more likely to be visited on a daily basis. The latter result, however, was not statistically significant, albeit that even a significant contradictory result, like the contradictory but insignificant one, as mentioned above, may be attributable to the asynchronous nature of the patient and treatment buddy surveys.

Figure 6.4: Daily treatment buddy visits, by relationship with treatment buddy

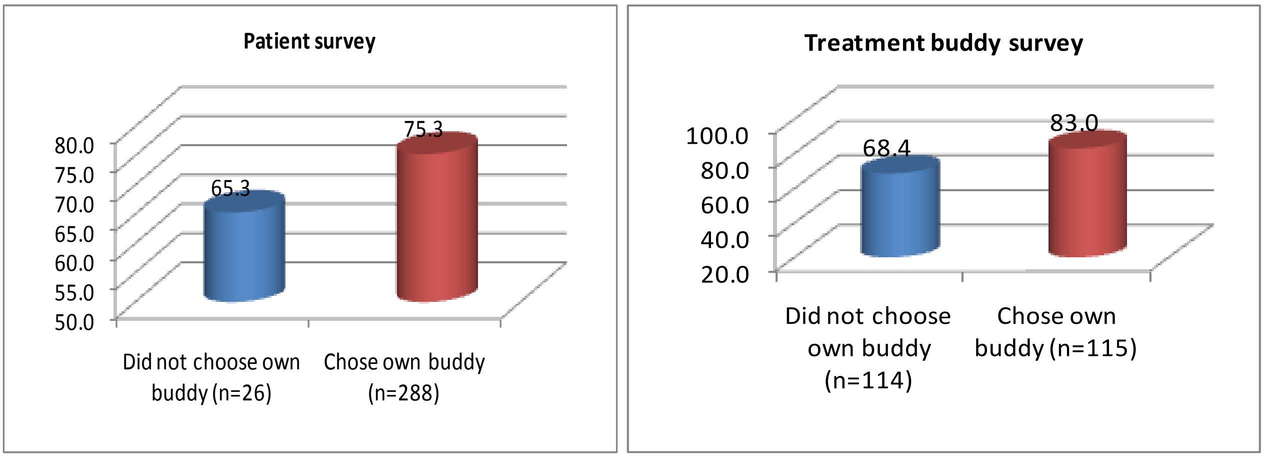


Results are statistically significant at the 1% level (chi2=18.52, p=0.003). Results are statistically significant at the 1% level (chi2=19.91, p=0.001).

Figure 6.4 suggests that daily treatment buddy visits varied significantly by the relationship of the patient with his/her treatment buddy ($p<0.01$). In the patient survey, daily treatment buddy visits were higher among patients whose treatment buddies were parents (87%), siblings (79%), and other relations (including friends, neighbours and extended family members)(78%). Daily treatment buddy visits were low among patients who had partners (76%) and lowest among patients who had their children as treatment buddies (59%). The reason behind this could be that some patients even though they had partners/spouses, did not cohabit with their partner/spouse. The same may apply to those patients whose siblings or children were their treatment buddies. It could be that these siblings or children do not reside with patients and as a result, were less likely to be visited on a daily basis, which may also explain the irregular visits from younger treatment buddies reported in Table 6.3 above. It is possible, however, that the patient did reside with their parents, which could explain the relatively high proportion of patients whose treatment buddies are their parents, whom received daily treatment buddy visits.

In the treatment buddy survey, daily treatment buddy visits were more likely among buddies who reported that they were their patients' partner (88%), parent (83%) or child (79%), but markedly lower among patients who had siblings (58%) and distant others (56%) as treatment buddies. These results are sensible , as it is expected that partners, parents and children, as relatively close family members often cohabiting with each other, may be in contact with the patient more frequently compared to more distant relations, , thus increasing the chances of daily treatment buddy visits.

Figure 6.5: Daily treatment buddy visits, by choice of treatment buddy



Note: Results are not statistically significant (chi2=0.094, p=0.264). Results are statistically significant at the 5% level (chi2=6.23, p=0.013)

Choice of treatment buddy did not impact significantly on daily treatment buddy visits in the patient survey. Figure 6.5, though, shows that daily treatment buddy visits, as expected, were significantly more common among patients who chose their own treatment buddies (83%) compared to patients whose treatment buddies were assigned to them by someone else (68%) ($p<0.05$). The reason for this could be that patients who chose their own treatment buddies chose people known and close to them, while those patients who did not chose their own buddies, have a buddy whom they did not share any close connection with and whom therefore were less likely to be visited on a daily basis. Although the results from the patient survey were not significant, it reflects the same expected relationship between the intensity of treatment buddy support and choice of treatment buddy as the treatment buddy survey (refer Figure 6.5).

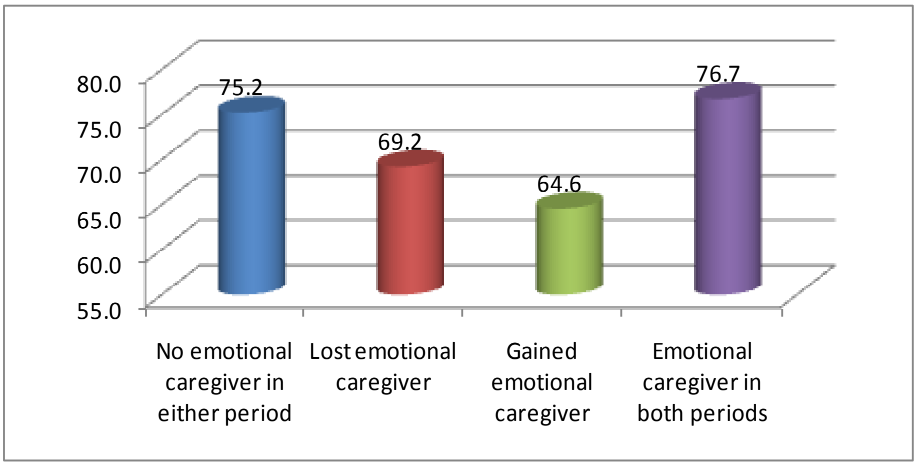
6.2.3. Current intensity of treatment buddy support and transitions in access to other support

This section assesses how transitions in access to other support may influence current intensity of treatment buddy visits. The focus shifts from informal, individualised forms of support such as an emotional and physical caregiver to more formal and group-based forms of support such as a community health worker and support group, respectively.

6.2.3. (a) Transitions in access to an emotional caregiver

Transitions in access to an emotional caregiver in the recent past did not impact significantly on the frequency of treatment buddy visits. According to Figure 6.6, daily treatment buddy visits were highest and almost similar among patients who had access to an emotional caregiver in both periods (77%) and among patients who had no emotional caregiver in either period (75%). This result suggests therefore that daily treatment buddy visits did not depend on the presence of an emotional caregiver. The low proportion among those who recently gained access to an emotional caregiver who received daily treatment buddy visits may however reflect a proactive response on the patient's part to infrequent treatment buddy visits in the case of access to supplementary support from an emotional caregiver.

Figure 6.6: Daily treatment buddy visits, by transitions in access to an emotional caregiver (n=247)

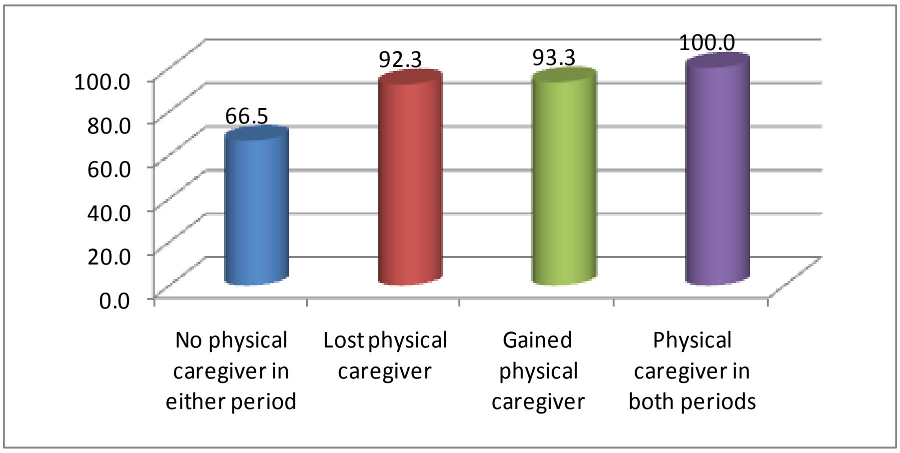


Note: Results are not statistically significant (chi2=2.53, p=0.469).

6.2.3. (b) Transitions in access to a physical caregiver

According to Figure 6.7, transitions in access to a physical caregiver impacted significantly on the intensity of treatment buddy support ($p<0.01$). Patients who had no physical caregiver in either period were least likely to receive daily treatment buddy visits, whereas all patients who had access to a physical caregiver in both periods received daily treatment buddy visits. Daily treatment buddy visits were generally higher among patients who lost or gained access to a physical caregiver, respectively. In all cases, patients with a physical caregiver at some point in time or always received more daily visits compared to patients without access to a physical caregiver, which may be the result of physical caregivers being the same persons as the treatment buddy.

Figure 6.7: Daily treatment buddy visits, by transitions in access to a physical caregiver (n=247)

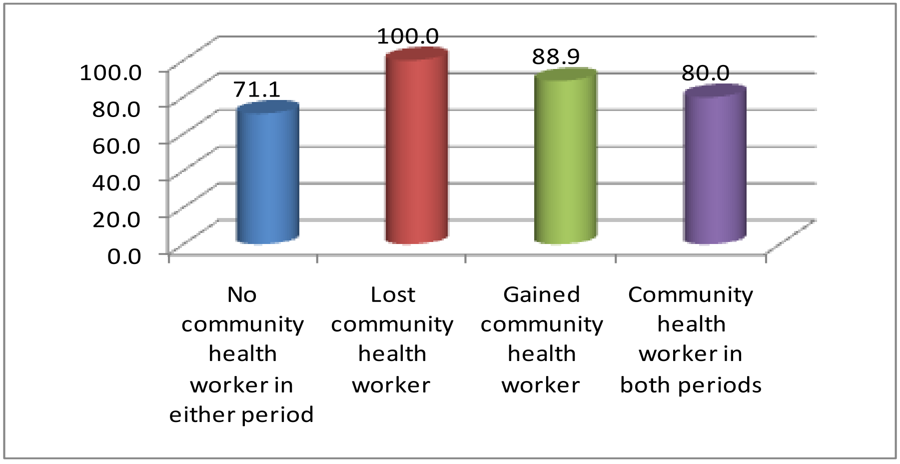


Note: Results are statistically significant at the 1% level (chi2=16.37, p=0.001).

6.2.3. (c) Transitions in access to a community health worker

Figure 6.8 demonstrates that daily treatment buddy visits did not differ significantly by transitions in access to a community health worker. Daily treatment buddy visits were higher for patients who at some point in time in the recent past were visited by a community health worker compared to those never visited by a community health worker. Similar to most other figures above, Figure 6.8 suggests that transitions in access to a community health worker, like many other sources of support, did not influence the frequency of treatment buddy visits.

Figure 6.8: Daily treatment buddy visits, by transitions in access to a community health worker 9n=247)

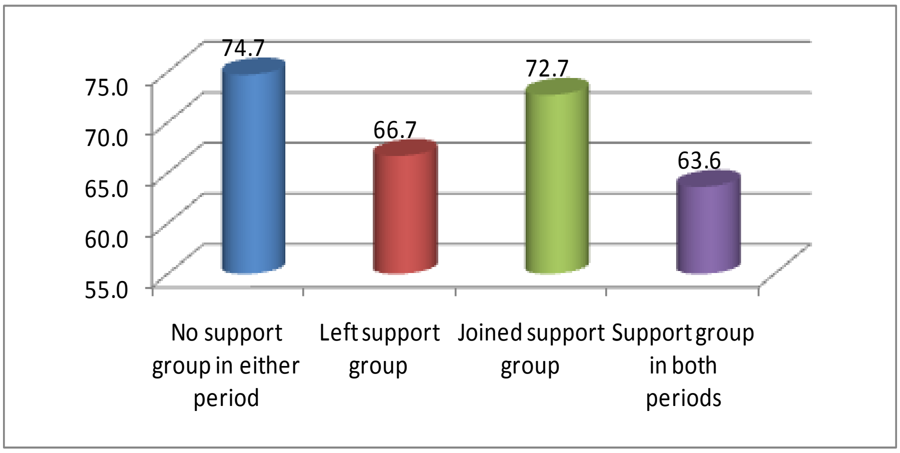


Note: Results are not statistically significant (chi2=3.48, p=0.322).

6.2.3. (d) Transitions in participation in a support group

Figure 6.9 reveals that the intensity of treatment buddy support did not vary significantly by recent transitions in participation in a support group. Daily treatment buddy visits were highest among patients who did not participate in a support group in either period, but lowest among those who participated in a support group in both periods. Fewer treatment buddy visits would be expected if participating in a support group substitute for frequent treatment buddy visits. Daily treatment buddies visits were lower among patients who discontinued participating in a support group and higher among patients who recently joined a support group.

Figure 6.9: Daily treatment buddy visits, by transitions in participation in a support group (n=247)



Note: Results are not statistically significant (chi2=2.10, p=0.550).

6.2.4. Household size and current intensity of treatment buddy support

Table 6.4 illustrates that household size did not significantly impact on the intensity of treatment buddy support. Patients were visited daily by treatment buddies irrespective, therefore, of household size. Yet, patients who were visited daily lived in slightly larger households, which one would expect if treatment buddies generally are close family members of the patient, as was reported in Chapter 4.

Table 6.4: Past household size, by frequency of treatment buddy visits

Current regularity of visits	Summary of past household size							
	Mean	*SD*	*p25*	*p75*	*Median*	*Min*	*Max*	*Frequency*
Irregular intervals	4.10	2.41	2	5	4	1	14	68
Daily	4.47	2.04	3	6	4	1	12	179
Total	**4.37**	**2.15**	**3**	**6**	**4**	**1**	**14**	**247**

Note: Results are not statistically significant (F=1.48, p=0.225).

Table 6.5: Changes in household size, by frequency of treatment buddy visits

Current regularity of visits	Summary of changes in household size							
	Mean	*SD*	*p25*	*p75*	*Median*	*Min*	*Max*	*Frequency*
Irregular intervals	-0.29	1.66	0	0	0	-7	6	68
Daily	0.04	1.40	0	0	0	-8	8	178
Total	**-0.05**	**1.48**	**0**	**0**	**0**	**-8**	**8**	**246**

Note: Results are not statistically significant (F=2.60, p=0.108).

Table 6.5 reveals that changes in household size did not significantly impact on the regularity of treatment buddy visits. However, the results were almost statistically significant, albeit weakly ($p<0.10$). Daily visits were more likely for patients living in households that increased in size compared to patients who received irregular visits, who lived in households that declined in size in the recent past; a rather expected result that, however, is again not statistically significant.

6.2.5. Determinants of the current intensity of treatment buddy support

Table 6.6 reports the regression results on the potential determinants of daily treatment buddy visits, based on the data from the patient survey. The reported results are for the pooled regression model, which performed adequately in terms of goodness-of-fit ($p<0.01$). The same regression model was performed twice, first including EQ-VAS as measure of health-related quality of life and then adopting EQ-5D as measure of health-related quality of life. Models with alternative measures of health-related quality of life were estimated to establish whether the regression results remain robust, irrespective of the choice of measure of health-related quality of life. Determinants of the intensity of treatment buddy support using the treatment buddy survey could not be estimated with the aid of regression analysis due to a small number of observations.

According to table 6.6, living with partner or spouse had odds ratios of 3.81 and 3.94 respectively and was significant at the 1% level. This means that patients who cohabited were almost four times more likely than single patients to receive daily treatment buddy visits. This result is expected since living with a partner or spouse, as reported in Chapter 5, significantly increases the chances of having a treatment buddy. The age of the treatment buddy was also significant at the 1% level with an odds ratio of 1.04, which means that for each increase of one year in the age of the treatment buddy, the odds of the patient receiving daily treatment buddy visits increase by approximately 4%.

The variable 'chose own buddy' has an odds ratio of 4.91 and was significant at the 10% level only, which means that patients who chose their own treatment buddies were almost five times more likely to receive daily treatment buddy visits compared to patients who were assigned treatment buddies. A similar size effect was reported for this variable in the other regression model, but the result was not statistically significant This means that patients should not only be required to choose someone, but that it may be much more important that they choose the correct or most suitable kind of person to provide support.

Table 6.6: Need, access to support and treatment buddy characteristics as determinants of daily treatment buddy visits

Independent variables	**Odds ratio** **EQ-VAS**		**Odds ratio** **EQ-5D**	
1. Sociodemographic variables				
Age	0.942		0.946	
Age2	1.001		1.001	
Female (*male=0/female=1* **)**	0.680			
Marital status				
[comparison group=single]				
Not living with partner	1.400		1.654	
Living with partner	3.811	*	3.947	*
Educational status				
[comparison group=no formal education]				
Primary education	0.595		0.541	
Secondary education	0.204		0.181	
Grade 12	0.156		0.157	
Tertiary education	0.083		0.106	
2. Need variables				
Treatment career				
[comparison group=0-6months]				
6-12months	1.438		1.423	
18-30months	1.897		1.820	
30-42months(omitted)				
Past level of health related quality of life (EQ-VAS)	1.008		0.609	
Changes in the level of health related quality of life (EQ-VAS)	1.016		2.811	
Past level of health related quality of life (EQ-5D)			0.609	
Changes in the level of health related quality of life (EQ-5D)			2.811	
3. Treatment buddy characteristics				
Age	1.044	*	1.046	*
Gender (*male=0/female=1*)	1.107		1.104	
Treatment buddy attended drug rediness training (*no=0/yes=1*)	2.033		1.887	
Relationship with the patient				
[comparison group=parent]				
Partner	1.228		1.157	
Sibling	2.024		2.233	
Child	1.500		1.561	
Other	1.071		1.057	
Satisfaction with treatment buddy *(omitted)*				
Treatment buddy assists with adherence (*no=0/yes=1*) (*omitted*)				
Chose own treatment buddy (*no-0/yes=1)*	4.915	*	5.504	
4. Access to support variables				
Transitions in access to emotional caregiver				
[comparison group=no emotional caregiver in either period]				
Lost emotional caregiver	0.484		0.447	
Gained emotional caregiver	0.253	**	0.261	**
Had emotional caregiver in both periods	0.437		0.469	
Transitions in access to physical caregiver				
[comparison group=no physical caregiver in either period]				
Lost physical caregiver	0.422		7.106	
Gained physical caregiver	11.515	**	12.444	**
Had physical caregiver in both periods(omitted)				
Transitions in access to community health worker				
[comparison group=no community health worker in either period]				
Lost community health worker (omitted)				
Gained community health worker	0.542		0.570	
Had community health worker in both periods	0.433		0.419	
Transitions in participation in support groups				
[comparison group=no participation in either period]				
Stopped participating	0.458		0.503	
Started participating	0.956		1.216	
Participated in both periods	0.678		0.789	
Past household size	1.581	***	1.577	***
Changes in household size	1.867	***	1.879	***
Sample size	*213*		*213*	
LR chi2 (P)	*77.52 (P<0.01)*		*77.45 (P<0.01)*	
Note: Results are for the Pooled regression model.FE and RE could not be estimated				
**** significant at 1% level; ** significant at 5% level; *significant at 10% level*				

Gaining access to an emotional caregiver has an odds ratio of 0.25 and 0.26 respectively and is significant at the 5% level. This means that patients who gained access to an emotional caregiver are 39% less likely to have received daily treatment buddy visits compared to patients who did not have an emotional caregiver in either period. Gaining access to a physical caregiver is also significant at the 5% level, with odds ratios of

11.51 and 12.44, respectively, which means that patients who gained access to a physical caregiver were almost 12 times more likely to be visited on a daily basis compared to patients who did not have access to a physical caregiver in either period, a result one would expect if the physical caregiver and the buddy was in fact the same person, whom take on different roles in support the patient.

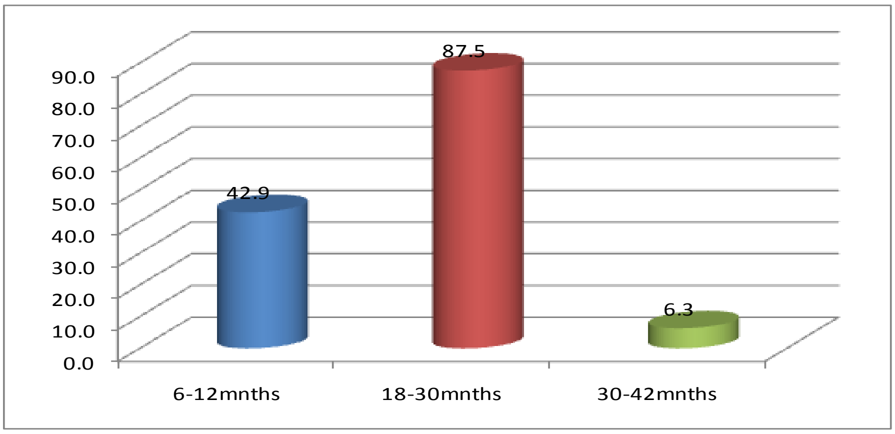
Past household size is significant at the 1% level, with an odds ratio of 1.58, which means that for each increase in past household size of one person, the odds of receiving daily treatment buddy visits increase by 58%. This means that patients from larger households were significantly more likely to be visited daily by their treatment buddy. Change in household size is also significant at the 1% level. The odds ratio of 1.87 means that for each increase over time in household size of one person, the odds of receiving daily treatment buddy visits increase by as much as 87%. It is expected for patients from larger and growing households to receive daily visits because of the greater availability of support within large and growing families.

In the subsequent two main sections of this chapter, the focus shifts to an investigation on the determinants of transitions in the intensity of treatment buddy support from daily to irregular and from irregular to daily, respectively. As only the patient survey contains longitudinal data, which is necessary to identify transitions in a study outcome, the focus here is on the results of analyses of the patient survey data only. The treatment buddy survey data is not used here as it represents cross-sectional data only, which does not allow one to identify transitions in study outcomes.

6.3. Transitions in intensity of treatment buddy support from daily to irregular visits

This section focuses on how need and other forms of support may impact on transitions from daily to irregular intervals.

Figure 6.10: Transitions from daily to irregular treatment buddy visits, by treatment career phase (n=47)



Note: Results are statistically significant at the 1% level (chi2=23.52, p<0.001).

According to figure 6.10, transitions from daily to irregular treatment buddy visits varied significantly over the treatment career. Transitions from daily to irregular treatment buddy visits were lower among patients who had been on treatment for a long duration. Transitions from daily to irregular treatment buddy visits were however higher among patients who have been on treatment for 18-30 months. The results display a kind of inverted-U shape in terms of how the outcome changes over the treatment career. The results are plausible since it would be expected that intensity of support changes, thus rendering a possibility to switch from providing daily visits to providing support at irregular visits.

6.3.1. Need and transitions in the intensity of treatment buddy support from daily to irregular visits

Table 6.7 below indicates that transitions from daily to irregular visits did not impact significantly on patient's health status. Further, transitions from daily to irregular visits were more common among patients who in the past reported lower health related quality of life. These results, although statistically insignificant, are rather contradictory as one would expect patients with lower health-related quality of life to be visited daily other than at irregular intervals, by treatment buddies.

Table 6.7: Past levels of health-related quality of life, by transitions from daily to irregular treatment buddy visits

Change from daily visits to irregular intervals	**Summary of past health-related quality of life (EQ-VAS)**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
Daily visits in both periods	70.05	20.00	50	90	70	30	**100**	35
Losing daily visits	69.66	18.20	55.5	82.5	65	50	**100**	12
Total	**69.95**	**19.36**	**50**	**90**	**70**	**30**	**100**	**47**

Change from daily visits to irregular intervals	**Summary of past health-related quality of life (EQ-5D)**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
Daily visits in both periods	0.90	0.22	1	1	1	0.18	1	**35**
Losing daily visits	0.78	0.28	0.63	1	0.92	0.29	1	**12**
Total	**0.87**	**0.24**	**0.76**	**1**	**1**	**0.18**	**1**	**47**

Note: EQ-VAS: results are not statistically significant (F=0.00, p=0.952). EQ-5D: results are not statistically significant (F=1.95, p=0.169).

Table 6.8: Past changes in the level of health-related quality of life, by transitions from daily to irregular treatment buddy visits

Change from daily visits to irregular intervals	**Summary of past changes in health-related quality of life (EQ-VAS)**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
Daily visits in both periods	0.29	18.72	-10	10	0	-60	**50**	31
Losing daily visits	-3.88	25.71	-20	10	-10	-40	**40**	9
Total	**-0.65**	**20.71**	**-10**	**10**	**0**	**-60**	**50**	**40**

Change from daily visits to irregular intervals	**Summary of past changes in health-related quality of life (EQ-5D)**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
Daily visits in both periods	0.02	0.17	0	0	0	-0.66	0.38	**31**
Losing daily visits	-0.10	0.28	-0.43	0	0	-0.48	0.27	**9**
Total	**0.00**	**0.21**	**0**	**0**	**0**	**-0.66**	**0.38**	**40**

Note: EQ-VAS: results are not statistically significant (F=0.29, p=0.591). EQ-5D: results are not statistically significant (F=2.63, P=0.113).

Table 6.8 shows that changes in health status did not impact significantly on transitions from daily to irregular intervals. Although statistically insignificant, the results are rather expected, because patients whose health status declined were more likely to be visited infrequently, while patients whose health improved were still visited daily, based on the signs of the mean differences in health status reported in Table 6.8 above.

6.3.2. Transitions in the intensity of treatment buddy support from daily to irregular visits and treatment buddy characteristics

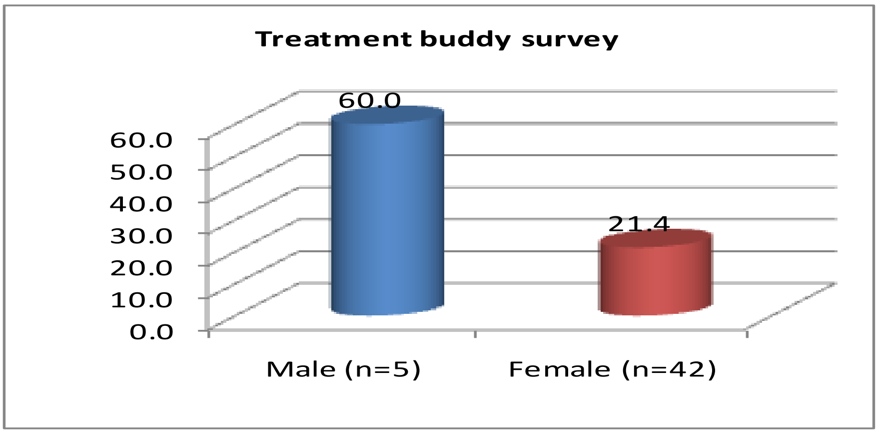
Table 6.10 reveals that the mean age of treatment buddies did not vary significantly by transitions from daily to irregular treatment buddy visits. Treatment buddies of patients who were now visited at daily rather than irregular intervals were older compared to treatment buddies who visited their patients daily in both periods. This is an unexpected result, since younger treatment buddies are expected to visit their patients at irregular intervals, because of other possible commitments such as school, employment and the like, which may impact negatively on their availability for continued daily visits to their patient.

Table 6.9: Age of treatment buddy, by transitions from daily to irregular treatment buddy visits

Change from daily visits to irregular intervals	Summary of age of treatment buddy							
	Mean	*SD*	*p25*	*p75*	*Median*	*Min*	*Max*	*Frequency*
Daily visits in both periods	24.25	13.01	13	32	21	8	**54**	35
Losing daily visits	31.25	10.71	24	36	32	12	**56**	12
Total	**26.04**	**12.73**	**14**	**35**	**28**	**8**	**56**	**47**

Note: Results are not statistically significant (F=2.80, p=0.101).

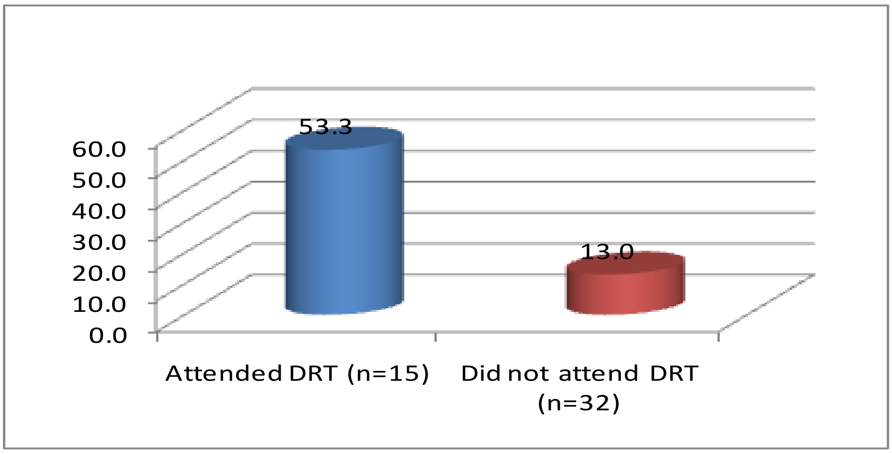
Figure 6.11: Transitions from daily to irregular treatment buddy visits, by gender of treatment buddy



Note: Results are statistically significant at the 10% level (chi2=3.49, p=0.062).

Figure 6.11 demonstrates that transitions from daily to irregular treatment buddy visits varied significantly by gender of the patient's treatment buddy (p<0.10). Male treatment buddies were more likely to visit patients at irregular rather than daily intervals (60%), compared to female treatment buddies. This finding is expected since the support provided by men is generally not comparable or at the same level as that of females.

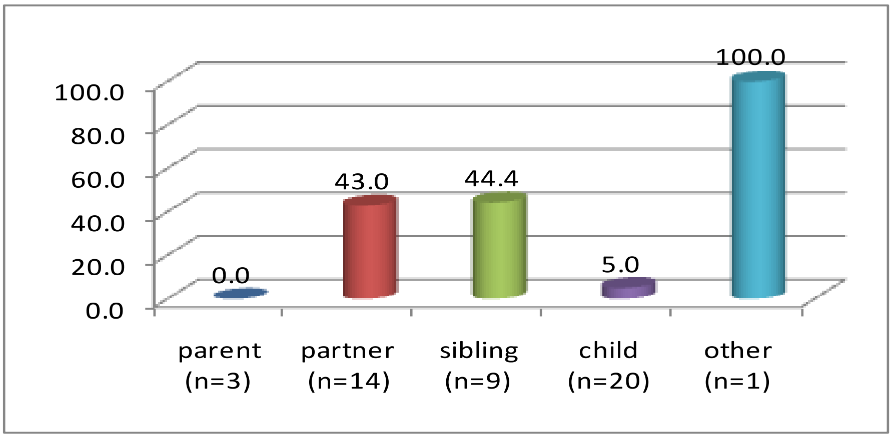
Figure 6.12: Transitions from daily to irregular treatment buddy visits, by attendance of drug readiness training



Note: Results are statistically significant at the 1% level (chi2=8.95, p=0.003).

Figure 6.12 above demonstrates that transitions from daily to irregular treatment buddy visits varied significantly by attendance of drug readiness training by the patient's treatment buddy (p<0.01). Patients who received irregular rather than daily treatment buddy visits had treatment buddies who attended the drug readiness training. These findings are rather contradictory since patients with treatment buddies who attended the drug readiness training would be expected to receive daily rather than irregular visits.

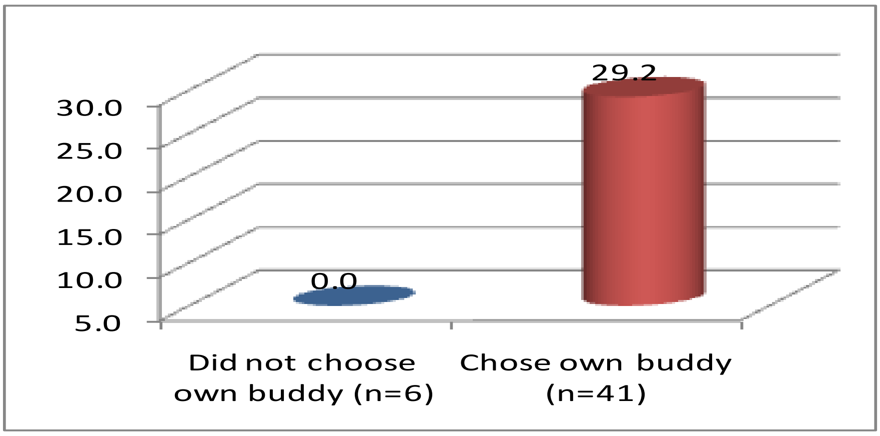
Figure 6.13: Transitions from daily to irregular treatment buddy visits, by relationship with treatment buddy



Note: Results are statistically significant at the 5% level (chi2=12.28, p=0.015).

Figure 6.13 indicates that transitions from daily to irregular treatment buddy visits varied significantly by the treatment buddy's relationship with their patient (p<0.05). Transitions from daily to irregular treatment buddy visits were low among patients whose treatment buddies were parents or children. Patients whose treatment buddies were more distant than others, were more likely to receive irregular rather than daily visits. Transitions from daily to irregular treatment buddy visits by distant others is rather plausible since these people do not reside with patients in most instances.

Figure 6.14: Transitions from daily to irregular treatment buddy visits, by choice of treatment buddy



Note: Results are not statistically significant (chi2=2.35, p=0.125).

Figure 6.14 illustrates that transitions from daily to irregular treatment buddy visits did not vary significantly by choice of treatment buddy. Treatment buddies chosen by patients were more likely to visit patients at irregular rather than daily intervals. None of the treatment buddies who were not chosen by patients themselves, visited at irregular rather than daily intervals. These results are unexpected, since one would imagine that most patients chose close family members whom they are most likely to reside with; hence transitions from daily to irregular treatment buddy visits would be less likely compared with patients whose treatment buddies were assigned to them.

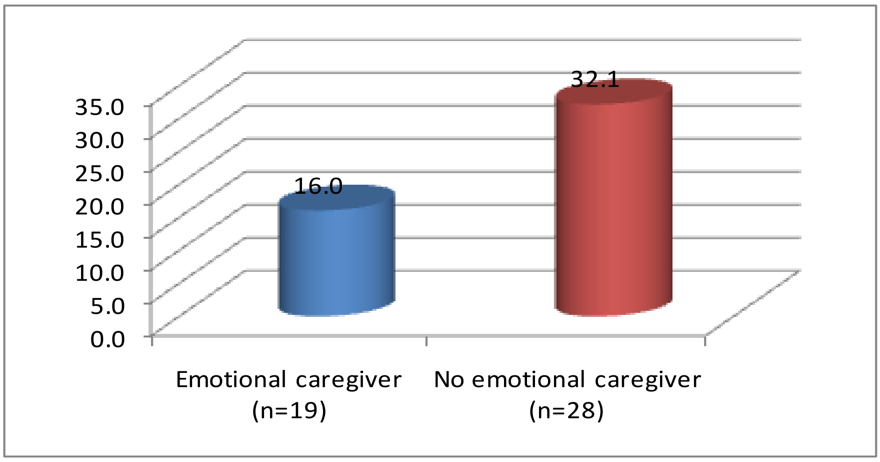
6.3.3. Transitions in the intensity of treatment buddy support from daily to irregular visits and transitions in access to other support

This section assesses how transitions in access to other forms of support may influence transitions in the intensity of treatment buddy visits. The focus shifts from informal, individualised forms of support, such as an emotional and physical caregiver, to more formal and group-based forms of support, such as a community health worker and support group, respectively.

6.3.3. (a) Past access to an emotional caregiver

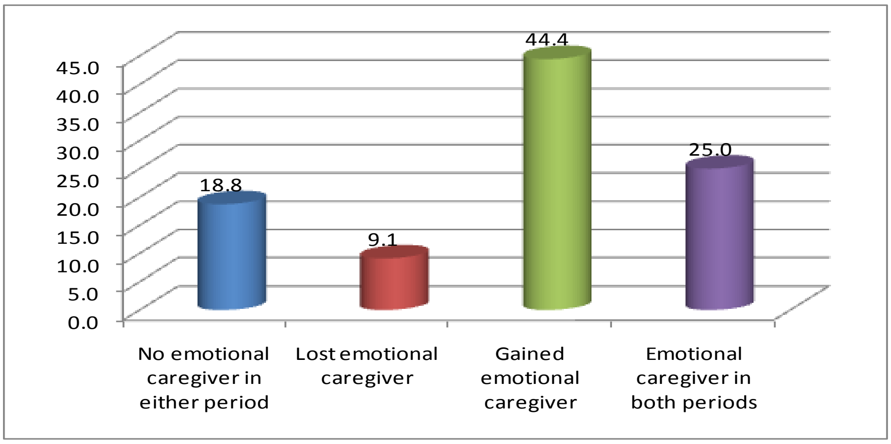
Figure 6.15 shows that transitions from daily to irregular treatment buddy visits did not differ significantly by past access to an emotional caregiver. However, transitions from daily to irregular treatment buddy visits were higher among patients who did not previously have access to an emotional caregiver. As expected, treatment buddy visits were lower among patients who had access to an emotional caregiver in the previous period.

Figure 6.15: Transitions from daily to irregular treatment buddy visits, by past access to an emotional caregiver



Note: Results are not statistically significant (chi2=1.59, p=0.207).

Figure 6.16: Transitions from daily to irregular treatment buddy visits, by past transitions in access to an emotional caregiver (n=40)



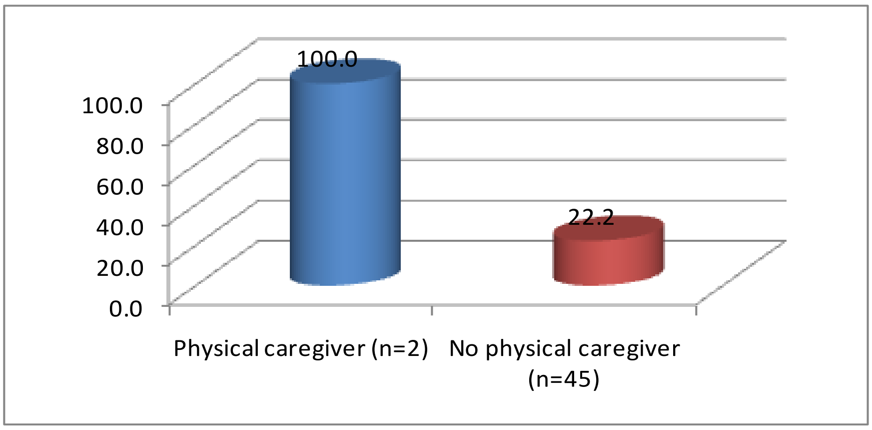
Note: Results are not statistically significant (chi2=3.76, p=0.288).

Figure 6.16 shows that transitions from daily to irregular treatment buddy visits did not differ significantly by past transitions in access to an emotional caregiver. Figure 6.16 further demonstrates that transitions from daily to irregular treatment buddy visits were highest among patients who gained access to an emotional caregiver. Transitions from daily to irregular treatment buddy visits were lowest in turn among patients who lost access to an emotional caregiver in the previous period. Results indicate that transitions from daily to irregular visits were more common among patients who in the past, gained or had access to an emotional caregiver in both periods, which indicates that patients are now visited at irregular intervals either because they have access to an emotional caregiver or because of the possibility that these emotional caregivers also serve as treatment buddies.

6.3.3. (b) Past access to a physical caregiver

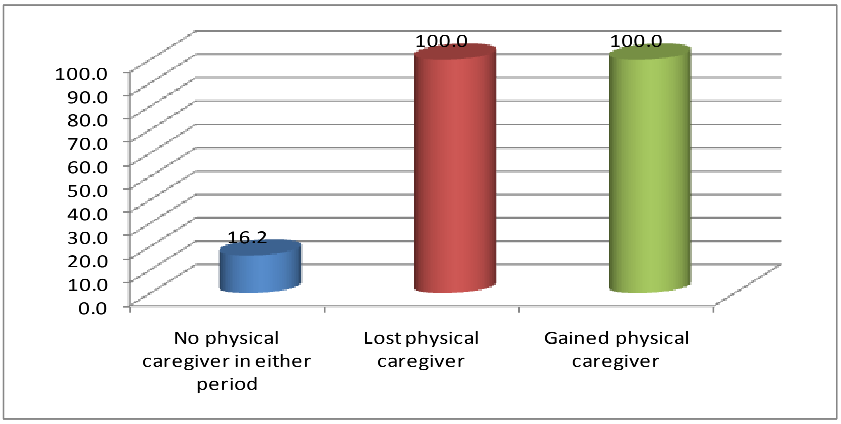
Figure 6.17 illustrates that transitions from daily to irregular treatment buddy visits varied significantly by past access to a physical caregiver ($p<0.05$). Further, transitions from daily to irregular treatment buddy visits were more common among patients who had a physical caregiver in the past , compared to patients who did not have access to a physical caregiver. This finding is plausible because one would expect that treatment buddy visits would be irregular if the patient previously had a physical caregiver as well.

Figure 6.17: Transitions from daily to irregular treatment buddy visits, by past access to a physical caregiver



Note: Results are statistically significant at the 5% level (chi2=6.09, p=0.014).

Figure 6.18: Transitions from daily to irregular treatment buddy visits, by past transitions in access to a physical caregiver (n=40)



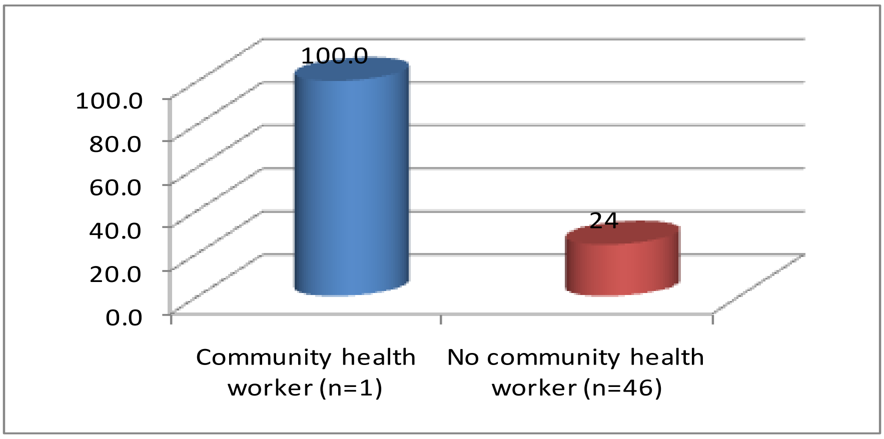
Note: Results are statistically significant at the 1% level (chi2=11.17, p=0.004).

Figure 6.18 shows that transitions from daily to irregular treatment buddy visits varied significantly by past transitions in access to a physical caregiver. Transitions from daily to irregular treatment buddy visits were lowest among patients who did not have access to a physical caregiver in either period. Transitions from daily to irregular treatment buddies were most common among patients who previously gained or lost access to a physical caregiver. In other words, patients were visited at irregular intervals irrespective of transitions in past access to a physical caregiver. A possible explanation for this finding is the possibility that the physical caregiver might be the same person as the patient's treatment buddy, resulting in a high correspondence and significant association between transitions in the two forms of support, including, as is the case here, the intensity of treatment buddy support.

6.3.3. (c) Past access to a community health worker

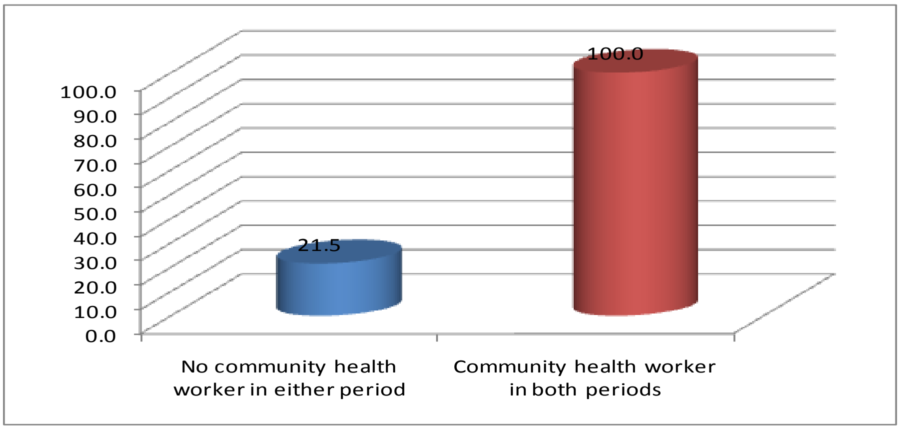
Figure 6.19 shows a significant but weak difference between transitions from daily to irregular treatment buddy visits and past access to a community health worker. Transitions from daily to irregular treatment buddy visits were higher among patients who previously had access to a community health worker compared to patients who previously did not have access to a community health worker. It would not be expected but it is possible for community health workers to visit patients at irregular intervals given the nature and scope of the work of community health workers. Transitions from daily to irregular treatment buddy visits would be expected if patients also receive visits from community health workers.

Figure 6.19: Transitions from daily to irregular treatment buddy visits, by past access to a community health worker



Note: Results are statistically significant at the 10% level (chi2=2.98, p=0.084).

Figure 6.20: Transitions from daily to irregular treatment buddy visits, by past transitions in access to a community health (n=40)



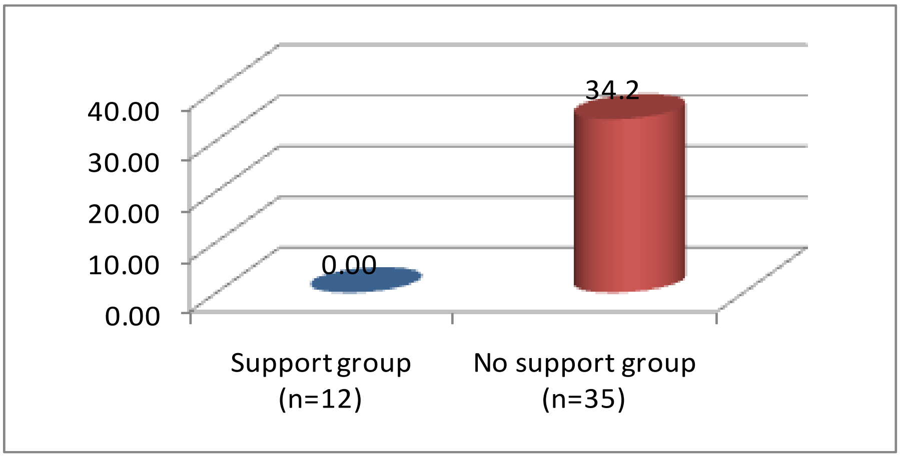
Note: Results are statistically significant at the 10% level (chi2=3.53, p=0.060).

Figure 6.20 denotes that transitions from daily to irregular treatment buddy visits varied significantly by past transitions in access to a community health worker. Furthermore, transitions from daily to irregular treatment buddy visits were more common among patients who had access to community health workers in both periods. This particular result makes sense insofar as one would expect community health workers to visit patients on a daily basis as well.

6.3.3. (d) Past participation in a support group

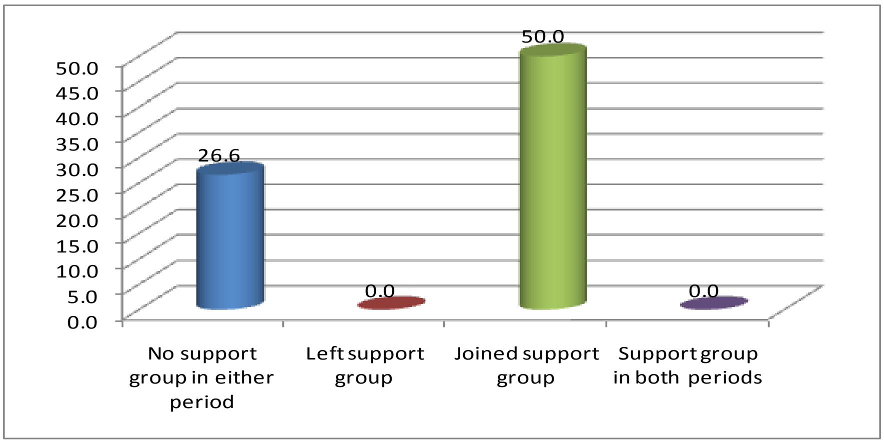
Figure 6.21 demonstrates that transitions from daily to irregular treatment buddy visits differed significantly by past participation in a support group (p<0.05). None of the patients who participated in a support group in the past were visited at irregular intervals, while all patients who did not participate in a support group were visited at irregular intervals. This finding may suggest that participation in a support group increases the likelihood of daily visits while not participating in a support group increases the chances of being visited at irregular intervals, especially if treatment buddies are also support group members.

Figure 6.21: Transitions from daily to irregular treatment buddy visits, by past participation in a participation in support group



Note: Results are statistically significant at the 5% level (chi2=5.52, p=0.019).

Figure 6.22: Transitions from daily to irregular treatment buddy visits, by past transitions in participation in a support group (n=40)



Note: Results are not statistically significant (chi2= 4.84, p=0.183).

According to Figure 6.23, there were no significant differences between transitions from daily to irregular treatment buddy visits and past transitions in participation in a support group. None of the patients who participated in a support group in both periods or discontinued participation participating in a support group were visited at irregular intervals. Patients who recently had joined a support group were more likely to be visited at irregular intervals. These results are however not statistically significant.

6.3.4. Household size and transitions from daily to irregular treatment buddy visits

Table 6.10 shows that household size did not impact significantly on transitions from daily to irregular treatment buddy visits. Transitions from daily to irregular treatment buddy visits were common among patients from smaller households compared to patients who received daily visits in both periods. It is expected that patients from larger households would be more likely to receive daily visits compared to patients from smaller households, which may be true in this case.

Table 6.10: Past household size, by transitions from daily to irregular treatment buddy visits

Change from daily visits to irregular intervals	**Summary of past household size**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
Daily visits in both periods	3.94	2.02	2	5	4	1	**9**	35
Losing daily visits	3.33	1.30	2.5	4	3.5	1	**6**	12
Total	**3.78**	**1.87**	**2**	**4**	**4**	**1**	**9**	**47**

Note: Results are not statistically significant (F=0.94, p=0.336).

Table 6.11: Past changes in household size, by transitions from daily to irregular treatment buddy visits

Change from daily visits to irregular intervals	**Summary of past changes in household size**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
Daily visits in both periods	-0.11	0.67	0	0	0	-4	**0**	35
Losing daily visits	0.54	0.93	0	1	0	0	**3**	12
Total	**0.04**	**0.78**	**0**	**0**	**0**	**-4**	**3**	**47**

Note: Results are statistically significant at the 5% level (F=6.60, p=0.013).

Table 6.10 shows that there was a significant association between past changes in household size and transitions from daily to irregular treatment buddy visits. Contrary to expectations, transitions from daily to irregular treatment buddy visits were mostly common among patients from larger households compared to patients who reported declines in household size. This highly significant result is rather unexpected, as one would expect increased in daily visits among patients from larger households.

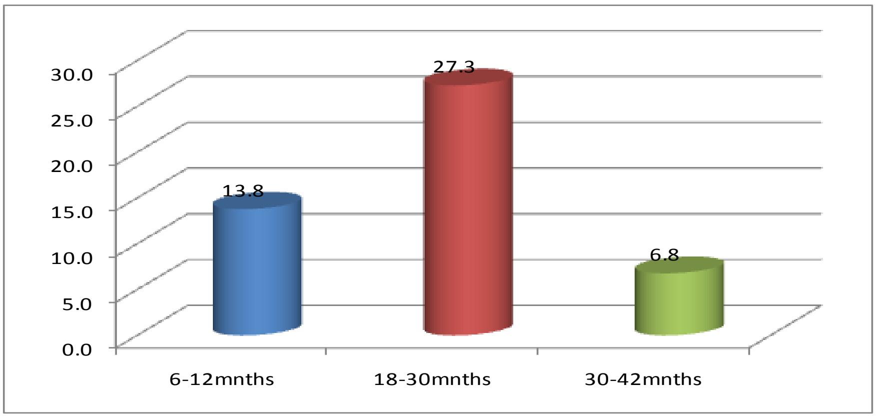
6.3.5. Determinants of transitions from daily to irregular treatment buddy visits

The exact logistic regression model to estimate the treatment buddy characteristics as determinants of transitions from daily to irregular treatment buddy visits was significant at 10% level (p=0.0752), but none of the variables were statistically significant determinants of transitions from daily to irregular treatment buddy visits.

6.4. Transitions_in the intensity of treatment buddy support from irregular to daily visits

According to Figure 6.23, transitions from irregular to daily treatment buddy visits varied significantly across the treatment career (p<0.05). Transitions from irregular to daily treatment buddy visits were more common among patients who have been on treatment for 18 to 30 months. And lower among patients who had been on treatment six to twelve months and more than 30 months This result could be indicative of a reduced need for adherence support among patients who have been on treatment for longer and/or could simply mean that the chances of getting daily visits once you are visited irregularly only is rather small, given the relatively low figures across all the phases in the treatment career.

Figure 6.23: Transitions from irregular to daily treatment buddy visits, by treatment career phase (n=125)



Note: Results are statistically significant at the 5% level (chi2=6.87, p=0.032).

6.4.1. Need and transitions in the intensity of treatment buddy support from irregular to daily visits

Table 6.12 reveals that past levels of health-related quality of life did not impact significantly on transitions from irregular to daily treatment buddy visits. Based on the EQ-VAS comparisons patients who reported lower health-related quality of life we less likely to receive irregular rather than daily visits. The results for EQ-5D on the other hand exhibited almost no difference in initial health status, with a difference of only

0.01 in health-related quality of life. Patients, who were now visited daily, had slightly improved level of health related of health quality of life.

Table 6.12: Past levels of health-related quality of life, by transitions from irregular to daily visits

Change from to irregular intervals to daily visits	**Summary of past health-related quality of life (EQ-VAS)**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
No daily visits in either period	72.89	18.62	60	90	70	30	**100**	110
Gaining daily visits	68.80	13.28	60	80	70	50	**90**	15
Total	**72.40**	**18.07**	**60**	**90**	**70**	**30**	**100**	**125**

Change from to irregular intervals to daily visits	**Summary of past health-related quality of life (EQ-5D)**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
No daily visits in either period	0.86	0.26	0.84	1	1	0.00	1	**110**
Gaining daily visits	0.87	0.15	0.76	1	1	0.51	1	**15**
Total	**0.87**	**0.25**	**0.84**	**1**	**1**	**0.00**	**1**	**125**

Note: EQ-VAS: results are not statistically significant (F=0.67, p=0.413). EQ-5D: results are not statistically significant (F=0.02, p=0.901).

Table 6.13: Past changes in the level of health-related quality of life, by transitions from irregular to daily visits

Change from to irregular intervals to daily visits	**Summary of past changes in health-related quality of life (EQ-VAS)**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
No daily visits in either period	4.18	19.83	-10	15	0	-40	**65**	85
Gaining daily visits	-6.54	13.77	-20	1	-10	-20	**20**	11
Total	**2.95**	**19.48**	**-10**	**12.5**	**0**	**-40**	**65**	**96**

Change from to irregular intervals to daily visits	**Summary of past changes in health-related quality of life (EQ-5D)**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
No daily visits in either period	0.01	0.20	0	0	0	-0.82	0.7	**85**
Gaining daily visits	0.07	0.38	-0.2	0.15	0	-0.48	0.8	**11**
Total	**0.02**	**0.22**	**0**	**0**	**0**	**-0.82**	**0.8**	**96**

Note: EQ-VAS: results are statistically significant at the 10% level (F=3.02, p=0.085). EQ-5D: results are not statistically significant (F=0.58, p=0.446).

According to Table 6.13, changes in the level of health-related quality of life as measured by EQ-VAS varied significantly by transitions from irregular to daily treatment buddy visits_(p<0.10). Patients who received daily rather than irregular visits had better or improved health-related quality of life compared to patients who did not receive daily visits in either period. The results indicate that the intensity of support in this case is influenced by the patient's health status and implied need for support. Patients with improved health-related quality of life were still visited at irregular intervals rather than on a daily basis, while patients whose health status declined were now visited on a daily basis by their treatment buddy. In the case of EQ-5D, however, no significant differences were observed between past changes in health status and transitions from irregular to daily treatment buddy support.

6.4.2. Transitions in the intensity of treatment buddy support from irregular intervals to daily visits and treatment buddy characteristics

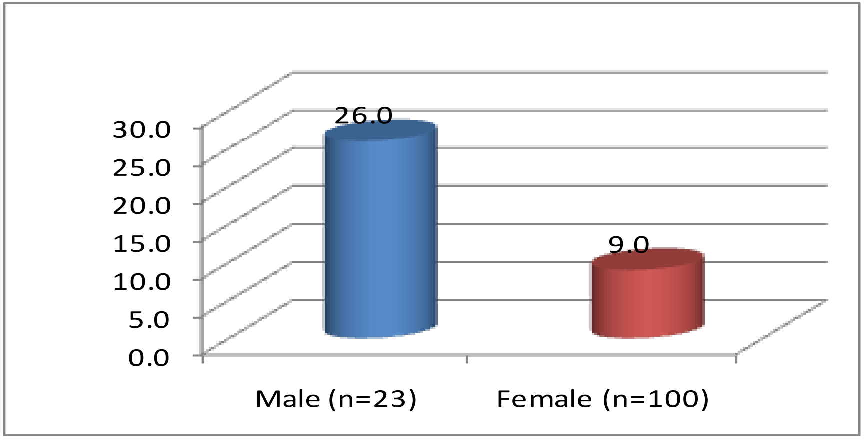
Table 6.14, reveals that there were no significant differences between age of treatment buddy and transitions from irregular to daily treatment buddy visits. As expected, younger treatment buddies were more likely to visit patients on a daily visit, while older treatment buddies visited patients at irregular visits. The results are however not statistically significant.

Table 6.14: Age of treatment buddy, by transitions from irregular to daily visits

Change from to irregular intervals to daily visits	**Summary of age of treatment buddy**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
No daily visits in either period	35.84	16.16	23.5	48	34.5	1	72	**104**
Gaining daily visits	32.50	14.75	31	35	32.5	5	68	**14**
Total	**35.44**	**15.97**	**25**	**48**	**33.5**	**1**	**72**	**118**

Note: Results are not statistically significant (chi2=0.54, p=0.464).

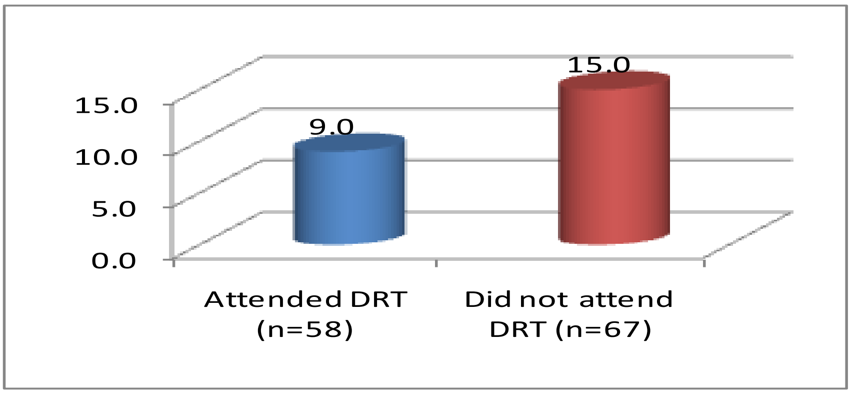
Figure 6.24: Transitions from irregular to daily visits, by gender of treatment buddy



Note: Results are statistically significant at the 5% level chi2=5.09, (p=0.024).

Figure 6.24 revealed that transitions from irregular to daily treatment buddy visits varied significantly by gender of treatment buddy (p<0.05). Transitions from irregular to daily treatment buddy visits were more common among male treatments buddies compared to female treatment buddies. Male treatment buddies were more likely to visit patients on a daily basis, while only a small percentage of female treatment buddies visited patients on a daily basis. These results are rather unexpected as one would expect female treatment buddies to visit patients on a daily rather than irregular basis, unless if the treatment buddy resided with patients /cohabited in case of a partner.

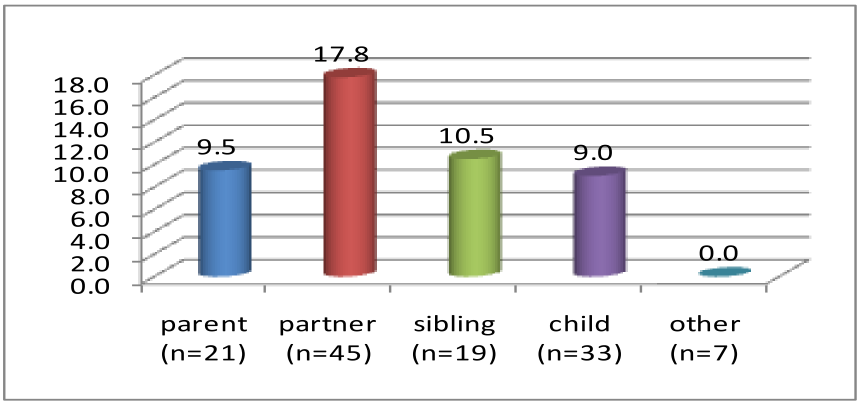
Figure 6.25: Transitions from irregular to daily visits, by attendance of drug readiness training



Note: Results are not statistically significant (chi2=1.17, p=0.279).

Figure 6.25 demonstrates that transitions from irregular to daily treatment buddy visits did not differ by the attendance of drug readiness training by patients' treatment buddies. Contrary to expectations, transitions from irregular to daily treatment buddy visits were more common among treatment buddies who did not attend drug readiness training compared to treatment buddies who attended the drug readiness training. These results are however not statistically significant.

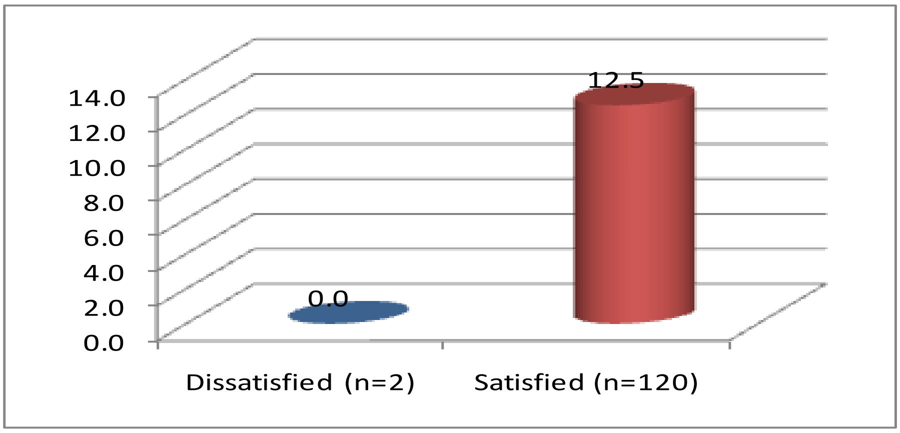
Figure 6.26: Transitions from irregular to daily visits, by relationship with treatment buddy



Note: Results are not statistically significant (chi2=2.80, p=0.591).

Figure 6.26 reveal that transitions from irregular to daily treatment buddy visits did not differ by treatment buddy's relationship with the patient. As expected, transitions from irregular to daily treatment buddy visits were mostly common among treatment buddies who are partners and transitions from irregular to daily treatment buddy visits also occurred among treatment buddies who were family members. Suggesting that patients were more likely to reside with family members, and hence receive daily rather than irregular visits.

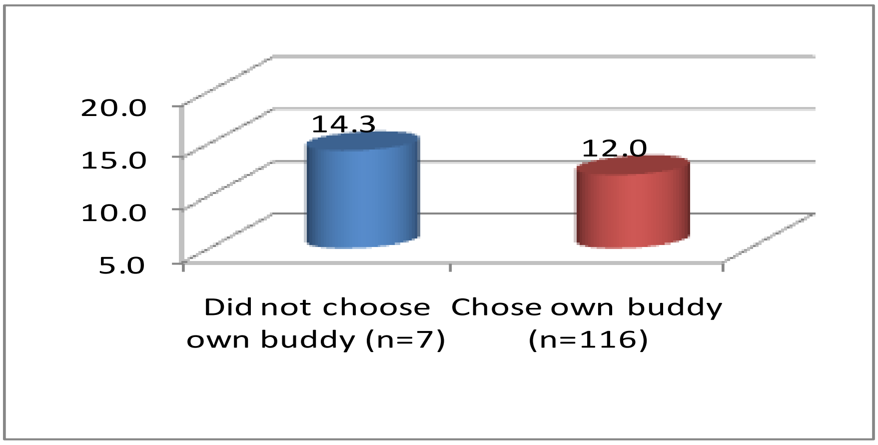
Figure 6.27: Transitions from irregular to daily visits, by satisfaction with treatment buddy



Note: Results are not statistically significant (chi2=0.28, p=0.593).

Figure 6.27 shows that transitions from irregular to daily treatment buddy visits did not differ by patients' level of satisfaction with the support provided by their treatment buddy. Further, transitions from irregular to daily treatment buddy visits were more common among patients who were satisfied with support. As expected, being visited daily is likely to improve patients' satisfaction levels.

Figure 6.28: Transitions from irregular to daily visits, by choice of treatment buddy



Note: Results are not statistically significant (chi2=0.03, p=0.862).

According to Figure 6.28, transitions from irregular to daily treatment buddy visits did not vary significantly by choice of treatment buddy. In addition, transitions from irregular to daily treatment buddy visits were common among patients who did not choose their own treatment buddies, compared to patients who did choose their own treatment buddies. This is sensible if assigned treatment buddies were allocated by some formal institutions, which automatically monitor the work of treatment buddies.

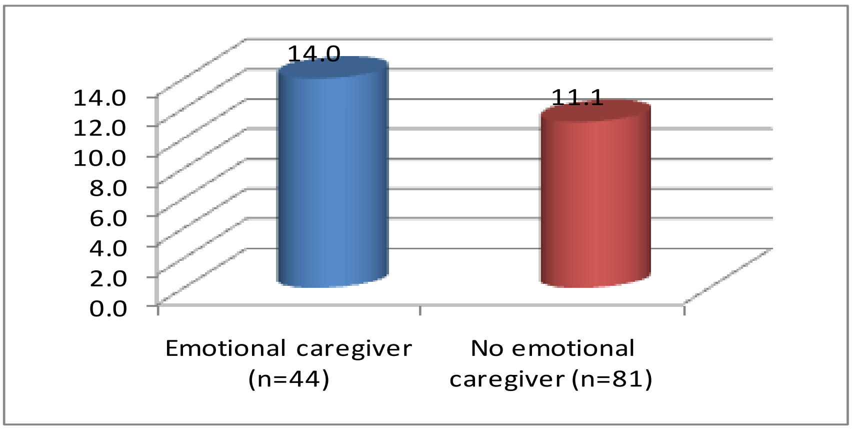
6.4.3. Transitions in the intensity of treatment buddy support from irregular intervals to daily visits and transitions in access to other support

This section assesses how transitions in access to other support may influence transitions in the intensity of treatment buddy visits. The focus shifts from informal, individualised forms of support such as an emotional and physical caregiver to more formal and group-based forms of support such as a community health worker and support group, respectively.

6.4.3. (a) Past access to an emotional caregiver

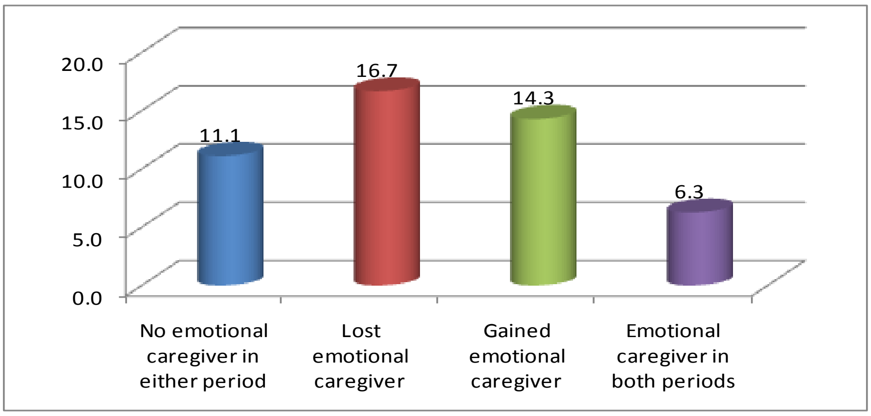
Figure 6.29 indicates that transitions from irregular to daily visits did not differ significantly by past access to an emotional caregiver. Moreover, transitions from irregular to daily treatment buddy visits were more common among patients who previously had access to an emotional caregiver, suggesting that patients were visited frequently because they did not have any support.

Figure 6.29: Transitions from irregular to daily visits, by past access to an emotional caregiver



Note: Results are not statistically significant (chi2=0.17 p=0.678).

Figure 6.30: Transitions from irregular to daily visits, by past transitions in access to an emotional caregiver (n=96)



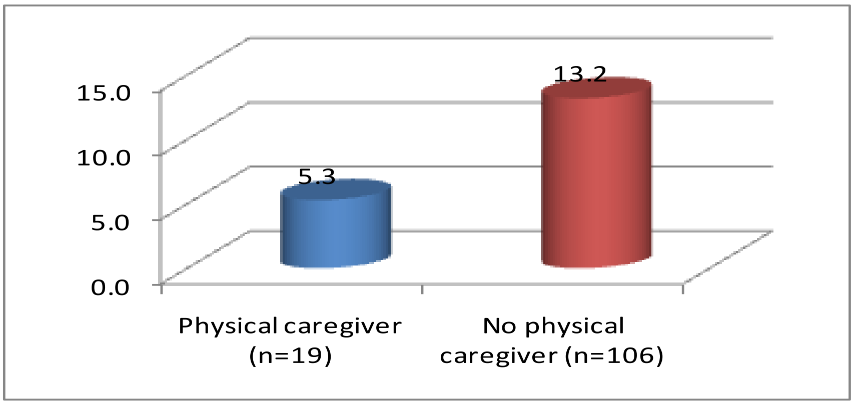
Note: Results are not statistically significant (chi2=0.86, p=0.834).

Figure 6.30 indicates that past transitions in access to an emotional caregiver did not impact on transitions from irregular to daily treatment buddy visits. Transitions from irregular to daily visits were more common among patients who lost access to an emotional caregiver and patients who gained access to an emotional caregiver. Patients who had access to an emotional caregiver in both periods were less likely to receive daily rather than irregular visits.

6.4.3. (b) Past access to a physical caregiver

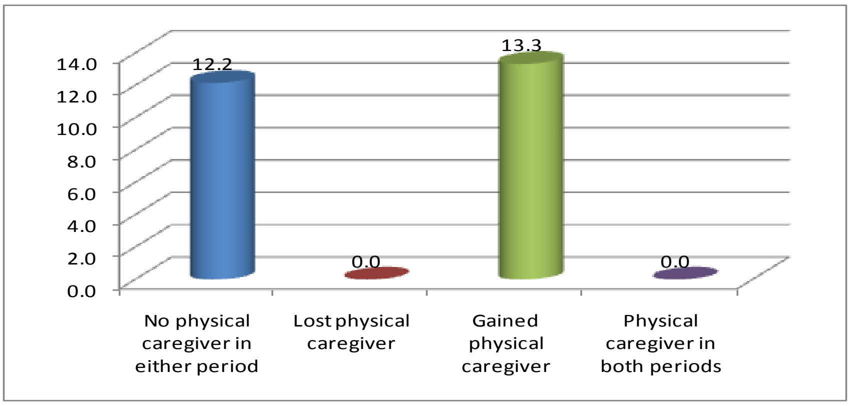
According to Figure 6.31, transitions from irregular to daily treatment buddy visits did not differ significantly by past transitions in access to a physical caregiver. Transitions from irregular to daily visits were more common among patients who previously did not have access to a physical caregiver, compared to patients who previously had access to a physical caregiver. It makes perfect sense to have patients without physical caregivers visited daily, but these results are not statistically significant.

Figure 6.31: Transitions from irregular to daily visits, by past access to a physical caregiver



Note: Results are not statistically significant (chi2=0.96, p=0.326).

Figure 6.32: Transitions from irregular to daily visits, by past transitions in access to a physical caregiver (n=96)



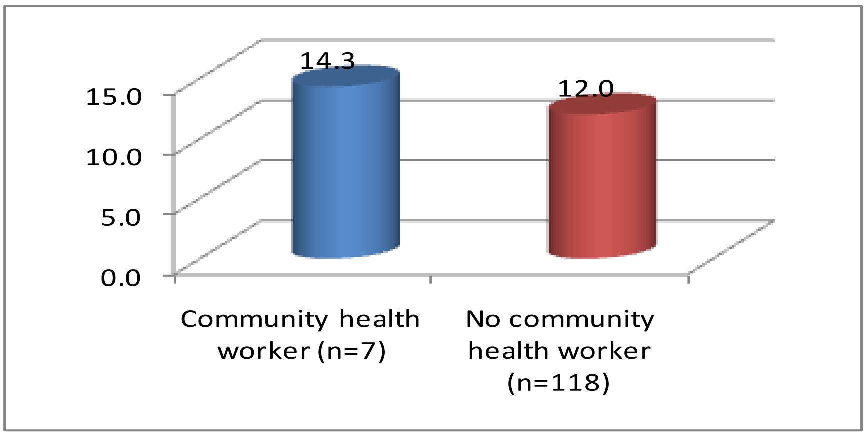
Note: Results are not statistically significant (chi2=0.99, p=0.803).

According to Figure 6.32, transitions from irregular to daily visits did not differ by transitions if patients gained access to a physical caregiver. Transitions from irregular to daily visits were more common among patients who gained access to a physical caregiver and patients who did not have access to a physical caregiver in both periods.

6.4.3. (c) Past access to a community health worker

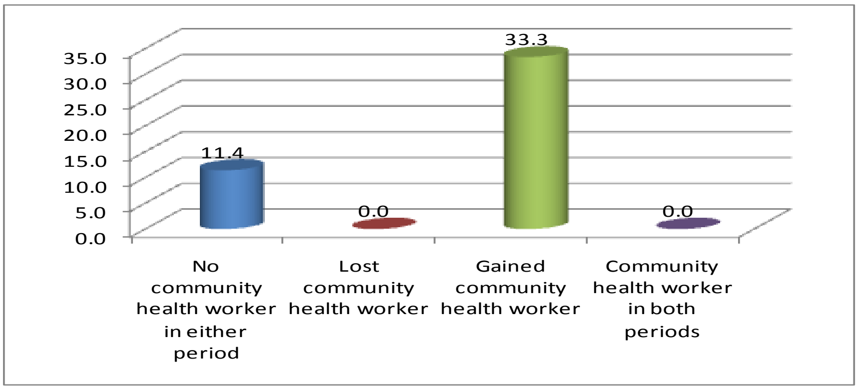
Figure 6.33 indicates that transitions from irregular to daily treatment buddy visits did not differ by past access to a community health worker. Transitions from irregular to daily treatment buddy visits were more common among patients who in the past had access to a community health worker, compared to patients who did not have access to a community health worker.

Figure 6.33: Transitions from irregular to daily visits, by past access to a community health worker



Note: Results are not statistically significant (chi2=0.03, p=0.848).

Figure 6.34: Transitions from irregular to daily visits, by past transitions in access to a community health worker (n=96)



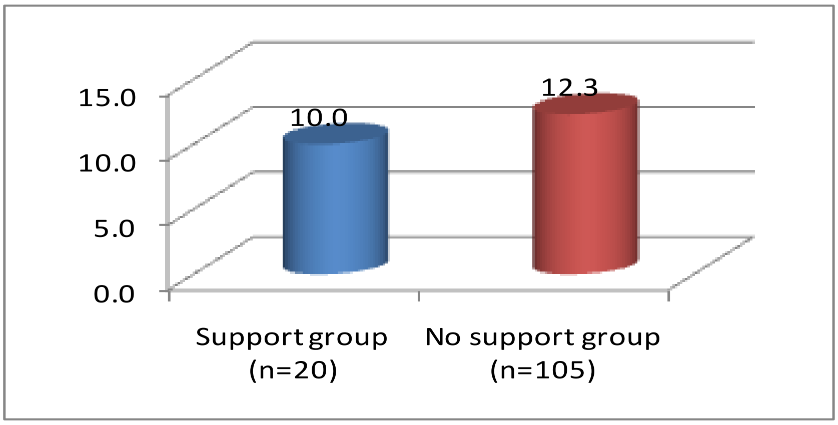
Note: Results are not statistically significant (chi2=2.06, p=0.559).

Figure 6.34 shows that transitions from irregular to daily treatment buddy visits were common among patients who gained access to a community health worker. Even though these differences were not significant, transitions from irregular to daily treatment buddy visits were more common among patients who previously gained access to community health workers. Not one patient who had lost or had access to a community health worker in both periods received daily rather than irregular treatment buddy visits.

6.4.3. (d) Past participation in a support group

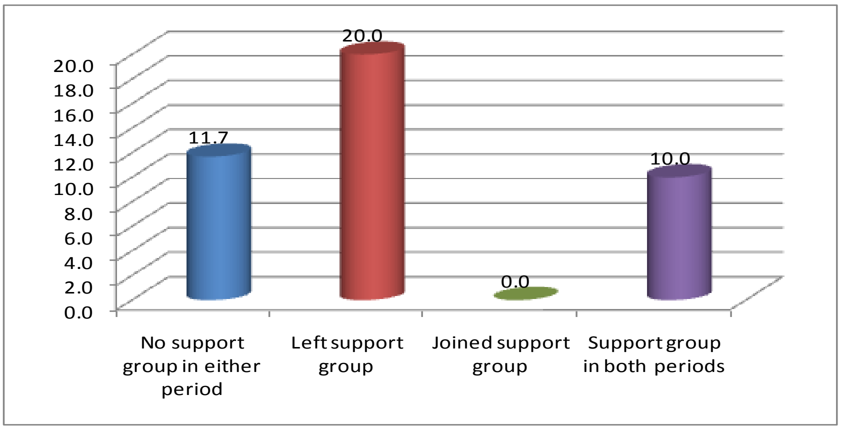
Figure 6.35 illustrates that transitions from irregular to daily rather than irregular treatment buddy visits did not differ significantly by past participation in a support group. The majority of patients who received daily rather than irregular treatment buddy visits did not previously participate in a support group, while only a small percentage of patients that participated in a support group in the past received daily rather than irregular visits. This suggests that patients participating in a support group may be attending a support group; hence a reduced need for daily treatment buddy visits.

Figure 6.35: Transitions from irregular to daily visits, by past participation in a support group



Note: Results are not statistically significant (chi2=0.09, p=0.764).

Figure 6.36: Transitions from irregular to daily visits, by past transitions in participation in a support group (n=96)



Note: Results are not statistically significant (chi2=0.90, p=0.825).

Figure 6.36 shows that transitions from daily rather than irregular treatment buddy visits did not vary significantly by transitions in participation in a support group (Figure 6.36). Transitions from irregular to daily treatment buddy visits were common among patients who recently stopped participation in a support group. There were no transitions from irregular to daily visits among patients who previously joined a support group. According to Figure 6.36, patients were less likely to receive daily visits irrespective of whether they participated in a support group in both periods or did not participate in either period.

6.4.4. Household size and transitions from irregular to daily visits

Table 6.15 illustrates that previous household size did not impact significantly on transitions in the intensity of treatment buddy support from irregular to daily visits. However, contrary to expectations, patients who continued to receive irregular visits were from slightly larger households and patients who started receiving daily visits were from smaller households. Patients from larger households are expected to receive daily visits. However, these results were not statistically significant.

Table 6.15: Past household size, by transitions from irregular to daily visits

Change from to irregular intervals to daily visits	**Summary of past household size**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
No daily visits in either period	4.55	1.87	3	6	4	2	9	**110**
Gaining daily visits	4.33	1.98	3	5	4	2	9	**15**
Total	**4.52**	**1.88**	**3**	**6**	**4**	**2**	**9**	**125**

Note: Results are not statistically significant (chi2=0.18, p=0.671).

Table 6.16: Past changes in household size, by transitions from irregular to daily visits

Change from to irregular intervals to daily visits	Summary of past changes in household size							
	Mean	*SD*	*p25*	*p75*	*Median*	*Min*	*Max*	*Frequency*
No daily visits in either period	-0.05	1.14	0	0	0	-5	8	**110**
Gaining daily visits	0.20	2.00	-1	1	0	-3	6	**15**
Total	**-0.02**	**1.26**	**0**	**0**	**0**	**-5**	**8**	**125**

Note: Results are not statistically significant (chi2=0.53, p=0.467).

According to Table 6.16, past changes in household size did not impact significantly on transitions from irregular to daily treatment buddy visits. However, patients who received irregular visits in both periods were from households that declined in size compared to patients who started receiving daily rather than irregular visits, who were from households that increased in size. The results seem sensible, because patients from larger households are more likely to receive support, in this case in the form of more regular visits, than patients from smaller households, given that increases in household size imply an increase in the potential supply of frequent treatment buddy support.

6.4.5. Determinants of transitions in the intensity of treatment buddy support from irregular to daily intervals

Table 6.17 reports the determinants of transitions from irregular to daily treatment buddy visits. Two regressions models were performed using each of the alternative measures of health-related quality of life, one for EQ-VAS and the other for EQ-5D. The aim was to establish whether the regression results will differ based on the measure of health-related quality of life or whether the findings would be consistent across both measures of health-related quality of life. The reported results are for the pooled regression model and the overall model performed adequately in terms of goodness-of-fit (p<0.01).

According to Table 6.17 gender has odds ratios of 0.002 and significant at the 5% respectively. This denotes that the odds of gaining treatment buddy visits decreased among female patients. Living with partner/spouse was significant at 1% level with the odds ratio of 1.820. This finding suggests that patients cohabiting with partners/spouses were almost 2 times more likely to transition from irregular to daily treatment buddy visits, compared to single patients. This finding is plausible, because these patients cohabited with their treatment buddies. Not cohabiting was significant at 5% respectively with the odds ratio of 0.004. Patients not cohabiting were less likely to receive/gain daily treatment buddy visits compared to single patients. The partner variable was significant at 1% level with the odds ratio of 5.940. Patients whose treatment buddies were partners/spouses were 6 times more likely to gain daily treatment buddy visits. The children variable is significant at 10% level with the odds ratio of 0.000, therefore patients whose treatment buddies were their children were less likely to gain daily treatment buddy visits.

Past access to a physical caregiver has an odds ratio of 0.000 and significant at 5% respectively, which signifies that daily treatment buddy visits were lower among patients who had access to a physical caregiver. Past access to a community health worker has an odds ratio 176.820 and significant at 10% respectively. This finding means that transitions from irregular to daily treatment buddy visits were higher among patients who previously received visits from community health workers. This is expected if these community health workers are also treatment buddies.

Table 6.17: Determinants of transitions from irregular to daily treatment buddy visits

Independent variables	**Odds ratio**		
		EQ-VAS	EQ-5D
1. Sociodemographic variables			
Age	1.930		
Age2	0.994		
Female (*male=0/female=1*)	0.002	**	**
Marital status			
[comparison group=single]			
Living with partner	1.820		***
Not living with partner	0.004	**	**
Educational status			
[comparison group=no formal education]			
Primary education	0.033		
Secondary education	1.557		
Grade 12	1.575		
Tertiary education (omitted)			
2. Need variables			
Treatment career			
[comparison group=0-6months]			
6-12months	0.951		
18-30months(omitted)			
30-42months	0.297		
Past health related quality of life *(EQ-VAS)*	0.981		
Past health related quality of life *(EQ-5D)*	0.413		
3. Treatment buddy characteristics			
Age	0.821	**	*
Gender (*male=0/female=1*)	0.000	**	**
Treatment buddy attended drug rediness training (*no=0/yes=1*)	0.223		
Relationship with the patient			
[comparison group=parent]			
Partner	5.940	***	
Sibling	5.910		
Child	0.000	*	*
Other (omitted)			
Satisfaction with treatment buddy *(omitted)*			
Treatment buddy assists with adherence (*no=0/yes=1*) (*omitted*)			
Chose own treatment buddy (*no-0/yes=1)*	760.576		
4. Access to support variables			
Past access to emotional carer	5.325		
Past access to physical carer	0.000	**	**
Past access to CHW	176.820	*	*
Past participation in support groups	0.375		
Past household size	0.646		
Sample size	*104*		
LR chi2 (p)	*37.46 (p<0.0291)*		

Note: Results are for the Pooled regression model.

**** significant at 1% level; ** significant at 5% level; *significant at 10% level*

6.5. Summary

This chapter reveals that the intensity of treatment buddy support declined over the treatment career for all three outcomes. A decline in intensity of treatment buddy support is indicative of health improvements among patients on treatment, but may also be an indication of the possible need for other types of support among patients who have been on treatment for longer.

Past access or changes in access to support did influence the frequency of treatment buddy visits. Daily visits were more common among patients who had access to an emotional caregiver, while transitions from daily to irregular visits were lower and transitions from irregular to daily visits were more common among patients who had access to an emotional caregiver. Daily visits were also common among patients who had access to a physical caregiver. Furthermore, transitions from irregular to daily treatment buddy visits were more common among patients who had access to a community health worker and a support group. Past access to a physical caregiver reduced the odds of gaining/receiving daily treatment buddy visits. This chapter therefore has pointed out the importance of various forms of social support in influencing the intensity of treatment buddy visits. Moreover, there was association between household size and the intensity of visits. Patients from larger households were more likely to have received daily rather than irregular treatment buddy visits, which highlights the important role of household members in providing the necessary adherence support to ART clients.

Having a partner increased the odds of receiving daily visits. The multivariate results indicated that patients who had partners were more likely to gain daily treatment buddy visits. Among treatment buddy characteristics, gender of treatment buddy, attendance of drug readiness training, and the treatment buddy's relationship with the patient, were associated with daily treatment buddy visits. The attendance of drug readiness training was consistently associated with the intensity of support, which confirms the hypothesis that having a treatment buddy may not be important in itself, but that characteristics of treatment buddies may actually matter more in terms of achieving optimal adherence support. Transitions from irregular to daily visits were common among patients whose treatment buddies attended the drug readiness training, while there were also fewer transitions from daily to irregular visits among patients whose treatment buddies attended drug readiness. Moreover, daily visits were more likely among patients who chose their own treatment buddies compared to patients who were assigned a treatment buddy.

CHAPTER 7
ADHERENCE KNOWLEDGE

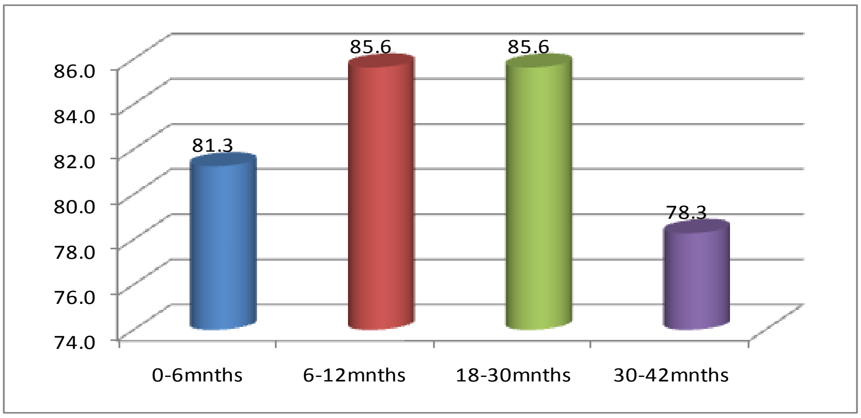
7.1 Introduction

The focus of this chapter is on establishing how access to a treatment buddy and treatment buddy characteristics impact on adherence/medication knowledge. This chapter also sets out to determine whether or not the hypothesis holds, that patients who have a treatment buddy and/or are visited regularly may have better adherence or medication knowledge compared to patients without a treatment buddy. Bivariate analyses are performed, then followed by multiple regression analyses.

The chapter explores three main outcomes, namely (i) the role of treatment buddy access and characteristics in explaining current adherence knowledge to their role in explaining transitions in adherence knowledge over time from (ii) transitions from perfect to imperfect adherence knowledge and (iii) transitions from imperfect to perfect adherence knowledge, respectively. Bivariate analyses on how these adherence knowledge outcomes differ by need for support; access to a treatment buddy and treatment buddy characteristics is performed. This is followed by multiple regression analyses, exploring e the role of the former outcomes in predicting adherence knowledge.

7.2 Adherence knowledge

Figure 7.1: Perfect adherence knowledge, by treatment career phase (n=945)



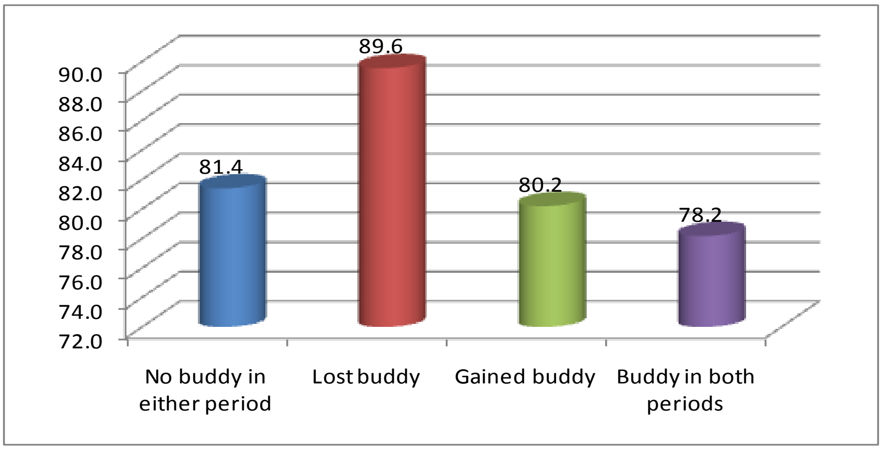
Note: Results are statistically significant at the 10% level (chi2=6.71, p=0.081).

Figure 7.1 demonstrates that the proportion of patients with perfect adherence knowledge varied significantly but weakly by treatment duration (p<0.10). Perfect adherence knowledge increased as treatment duration increased, but declined again at 30-42 months on treatment. Hence, perfect adherence knowledge was low among patients who had just started treatment and lowest among patients who had been on treatment for more than 30 months.

7.2.1 Current adherence knowledge and access to a treatment buddy

This section establishes how access to treatment buddy may impact on current adherence knowledge.

Figure 7.2: Perfect adherence knowledge, by transitions in access to a treatment buddy (n=779)



Note: Results are not statistically significant (chi2=430, p=0.230).

Perfect adherence knowledge did not vary significantly by transitions in access to a treatment buddy. However, perfect adherence knowledge was highest among patients who previously had access to a treatment buddy, but did not have a buddy any longer, which suggests that these patients were provided with information when they still had treatment buddies. Perfect adherence was lowest among patients who had access to treatment buddies. This raises questions about the role of treatment buddies in providing information about the importance of adherence, which in turn may improve adherence to treatment. However, differences in adherence knowledge by transitions in access to treatment buddy support are not statistically significant, with the result that one should not read too much into these somewhat contradictory results.

7.2.2 Current adherence knowledge and treatment buddy characteristics

This section assesses how treatment buddy characteristics may impact on current adherence knowledge.

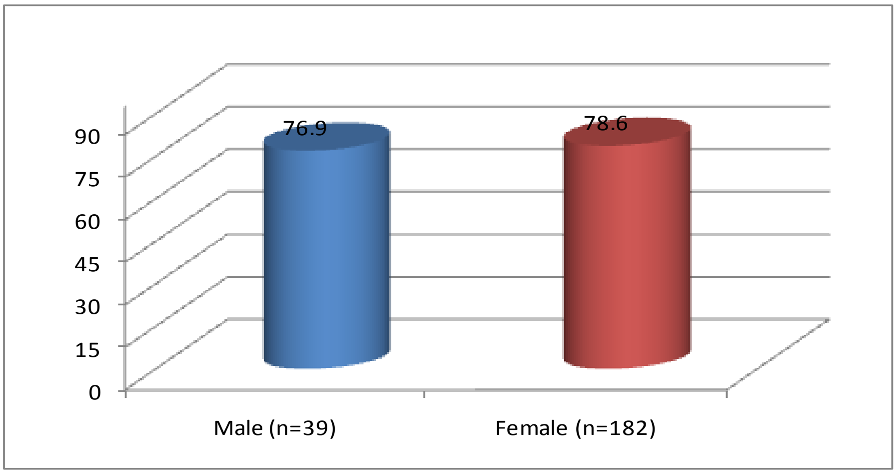
Table 7.1: Age of treatment buddy, by perfect adherence knowledge

Current adherence knowledge	**Summary of age of a treatment buddy**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
Imperfect	31.84	18.00	20	40	32	1	89	45
Perfect	33.22	16.18	21	46	32	2	78	171
Total	**32.93**	**16.54**	**21**	**44.5**	**32**	**1**	**89**	**216**

Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (F=0.25, p=0.620).

Perfect adherence knowledge did not differ significantly by age of treatment buddy. Perfect knowledge was higher among patients who had older treatment buddies, suggesting that younger treatment buddies may not have the necessary knowledge, but results were not statistically significant.

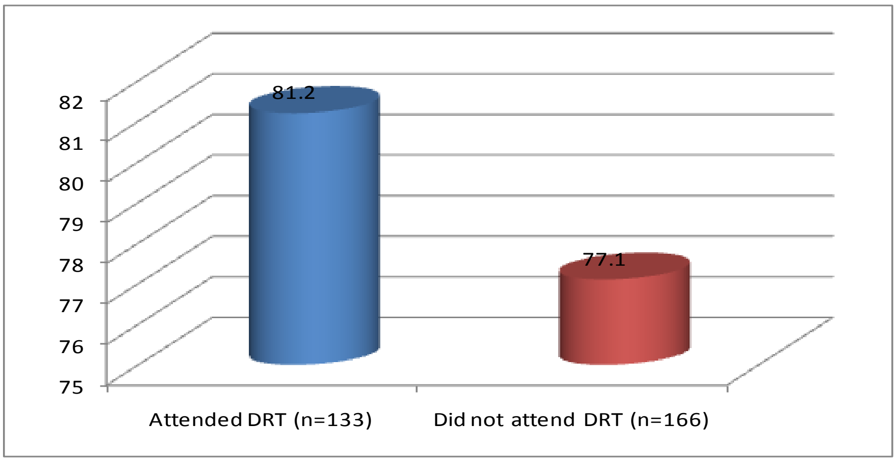
Figure 7.3: Perfect adherence knowledge, by gender of a treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=0.05, p=0.830).

Adherence knowledge did not vary significantly by gender of the treatment buddy. However, slightly more patients with female treatment buddies reported perfect adherence knowledge compared to patients whose treatment buddies were male.

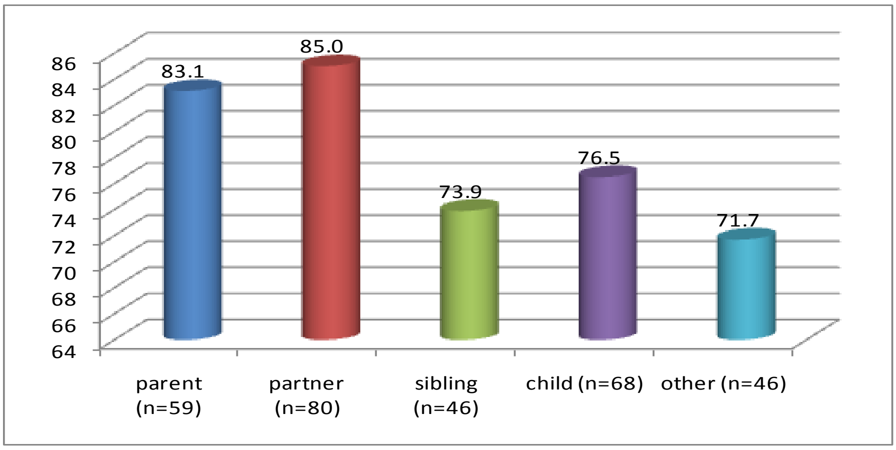
Figure 7.4: Perfect adherence knowledge, by attendance of drug readiness training



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=0.74, p=0.388).

Adherence knowledge also did not differ significantly by attendance of drug readiness training among treatment buddies. According to Figure 7.4, perfect adherence knowledge, as expected, was slightly higher among patients whose treatment buddies did attend drug readiness training (81%), compared to patients whose treatment buddies did not attend the drug readiness training (77%).

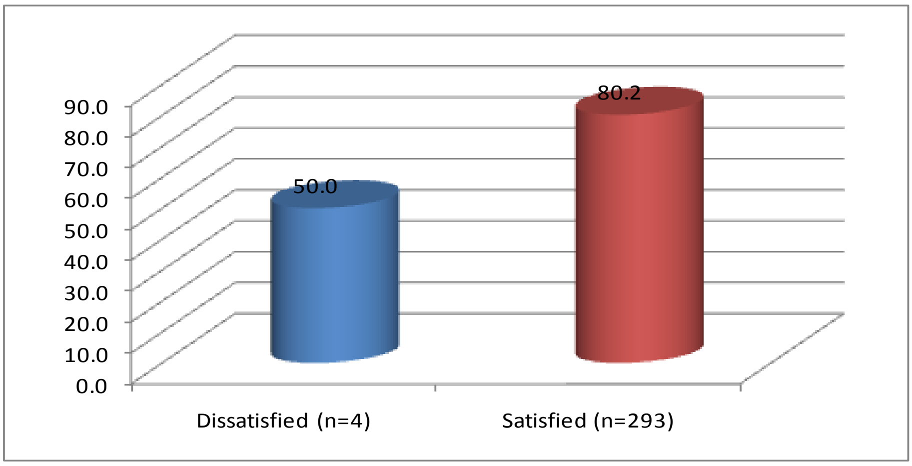
Figure 7.5: Perfect adherence knowledge, by relationship with a treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=4.74, p=0.314).

Perfect adherence knowledge did not vary significantly with the treatment buddy's relationship with the patient. Even though these results are not statistically significant, perfect adherence knowledge was highest among patients whose treatment buddies were partners or parents, which may be due to the possibility that patients in this case are more likely to reside with these relations. According to Figure 7.5, perfect adherence knowledge was lowest among patients whose treatment buddies were not close family members, but more distant relations, friends or colleagues at work.

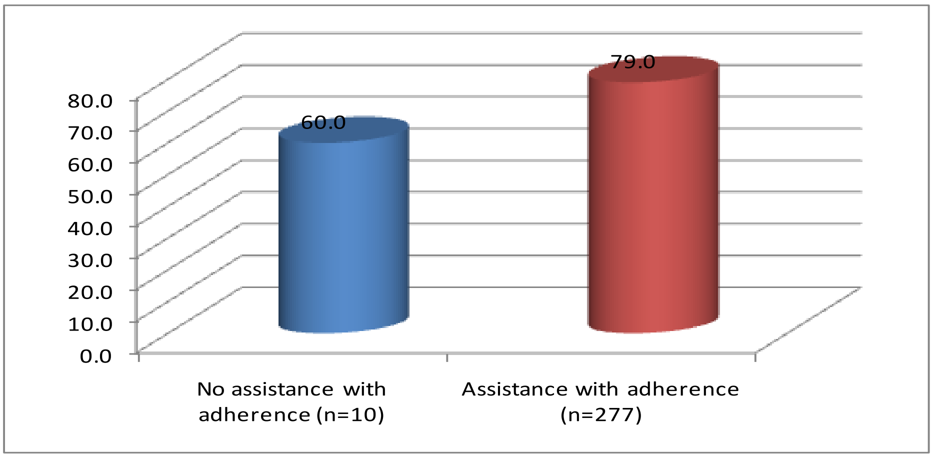
Figure 7.6: Perfect adherence knowledge, by satisfaction with a treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=2.23, p=0.135).

According to Figure 7.7, adherence knowledge did not differ significantly by satisfaction with the support provided by a treatment buddy. Nevertheless, adherence knowledge, as expected, was higher among patients who were satisfied with support provided by a treatment buddy and lower among patients dissatisfied with the support from their treatment buddy.

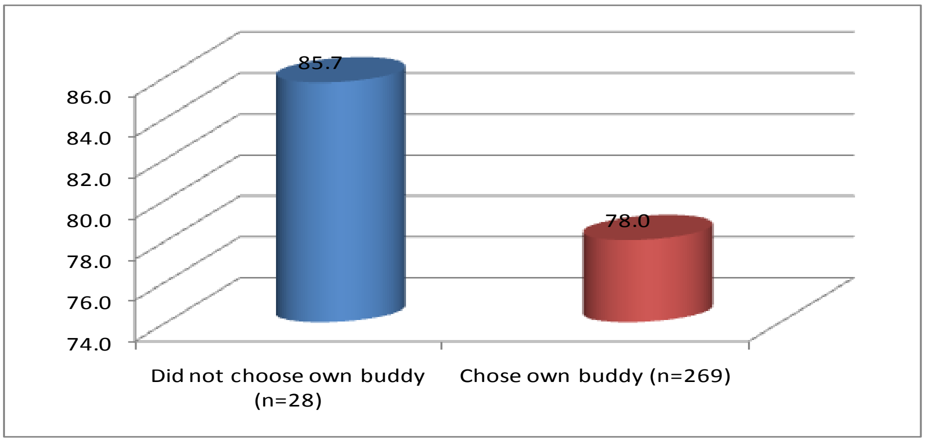
Figure 7.7: Perfect adherence knowledge, by assistance with adherence



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=2.07, p=0.150).

Although not statistically significant, perfect adherence knowledge, as expected, is higher among patients who received assistance with adherence from their treatment buddy and lower among patients who did not receive assistance specifically with adherence (Figure 7.7). This result implies that adherence assistance perhaps included the provision of information concerning the medication and the importance of adherence, thus resulting in higher levels of adherence knowledge.

Figure 7.8: Perfect adherence knowledge, by choice of a treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=0.88, p=0.346).

Perfect adherence knowledge did not vary significantly by choice of treatment buddy (Figure 7.8). Yet, perfect adherence knowledge was higher among patients who chose their own treatment buddies when compared to patients who did not choose their own treatment buddies, but were assigned a treatment buddy. This is rather an unexpected result, but it could be true if assigned treatment buddies are not known to patients, which may have an impact on the extent of support provided.

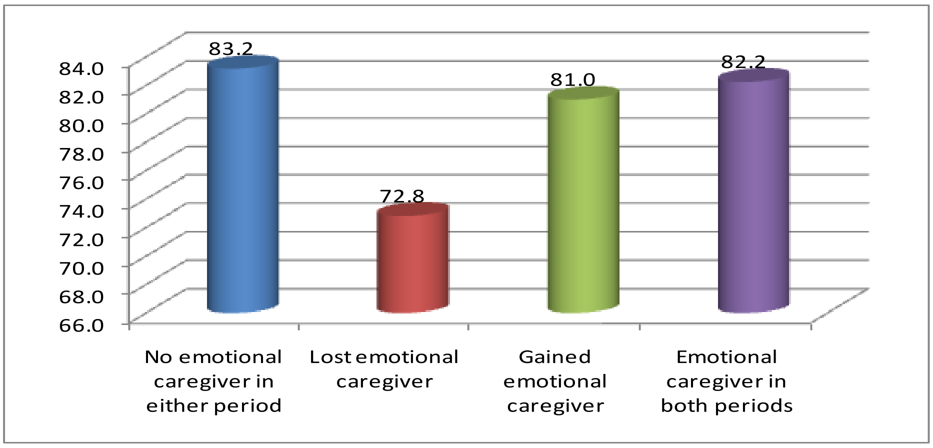
7.3.2 Current adherence knowledge and transitions in access to other support

This section tries to establish the extent of transitions in access to different forms of support and how this impacts on current adherence knowledge.

7.2.3 (a) Transitions in access to an emotional caregiver

Adherence knowledge did not vary significantly by transitions in access to an emotional caregiver (Figure 7.9). However, perfect adherence knowledge was lower among patients who actually lost access to an emotional caregiver. Furthermore, perfect adherence knowledge was higher, irrespective of whether patients had access to an emotional caregiver in neither period or in both periods.

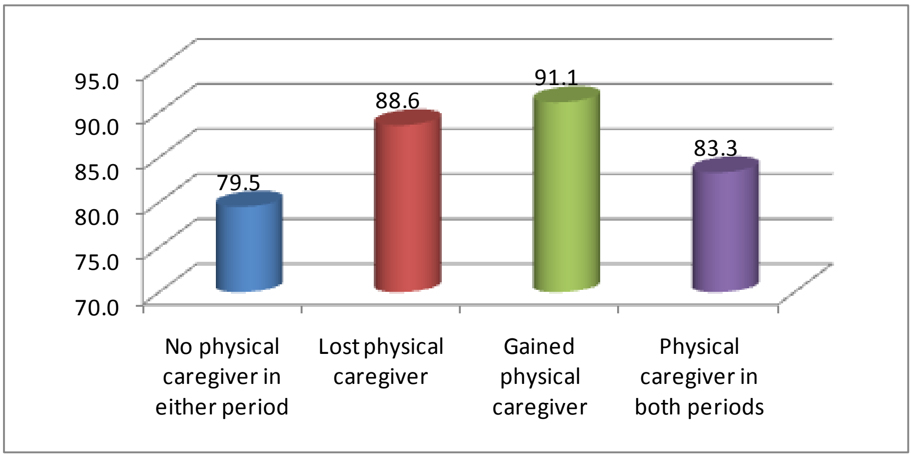
Figure 7.9: Perfect adherence knowledge, by transitions in access to an emotional caregiver (n=783)



Note: Results are not statistically significant (chi2=5.83, p=0.120).

7.2.3. (b) Transitions in access to a physical caregiver

Figure 7.10: Perfect adherence knowledge, by transitions in access to a physical caregiver (n=785)

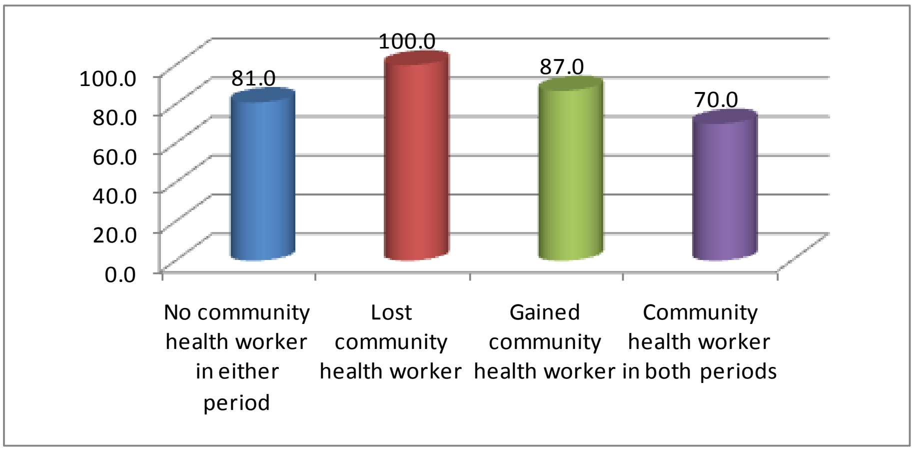


Note: Results are statistically significant at the 10% level (chi2=7.70, p=0.052).

Figure 7.10 shows significant differences in perfect adherence knowledge across transitions in access to a physical caregiver ($p<0.10$). According to the results, perfect adherence knowledge was more common among patients who gained access to a physical caregiver or had lost a physical caregiver in both period or in the recent past. Perfect adherence knowledge was lowest however among patients who did not have access to a physical caregiver in either period. This result makes sense, as it is expected that a physical caregiver would impart some knowledge, hence the higher knowledge among all those that at some stage had access to a physical caregiver.

7.2.3. (c) Transitions in access to a community health worker

Figure 7.11: Perfect adherence knowledge, by transitions in access to a community health worker (n=785)



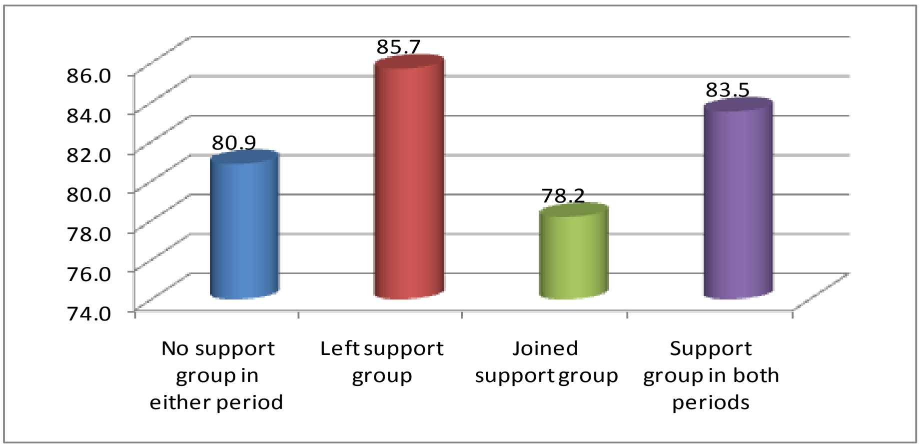
Note: Results are not statistically significant (chi2=3.90, p=0.272).

Perfect adherence knowledge did not differ significantly by transitions in access to a community health worker (Figure 7.11). Perfect adherence knowledge was however, highest among patients who previously received community health worker visits and lowest among patients who had community health worker visits in both periods. However, differences in adherence knowledge by transitions in access to a community health worker are not statistically significant, with the result that one should not read too much into these somewhat contradictory results.

7.2.3. (d) Transitions in participation in a support group

According to Figure 7.12, adherence knowledge did not differ significantly by transitions in participation in a support group. Perfect adherence knowledge was highest among patients who recently stopped participating in a support group and almost as high among patients who were members of a support group in both periods. These results make sense; it is expected that patients who are part of a support group would have higher adherence knowledge.

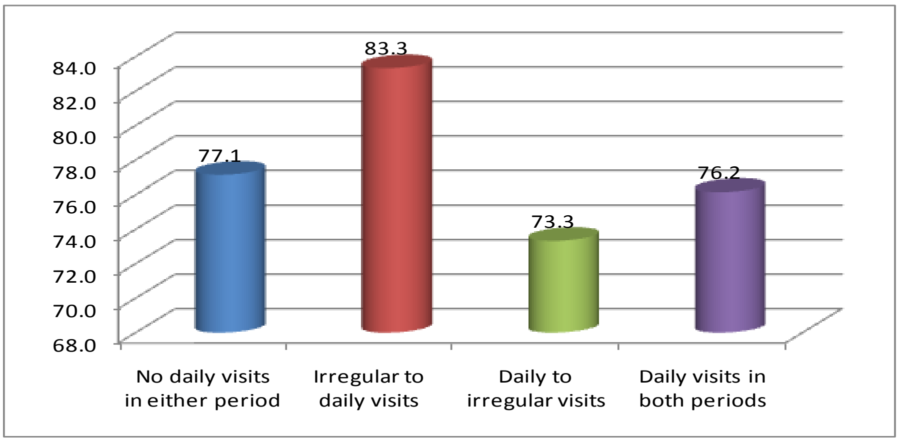
Figure 7.12: **Perfect adherence knowledge, by transitions in participation in a support group (n=785)**



Note: Results are not statistically significant (chi2=1.32, p=0.723).

7.2.4 Current adherence knowledge and intensity of treatment buddy support

Figure 7.13: Perfect adherence knowledge, by transitions in the frequency of treatment buddy support (n=171)



Note: Results are not statistically significant (chi2=0.411, p=0.938).

Figure 7.13 shows that perfect adherence knowledge did not differ significantly by transitions in the frequency of past treatment buddy visits. As expected, however, perfect adherence knowledge was most likely among patients who started receiving daily visits and least likely among patients who stopped receiving daily visits. This result makes sense that adherence knowledge is most likely among patients who started receiving daily visits, because it is expected that knowledge and information would be shared between treatment buddy and patient during the daily visits. Perfect adherence knowledge was also higher among patients who received daily visits in both periods, but not very different from levels of adherence knowledge in patients who received irregular visits only in both periods.

7.2.4. Determinants of current adherence knowledge

Two different approaches are followed in investigating the determinants of current adherence knowledge. Firstly, a regression analysis is used to investigate need and access to support as determinants of current adherence knowledge and secondly, a regression analysis investigates treatment buddy characteristics as determinants of current adherence knowledge. However, with reference to the latter, none of the regression models performed adequately in terms of goodness-of-fit and none of the treatment buddy variables were significant predictors of current perfect adherence knowledge. Therefore the regression results reported in this section are for the former.

7.2.4. (a) Need and access to support as determinants of current adherence knowledge

Table 7.2 reports the results of the pooled regression model. This model performed well in terms of overall fit ($p<0.05$). The fixed effects (FE) model could not be estimated, however, the random effects (RE) model was the best model according to the diagnostic test, but did not perform well in terms of overall fit ($p=0.400$).

Table 7.2: Need and access to support as determinants of current perfect adherence knowledge

Independent variables	Odds ratio
1. Sociodemographic variables	
Age	0.894
Age2	1.001
Female (*male=0/female=1)*	1.846 ***
Marital status	
[comparison group=single]	
No living with partner	1.399
Living with partner	2.352 ***
Educational status	
[comparison group=no formal education]	
Primary education	0.825
Secondary education	0.959
Grade 12	1.083
Tertiary education	4.152
2. Need variables	
Treatment career	
[comparison group=0-6months]	
6-12months	1.513
18-30months	1.456
30-42months(omitted)	
3. Access to support variables	
Transitions in access to treatment buddy	
[comparison group=no treatment buddy in either period]	
Lost treatment buddy	1.256
Gained treatment buddy	0.649
Had treatment buddy in both periods	0.656 *
Transitions in access to emotional carer	
[comparison group=no emotional carer in either period]	
Lost emotional carer	0.473 ***
Gained emotional carer	0.630 *
Had emotional carer in both periods	0.766
Transitions in access to physical carer	
[comparison group=no physical carer in either period]	
Lost physical carer	1.509
Gained physical carer	2.058 *
Had physical carer in both periods	1.079
Transitions in access to community health worker	
[comparison group=no community health worker in either period]	
Lost community health worker (omitted)	
Gained community health worker	1.065
Had community health worker in both periods	0.458
Transitions in participation in support groups	
[comparison group=no participation in either period]	
Stopped participating	1.693
Started participating	0.934
Participated in both periods	1.513
Sample size	*746*
Wald chi2 (p)	*27.16 (p=0.400)*
LR chi2 (p)	*41.74 (p=0.019)*
$H_{0:}$ pooled model vs. Ha: RE (LR test)	*16.51 (p<0.001)*

Note: FE could not be estimated. Results are for the Pooled regression model. RE was not appropriate in terms of overall fit.
**** significant at 1% level; ** significant at 5% level; *significant at 10% level*

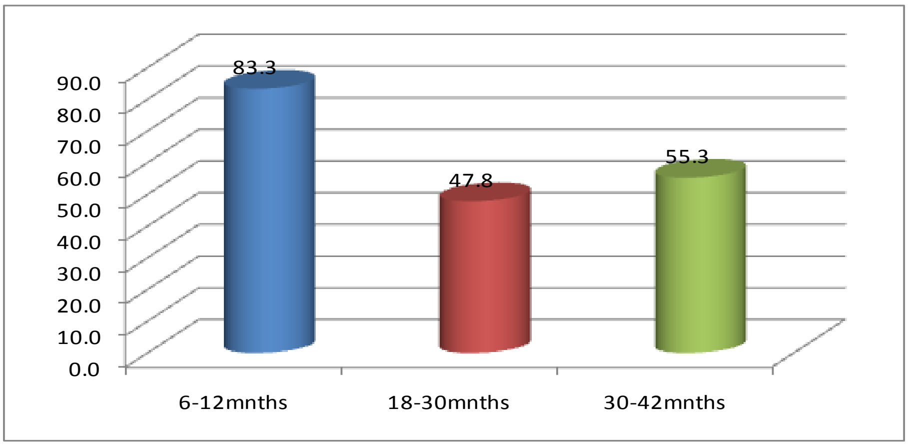
According to the regression output in Table 7.2 above, gender is significant at the 1% level. The odds ratio of 1.84, means that for female patients, the odds of having perfect adherence knowledge is 1.8 times greater than for males. Living with a partner is significant at the 1% level and the odds ratio of 2.35 indicates that patients living with their partners are 2.3 times more likely to have perfect adherence knowledge, compared to single patients Having a treatment buddy in both periods had an odds ratio of 0.65 and was significant at the 10% level. This means that patients who had a treatment buddy in both periods are 50% less likely to have perfect adherence knowledge, compared to those who did not have a treatment buddy in either period. This is rather a contradictory result, since it would be expected that patients who have treatment buddies would have perfect adherence knowledge. A possible reason for this could be that the treatment buddies may not necessarily focus on sharing with and providing information for patients.

Losing access to an emotional caregiver was significant at the 1% level and has an odds ratio of 0.47, which means that the odds of having perfect adherence knowledge is 95% lower for patients who lost access to an emotional caregiver compared to patients who did not have an emotional caregiver in either period. Gaining access to an emotional caregiver in turn was significant at the 10% level and has an odds ratio of 0.63. This result means that an odds of having perfect adherence knowledge is 50% lower for patients who gained access to an emotional caregiver, compared to patients without an emotional caregiver in either period. Gaining access to a physical caregiver was significant at the 10% level and has an odds ratio of 2.05, which means that patients who gained access to physical caregivers are 2 times more likely to have perfect adherence knowledge, compared to patients who did not have a physical caregiver in either period.

7.3. Transitions from perfect to imperfect adherence knowledge

Transitions from perfect to imperfect adherence knowledge varied significantly by treatment duration ($p<0.05$). Figure 7.14 shows that transitions from perfect to imperfect adherence knowledge declined as treatment duration increased. Transitions from perfect to imperfect adherence knowledge were common among patients who had been on treatment for six to twelve months. This result is expected - adherence knowledge among patients who just initiated treatment could be generally low. Even though transitions from perfect to imperfect adherence knowledge were uncommon among patients who had been on treatment for 18 to 30 months, there were increases in transitions from imperfect to perfect adherence knowledge among patients who had been on treatment for more than 30 months. A decline in transitions from perfect to imperfect adherence knowledge would be expected among patients who have been on treatment for longer, but an increase is a rather unexpected result.

Figure 7.14: Transitions from perfect to imperfect adherence knowledge, by treatment career phase n=138)



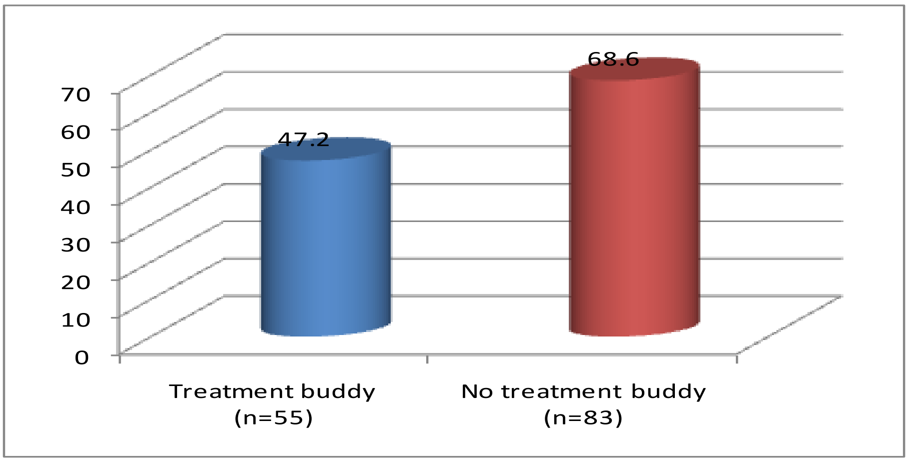
Note: Results are statistically significant at the 5% level (chi2=9.01, p=0.011).

7.3.1 Transitions from perfect to imperfect adherence knowledge and access to a treatment buddy

In this section, the focus is on how transitions from perfect to imperfect adherence knowledge impact on transitions in access to a treatment buddy.

7.3.1. (a) Past access to a treatment buddy

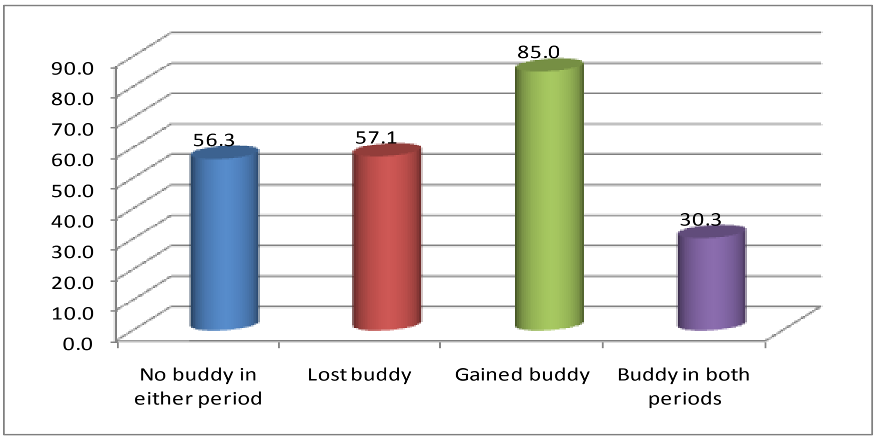
Figure 7.15: Transitions from perfect to imperfect adherence knowledge, by past access to a treatment buddy



Note: Results are statistically significant at the 5% level (chi2=6.32, p=0.012).

Transitions from perfect to imperfect adherence knowledge varied significantly by past access to a treatment buddy ($p<0.05$). According to Figure 7.15, patients who previously had a treatment buddy are less likely to have experienced a transition from perfect to imperfect adherence knowledge, which was significantly more common among those without a treatment buddy in the past. This finding highlights the potentially important role of treatment buddies in providing adherence support and in imparting adherence knowledge to their patients.

Figure 7.16: Transitions from perfect to imperfect adherence knowledge, by past transitions in access to a treatment buddy (n=108)



Note: Results are statistically significant at the 1% level (chi2=15.30, p=0.002).

Transitions from perfect to imperfect adherence knowledge varied significantly by past transitions in access to a treatment buddy ($p<0.01$). Figure 7.16 indicates that patients who previously gained access to a treatment buddy are more likely to have experienced a transition from perfect to imperfect adherence knowledge, which was significantly more common among those without a treatment buddy in the past. This result is somewhat unexpected as patient would not be expected to transition from perfect to imperfect. Patients who previously lost treatment buddy and patients who had treatment buddies in both periods were more likely to have experienced a transition in knowledge from perfect to imperfect. Furthermore, as expected, patients who had treatment buddies in all periods were less likely to have experienced a transition in knowledge from perfect to imperfect. This finding is indicative of the importance of treatment buddies in enhancing adherence through the provision of information.

7.3.2 Transitions from perfect to imperfect adherence knowledge and treatment buddy characteristics

In this section, the focus is on how treatment buddy characteristics impact or influence transitions from perfect to imperfect adherence knowledge.

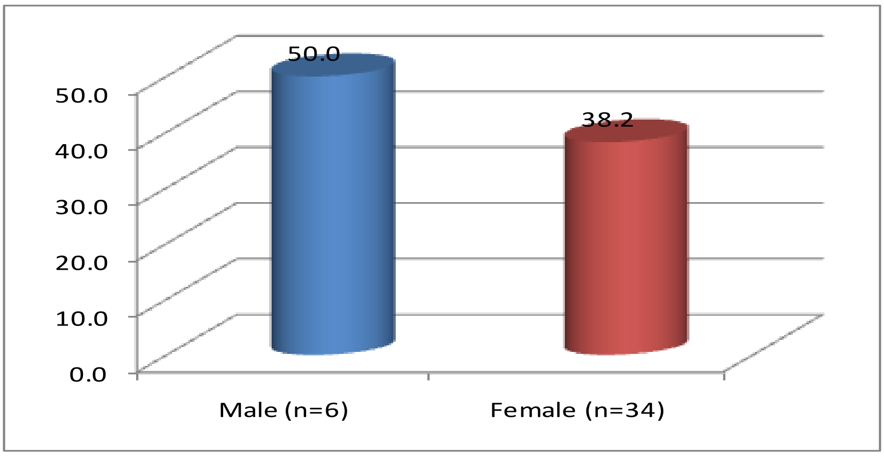
Table 7.3: Age of treatment buddy, by transitions from perfect to imperfect adherence knowledge

Adherence knowledge	Summary of age of a treatment buddy							
	Mean	*SD*	*p25*	*p75*	*Median*	*Min*	*Max*	*Frequency*
Perfect knowledge in both periods	31.52	16.19	20	40	33	1	68	23
Imperfect knowledge	30.86	15.67	18	48	30	12	57	15
Total	**31.26**	**15.77**	**19**	**40**	**32.5**	**1**	**68**	**38**

Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (F=0.02, p=0.902).

According to Table 7.3, age of treatment buddy did not vary by transitions from perfect to imperfect adherence knowledge. The mean ages of treatment buddies for patients who transitioned from perfect to imperfect adherence knowledge was lower compared to the age of treatment buddies of patients who had perfect knowledge in both periods. Therefore, treatment buddies of patients who transitioned from perfect to imperfect knowledge were younger. However, these results are not significant.

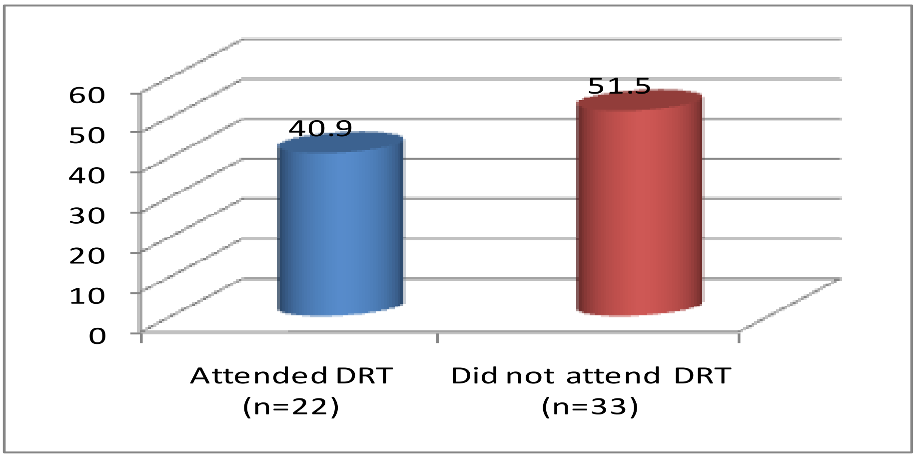
Figure 7.17: Transitions from perfect to imperfect adherence knowledge, by gender of treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=0.29, p=0.588).

Figure 7.17 demonstrates that the gender of the treatment buddy did not vary significantly by transitions from perfect to imperfect adherence knowledge. However, transitions from perfect to imperfect adherence knowledge were common among patients whose treatment buddies were male, but these results are, however, not significant.

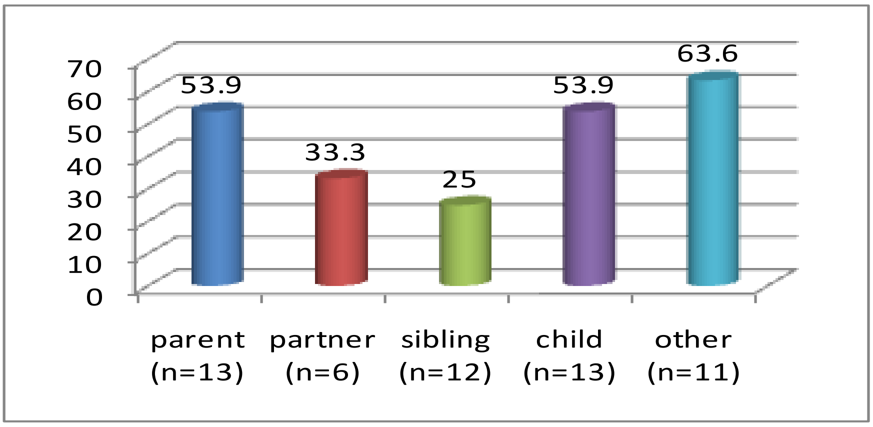
Figure 7.18: Transitions from perfect to imperfect adherence knowledge, by attendance of drug readiness training



Treatment buddy characteristics as observed in the previous period. Note: Results are not statistically significant (chi2=0.59, p=0.440).

Figure 7.18 shows that transitions from perfect to imperfect adherence knowledge did vary significantly by the treatment buddy's attendance of drug readiness training. Transitions from perfect to imperfect adherence knowledge were common among patients whose treatment buddies did not attend a drug readiness training. This result is expected, as treatment buddies who attended a drug readiness programme are expected to have a higher adherence knowledge which, in turn, may be imparted to patients.

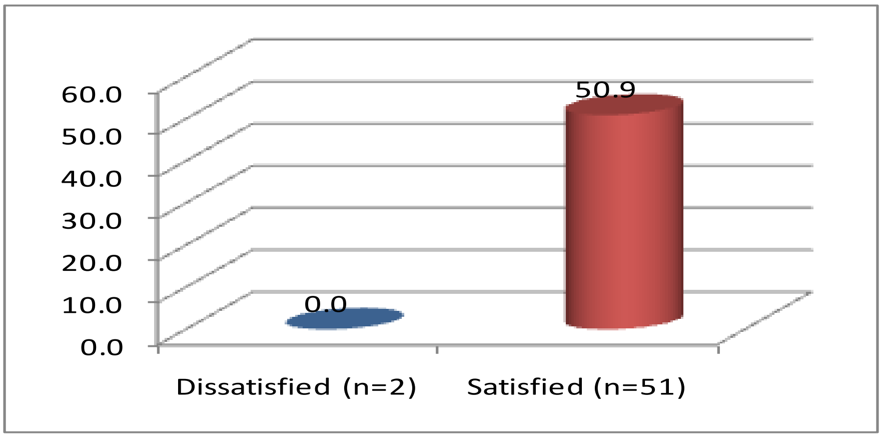
Figure 7.19: Transitions from perfect to imperfect adherence knowledge, by relationship with a treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=4.48, p=0.344).

Figure 7.19 shows that transitions from perfect to imperfect adherence knowledge did not vary significantly by past transitions in access to a treatment buddy. However, transitions from perfect to imperfect adherence knowledge were mostly common among patients whose treatment buddies were more distant than others. Transitions from perfect to imperfect adherence knowledge were uncommon among patients whose treatment buddies were family members. These results suggest that family members may have mostly provided adherence information to their patients.

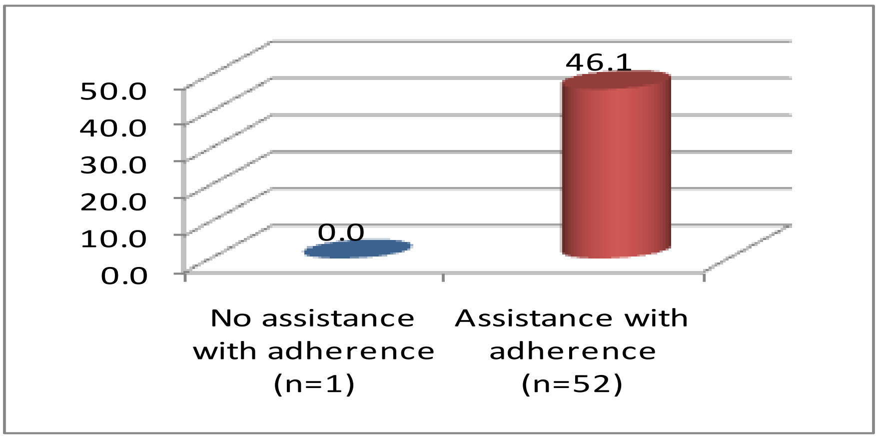
Figure 7.20: Transitions from perfect to imperfect adherence knowledge, by satisfaction with a treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=2.00, p=0.157).

Transitions from perfect to imperfect adherence knowledge did not vary significantly by satisfaction with support provided by a treatment buddy. Figure 7.20 indicates that transitions from perfect to imperfect knowledge was common among patients who were satisfied with support provided by treatment buddies, while none of the patients who were dissatisfied with the support given by their treatment buddy experienced a transition from perfect to imperfect adherence knowledge.

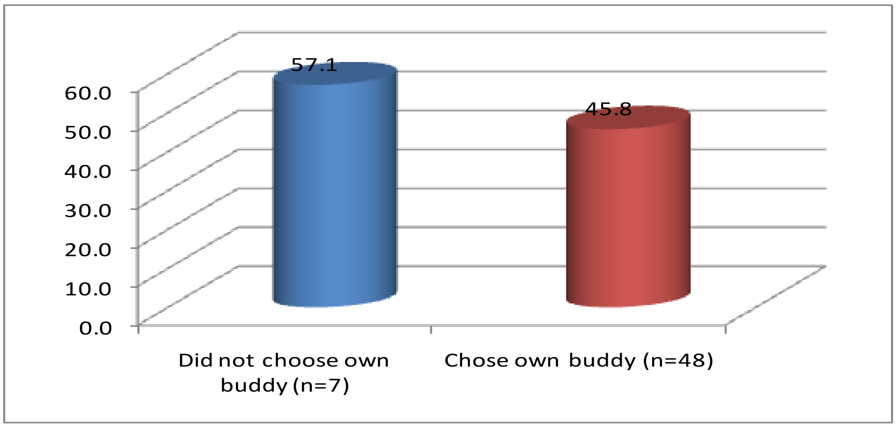
Figure 7.21: Transitions from perfect to imperfect adherence knowledge, by assistance with adherence



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=0.84, p=0.358).

Figure 7.21 shows that transitions from perfect to imperfect adherence knowledge did not vary significantly by assistance with adherence by a treatment buddy. Although, insignificantly, transitions from perfect to imperfect adherence knowledge was common among patients who received assistance with adherence by treatment buddies, none of the patients who reported not receiving assistance with adherence experienced a transition from perfect to imperfect adherence knowledge. These results are rather contradictory; transitions from perfect to imperfect would be expected to be low among patients who receive adherence support from treatment buddies.

Figure 7.22: Transitions from perfect to imperfect adherence knowledge, by choice of a treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=0.31, p=0.576).

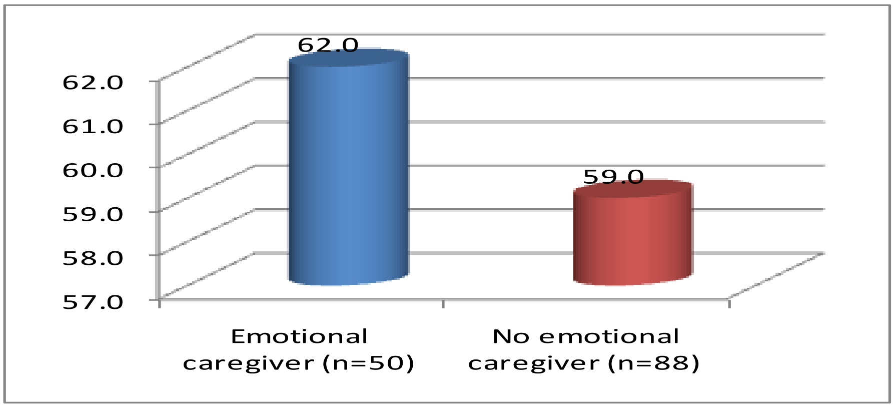
There was no significant association between transitions from perfect to imperfect knowledge and the choice of treatment buddy (Figure 7.22). Transitions from perfect to imperfect adherence knowledge were more common among patients who did not choose their own treatment buddy. This result suggests that assigned treatment buddies might not have focused on sharing or providing adherence information with patients.

7.3.3 Transitions from perfect to imperfect adherence knowledge and changes in access to other support

This section focused on how changes in access to other support impacted on transitions from perfect to imperfect adherence knowledge.

7.3.3. (a) Past access to an emotional caregiver

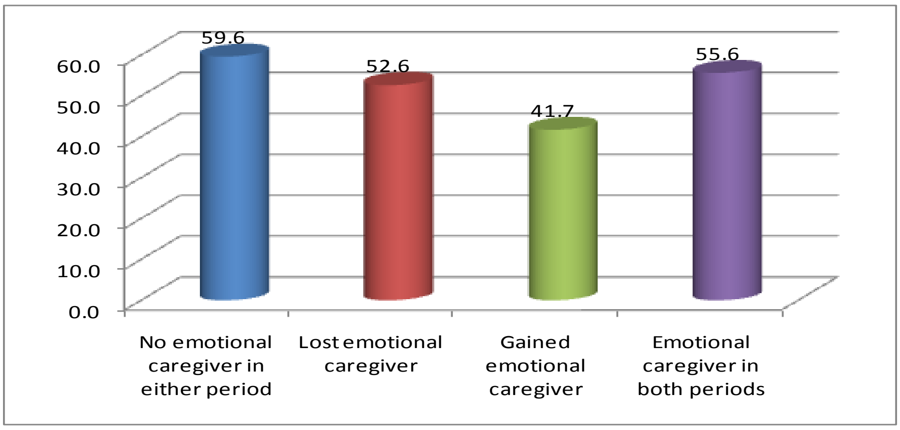
Figure 7.23: Transitions from perfect to imperfect adherence knowledge, by past access to an emotional caregiver



Note: Results are not statistically significant (chi2=0.11, p=0.737).

Transitions from perfect to imperfect adherence knowledge did not vary significantly by past access to an emotional caregiver. Figure 7.23 demonstrates transitions from perfect to imperfect knowledge were more common among patients who in the past had an emotional caregiver than among patients without an emotional caregiver. These results are rather unexpected, as it would be expected that transitions from perfect to imperfect adherence knowledge would be more common among patients who did not have an emotional caregiver in the past, albeit these differences are not statistically significant.

Figure 7.24: Transitions from perfect to imperfect adherence knowledge, by past transitions in access to an emotional caregiver (n=108)



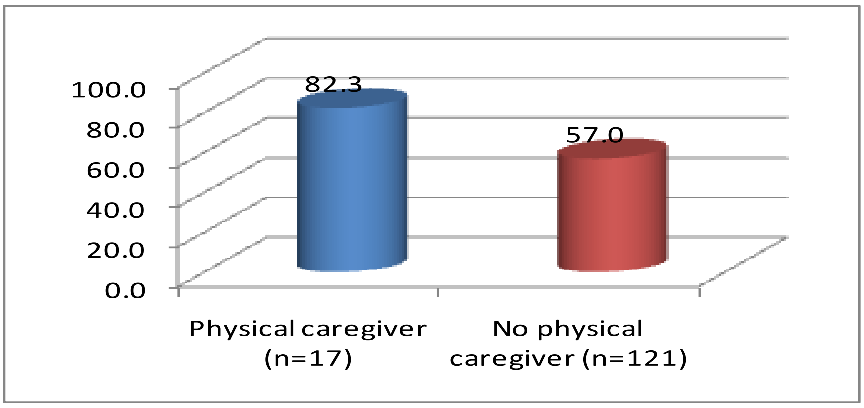
Note: Results are not statistically significant (chi2=2.08, p=0.555)

According to Figure 7.24, transitions in access to an emotional caregiver did not impact significantly on transitions from perfect to imperfect adherence knowledge. Transitions from perfect to imperfect adherence knowledge were more common among patients who did not have emotional caregivers in either period and among patients who had emotional caregivers in both periods. This result suggests that the focus of emotional caregivers might not have been to provide or share adherence information with patients. More common transitions from perfect to imperfect adherence knowledge among patients who lost emotional caregivers and among patients who did not have physical caregivers in either period, makes sense, as it would be expected that lack of support would impact on transitions in adherence knowledge. As expected, transitions from perfect to imperfect adherence knowledge are low among patients who in the past gained access to an emotional caregiver.

7.3.3. (b) Past access to a physical caregiver

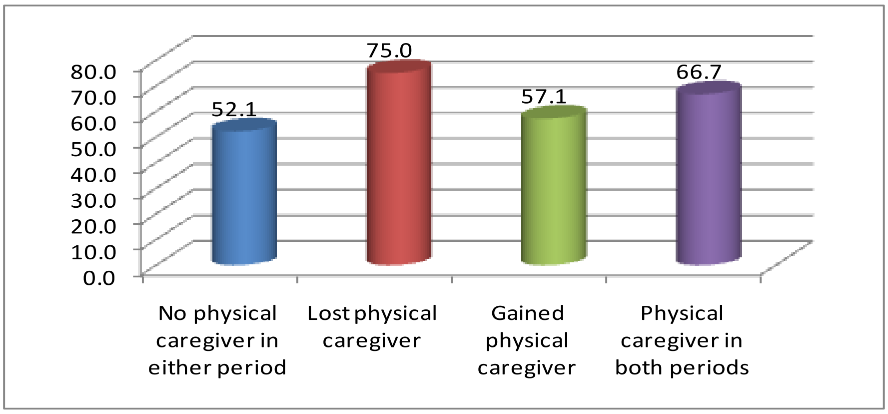
Figure 7.25 shows that transitions from perfect to imperfect adherence knowledge varied significantly by past access to a physical caregiver ($p<0.05$). Transitions from perfect to imperfect adherence knowledge were more common among patients who had access to a physical caregiver. These results are rather contradictory; transitions from perfect to imperfect would be expected to be low among patients who have access to a physical caregiver. Possible explanations for this could be linked to physical limitations, if patients accessing physical supporters are not fit to comprehend information provided or maintained by physical caregivers maintaining their knowledge. Physical caregivers themselves may lack information about adherence.

Figure 7.25: Transitions from perfect to imperfect adherence knowledge, by past access to a physical caregiver



Note: Results are statistically significant at the 5% level (chi2=3.98, p=0.046).

Figure 7.26: Transitions from perfect to imperfect adherence knowledge, by past transitions in access to a physical caregiver (n=108)

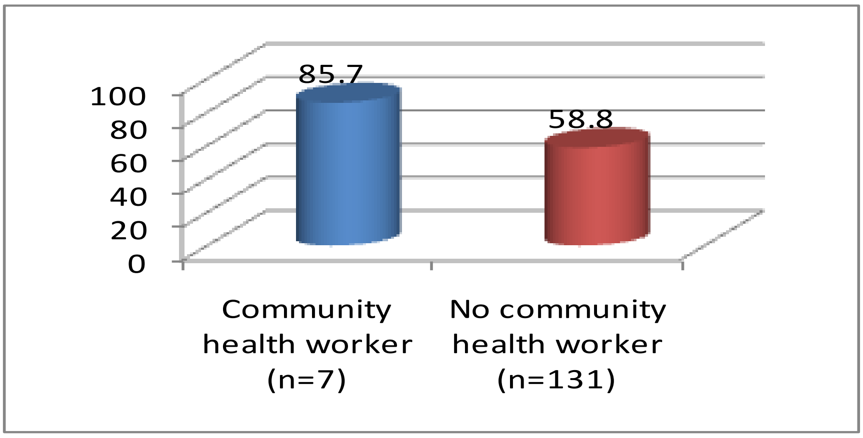


Note: Results are not statistically significant (chi2=1.05, p=0.787).

Figure 7.26 indicates that transitions in access to a physical caregiver did not impact significantly on transitions from perfect to imperfect adherence knowledge. Transitions from perfect to imperfect adherence knowledge were common among patients who lost access to a physical caregiver (75%) and lowest among patients who did not have access to a physical caregiver in both periods (52%). As expected, transitions from perfect to imperfect adherence knowledge were low among patients who gained access to a physical caregiver (57%). In addition, transitions from perfect to imperfect adherence knowledge were common among patients who had physical caregivers in both periods (67%). This is rather an unexpected result, but differences are not significant.

7.3.3. (c) Past access to a community health worker

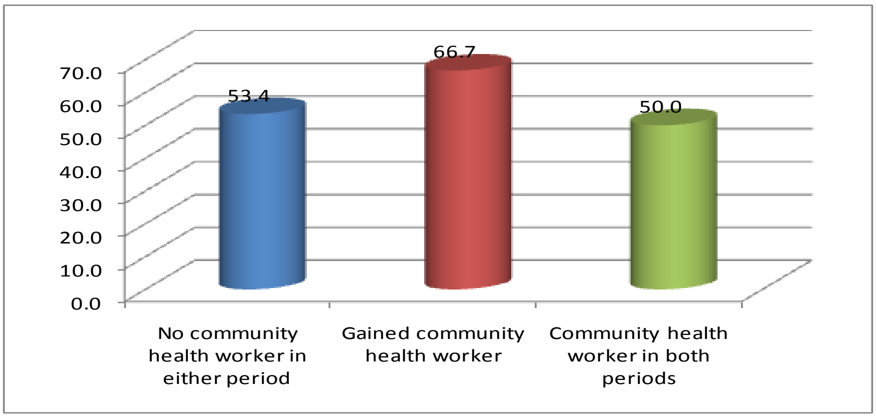
Figure 7.27: Transitions from perfect to imperfect adherence knowledge, by past access to a community health worker



Note: Results are not statistically significant (chi2=2.01, p=0.156).

Past access to community health workers did not impact significantly on transitions from perfect to imperfect adherence knowledge. Transitions from perfect to imperfect adherence knowledge were common among patients who previously had access to a community health worker. This is a rather unexpected result, since community health workers are expected to provide and share information about medication and adherence with patients.

Figure 7.28: Transitions from perfect to imperfect adherence knowledge, by past transitions in access to a community health worker (n=108)

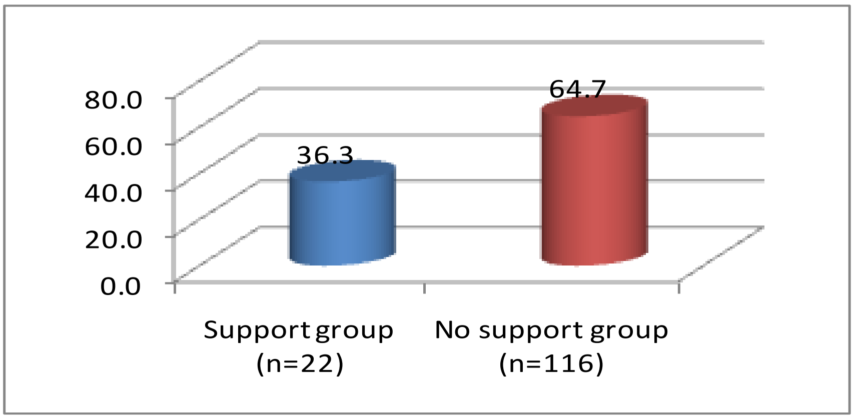


Note: Results are not statistically significant (chi2=2.17, p=0.897).

Figure 7.28 indicates that transitions in access to a community health worker did not impact significantly on transitions from perfect to imperfect adherence knowledge. Transitions from perfect to imperfect adherence knowledge were common among patients who gained access to a community health worker (67%) and lowest among patients who had access to a community health worker for both periods (50%). This is rather an unexpected result and raises questions about the role of community health workers in providing information about adherence. Differences in these results, however, are not significant.

7.3.3. (d) Past participation in a support group

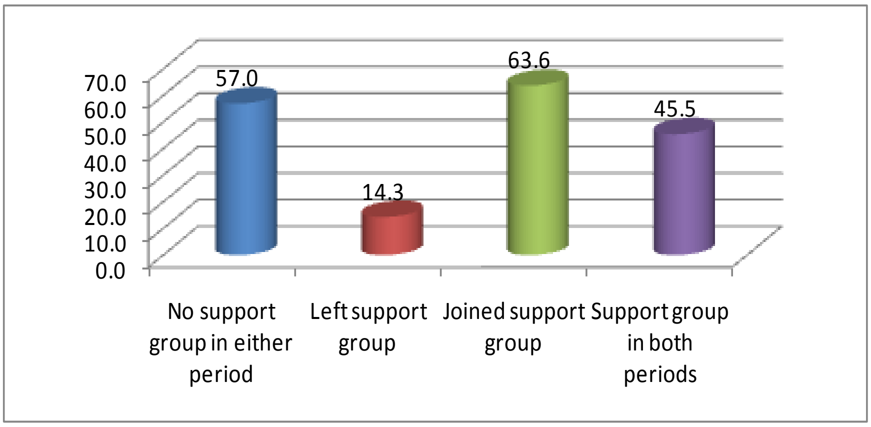
Figure 7.29: Transitions from perfect to imperfect adherence knowledge, by past participation in a support group



Note: Results are statistically significant at the 5% level (chi2=6.17, p=0.013).

According to Figure 7.29, past participation in a support group impacted significantly on transitions from perfect to imperfect adherence knowledge ($p<0.05$). As expected, patients who did not participate in a support group were more likely to have their knowledge change from perfect to imperfect ($p<0.05$). This finding highlights the potential importance of support groups in providing and maintaining information about antiretroviral treatment and the importance of adherence.

Figure 7.30: Transitions from perfect to imperfect adherence knowledge, by past transitions in participation in a support group (n=108)



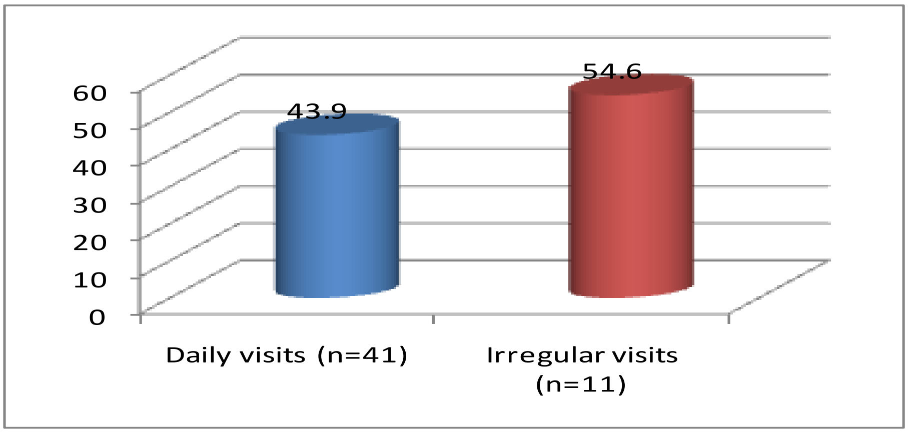
Note: Results are not statistically significant (chi2=5.44, p=0.142).

According to Figure 7.30, transitions in participation in support groups did not significantly impact on transitions from perfect to imperfect adherence knowledge. Transitions from perfect to imperfect adherence knowledge was common among patients who joined support groups (66%) and lowest among patients who discontinued participating in a support group. Common transitions from perfect to imperfect adherence knowledge among patients who did not participate in a support group make sense, although these differences are not significant.

7.3.4 Transitions from perfect to imperfect adherence knowledge and intensity of treatment buddy support

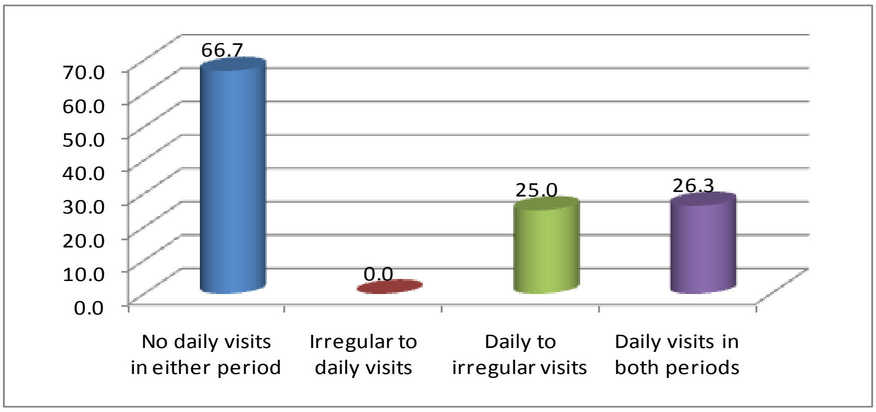
According to Figure 7.31, frequency of treatment buddy support did not significantly impact on transitions from perfect to imperfect adherence knowledge. Patients who in the past received irregular visits are more likely to have seen their knowledge change from perfect to imperfect than a patient receiving daily visits. These results highlight the importance of frequent or daily visits by treatment buddies in order to maintain patients' adherence knowledge.

Figure 7.31: Transitions from perfect to imperfect adherence knowledge, by past frequency of treatment buddy support



Note: Results are not statistically significant (chi2=0.39, p=0.530).

Figure 7.32: Transitions from perfect to imperfect adherence knowledge, by past transitions in daily visits (n=31)



Note: Results are not statistically significant (chi2=4.60, p=0.203).

Figure 7.32 shows that transitions in daily visits did not impact significantly on transitions from perfect to imperfect adherence knowledge. As expected, patients who did not receive any daily visits in either period were more likely to have seen their knowledge change from perfect to imperfect. Transitions from perfect to imperfect adherence knowledge were low among patients who started receiving daily visits and among those who received daily visits in both periods. These results highlight the importance of frequent visits by treatment buddies in maintaining the perfect adherence knowledge of patients.

7.3.5 Determinants of transitions from perfect to imperfect adherence knowledge

Two different approaches are followed investigating the determinants of transitions from perfect to imperfect adherence knowledge. Firstly, there is a regression analysis to investigate need and access to support as determinants of transitions from perfect to imperfect and secondly, there is a regression analyses to investigate treatment buddy characteristics as determinants of transitions from perfect to imperfect. However, with reference to the latter, none of the regression models performed adequately in terms of goodness-of-fit and none of the treatment buddy variables were significant predictors of transitions from perfect to imperfect adherence knowledge. Therefore the regression results reported in this section are for the former.

7.3.5 (a) Need and access to support

The reported results in Table 7.4 are for the pooled regression model. The fixed effects (FE) model could not be estimated, while the likelihood ratio test indicated that the pooled model outperformed the random effects (RE) model. The pooled performed well in terms of overall fit (p<0.001).

Table 7.4: Need and access to support as determinants of transitions from perfect to imperfect adherence knowledge

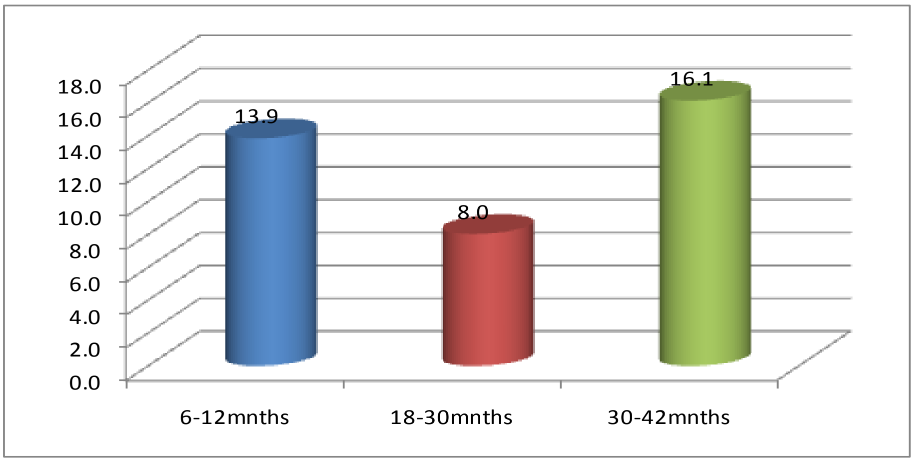
Independent variables	**Odds ratio**
1. Sociodemographic variables	
Age	0.905
Age2	1.001
Female (*male=0/female=1)*	2.232 *
Marital status	
[comparison group=single]	
Living with partner	3.917 **
Not living with partner	0.528
Educational status	
[comparison group=no formal education]	
Primary education	1.220
Secondary education	1.658
Grade 12	4.182
Tertiary education (omitted)	
2. Need variables	
Treatment career	
[comparison group=0-6months]	
6-12months	4.261 **
18-30months	0.823
30-42months(omitted)	
3. Access to support variables	
Past access to treatment buddy	0.253 ***
Past access to emotional carer	0.549
Past access to physical carer	3.201
Past access to CHW	4.784
Past participation in support groups	0.392
Sample size	*131*
LR chi2 (p)	*38.33 (p<0.001)*
$H_{0:}$ pooled model vs. Ha: RE (LR test)	*1.05 (p=0.499)*

Note: FE could not be estimated. Results are for the Pooled regression model.
**** significant at 1% level; ** significant at 5% level; *significant at 10% level*

According to the results in Table 7.4, gender has an odds ratio of 2.23 and is significant at the 10% level, which means that female patients are twice as likely as male patients to have experienced a transition from perfect to imperfect adherence knowledge. Living with partner has an odds ratio of 3.91 and is significant at the 5% level. This means that patients living with their partner are almost four times more likely than single patients to have experienced a transition in their adherence knowledge from perfect to imperfect. The variable '6-12 months' is significant at the 5% level. An odds ratio of 4.26 means that for patients who have been on treatment for a year or less, were 4 times more likely to have their adherence knowledge change from perfect to imperfect, compared to patients who have been on treatment for less than 6 months. This means that patients who had access to a treatment buddy were 75% less likely to have their adherence knowledge change from perfect to imperfect, compared to patients who did not have treatment buddy.

7.4 Transitions from imperfect to perfect adherence knowledge

Figure 7.33: Transitions from imperfect to perfect to imperfect adherence knowledge, by treatment career phase (n=645)



Note: Results are statistically significant at the 10% level (chi2=5.50, p=0.064).

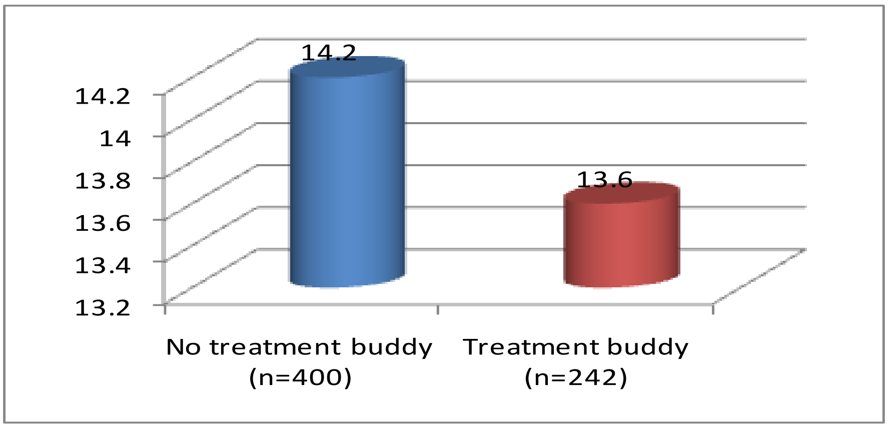
According to Figure 7.33, transitions from imperfect to perfect adherence knowledge varied significantly by the treatment duration ($p<0.10$). The first phase (0-6 months) is automatically excluded because it is the base outcome. Transitions from imperfect to perfect adherence knowledge were uncommon among patients who had been on treatment for 18-30 months had lower perfect adherence knowledge, even lower than for patients who had been on treatment for a short period of time. Further, transitions from imperfect to perfect adherence knowledge are common among patients who had been on treatment for more than 30 months. This result suggests that positive transitions are more likely by the 2nd and 4th phases of the career.

7.4.1 Transitions from imperfect to perfect adherence knowledge and access to a treatment buddy

This sections deals with the impact of having a treatment buddies and other forms of support on transitions from imperfect to perfect adherence knowledge. The impact of health-related quality of life on transitions from imperfect to perfect adherence knowledge and lastly the impact of household size on transitions from imperfect to perfect adherence knowledge will be discussed.

7.4.1 (a) Past access to a treatment buddy

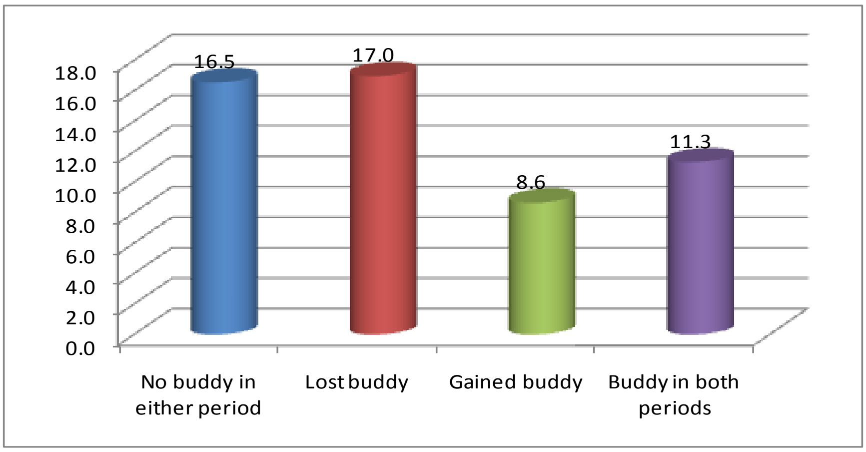
Figure 7.34: Transitions from imperfect to perfect adherence knowledge, by past access to a treatment buddy



Note: Results are not statistically significant (chi2=0.04, p=0.828).

Figure 7.34, shows that past access to a treatment buddy did not significantly impact on transitions from imperfect to perfect adherence knowledge. Transitions from imperfect to perfect adherence knowledge were more common among patients who in the past did not have a treatment buddy. These results are contradictory to what one may expect. Transitions from imperfect to perfect adherence knowledge were expected to be more common among patients who in the past had access to treatment buddy. However, these results are not statistically significant.

Figure 7.35: 'Transitions from imperfect to perfect adherence knowledge, by past transitions in access to a treatment buddy (n=509)



Note: Results are not statistically significant (chi2=4.36, p=0.225).

Figure 7.35 shows that past transitions in access to a treatment buddy do not impact significantly on transitions from imperfect to perfect adherence knowledge. Patients who lost access to treatment buddy and patients who did not have treatment buddy in either period were more likely to have their adherence knowledge, change from imperfect to perfect. Patients who had treatment buddies in both periods and patients who gained access to a treatment buddy were less likely to have their adherence knowledge change from imperfect to perfect. One would rather expect transitions from imperfect to perfect adherence knowledge to be more common among patients with treatment buddies. The results are however statistically significant, with the result that one should not read too much into these somewhat contradictory results.

7.4.2 Transitions from imperfect to perfect adherence knowledge and treatment buddy characteristics

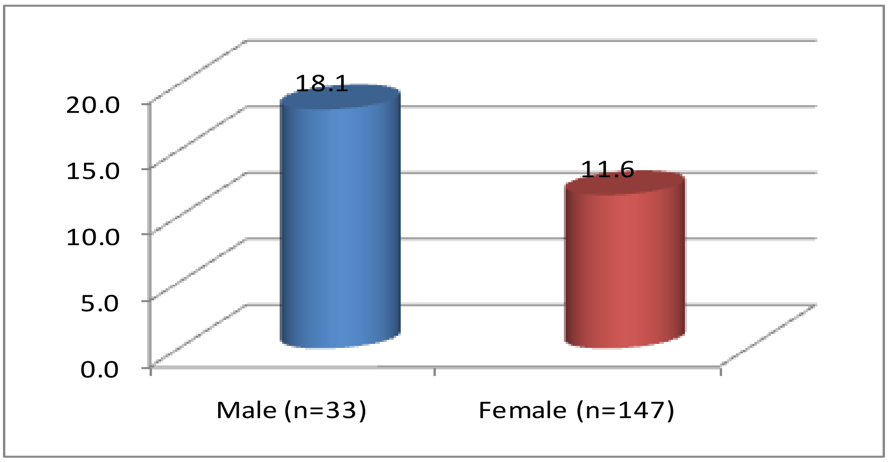
According to Table 7.5, age of the treatment buddy in the previous period did not impact significantly on transitions from imperfect to perfect adherence knowledge. Treatment buddies of patients who transitioned from imperfect to perfect adherence knowledge were slightly younger than treatment buddies of patients who did not have perfect knowledge in either period.

Table 7.5: Age of a treatment buddy, by transitions from imperfect to perfect adherence knowledge

Adherence knowledge	**Summary of age of a treatment buddy**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
No perfect knowledge in either period	33.44	16.26	20	45.5	32	2	78	156
			22					
Perfect knowledge	32.33	20.59	14	40	31	5	89	21
Total	**33.31**	**16.77**	**21**	**45**	**32**	**2**	**89**	**1778**

Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (F=0.08, p=0.775).

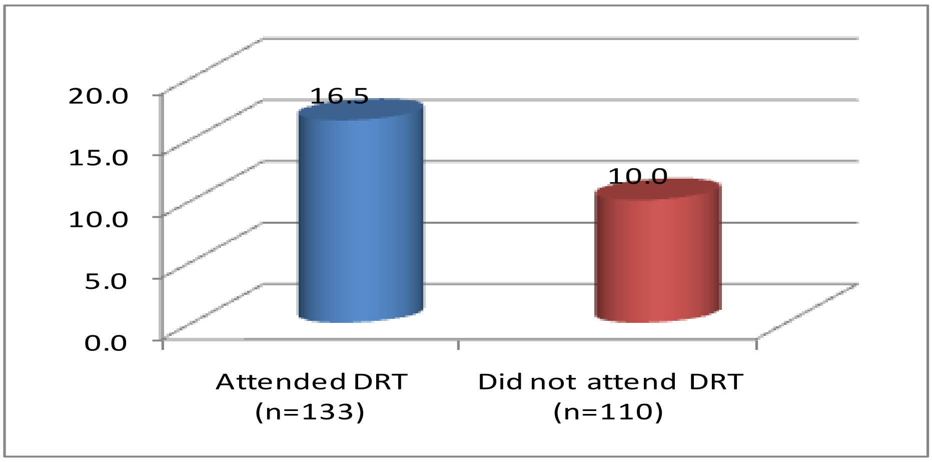
Figure 7.36: Transitions from imperfect to perfect adherence knowledge, by gender of a treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=1.05, p=0.303).

Figure 7.36 indicated that the gender of the treatment buddy did not significantly impact on transitions from imperfect to perfect adherence knowledge. Transitions from imperfect to perfect adherence knowledge were more common among patients whose treatment buddies were male.

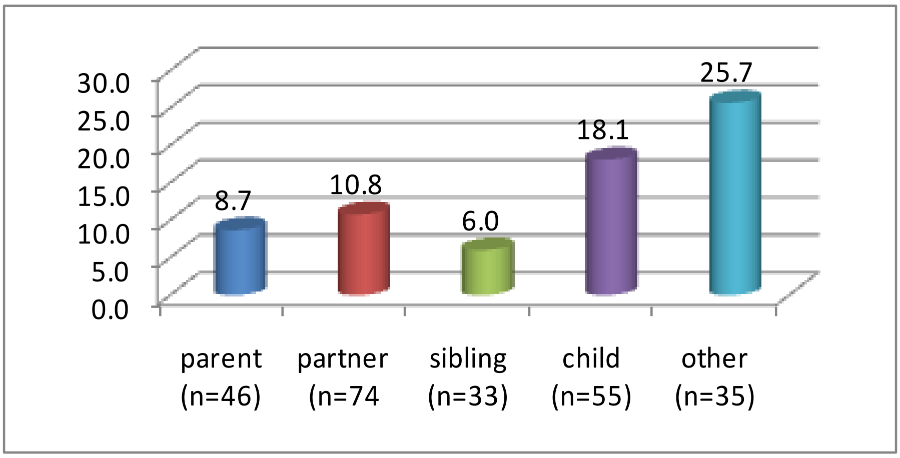
Figure 7.37: Transitions from imperfect to perfect to imperfect adherence knowledge, by attendance of drug readiness training



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=2.19, p=0.138).

Past attendance of drug readiness training by treatment buddy did not vary significantly by transitions from imperfect to perfect adherence knowledge. Figure 7.37, shows that transitions from imperfect to perfect adherence knowledge were more common among patients whose treatment buddies attended drug readiness training. These results make sense because patients whose treatment buddies attended at drug readiness training would be expected to have better adherence knowledge, these differences are however not significant.

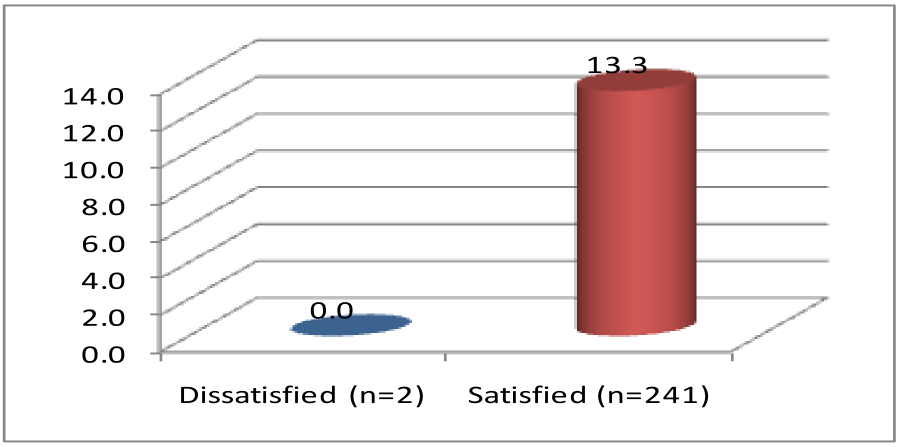
Figure 7.38: Transitions from imperfect to perfect adherence knowledge, by relationship with a treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are statistically significant at the 10% level (chi2=8.39, p=0.078).

Patient's past relationship with a treatment buddy impact significantly, though weak on transitions from imperfect to perfect adherence knowledge (p<0.10). Figure 7.38 indicates that patients whose treatment buddies were distant others were more likely to have their adherence knowledge change from imperfect to perfect. Further, patients whose treatment buddies were close family were less likely to have their knowledge change from imperfect to perfect. These results suggest that distant others may have mostly provided and maintained adherence information.

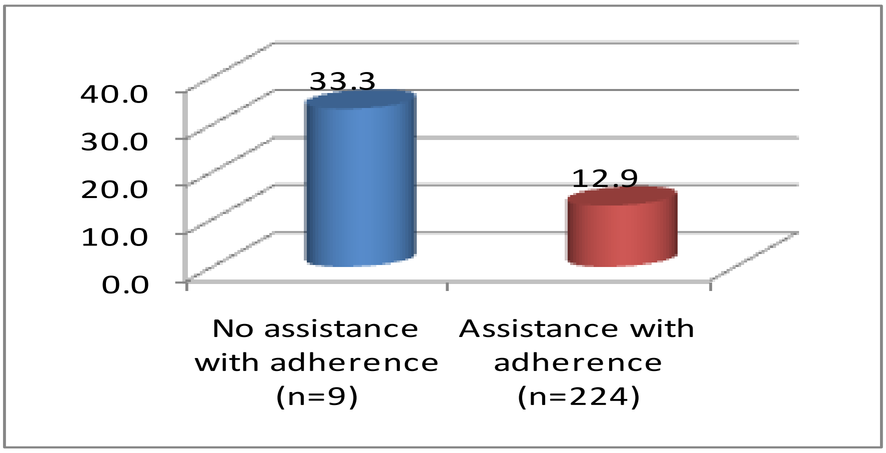
Figure 7.39: Transitions from imperfect to perfect adherence knowledge, by satisfaction with a treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=0.30, p=0.580).

Past satisfaction with a treatment buddy did not significantly impact on transitions from imperfect to perfect adherence knowledge (Figure 7.39). As expected, patients who were highly satisfied with support provided by their treatment buddy were more likely to have their adherence knowledge change from imperfect to perfect. On the other hand, none of the patients who were dissatisfied with the support provided by their treatment buddy had their adherence knowledge change from imperfect to perfect, these differences were however not significant.

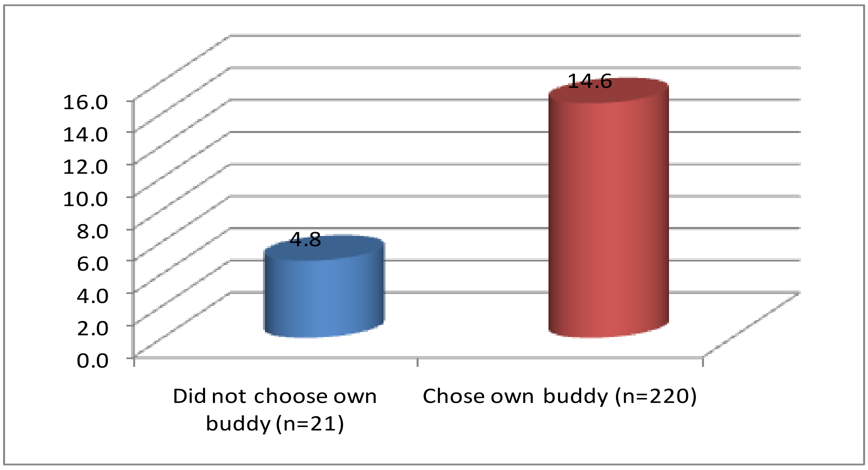
Figure 7.40: Transitions from imperfect to perfect adherence knowledge, by assistance with adherence



Note: Treatment buddy characteristics as observed in the previous period. Results are statistically significant at the 10% level (chi2=3.03, p=0.081).

Past assistance with adherence, by treatment buddy impact significantly on transitions from imperfect to perfect adherence knowledge ($p<0.10$). Figure 7.40 shows that patients whose buddies did not provide adherence support were more likely to have gained perfect knowledge than those with buddies who assisted them with adherence. Further, these results are contradictory as it would be expected that patients who received adherence support would be more likely to have adherence knowledge change from imperfect to perfect. A possible explanation for these results could be the possibility that patients, who have issues/difficulty in maintaining adherence due to insufficient information about adherence, would automatically receive assistance by treatment buddy. However, these results are statistically insignificant.

Figure 7.41: Transitions from imperfect to perfect adherence knowledge, by choice of a treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=1.55, p=0.213).

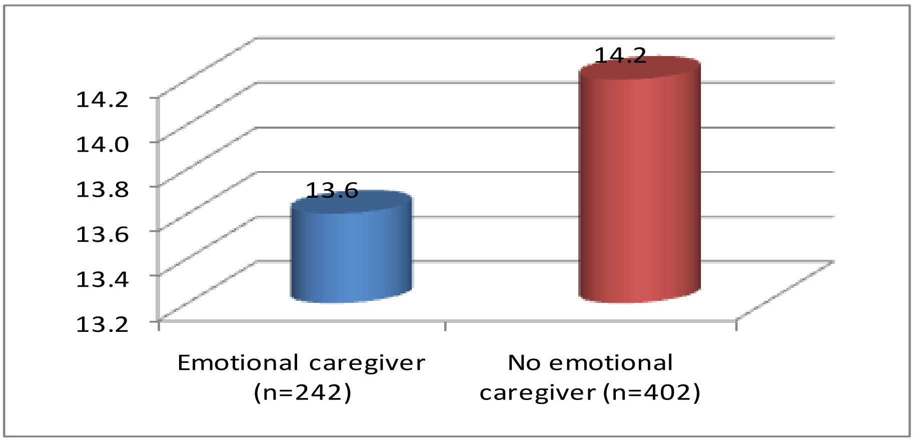
Past choice of treatment buddy did not significantly impact on transitions from imperfect to perfect adherence knowledge. Yet, as expected, patients who chose own treatment buddies were more likely to have their adherence knowledge change from imperfect to perfect. This finding raises some questions about the role of assigned treatment buddies in providing and maintaining adherence information.

7.4.3 Transitions from imperfect to perfect adherence knowledge and changes in access to other support

This section establishes how changes in access to other support impact on transitions from imperfect to perfect adherence knowledge.

7.4.3 (a) Past access to an emotional caregiver

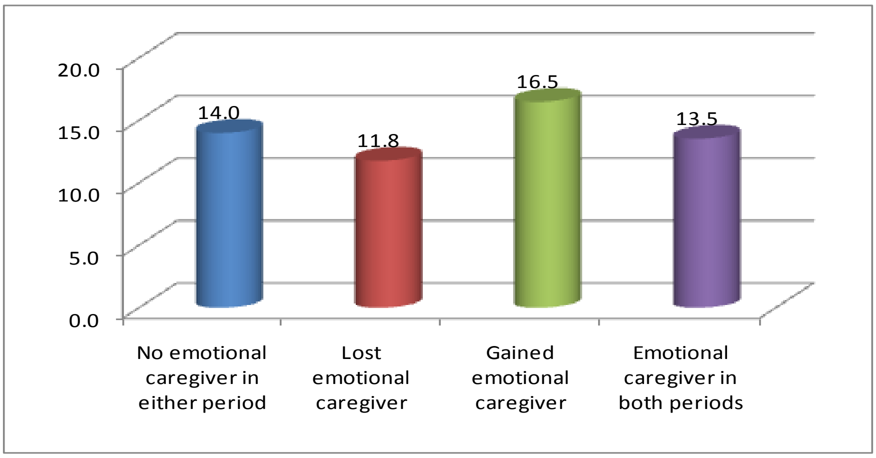
Figure 7.42: Transitions from imperfect to perfect adherence knowledge, by past access to an emotional caregiver



Note: Results are not statistically significant (chi2=0.03, p=0.847).

Figure 7.42 shows that past access to an emotional caregiver did not impact significantly on transitions from imperfect to perfect adherence knowledge. Patients, who in the past did not have access to an emotional caregiver, were more likely to have their adherence knowledge change from imperfect to perfect. These results are contrary to what is expected, differences in transitions from imperfect to perfect adherence knowledge by past access to emotional caregiver support are not statistically significant, with the result that one should not read too much into these somewhat contradictory results.

Figure 7.43: Transitions from imperfect to perfect to imperfect adherence knowledge, by past transitions in access to an emotional caregiver (n=513)



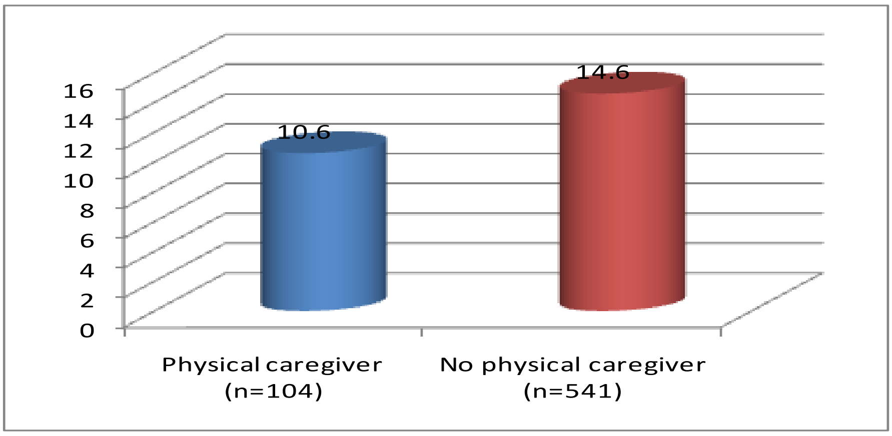
Note: Results are not statistically significant (chi2=0.76, p=0.857).

Figure 7.43 shows that past transitions in access to emotional caregiver did not impact significantly on transitions from imperfect to perfect adherence knowledge. As expected, patients who gained access to an emotional caregiver were more likely to have their adherence knowledge change from imperfect to perfect. Furthermore, patients who lost access to an emotional caregiver were less likely to have their adherence knowledge change from imperfect to perfect. These differences are however not statistically significant.

7.4.3. (b).Past access to a physical caregiver

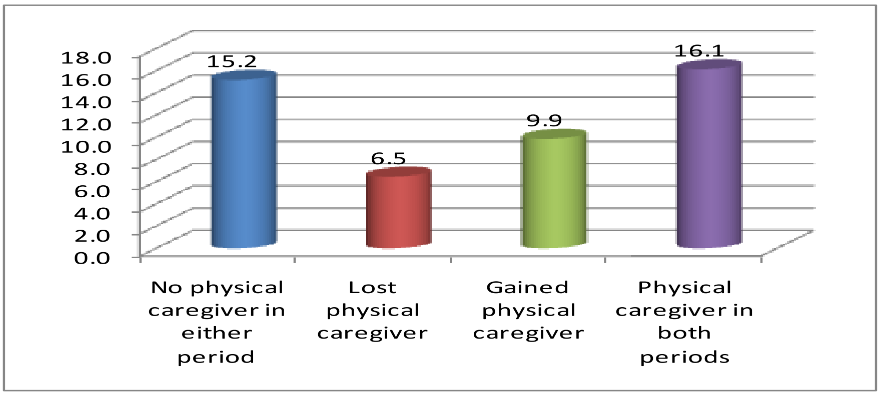
Figure 7.44 shows that past access to a physical caregiver did not impact significantly on transitions from imperfect to perfect adherence knowledge. Patients, who in the past did not have access to a physical caregiver, were more likely to have their adherence knowledge change from imperfect to perfect. These results are contrary to what is expected, differences in transitions from imperfect to perfect adherence knowledge by past access to physical caregiver support are not statistically significant, with the result that one should not read too much into these somewhat contradictory results.

Figure 7.44: Transitions from imperfect to perfect adherence knowledge, by past access to a physical caregiver



Note: Results are not statistically significant (chi2=1.17, p=0.278).

Figure 7.45: Transitions from imperfect to perfect adherence knowledge, by past transitions in access to a physical caregiver (n=515)

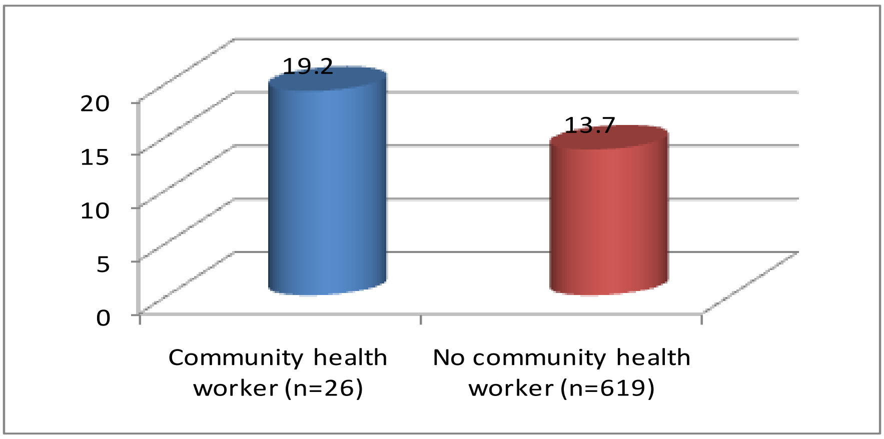


Note: Results are not statistically significant (chi2=3.04, p=0.385).

According to Figure 7.45, past transitions in access to a physical caregiver did not impact significantly on transitions from imperfect to perfect adherence knowledge. As expected, patients who had access to a physical caregiver in both periods were more likely to have their adherence knowledge change from imperfect to perfect. Patients who gained access to a physical caregiver were also more likely to have their adherence knowledge change from imperfect to perfect. Furthermore, patients who lost access to a physical caregiver were less likely to have their adherence knowledge change from imperfect to perfect. These differences are however not statistically significant.

7.4.3. (c) Past access to a community health worker

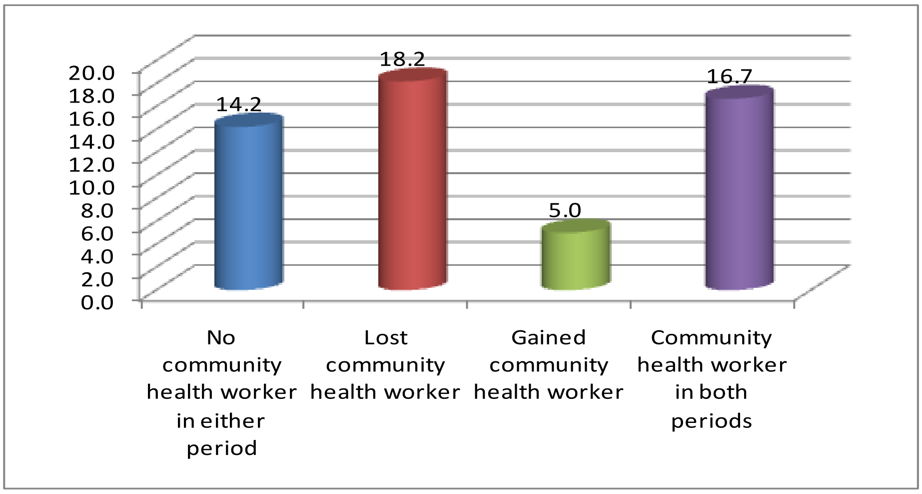
Figure 7.46: Transitions from imperfect to perfect adherence knowledge, by past access to a community health worker



Note: Results are not statistically significant (chi2=0.62, p=0.156).

Figure 7.46 shows that past access to a community health worker did not impact significantly on transitions from imperfect to perfect adherence knowledge. As expected, patients who in the past received visits from a community health worker were more likely to have their adherence knowledge change from imperfect to perfect. Common transitions from imperfect to perfect adherence knowledge among patients, who received community health worker visits, could be an indicative of the role of community health workers in imparting and maintaining information about medication and adherence.

Figure 7.47: Transitions from imperfect to perfect adherence knowledge, by past transitions in access to a community health worker (n=515)



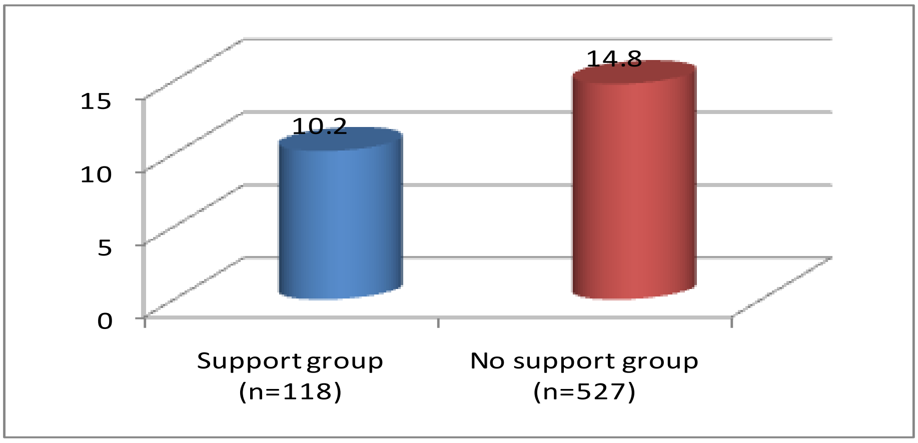
Note: Results are not statistically significant (chi2=1.56, p=0.668).

Figure 7.47, shows that past transitions in access to a community health worker did not impact significantly on transitions from imperfect to perfect adherence knowledge. As expected, patients who had access to a community health worker were more likely to have their adherence knowledge change from imperfect to perfect. However, transitions from imperfect to perfect adherence knowledge were more common among patients who lost access to community health worker. Patients who gained access to a community health worker and patients who did not have access to a community health worker, were less likely to have their adherence knowledge change from imperfect to perfect. These differences are however not statistically significant.

7.4.3 (d) Past participation in a support group

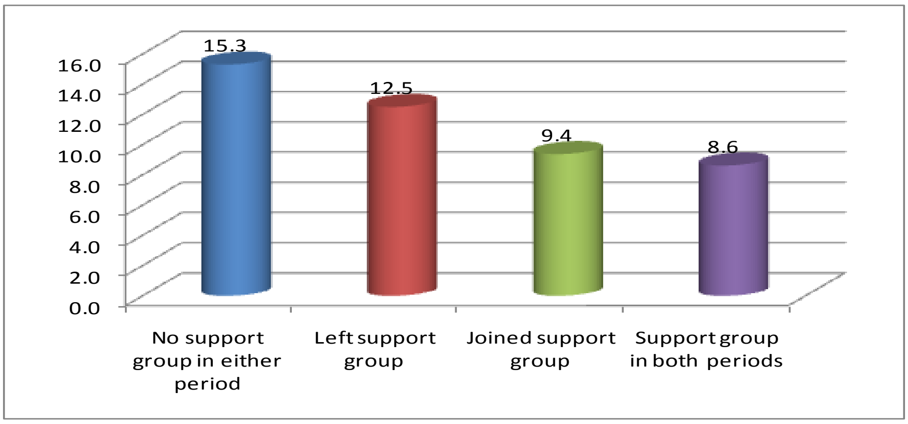
Figure 7.48 shows that past participation in a support group did not impact significantly on transitions from imperfect to perfect adherence knowledge. Patients, who in the past did not have access to a support group, were more likely to have their adherence knowledge change from imperfect to perfect. These results are contrary to what is expected, differences in transitions from imperfect to perfect adherence knowledge by past participation in support groups are not statistically significant, with the result that one should not read too much into these somewhat contradictory results.

Figure 7.48: Transitions from imperfect to perfect adherence knowledge, by past participation in a support group



Note: Results are not statistically significant (chi2=1.72, p=0.189).

Figure 7.49: Transitions from imperfect to perfect adherence knowledge, by past transitions in participation in a support group (n=515)



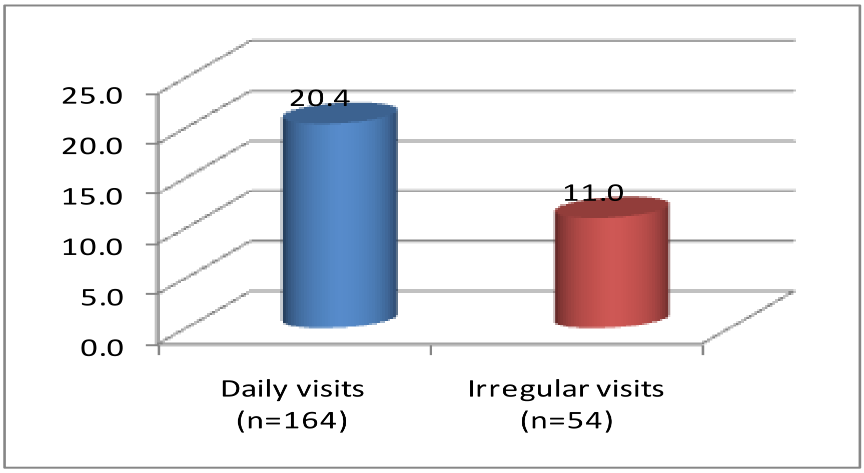
Note: Results are not statistically significant (chi2=260, p=0.457).

Figure 7.49, shows that past transitions in participation in support groups did not impact significantly on transitions from imperfect to perfect adherence knowledge. A rather unexpected downward trend is presented. Hence, patients who did not participate in a support group in either period were more likely to have their adherence knowledge change from imperfect to perfect. Moreover, patients who discontinued their participation in a support group were more likely to have their adherence knowledge change from imperfect to perfect. Patients who joined a support group and patients who participated in support groups in both periods were less likely to have their adherence knowledge change from imperfect to perfect. These rather contradictory results are not statistically significant.

7.4.4 Transitions from imperfect to perfect adherence knowledge and intensity of treatment buddy support

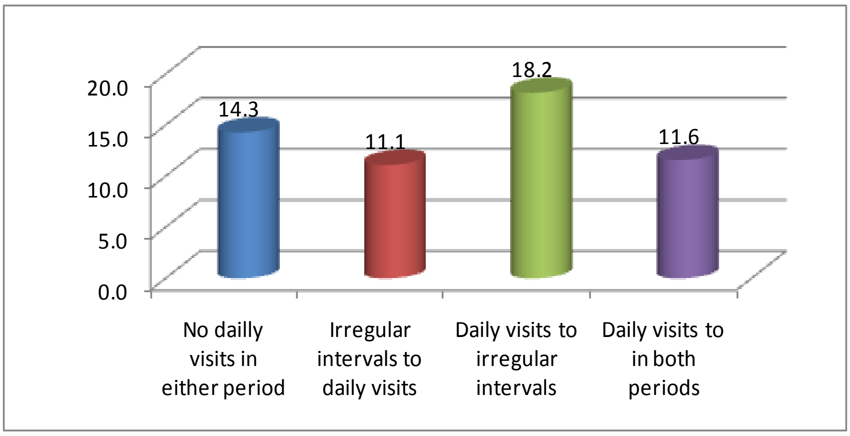
Figure 7.50 indicates that past frequency of visits did not impact significantly on transitions from imperfect to perfect adherence knowledge. As expected, patients who were previously visited daily by their treatment buddy were more likely to have their adherence knowledge change from imperfect to perfect compared to patients whose treatment buddies visited them irregularly, who were more likely to still have imperfect adherence knowledge. This result suggests that patients who were visited daily may have been more likely to be provided with adherence and treatment related information which improved their knowledge.

Figure 7.50: Transitions from imperfect to perfect to imperfect adherence knowledge, by past frequency of treatment buddy support



Note: Results are statistically significant at the 10% level (chi2=3.10, p=0.078).

Figure 7.51: Transitions from imperfect to perfect adherence knowledge, by past transitions in frequency of treatment buddy support (n=95)



Note: Results are not statistically significant (chi2=0.75, p=0.861).

According to Figure 7.51, past transitions in participation in support group did not impact significantly on transitions from imperfect to perfect adherence knowledge. Patients who received daily visits in both periods were less likely to have their adherence knowledge change from imperfect to perfect. However, patients who gained daily visits were more likely to have their adherence knowledge change from imperfect to perfect. Furthermore, patients who discontinued participation in a support group were less likely to have their adherence knowledge change from imperfect to perfect. These rather somewhat contradictory differences are however not statistically significant.

7.4.5 Determinants of transitions from imperfect to perfect adherence knowledge

None of the regression models were appropriate in terms of goodness-of-fit. The pooled regression model was the best model but the overall model was not significant (p=0.423).

7.5 Summary

This chapter reveals that adherence knowledge increased over the treatment duration. Further, transitions from perfect to imperfect adherence knowledge declined while transitions from imperfect to perfect adherence knowledge increased. The availability of support may be responsible for the increased adherence knowledge. A Zambian study by Samuels *et al* 2008, reported that ART patients who received treatment support had improved adherence knowledge.

Contrary to the hypotheses in this chapter, access to treatment buddy did not have significant impact on adherence/medication knowledge; however transitions from prefect to imperfect adherence knowledge were low among patients who had access to a treatment buddy.

None of the treatment buddy characteristics were associated with adherence knowledge however adherence knowledge was more common among patients whose treatment buddies attended the drug readiness training, there were fewer transitions from perfect to imperfect adherence knowledge among patients whose treatment buddies attended drug readiness training and there were more transitions from imperfect to perfect knowledge among patients whose treatment buddies attended the drug readiness training. Further, there were fewer transitions from perfect to imperfect adherence knowledge among patients who chose own treatment buddies and there were more transitions from imperfect to perfect adherence knowledge among patients who chose own treatment buddies. It should however be noted that these results seem plausible, but lack statistical significance.

Contrary to the hypothesis, intensity of treatment buddy support as measured by regularity of visits did not have a significant impact on medication/adherence knowledge. However, there were fewer transitions from perfect to imperfect adherence knowledge among patients who received daily visits from treatment buddies and there were more transitions from imperfect to perfect adherence knowledge among patients who received daily visits from their treatment buddies. Again, there is plausibility, but lack of statistical significance.

Only two socio-demographic variables were consistently significant in the two regression models performed in this chapter; (gender and marital status). Female patients were more likely to have perfect adherence knowledge than male patients. Patients living with partner were more likely have perfect adherence knowledge than single patients. In the second model however, female patients were more likely than males to have their adherence knowledge change from perfect to imperfect. Similarly, patients living with partners were also more likely to have their adherence knowledge change from perfect to imperfect compared to single patients.

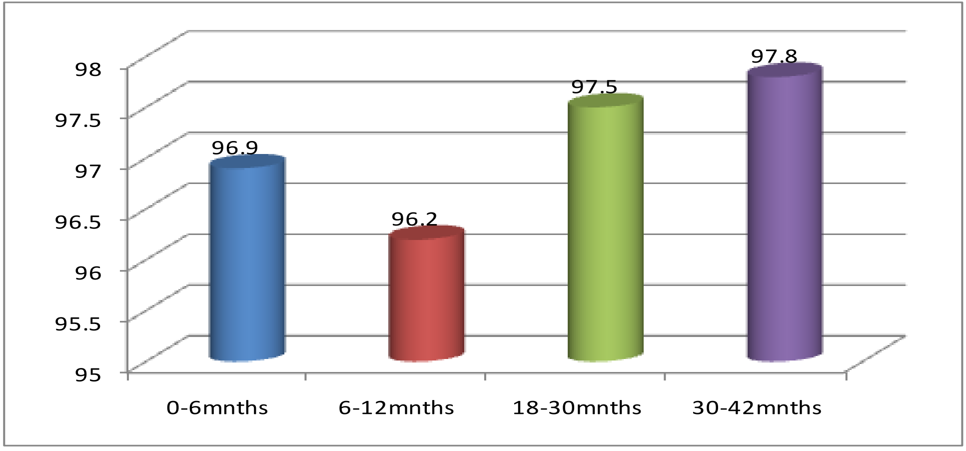
CHAPTER 8
SELF-REPORTED ADHERENCE

8.1. Introduction

This chapter aims to determine how access to treatment buddy and treatment buddy characteristics impact on self-reported adherence. The chapter sets out to determine whether the hypothesis that access to a treatment buddy enhances self-reported adherence is correct or not. The chapter explores three main outcomes, namely (i) current levels of self-reported adherence, (ii) transitions in self-reported adherence from being adherent to being non-adherent, and (iii) transitions in self-reported adherence from being non-adherent to being adherent. Bivariate analyses on how these self-reported adherence outcomes differ by access to a treatment buddy and treatment buddy characteristics, and other support are performed, followed by multiple regression analyses exploring the role of the former outcomes in predicting self-reported adherence.

8.2. Self-reported adherence

Figure 8.1: Self-reported adherence, by treatment career phase (n=615)

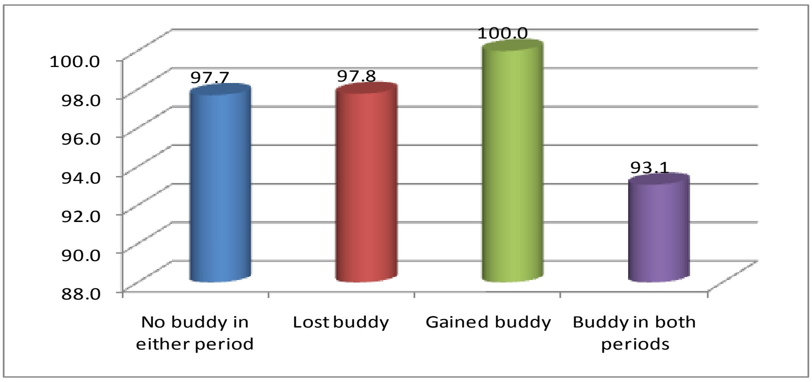


Note: Results are not statistically significant (chi2=0.74, p=0.863).

Figure 8.1 shows that self-reported adherence did not differ significantly by treatment career. On aggregate, adherence was reportedly higher across the entire treatment career phase. However, self-reported adherence was lower among patients who had been on treatment for a year or less compared to patients who had been on treatment for more than a year.

8.2.1. Current self-reported adherence and access to a treatment buddy

Figure 8.2: Self-reported adherence, by transitions in access to a treatment buddy (n=449)



Note: Results are statistically significant at the 5% level (chi2=0.8.75, p=0.022).

Figure 8.2 shows that there was a significant association between self-reported adherence and transitions in access to treatment buddy (p<0.05). Self-reported adherence was perfect among patients who gained access to a treatment buddy, but lower among patients who had access to treatment buddy in both periods (93%). However, self-reported adherence was higher among patients who gained access to treatment buddy. The low level of adherence among patients who had treatment buddies in both periods raises questions about the role of treatment buddies in enhancing adherence among patients on treatment. Yet, these results should also be interpreted with care, given the well-documented short-comings of self-reported measures of adherence.

8.2.2. Current self-reported adherence and treatment buddy characteristics

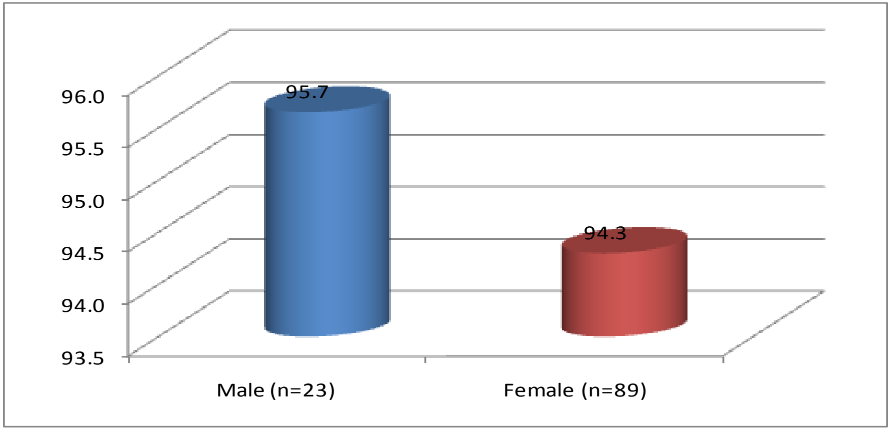
Table 8.3: Age of treatment buddy, by self-reported adherence

Current self reported adherence	**Summary of age of a treatment buddy**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
Non adherence	30.16	10.41	19	32	32	19	47	6
Adherence	35.35	17.01	24	46	35	2	89	105
Total	**35.07**	**16.73**	**23**	**46**	**34**	**2**	**89**	**111**

Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (F=0.54, p=0.463).

Table 8.3, shows that current self-reported adherence was not significantly associated with age of treatment buddy. However, adherent patients had slightly older treatment buddies compared to patients who were non-adherent

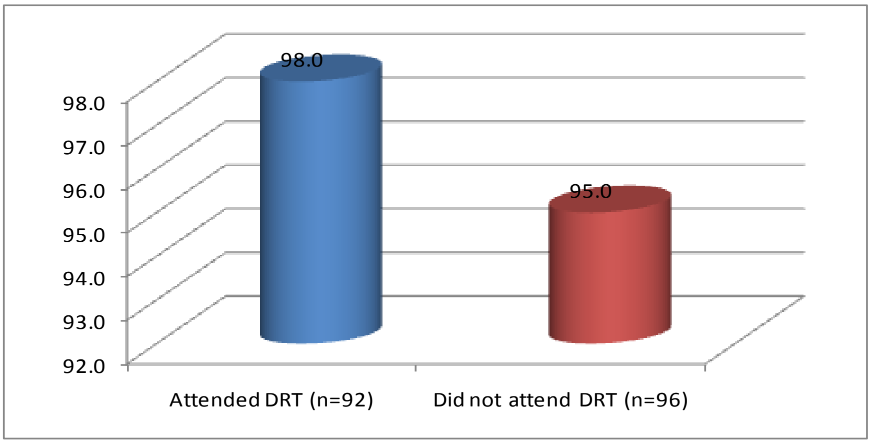
Figure 8.3: Self-reported adherence, by gender of treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=0.05, p=0.809).

According to Figure 8.3, self-reported adherence was not significantly associated with gender of treatment buddy. However, self-reported adherence was higher among patients whose treatment buddies were male. This finding suggests that male treatment buddies may be more available to provide adherence support than female treatment buddies.

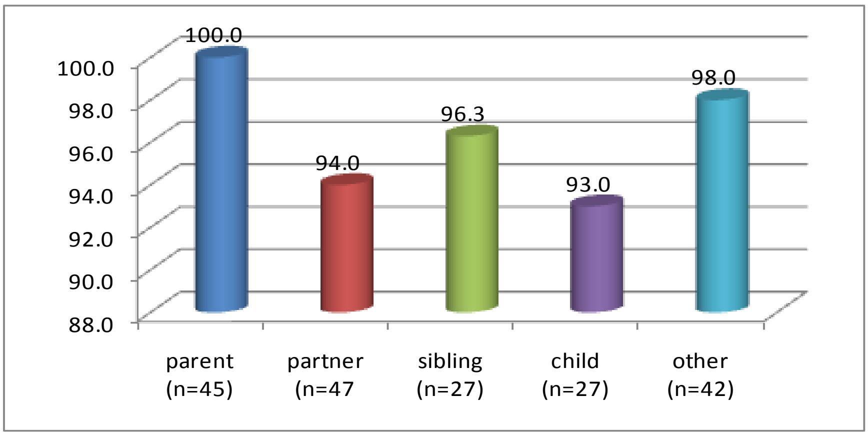
Figure 8.4: Self-reported adherence, by attendance of drug readiness training



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=1.47, p=0.225).

According to Figure, 8.4, self-reported adherence was not significantly associated with attendance of drug readiness training by the patient's treatment buddy. Even though these differences were not significant, adherence, as may be expected, was slightly higher among patients whose treatment buddies attended drug readiness training.

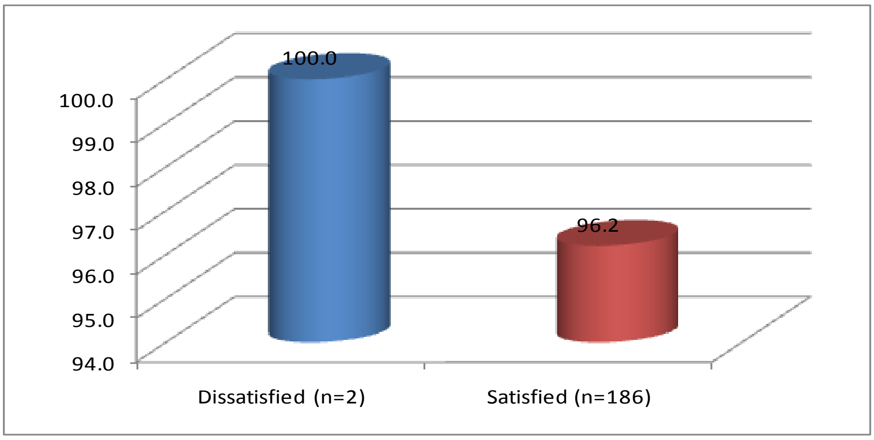
Figure 8.5: Self-reported adherence, by relationship with treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=0.39, p=0.420).

According to Figure 8.5, self-reported adherence did not differ significantly by the treatment buddy's relationship with the patient. In addition, self-reported adherence was generally high across categories. Therefore, self-reported adherence among patients was high, irrespective of the patient's relationship with treatment buddy.

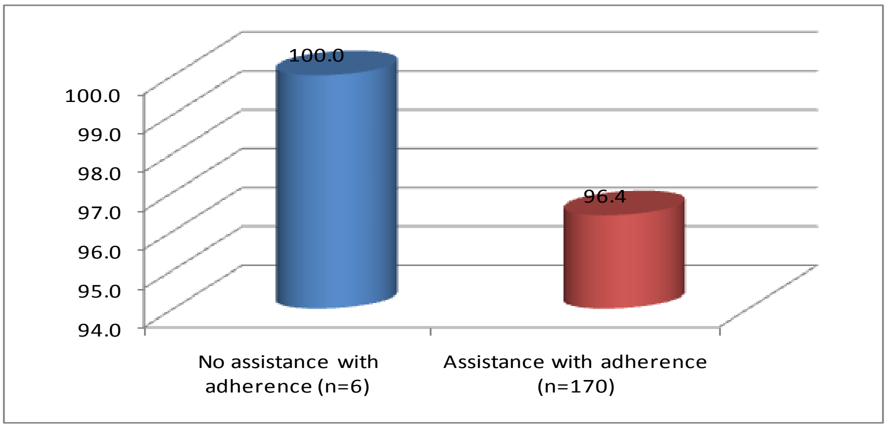
Figure 8.6: Self-reported adherence, by satisfaction with treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=0.07, p=0.780).

Table 8.6 demonstrates that self-reported adherence was not significantly associated with patients' satisfaction with the support provided by their treatment buddy. In fact, self-reported adherence was perfect and higher among patients who were dissatisfied with their treatment buddy's support compared to satisfied patients.

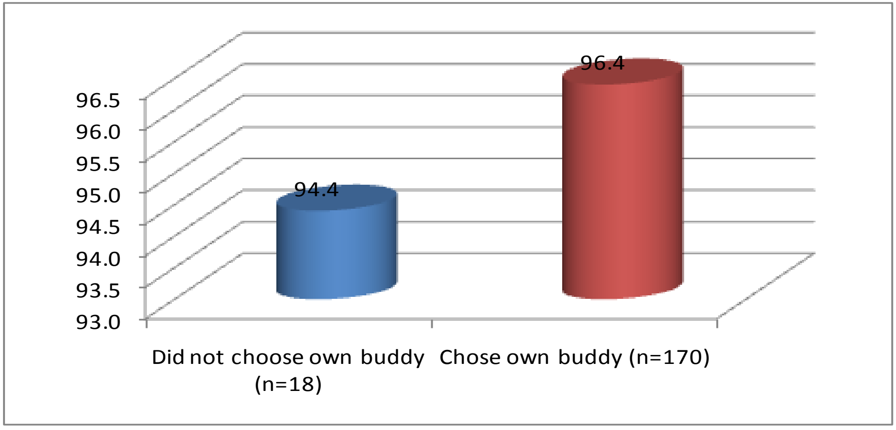
Figure 8.7: Self-reported adherence, by assistance with adherence



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=0.21, p=0.640).

Self-reported adherence was not associated with assistance with adherence by treatment buddy (Figure 8.7). Even though these differences were not significant, self-reported adherence, unexpectedly, was higher among patients who did not receive any adherence assistance from their treatment buddies. A possible explanation for this finding is that these patients may have access to other forms of support.

Figure 8.8: Self-reported adherence by choice of treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=0.18, p=0.666).

Figure 8.8, denotes that self-reported adherence was also not significantly associated with choice of treatment buddy. Even though these results are not significant, self-reported adherence, as expected, was higher among patients who chose their own treatment buddies compared to patients who did not choose own treatment buddies. Low self-reported adherence among patients who did not choose own buddies; could be explained by the argument that assigned treatment buddies may not be known to patients and may not be at ease such treatment buddies, which may have an impact on the extent of support provided.

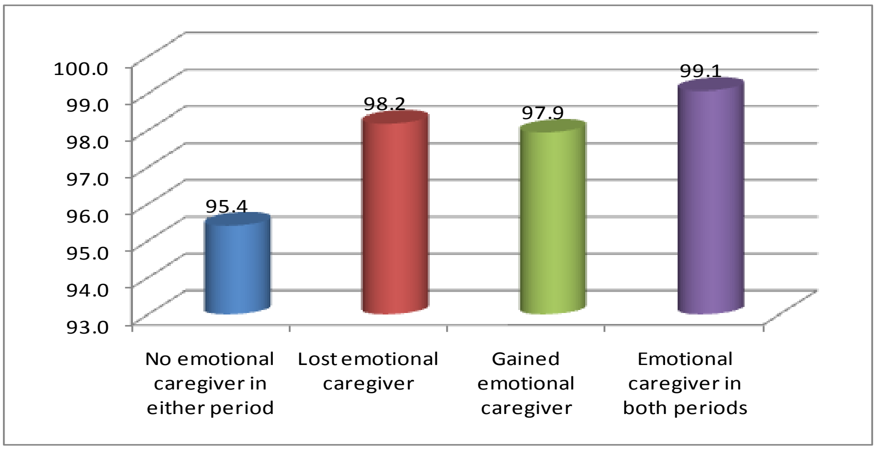
8.2.3. Current self-reported adherence and changes in access to other support

This section, tries to establish how changes in access to other support impact on self-reported adherence.

8.2.3. (a) Transitions in access to emotional caregiver

Self-reported adherence did not vary significantly by past transitions in access to emotional caregiver (Figure.8.9). On aggregate, self-reported adherence was higher across categories. Self-reported adherence was highest among patients who had access to an emotional caregiver in both periods and lowest among patients who did not have access to emotional caregiver in either period. This finding could highlight the role of emotional caregivers in enhancing patients' adherence to treatment. But these results are not significant.

Figure 8.9: Self-reported adherence, by transitions in access to an emotional caregiver (n=295)

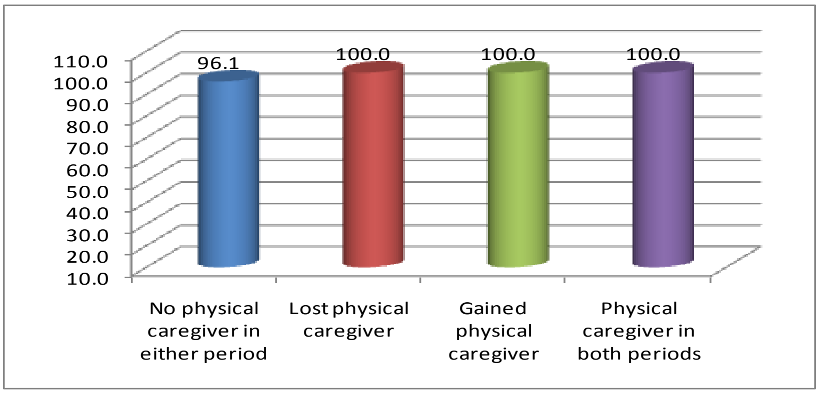


Note: Results are not statistically significant (chi2=0.39, p=0.263).

8.2.3. (b) Transitions in access to a physical caregiver

Figure 8.10 shows that self-reported adherence was not significantly associated with past transitions in access to a physical caregiver. Self-reported adherence was however, high in all categories, except among patients who did not have access to a physical carer in either period, where self-reported adherence was slightly lower.

Figure 8.10: Self-reported adherence, by transitions in access to a physical caregiver (n=295)

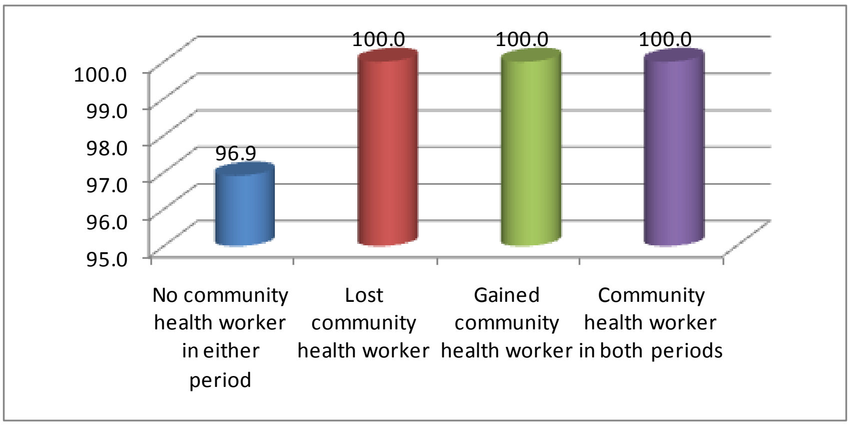


Note: Results are not statistically significant (chi2=0.506, p=0.167).

8.2.3. (c) Transitions in access to a community health worker

According to Figure 8.11, self-reported adherence did not vary significantly by past transitions in access to a community health worker. Self-reported adherence was higher in all categories, but again lowest among patients who did not receive visits from a community health worker in other period. This finding highlights the role of community health workers in providing adherence support.

Figure 8.11: Self-reported adherence, by transitions in access to a community health worker (n=295)

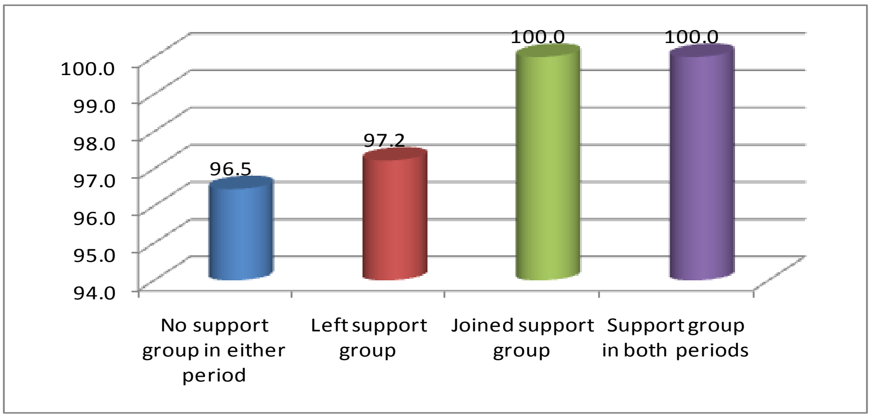


Note: Results are not statistically significant (chi2=1.08, p=0.782)

8.2.3. (d) Transitions in participation in a support group

Self-reported adherence did not vary significantly by transitions in past participation in support groups. Even though these differences are not significant, self-reported adherence, as expected, was higher among patients who joined support groups and those who participated in a support group in both periods, and lower among patients who did not participate in a support group in either period and among those who stopped participating in a support group. This result hints at the potential importance of support groups in facilitating and enhancing adherence to treatment.

Figure 8.12: Self-reported adherence, by transitions in participation in a support group (n=295)

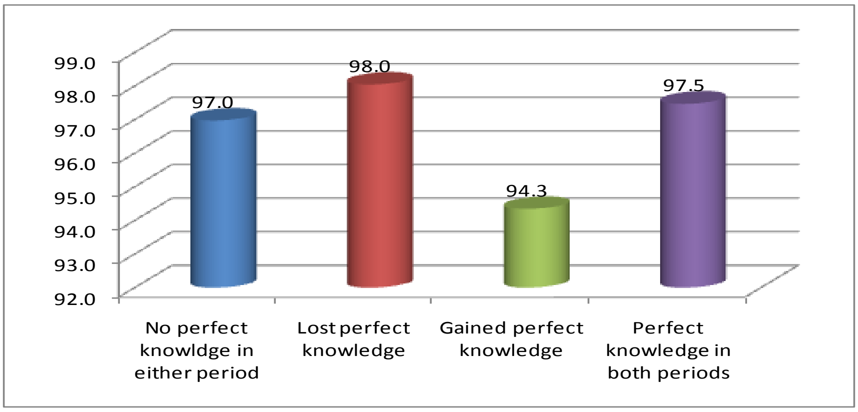


Note: Results are not statistically significant (chi2=2.96, p=0.397).

8.2.4. Current self-reported adherence and adherence knowledge

Self-reported adherence did not vary significantly by past transitions in adherence knowledge. According to Figure 8.13, self-reported adherence was relatively high irrespective of whether patients had perfect or imperfect adherence knowledge. These results mean that patients were adherent to treatment whether they had perfect or imperfect adherence knowledge. However, these results should be interpreted with caution given the use of a weak adherence measure of self-reported adherence

Figure 8.13: Self-reported adherence, by transitions in perfect adherence knowledge (n=453)



Note: Results are not statistically significant (chi2=1.76, p=0.623).

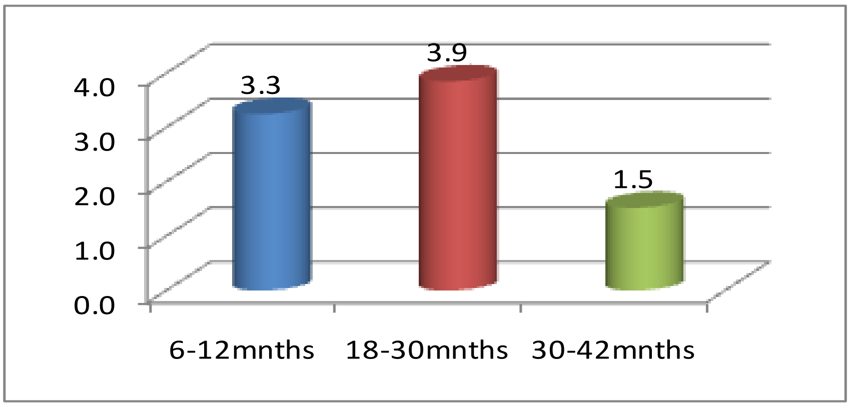
8.2.5. Determinants of self-reported adherence

The random effects (RE) model was the best model compared to the pooled regression model, but did not perform well in terms of the overall fit (p=0.999). The pooled regression model was also not significant in terms of overall fit. None of the models which estimated treatment buddy characteristics were significant in terms of overall fit. As a result, it was not possible to report and interpret regression on the potential statistical and practical significance of alternative determinants of self-reported adherence, including access to a treatment buddy and alternative treatment buddy characteristics.

8.3. Transitions from self-reported adherence to non-adherence

According to Figure 8.14, transitions from self-reported adherence to non-adherence did not vary significantly by treatment duration. Transitions from self-reported adherence to non-adherence were low among patients who had been on treatment for more than 30 months and were more common among patients who had been on treatment for 18 to 30 months. This is rather an expected result since patients who have been on treatment for longer have been absorbed into the system, fully comprehend how the treatment works and are used to treatment, and therefore are less likely be non-adherent.

Figure 8.14: Transitions from self-reported adherence to non-adherence, by treatment career phase (n=442)



Note: Results are statistically not significant (chi2=1.43, p=0.487).

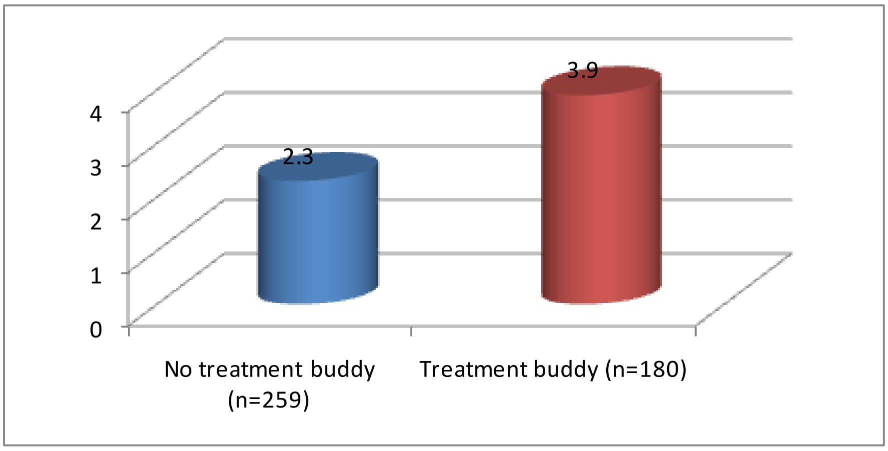
8.3.1. Transitions from self-reported adherence to non-adherence and access to a treatment buddy

This section attempts to establish how access to a treatment buddy impact on transitions from self-reported adherence to non-adherence.

(a) Past access to treatment buddy

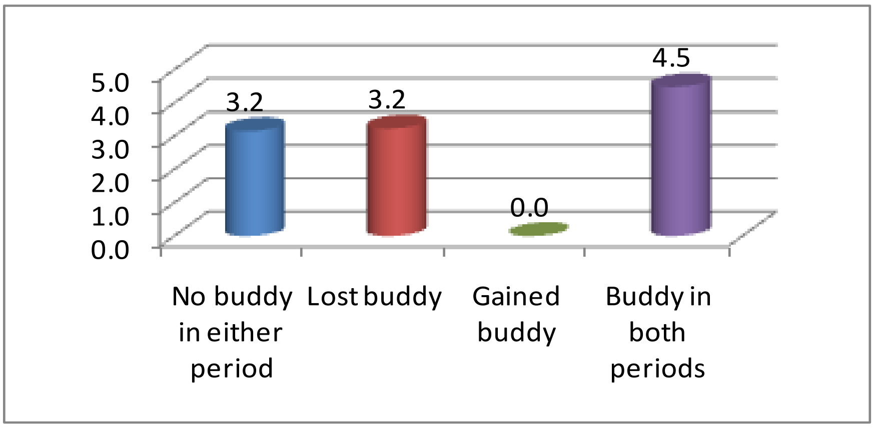
Figure 8.15 reveals that transitions from self-reported adherence to non-adherence were not associated with past access to treatment buddy. However, transitions from self-reported adherence to non-adherence were more common among patients who had access to a treatment buddy. These results raise questions about the role of treatment buddies in enhancing adherence among patients on treatment. Yet, these results should also be interpreted with care, given the well-documented short-comings of self-reported measures of adherence.

Figure 8.15: Transitions from self-reported adherence to non-adherence, by past access to a treatment buddy



Note: Results are not statistically significant (chi2=0.91, p=0.339).

Figure 8.16: Transitions from self-reported adherence to non-adherence, by past transitions in access to a treatment buddy (n=284)



Note: Results are not statistically significant (chi2=2.45, p=0.4837).

Transitions from self-reported adherence to non-adherence were not significantly associated with past transitions in access to treatment buddy. According to Figure 8.16, patients who previously had access to treatment buddy in both periods were more likely to transition from adherence to non-adherence compared to patients who gained access to treatment buddy. Common transitions from self-reported adherence to non-adherence among patients with treatment buddies are rather unexpected and raise questions about the effectiveness of treatment buddies in enhancing and reinforcing adherence. These results were however not significant.

8.3.2. Transitions from self-reported adherence to non-adherence and treatment buddy characteristics

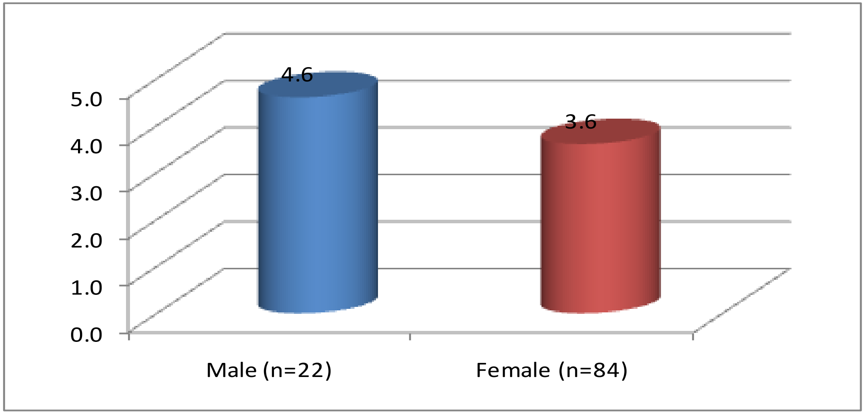
Table 8.3: Age of treatment buddy, by transitions from self-reported adherence to non-adherence

Self reported adherence	Summary of age of a treatment buddy							
	Mean	*SD*	*p25*	*p75*	*Median*	*Min*	*Max*	*Frequency*
Adherence in both periods	35.34	16.90	24	46	35	2	89	101
Adherence to non-adherence	35.5	22.69	18.5	52.5	40.5	5	56	4
Total	**35.35**	**17.07**	**24**	**46**	**35**	**2**	**89**	**105**

Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (F=0.00, p=0.986).

Transitions from self-reported adherence to non-adherence were not significantly associated with the age of treatment buddy (Table 8.3). However, adherent patients who became non-adherent had slightly older treatment buddies compared to patients who remain adherent

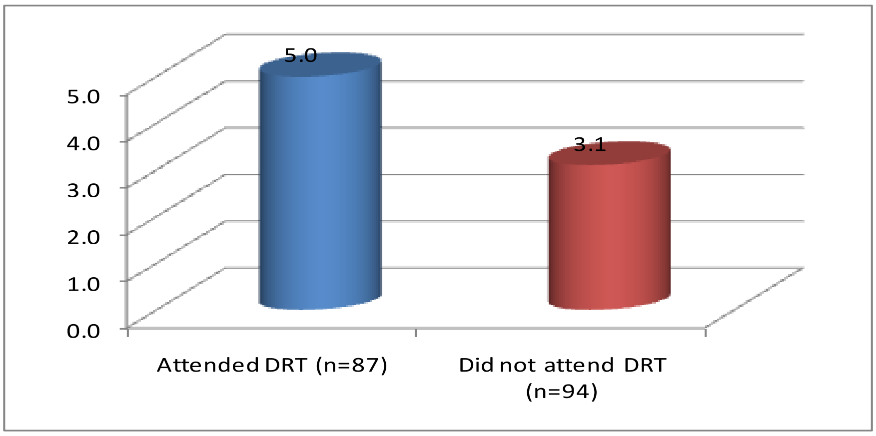
Figure 8.17: Transitions from self-reported adherence to non-adherence, by gender of treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=0.04, p=0.831).

Transitions from self-reported adherence to non-adherence did not vary significantly by gender of treatment buddy. Though, Figure 8 .17 indicates that transitions from self-reported adherence to non-adherence were common among patients whose treatment buddies were male compared to patients whose treatment buddies were female. However these results are not statistically significant

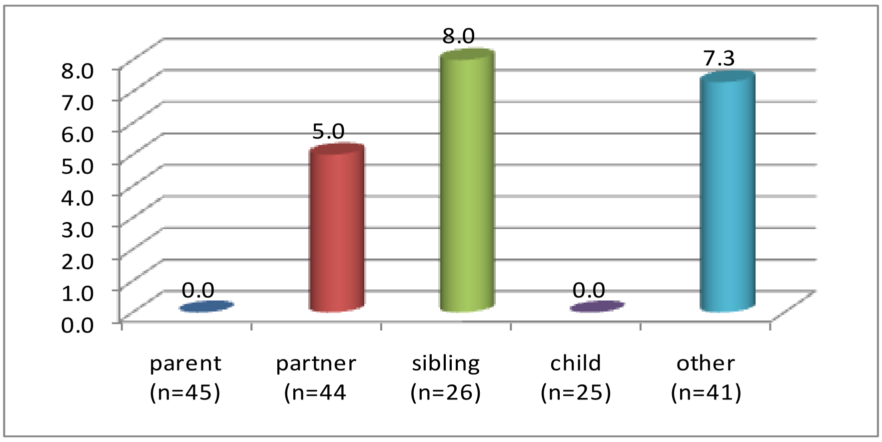
Figure 8.18: Transitions from self-reported adherence to non-adherence, by attendance of drug readiness training



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=0.24, p=0.6244).

Table 8.18 shows that transitions from self-reported adherence to non-adherence were not significantly associated with the attendance of drug readiness training by the patient's treatment buddy. However, transitions from self-reported adherence to non-adherence were low among patients of treatment buddies who previously attended the drug readiness training compared to patients whose treatment buddies did not attend the drug readiness training. This finding, demonstrates the importance of attending the drug readiness training by treatment buddies, in order to provide effective support and enhance adherence to medication.

Figure 8.19: Transitions from self-reported adherence to non-adherence, by relationship with treatment buddy

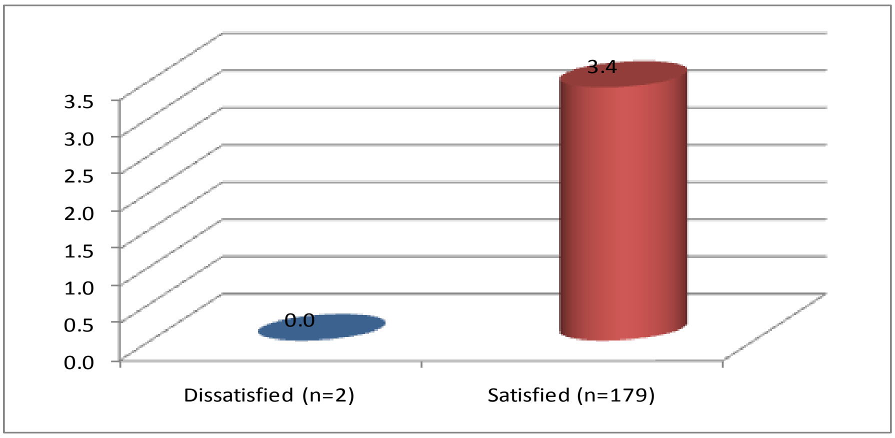


Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=5.20, p=0.267).

Figure 8.19 indicates that transitions from self-reported adherence to non-adherence did not vary significantly by the patient's relationship with the treatment buddy. There were no transitions from self reported adherence to non-adherence among patients whose treatment buddies were either parents or children. Though the results are insignificant, transitions from self-reported adherence to non-adherence were more common among patients whose treatment buddies were either siblings or distant others.

Moreover, self-reported adherence to non-adherence was lower among patients whose treatment buddies were partner or sibling. This result highlights the potentially important role partners of patients may play in providing adherence support.

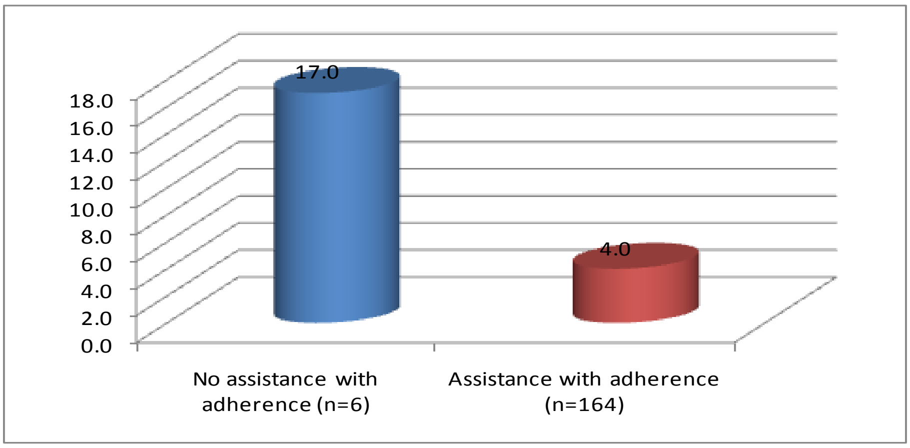
Figure 8.20: Transitions from self-reported adherence to non-adherence, by satisfaction with treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=0.06, p=0.792).

Figure 8.20 shows that transitions from self-reported adherence to non-adherence did not vary significantly by patients' satisfaction with support provided by treatment buddy. Transitions from self-reported adherence to non-adherence common among patients who were satisfied with support and there were no transitions from self-reported adherence to non-adherence among patients who were dissatisfied with support provided by treatment buddy. This result is rather unexpected however; this could indicate that patients were still adhering to treatment irrespective of their dissatisfaction. This results are however not significant.

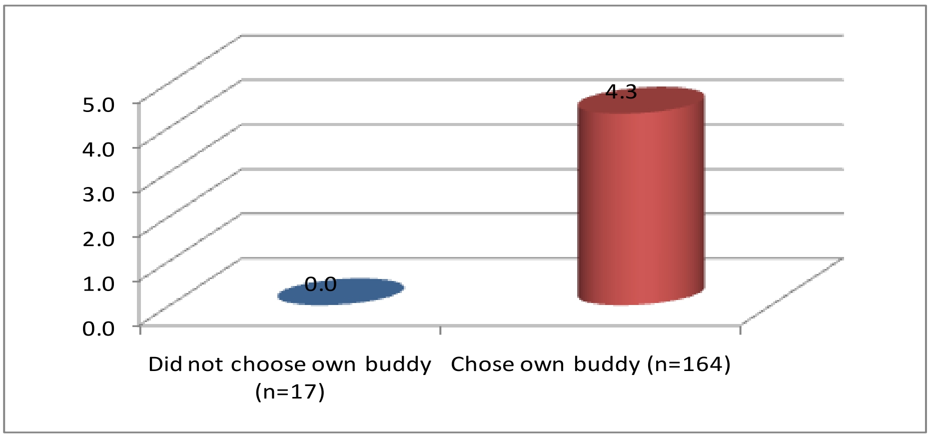
Figure 8.21: Transitions from self-reported adherence to non-adherence, by assistance with adherence



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=2.48, p=0.115).

Transitions from self-reported adherence to non-adherence were not significantly associated with assistance with adherence by treatment buddy (Figure 8.21). However, transitions from self-reported adherence to non-adherence were lower among patients who received adherence support from their treatment buddy. This rather expected result suggests that treatment buddies have a role to play in preventing non-adherence by providing adherence support.

Figure 8.22: Transitions from self-reported adherence to non-adherence, by choice of treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=0.75, p=0.385).

Figure 8.22 reveals that transitions from self-reported adherence to non-adherence were not significantly associated with choice of treatment buddy. However, transitions from self-reported adherence to non-adherence were only among patients who chose their own treatment buddies. There were not transitions from self-reported adherence to non-adherence among patients who were assigned treatment buddies. These results are however not significant.

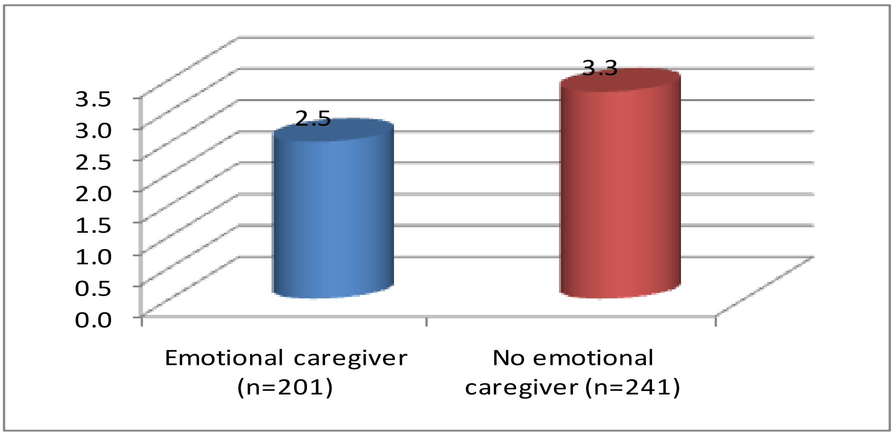
8.3.3. Transitions from self-reported adherence to non-adherence and changes in access to support

This section assesses how changes in access to other forms of support impart on ttransitions from self-reported adherence to non-adherence

8.3.3. (a) Past access to an emotional caregiver

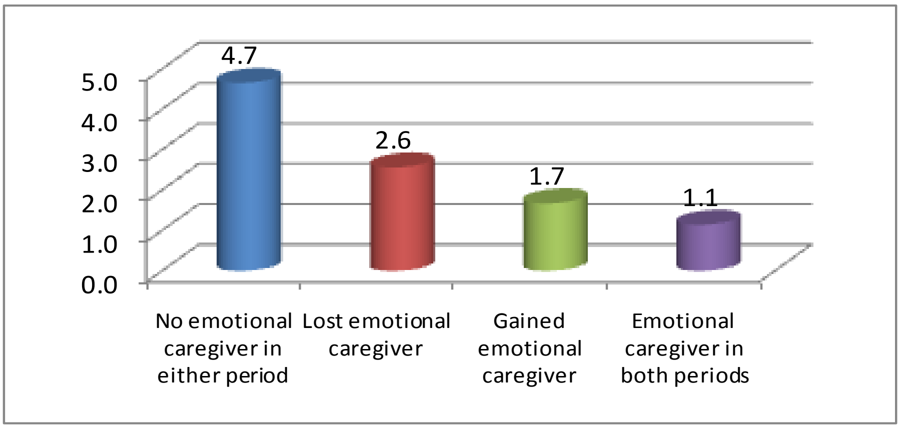
According to Figure 8.23, transitions from self-reported adherence to non-adherence did not vary significantly by past access to an emotional caregiver. However, transitions from self-reported adherence to non-adherence were common among patients who did not have access to an emotional caregiver. Although not significant, these finding are expected, since patients who have access to support are expected to have higher adherence levels.

Figure 8.23: Transitions from self-reported adherence to non-adherence, by past access to an emotional caregiver



Note: Results are not statistically significant (chi2=0.26, p=0.606).

Figure 8.24: Transitions from self-reported adherence to non-adherence, by past transitions in access to an emotional caregiver (n=288)



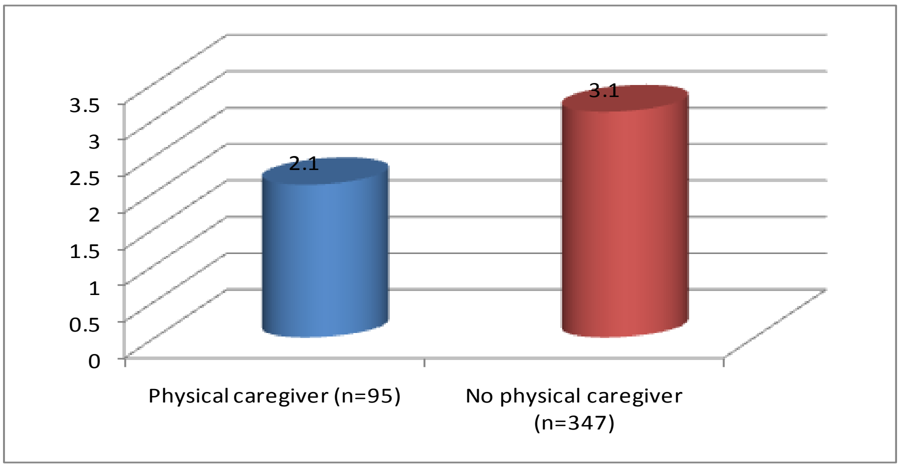
Note: Results are not statistically significant (chi2=2.92, p=0.403).

Figure 8.24 demonstrate that transitions from self-reported adherence to non-adherence did not vary significantly by past transitions in access to emotional caregiver. Transitions from self-reported adherence to non-adherence were common among patients who did not have access to an emotional caregiver in either period. Moreover, transitions from self-reported adherence to non-adherence were low among patients who had access to an emotional caregiver in both periods. These finding make sense because it would be expected that patients who have access to support would have higher adherence levels, hence lower m transitions from self-reported adherence to non-adherence.

8.3.3 (b) Past access to a physical caregiver

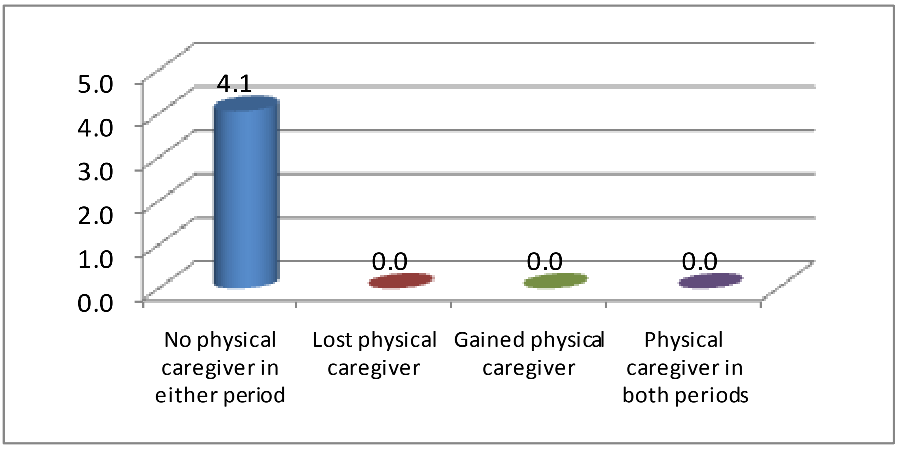
Figure 8.25 shows that transitions from self-reported adherence to non-adherence did not vary significantly by past access to a physical caregiver. Even though, these results are insignificant, transitions from self-reported adherence to non-adherence are common among patients who previously had access to physical caregiver. These results make sense because patients who have access to support are expected to have higher adherence levels.

Figure 8.25: Transitions from self-reported adherence to non-adherence, by past access to a physical caregiver



Note: Results are not statistically significant (chi2=0.29, p=0.586).

Figure 8.26: Transitions from self-reported adherence to non-adherence, by past transitions in access to a physical caregiver (n=288)



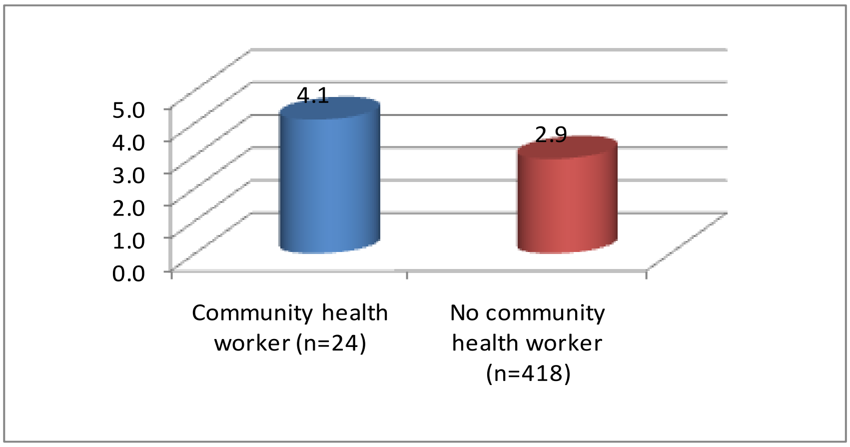
Note: Results are not statistically significant (chi2=3.80, p=0.284).

Figure 8.26 demonstrate that transitions from self-reported adherence to non-adherence did not vary significantly by past transitions in access to physical caregiver. Transitions from self-reported adherence to non-adherence were only among patients who did not have access to a physical caregiver in either period.

8.3.3 (c) Past access to a community health worker

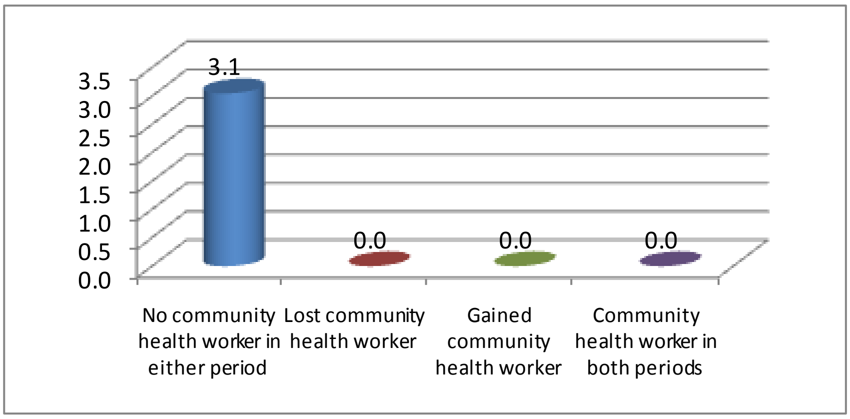
Transitions from self-reported adherence to non-adherence did not vary significantly by past access to a community health worker (Figure 8.27. Transitions from self-reported adherence to non-adherence were more common among patients who in the past received visits from community health worker. This rather unexpected results raise questions about the role of community health workers in enhancing and maintaining adherence, these results are however not significant.

Figure 8.27: Transitions from self-reported adherence to non-adherence, by past access to a community health worker



Note: Results are not statistically significant (chi2=0.13, p=0.717).

Figure 8.28: Transitions from self-reported adherence to non-adherence, by past transitions in access to a community health worker (n=288)



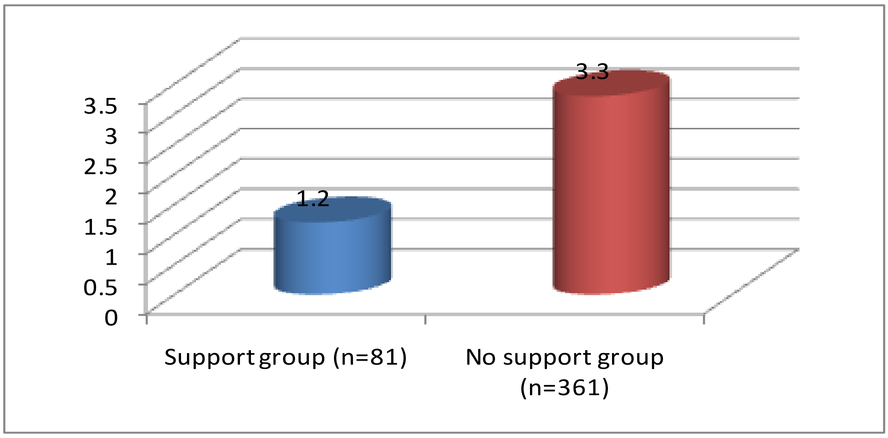
Note: Results are not statistically significant (chi2=0.81, p=0.845).

Figure 8.28 demonstrate that transitions from self-reported adherence to non-adherence did not vary significantly by past transitions in access to a community health worker. Transitions from self-reported adherence to non-adherence were only among patients who did not have access to a community health worker in either period.

8.3.3. (d) Past participation in a support group

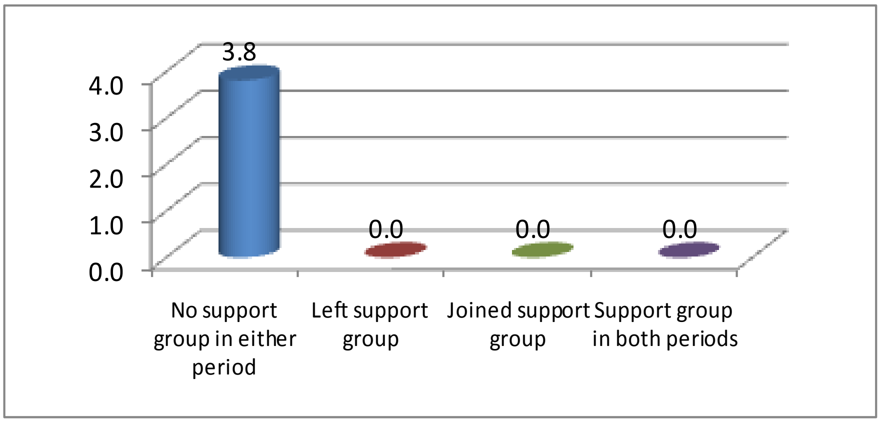
Figure 8.29 shows that transitions from self-reported adherence to non-adherence did not vary significantly by past participation in a support group. Even though, these results are insignificant, transitions from self-reported adherence to non-adherence are common among patients who did not participate in a support group. These results make sense, as they highlight the potential role of support groups in enhancing adherence and maintaining adherence.

Figure 8.29: Transitions from self-reported adherence to non-adherence, by past participation in a support group



Note: Results are not statistically significant (chi2=1.01, p=0.314).

Figure 8.30: Transitions from self-reported adherence to non-adherence, by past transitions in participation in support group (n=288)



Note: Results are not statistically significant (chi2=3.05, p=0.383).

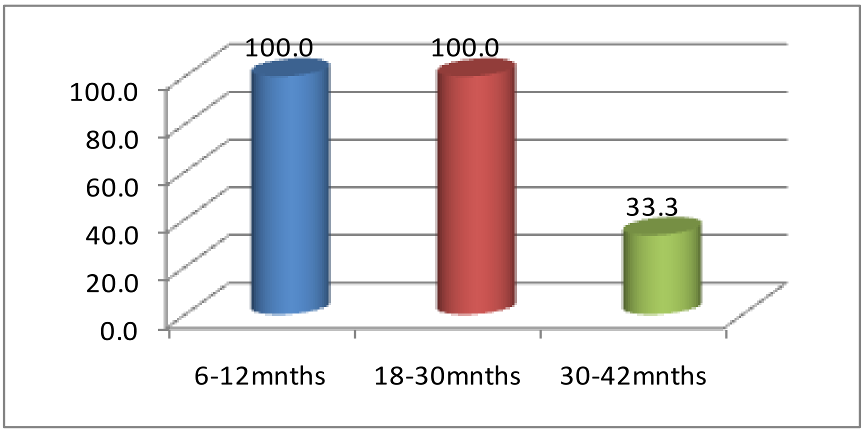
Figure 8.30 demonstrate that transitions from self-reported adherence to non-adherence did not vary significantly by past transitions in participation in support groups. Transitions from self-reported adherence to non-adherence were only among patients who did not participate in a support group in either period.

8.3.4. Determinants of transitions from self-reported adherence to non-adherence

The random effects (RE) and Fixed Effects (FE) models could not be estimated. The pooled regression models did not perform adequately in terms of goodness-of-fit ($p<0.3485$) and ($p<0.1022$). None of the models which estimated treatment buddy characteristics were significant in terms of the overall fit. As a result, it was not possible to report and interpret regression on the potential statistical and practical significance of alternative determinants of transitions from self-reported adherence to non-adherence, including access to a treatment buddy and alternative treatment buddy characteristics.

8.4 Transitions from self-reported non-adherence to adherence

Figure 8.31: Transitions from self-reported non-adherence to adherence, by treatment career phase (n=13)



Note: Results are not statistically significant (chi2=7.87, p=0.019).

Figure 8.31 shows that transitions from self-reported non-adherence to adherence varied significantly by treatment duration ($p<0.05$). Transitions from self-reported non-adherence to adherence declined as treatment duration increased. Transitions from self-reported non-adherence to adherence were common among patients who had been on treatment for less than 30 months. Further, transitions from self-reported non-adherence to adherence were low among patients who had been on treatment for longer. This result could be due to the possibility that patients who have been on treatment for longer have been absorbed into the system and fully comprehend how the treatment works and are used to treatment, therefore less likely to transition.

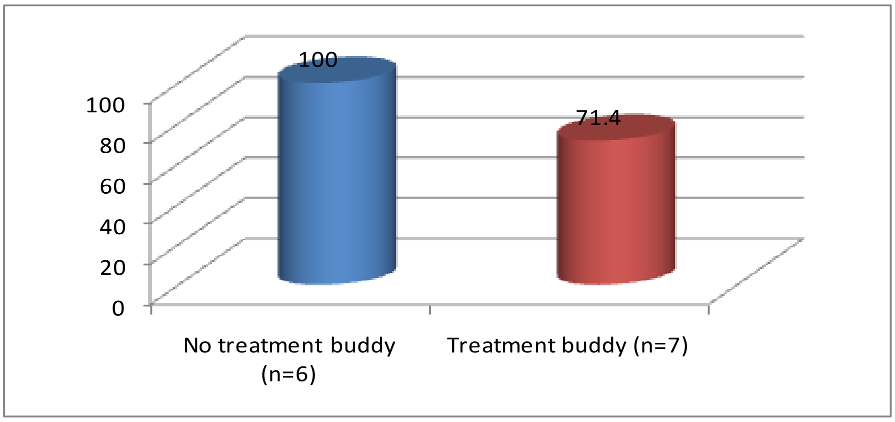
8.4.1. Transitions from self-reported non-adherence to adherence and access to a treatment buddy

This section focuses on how access to treatment buddy impact on transitions from self-reported non-adherence to adherence

8.4.1 (a) Past access to a treatment buddy

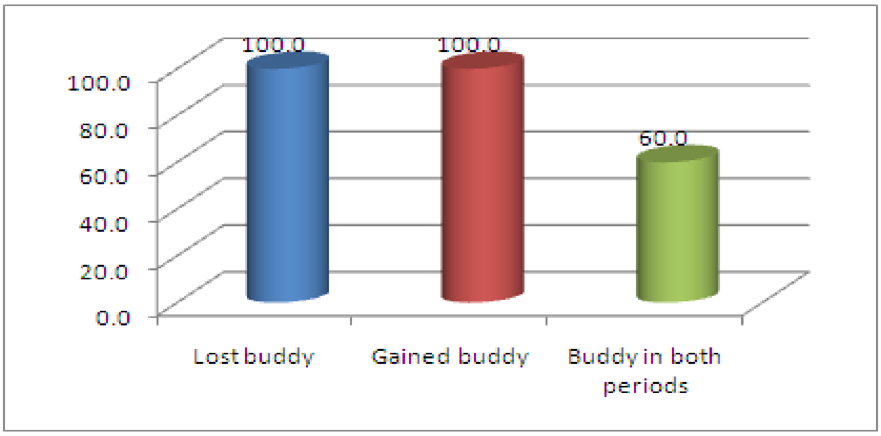
Figure 8.32 shows that transitions from self-reported non-adherence to adherence did not differ significantly by past access to a treatment buddy. However transitions from self-reported non-adherence to adherence were higher among patients who did not have access to a treatment buddy. These results are rather contradictory but are not statistically significant.

Figure 8.32: Transitions from self-reported non-adherence to adherence, by past access to a treatment buddy



Note: Results are not statistically significant (chi2=2.02, p=0.155)

Figure 8.33: Transitions from self-reported non-adherence to adherence, by past transitions in access to a treatment buddy (n=7)



Note: Results are not statistically significant (chi2=5.39, p=0.051).

Transitions from self-reported non-adherence to adherence were significantly associated with transitions in access to treatment buddy. According to Figure 8.33, though, Transitions from self-reported non-adherence to adherence were higher among patients who lost and gained access to a treatment buddy. Patients who had treatment buddies in both periods were less likely to transition from self-reported non-adherence to adherence buddy.

8.4.2. Transitions from self-reported non-adherence to adherence and treatment buddy characteristics

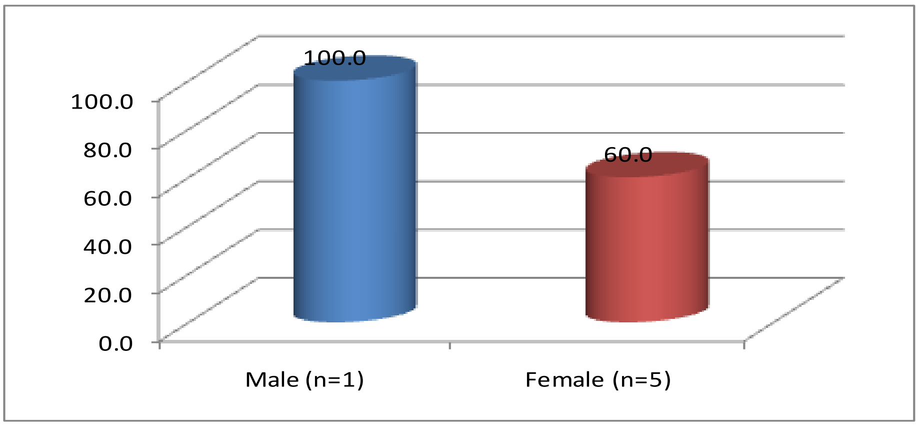
Table 8.5: Age of treatment buddy, by transitions from self-reported non-adherence to adherence

Self reported adherence	Summary of age of a treatment buddy							
	Mean	*SD*	*p25*	*p75*	*Median*	*Min*	*Max*	*Frequency*
No adherence in either period	32	0.00	32	32	32	32	32	2
Non-adherence to adherence	29.25	13.32	19	39.5	25.5	19	47	4
Total	**30.16**	**10.41**	**19**	**32**	**32**	**19**	**47**	**6**

Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (F=0.08, p=0.796).

Table 8.3 shows that transitions from self-reported non-adherence to adherence were not associated with age of treatment buddy. However, non-adherence patients who became adherent had younger treatment buddies compared to patients who remain non-adherence.

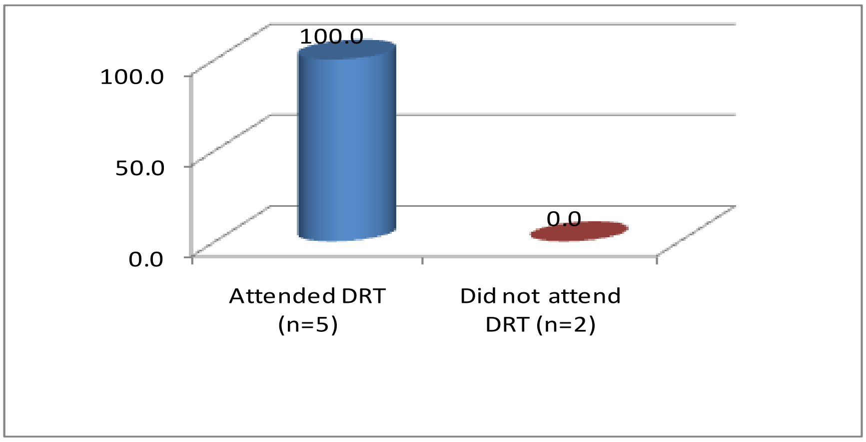
Figure 8.34: Transitions from self-reported non-adherence to adherence, by gender of treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=0.60, p=0.439).

Figure 8.34 shows that transitions from self-reported non-adherence to adherence were not significantly associated with the gender of the treatment buddy. Transitions from self-reported non-adherence to adherence were higher among patients who had male than female treatment buddies

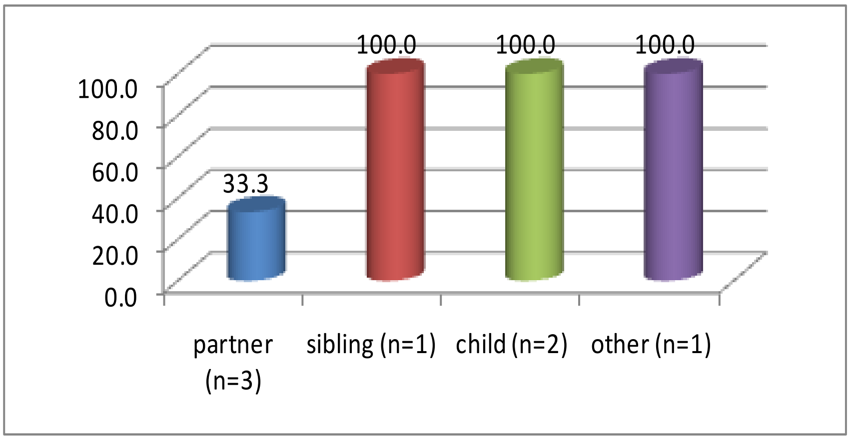
Figure 8.35: Transitions from self-reported non-adherence to adherence, by attendance of drug readiness training



Note: Treatment buddy characteristics as observed in the previous period. Results are statistically significant at the 1% level (chi2=7.00, p=0.008).

Figure 8.35 shows that transitions from self-reported non-adherence to adherence were significantly associated with the attendance of drug readiness training by the patient's treatment buddy (p<0.01). Moreover, transitions from self-reported non-adherence to adherence occurred to all patients whose treatment buddies attended drug readiness training. This finding demonstrates the importance of treatment buddies attending the drug readiness training offered to patients in order to provide effective support and enhance adherence to medication.

Figure 8.36: Transitions from self-reported non-adherence to adherence, by relationship with treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=3.73, p=0.292).

Figure 8.36 shows that transitions from self-reported non-adherence to adherence were not associated with the treatment buddy's relationship with the patient. Transitions from self-reported non-adherence to adherence occurred to all patients regardless of the relation, except for patients whose treatment buddies were partners. This is rather an unexpected finding but not statistically significant

With reference to transitions from self-reported non-adherence to adherence, by satisfaction with support provided by treatment buddy, all patients who transitioned from non-adherence to adherence were highly satisfied with support provided by treatment buddy. With reference to transitions from self-reported non-adherence to adherence by assistance with adherence by treatment buddy, all patients who transitioned from non-adherence to adherence received assistance with adherence from treatment buddies. With reference to transitions from self-reported non-adherence to adherence by choice of treatment buddy, all patients who transitioned from non-adherence to adherence chose own treatment buddies.

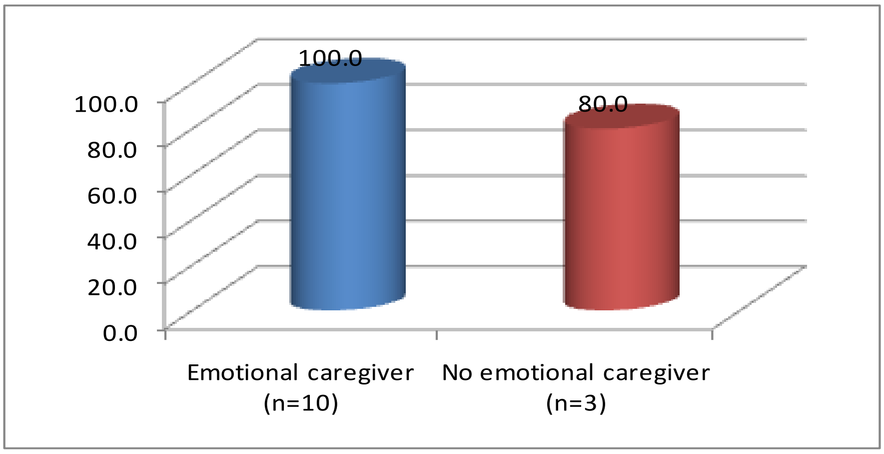
8.4.3. Transitions from self-reported non-adherence to adherence and changes in access to other support

The section establishes how changes in access to other support impact on transitions from self-reported non-adherence to adherence

8.4.3. (a) Past access to an emotional caregiver

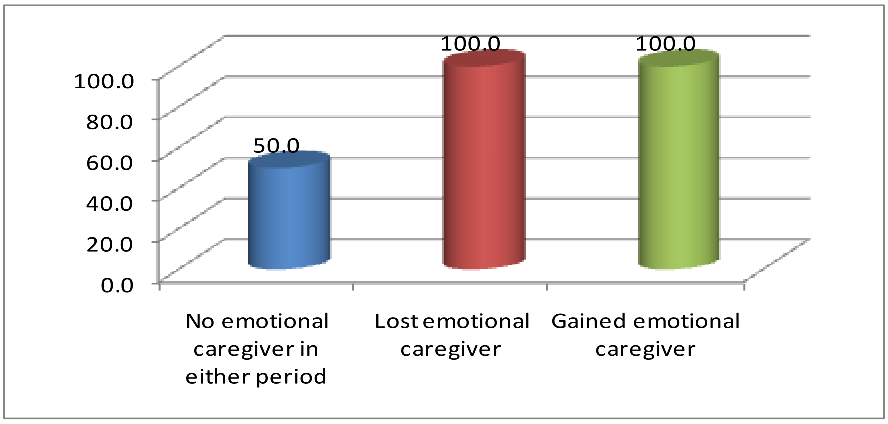
Figure 8.37 shows that transitions from self-reported non-adherence to adherence were not significantly associated with past access to emotional caregiver. However, transitions from self-reported non-adherence to adherence were common among patients who in the past had access to an emotional caregiver. These finding make sense because it would be expected that patients who have access to emotional caregivers or any support would have higher adherence levels, hence higher transitions from self-reported non-adherence to adherence.

Figure 8.37: Transitions from self-reported non-adherence to adherence, by past access to an emotional caregiver



Note: Results are not statistically significant (chi2=0.70, p=0.400).

Figure 8.38: Transitions from self-reported non-adherence to adherence, by past transitions in access to an emotional caregiver (n=7)



Note: Results are not statistically significant (chi2=2.10, p=0.350).

Figure 8.38 shows that transitions from self-reported non-adherence to adherence were not significantly associated with past transitions in access to emotional caregiver. However, transitions from self-reported non-adherence to adherence were common among patients who previously had but lost access to an emotional caregiver and those who gained access to an emotional caregiver. As expected, patients who did not have access to an emotional caregiver in either period, were less likely to transition to adherence. These findings highlight the potential role of emotional caregivers in enhancing adherence. However, these results are not significant.

8.4.3. (b) Past access and past transitions in access to a physical caregiver

With reference to transitions from self-reported non-adherence to adherence, by past access to a physical caregiver, all patients who transitioned from self-reported adherence to adherence did not have access to a physical caregiver in the previous period.

With reference to transitions from self-reported non-adherence to adherence, by past transitions in access to a physical caregiver, all patients who transitioned from non-adherence to adherence did not have access to a physical caregiver in either period.

8.4.3. (c) Past access and past transitions in access to a community health worker

With reference to transitions from self-reported non-adherence to adherence, by past access to a community health worker, all patients who transitioned from self-reported adherence to adherence did not have access to a community health worker in the previous period.

With reference to transitions from self-reported non-adherence to adherence, by past transitions in access to a community health worker, all patients who transitioned from non-adherence to adherence did not have access to a community health worker in either period.

8.4.3. (d) Past participation and past transitions in participation in a support group

With reference to transitions from self-reported non-adherence to adherence, by past participation in a support group, all patients who transitioned from self-reported adherence to adherence did not participate in a support group in the previous period.

With reference to transitions from self-reported non-adherence to adherence, by past transitions in participation in a support group, all patients who transitioned from non-adherence to adherence did not participate in a support group in either period.

8.4.4. Determinants of transitions from self-reported non-adherence to adherence.

None of the regression models performed adequately in terms of goodness of fit. The pooled model was the best model according to the diagnostic test, but the overall model was not significant (p=0.117). None of the treatment buddy variables were significant predictors of transitions from self-reported non-adherence to adherence. As a result, it was not possible to discuss any potentially statistically and/or practically significant determinants of transitions from self-reported non-adherence to adherence, including past access to a treatment buddy and alternative treatment buddy characteristics.

8.5. Summary

This chapter reveals that self-reported adherence increased as treatment duration increased and clinical-reported non-adherence increased as treatment duration increased. Moreover, access to treatment buddy was not associated with self-reported adherence or non-adherence. This is contradictory to other studies. For example, a study by Yoder *et al*, 2009 conducted in KwaZulu Natal reported that treatment supporters were key to adherence among patients on ART. Moreover, a study conducted by Unge *et al*, 2010 in Sub-Saharan Africa reported that not having a treatment buddy was associated with non-adherence.

None of the treatment buddy characteristics were associated with self-reported adherence, but self-reported adherence was more common among patients with treatment buddies who attended the drug readiness training; transitions from self-reported adherence to non-adherence were lower among patients with treatment buddies who attended drug readiness training; and transitions from non-adherence to adherence were more common among patients with treatment buddies who attended a drug readiness training. Attendance of drug readiness training consistently features across all outcomes, this highlights the importance of attending drug readiness training for treatment buddies to enhance and maintain adherence. These above mentioned findings suggest that access to a treatment buddy was not important in any of the self-reported adherence outcomes but treatment buddy characteristics were.

Furthermore, access to an emotional caregiver explained self-reported adherence and both transitions from self-reported adherence to non-adherence and transitions from self-reported non-adherence to adherence Patients who had emotional caregivers had higher self-reported adherence and lower self-reported non-adherence.

In addition, access to a physical caregiver explained both transitions from self-reported adherence to non-adherence and transitions from self-reported non-adherence to adherence Patients who had access to a physical caregiver had higher self-reported adherence and lower non-adherence.

Transitions from self-reported non-adherence to adherence were more common among patients who had access to a community health worker and transitions from self-reported adherence to non-adherence were low among patients who had access to a community health worker. Self-reported adherence was more common among patients who participated in a support group and transitions from self-reported adherence to non-adherence were low among patients who participated in a support group. The above mentioned findings highlight the importance of support in enhancing and maintaining adherence. The small number of non-adherent cases, which constrain the analysis in terms of variation in the outcomes is the result in part of the weaknesses of self-reported adherence measures and, is a key limitations in this particular chapter.

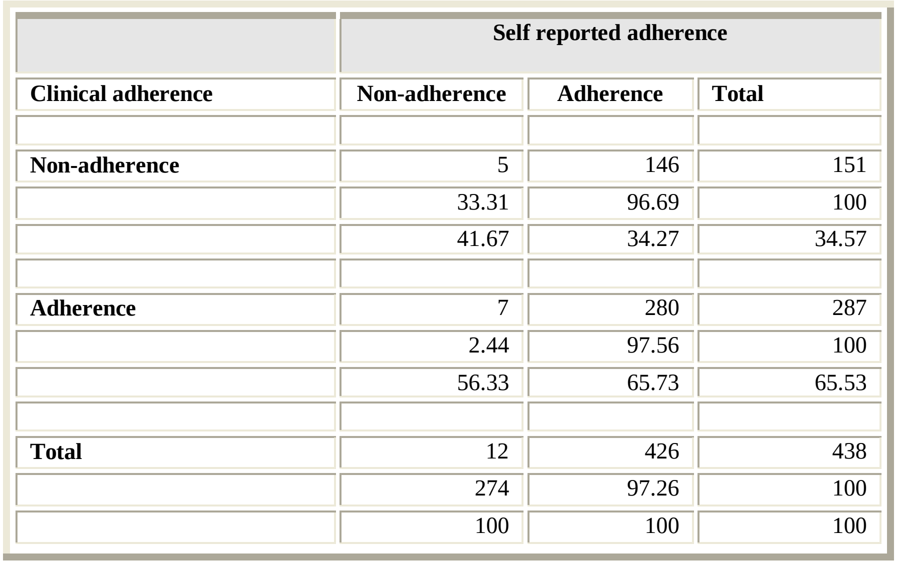
CHAPTER 9
CLINICAL ADHERENCE

9.1. Introduction

This chapter aims to determine how access to treatment buddy and treatment buddy characteristics impact on clinical adherence. The chapter sets out to determine whether the hypothesis that access to a treatment buddy enhances clinical adherence is correct or not. The chapter explores three main outcomes, namely (i) current levels of clinical adherence, (ii) transitions in clinical adherence from being adherent to being non-adherent, and (iii) transitions in clinical adherence from being non-adherent to being adherent. Bivariate analyses on how; self-reported and clinical adherence outcomes are correlated; clinical adherence outcomes differ by need for support, access to a treatment buddy and treatment buddy characteristics, and other support are performed, followed by multiple regression analyses exploring the role of the former outcomes in predicting clinical adherence.

9.2. Clinical adherence

Table 9.1: Association between clinical and self-reported adherence



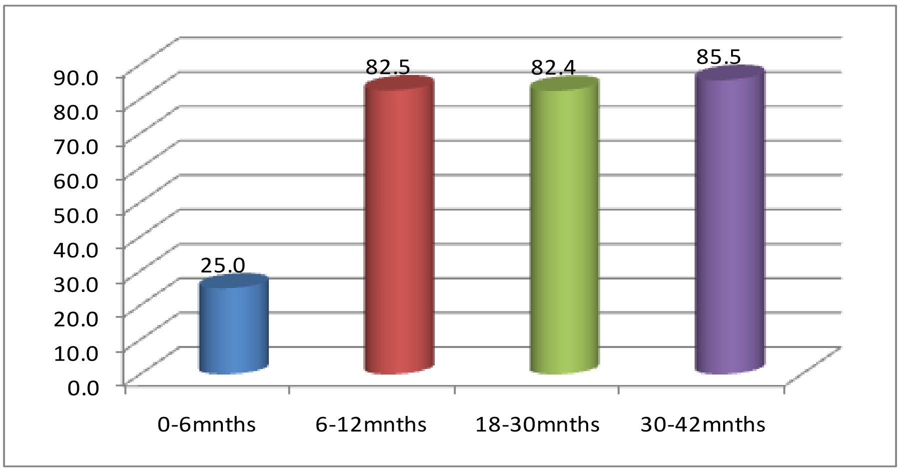
	Self reported adherence		
Clinical adherence	**Non-adherence**	**Adherence**	**Total**
Non-adherence	5	146	151
	33.31	96.69	100
	41.67	34.27	34.57
Adherence	7	280	287
	2.44	97.56	100
	56.33	65.73	65.53
Total	12	426	438
	274	97.26	100
	100	100	100

Note: Results are not statistically significant (chi2=0.28., p=0.595).

Table 9.1 indicates that clinical adherence was not associated with self-reported adherence. Adherence is higher in both measures of adherence. Very few patients reported clinical and self-reported adherence.

Approximately, 96% of patients reported adherence, compared to 56% clinical adherence results. This is indication of the possibility of over reporting among patients. These results concur with that of a study conducted in Sub-Saharan Africa by Kabore *et al*, 2010, where self reported adherence rates were higher than clinic adherence rates.

Figure 9.1: Clinical adherence, by treatment career phase (n=591)



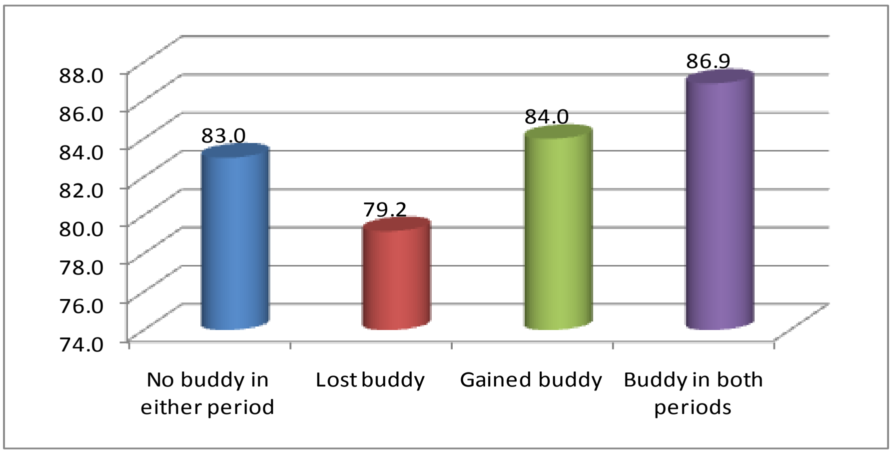
Note: Results are statistically significant at the 1% level (chi2=175.11, p<0.001).

Figure 9.1 shows that clinical adherence varied significantly by treatment career (p<0.001). Clinical adherence was lowest among patients who had been on treatment for less than 6 months, but increased as treatment career increased. Low figure for 0-6 months is plausible, given that patients in this phase have just commenced treatment. Furthermore; clinical adherence was highest among patients who had been on treatment for more than 30 months. Similar to a study conducted in Khayelitsha, clinical adherence increased as months on treatment increased (Khayelitsha activity report, 2005). These findings are also consistent with that of a cohort study of adherence to ART among patients in an American Clinic where there was an increase in adherence (as measured by viral load) over time (Cambiano *et al*, 2010).

9.2.1. Clinical adherence and access to a treatment buddy

Clinical adherence was not significantly associated with transitions in access to a treatment buddy. Figure 9.2 show that clinical adherence was highest among patients who had access to a treatment buddy in both periods and lowest among patients who lost access to a treatment buddy in the past. This is rather an expected finding, higher clinical adherence among patients with treatment buddies, highlight the potential role of treatment buddies in reinforcing adherence behaviour by providing necessary support. However, these findings are not statistically significant.

Figure 9.2: Clinical adherence, by transitions in access to a treatment buddy (n=451)



Note: Results are not statistically significant (chi2=1.711, p=0.634).

Clinical adherence was not significantly associated with transitions in access to a treatment buddy. Figure 9.2 show that clinical adherence was highest among patients who had access to a treatment buddy in both periods and lowest among patients who lost access to a treatment buddy in the past. This is rather an expected finding, higher clinical adherence among patients with treatment buddies, highlight the potential role of treatment buddies in reinforcing adherence behaviour by providing necessary support. However, these findings are not statistically significant.

9.2.2. Clinical adherence and treatment buddy characteristics

In this section, an attempt is made to establish how clinical adherence differs by treatment buddy characteristics. The focus is on seven treatment buddy characteristics and analysis is done on each characteristic namely: age; gender; attendance of drug readiness training; relationship with the patient; satisfaction with treatment buddy; assistance with adherence and choice of treatment buddy**.**

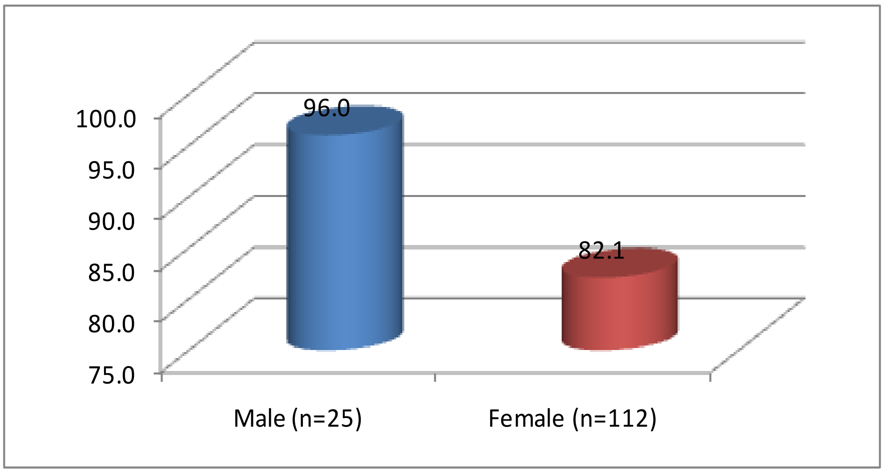
Table 9.2: Age of treatment buddy, by clinical adherence

Current clinical adherence	**Summary of age of a treatment buddy**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
Non adherence	41.73	17.89	29	52	45	15.0	89	**19**
Adherence	33.92	16.55	22	46	32	5	78	**113**
Total	**35.04**	**16.90**	**22.5**	47	**32**	**5**	**89**	**132**

Note: Treatment buddy characteristics as observed in the previous period. Results are statistically significant at the 10% level (F=3.54, p=0.062).

Clinical adherence varied significantly by age of the patient's treatment buddy. According to Table 9.2, shows that adherent patients had younger treatment buddies compared to non-adherent patients, who had older treatment buddies.

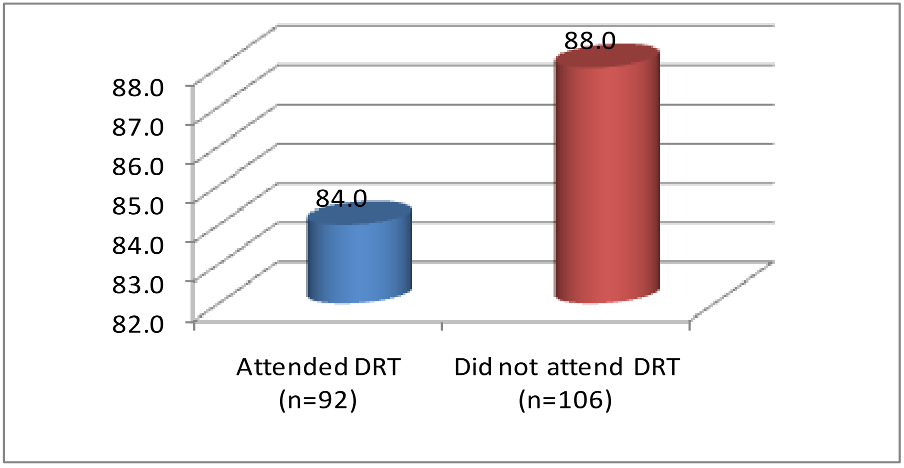
Figure 9.3: Clinical adherence, by gender of treatment buddy



Note: Treatment buddy characteristics as observed in the previous period.Results are statistically significant at the 10% level (chi2=3.02, p=0.082).

According to Figure 9.3, clinical adherence varied significantly by gender of the patient's treatment buddy (p<0.10). Clinical adherence was significantly higher among patients whose treatment buddies were male and lower among patients whose treatment buddies were female. These results were however not statistically significant.

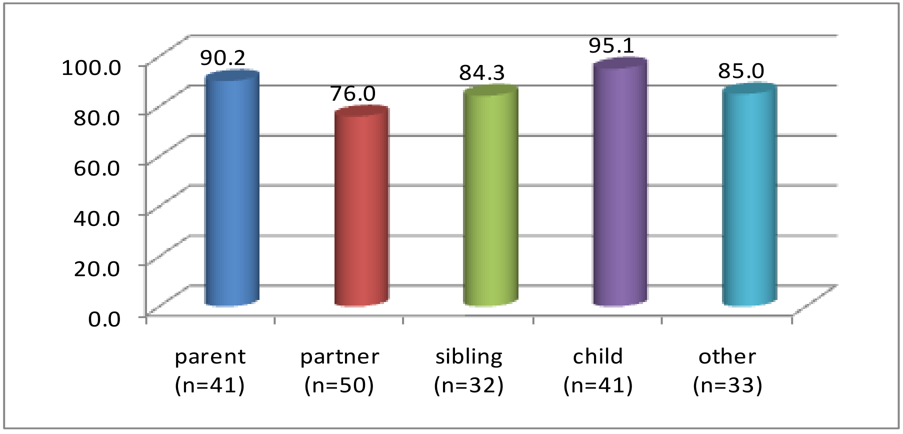
Figure 9.4: Clinical adherence, by attendance of drug readiness training



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=0.66, p=0.416).

Clinical adherence did not vary significantly by the attendance of drug readiness training by the patient's treatment buddy (Figure 9.4). Clinical adherence, contrary to expectations, was slightly higher among patients whose treatment buddies did not the attend drug readiness training. The results, however, are not statistically significant, which implies that one should not read too much into such contradictory finding.

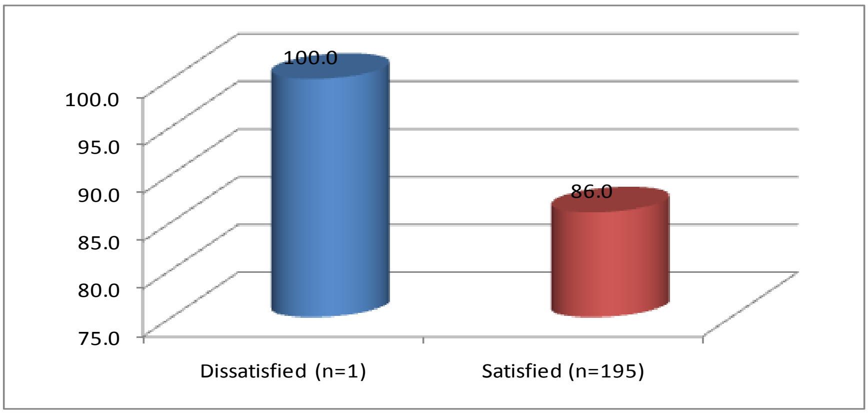
Figure 9.5: Clinical adherence, by relationship with treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=7.60, p=0.107).

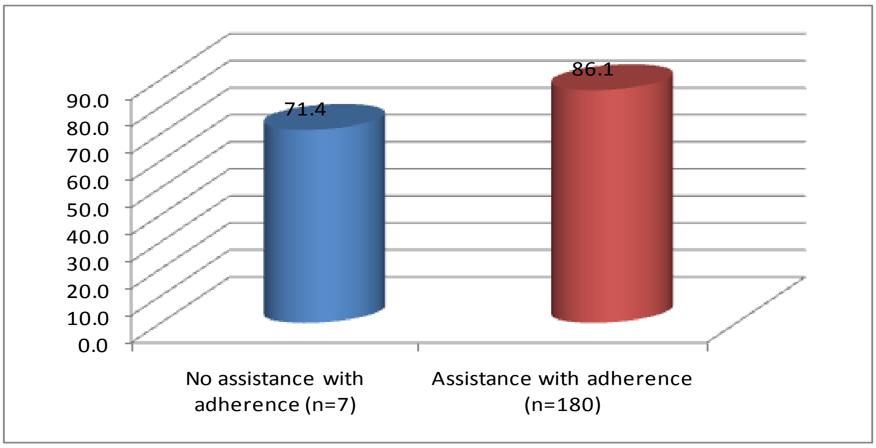
Clinical adherence was not significantly associated with patients' satisfaction with the support provided by their treatment buddy. In fact, Figure 9.6 reveals that clinical adherence was higher among patients who were not satisfied with the support provided by their treatment buddy and lower among patients who were satisfied with the support provided by their treatment buddy. As the reported differences are not statistically significant, however, one should not read too much into this contradictory finding.

Figure 9.6: Clinical adherence, by satisfaction with treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=0.16, p=0.682).

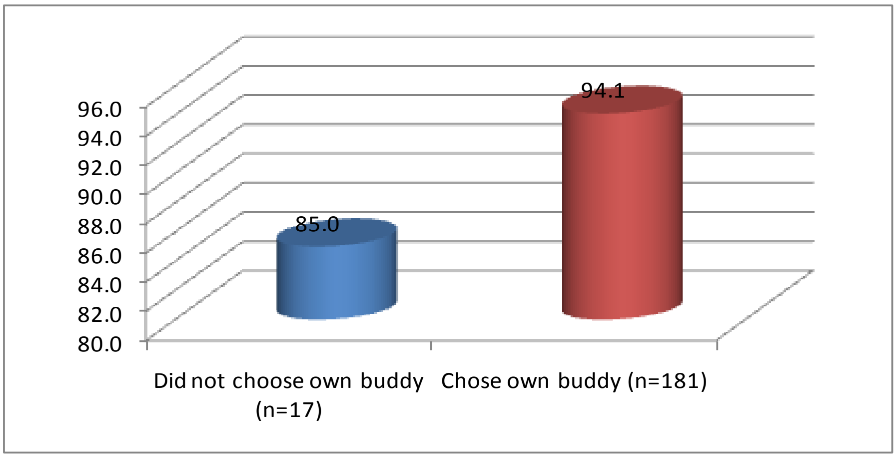
Figure 9.7: Clinical adherence, by assistance with adherence



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=1.17, p=0.278).

Figure 9.7 shows that clinical adherence, as expected, was higher among patients who received assistance with adherence from their treatment buddies and lower among those who did not receive adherence support. This finding highlights the potential importance of adherence support in enhancing level of adherence. The reported differences are however not statistically significant.

Figure 9.8: Clinical adherence, choice of treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=1.04, p=0.307).

Clinical adherence did not vary significantly by the choice of treatment buddy. However, clinical adherence, as expected, was higher among patients who chose own treatment buddies and lower among patients who did not choose their own treatment buddies. The reason behind this finding could be that patients who chose their own buddies have a close connection with their treatment, hence adherence support may be provided more often, which may in turn, translate into better treatment outcomes.

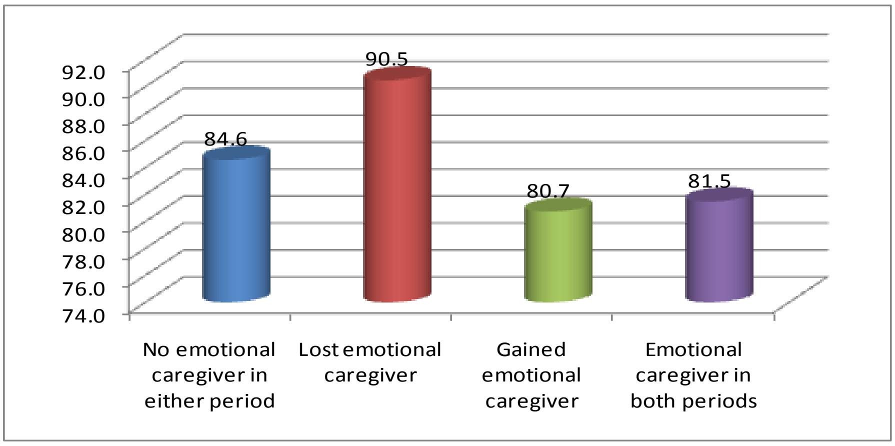
9.2.3. Clinical adherence and transitions in access to other support

The focus of this section is on determining how transitions in access to other support impact on clinical adherence.

9.2.3. (a) Transitions in access to an emotional caregiver

According to Figure 9.9, clinical adherence did not vary significantly by transitions in access to an emotional caregiver. Clinical adherence was highest among patients who in the recent past lost access to an emotional caregiver and lowest among patients who gained access to an emotional carer. Clinical adherence was similar between patients who had access to an emotional caregiver in both periods and those who gained access to an emotional caregiver Figure 9.9 therefore suggests that clinical adherence was not influenced by recent transitions in access to an emotional caregiver, though results were not statistically significant.

Figure 9.9: Clinical adherence, by transitions in access to an emotional caregiver (n=455)

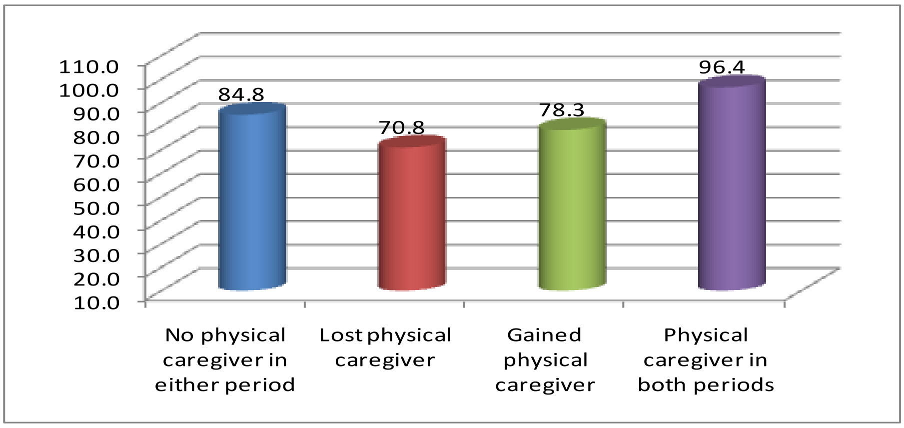


Note: Results are not statistically significant (chi2=3.18, p=0.365).

9.2.3. (b) Transitions in access to a physical caregiver

Clinical adherence was significantly associated with recent transitions in access to a physical caregiver (p<0.05). Figure 9.10 reveals that clinical adherence, true to expectations, was highest among patients who had access to physical caregivers in both periods. Clinical adherence, similarly, was lowest among patients who lost access to a physical caregiver. Having a physical caregiver in both periods or having gained access to a physical caregiver in the recent past seem to be associated with improved clinical adherence compared to having lost the services of a physical caregiver in the recent past. However, clinical adherence was relatively high among patients without access to a physical caregiver in either period, a result contrary to expectations. The results may indicate the potential role of physical caregivers in reinforcing adherence through the provision of support.

Figure 9.10: Clinical adherence, by transitions in access to a physical caregiver (n=455)

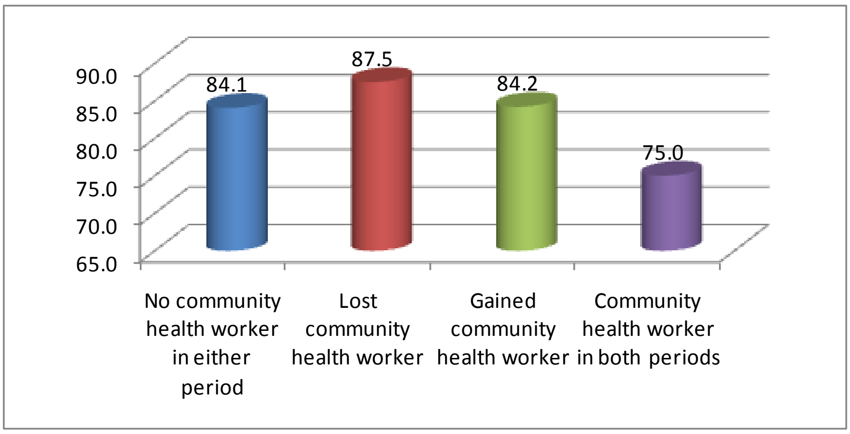


Note: Results are statistically significant at the 5% level (chi2=7.90, p=0.048).

9.2.3. (c) Transitions in access to a community health worker

According to Figure 9.11, clinical adherence did not vary significantly by recent transitions in access to a community health worker. Clinical adherence, contrary to expectations, was higher among patients who lost access to a community health worker and lowest among patients who were visited by a community health worker in both periods. The results were however, not significant.

Figure 9.11: Clinical adherence, by transitions in access to a community health worker (n=455)

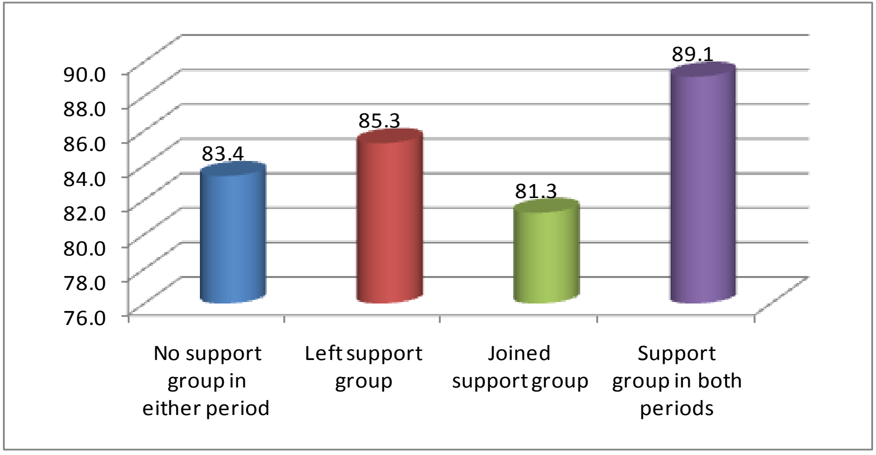


Note: Results are not statistically significant (chi2=0.55, p=0.907).

9.2.3. (d) Transitions in participation in a support group

Figure 9.12 demonstrate that clinical adherence did not vary significantly by transitions in participation in a support group Clinical adherence, as one would expect, was however highest among patients who participated in a support group in both periods and lowest among those who recently joined a support group. Low clinical adherence among those who joined a support group could be explained by an argument that low clinical adherence may have had prompted patients to join the support group in the first place.

Figure 9.12: Clinical adherence, by transitions in participation in a support group (n=455)

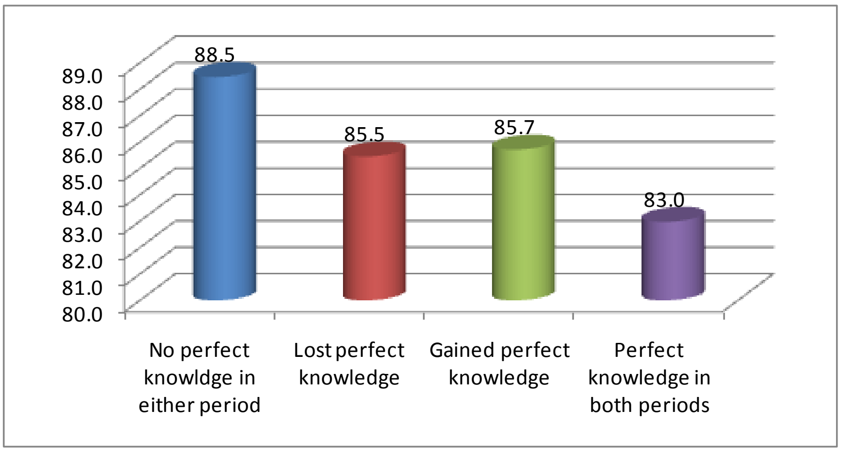


Note: Results are not statistically significant (chi2=1.21, p=0.749).

9.2.4. Clinical adherence and adherence knowledge

There were no significant differences between clinical adherence and transitions in adherence knowledge. Figure 9.13 reveals that clinical adherence, contrary to expectations, was highest among patients who did not have perfect adherence knowledge in either period and lowest among those patients who had perfect adherence knowledge in both periods. The results, however, are not statistically significant, which implies that one should not read too much into such contradictory finding.

Figure 9.13: Clinical adherence, by transitions in adherence knowledge (n=453)



Note: Results are not statistically significant (chi2=0.82, p=0.844).

9.2.5. Determinants of clinical adherence

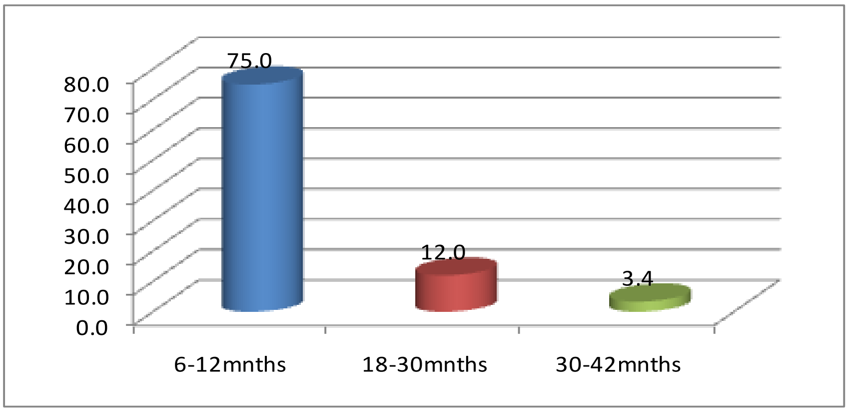
The random effects (RE) model was better compared to the pooled, but did not perform well in terms of overall fit (p=0.9411). The pooled model was also not statically significant in terms of overall fit (p=1.464). Hence, none of the regression models to be used to investigate how access to a treatment buddy and treatment buddy characteristics may matter for clinical adherence, were significant in terms of overall fit. As a result, it was not possible to reflect on how treatment buddy support may impact on clinical adherence when adjusting for other factors.

9.3. Transitions from clinical adherence to non-adherence

Figure 9.14: reveals that transitions from clinical adherence to non-adherence varied significantly by treatment career (p<0.001). The prevalence of transitions from clinical adherence to non-adherence declined as treatment career increased across the different phases of the treatment career. The proportion of patients who transitioned from adherence to non-adherence was highest among patients who had been on treatment for a short period of time only. Patients who had been on treatment for more than 30 months, were least

likely to transition from clinical adherence to non-adherence. Patients who have been on treatment for longer may be more likely to have stabilized and to comprehend or understand the importance of adherence. These results are consistent with that from a prospective cohort study of patients on antiretroviral therapy in Khayelitsha, South Africa (Coetzee *et al,* 2004), which revealed that adherence (as measured by viral load) declined as treatment career increased.

Figure 9.14: Transitions from clinical adherence to non-adherence, by treatment career phase (n=340)

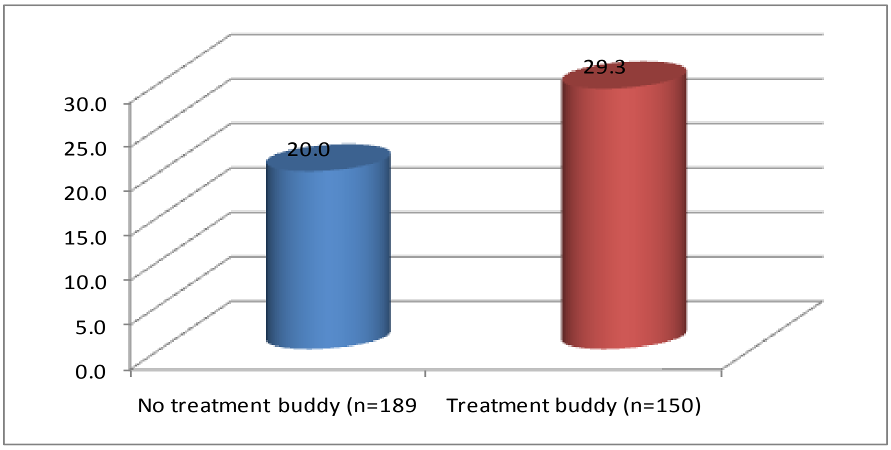


Note: Results are statistically significant at the 1% level (chi2=173.49, p<0.001).

9.3.1. Transitions_from clinical adherence to non-adherence and access to a treatment buddy

This section focuses on how access to treatment buddy and treatment buddy characteristics impact on transitions from clinical adherence to non-adherence.

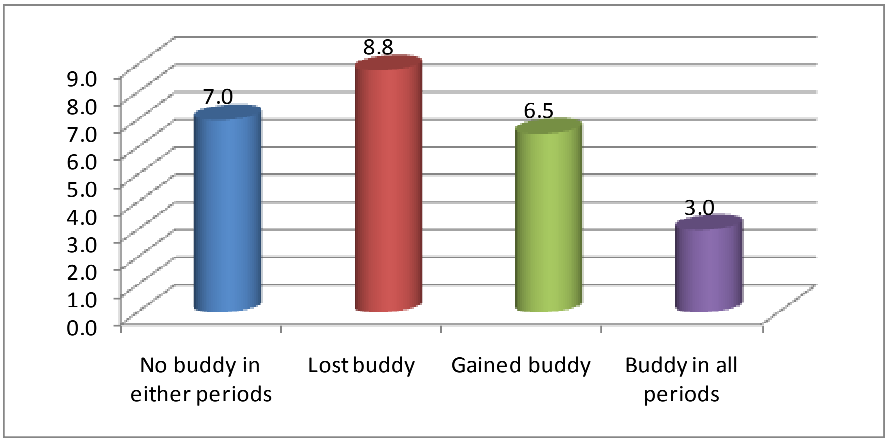
Figure 9.15: Transitions from clinical adherence to non-adherence, by past access to a treatment buddy



Note: Results are statistically significant at the 5% level (chi2=4.37, p=0.036).

Figure 9.15 reveals that transitions from clinical adherence to non-adherence varied significantly by past access to a treatment buddy (p<0.05). Transitions from clinical adherence to non-adherence was higher among patients who had access to a treatment buddy compared to patients who did not have access to treatment buddy. These results are rather contradictory as one would expect low transitions from clinical adherence to non-adherence.

Figure 9.16: Transitions from clinical adherence to non-adherence, by past transitions in access to a treatment buddy (n=250)



Note: Results are not statistically significant (chi2=1.57, p=0.666).

According to Figure 9.16, transitions from clinical adherence to non-adherence did not vary significantly by past transitions in access to a treatment buddy. Transitions from clinical non-adherence to adherence were higher among patients who lost and among patients who did not have access to treatment buddy in either period. Patients who had treatment buddies in both periods were less likely to transition from clinical adherence to non-adherence.

9.3.2. Transitions from clinical adherence to non-adherence and treatment buddy characteristics

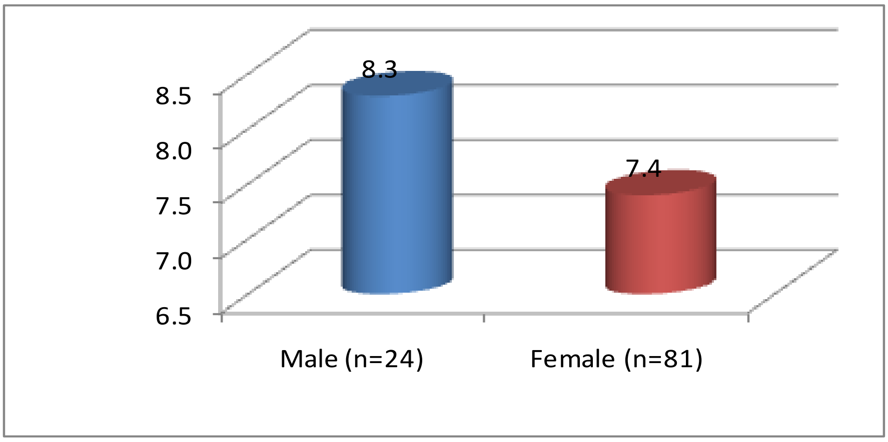
Table 9.3: Age of treatment buddy, by transitions from clinical adherence to non-adherence

Clinical adherence	**Summary of age of a treatment buddy**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
Clinical adherence in both periods	38.76	15.72	29	52	45	15	61	**13**
Adherence to non-adherence	37.75	17.11	29.5	51	36.5	7	61	**8**
Total	**38.38**	**15.84**	**29**	52	**38**	**7**	**61**	**21**

Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (F=0.24, p=0.890).

Table 9.3 shows that age of the treatment buddy did not vary significantly by transitions from clinical adherence to non-adherence. Patients who transitioned from adherence to non-adherence had treatment buddies of younger age compared to patients who had clinical adherence in both periods. However, these differences were relatively small and were not statistically significant.

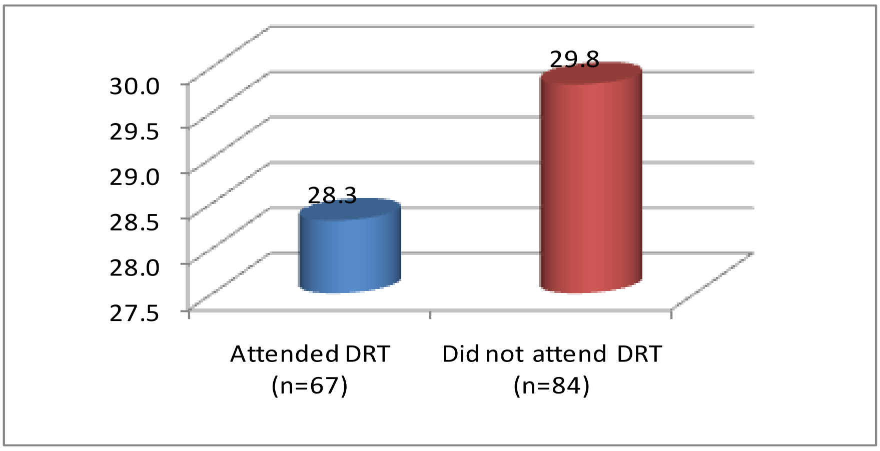
Figure 9.17: Transitions from clinical adherence to non-adherence, by gender of treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=0.02, p=0.881).

Figure 9.17 shows that transitions from clinical adherence to non-adherence did not vary significantly by gender of the treatment buddy. Transitions from clinical non-adherence to adherence were higher among patients who had male other than female treatment buddies.

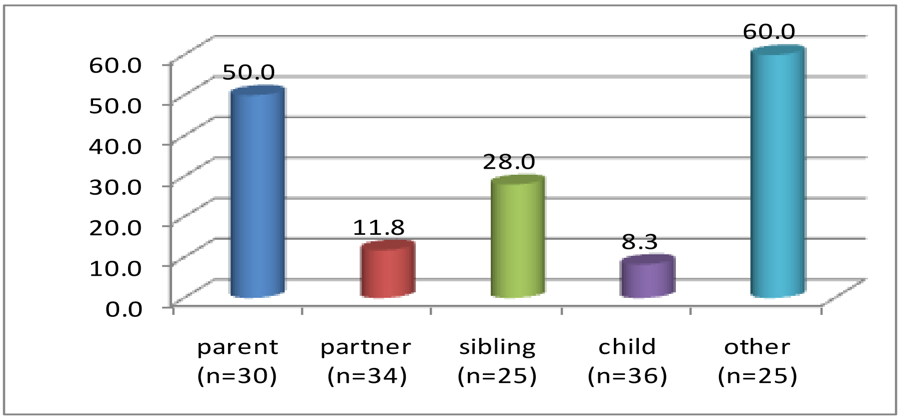
Figure 9.18: Transitions from clinical adherence to non-adherence, by attendance of drug readiness training



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=0.35, p=0.850).

Figure 9.18 shows that transitions from clinical adherence to non-adherence did not vary significantly by attendance of drug readiness training transitions from clinical adherence to non-adherence, as expected were common among patients with treatment buddies who did not attend the drug readiness training. These results make sense but are not statistically significant.

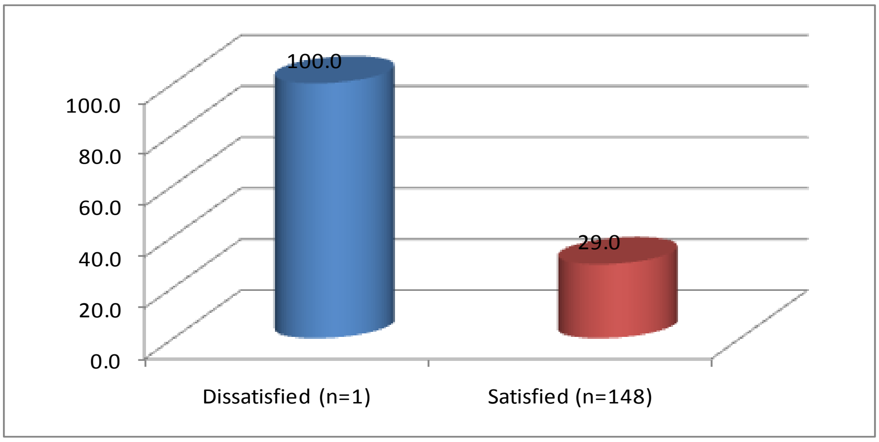
Figure 9.19: Transitions from clinical adherence to non-adherence, by relationship with a treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are statistically significant at 1% level (chi2=30.26, p<0.001).

Figure 9.19 demonstrates that transitions from clinical adherence to non-adherence varied significantly by patients' relationship with their treatment buddy (p<0.001). Transitions from adherence to non-adherence were least common among patients whose treatment buddies were partners and most likely among patients whose buddies were parents or other relations. This particular finding may be attributable to the fact that many patients reside with a partner/spouse, which would mean that adherence support is provided frequently compared to treatment buddies who are parents and other relations to patients, who are less likely to interact with patients on a regular basis.

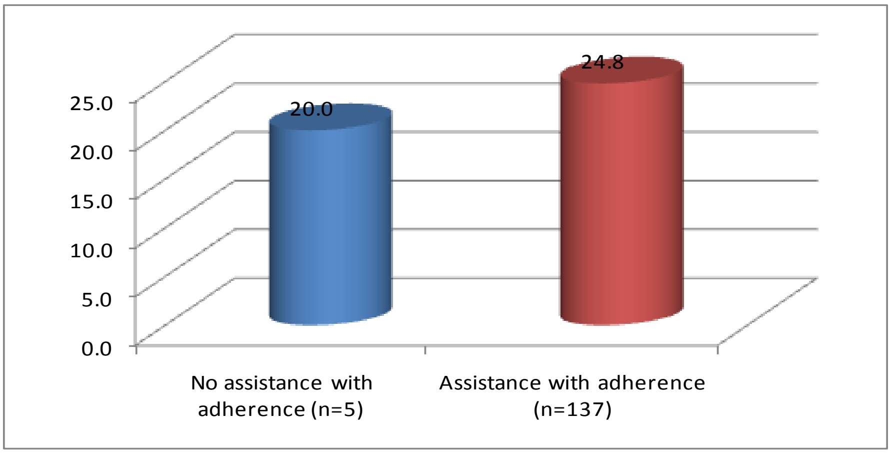
Figure 9.20: Transitions from clinical adherence to non-adherence, by satisfaction with treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=2.40, p=0.122).

According to Figure 9.20, transitions from clinical adherence to non-adherence did not vary significantly by patients' satisfaction with the support provided by their treatment buddy. Transitions from clinical adherence to non-adherence were more common among patients who were dissatisfied with the support provided by their treatment buddy Dissatisfaction with support may explain such a higher albeit statistically insignificant prevalence of transitions from adherence to non-adherence.

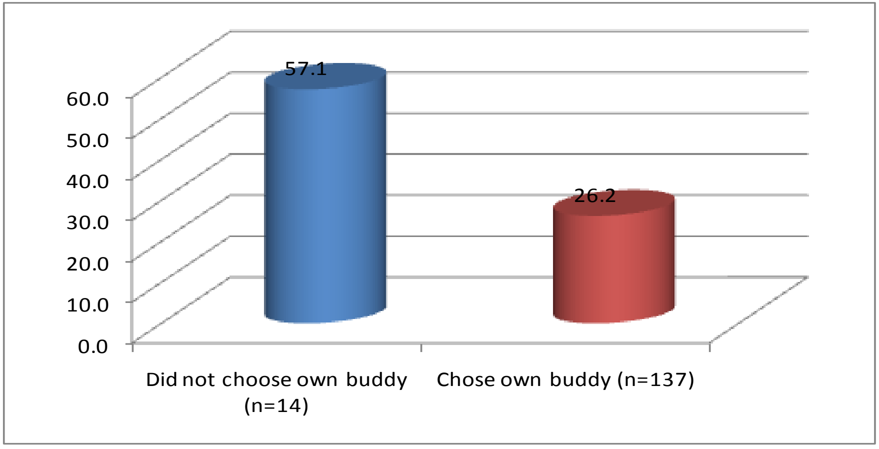
Figure 9.21: Transitions from clinical adherence to non-adherence, by assistance with adherence



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=0.06, p=0.806).

Figure 9.21 shows that transitions from clinical adherence to non-adherence did not vary significantly by assistance with adherence from treatment buddy. Contrary to expectations, transitions from clinical adherence to non-adherence were more common among patients who received assistance with adherence from their treatment buddy. However, differences in transitions from clinical adherence to non-adherence are not statistically significant, with the result that one should not read too much into these somewhat contradictory results.

Figure 9.22: Transitions from clinical adherence to non-adherence, by choice of treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=0.58, p=0.015).

Figure 9.22 denotes that transitions from clinical adherence to non-adherence significantly varied by choice of treatment buddy ($p<0.05$). As expected transitions from clinical adherence to non-adherence were more common among patients who were assigned treatment buddy compared patients who chose their own treatment buddy.

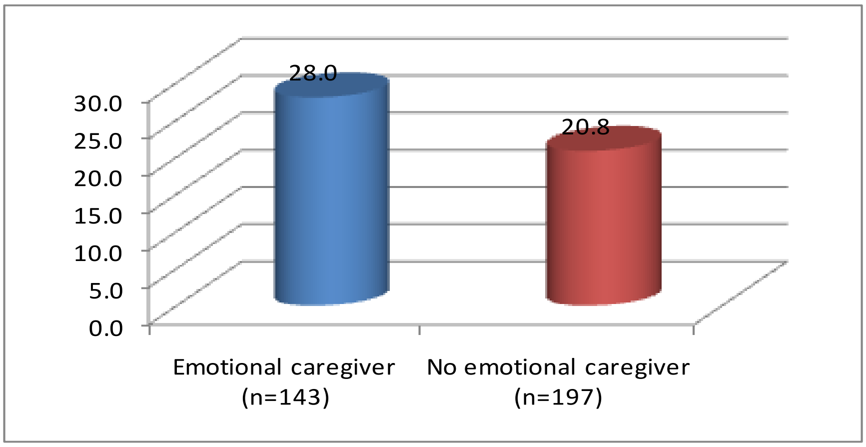
9.3.3. Transitions from clinical adherence to non-adherence and transitions_in access to other support

The focus here is on understanding the nature of potential causal impacts between the relevant variables. This section assesses how past access to other forms of support and past impact on transitions from clinical adherence to non-adherence.

9.3.3. (a) Past access to an emotional caregiver

Figure 9.23 shows that transitions from clinical adherence to non-adherence did not vary significantly by past access to an emotional caregiver. However, contrary to expectations, transitions from clinical adherence to non-adherence were more common among patients who previously had access to an emotional caregiver. These results are rather unexpected as one would imagine that the presence of the emotional caregiver would influence clinical adherence but are not statistically significant.

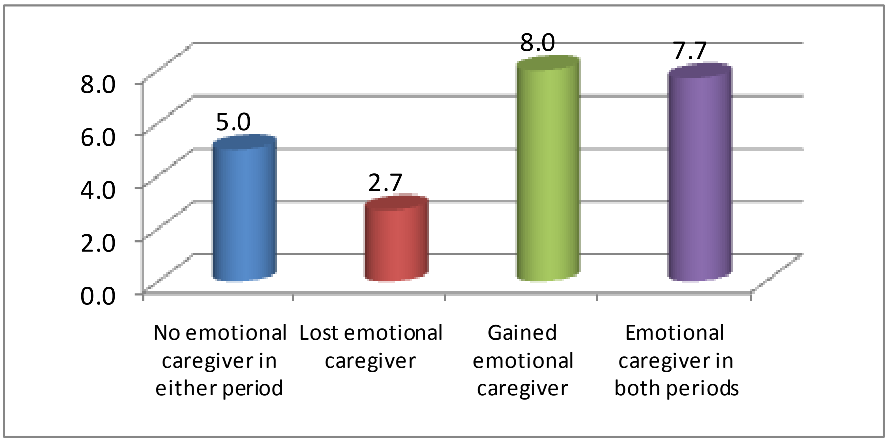
Figure 9.23: Transitions from clinical adherence to non-adherence, by past access to an emotional caregiver



Note: Results are not statistically significant (chi2=2.34, p=0.126).

According to Figure 9.24, transitions from clinical adherence to non-adherence did not vary significantly by past transitions in access to an emotional caregiver. However, transitions from clinical adherence to non-adherence were more common among patients who gained access to an emotional caregiver and among patients who had access to emotional caregiver in both periods. Transitions from clinical adherence to non-adherence were low among patients who lost access to an emotional caregiver and among patients who did not have emotional caregivers in either period. These results are contradictory as one would expect lower transitions from clinical adherence to non-adherence among patients who had access to emotional caregiver.

Figure 9.24 Transitions from clinical adherence to non-adherence, by past transitions in access to emotional caregiver (n=252)

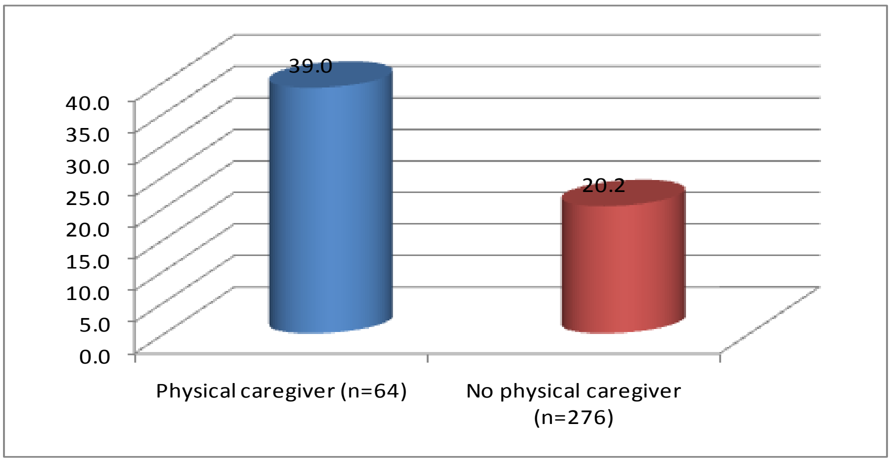


Note: Results are not statistically significant (chi2=1.58, p=0.663).

9.3.3. (b) Past access to a physical caregiver

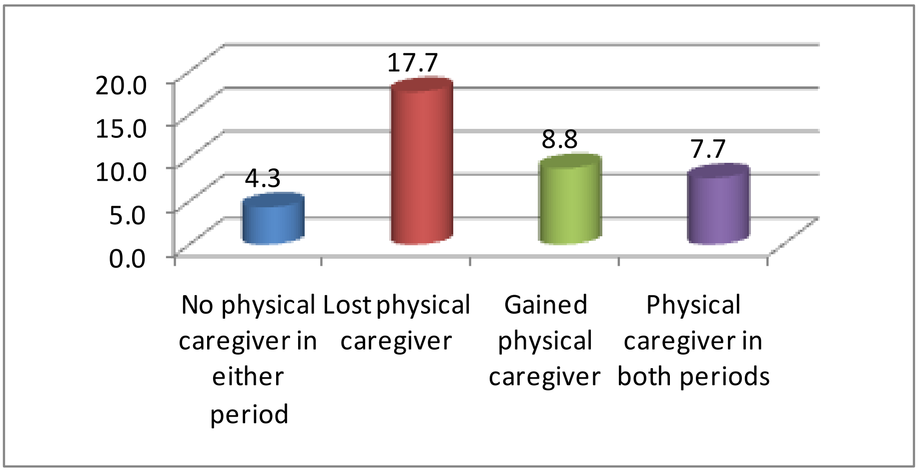
Figure 9.25 indicates that transitions from clinical adherence to non-adherence varied significantly by past access to a physical caregiver (p<0.01). Contrary to expectations, transitions from clinical adherence to non-adherence were common among patients who previously had access to a physical caregiver compared to patients who did not in the past have access to a physical caregiver.

Figure 9.25: Transitions from clinical adherence to non-adherence, by past access to a physical caregiver



Note: Results are statistically significant at the 1% level (chi2=10.08, p=0.001).

Figure 9.26: Transitions from clinical adherence to non-adherence, by past transitions in access to a physical caregiver (n=252)



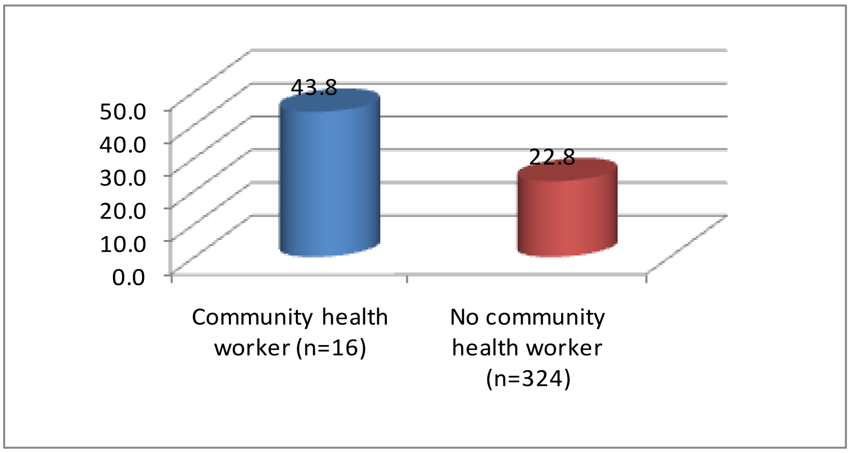
Note: Results are not statistically significant (chi2=5.53, p=0.137).

According to Figure 9.26, transitions from clinical adherence to non-adherence did not vary significantly by past transitions in access to a physical caregiver. However, as expected, transitions from clinical adherence to non-adherence were more common among patients who lost access to physical caregiver. Further, transitions from clinical adherence to non-adherence were lower among patients who lost access to a physical caregiver. Transitions from adherence to non-adherence were not influenced by past transitions in access to a physical caregiver insofar as the results were not statistically significant.

9.3.3. (c) Past access to a community health worker

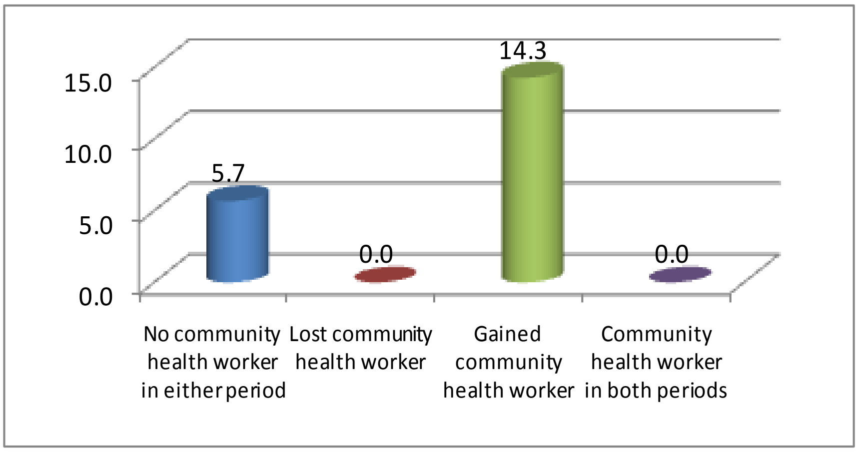
According to figure 9.27, transitions from clinical adherence to non-adherence were significantly associated with past access to a community health worker ($p<0.10$). Contrary to expectations, transitions from clinical adherence to non-adherence were more common among patients who in the past had access to a community health workers. These finding may be plausible if the community health worker visited to check up on these patients, who did poorly on outcomes and were still doing poorly not long afterwards.

Figure 9.27: Transitions from clinical adherence to non-adherence, by past access to a community health worker



Note: Results are statistically significant at the 10% level (chi2=3.67, p=0.055).

Figure 9.28: Transitions from clinical adherence to non-adherence, by past transitions in access to a community health worker (n=252)



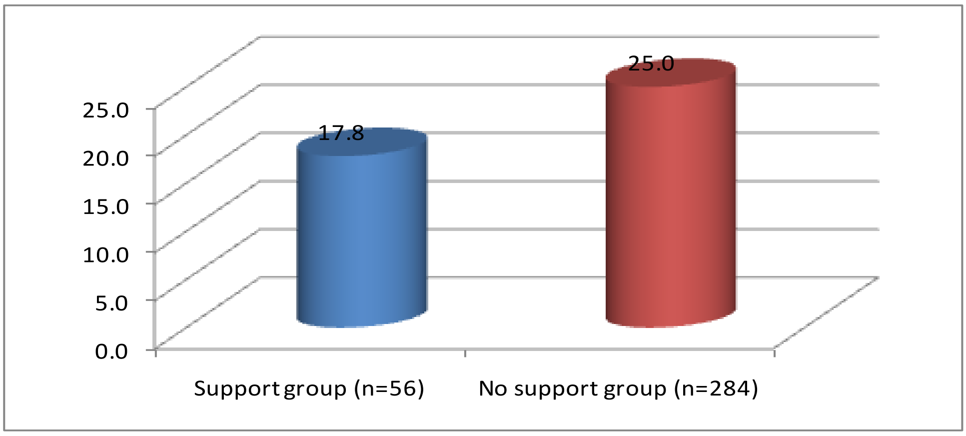
Note: Results are not statistically significant (chi2=2.33, p=0.505).

Transitions from clinical adherence to non-adherence did not vary significantly by past transitions in access to a community health worker. According to Figure 9.28, transitions from clinical adherence to non-adherence were more common among patients who gained access to a community health worker and among patients who did not have a community health worker in either period. None of the transitions happened among patients who had community health worker in both periods and patients who lost community health worker. The finding that transitions from clinical adherence to non-adherence were more common among patients who in the past gained access to a community health workers, may be plausible if the community health worker visited to check up on these patients, who did poorly on outcomes and were still doing poorly not long afterwards.

9.3.3. (d) Past participation in a support group

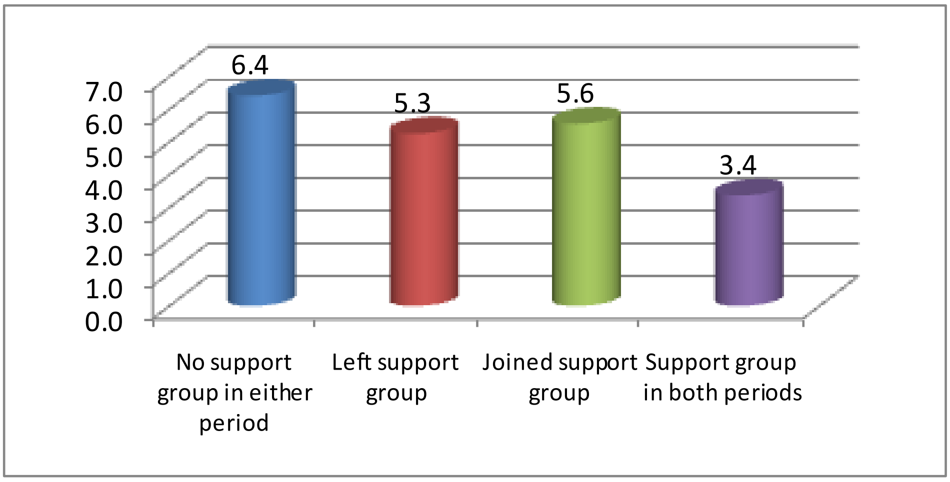
Transitions from clinical adherence to non-adherence did not vary significantly by past participation in support group. Figure 9.29, shows that as expected, transitions from clinical adherence to non-adherence were common among patients who in the past did not participate in a support group and lower among patients who previously participated in a support group. These results hint on the potential importance of support groups in enhancing adherence through the provision of support, albeit results are not significant.

Figure 9.29: Transitions from clinical adherence to non-adherence, by past participation in a support group



Note: Results are not statistically significant (chi2=1.31, p=0.251).

Figure 9.30: Transitions from clinical adherence to non-adherence, by past transitions in participation in a support group (n=252)



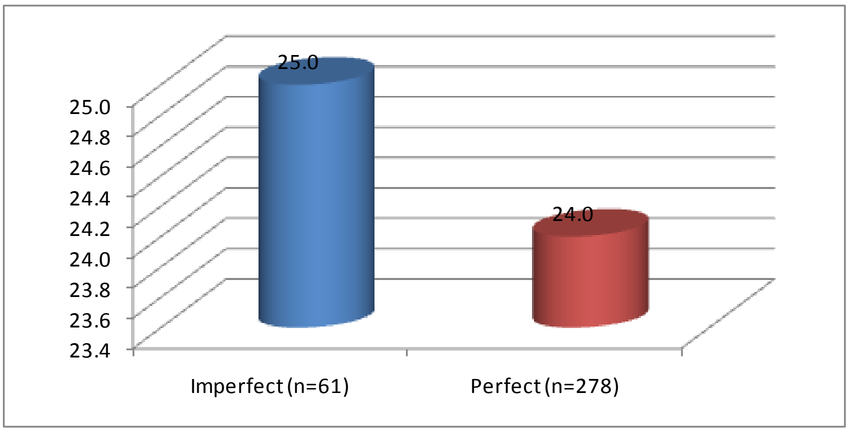
Note: Results are not statistically significant (chi2=0.37, p=0.945).

Transitions from clinical adherence to non-adherence did not vary significantly by past transitions in participating in a support group. According to Figure 9.30, transitions from adherence to non-adherence were lower among patients participated in support groups in both periods and higher among patients who did not participate in a support group. These rather expected results hint on the potential importance of support groups in enhancing adherence through the provision of support, even though results are not significant.

9.3.4. Transitions from clinical adherence to non-adherence and adherence knowledge

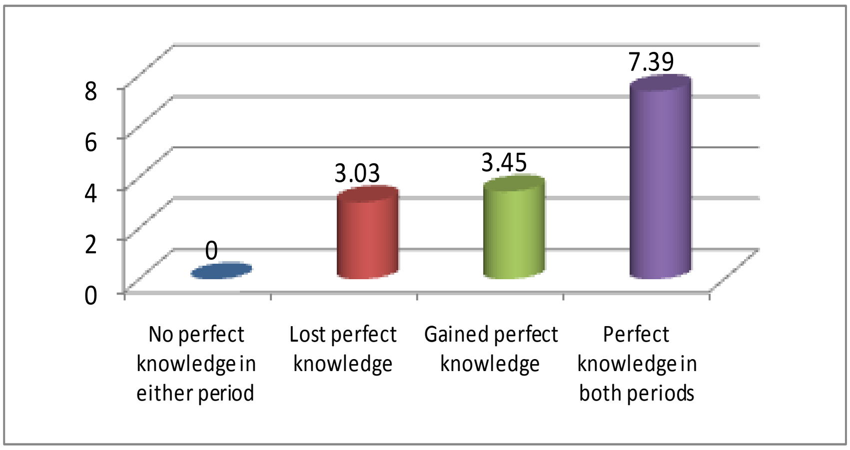
According to Figure 9.31, transitions from clinical adherence to non-adherence did not vary significantly by past adherence knowledge. However, in line with expectations, a larger proportion of patients who transitioned from clinical adherence to non-adherence had imperfect adherence knowledge compared to the prevalence of transitions to clinical non-adherence observed among patients who held perfect adherence knowledge. Lower transitions among patients who had perfect adherence knowledge is indicative of the importance of adherence knowledge in influencing adherence, results were however not significant.

Figure 9.31: Transitions from clinical adherence to non-adherence, by past adherence knowledge



Note: Results are not statistically significant (chi2=0.01, p=0.888).

Figure 9.32: Transitions from clinical adherence to non-adherence, by past transitions in adherence knowledge (n=250)



Note: Results are not statistically significant (chi2=2.216, p=0.529).

Transitions from clinical adherence to non-adherence did not vary significantly by past transitions in adherence knowledge (Figure 9.32). The figure indicates that transitions were more common among patients who had perfect adherence knowledge in both periods. These unexpected results are however not statistically significant.

9.3.5. Determinants of transitions from clinical adherence to non-adherence

The results reported in Table 9.4 are for the pooled regression model, which performed well in terms of overall fit (p<0.001). The random effects (RE) and the fixed effects (FE) regression models could not be estimated. None of the models which estimated treatment buddy characteristics were significant in terms of the overall fit. As a result, it was not possible to report and interpret regression on the potential statistical and practical significance of alternative determinants of transitions from clinical adherence to non-adherence, including access to a treatment buddy and alternative treatment buddy characteristics.

The variable '6-12 months' is significant at the 1% level with an odds ratio of 0.04, which means that the odds of transitions from clinical adherence to non-adherence decrease by 60% among patients who had been on treatment for 6-12 months compared to patients who had only just initiated their treatment. The variable '18-30 months' is also significant at the 1% level and has odds ratios of 0.007. These odds ratios mean that the odds of transitions from clinical adherence to non-adherence decrease among patients who had been on treatment for 18-30 months compared to patients who had been on treatment for less than six months.

Table 9.4: Need and access to support as determinants of transitions from clinical adherence to non-adherence

Independent variables		
1. Sociodemographic variables		
Age	0.977	
Age2	0.999	
Female (*male=0/female=1)*	0.973	
Marital status		
[comparison group=single]		
Not living with partner	1.138	
Living with partner	0.779	
Educational status		
[comparison group=no formal education]		
Primary education	0.541	
Secondary education	0.739	
Grade 12	0.732	
Tertiary education (omitted)		
2. Need variables		
Treatment career		
[comparison group=0-6months]		
6-12months	0.041	***
18-30months	0.007	***
30-42months(omitted)		
3. Access to support variables		
Past access to treatment buddy	0.885	
Past access to emotional carer	1.473	
Past access to physical carer	0.999	
Past access to CHW	2.186	
Past participation in support groups	0.958	
Past adherence knowledge	1.646	
Sample size	*59*	
LR chi2 (p)	*175.77 (p<0.001)*	
$H_{0:}$ pooled model vs. Ha: RE (LR test)	*1.10(p=0.148)*	

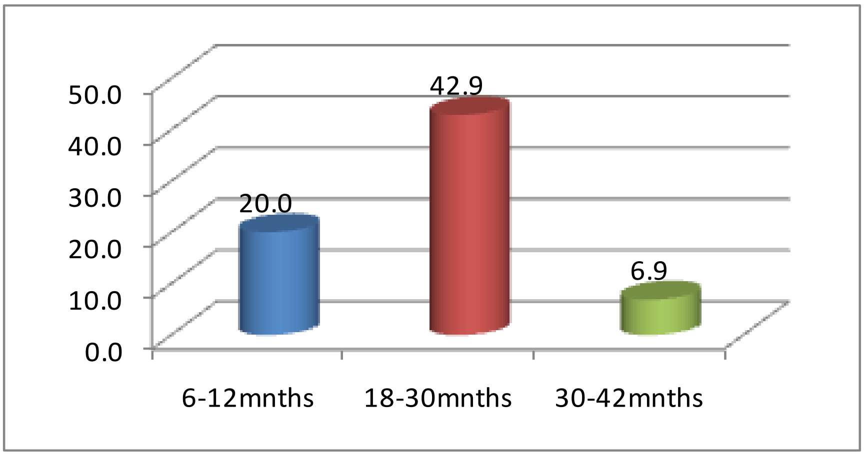
Note: FE could not be estimated. Results are for the Pooled regression model.

**** significant at 1% level; ** significant at 5% level; *significant at 10% level*

9.4. Transitions from clinical non-adherence to adherence

Transitions from clinical non-adherence to adherence varied significantly across the treatment career (p<0.05) (Figure 9.33). The prevalence of transitions from clinical non-adherence to adherence declined consistently across the treatment career phases as treatment career increased. Transitions from clinical non-adherence to adherence were common among patients who had been on treatment for 18 to 30 months and lower among patients who had been on treatment for longer than 30 months.

Figure 9.33: Transitions from clinical non-adherence to adherence, by treatment career phase (n=63)

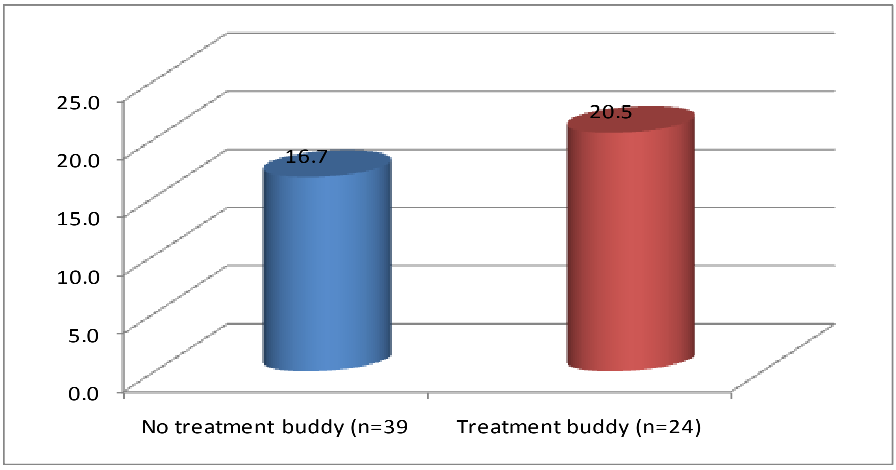


Note: Results are statistically significant at the 5% level (chi2=7.93, p=0.019).

9.4.1. Transitions from clinical non-adherence to adherence and access to a treatment buddy

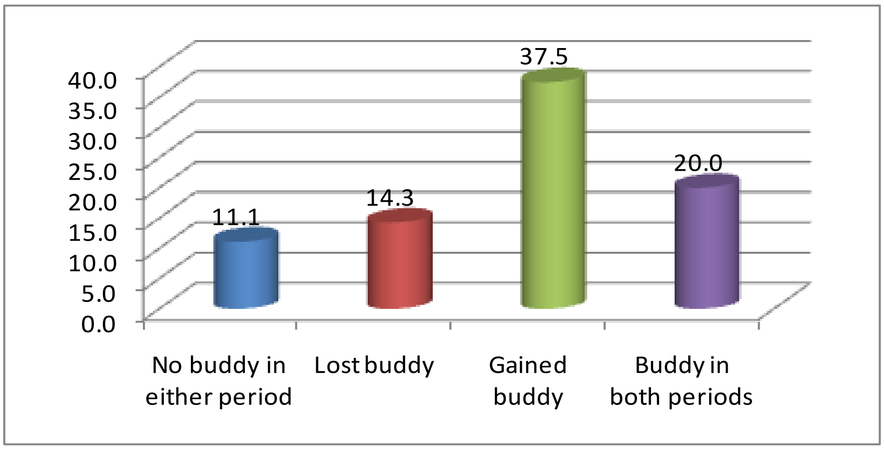
According to Figure 9.34, transitions from clinical non-adherence to adherence did not vary significantly by past access to a treatment buddy. However, contrary to expectations, transitions from clinical non-adherence to adherence are higher among patients who did not have a treatment buddy compared to patients who had treatment buddies These results are rather contradictory as one would expect higher transitions from non-clinical adherence to adherence among patients who have treatment buddies, but the results are not statistically significant.

Figure 9.34: Transitions from clinical non-adherence to adherence, by past access to a treatment buddy



Note: Results are not statistically significant (chi2=0.14, p=0.706).

Figure 9.35: Transitions from clinical non-adherence to adherence, by past transitions in access to a treatment buddy (n=43)



Note: Results are not statistically significant (chi2= 2.65, p=0.448).

Figure 9.35 shows that transitions from clinical non-adherence to adherence did not vary significantly by past transitions in access to treatment buddy. Transitions from clinical non-adherence to adherence were more common among patients who gained access to a treatment buddy compared to patients who had treatment buddies in both periods. Transitions from clinical non-adherence to adherence were lower among patients who did not have a treatment buddy in either period.

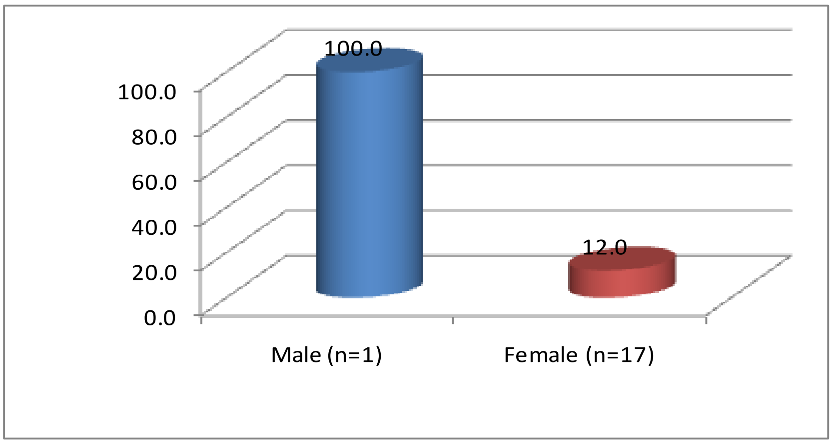
9.4.2. Transitions from clinical non-adherence to adherence and treatment buddy characteristics

Table 9.5: Age of treatment buddy, by transitions from clinical non-adherence to adherence

Clinical adherence	**Summary of age of a treatment buddy**							
	Mean	***SD***	***p25***	***p75***	***Median***	***Min***	***Max***	***Frequency***
No clinical adherence in either period	33.54	16.59	21	46	30.5	5	61	**78**
Non-adherence to adherence	40.33	12.66	26	50	45	26	61	**50**
Total	**33.75**	**16.47**	**21**	46	**31**	**5**	**61**	**78**

Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (F=0.49, p=0.485).

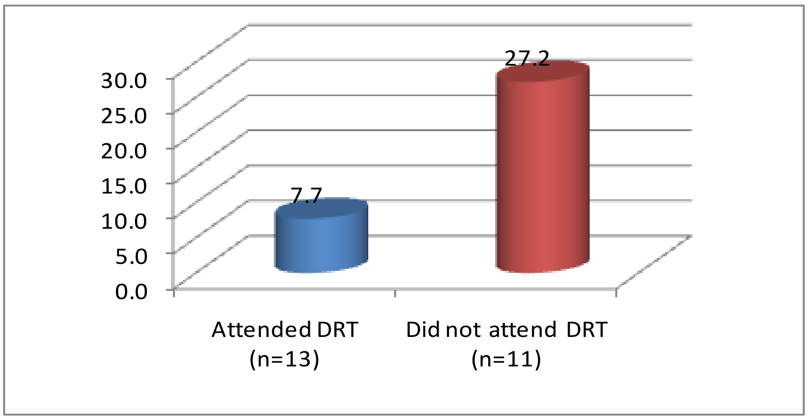
Figure 9.36: Transitions from clinical non-adherence to adherence, by gender of treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are statistically significant at the 5% level (chi2=p=5.29, p=0.021).

Figure 9.36 shows that transitions from clinical non-adherence to adherence did not vary significantly by gender of the treatment buddy ($p<0.05$). Transitions from clinical non-adherence to adherence were more common among patients whose treatment buddies are male compared to patients whose treatment buddies are female.

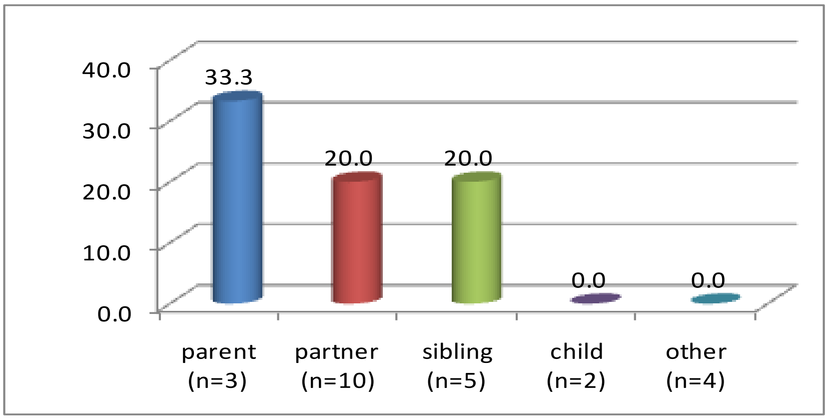
Figure 9.37: Transitions from clinical adherence to non-adherence, by attendance of drug readiness training



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=0.61, p=0.432).

Figure 9.37, shows that transitions from non-adherence to adherence did not vary significantly by attendance of drug readiness training by the patient's treatment buddy. Contrary to expectations, transitions from non-adherence to adherence were more common among patients whose treatment buddies did not attend the drug readiness training. The results, however, are not statistically significant, which implies that one should not read too much into such contradictory finding.

Figure 9.38: Transitions from clinical non-adherence to adherence, by relationship with treatment buddy



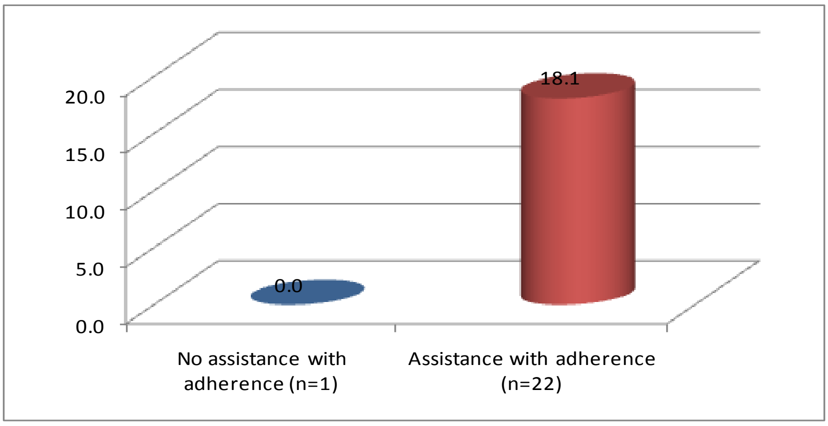
Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=2.70, p=0.609).

Figure 9.38, denotes that transitions from non-adherence to adherence did not vary significantly by patients' relationship with their treatment buddy. Transitions from non-adherence to adherence were common among patients whose treatment buddies are closer family members.

None of the patients who had children or other relations as treatment buddies transitioned from non-adherence to adherence

With reference to transitions from non-adherence to adherence, by satisfaction with support provided by treatment buddy, all patients who transitioned from non-adherence to adherence, as expected, were satisfied with the support provided by their treatment buddies.

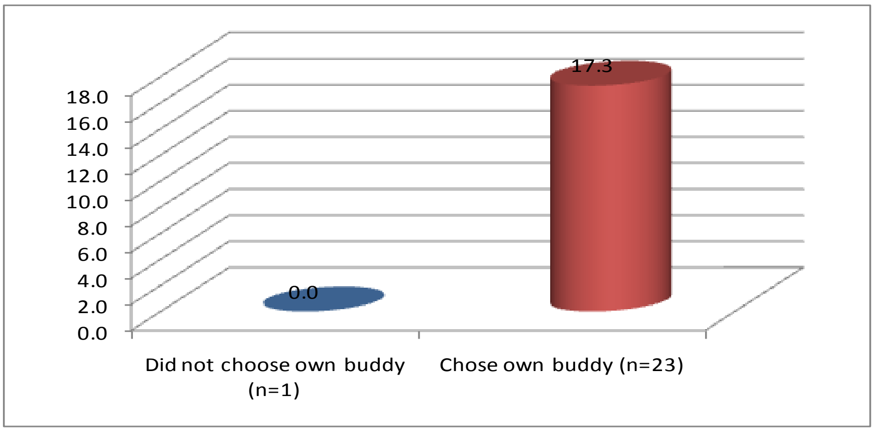
Figure 9.39: Transitions from clinical non-adherence to adherence, by assistance with adherence



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=0.15, p=0.694).

Figure 9.39 revealed that transitions from clinical non-adherence to adherence did not vary significantly by assistance with adherence by the patient's treatment buddy. As expected, transitions from clinical non-adherence to adherence were more common among patients whose treatment buddies assisted with adherence. This result suggests that treatment buddies have a role to play in preventing non-adherence by providing adherence support

Figure 9.40: Transitions from clinical non-adherence to adherence, by choice of treatment buddy



Note: Treatment buddy characteristics as observed in the previous period. Results are not statistically significant (chi2=0.23, p=0.626).

Figure 9.40 denotes that transitions from clinical non-adherence to adherence did not vary significantly by choice of treatment buddy. As expected, transitions from clinical non-adherence was more common among patients who chose own treatment buddies compared to patients who were assigned treatment buddies. These results are however not significant.

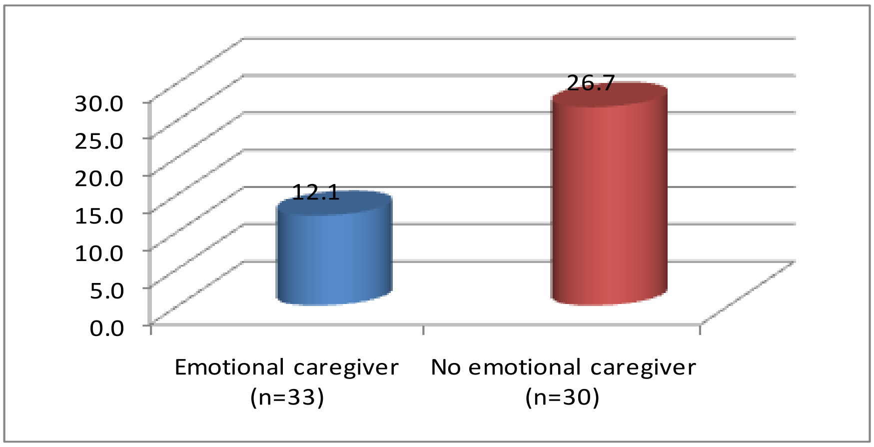
9.4.3. Transitions from clinical non-adherence to adherence and transitions in access to other support

This section assesses how previous access to other support impact on transitions from clinical non-adherence to adherence over time: the focus shifts from access to an emotional or physical caregiver, to access to a community health worker or support group, a proxy of the supply of informal support may impacts on transitions from clinical non-adherence to adherence

9.4.3. (a) Past access to an emotional caregiver

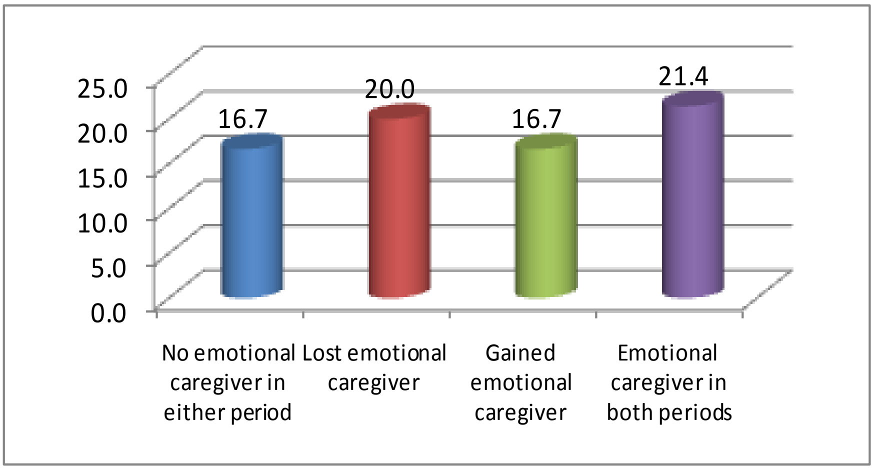
According to Figure 9.41, transitions from clinical non-adherence to adherence did not vary significantly by past access to an emotional caregiver Contrary to expectations; transitions from clinical non-adherence to adherence were more common among patients who did not have access to an emotional caregiver. The results, however, are not statistically significant, which implies that one should not read too much into such contradictory finding.

Figure 9.41: Transitions from clinical non-adherence to adherence, by past access to an emotional caregiver



Note: Results are not statistically significant (chi2=0.19, p=0.656).

Figure 9.42: Transitions from clinical non-adherence to adherence, by past transitions in access to an emotional caregiver (n=43)



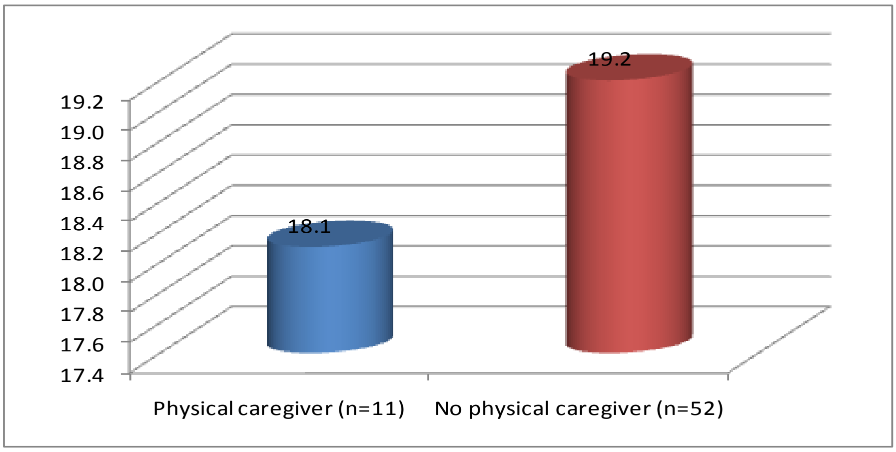
Note: Results are not statistically significant (chi2=0.13, p=0.987).

Figure 9:42 shows that transitions from clinical non-adherence to adherence also did not vary significantly by past transitions in access to an emotional caregiver. As expected, transitions from clinical non-adherence to adherence were more common among patients who had access to an emotional caregiver in both periods. Moreover, transitions from clinical non-adherence to adherence were lower among patients who previously gained access to an emotional caregiver and among patients who did not have an emotional caregiver in either period.

9.4.3. (b) Past access to a physical carer

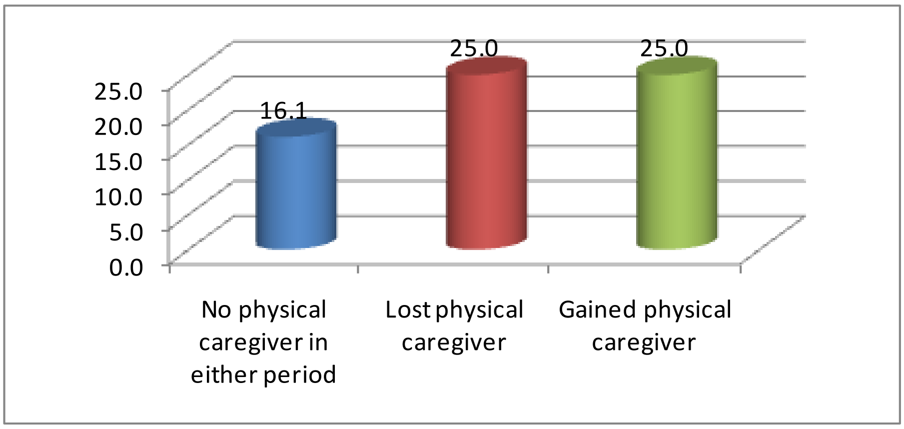
According to Figure 9.43, transitions from non-adherence to adherence did not vary significantly by past access to a physical caregiver. Contrary to expectations, transitions from clinical non-adherence to adherence were higher among patients who previously did not have access to a physical caregiver and lower among patients who previously had physical caregivers. The results, however, are not statistically significant, which implies that one should not read too much into such contradictory finding.

Figure 9.43: Transitions from clinical non-adherence to adherence, by past access to a physical caregiver



Note: Results are not statistically significant (chi2=0.02, p=0.879).

Figure 9.44: Transitions from clinical non-adherence to adherence, by past transitions in access to a physical access to a treatment buddy (n=43)



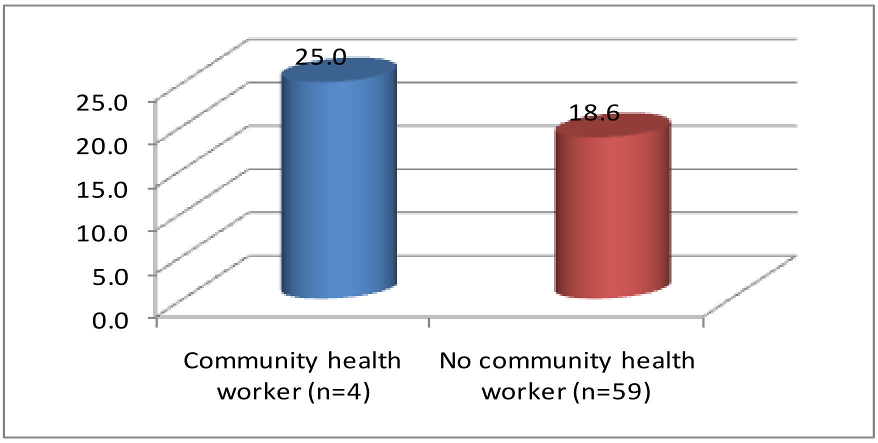
Note: Results are not statistically significant (chi2=2.02, p=0.7997).

As for most other forms of support, transitions from clinical non-adherence to adherence did not vary significantly by past transitions in access to a physical caregiver. Figure 9.44 shows transitions from clinical non-adherence to adherence were lower among patients who in the past did not have access to a physical caregiver

9.4.3. (c) Past access to a community health worker

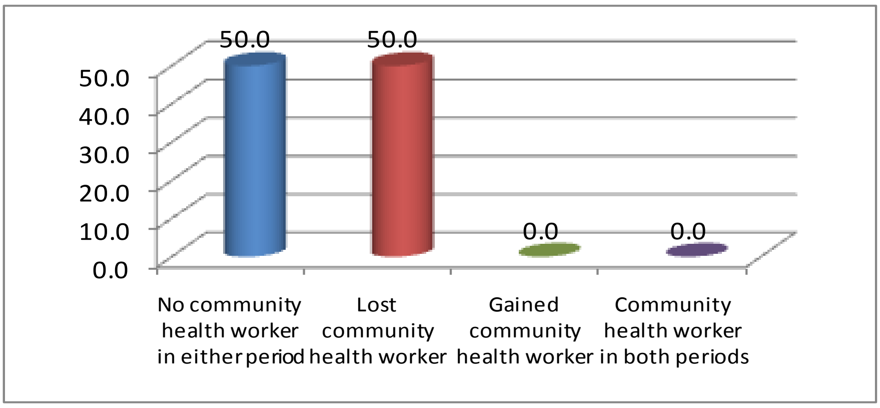
According to Figure 9.45, transitions from clinical non-adherence to adherence did not vary significantly by past access to a community health worker. As expected, transitions from clinical non-adherence to adherence were more common among patients who previously received community health worker visits compared to patients who were not visited. These results are however not significant.

Figure 9.45: Transitions from clinical non-adherence to adherence, by past access to a community health worker



Note: Results are not statistically significant (chi2=0.76, p=0.383).

Figure 9.46: Transitions from clinical non-adherence to adherence, by past transitions in access to a community health worker (n=43)



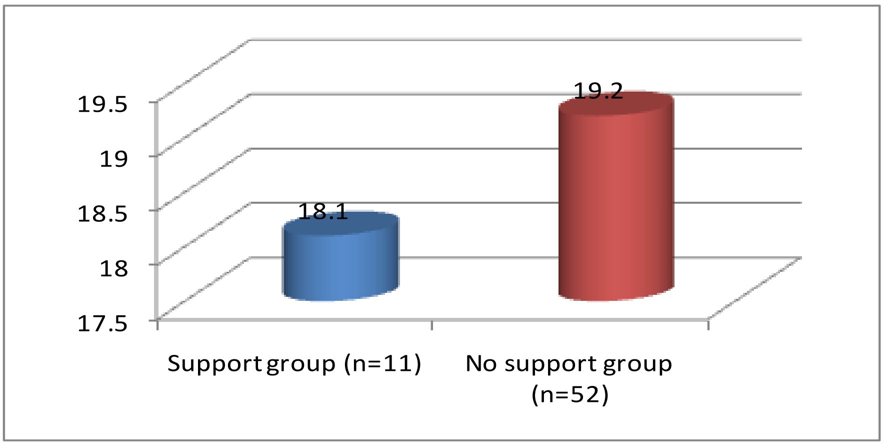
Note: Results are not statistically significant (chi2=3.96, p=0.266).

Figure 9.46 illustrates that transitions from clinical non-adherence to adherence also did not vary significantly by past transitions in access to community health worker. Contrary to what is expected, transitions from clinical non-adherence to adherence were only among patients who lost access to community health worker and among patients who did not receive community health worker visits in either period.

9.4.3. (d) Past participation in a support group

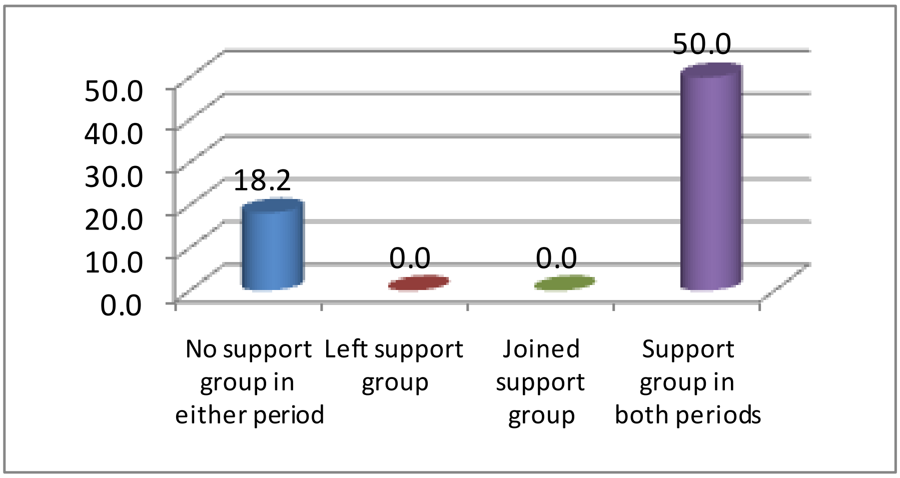
According to Figure 9.47, transitions from clinical non-adherence to adherence did not vary significantly by past participation in a support group. On a contrary, transitions from clinical non-adherence to adherence were common among patients who did not participate in a support group compared to patients who participated. These unexpected results are, not statistically significant.

Figure 9.47: Transitions from clinical non-adherence to adherence, by past participation in a support group



Note: Results are not statistically significant (chi2=0.00, p=0.936).

Figure 9.48: Transitions from clinical non-adherence to adherence, by past transitions in participation in a support group (n=43)



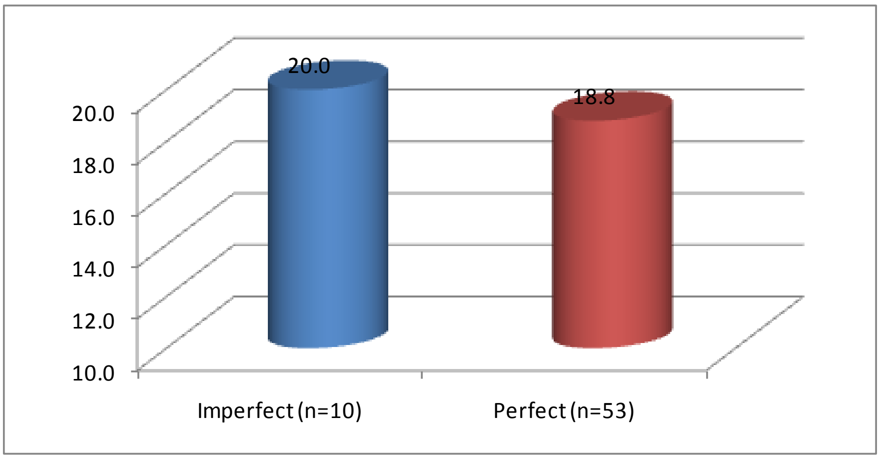
Note: Results are not statistically significant (chi2=2.39, p=0.264).

According to Figure 9.48, transitions from clinical non-adherence to adherence did not vary significantly by past transitions in participation in a support group. As expected, transitions from clinical non-adherence to adherence was more common among patients who participated in a support group in both periods and lower among patients who did not participate in either period. These results suggest that support groups may influence adherence, but results are not significant.

9.4.4. Transitions from clinical non-adherence to adherence and adherence knowledge

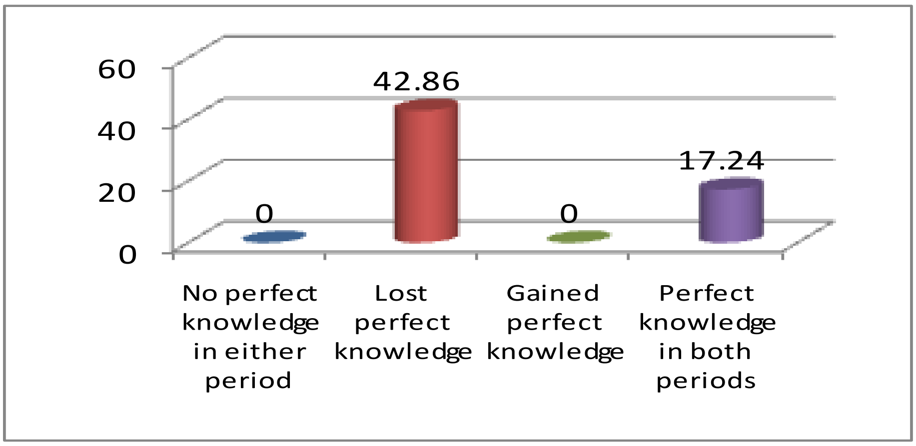
Figure 9.49 reveals that transitions from clinical non-adherence to adherence did not differ significantly by past adherence knowledge. However, transitions from clinical non-adherence to adherence were higher among patients who had imperfect adherence knowledge compared to patients who had perfect knowledge. These contradictory results were not statistically significant.

Figure 9.49: Transitions from clinical non-adherence to adherence, by past adherence knowledge



Note: Results are not statistically significant (chi2=0.01, p=0.918).

Figure 9.50: Transitions from clinical non-adherence to adherence, by past transitions in adherence knowledge (n=43)



Note: Results are not statistically significant (chi2=4.47, p=0.214).

Figure 9.50, denotes that transitions from clinical non-adherence to adherence were not significantly associated with transitions in past adherence knowledge. Transitions from clinical non-adherence to adherence were higher among patients who lost perfect knowledge. These results were however, not statistically significant.

9.4.5. Determinants of transitions from clinical non-adherence to adherence

The reported results in Table 9.6 are for the pooled regression model. The fixed effects (FE) model could not be estimated, while the likelihood ratio test indicated that the pooled model outperformed the random effects (RE) model. The pooled performed well in terms of overall fit ($p<0.001$). None of the models which estimated treatment buddy characteristics were significant in terms of the overall fit. As a result, it was not possible to report and interpret regression on the potential statistical and practical significance of alternative determinants of transitions from self-reported adherence to non-adherence, including access to a treatment buddy and alternative treatment buddy characteristics.

Table 9.6: Access to support as determinants of transitions from clinical non-adherence to adherence

Independent variables		
1. Sociodemographic variables		
Age	1.917	
Age2	0.993	
Female (*male=0/female=1*)	1.558	
Marital status		
[comparison group=single]		
Not living with partner	0.011 **	
Living with partner	1.483	
Educational status		
[comparison group=no formal education]		
Primary education	0.783	
Secondary education	0.443	
Grade 12	1.489	
Tertiary education (omitted)		
2. Need variables		
Treatment career		
[comparison group=0-6months]		
6-12months	0.042	*
18-30months	0.030	*
30-42months(omitted)		
3. Access to support variables		
Past access to treatment buddy	0.572	
Past access to emotional carer	0.061	**
Past access to physical carer	0.837	
Past access to CHW	0.589	
Past participation in support groups	3.319	
Past adherence knowledge	1.408	
Sample size	*59*	
LR chi2 (p)	*25.88 (p<0.001)*	
H_0: pooled model vs. Ha: RE (LR test)	*0.00(p=1.000)*	

Note: FE could not be estimated. Results are for the Pooled regression model.

**** significant at 1% level; ** significant at 5% level; *significant at 10% level*

According to the results in Table 9.6, not living with partner has an odds ratio of 0.01 and is significant at the 5% level. This means that patients not living with their partner are less likely to transition from clinical non-adherence to adherence. The variable '6-12 months' is significant at the 10% level with an odds ratio of 0.04, which means that for patients who have been on treatment for 6-12 months, the likelihood of transitioning from clinical non-adherence to adherence decrease. The variable '18-30months' is significant at the 10% level with an odds ratio of 0.03 denoting that patients who had been on treatment for 18-30 months were less likely to transition from clinical non-adherence to adherence. Past access to an emotional caregiver is significant at the 10% level and the odds ratio indicating that patients who had access to an emotional caregiver were less likely to transition from clinical non-adherence to adherence.

9.5. Summary

This chapter reveals that clinical adherence varied significantly by treatment career. Clinical adherence increased as treatment career increased, transitions from clinical adherence to non-adherence declined and transitions from clinical non-adherence to adherence increased. Access to a treatment buddy did not significantly explain clinical adherence, but clinical adherence was higher among patients who had access to a treatment buddy, transitions from non-adherence were higher among patients who have access to treatment buddies.

Access to a treatment buddy significantly influence clinical adherence. Moreover, some treatment buddy characteristics also influenced clinical adherence. Attendance of drug readiness training by treatment buddies was associated with clinical adherence and transitions from non-adherence to adherence. Attendance of drug-readiness training by treatment buddies was prevalent in all outcome thereby, the importance of drug readiness training in enhancing and maintaining adherence.

Although not significant throughout, access to different forms of support explained clinical adherence. Previous access to an emotional caregiver; physical caregiver; community health worker explained clinical adherence, including transitions from non-adherence to adherence and transitions from adherence to non-adherence. A study by Peltzer *et al*, 2010, also reported that the presence of social support predicted adherence levels in a study conducted among ART patients in KwaZulu Natal. Access to a treatment buddy was not associated with clinical adherence and only age and gender and relationship with treatment buddy were associated with clinical adherence. The results suggest that the characteristics of treatment buddy and relationship factors may influence a patient's adherence to antiretroviral therapy. Of the forms of support, only access to a physical caregiver was associated with clinical adherence. In addition, adherence knowledge was not associated with clinical adherence or transitions.

Where the analyses lacked statistical power due to the lack of variation in the outcome, may be attributable to a shortcoming of the study, in this case lacking statistical power because of having to use only the subset of the data with clinical markers observed in close enough proximity to the interviews.

CHAPTER 10

CONCLUSION AND RECOMMENDATIONS

10.1. Introduction

Adherence to ART still dominates debates as one of the challenges facing HIV positive patients and the health service delivery. Thus, support for people on ART becomes fundamental. It is therefore argued that treatment buddies can be a critical element in enhancing adherence and in retaining patients in care (Lyon *et al*, 2003; NDoH, 2003).

In the light of this, the aim of the study was to assess the role of treatment buddies in the South African public sector antiretroviral treatment programme as implemented in the Free State province and several objectives were outline. This chapter therefore reflects on the main findings of the study and key conclusions which inform the aim of the study will be inferred. The objectives of the study (see Chapter 1) and key outcomes as discussed in chapter 4 (see Figure 4.7) directed the structure of the discussion. Only statistically strong and practically significant findings are discussed (results significant in both bivariate and multivariate analyses and have a strong size effect).

10.2. Access to treatment buddy

This section summarises the main findings of the key outcome or objective discussed in Chapter 5, by recapping on findings that either support or are contrary to the hypothesis.

10.2.1. Access to treatment buddy and treatment career

Throughout the study, access treatment buddy declined as over the treatment duration. A decline in access to treatment buddy as treatment duration increased could be linked to two possible reasons (i) policy related changes, when the public-sector antiretroviral therapy was initiated in 2004, one of the eligibility criteria required patients to identify at least one person to act as a 'treatment buddy, however concerns regarding this criteria surfaced and even though, this criteria was not changed or abandoned, changes were made and access to treatment was possible irrespective of access to a treatment buddy. This may be the reason for a decline in the proportion of patients with treatment buddies. (ii) the other reason is related to improved health status of patients. The need for support declines as the health status improves which means that own routines with regards to medication taking are established.

A decline in access to treatment buddy over a long period of time has some implications for a treatment buddy strategy in a long-term (its existence and effectiveness in a long-term). A decline in access to treatment buddy over the treatment career could suggest the role of a treatment buddy which is to enhance adherence, through the provision of adherence support visits and reminders, is important as patient start treatment but that the need for such support declines in the long term due to the possibility that patients get used to treatment and establish their own routines.

10.2.2 Need as measured by health-related quality of life and access to treatment buddy

As expected, health related quality of life consistently impacted on access and transitions in access to treatment buddy. Patients who had access to a treatment buddy had improved health-related quality of life. This finding could be an indication that having a treatment buddy improved patient's health status or could connote that patients with better health were better able to access support.

The results indicated that the probability of having a treatment buddy decreases as the health related quality of life improves. Further, the transition results also indicated that the probability of losing a treatment buddy increased as health related quality of improved and the probability of gaining a treatment decreased as health related quality of life improved. The findings of this study confirm the hypothesis that improving levels of health status are associated with a decline in access to a treatment buddy. The findings in this section have policy implication as regards to the treatment buddy strategy; improving health status in the presence of treatment buddies is an indication of a possible benefit for having a treatment buddy. Moreover, a reduced need for treatment buddy support, over a period of time, is driven by changes in patients needs which could necessitate implementation of a strategy to address possible emerging patients needs (e.g. pill fatigue).

10.2.3. Access to treatment buddy and access to other support mechanisms

The study finding reveal that similar to access to treatment buddy, access to alternative support mechanisms declined as treatment career increased. However a significant decline over the treatment career phase was only on access to informal, individualized support (such as treatment buddy and emotional and physical caregivers). Access to more formal support (community health workers) and group-based support (support groups) did not form a similar trend as informal support as stated above. In chapter 2, an argument to consider the inclusion of community level support when discussing the convoy model of social support was made. This was based on the argument that the presence of informal support (mostly family members) does not always guarantee access to support, hence highlighting the need for the involvement of formal support.

Access to a physical caregiver, community health worker and participation in support groups were consistently significant. Participation in support group complemented access to a treatment buddy. The results highlight the simultaneous use of these forms of support, in both, bivariate and multivariate analyses. Access to treatment buddy was high among patients who participated in support groups and patients who participated in support groups were more likely to gain access to support group. This could imply that participation in support group may have increased access to treatment buddies, by possibly using support group members as treatment buddies.

Access to a physical caregiver reduced the likelihood of having a treatment buddy. Access to a physical caregiver explained both losing and gaining a treatment buddy. Firstly, patients who had access to a physical caregiver were more likely to lose treatment buddies. This implies that physical limitations could automatically reduce access to a treatment buddy and secondly, patients who had physical caregivers were more likely to gain access to a treatment buddy, suggesting that these forms actually be complementary rather than substitute each other. In addition, access to emotional caregiver featured strongly in the transitions. Access to emotional caregiver declined treatment duration increased. The similar trend as with access to treatment buddy raises suspicions that emotional caregivers could actually be same person as the treatment buddy. Access to emotional caregiver declined as access to treatment buddy decline and similarly the probability of losing access to an emotional caregiver declined with a strong size effect as patients gained access to treatment buddy Even though, not significant throughout, the results indicate that other forms of support are complements rather than substitutes for access to treatment buddy.

Similar to other above mentioned support mechanisms, access to a community health worker declined as access to treatment buddy declined and access increased as access to treatment buddy increased. Further, participation in a support increased access to a treatment buddy. Hence, simultaneous use of treatment buddies and the above mentioned support mechanisms indicate that these forms complement rather than substituting for access to treatment buddy. The findings suggest that treatment buddies may not only be providing adherence support but physical and emotional support, hence a decline in access treatment buddy and a decline in access to these support mechanisms. This has implications for support because diminishing access to treatment buddy would mean disappearance of any form of support for patient. These findings should however be interpreted with caution given limitation to the study as discussed in chapter 4. One of the socio-demographic variables “marital status” was consistently associated with access to a treatment buddy. Being single decreased the probability of having access to a treatment buddy, in other words, patients living with their partners were more likely respectively to have a treatment buddy compared to patients who are single. This finding makes sense because married unlike single patients have partners who are more likely to provide support as treatment buddy. Furthermore, the size effect on cohabitation was larger than on non-cohabitation, meaning that the likelihood for access to treatment buddy is higher among patients living with partner, therefore highlighting the importance of partners in the provision of treatment buddy support but also access gap among single patients.

The reported findings concur with the hypothesis (as mentioned in Chapter 1) that improved health status and longer years on treatment are associated with a decline in access to a treatment buddy and that other social support mechanisms are more likely to complement rather than substitute for treatment buddy support.

10.3. Intensity of treatment buddy support

This section summarises the findings of this key outcome or objective as discussed in Chapter 6, by recapping on findings that either support or are contrary to the hypothesis.

10.3.1 Frequency of treatment buddy visits and treatment career

This section reveals that frequency of treatment buddy visits declined over the treatment career. It can be argued that as months on treatment increase, patients get used to treatment and establish their own routines with regards to medication taking and that improved health status is achieved, thus reducing the need for regular or daily visits by a treatment buddy. However, it may also be explained by buddies becoming 'tired' and actually making fewer visits. A decline in frequency of treatment buddy visit can also be an indication of the possible need for other types of support for patients who have been on treatment for longer. This finding has policy implications especially if the decline in treatment buddy visits is due to new needs of patients that cannot be addressed by a treatment buddy.

10.3.2 Treatment buddy characteristics and increased frequency of treatment buddy visits

Findings reveal that having an older treatment buddy was associated with increased treatment buddy visits. This finding indicates that patients who had older treatment buddies were more likely to be visited on a frequent basis, were more likely to be visited frequently. Attendance of drug readiness training was consistently associated with frequency of treatment buddy visits. Treatment buddies, who attended the drug readiness training, mostly visited patients on daily basis, which confirms the hypothesis that having a treatment buddy may not be important in explaining the outcome but characteristics of treatment buddies may actually matter.

Treatment buddy relationship with the patients was also a significant predictor of frequency of visits. Treatment buddies who were close family members other than distant others, were more likely to visit patients on daily basis, hence highlighting the role of family members in the provision of support as discussed in Chapter 2. Furthermore, patients who chose their own treatment buddies were visited more frequently than patients who were assigned treatment buddies. This finding indicates the need for the review of the treatment buddy strategy as one would expect frequently structured visits by assigned treatment buddies. On the other hand, this finding highlights the importance of choosing own treatment buddy as this would be determine by the type of relationship the patient has with a treatment buddy.

10.3.3 Access to other forms of support and frequency of treatment buddy visits

Access to other forms of support increased the frequency of treatment buddy visits. Access to an emotional caregiver increased frequency of treatment buddy visits with a very strong effect. Similarly, access to physical caregiver increased the frequency of treatment buddy visits. Patients who participated in support group were more likely to receive daily visits. In addition, household size was frequency associated with treatment buddy visits. Indicating that patients from larger households were more likely to receive daily treatment buddy visits, thus a larger household sizes expands the support structure. The association between the frequency of treatment buddy visits and access to emotional and physical caregiver points out the possibility that emotional and or physical caregiver is the same person as treatment buddy. This paragraph emphasises the importance of alternative forms of support in strengthening treatment buddy services.

10.4. Adherence knowledge

This section summarises the findings of this key outcome or objective as discussed in Chapter 7, by recapping on findings that either support or are contrary to the hypothesis.

10.4.1. Adherence knowledge and treatment career

A clear trend between adherence knowledge and the treatment career was non existent. This section reveals that adherence knowledge increased over the treatment career. Further, transitions from perfect to imperfect adherence knowledge declined while transitions from imperfect to perfect adherence knowledge increased. This means that patients who had been on treatment for a longer duration had higher adherence knowledge.

10.4.2. Access to a treatment buddy and treatment buddy characteristics and adherence knowledge

The findings revealed that access to treatment buddy was associated with improved adherence knowledge. This finding denotes that patients who had access to a treatment buddy in both periods were more likely to have improved adherence knowledge. Transitions from perfect to imperfect adherence knowledge were lower among patients with a treatment buddy. This finding points out the importance of treatment buddies in enhancing adherence through sharing and imparting of information about the importance of adherence. None of the treatment buddy characteristics significantly impacted on adherence knowledge.

10.4.3. Intensity of treatment buddy support and adherence knowledge

Contrary to the hypothesis as outlined in Chapter 1, the frequency of treatment buddy visits was not associated with improved adherence knowledge. Reported adherence knowledge levels were high irrespective of the frequency of visits.

10.4.4. Access to other forms of support and adherence knowledge

Only accesses to emotional and physical caregivers were associated with adherence knowledge. In other words patients who had either emotional caregiver or physical caregivers had improved adherence knowledge. This finding highlights the importance of social support in providing necessary information about medication and adherence. Gender and marital status was associated with increased adherence knowledge. Female patients were more likely to have perfect adherence knowledge. In addition, patients who cohabited with their partners/spouses were more likely to have perfect adherence knowledge.

Patients reported very high levels of medication/adherence knowledge, this caused a skewed distribution of this key outcome and led to a ceiling effect, which hampered its predictive power in a regression analysis, predicting transitions from perfect to imperfect adherence knowledge and transitions from imperfect to perfect adherence knowledge.

10. 5. Self-reported adherence

In this section a recap of main significant findings of the key outcome as discussed in Chapter 8 is done. The summary also focuses on findings that either support or are contrary to the hypothesis.

The small number of non-adherent cases, which constrain the analysis in terms of variation in the outcomes is the result in part of the weaknesses of self-reported adherence measures and, is a key limitation of the study in this particular chapter. As a result, there were few significant differences surfaced between the key outcome variable and other explanatory variables. The results revealed that transitions from self-reported non-adherence to adherence were low among patients who had been on treatment for longer. This could be due to the possibility that patients who have been on treatment for longer have been absorbed into the system and fully comprehend how the treatment works and are used to treatment, therefore less likely to transition compared to patients who have just started on treatment. Further, transitions from self reported non-adherence to adherence were significantly low among patients who had access to a treatment buddy, which is sensible given the fact that these patients were already receiving adherence support from their treatment buddies. Although not statistically significant, attendance of drug readiness training was associated with self reported adherence. This highlights the importance of attending drug readiness training for treatment buddies to enhance and maintain adherence.

Contrary to the study hypothesis access to other sources of support, frequency of treatment buddy visits, adherence knowledge were not significantly associated with self-reported adherence. These above mentioned findings suggest that access to a treatment buddy was not important in any of the self-reported adherence outcomes but some treatment buddy characteristics were. These findings concur with the hypothesis stated in a conceptual framework in Chapter 1 that access to a treatment may not impact on each of the key outcomes but certain characteristics of the treatment buddy may be important as these characteristics may impact on each of the outcomes.

10.6. Clinical Adherence

In this section a recap of main significant findings of the key outcome as discussed in Chapter 9 is done. The summary also focuses on findings that either support or are contrary to the hypothesis.

10.6.1. Clinical adherence and the treatment career

Clinical adherence varied significantly by treatment career. Clinical adherence increased as treatment career increased. As expected, clinical adherence was lower among patients who had been on treatment for 6 to 12 months and higher among patients who have been on treatment for a longer duration. Higher clinical adherence levels indicate improved health status among patients on antiretroviral therapy.

10.6.2. Access to treatment buddy and clinical adherence

Contrary to the study hypothesis, access to a treatment buddy did not significantly influence clinical adherence.

10.6.3. Treatment buddy characteristics and clinical adherence

Age of the treatment buddy was significantly associated with clinical adherence. Patients with younger treatment buddies were more likely to adhere compared to patients with older treatment buddies. Attendance of drug readiness training by treatment buddies was associated with clinical adherence and transitions from non-adherence to adherence. Attendance of drug readiness training by treatment buddies was prevalent in all outcome thereby, the importance of drug readiness training in enhancing and maintaining clinical adherence. Relationship with treatment buddy was associated with clinical adherence. This means that patients who had distant others as treatment buddies were less likely to adhere. The results suggest that the characteristics of treatment buddy and relationship factors may influence a patient's adherence to antiretroviral therapy.

10.6.4. Access to other sources of support and clinical adherence

Of the four forms of support, only access to a physical caregiver in both periods was significantly associated with clinical adherence. This finding highlights the role of physical caregivers in reinforcing adherence through the provision of physical support. In addition, adherence knowledge was not associated with clinical adherence or transitions. This finding contradict the hypothesis in Chapter 1 that adherence knowledge is likely to lead to higher levels of self-reported adherence which, may in turn be reflected in suppressed viral load, a clinical measure of treatment adherence. This outcome however, has its own limitations (see Chapter4).

Transitions from clinical adherence to non-adherence were more common among patients whose treatment buddies were not close family members. In addition, transitions from clinical adherence to non-adherence were more common among patients who previously had a physical caregivers and community health workers. This could be due to physical limitations related to health status.

There was no association between clinical and self reported adherence, higher levels of self reported adherence and lower levels of clinical adherence highlight the shortcoming of relying only on the self reported data. The use of two different adherence measures was important for reducing bias.

In conclusion, the strength of this study is that it was unique in its kind. The strengths include its longitudinal character and the availability of information on an understudied population. Further, this study investigated complex interrelationships between access to treatment buddies, intensity of support, adherence/medication knowledge and adherence outcomes. In addition, unlike most studies, the focus in this study was on causal dynamics of cause-and-effect.

10.7. Recommendations

Recommendations are proposed based on the main conclusions deducted from the findings of the research. The recommendations are aimed at enhancing the perceived role of treatment buddies with specific reference to their role in enhancing adherence through the provision of support.

10.7.1 Ensure sustainability of the treatment buddy strategy

A decline in access to treatment buddies over time could be an indication of changing needs of patients due to improvements in health status or could be due to fatigue by treatment buddies prompted by to the long-term provision of support provided to patients. This may not be the only reasons for the decline in access to treatment buddies. The other reason could be attributed to changing needs of patients overtime. A number of studies (Yoder *et al,* 2009; Foster *et al*, 2010) conducted on the role of treatment supporters in enhancing adherence reported a decline in access to treatment buddy over a long period time. The above mentioned reasons necessitate a need to revisit the treatment buddy strategy in terms of its relevant and importance over time. In fact greater efforts on ensuring the sustainability of the treatment buddy strategy are needed.

10.7.2 Design a long-term adherence strategy to complement the treatment buddy strategy

Changes in patients' needs in a long-term call upon a development of the strategy or intervention that will complement the existing strategy, by ensuring the provision of relevant and effective support. The current treatment buddy strategy focuses mainly on the provision of adherence support, which is very important as patients commence on treatment, however changes in patients' needs over time will jeopardize the effectiveness of the current strategy mainly because treatment buddies are currently not equipped to deal with and address needs other than adherence support. The proposed strategy will therefore ensure that crucial aspects are addressed by providing; emotional support and information about dealing with long-term effects of treatment.

10.7.3 Recruitment of informal support networks (family and community members)

The findings of the study highlighted the importance of using significant others (close family member) as treatment buddies. Therefore, the emphasis should be more on the use of family members as treatment buddies, however this does not discard the importance of community level support as family support is not always available. The benefits of using family members include;

- increased frequency of support;
- and closer effective monitoring of patients and
- the provision of spontaneous information on adherence and antiretroviral treatment

As mentioned above as much as family support is important, it is not always available, therefore community support initiatives can also add value and meet new needs of patients including providing continued emotional support and creating a safe environment in which to discuss issues related to the antiretroviral therapy.

10.7.4 Focus on enacted rather than perceived support

Up to so far the focus has been on whether the patients have access to a treatment buddy other than whether patients do in fact receive support. The study findings pointed out on the need to ensure actual provision of support. The assessment of actual versus perceived support was based on the argument that having a treatment may not necessarily influence outcomes but treatment buddy characteristics may actually matter. To ensure that patients do receive required support the following should be considered;

- **The provision of training to treatment supporters==**-that will equip treatment buddies with necessary skills and knowledge to ensure effective provision of adherence support. Attendance of drug readiness training by treatment buddies was constantly positively associated with most key outcomes, highlighting the importance of training of treatment buddies to ensure optimal support of patients regarding medication adherence.

- **Patient's relationship with the treatment buddy**==this is crucial as it will affect the type, the intensity and the effectiveness of support provided
- **Choice of treatment buddies**==ideally, patients should identify and choose own treatment buddies, however, that is not always possible; hence the assigning of treatment buddies has been the case. However, assessment of the suitability and the availability should be done before the allocation of the treatment buddy is done.

10.7.5 Develop a support strategy to cater for single patients

The findings of this study revealed that single patients were less likely to have access to a treatment buddy compared to married or cohabiting patients (refer to Chapter 5). In addition, the study findings revealed that having a partner/spouse was significantly associated with access to a treatment buddy. The majority of patients had partners/spouses as their treatment buddies (refer to Chapter 4). This highlights the important role of partners/spouses in providing desired support and highlights a gap or a need for a support structure specifically designed for single patients or patients without family support.

10.8. Summary

In summary, the research indicates that treatment buddies represent an important form of informal adherence and psycho-social support in the early phase of the ARV treatment career, particularly among married ART clients. Access to treatment buddies declines later in the treatment career as clients' health-related quality of life improves. Policy makers and programme managers should develop suitable adherence support strategies for single clients as well as suitable longer-term adherence support strategies for clients facing challenges with medication adherence later in the treatment career.

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Quest no.:

PATIENT QUESTIONNAIRE

Interview completed:

Treatment and non-treatment patients *18 YEARS AND OLDER*

Follow-up and once-off interview

English

1. INTERVIEW PARTICULARS (IN BLACK PEN)

1.1 Questionnaire number:

V

1.2 Survey wave:

V **2**

1.3 Sample group:

Treatment	1
Non-treatment	2

V

1.4 Treatment group:

Receiving treatment	1
Not yet receiving treatment	2
Treatment stopped	3

V

1.5 Interview group:

New interviewee	1
Repeat interviewee	2

V

1.6 Analysis group:

Cohort (follow-up interviewee)	1
Cross section (once-off interviewee)	2

V

1.7 Interview number (i.e. the number of interviews that have been conducted with respondent, including this one):

V

1.8 Name of interviewer:

V

1.9 Date of interview:

Day	Month	Year
		2005

DD/MM/YYYY

/

V/2005

1.10 Time interview started:

V

1.11 Health district:

Lejweleputswa	1
Motheo	2
Northern Free State	3
Thabo Mofutsanyana	4
Xhariep	5

V

2. ADMINISTRATIVE INFORMATION

2.1 In-field editing (in blue pen)

Name & date:			V
Corrections:			V
Corrections completed:		Submitted (team leader)	V

2.2 Site visit editing (in green pen)

Name & date:			V ☐
Corrections required:			V
Corrections completed:		Accepted	V

2.3 Data coding (in red pen)

Name & date:			V
Corrections required:			V ☐
Corrections completed:		Completed	V

2.4 Data capturing

Date:………………………… By: ☐ V

2.5 Admin

Received: ☐ Coded: ☐ Captured: ☐ V

UNIVERSITEIT VAN DIE VRYSTAAT
UNIVERSITY OF THE FREE STATE
YUNIVESITHI YA FREISTATA

Centre for Health Systems Research & Development
Sentrum vir Gesondheidsisteemnavorsing & Ontwikkeling
FACULTY OF THE HUMANITIES/FAKULTEIT GEESTESWETENSKAPPE

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☎ SA (051) 401-2181/3256
Fax/Faks: SA (051) 448-0370

Ref: Prof. H.C.J. van Rensburg (Director)
Ms Ohna Nel (Secretary)

CONSENT FORM

PUBLIC SECTOR ANTI-RETROVIRAL TREATMENT PROJECT

You are kindly invited to participate in a survey. Before you decide whether to take part, here is what it involves.

What is the purpose of the study?

The University of the Free State is doing research to assess the experiences of people using anti-retrovirals and the effect of these medications on them. This information will be obtained by means of face-to-face interviews and accessing patient records.

What are the possible benefits of participating?

The data that we obtain from the study will enable us to provide the department of health/local authority with information to improve the implementation and management of anti-retrovirals among patients.

What are the possible drawbacks or discomforts in participating?

This is only a survey, however, the issue of HIV/AIDS is very personal and sensitive. Some people may find it painful to recall and discuss their own experience.

Do I have to participate?

Your participation in this study is voluntary. Should you agree to participate, you are required to sign this form. You are free to withdraw from the study at any stage and this will in no way affect your ARV treatment.

What will happen to me if I participate?

Information regarding your experience with anti-retrovirals will be recorded. If applicable, you will then be requested to return to the clinic in six months for a follow-up interview.

Will the information be treated confidentially?

Yes, should you agree to participate in the study, we also request your consent to access your patient file/data. Your information will not be viewed by any other persons or parties not involved in this study.

I, ... (name of patient in block letters) have read and understood all the information given to me about my participation in this study and I was given the opportunity to discuss it and ask questions. I volunteer to take part in this study and also give permission to the research team to access my patient records. I have received a copy of this consent form.

______________________________ ________________
Signature of patient **Date**

Fieldworker: I have:

Explained the nature and purpose of the study to patient	N	Y

In-field editing	Site visit editing	Coding

Handed over a copy of the consent form to patient	N	Y

Signature of fieldworker

Date

3. NON-INTERVIEW INFORMATION

If it is not able to conduct an interview with the person sampled, please indicate the following:

3.1 Sex of sampled patient who could not be interviewed.

Male	1
Female	2

V

3.2 Age of sampled patient who could not be interviewed.

____

3.3 Town where sampled patient who could not be interviewed was/is resident.

____

3.4 Reason(s) for not interviewing patient who was sampled.

Refused	1	⇩
Moved outside Free State	2	⇩
Untraceable	3	⇩
Died	4	➔
Other (specify)		

↴ *If DIED:*

3.5 Date of death of sampled patient not interviewed.

Day	Month	Year
		200

V

DD / MM /YYYY

/ /200

3.6 Cause(s) of death of sampled patient not interviewed.

Tuberculosis (TB)	1
Pneumonia	2
AIDS	3
Meningitis	4
Do not know	5
Other (specify)	

4. DEMOGRAPHIC AND BIOGRAPHIC INFORMATION

4.1 Patient file number:

<

4.2 What is your first name?

<

4.3 What is your surname?

<

4.4 Please give me your identity (RSA ID) number?

<

4.5 What is your current address?

1 House number: ______________________ <
2 Building/complex name: ______________________ <
3 Street name: ______________________ <
4 Neighbourhood: ______________________ <
5 Suburb: ______________________ <
6 Town/city: ______________________ <
7 Province:

Eastern Cape	1
Free State	2

In-field editing	Site visit editing	Coding

Gauteng	3
KwaZulu-Natal	4
Limpopo	5
Mpumalanga	6
North West	7
Northern Cape	8
Western Cape	9
Other (specify)	

4.6 Are there any additional directions to reach your address, should we want to interview you again in the future?

<

……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

4.7 How long have you lived at this address?

_________weeks _________months _________years

4.8 What is your telephone/cell phone number?

<

4.9 Can you provide me with the name of another person through whom we can reach you, if necessary?

<

4.10 What is the telephone/cell phone number of this person?

<

4.11 What is your sex?

Male	1
Female	2

V

4.12 Which population group do you consider yourself part of?

Black (African)	1
Coloured	2
Indian/Asian	3
White	4
Other (specify)	

4.13 What is your date of birth?

Day	Month	Year
		19

V

DD / MM /YYYY

/ /19

4.14 What is your marital status at present?

Living together: married	1
Living together: unmarried	2
Spouse/partner living elsewhere	3
Single	4
Other (specify)	

4.15 At present, do you have access to a medical aid?

No	0
Yes	1

4.16 What is the highest FORMAL educational level that you have COMPLETED?

No formal education	0
Grade 1/Sub A	1

Grade 2/Sub B	2
Grade 3/Standard 1	3
Grade 4/Standard 2/ABET L1	4
Grade 5/Standard 3	5
Grade 6/Standard 4/ABET L2	6
Grade 7/Standard 5	7
Grade 8/Standard 6/ABET L3	8
Grade 9/Standard 7	9
Grade 10/Standard 8/ABET L4	10
Grade 11/Standard 9	11
Grade 12/Standard 10/ABET L5	12
Diploma	13
Degree	14
Other (specify)	

5. *QUALITY OF LIFE*

The following questions are about your life in general.

5.1 Taking all things together, how satisfied are you with your life on the whole these days? Generally speaking would you say you are:

Very satisfied	Satisfied	Neither satisfied nor dissatisfied	Dissatisfied	Very dissatisfied	Do not know
1	2	3	4	5	0

5.2 Please explain.

....

....

....

....

5.3 I shall read to you a number of aspects of people's lives. I would like you to tell me how satisfied you are with each aspect.

Sub-question	Very satisfied	Satisfied	Neither satisfied nor dis-satisfied	Dis-satisfied	Very dis-satisfied	Not im-portant	Not applica-ble	Do not know
1 Your education	1	2	3	4	5	-2	▨	0
2 Your family's health	1	2	3	4	5	-2	-1	0
3 Your family's happiness	1	2	3	4	5	-2	-1	0
4 Your salary/wage/(self-)employment income	1	2	3	4	5	-2	-1	0
5 The food you eat	1	2	3	4	5	-2	▨	0
6 Your life compared to that of other race groups	1	2	3	4	5	-2	▨	0
7 Job opportunities	1	2	3	4	5	-2	▨	0
8 Your ability to provide for your family	1	2	3	4	5	-2	-1	0
9 Your dwelling	1	2	3	4	5	-2	▨	0
10 Your family's income if you should become ill or die	1	2	3	4	5	-2	-1	0
11 Public services in your community	1	2	3	4	5	-2	▨	0
12 The size of your dwelling	1	2	3	4	5	-2	▨	0
13 Your freedom of movement within South Africa	1	2	3	4	5	-2	▨	0
14 Your income when you become old	1	2	3	4	5	-2	▨	0
15 Your choice of where to live	1	2	3	4	5	-2	▨	0
16 The respect shown to you by other race groups	1	2	3	4	5	-2	-1	0
17 The right to vote	1	2	3	4	5	-2	▨	0
18 The way you are treated at work	1	2	3	4	5	-2	-1	0
19 Your security against crime	1	2	3	4	5	-2	▨	0
20 The housing available for your demographic group (i.e. age, population group, income, etc.)	1	2	3	4	5	-2	▨	0
21 The way you get on with other race groups	1	2	3	4	5	-2	-1	0
22 Your travelling expenses	1	2	3	4	5	-2	-1	0

5.4 I shall read to you a number of things which people have told us are important to them. I would like you to tell me how satisfied you are with these things in your life.

Sub-question	Very satisfied	Satisfied	Neither satisfied nor dis-satisfied	Dis-satisfied	Very dis-satisfied	Not im-portant	Not applica-ble	Do not know
1 The loyalty of your friends	1	2	3	4	5	-2	-1	0
2 The fun you get out of life	1	2	3	4	5	-2	▨	0
3 How you fit in with your age group	1	2	3	4	5	-2	▨	0
4 Your most intimate relationship with a man/woman	1	2	3	4	5	-2	-1	0
5 The respect you get in the community	1	2	3	4	5	-2	▨	0
6 The independence you have at work	1	2	3	4	5	-2	-1	0
7 Your leisure time activities	1	2	3	4	5	-2	▨	0
8 Yourself as a person	1	2	3	4	5	-2	▨	0

1 ☐
2 ☐
3 ☐
4 ☐
5 ☐
6 ☐
7 ☐
8 ☐

5.5 Taking all things together, in your life, how would you say things are these days? Would you say you are:

Very happy	Fairly happy	Neither happy nor unhappy	Fairly unhappy	Very unhappy	Do not know
1	2	3	4	5	0

☐

6. *QUALITY OF HEALTH*

6.1 Do you consider yourself currently ill?

No	0 ⇩
Yes	1 ➔

↴ *If YES:*

☐

6.2 What do you think is wrong with you?

....

....

....

....

The following questions are about your general health. Please indicate which statements best describe YOUR OWN STATE OF HEALTH TODAY.

6.3 Mobility

I have no problems in walking about	1
I have some problems in walking about	2
I am confined to bed	3

☐

6.4 Self-care

I have no problems with self-care	1
I have some problems washing or dressing myself	2
I am unable to wash or dress myself	3

☐

6.5 Usual activities (e.g. work, study, housework, family or leisure activities)

I have no problems with performing my usual activities	1
I have some problems with performing my usual activities	2
I am unable to perform my usual activities	3

☐

6.6 Pain/discomfort

I have no pain or discomfort	1
I have moderate pain or discomfort	2
I have extreme pain or discomfort	3

☐

6.7 Anxiety/depression

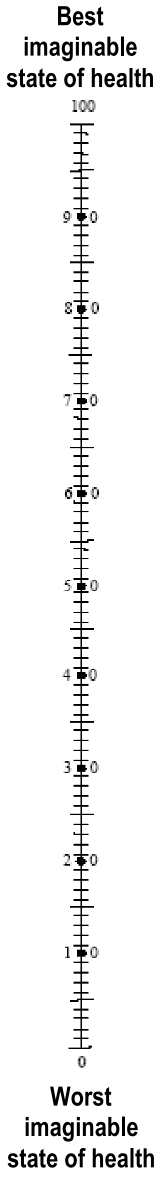
I am not anxious or depressed	1
I am moderately anxious or depressed	2
I am extremely anxious or depressed	3

☐

6.8 To help people say how good or bad their state of health is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale, in your opinion, how good or bad YOUR OWN HEALTH IS TODAY. Please do this by drawing a line from the box to whichever point on the scale indicates how good or bad your state of health is TODAY.

Your own state of health today



7. LIVING CIRCUMSTANCES

The following questions are about your living circumstances.
Some of these questions pertain to your household. When we talk about a household we refer to "people living together at least four nights a week at the same address, AND who share resources".

7.1 Indicate the type of dwelling that you currently live in?

House or brick structure on a separate stand or yard	1
Town/cluster/semi-detached house (simplex, duplex or triplex)	2
Flat or apartment in a block of flats	3
Unit in a retirement village	4
Workers' hostel	5
House/flat/room in back yard	6
Traditional dwelling/hut/structure made of traditional materials, e.g. mud, grass, etc.	7
Informal dwelling/shack in informal/squatter settlement	8
Informal dwelling/shack in backyard	9
Caravan or tent	10
Other (specify)	

7.2 **How many rooms do your household use (excluding bathrooms and toilets; including living rooms, bedrooms and kitchen)?**

__________ room(s) ☐

7.3 **How many rooms do your household use for sleeping (including kitchen and living room if used for sleeping)?**

__________ room(s) ☐

7.4 **Where does your household obtain water for drinking/cooking?** ☐

Tap inside dwelling	1
Tap in yard	2
Communal tap	3
Rainwater tank	4
Borehole	5
River/stream	6
Dam	7
Other (specify)	

7.5 **What is the MAIN type of TOILET facility that is available for use by your household?** ☐

	Inside dwelling	**On-site/ in yard**	**Off-site/ outside yard**
Flush toilet	11	21	31
Chemical toilet	12	22	32
Pit latrine	▨	23	33
Bucket latrine	▨	24	34
None	▨	▨	35
Other (specify)			

8. SOCIO-ECONOMIC DETAILS

We would like some information about YOUR work status and income.

8.1 **In the SEVEN (7) DAYS preceding this interview did you have a work for PAY (in cash or in kind), PROFIT or FAMILY GAIN, for one hour or more?** ☐

Yes: formal registered (non-farming)	1	⇩
Yes: informal unregistered (non-farming)	2	⇩
Yes: farming	3	⇩
Yes: had work but was temporarily absent	4	⇩
No: did not have work	5	➔
Other (specify)		

↴ *If NO:*

8.2 **What is the MAIN reason why you did not have work in the SEVEN (7) days preceding this interview?** ☐

Learner or student	1
Housewife	2
Pensioner or retired person/too old to work	3
Unable to work due to illness or disability	4
Seasonal worker not working presently	5
Chose not to work	6
Could not find work	7
Other (specify)	

8.3 **In the PAST FOUR (4) WEEKS before this interview, have you taken active steps to find employment?** ☐

No	0
Yes	1

☛ *Go to question 8.7.*

8.4 **What is your MAIN occupation?**

______________________________ ☐

8.5 **How many hours did you work in total during the SEVEN (7) days preceding this interview?**

__________ hours ☐

8.6 For how long have you been doing this work?

Days	Weeks	Months	Years

D	W	M	Y

8.7 What is your total personal MONTHLY income from the following:

Category		Total monthly amount
Refused	0	▨
Salary	1	R
Wage	2	R
Grant(s)	3	R
Other (specify)		R
		R

Cat	R

8.8 Are you the MAIN income generator (breadwinner) in your household?

No	0
Yes	1

☐

8.9 How many people are part of your household, i.e. live together at least four nights a week AND share resources?

_____________people

☐

8.10 How many people in each of the following categories live in your household?

Age category	Employed full-time	Employed part-time	Employed casually	Unemployed
14 years and younger				
15-59 years				
60 years and older				

EF	EP	EC	UE

9. PERCEPTION OF ARV TREATMENT PROGRAMME

This section deals with your perception of the government's ARV Treatment Programme.

9.1 Have you ever moved, i.e. from one place of residence to another, as a result of YOU wanting to receive ARV treatment?

No	0	⇩
Yes	1	➔

↴ *If YES:*

☐

9.2 Please specify where you were staying when you made this decision?

1 Neighbourhood:______________________________

2 Suburb:______________________________

3 Town/city:______________________________

4 District:______________________________

5 Province:______________________________

6 Country:______________________________

1	
2	
3	
4	
5	
6	

9.3 What is your opinion about the government's ARV Treatment Programme?

____

____

____

____

- For ***first-time*** *(NEW) respondents continue with Section 10.*
- For ***follow-up*** *(REPEAT) respondents go to Section 11 on page 324.*

10. CARE-SEEKING BEHAVIOUR

The following questions relate to the health care facilities or providers you consulted BEFORE starting with the government ARV Treatment Programme.

10.1 When did you first test positive for HIV?

Month	Year

MM/YYYY
/

10.2 When you FIRST tested positive, what prompted you to take the test? (Please list all.)

Tested without my knowledge	2
Became ill	3
Part of routine health/medical screening	4
For insurance purposes	5
Cannot remember	6
To access ARV medication	7
Spouse/partner found to be infected	12
Child found to be infected	14
Needle prick/stick	21
Unprotected sex	22
Rape/forced sex	23
Assault (physical violence/attack without sexual penetration)	24
Other (specify)	

10.3 When you FIRST tested positive, who convinced you to take the test? (Please list all.)

Own choice/decision	1
Doctor	2
Nurse	3
Spouse/partner	4
Household member	5
Family member (not part of household)	6
Insurance agent/broker	7
Cannot remember	8
Other (specify)	

10.4 At which health care facility were you FIRST diagnosed?

Category		Facility name	Suburb	Town/city	Province	Country
Clinic/CHC	1					
Public hospital	2					
Private hospital	3					
Private doctor	4	▨				
Other (*specify*)						

Cat	F	S	V	P	C

10.5 Did you receive counselling (or a detailed discussion) BEFORE you FIRST tested positive?

No	0
Yes	1
Cannot remember	2

10.6 Did you receive counselling (or a detailed discussion) AFTER you FIRST tested-positive?

No	0
Yes	1
Cannot remember	2

10.7 Have you PREVIOUSLY received ARV treatment BEFORE this public programme (excluding PMTCT & PEP)?

No	0 ⇩
Yes	1 ➔

↴ *If YES:*

10.8 For how long did you receive this treatment?

Weeks	Months	Years

W	M	Y

10.9 Where did you receive this treatment?

Category		Specify/describe
Employer	1	
NGO	2	

Cat	Spec	

Private health care	3	
Other (specify)		

10.10 How was this treatment paid for? (Indicate all that apply.)

Own pocket	1
Medical aid	2
Employer provided free of charge	3
NGO/FBO	4
Prison	5
Other (specify)	

10.11 Why did you stop receiving treatment from this provider and start treatment at government facilities?

10.12 From whom or how did you FIRST learn about the government's free ARV Treatment Programme?

Clinic	1
Public hospital	2
Private hospital	3
Step-down facility	4
Community health worker (home-based carer, lay counsellor, DOT supporter, etc.)	5
Friend	6
Spouse/partner	7
Relative	8
Radio	9
TV	10
Newspaper	11
Magazine	12
Road show	13
Other (*specify*)	

11. CURRENT ARV TREATMENT

The following questions relate to the ARV treatment provided currently at government health facilities.

11.1 Are you currently receiving ARVs?

No	0	⇩
Yes	1	➔

↴ *If YES:*

11.2 When did you start receiving ARVs from the government's ARV programme?

Day	Month	Year
		200

☛ *Go to Section 12.*

DD / MM /YYYY

/ /200

11.3 What is the reason for you not receiving ARVs?

Waiting to start treatment	1	⇩
Treatment stopped due to side-effects	2	➔
Treatment stopped due to other reasons	3	➔

↴ *If STOPPED:*

11.4 When did you stop taking ARVs?

Day	Month	Year
		200

DD / MM /YYYY

/ /200

12. TREATMENT AND ASSESSMENT SITE INFORMATION

12.1 What is the name of your ASSESSMENT site?

'ASSESSMENT site', refers to the government health facility where you receive your monthly ARV medication.

____

12.2 What is the name of your TREATMENT site?

'TREATMENT site', refers to the government health facility where you meet with a doctor in relation to your ARV treatment.

____

- *If 12.1 and 12.2 are the* ***SAME*** *go to Section 14 on page 326.*
- *If 12.1 and 12.2 are* ***DIFFERENT*** *continue with Section 13.*

13. ASSESSMENT SITE ACCESSIBILITY

This section deals with your visits to the ASSESSMENT site for ARV-RELATED treatment, care and support.

13.1 Since [commencing the government's ARV Treatment Programme/*the previous interview*], have you ever left the ASSESSMENT site without being helped during a visit for your ARV-RELATED treatment, care or support?

No 0 ⇩
Yes 1 ➔ ↴ *If YES:*

13.2 Why did you leave without being helped with your ARV-RELATED treatment, care or support?

____

____

____

____

13.3 Do you experience any difficulty to visit the ASSESSMENT site for your ARV-RELATED treatment, care and support as expected according to your schedule?

No 0 ⇩
Yes 1 ➔ ↴ *If YES:*

13.4 What are the MOST IMPORTANT difficulties to visit the ASSESSMENT site for ARV-RELATED treatment, care and support as expected?

____

____

____

____

13.5 Since [commencing the government's ARV Treatment Programme/*the previous interview*], how many SCHEDULED appointments did you have at the ASSESSMENT site for ARV-RELATED treatment, care and support? (Excluding non-scheduled appointments.)

__________time(s)

13.6 Since [commencing the government's ARV Treatment Programme/*the previous interview*], how many SCHEDULED visits did you ACTUALLY make to the ASSESSMENT site for ARV-RELATED treatment, care and support?

__________time(s)

13.7 Since [commencing the government's ARV Treatment Programme/*the previous interview*], did you miss any of your scheduled appointments at the ASSESSMENT site for ARV-RELATED treatment, care and support? (INCLUDING missed appointments that were re-scheduled.)

No 0 ⇩

Yes	1	➔

↴ *If YES:*

13.8 What was the reason(s) for you missing scheduled appointments for <u>ARV-RELATED</u> treatment, care and support at the ASSESSMENT site?

....

....

....

....

13.9 How often do you CURRENTLY visit the ASSESSMENT site regarding your <u>ARV-RELATED</u> treatment, care and support?

Once a week	1
Once every second week	2
Once every three weeks	3
Once a month	4
Other (specify)	

13.10 Is there a separate WAITING area for ARV patients at the ASSESSMENT site?

No	0
Yes	1

13.11 What is your view about this?

....

....

....

....

13.12 Do the same health care staff (e.g. same nurse) see you every time you visit the ASSESSMENT site for <u>ARV-RELATED</u> treatment, care and support?

No	0
Yes	1

13.13 How much do the following cost YOU when visiting the ASSESSMENT site for your <u>ARV-RELATED</u> treatment, care and support?

Sub-question		**Cost per trip/visit**	**Frequency (if not per visit)**
Travel cost when travelling to AND from ASSESSMENT site	1	**R**	/
Accommodation (if need to stay over) during visit	2	**R**	/
Subsistence (food) during visit	3	**R**	/
Medication received at ASSESSMENT site	4	**R**	/
Consultation at ASSESSMENT site	5	**R**	/
Other (specify)		**R**	/
		R	/

Cat	R	*f*

13.14 Do you have to take time off from work when going to the ASSESSMENT site for <u>ARV-RELATED</u> treatment, care and support?

No	0	➔
Yes	1	➔
Not applicable	-1	⇩

↴ *If NO or YES:*

13.15 Do you have to apply for leave to visit the ASSESSMENT site for <u>ARV-RELATED</u> treatment, care and support?

No	0
Yes, sick leave	1
Yes, vacation leave	2

13.16 Do you loose income when visiting the ASSESSMENT site for <u>ARV-RELATED</u> treatment, care and support?

No	0	⇩
Yes	1	➔

↴ *If YES:*

13.17 How much (self-)employment income do you loose per visit?

R .... per visit

14. TREATMENT SITE ACCESSIBILITY

This section deals with your visits to the TREATMENT site for ARV-RELATED treatment, care and support.

14.1 Since [commencing the government's ARV Treatment Programme/*the previous interview*], have you ever left the TREATMENT site without being helped during a visit for your ARV-RELATED treatment, care and support?

No	0	⇩
Yes	1	➔

↴ *If YES:*

14.2 Why did you leave without being helped with your ARV-RELATED treatment, care and support?

14.3 Do you experience any difficulty to visit the TREATMENT site for your ARV-RELATED treatment, care and support as expected according to your schedule?

No	0	⇩
Yes	1	➔

↴ *If YES:*

14.4 What are the MOST IMPORTANT difficulties to visit the TREATMENT site for ARV-RELATED treatment, care and support as expected?

14.5 Since [commencing the government's ARV Treatment Programme/*the previous interview*], how many SCHEDULED appointments did you have at the TREATMENT site for ARV-RELATED treatment, care and support?

______________time(s)

14.6 Since [commencing the government's ARV Treatment Programme/*the previous interview*], how many scheduled visits did you ACTUALLY make to the TREATMENT site for ARV-RELATED treatment, care and support?

______________time(s)

14.7 Since [commencing the government's ARV Treatment Programme/*the previous interview*], did you miss any of your scheduled appointments at the TREATMENT site for ARV-RELATED treatment, care and support? (INCLUDING missed appointments that were re-scheduled.)

No	0	⇩
Yes	1	➔

↴ *If YES:*

14.8 What was the reason(s) for you missing scheduled appointments for ARV-RELATED treatment, care and support at the TREATMENT site?

14.9 How often do you currently visit the TREATMENT site regarding your ARV-RELATED treatment, care and support?

Once a week	1
Once every second week	2
Once every three weeks	3
Once a month	4
Other (specify)	

14.10 Is there a separate WAITING area for ARV-RELATED treatment, care and support at the TREATMENT site?

No	0
Yes	1

14.11 What is your view about this?

14.12 Do the same health care staff see you every time you visit the TREATMENT site for ARV-RELATED treatment, care and support?

Sub-question	No, different staff	Yes, same staff
Nurse	0	1
Doctor	0	1

14.13 How much do the following cost YOU when visiting the TREATMENT site for ARV-RELATED treatment, care and support when visiting the TREATMENT site:

Sub-question		Cost per trip/visit	Frequency (if not per visit)
Travel cost when travelling to AND from TREATMENT site	1	R	/
Accommodation (if need to stay over) during visit	2	R	/
Subsistence (food) during visit	3	R	/
Medication received at TREATMENT site	4	R	/
Consultation at TREATMENT site	5	R	/
Other (specify)		R	/
		R	/

Cat	R	*f*

14.14 Do you have to take time off from work when going to the TREATMENT site for ARV-RELATED treatment, care and support?

No	0	➔
Yes	1	➔
Not applicable	-1	⇩

↴ *If NO or YES:*

14.15 Do you have to apply for leave to visit the TREATMENT site for ARV-RELATED treatment, care and support?

No	0
Yes, sick leave	1
Yes, vacation leave	2

14.16 Do you loose income when visiting the TREATMENT site for ARV-RELATED treatment, care and support?

No	0	⇩
Yes	1	➔

↴ *If YES:*

14.17 How much income do you loose per visit?

R _____________per visit

14.18 Have you been hospitalised (i.e. overnight stay in ANY hospital) since [commencing the government's ARV Treatment Programme/*the previous interview*]?

No	0	⇩
Yes	1	➔

↴ *If YES:*

14.19 How many times have you been hospitalised since [commencing the government's ARV Treatment Programme/*the previous interview*]?

_______________time(s)

14.20 What [is the name/*are the names*] of the hospital(*s*) where you were hospitalised?	14.21 For what condition(s) were you hospitalised?	14.22 For how many days were you hospitalised?

Hosp	Condition	Days

15. USE OF TRADITIONAL HEALERS

This section deals with traditional medicine and healers.

15.1 Are you currently using traditional medicine (muti) for any illness/ailment/disease?

No	0	⇩
Yes	1	➔

↴ *If YES:*

15.2 For what illness/ailment/disease do you use this?

15.3 What is this traditional medicine (muti) called?

15.4 What is this traditional medicine (muti) intended to do?

15.5 Did you inform a health care worker (nurse or doctor) involved with your <u>ARV-RELATED</u> treatment, care and support at the clinic/hospital/CHC that you are taking traditional medicine (muti)?

No	0	⇩
Yes	1	➔

↴ *If YES:*

15.6 What was her/his/their reaction?

☛ *Go to Section 15.8.*

15.7 Why did you not inform a health care worker of you taking traditional medicine (muti)?

15.8 Have you visited a traditional healer since [you commenced the government's ARV Treatment Programme/*the previous interview*]?

No	0	⇩
Yes	1	➔

↴ *If YES:*

15.9 How often do you consult a traditional healer?

Irregular intervals	1
Once a week	2
Once every two weeks	3
Once every three weeks	4
Once a month	5
Other (specify)	

15.10 What are your reasons for visiting a traditional healer?

15.11 Does the traditional healer know you are [HIV positive/*taking ARV medication*]?

No	0
Yes	1
Do not know	2

16. DISCLOSURE

This section deals with telling other people about your HIV status.

16.1 Do you try to keep your HIV status a secret?

No	0 ⇩
Yes	1 ➔

↴ *If YES:*

16.2 For what reason(s) do you want to keep your HIV status a secret?

16.3 Do you have any difficulties keeping your HIV status confidential?

No	0 ⇩
Yes	1 ➔

↴ *If YES:*

16.4 Please list all these difficulties.

It is difficult to take my ARV medication without others noticing	1
It is difficult to conceal the physical signs of my illness, e.g. loss of weight	2
It is difficult to explain bouts of illness, i.e. being hospitalised or bedridden	3
People gossip	4
Other (specify)	

16.5 Do the following people know about your HIV status?

☛ *Note skips at each answer.*

↴ *If YES:*

↴ *Note applicable skips.*

Sub-question	**16.5** NA	No	Yes	Do not know	**16.6 Did you person-ally tell them that you are HIV positive?** No	Yes	**16.7 Was this before or after [commencing with the government's ARV Treatment Programme/ *the previous interview*]?** New interviewee: Before com-mencing ART Pro-gramme	New interviewee: After com-mencing ART Pro-gramme	Repeat interviewee: Before previous interview	Repeat interviewee: After previous interview	**16.8 What was the consequence(s) of this disclosure?**
1 Spouse/ partner	-1 ⇩	0 ⇩	1 ➔	2 ⇩	0 ➔	1 ➔	0 ➔	1 ➔	-1 ⇩	2 ➔	
2 Parent	-1 ⇩	0 ⇩	1 ➔	2 ⇩	0 ➔	1 ➔	0 ➔	1 ➔	-1 ⇩	2 ➔	
3 Family member (in house-hold)	-1 ⇩	0 ⇩	1 ➔	2 ⇩	0 ➔	1 ➔	0 ➔	1 ➔	-1 ⇩	2 ➔	
4 Relative (not in	-1 ⇩	0 ⇩	1 ➔	2 ⇩	0 ➔	1 ➔	0 ➔	1 ➔	-1 ⇩	2 ➔	

	Know	Tell	B/A	Conseq	
1					
2					
3					
4					

house-hold)												
5 Friend	-1 ⇩	0 ⇩	1 ➔	2 ⇩	0 ➔	1 ➔	0 ➔	1 ➔	-1 ⇩	2 ➔		5
6 Neighbour	▨	0 ⇩	1 ➔	2 ⇩	0 ➔	1 ➔	0 ➔	1 ➔	-1 ⇩	2 ➔		6
7 At work (colleague/ co-worker)	-1 ⇩	0 ⇩	1 ➔	2 ⇩	0 ➔	1 ➔	0 ➔	1 ➔	-1 ⇩	2 ➔		7
8 Church	-1 ⇩	0 ⇩	1 ➔	2 ⇩	0 ➔	1 ➔	0 ➔	1 ➔	-1 ⇩	2 ➔		8
9 Community (public disclosure)	▨	0 ⇩	1 ➔	2 ⇩	0 ➔	1 ➔	0 ➔	1 ➔	-1 ⇩	2 ➔		9

16.9 Since [commencing the government's ARV Treatment Programme/*the previous interview*], has your HIV status been disclosed to other people without your permission?

No	0	⇩
Yes	1	➔ ↴ *If YES:*
Do not know	2	⇩

16.10 Who disclosed your status without your permission?

17. USE AND EFFECTS OF ARV MEDICATION

This section deals with the use of ARV medication, and the effects it has on you.

17.1 Have you MADE any changes to your behaviour/activities/lifestyle?
This includes, but is not limited to, diet, exercise, rest, smoking, alcohol, sexual practices, etc.

No	0
Yes	1

17.2 Please explain.

17.3 Do you currently have a regular sexual partner, an occasional sexual partner, or no sexual partner at all?

Yes, one regular sexual partner	1	➔
Yes, two or more regular sexual partners	2	➔ ↴ *If YES:*
Yes, an occasional sexual partner	3	➔
No sexual partner	4	⇩

Other (specify)

17.4 Do(es) your sexual partner(s) have any other sexual partners besides yourself?

No	0	⇩
Yes	1	➔
Do not know	2	⇩

↴ *If YES:*

17.5 How many other sexual partners do(es) she/he/they have, besides yourself?

____

Now I need to ask you some questions about sexual activity in order to gain a better understanding of some health and family planning issues.

17.6 When was the last time you had sexual intercourse (if ever)?

	Number	Category	
0	▨	Never	⇩
1		day(s) ago	➔
2		week(s) ago	➔
3		month(s) ago	➔
4		year(s) ago	➔

↴ *If EVER had sex:*

Cat	Number

17.7 Please describe your relationship to the person you last had sexual intercourse with?

Marital partner	1
Other regular partner (if more than one)	2
Casual acquaintance	3
Someone just met	4
Commercial sex worker	5
Partner (unmarried)	6
Other (specify)	

17.8 The last time you had sex, was a condom used?

No	0
Yes	1
Cannot remember	2

17.9 In the last <u>12 months</u> (year), with how many people have you had sexual intercourse?

☛ *I.e. <u>including</u> time BEFORE [commencing the ARV Treatment Programme/the previous interview].*

__________________person/people

17.10 <u>SINCE</u> [commencing the government's ARV Treatment Programme/*the previous interview*], with how many people have you had sexual intercourse?

__________________person/people

17.11 Do you know of a place where you can get condoms?

No	0	⇩
Yes	1	➔

↴ *If YES:*

17.12 Where is that?

Government (public) hospital	1
Government (public) clinic/CHC	2
Mobile clinic	3
Community health worker	4
Private hospital/clinic	5
Pharmacy	6
Private doctor	7

Shop	8
Friend(s)/relative(s)	9
Other (specify)	

17.13 Do you want/desire to have [a child/*children*] in the future?

No	0
Yes	1
Do not know	2

17.14 Please explain.

17.15 Do you know of any people who share their ARV medication with other persons?

No	0
Yes	1 ➔

↴ *If YES:*

17.16 Please explain.

17.17 Have you ever shared your own ARV medication with other people?

No	0 ⇩
Yes	1 ➔

↴ *If YES:*

17.18 Why?

17.19 Are there people who are interested in buying your ARV medication?

No	0
Yes	1

17.20 Do you know of people who have sold their ARV medication?

No	0
Yes	1

17.21 Do you receive food supplements from government as part of the ARV Treatment Programme?

No	0 ⇩
Yes	1 ➔

↴ *If YES:*

17.22 Do you share these FOOD SUPPLEMENTS with others?

No	0 ⇩
Yes	1 ➔

↴ *If YES:*

17.23 With whom do you share you food SUPPLEMENTS?

17.24 During the past month (30 days), did you drink alcohol?

No	0 ⇩
Yes	1 ➔

↴ *If YES:*

17.25 Do you drink alcohol more than once a week?

No	0
Yes	1

17.26 During the past month (30 days), did you smoke tobacco?

No	0 ⇩
Yes	1 ➔

↴ *If YES:*

17.27 During the past week (7 days), how many cigarettes/pipes did you smoke per day?

__________cigarettes/pipes per day

17.28 During the past month (30 days), did you smoke dagga?

No	0 ⇩
Yes	1 ➔

↴ *If YES:*

17.29 During the past week (7 days), on how many days did you have at least one smoke of dagga?

__________day(s)

- *If respondent is **NOT** taking ARV medication, go to Question 17.43 on page 336.*
- *If respondent **IS** taking ARV medication, continue with Question 17.30.*

Please look at this pamphlet and identify the ARV medication that has been prescribed to you by the doctor at the TREATMENT site.

17.30 Name of ARV	**17.31 Please list all the times of the day that you have to take [ARV NAME]?**	**17.32 How [many tablets/ *much liquid*] do you have to take at each of these times?**	**17.33 During the past week (7 days) did you take [ARV NAME] as you just explained?**			↴ *If NO:* **17.34 During the past week (7 days), how many [tablets/*liquid dosages*] have you missed (did not take)?**	**17.35 What was/were the reason(s) for you not taking [ARV NAME]?** ☛ *Remember to ask Question 17.36 on page 336 AFTER completing all ARV information.*
			No	**Yes**	**Cannot remember**		
	➔	➔	0➔	1⇩	2⇩	➔	⇩
	➔	➔	0➔	1⇩	2⇩	➔	⇩
	➔	➔	0➔	1⇩	2⇩	➔	⇩
	➔	➔	0➔	1⇩	2⇩	➔	⇩
	➔	➔	0➔	1⇩	2⇩	➔	⇩
	➔	➔	0➔	1⇩	2⇩	➔	⇩
	➔	➔	0➔	1⇩	2⇩	➔	⇩
	➔	➔	0➔	1⇩	2⇩	➔	⇩
	➔	➔	0➔	1⇩	2⇩	➔	⇩
	➔	➔	0➔	1⇩	2⇩	➔	⇩
	➔	➔	0➔	1⇩	2⇩	➔	⇩
	➔	➔	0➔	1⇩	2⇩	➔	⇩
	➔	➔	0➔	1⇩	2⇩	➔	⇩
	➔	➔	0➔	1⇩	2⇩	➔	⇩
	➔	➔	0➔	1⇩	2⇩	➔	⇩

☛ *If NO to any ARV in 17.33, remember to ask 17.36 on page 336 AFTER completing all ARV information.*

Name	Times	Dose	Adher	Reason			

☛ *Is 17.36 applicable?*

17.36 Did you inform a health worker about not taking your ARV medication as prescribed?

No	0 ⇩
Yes	1 ➔

↴ *If YES:*

17.37 What was her/his/their reaction?

……………………………………………………………

……………………………………………………………

……………………………………………………………

……………………………………………………………

17.38 Do you experience any side effects when taking ARV medication?

No	0 ⇩
Yes	1 ➔

↴ *If YES:*

17.39 What side effects do you experience with regard to your ARV medication?	**17.40 When do you typically experience this side-effect?**	**17.41 How disruptive is this to you?** 1 Not at all disruptive 2 Somewhat disruptive 3 Very disruptive
1		
2		
3		
4		
5		
6		

	SE	When		Disrupt
1				
2				
3				
4				
5				
6				

17.42 What is the impact/influence/effect of <u>ARV medication</u> on your daily life?

……………………………………………………………

……………………………………………………………

……………………………………………………………

……………………………………………………………

17.43 Since [commencing the government's ARV Treatment Programme/*the previous interview*], has the following changed:

Sub-question	Improved	Remained the same	Deteriorated	Fluctuated
1 Your physical health	1	2	3	4
2 Your emotional well-being	1	2	3	4

1

2

18. KNOWLEDGE ABOUT HIV/AIDS AND ARV TREATMENT

This section contains questions about HIV/AIDS and ARV treatment in general. Some of the following statements are true and others are false.
PLEASE, DO <u>NOT</u> TAKE THESE STATEMENTS AS INFORMATION ABOUT HIV/AIDS AND ARV MEDICATION.

18.1 Please indicate to what extent you agree or disagree with each of the following statements.

Sub-question	Definitely true	Partly true	Un-certain	Partly false	Totally false	
1 Unprotected sex is safe because of the new treatments.	1	2	3	4	5	1 ☐
2 People receiving ARV treatment can still transmit HIV to other people through unprotected sex.	1	2	3	4	5	2 ☐
3 Unprotected sex with withdrawal before ejaculating protects against HIV.	1	2	3	4	5	3 ☐
4 One should continue to take ARV treatment after gaining weight	1	2	3	4	5	4 ☐
5 It is correct to stop ARV treatment when one no longer suffers from opportunistic infections	1	2	3	4	5	5 ☐
6 One can protect other people from HIV by sharing one's ARV medication with them	1	2	3	4	5	6 ☐
7 ARV medication cures HIV	1	2	3	4	5	7 ☐
8 After a couple of years one can stop taking ARV medication	1	2	3	4	5	8 ☐
9 Missing a few doses of ARV medication is acceptable	1	2	3	4	5	9 ☐

19. FEAR, STIGMA AND DISCRIMINATION

This section contains questions about perceptions related to HIV/AIDS. There is no correct or wrong answer to the statements. Do not take these statements as information about HIV/AIDS and ARV medication.

19.1 To what extent do you agree/disagree with the following statements:

Sub-question	Not applicable	Strongly agree	Agree	Neither agree no disagree	Disagree	Strongly disagree	Not important	Do not know	
1 I am afraid of the physical pain associated with AIDS	▨	1	2	3	4	5	-2	0	1 ☐
2 I am afraid of dying	▨	1	2	3	4	5	-2	0	2 ☐
3 I am worried about who will look after me when I am sick	▨	1	2	3	4	5	-2	0	3 ☐
4 I am worried about who will look after my family when I am dead	-1	1	2	3	4	5	-2	0	4 ☐
5 I believe that having HIV/AIDS is punishment for bad behaviour	▨	1	2	3	4	5	-2	0	5 ☐
6 Some people in my community believe that having HIV/AIDS is punishment for bad behaviour	▨	1	2	3	4	5	-2	0	6 ☐
7 Some members of my household do not want to share eating utensils with me because I am HIV-positive	-1	1	2	3	4	5	-2	0	7 ☐
8 Some members of my household do not want to touch me because I am HIV-positive	-1	1	2	3	4	5	-2	0	8 ☐
9 My partner left me because I am HIV-positive	-1	1	2	3	4	5	-2	0	9 ☐
10 I was forced to leave my previous home due to my HIV status	-1	1	2	3	4	5	-2	0	10 ☐
11 I have lost my job because of my HIV status	-1	1	2	3	4	5	-2	0	11 ☐
12 I have been denied a public service (police, education, etc.) because of my HIV status	-1	1	2	3	4	5	-2	0	12 ☐
13 People with HIV should not have sex	▨	1	2	3	4	5	-2	0	13 ☐

19.2 Please indicate how much you experience the following:

Sub-question	Not at all	A moderate amount	An extreme amount	Do not know
1 Unpleasant physical problems related to your HIV infection	1	2	3	0
2 People blaming you for your HIV status	1	2	3	0
3 You blame yourself for your HIV infection	1	2	3	0
4 You feel guilty about being HIV-positive	1	2	3	0
5 How guilty you feel when you need help and care from others	1	2	3	0

1	
2	
3	
4	
5	

20. HOME CARE AND SUPPORT

This section contains questions about the care and support you receive at home, excluding health care workers.

20.1 Do you have a treatment buddy?

No	0 ⇩
Yes	1 ➔

↴ *If YES:*

20.2 How is your treatment buddy related to you?	**20.3 What is the sex of this person?**		**20.4 How old is this person?**
	Male	**Female**	
1 Spouse/partner	1	2	
2 Child	1	2	
3 Sibling (brother/sister)	1	2	
4 Former spouse/partner	1	2	
5 Friend	1	2	
8 Parent	1	2	
Other (specify)	1	2	
	1	2	

Buddy	Sex	Age

20.5 Please indicate what kind of support your treatment buddy provides you with.

....

....

....

....

20.6 Does your treatment buddy help you to adhere to your treatment?

No	0 ⇩
Yes	1 ➔

↴ *If YES:*

20.7 How often does this person help you with adherence?

At every dose time	1
In the mornings	2
In the afternoons	3
In the evenings	4
At irregular intervals	5
Other (specify)	

20.8 Did this person attend ARV drug readiness training?

No	0
Yes	1

20.9 Who chose this person as your treatment buddy?

Me/myself	1
Nurse at the ASSESSMENT site	2
Nurse at the TREATMENT site	6
Community health worker	3
Other (specify)	

20.10 How satisfied are you with this support?

Very satisfied	1
Satisfied	2
Neither satisfied nor dissatisfied	3
Dissatisfied	4
Very dissatisfied	5
Do not know	0

20.11 Please explain.

……………………………………………………

……………………………………………………

……………………………………………………

……………………………………………………

20.12 Do you have someone providing physical care to you at home, <u>excluding a treatment buddy or health worker</u>?

No	0	⇩
Yes	1	→

↴ *If YES:*

20.13 How [is this person/*are these persons*] related to you?	**20.14 What is the sex of this person?**		**20.15 How old is this person?**
	Male	**Female**	
	1	2	
	1	2	

Relation	Sex	Age

20.16 How satisfied are you with this physical care?

Very satisfied	1
Satisfied	2
Neither satisfied nor dissatisfied	3
Dissatisfied	4
Very dissatisfied	5
Do not know	0

20.17 Please explain.

……………………………………………………

……………………………………………………

……………………………………………………

……………………………………………………

20.18 Do you have someone who supports you emotionally, <u>excluding a treatment buddy or health worker</u>?

No	0 ⇩
Yes	1 ➔

↴ *If YES:*

20.19 How [is this person/*are these persons*] related to you?	**20.20 What is the sex of this person?**		**20.21 How old is this person?**
	Male	**Female**	
	1	2	
	1	2	

Relation	Sex	Age

20.22 How satisfied are you with this emotional support?

Very satisfied	1
Satisfied	2
Neither satisfied nor dissatisfied	3
Dissatisfied	4
Very dissatisfied	5
Do not know	0

20.23 Please explain.

V

V

V

V4

20.24 Do you currently have a community health worker assigned to care for and support you at home?

No	0 ⇩
Yes	1 ➔

↴ *If YES:*

20.25 What is the sex of the community health worker assigned to you?

Male	1
Female	2

20.26 Since when have you had this community health worker to care and support you at home?

Month	**Year**

MM/YYYY

/

20.27 How regularly does this person visit you?

20.28 On average, how long do these visits last?

_____ minutes _____ hours

20.29 What does this person usually do when he/she visits you?

V

V

V

V5

20.30 How satisfied are you with this care and support?

Very satisfied	1
Satisfied	2
Neither satisfied nor dissatisfied	3
Dissatisfied	4
Very dissatisfied	5
Do not know	0

20.31 Please explain.

....

....

....

....

V
V
V
V

20.32 Do you PARTICIPATE in a <u>support GROUP</u> for people living with HIV/AIDS (e.g. where PLWA meet to discuss issues/problems related to living with HIV and AIDS)?

No	0 ⇩
Yes	1 →

↴ *If YES:*

20.33 Please list the names of this/these organisation(s).	**20.34 How satisfied are you with this support?** Very satisfied	Satisfied	Neither satisfied nor dissatisfied	Dissatisfied	Very dissatisfied	Do not know	**20.35 Please explain.**
1	1	2	3	4	5	0	
2	1	2	3	4	5	0	
3	1	2	3	4	5	0	
4	1	2	3	4	5	0	

	Grp	Sat	Support
1			
2			
3			
4			

20.36 Do you receive <u>SUPPORT</u> OR <u>CARE</u> from any <u>other</u> organisation that provides services to people living with HIV/AIDS?

No	0 ⇩
Yes	1 →

↴ *If YES:*

20.37 Please list the names of this/these organisation(s).	**20.38 What kind of support do you receive from this organisation?**
1	
2	
3	
4	

	Org	Support
1		
2		
3		
4		

20.39 Do you need any HIV/AIDS-related services that are not available to you?

No	0	⇩
Yes	1	➔

↴ *If YES:*

20.40 Please explain.

....

....

....

....

- ☛ *For **follow-up** (repeat) respondents go to instructions preceding Section 22 on page 342.*
- ☛ *For **first-time** (new) respondents continue with Section 21.*

21. QUALITY OF SERVICE AT DRUG READINESS TRAINING

This section deals with the drug readiness training you received before commencing ARV treatment.

21.1 Please rate the drug readiness training you received in terms of the following:

Sub-question	Very good	Good	Neither good nor poor	Poor	Very poor	Do not know
1 Clarity of information provided	1	2	3	4	5	0
2 Opportunity to ask questions	1	2	3	4	5	0
3 Information thoroughly discussed	1	2	3	4	5	0
4 Health information provided to you in regard to AIDS	1	2	3	4	5	0
5 Health information on ARV medication	1	2	3	4	5	0
6 Language used	1	2	3	4	5	0

- ☛ *If ASSESSMENT and TREATMENT sites are the **same** go to Section 23 on page 343.*
- ☛ *If ASSESSMENT and TREATMENT sites are **different** continue with Section 22.*

22. QUALITY OF CARE AT ASSESSMENT SITE

This section deals with ARV-RELATED services you receive at the ASSESSMENT SITE.

22.1 Please rate the ARV-RELATED services you receive at the ASSESSMENT site in terms of the following:

Sub-question	Not applicable	Very satisfied	Satisfied	Neither satisfied nor dissatisfied	Dissatisfied	Very dissatisfied	Do not know
1 Medical care provided at the ASSESSMENT site	▨	1	2	3	4	5	0
2 Complaint procedure at the ASSESSMENT site	▨	1	2	3	4	5	0
3 Cleanliness of clinic	▨	1	2	3	4	5	0
4 Privacy during examinations	▨	1	2	3	4	5	0
5 Confidentiality of your medical record	▨	1	2	3	4	5	0
6 Respect shown by nurses at the ASSESSMENT site	-1	1	2	3	4	5	0
7 Respect shown by doctor(s) at the ASSESSMENT site	-1	1	2	3	4	5	0
8 Health information about HIV/AIDS	-1	1	2	3	4	5	0
9 Information about ARV medication provided by nurse(s)	-1	1	2	3	4	5	0
10 Information about ARV medication provided by doctor(s)	-1	1	2	3	4	5	0
11 Opportunity to ask questions	-1	1	2	3	4	5	0
12 Language used during consultations	▨	1	2	3	4	5	0
13 Hours that the ASSESSMENT site is open	▨	1	2	3	4	5	0
14 Waiting time before consultations	▨	1	2	3	4	5	0

22.2 Please rate the ARV-RELATED services you receive from the following staff at the ASSESSMENT SITE:

Sub-question	Not applicable	Very good	Good	Neither good nor bad	Poor	Very poor	Do not know
1 Nurse	-1	1	2	3	4	5	0
2 Doctor	-1	1	2	3	4	5	0
3 Lay counsellor	-1	1	2	3	4	5	0
4 Pharmacist	-1	1	2	3	4	5	0
5 Nutritionist/dietician	-1	1	2	3	4	5	0
6 Social worker/psychologist	-1	1	2	3	4	5	0
7 Clerk	-1	1	2	3	4	5	0
8 Attendant staff (e.g. cleaner, porter)	-1	1	2	3	4	5	0

22.3 Do you have any complaints about the service you receive at the ASSESSMENT site?

No	0
Yes	1

22.4 Please explain.

23. *QUALITY OF CARE AT TREATMENT SITE*

This section deals with the ARV-RELATED services you receive at the TREATMENT SITE.

23.1 Please rate the ARV-RELATED services you receive at the TREATMENT site in terms of the following:

Sub-question	Not applicable	Very satisfied	Satisfied	Neither satisfied nor dis-satisfied	Dis-satisfied	Very dis-satisfied	Do not know
1 Medical care provided at the TREATMENT site	▨	1	2	3	4	5	0
2 Complaint procedure at the TREATMENT site	▨	1	2	3	4	5	0
3 Cleanliness of TREATMENT site	▨	1	2	3	4	5	0
4 Privacy during examinations	▨	1	2	3	4	5	0
5 Confidentiality of your medical record	▨	1	2	3	4	5	0
6 Respect shown by nurses at the TREATMENT site	-1	1	2	3	4	5	0
7 Respect shown by doctor(s) at the TREATMENT site	-1	1	2	3	4	5	0
8 Health information about HIV/AIDS	-1	1	2	3	4	5	0
9 Information about ARV medication provided by nurse(s)	-1	1	2	3	4	5	0
10 Information about ARV medication provided by doctor(s)	-1	1	2	3	4	5	0
11 Opportunity to ask questions	-1	1	2	3	4	5	0
12 Language used during consultations	▨	1	2	3	4	5	0
13 Hours that the TREATMENT site is open	▨	1	2	3	4	5	0
14 Waiting time before consultation	▨	1	2	3	4	5	0

23.2 Please rate the ARV-RELATED services you receive from the following staff at the TREATMENT site:

Sub-question	Not applicable	Very good	Good	Uncertain	Poor	Very poor	Do not know
1 Nurse	-1	1	2	3	4	5	0
2 Doctor	-1	1	2	3	4	5	0
3 Lay counsellor	-1	1	2	3	4	5	0
4 Pharmacist	-1	1	2	3	4	5	0
5 Nutritionist/dietician	-1	1	2	3	4	5	0
6 Social worker/psychologist	-1	1	2	3	4	5	0
7 Clerk	-1	1	2	3	4	5	0
8 Attendant staff (e.g. cleaner, porter)	-1	1	2	3	4	5	0

23.3 Do you have any complaints about the service you receive at the TREATMENT site?

No	0
Yes	1

23.4 Please explain.

24. GENERAL

24.1 Lastly, how [do you think will/*does taking*] ARV medication, influence YOUR future?

24.2 Time interview ended.

24.3 Thank respondent for time!!!

APPENDIX B

Office use only

TREATMENT BUDDY QUESTIONNAIRE

INTRODUCTION

Good morning/afternoon/evening, My name is ……………………….from the Centre for Health Systems Research & Development. I am doing a study, aiming to understand the role of treatment buddies in the public-sector antiretroviral treatment programme. I received permission to contact you from…….………….and I would like to ask you few questions regarding your role as a treatment buddy. All this information will remain confidential. I will not, under any circumstances, provide any of your personal information to any third party. This interview will take 10-15 minutes. Are you prepared to participate?

INTERVIEW PARTICULARS

Questionnaire/ patient id no: ☐

Interviewer: ______________________

Date of the interview:

date	month	year

Health district:

Motheo	*Thabo Mofutsanyana*	▨
Fezile Dabi	*Lejweleputswa*	*Xhariep*

SOCIO-DEMOGRAPHIC CHARACTERISTICS

1. Gender

Male	*0*
Female	*1*

2. Age ______________ *years*

3. What is your highest qualification?

Sub A/ Grade 1	*1*	*Std 7 / Grade 9*	*9*
Sub B/ Grade 2	*2*	*Std 8 / Grade 10*	*10*
Std 1 / Grade 3	*3*	*Std 9 / Grade 11*	*11*
Std 2 / Grade 4	*4*	*Matric / Grade 12*	*12*
Std 3 / Grade 5	*5*	*Diploma/Certificate*	*13*
Std 4 / Grade 6	*6*	*Degree*	*14*
Std 5 / Grade 7	*7*	*Never attended school*	*15*
Std 6 / Grade 8	*8*	*Other (specify):*	

____

____

4. Are you currently employed?

Yes- full-time	*1*
Yes- part-time	*2*
Yes- informal	*3*
Yes- self-employed	*4*
No-unemployed	*5*

5. How are you related to the **patient?**

Spouse/partner	*1*
Child	*2*
Sibling	*3*
Friend	*4*
Parent	*5*
Other (specify):	

6. Who chose you to be a treatment buddy to the **patient?**

Myself	*1*
Patient	*2*
Nurse	*3*
CHW	*4*
Other(specify)	

TRAINING

7. Are you a lay worker/CHW?

Yes	*0*
No	*1*

8. **If yes** , have you been recruited for nursing assistant training?

Yes	*0*
No	*1*

9. Did you undergo any training for your position as a treatment buddy?

Yes	*0*	
No	*1*	***if no, skip to 15***

10. **If yes** , where were you trained?

11. When were you trained?

month ☐ *200*

12. Who conducted the training?

13. What was the duration of the training?

☐ *days*

14. What were you taught at the training (course-broad themes)?

15. Do you think, you need more training to improve your treatment buddy activities?

Yes	*0*
No	*1*

16. **If yes** , please explain:

INVOLVEMENT IN THE PROGRAMME

17. What is your main task as a treatment buddy?

18. What activities do you frequently perform for or with **patient** during visits?

19. What kind of support do you frequently offer **patient?**

Category	***Always***	***Mostly***	***some times***	***Seldo m***	**Never**
Emotional *(e.g. provide encouragement, love & care)*					
Instrumental *(e.g. providie food, transportation etc)*					
Informational *(e.g. givie information & advice)*					
Appraisal *(e.g. affirm the individual's ability to cope)*					
Adherence *(e.g. assist with medication)*					

20. How long have you been working with **patient?**

☐ weeks ☐ *months*

21. How regularly do you visit/contact **patient?**

At every dose	*1*
In the mornings	*2*
In the afternoons	*3*
In the evenings	*4*
At irregular intervals	*5*
other (specify)	

22. How much time do you spend with **patient?**

☐ *minutes* ☐ *hours*

23. Where do you and **patient** normally meet?

At the clinic	*1*
At his or her home	*2*
At your own home	*3*
At work	*4*
At church	*5*
In town	*6*
Other (specify):	

24. How much time do you spend travelling to your meeting point?

N/A ☐ *minutes* ☐ *hours*

25. How do you get to your meeting point?

Walk	*1*
Taxi	*2*
Own transpo	*3*
Other:	

26. How much do you spend when visiting **patient?**

R

27. How long have you known the **patient's** HIV positive status

☐ *weeks* ☐ *months* ☐ *years*

28. Are you on ARV treatment?

Yes	*0*
No	*1*

29. How confident are you of your effectiveness as a treatment buddy?

Very confide	*1*
Confident	*2*
Uncertain	*3*
Doubtful	*4*
Very doubtfu	*5*

30. In your opinion, what needs of **patient** are not being met?

KNOWLEDGE ABOUT ARV TREATMENT

31. Please indicate to what extent you agree or disagree with each of the following statements

Sub-question	**Definitely true**	**Partly true**	**Uncertain**	**Partly false**	**Totally false**
1. Unprotected sex is safe because of the new treatments					
2. People receiving ARV treatment can still transmit HIV to other people					
3. One should continue to take ARV treatment after gaining weight					
4. It is correct to stop ARV treatment when one no longer suffers from opportunistic infections					
5. One can protect other people by sharing medication with them					
6. ARV medication cures HIV					
7. After a couple of years one can stop taking ARV medication					
8. Missing few doses of ARV Medication is acceptable					

32. What are the most common side - effects of medication your patients experience?

33. How do you deal with side - effects of ARV medication?

34. What challenges do you encounter in your work as a treatment buddy?

THANK-YOU FOR YOUR TIME AND COOPERATION!!