

# **The development and evaluation of a social work programme for community caregivers to facilitate HIV and AIDS patients' adherence to antiretroviral treatment**

**R.M. Mokwele**

**Student number: 12166456**

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Promotor: Prof H Strydom

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It all starts here™

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## **ABSTRACT**

**Title: The development and evaluation of a social work programme for community caregivers to facilitate HIV and AIDS patients' adherence to antiretroviral treatment.**

**Keywords: Antiretroviral treatment, home community based care, community caregiver, empowerment, antiretroviral treatment adherence.**

The study focused on the empowerment of community caregivers to facilitate patients' adherence to antiretroviral treatment (ART). Adherence to ART poses a great challenge and ART success is highly dependent on the ability of the patient to fully adhere to the prescribed treatment. The overall aim of this study was to develop an empowerment programme for community caregivers to facilitate patients' adherence to ART.

The research followed a mixed method approach and particularly the multiphase mixed method in which both qualitative and quantitative methodology was used. The intervention research model was used which consists of six phases, namely, problem analysis and project planning, information gathering and synthesis, design, early development and pilot testing, evaluation and advance development and dissemination. The investigation focused on four phases. Phase one focused on a literature review, phase two focused on the need assessment and planning, phase three focused on the development of the social work empowerment programme and phase four focused on the implementation and evaluation of the social work empowerment programme.

Section A contains the general introduction to the study, problem statement, research objectives, the procedures and research methodology. Furthermore the limitations of this study are discussed as well as the definitions of key words and the composition of the research report is given.

Section B contains the results of the research according to the different articles. Each article focuses on specific goals and research methodologies which were done in order to achieve the overall goal to develop the empowerment programme.

In article 1 a theoretical perspective from the literature was obtained to determine the challenges that patients experience with regard to ART from the perspective of community caregivers. The aim of the literature study in article 1 was to explore factors that influence adherence of patients on ART in order to develop ART intervention programmes. This review followed a systems approach. A social-ecological framework was used for the exploration of barriers and facilitators to sustained treatment adherence of persons on ART.

In article 2 a literature study was done on the role of the community caregiver in the lives of persons on ART. This literature review explored the value of social support from the community caregiver regarding patients' adherence. This article applied the systems theory with a focus on the patient on ART, and the community caregiver. The literature review focused on the role of the community caregiver in antiretroviral treatment programmes; empowerment programmes for community caregivers; and made recommendations with regard to the role of the community caregiver during antiretroviral treatment in context of the information, motivation and behavioural skills model.

Article 3 aimed to explore and describe the perceptions of community caregivers with regard to patients' ART adherence and a social work empowerment programme to enhance their skills to facilitate the adherence of HIV and AIDS patients on ART. This study used a qualitative approach with a phenomenological design. Focus group discussions were facilitated with sixteen community caregivers to gain insights into patients and ART adherence and a social work empowerment programme. The results of these focus group discussions assisted with the development of the social work empowerment programme.

Article 4 focused on designing a social work empowerment programme for community caregivers. The literature and qualitative needs assessment identified many psychosocial challenges regarding patients' adherence to ART that was used for the design of the programme. Identified social workers participated in a peer review to evaluate the programme. In Article 4, an outline was given of the social work empowerment programme and the key elements of the programme were described, focussing on aspects of the implementation and facilitation of the programme.

The aim of article 5 was to implement and evaluate the effectiveness of the social work empowerment programme. For the purpose of this study, experimental and comparison groups were formed comprising of twelve caregivers each. The comparison group received both the pre-test, post-test and post-post-test at the same time as the experimental group, but did not receive the treatment. The effectiveness of the programme was evaluated by means of the Personal Multi-Screening Inventory (PMSI). Evaluation according to this measuring scale took place on three occasions: before the group started, at the end of the last group session and one month after the last group session. The research indicated that the community caregivers were empowered through the programme and that such an empowerment programme is needed.

Section C focuses on the conclusions and recommendations regarding the investigation. Section D consists of the combined references and section E consists of the annexures for the study.

## OPSOMMING

**Titel: Die Ontwikkeling en evaluering van 'n maatskaplikewerkprogram vir gemeenskapssorgwerkers vir die fasilitering van MIV en VIGS pasiënte se antiretrovale behandeling.**

**Sleutel terme: Antiretrovirale behandeling, tuis gemeenskapsorg, gemeenskapsversorger, bemagtiging, nakoming van antiretrovale behandelingvereistes.**

Die studie fokus op die bemagtiging van gemeenskapsorgwerkers om pasiënte se antiretrovirale behandeling (ARB) te fasiliteer. ARB vereis dat pasiënte die behandelingsvereistes baie streng nakom. Die oorkoepelende doel van hierdie studie was om 'n bemagtigingsprogram vir gemeenskapsorgwerkers te ontwikkel ten einde hulle in staat te stel om pasiënte se behandeling te fasiliteer.

Die navorsing was gebaseer op die gemengdenavorsings-metode met 'n fokus op die veelvoudige gemengde metode wat beide kwalitatiewe en kwantitatiewe benaderings insluit. Die intervensie navorsings model is gebruik. Die model bestaan uit ses fases, naamlik probleem- analyse en projek beplanning, insameling van inligting en sintese, ontwerp, vroeëre ontwikkeling en toetsing, evaluasie en verspreiding. Die navorsingsondersoek het gefokus op vier fases. Fase een het gefokus op 'n literatuurstudie, fase twee op behoeftebepaling, fase drie se fokus was op die ontwikkeling van die maatskaplikewerk bemagtigingsprogram en fase vier het gefokus op die implementering en evaluasie van die bemagtigingsprogram.

Afdeling A bevat die inleiding tot die studie, probleemstelling, navorsingsdoelwitte, prosedures en navorsingsmetodes. Verder is die beperkings van hierdie studie bespreek, die definisies van sleutelwoorde gegee asook 'n uiteensetting van die samestelling van die navorsingsverslag.

Afdeling B bevat die resultate van die navorsing na aanleiding van die artikels. Elke artikel fokus op spesifieke doelwitte en navorsings-metodes wat gebruik is om die oorkoepelende doel te bereik.

In artikel 1 is 'n teoretiese perspektief vanuit die literatuur verkry ten einde die probleme wat pasiënte ten opsigte van ARB ondervind vanuit die perspektief van die gemeenskapsorgwerker te ondersoek. Die doel van die literatuurstudie in artikel 1 was om die faktore wat aanleiding gee tot die nakoming van behandelingsvereistes van pasiënte te bepaal vir die ontwikkeling van ARB programme. Hierdie literatuur-oorsig het 'n sisteem-benadering gevolg. Die maatskaplike ekologiese raamwerk is gebruik vir die bepaling van oorsake en fasiliteerders vir volhoubare behandeling vir persone op ARB.

In artikel 2 is 'n literatuurstudie gedoen ten opsigte van die rol van die gemeenskapsorgwerker wat ARB van pasiënte fasiliteer. Hierdie literatuurstudie ondersoek die waarde van die gemeenskapsorgwerker se sosiale ondersteuning aan pasiënte om behandelingsvereistes na te kom. Die artikel is gebaseer op 'n sisteembenadering met 'n fokus op die pasiënt wat ARB ondergaan en die gemeenskapsorgwerker. Die literatuurstudie bied 'n oorsig van die rol van die gemeenskapsorgwerker in fasilitering van ARB en ARB programme in die raamwerk van die inligting, motivering en gedragvaardigheids-model.

Die doel van artikel 3 was om gemeenskapsorgwerkers se persepsies ten opsigte van ARB van pasiënte te bepaal asook hul persepsies ten opsigte van 'n maatskaplikewerk bemagtigingsprogram om hul vaardighede te ontwikkel ten einde pasiënte se ARB te fasiliteer. Hierdie studie het gebruik gemaak van 'n kwalitatiewe benadering met 'n fenomenologiese ontwerp. Fokusgroep besprekings het plaasgevind met sestien gemeenskapsorgwerkers om hul insigte oor ARB van pasiënte te bepaal asook hul insigte ten opsigte van 'n maatskaplikewerk bemagtigingsprogram. Hierdie inligting wat deur fokusgroepe verkry is was nuttig vir die ontwikkeling van die maatskaplikewerk bemagtigingsprogram.

In artikel 4 is gefokus op die ontwerp van die maatskaplikewerk bemagtigingsprogram vir gemeenskapsorgwerkers. Die literatuurstudie en behoeftebepaling het verskeie psigososiale probleme geïdentifiseer ten opsigte van die ARB vereistes van pasiënte wat gebruik kon word vir die ontwerp van die program. Geïdentifiseerde maatskaplikewerke het die program geëvalueer. Die hoof elemente van die program word bespreek in artikel 4, asook aspekte ten opsigte van die implementering en fasilitering van die program.

Die doel van artikel 5 was om die effektiwiteit van 'n maatskaplikewerk bemagtigingsprogram te evalueer. Vir die doelstelling van hierdie studie, is 'n eksperimentele en vergelykende groep saamgestel bestaande uit twaalf gemeenskapsorgwerkers elk. Die vergelykende groep was onderwerp aan die voortoets, na-toets en na-na-toets, op dieselfde tyd as die eksperimentele groep, maar het nie die behandeling (program) ontvang nie. Die effektiwiteit van die program is geëvalueer met behulp van die Persoonlike Multi-funksionering Inventaris. Die evaluasie het op drie geleenthede plaasgevind, naamlik, voor die aanvang van die groep, aan die einde van die groep-sessies en 'n maand na die afsluiting van die groep-sessies. Hierdie studie het bewys gemeenskapsorgwerkers is deur die program bemagtig en dat soortgelyke bemagtigingsprogramme nodig is.

In afdeling C word die belangrikste bevindinge en aanbevelings in geheel weergegee. Afdeling D gee 'n gesamentlikelys van die bronne wat in die studie gebruik is en afdeling E bevat die bylaes vir die studie.

## FOREWORD

The article format has been chosen in accordance with the regulation A12.2.2 of the yearbook 2016 North-West University for the PhD (SW) degree. **It is important to note that each article must form a functional unit. This implies that some of the data have to be repeated in different sections.**

The articles will comply with the requirements of the South African Journal titled *Social Work/Maatskaplike Werk* and *Practitioner Researcher/Maatskaplike Werk in praktyk*.

## **INSTRUCTIONS TO THE AUTHORS**

### **SOCIAL WORK/MAATSKAPLIKE WERK**

The Journal publishes articles, short communications, book reviews and commentary articles already published from the field of Social Work. Contributions may be written in English or Afrikaans. All contributions will be critically reviewed by at least two referees on whose advice contributions will be accepted or rejected by the editorial committee. All refereeing is strictly confidential. Manuscripts may be returned to the authors if extensive revision is required or if the style of presentation does not conform to the practice. Commentary on articles already published in the Journal must be submitted with appropriate citations, the name(s) and address (es) of the author(s) preferably not exceeding 5 pages. The whole manuscript plus one clear copy as well as a diskette, with all the text, preferably in Ms Word (Word Perfect) or ACSII must be submitted. Manuscripts must be typed, double spaced on one side of the A4 paper only. Use the Harvard system for references. Short references in the text: when word-for-word quotations, facts or arguments from other sources are cited, the surname(s) must appear in parenthesis in the text, e.g. %6 + (Berger, 1976:12). More details about resources referred to in the text should appear at the end of the manuscript under the caption %References+. The sources must be arranged alphabetically according to the surnames of the authors.

### **SOCIAL WORK PRACTITIONER-RESEARCHER**

A minimum length of 3,500 words and a maximum length of 6,000 words (excluding references). The text is 1,5 spaced; uses a 12-point font; employs italics, rather than underlining (except with URL addresses); and all illustrations, figures, and tables are placed within the text at the appropriate points, rather than at the end. On a separate page, a title of not more than ten words should be provided. The author's full name and title, position, institutional affiliation and e-mail address should be supplied. An abstract of 150 words plus up to six keywords, which encapsulate the principal topics of the paper, must be included. The abstract should summarise the key argument/s of the article and locate the article in its theoretical practice and context. Headings must be short, clear and not numbered. References to publications must be in modified Harvard style and checked for completeness, accuracy and consistency. The practice implications of the research should be spelled out. Sufficient and appropriate recent literature should be cited. The article should have a clear focus that contributes to knowledge building or informs policy and/or practice. Submissions may be returned to authors that do not adhere to the guidelines. The submission has not been previously published, nor is it before another journal for consideration.

## STATEMENT

I Roslind Mary Mokwele hereby state that this research report: **The development and evaluation of a social work programme for community caregivers to facilitate HIV and AIDS patients' adherence to antiretroviral treatment** is a product of my own work.

**RM Mokwele**

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## SECTION A

### GENERAL INTRODUCTION

#### 1.1 INTRODUCTION

The care for and support of people living with HIV and AIDS require extensive community action. The high HIV and AIDS prevalence places the focus on communities that have limited access to health care and limited resources. Families and communities increasingly take more responsibility to care for people living with HIV and AIDS (Dorrington *et al.*, 2004:2; WHO, 2003:35).

Good examples of successful intervention focus on community based care. The objectives of community based care are to promote the exchange of experience of dealing with the disease and its treatment, to provide comprehensive medical information and to promote patients responsibility for their own care. Community-based organisations, education of patients the assessment of social needs and family support have been reported as effective social interventions for improving adherence. The document on the expanded public works programme of the Department of Social Development (2004), defines home community based care as the provision of comprehensive services including health and social services by formal and informal caregivers in the home. Home community based caregivers refer to paid and unpaid volunteers who provide services to clients with chronic illnesses, within the context of their families and communities (Department of Health, 2010).

The task-shifting to lay community caregivers is increasingly suggested as a potential strategy to overcome the barriers facing sustainable antiretroviral treatment scale-up in settings with high HIV prevalence and limited resources. Task-shifting also has its aim to overcome a shortage in human resources (Callaghan *et al.*, 2010:2; Wouters *et al.*, 2012:1). The WHO (2008:96) defines task-shifting as %the rational redistribution of tasks among health work forces teams. Specific tasks are moved from qualified health workers to health workers with shorter training and fewer qualifications to make more use of the fewer human resources for health.+According to Wouters *et al.* (2012:3) recent health systems research has increasingly explored the potential benefits of two other types of task-shifting, namely the shifting of tasks to lay community providers (type iii) and counsellors and people living with HIV and AIDS themselves (type iv). The authors mention that according to literature review little research had been performed on the contributory role of this form of community support.

Wouters *et al.* (2012:10) mention that research studies use alternative names for the same type of community provider. Community health workers can be defined as %non-professional cadres

of health workers who undertake short course training and work within their own communities to compliment and support the services provided by other health workers+. They are divided into the following categories: Community care coordinators (people living with HIV and AIDS who are trained to perform the task of community health workers); peer health workers (community health workers who are HIV-positive and whose role it is to conduct adherence counselling and provide health education and psychosocial support); field officers (trained lay workers who support drug delivery and monitor patients); health extension workers (recruits from the community and trained to manage operations of health posts, conduct home visits and outreach services to promote preventive health actions, refer cases to health centres and follow up on referrals); HIV and AIDS lay counsellors (manage HIV testing, providing pre-ART training and ART adherence support, search for ART eligible people and track default HIV and AIDS patients). Directly observed therapy (DOT) for ART employs a community member close to the patient to directly monitor the daily medication intake. Adherence supporters are trained to promote healthy behaviours, share HIV and AIDS and ART-related knowledge, teach skills and to promote adherence by providing psychosocial support. Home based care volunteers or caregivers are community members trained to provide ART adherence counselling and to perform a wide range of home based care activities.

According to Wouters *et al.* (2012:3), five inter-related challenges are increasingly cited in health policy literature regarding antiretroviral treatment. These challenges are lack of integration of ART services into the general health system; the growing need for comprehensive care to address the psychosocial and economic dynamics of HIV and AIDS; the need to empower patients on ART towards self-management; the importance of defaulter tracing to improve retention in care and the crippling shortage in human resources for health.

From the previous discussion it is evident that international and local research studies emphasise the importance of community based care in antiretroviral adherence of patients. This research aims to extend the empirical research on the contribution of community based resources (community based caregivers) to ART, specifically the adherence of the patient to antiretroviral treatment with the aim to empower them.

The purpose of this study is to explore the perceptions of community caregivers with regard to an empowerment programme that will assist them to facilitate ART adherence of HIV and AIDS patients. The ultimate goal is for the community caregiver to empower patients as a means to address adherence. Recent studies have indicated that people living with HIV and AIDS should be empowered towards self-management of their illness (Mahungu *et al.*, 2009:125-128; Wouters *et al.*, 2012:1-17). These studies found that in practice patient empowerment entails a wide range of educational and counselling activities that are aimed at increasing HIV and AIDS and ART literacy and chronic disease management.

Studies by Schneider and Lehmann (2010:60-67), Kober and Van Damme (2004:103-107) and Van Damme *et al.* (2008:2108-2121) have indicated that overburdened health staff often have difficulty in conveying the practical skills required for practicing a more patient-centred and less technical model of patient care aimed at empowering people living with HIV and AIDS for informed day-to-day decision making. Community health workers can help patients to develop the self-management skills that are needed to take well-informed decisions regarding their health and treatment. The study of Kabore *et al.* (2010:581-594) focuses on the role of community caregivers with regard to empowering patients towards self-management and includes home based care, nutritional advice, drug literacy, training, prevention education, management of ART side-effects and general treatment guidance.

WHO (2003:28) states that adherence is a multidimensional phenomenon determined by the interplay of five sets of factors, namely health systems, social/economic, therapy related, patient-related and condition related factors. Patient related factors represent the resources, knowledge, attitude, beliefs, perceptions and expectations of the patient. Patients' knowledge and beliefs about their illness, motivation to manage it, confidence (self-efficacy) in their ability to engage in illness-management behaviours and expectations regarding the outcome of treatment, and the consequences of poor adherence, influence adherence behaviour.

According to the WHO (2003:30) some of the psychosocial patient related factors reported to affect adherence are forgetfulness, psychosocial stress; anxieties about possible adverse effects; low motivation; inadequate knowledge and skills in managing the disease symptoms and treatment; lack of self-perceived need for treatment; lack of perceived effect of treatment; misunderstanding and non-acceptance of the disease; negative beliefs of the efficacy; disbelief in the diagnosis; lack of perception of the health risks related to the disease; misunderstanding of treatment instructions; lack of acceptance of monitoring; low treatment expectations; low attendance at follow-up, or counselling appointments; motivational, behavioural or psychotherapy classes; hopelessness and negative feelings; frustration with health care providers; fear of dependency; anxiety over the complexity of the drug regimen; drug and alcohol abuse; and feeling stigmatised by the disease.

Stigma is a common problem for people on ART. The term refers to the prejudice, negative attitude, abuse and ill-treatment that HIV-positive persons are subjected to because of their HIV status. HIV-positive people may be shunned by their family, friends and the wider community and they may experience poor treatment (Ketlapile *et al.*, 2010:320; Maughan-Brown, 2010:369; Ogden, 2006: 335). Stigma not only has consequences and impact negatively on the patient, but also on the community caregivers who experience stigma-related challenges in their working environment. HIV and AIDS is highly stigmatised and many patients ask their caregivers not to disclose their HIV-status, causing isolation for the carer and patient. Carers themselves

sometimes keep the status of those in their care a secret for fear of the stigma and discrimination they may suffer while caregivers in home-based-care are often assumed or suspected to be HIV-positive themselves.

Motivation which drives sustainable good adherence is one of the most difficult elements for the health care system to provide in the long term. Over the past decade these difficulties have led to increased interest in the role of community based educational and self-management programmes aimed at adherence. Motivation can be defined as a psychological force that moves a person toward some kind of action (Bastable, 2007:146). Factors that influence motivation can serve as incentives or obstacles to achieve desired behaviour. Motivation can be intrinsic or extrinsic. Intrinsic motivation has emerged as an important phenomenon for HIV antiretroviral adherence. Intrinsic motivation is defined as the doing of an activity for its inherent satisfaction rather for some consequence as for extrinsic motivation. Intrinsic motivation is focused on psychological needs, namely the need for competence, autonomy and relatedness. Interpersonal events and structures that conduce towards feelings of competence can enhance intrinsic motivation, because they enhance the psychological need for competence or self-efficacy. The primary reason why people engage in extrinsic motivation is because it is valued by significant others such as family or friends (Bastable, 2007:146). For the purpose of this research the focus will be on community caregivers' extrinsic and intrinsic motivational roles.

Leventhal and Cameron in WHO (2003:139), outline five general theoretical perspectives on adherence, namely the bio-medical, behavioural, communication, cognitive and self-regulatory perspective. For the purpose of realising the goals of this research, the focus was on theories that form a basis for a theoretical framework, and are based on adherence, social work principles and learning outcomes.

Central to the purpose of this research is the self-regulation perspective which attempts to integrate environmental variables and the cognitive responses of individuals to health threats into the self-regulatory model. The essence of the model pertains to the central importance of the conceptualisation of a patient with an illness. The ideas patients have about a disease they suffer from and having to cope with are seen as mediating between the illness and the action taken. Thus adherence requires an appropriate model and the belief that one can manage his own environment and behaviour. Also, adherence requires specific coping skills and a belief that the issue requires one's attention and the modification of one's behaviour (WHO, 2003:99). These are strongly related to empowering both patients and caregivers, and thus, correlates with the focus of the study.

The information-motivation-behavioural skills model (IMB model) constructs how health behaviour pertains to adherence which is in line with the study. According to the IMB

information is the basic knowledge about a medical condition that might include how the disease develops, its expected course and effective strategies for its management. Motivation encompasses personal attitudes towards adherence behaviour, perceived social support for such behaviour and the patient's subjective norm or perception of how others with this medical condition might behave. Behavioural skills include ensuring that the patient has the specific behavioural tools or strategies necessary to perform adherence behaviour such as enlisting social support and other self-regulation strategies (Amico *et al.*, 2009:2).

The self-efficacy theory is based on a person's expectations relative to a specific course of action. It deals with the belief that one is competent and capable of accomplishing a specific behaviour. Self-efficacy is cognitively appraised and processed through four principle sources of information. Performance accomplishments are evidenced in self-mastery of similar expected behaviours through observing successful behaviour through the modelling of others and verbal persuasion by others who present realistic beliefs that the individual is capable of the expected behaviour (Bastable, 2006:159). The systems theory focuses on the person-and-situation as an interrelated whole. A person is viewed as an integral part of his or her life situation. In the systems theory we strive to understand the interaction between a client and other social systems (Compton *et al.*, 2005:24).

The above theories are in line with the four independent factors operating on adherence behaviour. A deficit in any one contributes to a risk of non-adherence as mentioned by WHO (2003:99), namely knowledge and skills about the health problem and self-regulation behaviour required; their mechanism of action and the importance of adherence beliefs; perceived severity and susceptibility; self-efficacy; outcome expectations and response cost. Motivation, value, reinforcement and internal attribution of success are important factors, and action is stimulated by relevant cues, driven by information recall, evaluation and selection of behavioural options and available resources.

Previous research stressed that the major barriers to adherence were lack of information and skills as they pertain to self-management, difficulty with motivation and self-efficacy, and lack of support for behavioural changes. Patients need to be informed, motivated and skilled in the use of cognitive and behavioural self-regulation strategies to cope effectively with the illness. For the effective provision of care, it is necessary to activate the patient and the community who support him or her, which this study is based on.

The participation of community-organisations has been shown to be effective in promoting the maintenance and motivation required for the self-management of the disease, keeping the patient active in the knowledge of his or her disease, and in the acquisition of new habits. For the effective provision of care it is necessary that the patient, the family and community support

play an active role. Social support, informal or formal from other members of their community has been consistently reported as an important factor affecting health outcomes and behaviour.

## **1.2 PROBLEM STATEMENT**

An estimated 6.4 million people were living with HIV and AIDS in South Africa in 2012, the highest number of people in any country. An estimated 31.2% were exposed to ART. Antiretroviral treatment exposure among People Living With HIV and AIDS (PLWHIV) had increased from 16,6% in 2008 to 31,2% in 2012 (South Africa, 2012:56; WHO, 2013a).

The focus of this study was to explore the perceptions of home community caregivers with regard to antiretroviral adherence of HIV and AIDS patients and a social empowerment programme to facilitate HIV and AIDS patients' adherence to antiretroviral treatment.

The National Antiretroviral Treatment Programme in South Africa commenced in 2004 and today South Africa has one of the largest antiretroviral treatment programmes for people living with HIV and AIDS in the world. According to the revised National Department of Health's Guideline for Antiretroviral Treatment (Department of Health, 2013:4; WHO, 2013b), the primary goals of ART is to decrease HIV-related morbidity and mortality and to retain patients on life-long therapy.

Previous research by Kagee (2008:413) and Van Dyk (2012:1) highlighted the growing concern about ART adherence and the development of drug-resistant HIV and drug failure. Adherence is defined as the extent to which a person's behaviour-taking medication, following a diet and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider (WHO, 2003:3). One of the concerns of ART programmes is the ability of people living with HIV and AIDS to maintain near perfect adherence in the long term. In order to achieve the goal of ART, such as maintaining undetectable levels of the virus, patients are required to maintain more than 90-95% adherence (WHO, 2003:3).

Williams (1997:18) points out that adherence to medical and health medications is the dynamic process of human behaviour and how human beings interact with their environment. According to Ketlhapile *et al.* (2010:48), antiretroviral treatment is a lifelong commitment that requires patients to adhere diligently to daily medication dosing schedules and make frequent clinic visits for care. The adherence activity requires a combination effect to assist the patients and to detect any barriers related to adherence. Resistance accounts for a large portion of treatment failures. Inadequate adherence to treatment is associated with detectable viral loads, declining CD4 counts, disease progression episodes of opportunistic infections and poorer health outcomes (Van Dyk, 2012:1).

In an effort to alleviate the burden placed on professional workers, lay counsellors have been employed to assist with antiretroviral treatment (Schneider *et al.*, 2006:16; Schneider *et al.*, 2008:179; Schneider & Lehmann, 2010:60). The Social Welfare Action Plan (Department Of Social Development, 1998:121) states as goal that appropriate social welfare services to individuals and their families in communities who are affected by chronic illnesses should be provided. The objective to achieve this goal is to develop home based, family orientated and community care strategies in collaboration with other stakeholders.

It was observed by the researcher that adherence to ART has become a serious concern in practice. Many cases of ART non-adherence are referred from hospitals and clinics to social workers and home community based care organisations for follow-up. These cases are being referred to social workers and home community based care centres due to the experience of social problems and the high percentage of default cases needing monitoring and assistance with treatment and adherence. People are often referred to community providers with little knowledge on and skills to adherence (Wouters *at al.*, 2012:17). During the research it was observed that caregivers at home community based care centres lack knowledge and skills to facilitate the adherence of patients on ART. There is also no formal programme to assist caregivers in their work to enhance their skills to effectively implement adherence strategies for patients.

Due to the shortage of professional personnel, especially social workers and health care professionals, the assistance of lay councillors is needed to attend to patients on ART, especially with regard to adherence. The impact of HIV and AIDS on a psychosocial level as found by Wessels (2003) are mainly associated with psychological conditions such as depression, stigma, rejection, discrimination and social indicators such as poverty, financial burdens, high prevalence of orphans, substance abuse and the availability of support systems. Previous research studies had found that intervention strategies with regard to support services rendered to people living with HIV and AIDS should focus on psychosocial challenges (Roux, 2002; Shobede, 2011; Simpson, 2006; Wessels, 2003).

The researcher's involvement created an awareness of the increased caregiving responsibilities of community caregivers. Much support needs to be given to these community caregivers in their service delivery to people living with HIV and AIDS. The area of psychosocial support to patients on antiretroviral treatment was identified as a crucial support area and is the focus of the research. Consequently a need exists to explore the perceptions of community caregivers with regard to the adherence of patients on antiretroviral treatment and a social work empowerment programme to assist them in their working environment.

Kagee (2008:413) mentioned that research focusing on behaviours, norms and culture specific issues may provide insights into adherence to be able to develop behavioural interventions enhancing adherence to ART. Most of the studies conducted have focused solely on adherence to treatment and have provided limited information on effective and practical psychosocial approaches to improve adherence. Research on community caregivers role with regard to adherence is limited (Wouters *et al.*, 2012:17).

### **1.3 RESEARCH QUESTIONS**

From the above discussion, the overall research question was formulated as follows:

*How can community caregivers be empowered to facilitate the adherence of patients on antiretroviral treatment?*

From the above six main questions were addressed in this study:

- What are the factors that influence patients adherence to ART?
- What is the role of the community caregiver regarding ART adherence?
- What are the perceptions of community caregivers regarding ART adherence of patients?
- What are the perceptions of community caregivers with regard to a social work empowerment programme to enhance their skills to facilitate antiretroviral adherence of patients?
- What should the content be of a social work empowerment programme for caregivers regarding the adherence of patients on antiretroviral treatment?
- Can the presentation of a social work empowerment programme be effective in empowering community caregivers to facilitate patients adherence to antiretroviral treatment?

### **1.4 AIM AND OBJECTIVES OF THE STUDY**

#### **1.4.1 Aim of the research**

The aim of the research was to develop, implement and evaluate a social work empowerment programme for community caregivers to facilitate the adherence of patients on antiretroviral treatment.

#### **1.4.2 Objectives of the research**

- To do a literature study to explore the factors that influence patients adherence to ART.
- To do a literature study on the role of the community caregiver regarding ART adherence of patients.

- To explore the perceptions of community caregivers with regard to the underlying psychosocial factors affecting antiretroviral adherence of HIV and AIDS patients.
- To explore the perceptions of community caregivers with regard to a social work empowerment programme to enhance their skills to facilitate HIV and AIDS patients' adherence to antiretroviral treatment.
- To develop a social work empowerment programme for community caregivers.
- To implement and evaluate the effectiveness of the social work empowerment programme for community caregivers.

## **1.5 CENTRAL THEORETICAL STATEMENT**

The central theoretical statement for the intended study can be formulated as follows:

A social work empowerment programme for community caregivers will enhance their skills to facilitate adherence of patients on antiretroviral treatment.

## **1.6 CONCEPTUAL FRAMEWORK**

The conceptual framework for this study is based on the following theories:

### **1.6.1 Self-regulation**

Self-regulation perspectives attempt to integrate environmental variables and the cognitive responses of individuals to health threats into the self-regulatory model. Adherence requires an appropriate model and the belief that one can manage his own environment and behaviour. Also adherence requires specific coping skills and a belief that the issue requires one's attention and the modification of one's behaviour (Bastable, 2006:159; WHO, 2003:99). Empowering the community caregiver to empower the patient will lead to more self-regulatory behaviour from patients.

### **1.6.2 Systems theory**

According to the systems theory the focus is on the person and situation as an interrelated whole. A person is viewed as an integral part of his or her life situation. By using the systems theory, one's aim is to understand the interaction between a client and other social systems. For the purpose of this study, patients' adherence to ART should be seen as the interaction with individuals, families and their environment while the patient, community and the community caregiver are seen as the systems. The systems theory serves the purpose well by shifting attention from the person or the environment alone to problems in the systemic interaction within the person-in-situation (Compton *et al.*, 2005:24). Stigma within communities is regarded as one of the main obstacles for adherence of patients on ART. Adherence behaviour is a multi-

dimensional phenomenon influenced by the interaction of the health care system, social and economic factors, factors related to the condition, treatment factors and person related factors (WHO, 2003). However, this is not applied in practice. Individuals are perceived as a system composed of biological, psychological, cognitive and emotional dimensions. The person-in-environment perspective recognises the interdependence of these various systems. A person's needs capacities and aspirations on the one hand and environmental resources and expectations on the other are at the core in assessing individual and collective life situations (Poulin *et al.*, 2005:27). This study focus on community based care: how people living with HIV and AIDS can be empowered by resources and systems in their community.

### **1.6.3 The information-motivation-behavioural skills model (IBM model)**

The information-motivation-behavioural skills model (IMB model) constructs how health behaviour pertains to adherence. According to the IBM information on the basic knowledge about a medical condition that might include how the disease develops, its expected course and effective strategies for its management is part of the IBM model. Motivation encompasses personal attitudes towards the adherence behaviour, perceived social support for such behaviour and the patient's subjective norm or perception of how others with this medical condition might behave. Behavioural skills include ensuring that the patient has the specific behavioural tools or strategies necessary to perform the adherence behaviour such as enlisting social support and other self-regulation strategies (Amico *et al.*, 2009:2; Fisher *et al.*, 2006:436; Kalichman *et al.*, 2008). Based on this, motivation and information can be facilitated by community caregivers within their communities.

### **1.6.4 Self-efficacy theory**

The self-efficacy theory is based on a person's expectations relative to a specific course of action. It deals with the belief that one is competent and capable of accomplishing a specific behaviour. Self-efficacy is cognitively appraised and processed through four principle sources of information. Performance accomplishments are evidenced in self-mastery of similar expected behaviours, the observation of successful behaviour as modelled by others and verbal persuasion by others who present realistic beliefs that the individual is capable of the expected behaviour (Bastable, 2006:159; Heyer & Ogunbanjo, 2006:7).

## **1.7 RESEARCH METHODOLOGY**

The research followed a mixed method approach by implementing both qualitative and quantitative methods. Creswell and Plano Clark (2014:228) and Delport and Fouché (2011:434) define mixed method research as follows: Mixed method research is a research design with philosophical assumptions as well as methods of inquiry that guide the collection and analysis

of data and the mixture of quantitative and qualitative approaches to enhance the strength of a study, gain triangulation of data and to utilize a variety of research procedures supplementary to each other in order to gain better results+.

The focus was on multiphase mixed methods (Creswell & Plano Clark, 2014:228). Creswell (2014:228) notes that researchers conduct several mixed methods projects by using the multiphase methods design, sometimes including mixed methods convergent or sequential approaches, sometimes including only quantitative or qualitative studies in a longitudinal study with a focus on a common objective for the multiple projects. This form of research is specifically appropriate for the evaluation or programme implementation fields in which multiple phases of the project stretch over time.

The intervention research model was used and consists of six phases namely, problem analysis and project planning; information gathering and synthesis; design, early development and pilot testing; evaluation and advance development; and dissemination (De Vos & Strydom, 2011:476). The investigation focused on four phases, phase one focused on a literature review, phase two focused on the need assessment and planning, phase three focused on the development of the empowerment programme and phase four focused on the implementation and evaluation of the empowerment programme as well as dissemination.

### ***1.7.1 Phase 1: Problem analysis and planning***

- **Literature review**

Fouché and Delport (2011:135) are of the view that a literature review assists the researcher with knowledge of the topic, knowledge of recent theories, as well as definitions and key concepts regarding the field of study. After identifying a problem situation from practice experience, a broad study of literature relating to ART and the psychosocial aspects of ART was done. It was found that much research had been done from a health perspective. However, many authors recommended that research be undertaken regarding the psychosocial aspects of ART. The need for research on the community based caregivers' role in ART, specifically the adherence of patients, was also emphasised. Intervention research with the focus on programme development was minimal. The search for relevant information was conducted at the Ferdinand Postma library, North-West University, Potchefstroom Campus, using local as well as international databases and was structured to include journals, books and electronic journals. An information search through the Internet was done through EBSCO Host and Google Scholar.

Article 1 focused on a literature study based on the underlying factors that influence adherence of patients to ART. The aim of the literature study in article 1 was to explore factors that

influence adherence to antiretroviral treatment of patients in order to develop ART intervention programmes. This review followed a systems approach. A social-ecological framework (Compton *et al.*, 2005:24) was used for the exploration of barriers and facilitators to sustained treatment adherence of persons on ART.

In article 2 a literature study was done on the role of the community caregiver regarding ART of patients, exploring the value of social support from the community caregiver regarding adherence of patients. The systems theory was applied with a focus on, the patient on ART, and the community caregiver. The literature review focused on (1) the role of the community caregiver in ART programmes; (2) empowerment programmes for community caregivers; and (3) made recommendations with regard to the role of the community caregiver in ART in context of the information, motivation and behavioural skills model.

This literature review assisted with the development of the qualitative interview schedule for the focus group discussions as well as the development of the social work empowerment programme.

## **7.2. Phase 2: Information gathering and synthesis**

- **Research paradigm**

Article 3 focused on empirical research. A qualitative approach was used to explore community caregivers' perceptions of patients' ART and a social work empowerment programme to facilitate adherence of patients on ART. Botma *et al.* (2010:190) and Niewenhuis (2009:50) concur that the fundamental purpose of qualitative research is to collect rich descriptive data on a particular phenomenon with the intention to gain an understanding of what is being observed or studied. It therefore focuses on how individuals and groups view and understand the world and construct meaning out of their experiences.

- **Research design**

Niewenhuis (2009:70) refers to research design as a plan or strategy comprising the underlying philosophical assumptions, specification of the selection of respondents, data gathering techniques to be used and the data analysis to be done. The research adopted a phenomenological design. Phenomenology focuses on people's subjected experiences and interpretation of the world. Fouché and Schurink (2011:316) claim, the purpose of a phenomenological approach is to understand the issue or topic from the everyday knowledge and perceptions of specific respondents or subgroups.

- **Participants**

The sampling technique used for this research was purposive sampling. The sample size was determined by saturation. Greeff (2011:367) defines saturation as the process when data become repetitive or no new ideas comes to the front. The exact amount of focus groups to be used when using this methodology could not be planned in advance. It evolved during the research process.

The sample determined inclusion criteria for the participants. The criteria included the following:

- Male and female home community based caregivers;
- Active involvement in service delivery to patients on ART;
- Serving home community based care programmes in Potchefstroom (Bambanani Youth Project, Baptist Children's centre and Hospice Emmanuel Loving Angels);
- At least one year experience working with HIV and AIDS patients on ART; and
- Ability to communicate in Tswana, Afrikaans or English.

Exclusion criteria were:

- Community caregivers who worked for less than one year at any of the organisations; and
- Inability to communicate in Tswana, Afrikaans or English.

Sixteen community caregivers participated in four focus group discussions. The groups consisted of 4 community caregivers each.

- **Data collection**

Data obtained from qualitative research methods aimed to explore the ways in which people construct social reality and the inherent meanings attached to these realities (Botma *et al.*, 2010:190; Niewenhuis, 2009:50). For the purpose of this study, data was collected using focus groups. Bryman (2008: 475) and Greeff (2011:348) describe focus groups as group interviews and a means of better understanding how people feel or think about an issue, product or service. Focus groups are especially useful when the knowledge about the research question is inadequate and elaboration is required. Participants are selected, because they have certain characteristics in common that relate to the topic of the focus group. According to Smith (2009:118), focus groups offer significant advantages in terms of empowerment and representing shared ideas and norms more effectively. These groups explored community caregivers' perceptions of patients' adherence to antiretroviral treatment and a social empowerment programme to facilitate patients' adherence to antiretroviral treatment. Four focus groups, consisting of four caregivers each were formed. Altogether sixteen caregivers took part

in the focus groups. The focus group questions were developed from the literature review. Each focus group followed an interview guide with open ended questions (Annexure F). This lasted for more or less 1.5 hours. Recordings were done by means of a tape recorder for which permission was granted by all participants. The researcher trained two assistants to help with the transcribing process. They were trained in confidentiality and had to sign a confidentiality contract. The focus group sessions were transcribed, data was analysed and notes were made during and at the end of the sessions.

By means of journal descriptions and narrative storytelling, participants described their experiences regarding adherence of patients. According to Alaszewski (2006) the aim of journals in social research is for participants to narrate their thoughts about a certain phenomenon, giving them the opportunity to return to the written text and supplement it with additional thoughts or information. The instructions for journal views were pre-printed in the journals and were collected after a month. Twelve participants reflected and narrated their experiences in the journals.

- **Research procedure**

Permission to conduct the research was obtained from the managers of the home community based care (HCBC) centres (Annexures A, B & C). They also assisted with the selection of the participants for the study. A meeting was scheduled at the three facilities for an introductory session. The sessions took place in the hall of each of the organisations. The halls were private and comfortable for the participants. During these meetings, participants were orientated on the nature of the research and processes and their willingness to take part in the study was discussed. Each participant received a document containing relevant information on the purpose and procedures of the study. Willing participants were asked to give written consent to participate in the research (Annexure E). Questions and doubts were answered before they signed the consent form. The process was facilitated by the principle researcher and two assistants who were previously caregivers within the community based care centres. Appointments for focus groups were scheduled with the participants. Journals were distributed to the participants at the initial meeting to capture their experiences regarding patients and antiretroviral treatment. The journals were collected after a month.

- **Data Analysis**

Qualitative data analysis involves making sense of text and image data. It involves preparing data for analysis, conducting different analyses, understanding the data, representing the data and making an interpretation of the larger meaning of the data. Creswell's data analysis spiral process indicates that, instead of a linear approach, the process moves in analytic circles

Creswell (2009:183.) The data analysis comprised of planning for recording the data, data collection and preliminary analysis, managing the data, reading and writing memos, generating categories and coding the data, testing emergent understandings and searching for alternative explanations, interpretation and developing typologies (Creswell, 2013:182).

Methods of presenting the data and collection and recording of data were prepared before going into the field. Collection and recording of data was carried out through focus group sessions. The narratives in journals were already in textual format suitable for analysis. The data consisted of field notes and tape recordings. Data was described and classified, and interpreted and categorised for identification of similarities, and organised according to different themes. Additional extracts resulting from the narratives in the journals were checked against the themes that emerged from the focus group discussions to identify new themes. Patterns of meaning held by participants were identified and these were reduced to sub-themes. The data in the findings were presented by means of narratives, themes, sub-themes and quotes from the focus groups and the journals, supported by the literature.

- **Ethical aspects**

Strydom (2011:114) defines ethics as %a set of moral principles that are suggested by an individual or group, are subsequently widely accepted, and offer rules and behavioural expectations about the most correct conduct towards experimental subjects and respondents, employers, sponsors, other researchers, assistants and students+. Ethical clearance for this study was granted by the ethics committee of the North-West University with the number NWU-00130-14-S1 (Annexure D). The following ethical principles were followed:

- **Potential harm to participants**

It is the researcher's ethical obligation to protect respondents against any form of physical discomfort that may emerge from the research project (Strydom, 2011:115). Since the topic was focused on HIV and AIDS matters, a cautious approach had to be followed to protect participants against emotional harm. The researcher informed the participants beforehand about the potential impact of the investigation. They were also offered counselling sessions if needed.

- **Informed consent and voluntary participation**

According to Moule and Hek (2011:37) obtaining informed consent implies that all possible or adequate information on the goal of the investigation, the procedures that will be followed during the investigation, possible advantages, disadvantages and danger to which respondents may be exposed to as well as the credibility of the researcher, was discussed with the potential participants. Before the onset of data collection, aspects pertaining to anonymity, confidentiality

and privacy were discussed with the participants. This information was included in the consent form in order to allow for participants to make a voluntary and thoroughly reasoned decision about their participation. They were also made aware of the fact that they could withdraw without reason from the investigation at any time before data analysis and they were assured that they would not be discriminated against or penalised in any way. The transcribers involved signed a confidentiality contract.

#### ➤ **Confidentiality**

Alston and Bowles (2007:21) view the right to privacy as taking into account the respondent's personal privacy and identity while handling information in a responsible manner. The researcher ensured the anonymity of participants. However, only partial anonymity could be ensured during the focus group sessions. Information was coded for reasons of anonymity. All information of the participants regarding the focus groups were kept safe by the researcher. All focus group sessions took place in a private hall at the different centres.

#### • **The trustworthiness of qualitative data**

Trustworthiness is a term used within qualitative research in order to describe the strength of the claims to knowledge the researcher is making. Trustworthiness can be established through the marshalling of evidence (Hammond & Wellington, 2013:147). The methods of trustworthiness proposed by Lincoln and Guba (in Babbie & Mouton, 1998:276) were utilised during this research. The aspects of credibility, transferability, dependability and confirmability were taken into account. The following methods were used to increase trustworthiness of the study:

#### ➤ **Credibility**

The researcher ensured credibility of the study through the following measures: Triangulation was achieved through the use of different methods, namely journals and focus groups. According to Smith (2009:65) triangulation will achieve greater confidence in research findings and greater depth of analysis. A pilot study was executed to test the focus group interview schedule. Focus group sessions were tape recorded and detailed notes were made of the sessions by two transcribers. Transcriptions of the focus group sessions were done after each focus group session. The biases, views, beliefs and opinions of the researcher were bracketed by maintaining an open mind approach.

#### ➤ **Transferability**

Transferability refers to the degree to which the findings of one's inquiry can apply beyond the boundaries of the project (Schurink *et al.*, 2011:397). This was done by establishing the degree

of similarity in the respondents' views with other literature on the same subject. The researcher described the research process in the final report with sufficient detail and precision in order to enable other researchers to judge whether the results are transferable to other contexts.

➤ **Dependability**

Dependability addresses the consistency or congruency of the results (Babbie & Mouton, 1998:278). Dependability considers the process of data collection, data analysis and theory generation, and is often evidenced by an audit trail of the data collection procedures. Theoretically at least, another researcher could follow the steps taken in the original study. The researcher described the data collection procedure in detail in the final report.

➤ **Confirmability**

Confirmability is generally taken as a measure of how well the findings are supported by the data. The researcher did an audit trail of the audio recordings, focus group schedule, field notes as well as themes that were developed. The auditing trail allows for understanding what was discovered and how it was discovered (Schurink *et al.*, 2011:422).

### **1.7.2 Phase 3: Programme development.**

Phase 3 of the research focused on the development of the social empowerment programme and focused on design, early development and pilot testing as set out in the intervention research model (De Vos & Strydom, 2011:476).

• **Design**

Phase 1 of the research focused on a literature study which revealed information based on the overall challenges with regard to ART. Phase 2 focused on a phenomenological study to explore community caregivers' experiences and challenges with regard to patients' adherence to ART and needs regarding an empowerment programme. This information was used to develop the social work empowerment programme.

• **Participants**

Six community caregivers and eight social workers of the Department of Social Development were purposely selected to participate in the pilot testing of the programme.

The inclusion criteria for the purposive sample included the following.

- Male and female home community based caregivers;
- Active involvement in service delivery to patients on ART;

- Serving home community based care programmes in Potchefstroom (Bambanani Youth Project, Baptist Children's centre and Hospice Emmanuel Loving Angels);
- At least three months experience working with HIV and AIDS patients on ART; and
- Ability to communicate in English, Afrikaans or Tswana.
- Social workers must have working experience as a coordinator of the HIV and AIDS programme for at least one year; and
- Both male and female.

- **Data collection**

A draft of the suggested empowerment programme was given to respondents. During phase 1, six community caregivers participated in a focus group session for the pilot testing of the social work empowerment programme to determine the effectiveness in terms of the practicality of the programme and the adaptability to various contexts of the intervention and to identify which elements of the prototype may need to be revised. The second phase of the pilot testing focused on a peer review with eight social workers involved in the HIV and AIDS programme from the Department of Social Development, North West Province, to give inputs in the preliminary empowerment programme. Semi-structured interviews according to a schedule were used (Annexure J). They were asked to rate the content relevance and make suggestions for the improvement of the social work empowerment programme. The questions for the semi-structured interviews were developed after the literature review of phase 1 and the focus group sessions of phase 2 of the research. The experiences of and feedback of social workers on the suggested empowerment programme were followed up by the researcher during telephonic semi-structured interviews.

- **Procedures**

- Permission was obtained from the Department of Social Development North West to include the eight social workers (HIV and AIDS coordinators in the research) (Annexure H).
- Permission was also obtained from home community based care centres to use the community caregivers for the pilot testing of the social empowerment programme.
- Participants were orientated on the nature of the pilot study and peer reviewed by the main investigator.
- The caregivers and social workers signed a consent form to participate voluntarily in the research (Annexure G & I).

- **Data Analysis**

Creswell's data analysis process was used to identify themes and to conduct further planning. The data was analysed manually. The participants were allowed to give their views from their own experiences in practice. Their views and opinions of the methods and content of the preliminary empowerment programme were taken into account in order to make adaptations to the programme.

- **The trustworthiness of qualitative data**

The methods of trustworthiness proposed by Lincoln and Guba (in Babbie & Mouton, 1998:276) were utilised, namely credibility, transferability, dependability and confirmability to measure the trustworthiness of the data.

- **Ethical aspects**

The ethical aspects that were taken into consideration for phase three of the study, included: Potential harm to participants (Strydom, 2011:115); justice (Botma *et al.* 2010:19); confidentiality (Alston and Bowles, 2007:21); and benefits (Botma *et al.*, 2010:21).

### **1.7.3 Phase 4: Programme implementation, evaluation and dissemination**

Phase 4 (Article 5) focused on the implementation, evaluation and dissemination of the social work empowerment programme.

- **Design**

The study focused on experimental research (Fouché *et al.*, 2011:145) in the context of mix method research and the quasi experimental design was chosen (Botma *et al.*, 2010:114; Cook & Wong, 2009). Quasi-experimental designs assist the researcher to test for casual factors where it is difficult to implement a true experiment. According to Fouché *et al.* (2011:148), a quasi-experimental design has some, but not all of the requirements of an ideal experiment. The comparison group pre-test-post-test design was chosen in order to determine how the programme will affect the experimental group by comparison of pre- and post-test results.

For the purpose of this research, an experimental and comparison group were formed comprising of twelve caregivers each. The caregivers in the experimental group received the empowerment programme while the comparison group did not participate in the programme. The comparison group received both the pre-test, post-test and post-post-test, at the same time as the experimental group, but did not receive the treatment (Rubin & Babbie, 2011: 271-278).

- **Participants**

The type of sampling chosen for this research was simple random sampling. According to Babbie (2010:189), each individual case in the population has an equal chance of being selected for the sample during simple random sampling. For the purpose of this study, 24 community caregivers were purposively selected for the experimental and comparison groups. Both groups consisted of twelve community caregivers working with patients on ART.

The criteria included the following:

- Male and female home community based caregivers with at least more than three months experience working with HIV and AIDS patients on ART;
- Active involvement in service delivery to patients on ART;
- Serving home community based care programmes in Potchefstroom (Bambanani Youth Project, Baptist Children's Centre and Hospice Emmanuel Loving Angels);
- Ability to communicate in English, Afrikaans or Tswana.

Exclusion criteria were:

- Community caregivers who worked for less than three months at any of the organisations; and
- Inability to communicate in Tswana, Afrikaans or English.

In quasi-experiments, assignment to treatment or comparison group status may be determined by self-selection or administrator decision. Selection to the groups was based on age, sex and years of experience, therefore, no absolute assurance could be given that the two groups would exactly be the same, however, all possible measures were done to select the two groups as similar as possible regarding age, sex, years of experience in care giving, etc (Rubin & Babbie, 2011:271-278).

- **Data collection**

For the purpose of this study, quantitative and qualitative research was used. Barker (2003: 354) defines quantitative research as follows: "Systematic investigations that include descriptive or inferential statistical analysis." Examples are experiments, survey research and investigations that make use of numerical comparisons. According to Delpont and Roestenburg (2011:181) the selection of data collection methods for a quantitative approach can include questionnaires, indexes and scales. The Personal Multi-Screening Inventory (PMSI) of the Perspective Training College (Annexure L) was used in the research to measure the personal functioning of the community caregivers before and after the presentation of the programme, based on the following areas: positive psychosocial functioning; negative psychosocial functioning; emotional

functioning; self-perception; interpersonal functioning; spiritual functioning; and physical functioning. This is a standardised questionnaire, which is valid and reliable as proposed by Botma *et al.* (2010:174).

A self-developed questionnaire (Annexure M) based on knowledge, skills and motivation was developed by the researcher, to measure the three dimensions of the caregivers (both experimental and comparison group). This is based on the information, motivation and behaviour skills model (IBM) for community caregivers to acquire the information, skills and motivation to attend to patients on antiretroviral treatment. After a baseline measurement, an intervention programme was conducted with only the experimental group, followed by a post-test with both experimental and comparison groups. A final post-post-test was conducted with both experimental and comparison groups one month after the intervention (empowerment programme). All sessions incorporated elements of information, motivation and behavioural skills.

A self-structured schedule with open and close ended questions was used as the qualitative measure in this study to evaluate the success of the social work empowerment programme (Annexure N &O).

- **Procedures**

Permission to conduct the research was obtained from the managers of the home community based care (HCBC) centres. They also assisted with the selection of the participants for the study. Participants gave written consent for participation (Annexure K). Before the first group session, the experimental and comparison group members completed the measuring scale of the perspective training college. The same measurement was repeated on both groups after the presentation of the empowerment sessions and a post-post test was done one month after completion of the empowerment sessions. The social work empowerment programme was implemented and evaluated by the group members in the experimental group by means of a self-administered schedule as an additional measure. The information of this study was prepared to be disseminated through publishing articles in accredited journals such as the Social Work.

- **Data analysis**

Fouché and Bartley (2011:249) mention that quantitative data analysis can be regarded as the technique by which researchers convert data to a numerical form and subject it to statistical analysis. Data from the Personal Multi-Screening Inventory (PMSI) scale was processed by a computer programme of the Perspective Training College. The self-developed questionnaire (Annexure M) based on knowledge, skills and motivation that was developed to measure the

three dimensions of the caregivers (both experimental and comparison group) was processed by the researcher. The schedule with open and close ended questions was also used to evaluate the success of the social work empowerment programme. The qualitative data from the self-administered schedule was analysed manually by means of the constant comparative method (Poggenpoel, 1998:338-339).

- **Reliability and validity of quantitative data**

### **Reliability**

Reliability refers to the consistency of the measure achieved. The researcher must be in a position to provide proof of the reliability of the instrument. Reliability was achieved by ensuring consistency in data collection through the data collection tools, (questionnaires). Content-related reliability was achieved through the use of self-developed questionnaires to collect detailed information from participants, (Botma *et al.*, 2010:177).

### **Validity**

Validity indicates whether the conclusion of the study are justified, based on the design and interpretation. Criterion validity was implemented, whereby the scores obtained in one measurement could be accurately compared with those obtained with a more direct or already validated measure of the same phenomenon. Content validity was achieved by ensuring that the data collection instruments measured what it is supposed to measure (Botma *et al.*, 2010: 174).

- **The trustworthiness of qualitative data**

The methods of trustworthiness proposed by Lincoln and Guba (in Babbie & Mouton, 1998:276) as discussed in Article 3 were utilised, namely credibility, transferability, dependability and confirmability.

- **Ethical aspects**

- The researcher ensured that the environment where sessions were conducted was relaxed. Participants were granted breaks if they required so.
- Participants were informed that they would be referred for appropriate counselling should they experience emotional discomfort as sensitive issues would be discussed.
- The researcher acknowledged the rights of participants and ensured their anonymity, adhere to their right to self-determination and treat all information in a responsible, confidential and respectful manner. All information regarding the empowerment sessions were kept private (Alston & Bowles, 2007:21).

- The researcher acted professional, tactful, honest and neutral at all times. The researcher respected the views and opinions of the participants and restrained herself from making value judgments.
- The researcher compiled the report as accurately and objectively as possible containing all essential information.
- The researcher undertake to release findings in such a manner that unitisation by others is encouraged, since that would be the ultimate goal of the research project.
- Information regarding the study will be made available to the participants in their own language through feedback information sessions after the completion of the study.

## 1.8 DEFINITIONS

- **Antiretroviral adherence**

Adherence is defined as the extent to which a person's behaviour-taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider (WHO, 2003:3). One of the concerns of the ART programme is the ability of people living with HIV and AIDS to maintain near perfect adherence in the long term. In order to achieve the goal of ART, i.e. undetectable levels of the virus in the blood, patients are required to maintain more than 90-95% adherence (WHO, 2003: 3).

- **Antiretroviral treatment**

Antiretroviral treatment target HIV at a multitude of points in the replication cycle, including reverse transcription of viral RNA, the assembly of new viral particles and the binding of HIV to cell membranes. Advances in ARV therapy have brought more simplified dosing schedules, multi-drug pills that combine two or three medications in a pill, and lower toxicities (Uldall *et al.*, 2004:74).

- **Home Community Based Care**

The document on the expanded public works programme of the Department of Social Development (2004), defines Home Community Based Care as the provision of comprehensive services including health and social services by formal and informal caregivers in the home.

Home Community Based Care encourages participation by people, responds to needs of people, encourages traditional community life and strengthens mutual aid opportunities and social responsibility in order to promote, restore and maintain a person's maximum level of comfort, function and health including care towards a dignified death.

- **Home Community Based Caregiver**

This term refers to paid and unpaid volunteers who provide services to clients with chronic illnesses, within the context of their families and communities (Department of Health, 2010). In this study community caregivers refer to the people working on a voluntarily basis with patients infected with HIV and AIDS. They act as support between the community and various health and social development services. Their role is to support and empower the community to make informed choices regarding their health and psychosocial well-being.

- **Empowerment**

Empowerment is defined as the process of helping individuals, families, groups and communities to increase their personal, interpersonal and socio-economic and political strengths and to develop influence toward improving their circumstances+(Zastrow, 2010:52).

According to Du Bois and Miley (2005:25), empowerment is a process of increasing personal, interpersonal, or political power so that individuals, families, and communities can take action to improve their situations+. Empowerment, according to Du Bois and Miley (2005:54) also means, releasing the potential and strength of social systems and discovering and creating resources and opportunities for promoting effective social functioning in client resolution of problems, issues and needs.

Hepworth *et al.* (2002:438) define empowerment as enabling groups or communities to gain or regain the capacity to interact with the environment in ways that enhance resources to meet their needs, contribute to their well-being potential and life satisfaction and provide control over their lives. This definition of empowerment supports the overall goal of the study, namely to empower community caregivers to render social intervention services to people living with HIV and AIDS on antiretroviral treatment to enhance adherence.

## **1.9 DURATION OF THE STUDY**

The study was initiated in 2014 with the research proposal. After approval from the ethics committee, the study commenced in 2015 with phase 1, which included a literature review.

During 2015, the qualitative research was implemented to explore the perceptions of community caregivers regarding ART. Focus group discussions were facilitated with sixteen community caregivers. The social work empowerment programme was developed and pilot tested with identified social workers who participated in a peer review.

During November to December 2015 the programme was presented and evaluated by means of the Personal Multi-screening Inventory of the Perspective Training College. During 2016, the

results were analysed by means of the computerised programme of the Perspective Training College and the questionnaire on knowledge, skills and attitude (motivation) as well as the qualitative schedule was analysed manually. Thereafter the final report was compiled.

### **1.10 LIMITATIONS OF THE STUDY**

The following limitations were identified:

- Qualitative research is context-specific and the findings of this study cannot be generalised to other settings.
- The study was limited to only three home community based care organisations. This means that the results of this study may not be applicable to other settings and different factors may be identified that influence adherence of patients, as well as needs for empowerment programmes.
- Some new data may arise when the same research is conducted in other home community based care facilities, however, similar studies need to be undertaken regarding community caregivers and ART adherence of patients.
- Only a selected number of participants were used.
- The quantitative measuring instrument might have been a challenge for the participants, due to the length of the questionnaire.
- The programme was implemented over a period of eight weeks. The conclusion can be drawn that the programme should be implemented over a longer time span with shorter sessions and time must be given to community caregivers to practice and internalise what they have learned.
- Selection to the groups was based on age, sex and years of experience. However, some other important criteria, e.g. marital status were overlooked, which formed a important part of the quantitative measuring instrument.

### **1.11 STRUCTURE OF THE RESEARCH REPORT**

#### **Section A: Introduction**

This section gives a brief overview of the research study that will be presented in article format. This section includes the introduction, problem formulation, aim and objectives of the study, central theoretical argument, as well as the research methodology and the limitations of the study.

**Section B will focus on the following:**

**Article 1: Factors that influence adherence to antiretroviral treatment of patients: a literature review**

This article explores factors that influence adherence to antiretroviral treatment (ART) of patients in order to develop ART intervention programmes. An overview was provided on the factors which influence patients' adherence to ART.

**Article 2: Antiretroviral roll-out and adherence: the role of the community caregiver**

This literature review explores the value of social support from the community caregiver regarding adherence of patients and focuses on the role of the community caregiver in ART programmes; empowerment programmes for community caregivers; and made recommendations with regard to the role of the community caregiver in ART in context of the information, motivation and behavioural skills model.

**Article 3: The perceptions of community caregivers with regard to antiretroviral treatment adherence of patients: a phenomenological study**

This study focuses on the perceptions of community caregivers with regard to patients' adherence to ART and a social work empowerment programme to enhance their skills to facilitate adherence of HIV and AIDS patients on ART.

**Article 4: Development of an empowerment programme for community caregivers to facilitate patients' adherence to antiretroviral treatment**

This study focuses on designing the social work empowerment programme for community caregivers to facilitate patients' adherence to ART. The programme that consists of a detailed workbook is included with article 4.

**Article 5: Evaluation of an empowerment programme for community caregivers to facilitate patient's adherence to antiretroviral treatment**

The results obtained from the Personal Multi-Screening Inventory (PMSI), the self-developed questionnaire on knowledge, skills and attitude (motivation), as well as the qualitative schedule to evaluate the programme are discussed in this article.

**Section C: Summary, Conclusions and Recommendations**

Section C presents the summary, conclusions and recommendations of this research.

**Section D: Consolidated references**

A consolidated list of references is listed in this section.

**Section E consists of the annexures.**

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## SECTION B

### ARTICLE 1

#### FACTORS THAT INFLUENCE ADHERENCE TO ANTIRETROVIRAL TREATMENT OF PATIENTS: A LITERATURE REVIEW

Mokwele, R.M and Strydom, H

Mokwele, R.M. is a PhD student and Social Worker at the Department of Social Development (North-West Province) and Strydom, H is a Professor in Social Work at the North-West University (Potchefstroom Campus) and a researcher in COMPRES (Community Psychosocial Research Unit).

#### **Abstract**

At the end of 2012 there were about 35.3 million people infected with HIV worldwide (UNAIDS Global Report, 2013:4). By the end of 2014, the number of people living with HIV increased to 36.9 million (UNAIDS, 2015:1). The presence of HIV infections is currently concentrated in the developing world and 25.8 million people living with HIV are living in Sub-Saharan Africa. The number of people dying from AIDS-related causes in Sub-Saharan Africa is estimated at 790 000 in 2014 (UNAIDS, 2015:1). HIV and AIDS is the cause of millions of deaths and there is no available cure. Successfully treating HIV and AIDS requires a high level of adherence to prescribed medication. The WHO (2003) has identified adherence as the most important issue for the scale-up of antiretroviral treatment (ART) programmes. ART has many benefits but also poses many challenges with regard to adherence of patients (Mills *et al.*, 2006:2040; Van Dyk, 2012:90). Many challenges had been identified by previous research studies regarding ART adherence of patients. This article focuses on the challenges of patients regarding ART adherence based on a literature review. A social-ecological perspective was used to review the factors that influence adherence to antiretroviral treatment.

#### **2.1 INTRODUCTION**

Globally there has been a rapid increase in access to ART in the last few years and 15.8 million people in low and middle-income countries had access to HIV treatment at the end of 2014 (UNAIDS, 2015:1). The introduction of antiretrovirals (ARVs) changed the progression of HIV to AIDS by increasing life expectancy and reduced HIV and AIDS related morbidity and mortality. Antiretroviral treatment (ART) has been shown to successfully decrease viral loads and increase CD4 cell count. Although ART has many benefits as highlighted by previous research

studies, it also poses many challenges. Lack of adherence to ART is one of the main causes for failure of treatment worldwide.

## **2.2 PROBLEM STATEMENT**

A meta-analysis by Mills *et al.* (2006) of adherence rates in Sub-Saharan African Countries found that an estimate of 77% of patients in Sub-Saharan Africa achieved adequate adherence. However, the challenge to achieve high adherence to ART in Sub-Saharan Africa remains high, due to the high number of people infected by HIV and AIDS. A lack of ART adherence can lead to, disease progression, development of drug resistance and it will ultimately lead to treatment failure (Hanif *et al.*, 2013:2; Mills *et al.*, 2006:2040; Van Dyk, 2012:90).

During the last decade, access to HIV and AIDS care in Sub-Saharan Africa has been improved by the reduction of the cost of ART and by the implementation of WHO guidelines promoting scaling up by task-shifting to less specialised health care workers. However, the challenge to achieve high adherence to ART in Sub-Saharan Africa remains high, due to the high number of people infected by HIV and AIDS. Sub-Saharan Africa also experiences other challenges such as patients lost to follow-up, maintaining high adherence rates and to reduce HIV and AIDS related morbidity and mortality. Limited research has been carried out to explore the factors that influence adherence to antiretroviral treatment. This literature review explores the factors that influence adherence to ART to be able to develop intervention programmes to increase adherence of patients.

## **2.3 AIM**

This literature review aims to explore factors that influence adherence to antiretroviral treatment of patients.

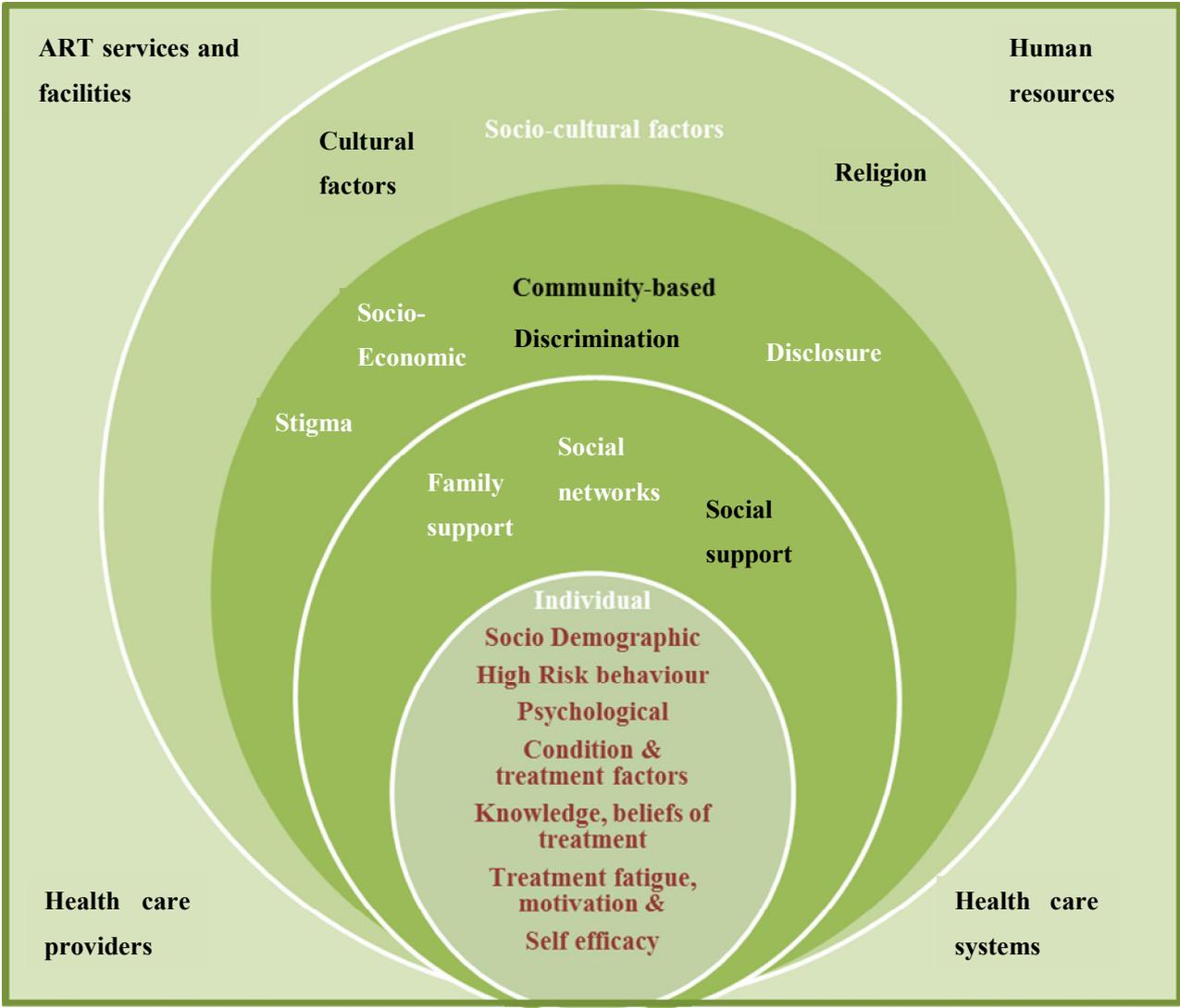
## **2.4 THEORETICAL FRAMEWORK**

Adherence is viewed as a multidimensional phenomenon determined by the interplay of five sets of factors or dimensions, namely, social and economic factors; therapy related factors; condition related factors; person related factors and health care team and system related factors. Some efforts have been made to examine ART adherence in relation to social contexts, such as using the socio-ecological theories of social capital and considering contextual and individual factors. The WHO (2003:27) argues for a systems approach to studying adherence as it encourages a holistic view and involves a conscious effort to understand how the various factors impact upon adherence behaviour. A social-ecological framework (Compton *et al.*, 2005:24) will be used for the exploration of barriers and facilitators to sustained treatment adherence of persons on ART. According to Roura *et al.* (2009:2), social-ecological theories

situate individuals in a dynamic social ecology in which individuals adapt their behaviour to their social environment. In their environment, individuals take decisions based on information, influence and interactions available through local social networks, relationships, and institutions.

**2.5 FACTORS INFLUENCING ADHERENCE TO ANTIRETROVIRAL TREATMENT**

Many factors have been reported to influence adherence to antiretroviral treatment. These factors include, socio-demographic factors, high risk behaviours, psychological factors, condition and treatment related factors, treatment fatigue, motivation and self-efficacy. The researcher developed a social-ecological framework (Fig 1.1) to illustrate the factors impacting on ART treatment adherence from the perceptions of community caregivers based on the literature review.



**Figure 1.1 Social-ecological-framework developed for factors that impact adherence to antiretroviral treatment.**

### **2.5.1 Individual factors**

This section focuses on individual factors that impact on adherence to ART. Studies in resource-rich countries have identified several individual factors that effects adherence to ART. For this literature review, individual factors impacting adherence to ART includes, socio-demographic factors, high risk behaviours, psychological factors, condition and treatment related factors, knowledge, beliefs and understanding of treatment and treatment fatigue, motivation and self-efficacy.

#### **2.5.1.1 Socio-demographic factors**

Researchers examining the relationships between adherence and demographic characteristics such as gender and social class have failed to identify consistently significant associations. Socio-demographic factors such as age, gender, race/ethnic group, occupation, education level and, literacy, are generally not predictive of adherence (Heyer & Ogunbanjo, 2006:8; Matchtinger & Bangsberg, 2006:9; WHO, 2003:28). When an association is found, the direction is consistent: younger age, non-white race/ethnicity, lower income, lower literacy and unstable housing are usually associated with non-adherence in resource poor countries. Extensive literature studies in developed and under developed countries found age as a predictive factor with adolescents, who struggle to adhere to ART, compared to adults. Researchers identified forgetfulness, cognitive, behavioural, mental health and emotional problems as well as negative peer relations as factors in adolescents who did not adhere to ART (Bhana *et al.*, 2014:1; Nglazi *et al.*, 2012:2). According to the UNGASS RSA Progress Report (2013:43) adherence to ART in children is a complex management issue, due to late diagnosis, dosing and often having to negotiate adherence with a caregiver.

#### **2.5.1.2 High risk behaviours**

The use of alcohol and other drugs have been associated with poor or no adherence to ART. Some studies have demonstrated that substance abuse is one of the stronger predictors of non-adherence (Coetzee *et al.*, 2011:148; Morojele *et al.*, 2014:522). Difficulties with adherence may be associated with the chaotic lifestyle of people who abuse drugs and alcohol. Alcohol and drug abuse are more likely to affect a person's ability to remember to take their medication and so negatively influence adherence. A qualitative study conducted by Rao *et al.* (2007:31) revealed that 72% of the respondents indicated that they took medication even when they drank alcohol. Substance abuse may lead to risky sexual practices and health compromising behaviour. A study done by Hahn *et al.* (2011:5) on alcohol's effect on the HIV epidemic in Sub-Saharan Africa indicated that alcohol consumption is associated with risky sexual behaviour and an increased risk of HIV infection. Appropriate interventions, targeting the risk of alcohol use

and high-risk sexual behaviour that increases the risk for HIV infection, should be developed and implemented. However, Hahn *et al.* (2011:5) described difficulty taking medications appropriately when using substances. In the before-mentioned study of Hahn *et al.* (2011:5), one participant describes how he managed this difficulty, *“I fall asleep before I get the chance to smoke. Sustiva will put you to sleep. It ain’t no fun.”*

### **2.5.1.3 Psychological factors**

Psychological factors relating to adherence behaviour includes depression, lack of social support, self-efficacy, body image and weight concerns, life stress and care-giving demands. A systematic review done by Nakimuli-Mphungu *et al.* (2012:2115) found depression is a strong predictor of non-adherence with HIV-positive individuals. Depression is associated with feelings of hopelessness with the loss of will to care for the self. The study of Yeyi *et al.* (2014:1485) found that higher levels of social support from close family members lead to lower depression levels. The study by Nakimuli-Mphungu *et al.* (2012:2115) revealed that interventions to improve mental health of HIV-positive individuals and to support adherence are desperately needed in Sub-Saharan Africa. All previous reviews on the association on depression and ART adherence have focused on high and middle-income countries. Based on the systemic literature review of Nakimuli-Mphungu *et al.* (2012:2115), the authors proposed extensive research on the association between depression and ART adherence in HIV positive individuals in Sub-Saharan Africa.

### **2.5.1.4 Condition and treatment related factors**

Treatment related factors that influence adherence are usually associated with the complexity of the regimen, previous treatment failures, the immediacy of beneficial results, adverse side effects and the medical and social support the person receives. Complexity refers to the treatment routine and duration, the dosing frequency and number of pills or fluid. The stage of HIV, severity of opportunistic infections and symptoms present at the onset of the treatment are factors that may influence adherence either negatively or positively (Matchinger & Bangsberg, 2006:9). Late or symptomatic HIV disease presentation may promote adherence, because people experience the beneficial effects of ART as they begin their recovery and regain their strength and health. However, some people stop taking their medication when they feel better and have no symptoms. A study done by Musheke *et al.* (2012:4) in Zambia, explored why some patients abandoned their treatment. One of the respondents in this study said *“to tell you the truth, I have consumed those drugs, I am now tired ... Now that I feel better, I have decided to stop.”*

Antiretroviral therapy can cause side effects. In a study done in Uganda one of the respondents states, “only fear the side-effects of the life-saving drug. I fear it will kill us instead of the HIV” (Hardon *et al.*, 2006:289). For patients without proper education and support side effects may be so severe that they may discontinue their treatment in favour of more immediate relief. Therefore, people on antiretroviral treatment must be educated about the potential adverse side effects they may experience and be advised on how to handle it (WHO, 2003:98).

In the case of antiretroviral treatment, adherence means taking the prescribed regimen of the drugs in the right doses, at the right time, every day for a lifetime (Gray *et al.*, 2009). This is the process that requires adjustment over time and across different aspects of one's lifestyle. In a review investigating patient-reported barriers to ART adherence, Mills *et al.* (2006:2051) listed complicated regimens as a significant factor affecting adherence. The frequency of dosing is a common reason reported by patients for missing doses. These conclusions highlight the significance of regimen burden on patients taking ARVs, and show how adherence is directly related to the complexity of their treatment. However, according to the UNGASS RSA Progress Report (2013:42), the complexity of regimens will now be addressed since the majority of South Africans in state sponsored ARV treatment programmes will only need one tablet, instead of the usual three tablets per day.

#### **2.5.1.5 Knowledge, beliefs and understanding of treatment**

According to the WHO (2003:99) adherence behaviour is based on a person's knowledge and beliefs about HIV as a disease, motivation to manage it, confidence and their ability to elicit the necessary behaviour. Knowledge and understanding of treatment outcomes and the consequences, as well as non-adherence, interact in ways that are truly complex, and not always clearly understood. A person's knowledge and beliefs about HIV and AIDS and ART can influence adherence (Miller *et al.*, 2010:50). Individuals, who understand the relationship between adherence and viral load and between viral load, and HIV disease progression, are more likely to be adhering than people who do not understand this relationship. Adherence is likely to be enhanced in people who strongly believe in the efficacy of ART. A study by Nachega *et al.* (2005:198) about the knowledge, attitudes, beliefs and practices about ART in Soweto, found a lower score for ART knowledge compared to general HIV and AIDS knowledge. Of the respondents, 49% believed that ART could cure HIV and 36% believed that ART would not cause side effects. Nachega *et al.* (2005:199) also found knowledge about the fact that missing ART doses can lead to disease progression was significantly higher among those not taking ART compared to those on ART. Some respondents on ART did not believe that missing doses of ART leads to disease progression. A finding by Dahab *et al.* (2008:3) from a qualitative South African workplace study examining barriers to, and facilitators of adherence, was denial about the existence of HIV disease and denial about a HIV positive diagnosis. According to this study

individuals with this belief will not take their treatment, because they do not believe that HIV is the cause of their illness. They believe they were bewitched and that the HIV virus has nothing to do with their illness, as echoed in statements such as the following: *“Those patients who are not adherent don’t believe that HIV is the cause of the illness... They believe that they are bewitched or it’s got nothing to do with the virus that’s causing AIDS.”*

The majority of current educational programs in South Africa focus on prevention strategies in order to encourage safer sex practices and decrease transmission of HIV. Information about disease progression and treatment are less prevalent in these initiatives and is one of the challenges highlighted in the UNGASS RSA Progress Report (2013). This lack of knowledge and information could influence adherence negatively and may cause the abandonment of ART if patients are not adequately educated. The WHO (2003:145) is of the opinion that individuals’ ability to make decisions and participate in discussions concerning treatment is central to achieving good patterns of adherence. Individuals who are well informed are more likely to be adherent, because they understand the reasoning behind treatment and the consequences of poor adherence. People on ART should receive information about their medication that is appropriate to their level of understanding. In this way individuals will receive information that will guide them towards behaviours for good adherence practice. Therefore, strategies need to be developed to support antiretroviral adherence that are practical, relevant and appropriate to the African context. For ART to be successful, education, improving knowledge and motivation regarding adherence should be at the core of a treatment programme. Patients must be educated with regard to the importance of adherence and the potential of developing resistance to ARV medication. However, the burden of education and training on ART falls on the health professionals. Consequently, due to a lack of time and overburdened staff, this is not always possible.

#### **2.5.1.6 Treatment fatigue, motivation and self-efficacy**

A person’s motivation to adhere as prescribed is influenced by the value the person places on treatment and the confidence he or she has to follow instructions as indicated. A person on treatment may choose to adhere or not to adhere based on his or her understanding of the risks and benefits of the prescribed treatment regimen. When the value of the treatment for a person’s daily functioning is pointed out during routine checkups, motivation is enhanced (WHO, 2003:146).

Heyer and Ogunbanjo (2006:7) explain self-efficacy as a person’s belief in his or her ability to take the medication as prescribed in order to manage their condition. Self-efficacy or the sense of being empowered to change factors affecting one’s life also affects adherence behaviour. Published studies report the success of programmes run jointly by clinicians and HIV and AIDS

patients to assist with self-efficacy skills building. Self-efficacy is cognitively appraised and processed through four principle sources of information. Performance accomplishments are evident in self-mastery of similar expected behaviours. Self-mastery happens by observing successful behaviour as modelled by others and verbal persuasion through realistic beliefs that the individual is capable of the expected behaviour (Bastable, 2006:159). Most of the projects employing this chronic disease self-management model are directed at relatively high functioning individuals. However, the use of this model in other chronic medical illnesses has been successful. Based on these successes and documented feasibility in a primary care setting, future research examining this type of provider-peer skills building intervention among HIV and AIDS patients with co-morbid conditions would be instructive (Uldall *et al.*, 2004:79).

### **2.5.2 Social networks**

Research studies emphasise the importance of social networks for increased adherence behaviour. This section focuses on the different social structures, including family, friends and peers, and the advantages of these social networks on adherence to ART.

#### **2.5.2.1 Family support**

The family plays an important role in adherence. According to researchers, family support, communication between family members, parental involvement, family dysfunction and a stable living situation, are determining factors for adherence. In a family where there is poor communication, and little support, especially with regard to children, it influences adherence negatively. Families must therefore be included in discussions to improve adherence (Bhana *et al.*, 2014:8). Furthermore, Aspeling and Van Wyk (2008:6) and Gilbert and Walker (2009:1127) found that the responsibility of parenthood and the desire to raise one's own children were huge motivating factors for adherence. This study found that children have a positive influence on adherence, because parents are determined to raise their children, and taking ART means that they can achieve their goal. Adherence behaviour was reinforced because children often reminded parents to take their medication.

#### **2.5.2.2 Social support**

Social support for adherence is defined as encouragement from family and friends for the person on ART to take their medication exactly as prescribed by their health care professional. Social support in HIV infection may also be described as the assistance offered to HIV positive persons by their social network as opposed to a professional and is often associated with improved health outcomes (Ncama *et al.*, 2008:1758). Yeji *et al.* (2014:1483) distinguish between two types of social support namely, emotional social support and instrumental support. Emotional social support involves the expression of feelings for a person, such as empathy,

love, trust or acceptance. Instrumental support is provided through tangible factors such as financial assistance, material goods and services.

A study by Gilbert and Walker (2009:1127) found that adherence rates are increased by significant others. Individuals who enjoy the privilege of supportive friends and families are appearing to adhere more stringently to their regimen than those without support. Individuals on treatment are encouraged to involve family and friends in their care and are also encouraged to join support groups. Social support is a critical aspect of living with HIV and AIDS to improve the person's quality of life. Therefore higher social support is associated with higher ART adherence. Quality of social support can influence adherence to treatment. Social support links the social and the individual, and most people view the satisfaction of their social relationships as being one of the most important determinants of their overall feelings of life satisfaction. Social support also acts as a buffer to many psychological problems and positively influences adherence behaviour. The presence of stable relationships and having access to social and emotional support increase the likelihood of optimal adherence. The absence of a supportive social environment and fear of stigmatisation are generally associated with non-adherence. People who live alone and who have poor social networks are less likely to be adherent (Heyer & Ogunbanjo, 2006:8). In the study by Cornett (2008:58) in Uganda, the following is reflected regarding social support: *Some only have a child of nine years old as a treatment supporter and they are alone at home. They find it difficult. Some clients don't have supporters. Some don't get financial support. Some patients struggle to earn something and people starve sometimes because they don't get any help.*"

Nachega *et al.* (2006:129) is of the opinion that for short-term support patients in the early stages of ART should be assisted with regard to physical adjustment. This requires physical and emotional support. Long-term support should focus on empowered living, meaning having the necessary motivation, support and knowledge to sustain adherence. To maintain successful ART for the long-term, empowered living must become a focus for the patient. A patient who did not disclose and lack social support has challenges to adhere to ART.

### **2.5.3 Community based factors**

Community based factors focusing on cultural beliefs and the health system influence adherence to ART as suggested by different researchers. This section will give an outline of these factors that influence ART adherence

#### **2.5.3.1 HIV stigma, discrimination and disclosure**

HIV-stigma is universal, pervading all regions of the globe. Stigma can, among other things discourage people from being tested, impede access to treatment and other health care

services, undermine adherence to treatment and discourage disclosure (Inungu & Karl, 2006:2). Combating HIV-stigma is thus widely recognised as a key ingredient in the struggle against HIV and AIDS world-wide. Stigma refers to a social process through which individuals are devalued on the basis of particular negatively perceived characteristics or status. HIV and AIDS related stigma and discrimination refers to the prejudice, negative attitudes, abuse and ill treatment that HIV positive persons are subjected to because of their HIV status. A quantitative study by Maughan-Brown (2010:369) found that HIV-stigma increased despite the availability of antiretroviral treatment, which was hoped to reduce the stigma.

Fear of being stigmatised and not disclosing HIV status, are factors that negatively influences adherence in Sub-Saharan Africa (Frank & Duncan, 2009:4; Inungu & Karl, 2006:2; Nachega *et al.*, 2005:200). HIV positive people may be shunned by their family and friends and the wider community and they may experience poor treatment by the health care providers. ARV users said that after disclosing their HIV-positive status, they had lost their job and were abandoned or badly treated by their partners or were isolated by community members. These negative experiences may prevent people from accessing testing and treatment. Stigma helps make AIDS the silent killer because people are terrified of rejection, shame and isolation. The fear of stigma and being seen taking ART by those outside of the individual's close social network present a significant barrier to normalising adherence behaviour.

In the study done by Cornett (2008:48) on the role of social support and counselling in antiretroviral treatment in Uganda, one of the counsellors stated: *"You know disclosure is a process. It is always difficult to go and disclose to somebody. Things are done step by step. Clients such as women who are married may fear to disclose to their spouses. They fear things like divorce. But some patients have disclosed to their family members. We tell them to disclose to people who they expect to support them financially, or to attend to them when they are sick and will be coming with them for ART counselling."* From research studies, it is evident that there is a relationship between stigma and disclosure. A qualitative study conducted by Dahab *et al.* (2008:3), respondents said the following regarding disclosure: *"Some are scared to disclose...If a person does not disclose to his partner he will have a problem in taking his medication, because he will have to hide... and if they have to hide medication...one day you are not going to take because you'll be scared. Oh is she going to see me? Let me not take it today. I'll take it when she is gone."*

This illustrates that patients who do not disclose, are forced to hide the fact that they are on ART. They have to hide their drugs and lie about their clinic appointments, which negatively influences a patient's ability to manage the disease and adhere to their medication regimen. Non-disclosure is also a massive obstacle for social support (Nachega *et al.*, 2006:131). Disclosure is especially problematic for partners. A study by Vu *et al.* (2012:136) found that 19%

of participants have not disclosed their HIV status to their most recent sex partner and 46.5% reported having partners with unknown HIV status. Although the prevalence of HIV stigma in Sub-Saharan Africa is high, a study done by Campbell *et al.* (2011:6) in Zimbabwe found that availability of ART can give ARV users a renewed sense of social value for the reduction of stigma. According to Tsai *et al.* (2013: 2726), research done by Castro and Farmer (2005) in Haiti on the early experiences with ART, found that treatment reduces the stigma of HIV, with an increased demand for HIV testing and counselling, fewer HIV related discriminatory events and increased social integration.

### **2.5.3.2 Socio-economic status**

Socio-economic factors play a substantial role in people's decisions about their health. The financial burden that accompanies ART presents a huge challenge to anyone who begins treatment. A study done by Cornell *et al.* (2009:723) found that 54% of participants did not have any monthly income and for those who received an income, the average was R740 per month. They also found that individuals with no income have poorer outcomes on ART. Low socio-economic status may put individuals on medication in a position where they may have to choose between competing priorities. For example, they may have to direct limited resources to meet the needs of other family members, including children or parents for whom they care.

Two of the most commonly reported ART-related expenses across sub-Saharan Africa are transportation and additional food requirements (Kagee *et al.*, 2011:85; Skovdal *et al.*, 2011:303; Tuller *et al.*, 2010:780). The study by Kagee *et al.* (2011:85), on structural barriers to ART adherence in South Africa, found problems with regard to access to transport as a major barrier to adherence. For example, a patient on ART must make several visits to the clinic. For this they have to rely on public transport, which is more expensive, unsafe and in some areas unavailable. The patients must travel long distances to reach facilities providing ART. Due to a lack of transport funds in many cases, patients will not be adequately monitored. This severely impacts adherence. Caregivers in the study in Uganda (Cornett, 2008:52) summarises the situation as follows: *"Sometimes they come from far that is costly or they come from villages where there is no transport. If they don't have money, and they run short of drugs....I think that is why some of them do not adhere well. Transport is a big obstacle for adherence."*

ARV users also complain about hunger during the initial stages of treatment. Patients who experience food shortages, are less likely to adhere and therefore more likely to experience opportunistic infections (Hardon *et al.*, 2006:9; Kagee *et al.*, 2011:4). A research study by Nachega *et al.* (2006:131) reveals the following regarding nutrition: *"It's very hard for people to take pills when they are hungry and the challenge is how do you link that person to a support mechanism that will ensure that there is some food on that person's table at least once a day"*.

In a study done by Hardon *et al.* (2006:67) one participant said, *“If we have no money to buy food, then this medicine is a problem.”*

Recent research studies confirm the importance of nutrition in antiretroviral treatment adherence. Patients receiving food assistance had higher adherence than patients who did not receive nutritional support. Research studies also found that disability grants are sometimes the only source of income for some people on ART. Research done by Kagee *et al.* (2011:86) and Leclerk-Madlada (2006:251) found that the qualifying criteria for the disability grant for people on ART poses a major challenge. Most people in the terminal stages receive the grant, while those in the early stages of HIV do not have access to the grant due to their CD4 count. This contributes to non-adherence of patients. In a study done by Leclerk-Madlada (2006:251) about the challenges of people receiving ART, one respondent said: *“They want us to wait until we are very sick, like almost dead! That’s the problem when they say your CD4 count is still high and you are still strong. Still strong for how long? My stomach is hungry now. If I don’t eat now I’ll be sick. That’s what they want for us to be sick.”*

Research studies done by Barnighausen *et al.* (2007:8) and Coetzee *et al.* (2011:148) revealed that the loss of a job and wages are some of the important concerns for patients on antiretroviral treatment. Employed individuals may have to choose between attending clinic and paying rent or feeding their children and therefore do not disclose their status to the employer. In the study of Musheke *et al.* (2012:6) a respondent said: *“I lost my marriage, when I told my husband my status...so I did not tell my boss that I was HIV-positive, so I feared that if I told her, she was going to fire me. So I decided to keep quiet so that I keep my job...instead, I decided to stop going to the clinic so that she does not know my status.”*

#### **2.5.4 Socio-cultural factors**

Socio-cultural factors influence adherence to ART as suggested by different researchers. This section will give an outline of these factors that influence ART adherence.

##### **2.5.4.1 Cultural factors**

Traditional and cultural beliefs play a major role in people’s expectations and knowledge of HIV. How individuals perceive the nature and cause of their illness may act as barrier to compliance. A study done by Aspeling and Van Wyk (2008:6), found that in seeking the cause of their illness, some patients have turned to traditional medicine for answers and a cure. It is not unusual for patients who hold traditional cultural beliefs to consult traditional healers in seeking to understand and treat the illness. Some patients put more trust in traditional healers because they believe that traditional medicine cure HIV. Aspeling and Van Wyk (2008:6) found that even though no participant reported taking traditional medicine, some believed that traditional

medicine can cure HIV. The consequences of this belief are that some people may combine traditional medicine with ART.

The Dahab *et al.* (2008:3) workplace study reported that both persons and health care providers agreed that ART and traditional medicine should not be taken at the same time. Traditional medicine's conflicting messages can negatively impact a patient's adherence. The consequence of this belief was that some persons reported that they stopped ARV treatment while they were on traditional medicine (Dahab *et al.*, 2008:3). In the qualitative study by Dahab *et al.* (2008:3) a respondent said: *"I had pain in my foot and the doctors could not help me... I went to my traditional healer. She gave me something... That is why I stopped the ART. You shouldn't mix the two!"*

#### **2.5.4.2 Religious factors**

Religion plays an important role for some patients in helping them to come to terms with their HIV status, in giving them hope and reaching a state of acceptance. Hope is giving inspiration and vitality to people. Faith in a higher power may help some patients to make sense of their world and act as a foundation for daily decision making. Church attendance, religious practices and spiritual beliefs contribute to the individual's health in general and may benefit the patient. However, Sanjobo *et al.* (2012:139) suggest that strong religious beliefs concerning sin and mortality may impact negatively in treatment adherence. Aspelung and Van Wyk (2008:7) also found that religion indirectly facilitated acceptance of HIV. Studies support the role of religion and spirituality in achieving hope and physical well-being among persons living with HIV. Hope contributes to the necessary lifestyle adjustment and is essential for adherence. These studies also found that prayer and spirituality help patients through difficulties they may experience and were considered to be a source of internal support during times of distress.

#### **2.5.5 Services related factors**

Service related factors influence adherence to ART significantly according to research done. This section will give an outline of factors that influence adherence to ART.

##### **2.5.5.1 Health care system**

The provision of ART is complicated and requires extensive resources and management. Ensuring life-long treatment, accessible and well-functioning health facilities, management of referral relationships, partnerships with non-state actors, monitoring and evaluation, and removing the many barriers to entry and remaining in care, all imply a high level of systems and managerial capacity. This makes ART more complex than many other health care interventions (Schneider *et al.*, 2006:16).

Numerous factors may contribute to poor medication adherence (WHO, 2003:29). Such factors include poorly developed health services, inadequate or non-existent health insurance, poor medication distribution, lack of knowledge and training of health care providers in chronic disease management, overworked health care providers, lack of incentives and feedback on performance, short consultations, weak capacity to educate both the person in need of treatment and health care provider, inadequate community support and health care provider support, lack of knowledge on adherence and interventions to improve adherence.

The UNGASS RSA Progress Report (2013:43) identified many barriers with regard to the provision of ART in South Africa. These health care system challenges poses a threat to reaching the goals as set out in the Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa, and is a barrier for patient adherence.

#### **2.5.5.2 Health care provider**

The qualities of the health care provider play an important role when helping persons on ART to adhere as prescribed (WHO, 2003:33). Some qualities are most necessary for recognizing the patient as partner in treatment decisions and for translating complex medical information in a manner that is clear and understandable to patients on treatment. These qualities include active listening, being sensitive to the patient's needs, emphasising, developing an understanding of the patient's situation and good communication skills. A health care provider-patient relationship of mutual trust and respect is likely to positively influence adherence behaviour because the patient feels comfortable to be honest about problems with regard to ART adherence.

A study conducted by Dahab *et al.* (2008:4) about HIV treatment adherence in a South African workplace programme revealed that communication, specifically language barriers, often impact the relationship between the patient and health care provider. With impaired communication and insufficient cultural understanding between patient and provider, instructions about ART may be misunderstood and any obstacles affecting adherence may not be appropriately addressed.

#### **2.5.5.3 Accessibility of ART Facilities**

Many people living with HIV and AIDS face barriers with regard to HIV and AIDS care, related to geographical distance from care, inadequate access to health infrastructure and a shortage of health care personnel and services. Clinics providing ART are often located far away and long waiting times result in limited consultation time with ARV users. A study done by Fredlund and Nash (2007:471) in Mseleni, KwaZulu-Natal found that the average distance from patient's homes to hospitals were approximately 90 km. That led to the decentralization of ART to the local clinics. The Mseleni treatment programme is an example of an integrated ART programme

consisting of professionals, the community and lay counsellors that was implemented to make ART more accessible to patients who would have never had access to ART.

#### **2.5.5.4 Human resource limitations**

The shortage of human resources is a barrier to the expansion of ART, because it impacts the intervention services rendered to patients, especially on a psychosocial level. Programmes providing pre-counselling and supportive adherence counselling as mentioned in the UNGASS RSA Progress Report (2013:44) are important for enhancing adherence, but personnel shortages impact negatively on the implementation of such programmes. Insufficient human resources causes stress to the limited staff available, leading to fatigue and a decrease in motivation (Schneider *et al.*, 2006:20).

## **2.6 DISCUSSION**

With the introduction of ART, adherence has become a challenge. There has been growing concern that people living with HIV and AIDS (PLWHIV) do not achieve optimal adherence levels needed for their treatment. According to the literature review, adherence to ART can be a huge challenge. Non-adherence has many consequences, including the development of drug-resistant strains of HIV. Drug resistance is directly correlated to adherence and, according to (Uldall *et al.*, 2004:72) may be the consequence of improper medication compliance. There is a great concern that the number of people developing resistance to ART will be escalating globally as more people worldwide gain access to ART.

The factors that impact ART adherence were discussed according to a social-ecological framework. Social-ecological approaches draws attention to the fact that interventions are required at both individual and social levels. The study has documented factors affecting adherence on individual level. Some studies have demonstrated that substance abuse is a high-risk behaviour and one of the strong predictors of non-adherence. A lack of psychological support also leads to non-adherence of patients. However, one of the most prominent factors on individual level was that patients do believe in the effectiveness of the treatment to achieve a healthy outcome. It was observed that people living with HIV and AIDS (PLWHIV) must have faith in the medication and this motivate them to continue with the treatment. This study has also highlighted treatment-related factors that influence adherence. These factors include side effects, the number of pills, dosing frequency and patient-provider relationships. Motivation and self-efficacy were highlighted as main facilitators for adherence to ART.

Studies found that social support from the family, friends and the community tremendously increase adherence rates. Stigma is a barrier to adherence and, as shown in this study, leads to discrimination. PLWHIV often face stigmatisation and discrimination from their communities,

including their own families. The failure to disclose leads to non-adherence as many PLWHIV has to take their pills secretively. Therefore anti-stigmatisation interventions with regard to ART should be enhanced and sustained and should focus on adherence support from family members and the community. Socio-economic factors like the lack of transportation and additional food requirements influence patients' adherence to ART. Studies have confirmed the importance proper nutrition in antiretroviral treatment and highlight the fact that this should be of high priority. Cultural and religious beliefs play a major role in people's expectations and knowledge of ART and can influence adherence to ART negatively.

This study also highlighted other barriers to adherence, including the health systems, inadequate infrastructure and lack of human resources. Thus the available staff cannot cope with the increasing demand for ARV treatment. ART requires close monitoring from the health care providers in order to achieve optimum adherence.

## **2.7 RECOMMENDATIONS**

Based on the literature review, the following recommendations can be made:

- Research studies to explore the psycho-social challenges regarding ART adherence should be encouraged.
- Research on community based interventions for ART adherence should be enhanced

## **2.8 CONCLUSIONS**

This review systematically discussed the factors associated with ART adherence through a social-ecological framework. The focus was on five categories, namely individual factors, social networks, community based factors, socio-economic status, socio-cultural factors and services related factors. This study emphasised a number of factors that contribute to non-adherence to ART. The review suggests that adherence is influenced by many psycho-social factors and in order to develop ART interventions, it is necessary to consider the challenges regarding antiretroviral treatment.

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## ARTICLE 2

### ANTIRETROVIRAL ROLL-OUT AND ADHERENCE: THE ROLE OF THE COMMUNITY CAREGIVER

Mokwele, R.M and Strydom, H

Mokwele, R.M. is a PhD student and Social Worker at the Department of Social Development (North-West Province) and Strydom, H is a Professor in Social Work at the North-West University (Potchefstroom Campus) and a researcher in COMPRES (Community Psychosocial Research Unit).

#### **Abstract**

HIV and AIDS has become a challenging issue globally. Recent statistics show that an estimated 2 million people became newly infected with HIV in 2014, and the number of people who died from AIDS-related causes world-wide was 1.2 million. Although significant progress has been made, only 15.8 million of those eligible received ART. The increased availability of treatment has dramatically improved survival rates and lowered the incidence of opportunistic infections in people with AIDS. A dramatic reduction in HIV and AIDS related morbidity and mortality has been observed in countries where ART has been made available. Due to the shortage of human resources task-shifting to less specialised workers are suggested in order to assist persons on ART with adherence challenges. This literature review explores the value of social support from the community caregiver regarding antiretroviral treatment (ART) adherence of people on treatment. The focus is on the promotion and maintenance of health by means of socio-environmental and behavioural changes through empowerment programmes for improved self-regulation and self-efficacy of the patient. Such programmes include information, motivation and behavioural skills development, which are in line with the Information-Motivation Behavioural skills-model (IMB) of ART adherence. According to the IMB model, adherence-related information and motivation are associated with adherence-related behavioural skills. This article also applied the systems theory with a focus on, the patient on antiretroviral treatment (ART), and the community caregiver. Based on this models the author is of the view that the involvement of community caregivers has a positive outcome to successful ART adherence which in turn can influence self-regulation and self-efficacy positively.

#### **3.1 INTRODUCTION**

Adherence to antiretroviral treatment (ART) has become a significant issue which increased with ART roll-out programmes. In the absence of a cure, ART is the only available option that offers the possibility of dramatically reducing AIDS-related morbidity and mortality, while

improving the quality of life of people living with HIV and AIDS. However, successful treatment depends largely on sustained and strict adherence to the prescribed regimens and requires near perfect adherence rates (as high as 95%). Failure to adhere to medication leads to treatment failure, disease progression and emergence of drug resistant HIV and AIDS strains (Mills *et al.*, 2006:2040; Van Dyk, 2012:90). This Literature review explores the role of the community caregiver regarding antiretroviral treatment adherence.

### **3.2 PROBLEM STATEMENT**

Globally there has been a rapid increase in the access to ART. At the end of 2012, 9.7 million people had access to HIV treatment (UNAIDS Global Report, 2013:46). Recent statistics showed an increase of 15.8 million people who have access to antiretroviral treatment (ART) (UNAIDS, 2015:1). The introduction of ARV increased life expectancy and reduced HIV and AIDS related morbidity and mortality. This literature review explores the role of the community caregiver with regard to antiretroviral adherence to support people on ART. Although ART has many benefits as highlighted by previous research studies, it also poses many challenges with regard to the scale-up of ART services and adherence of patients (Mills *et al.*, 2006:2040; Van Dyk, 2012:90). Some of the problems preventing effective ART scale-up and adherence is attributed to limited human resources to effectively follow up on patients. According to Dahab *et al.* (2008:4); Kagee *et al.* (2011:85) and Nachega *et al.* (2006:128) an important determinant for successful adherence to ART treatment is social support. Social support is described as the assistance offered to HIV-positive persons by their social network as opposed to a professional and is often associated with improved health outcomes (Ncama *et al.*, 2008:1758). Yeji *et al.* (2014:1483) distinguish between two types of social support, namely emotional and instrumental support. As more people gain access to ART, there is a concern that health workers and providers of psychosocial services will not have the time and resources to provide effective services and monitor patients' adherence properly. It is therefore important to conduct research to establish adherence challenges where after intervention strategies should be introduced to increase adherence to antiretroviral treatment. The research question flowing from the research problem is: *What is the role of the community caregivers regarding ART adherence?*

### **3.3 OBJECTIVES**

The objective of this literature review is (1) to review the role of the community caregiver in antiretroviral treatment programmes; (2) to review empowerment programmes for community caregivers; and (3) to make recommendations with regard to the role of the community caregiver in antiretroviral treatment in context of the Information, Motivation and Behavioural skills (IMB) model (Amico *et al.*, 2009:2).

### 3.4 THEORETICAL FRAMEWORK

The overall goal of this literature review is to explore the role of the community caregiver regarding ART adherence of persons on ART. The literature review uses different theoretical frameworks. The systems theory focuses on two systems which are interrelated and dependant on each other, namely, the patient on ART and the community caregiver, to understand the interaction between the person on ART and other social systems. Also of significance for the theoretical framework is the Information-Motivation Behavioural skills-model (IMB) of ART adherence (WHO, 2003:141), which argues that adherence-related information and motivation are associated with adherence-related behavioural skills. This model also argues that these skills directly predicts adherence to ART (Peltzer *et al.*, 2010:2). According to the IMB model, information, motivation and behavioural skills are principle determinants of health related behaviour (Amico *et al.* 2009:2; Fisher *et al.* 2006). In terms of ART, this model holds that People living with HIV and AIDS (PLWHIV) who are well informed, motivated to act and possess the behavioural skills that enable them to act effectively, will adhere to the ART treatment programme (Amico *et al.*, 2009:2; Fisher *et al.*, 2006:436). However, a well-informed, highly motivated person who lacks the required skills to take medication as prescribed, or lacks confidence in his/her ability to perform recommended medication intake would encounter problems with adherence. Adherence related information includes accurate information on particular regimens, correct ART intake and optimal adherence and side effects associated with the regimen (Amico *et al.*, 2009:2; Fisher *et al.*, 2006:436).

Adherence-related motivation include attitudes towards outcome of adherence, perceived social support for adherence behaviour and the ability of the person to comply with the wishes of their significant others (Amico *et al.* 2009:2). Adherence motivation comprises personal and social motivation. Personal motivation rests upon an individual's attitudes and beliefs about adherence and non-adherence and social motivation reflects the extent to which one feels that his or her adherence is supported by significant others (Roura *et al.*, 2009:2). Behavioural skills include factors such as the skills, tools and capabilities to adhere as well as the belief that they can effectively accomplish the adherence behaviour (Amico *et al.* 2009:2).

Several research studies focus on the IMB model for improved adherence. Amico *et al.* (2009:9) assessed the determinants of adherence behaviour postulated by the IMB model of ART adherence in a sample of 149 HIV-positive patients in Mississippi, USA. Their study indicated that ART related information correlated with personal and social motivation. Thus, being better informed and socially supported were related to stronger behavioural skills for taking medication which is in turn associated with self-reported adherence. Their findings based on the IMB model suggested that adherence interventions may be most effective if intervention components target adherence-related information; the minimisation of negative beliefs about HIV medications and

perceived negative lifestyle consequences of ART adherence; the development of adherence related social support and the development of practical skills in adhering to medications across various situations and contexts, as well as the confidence to implement them. For this review, the assumption is that if community caregivers in the HIV and AIDS programmes are empowered with information, motivation and skills, they will be able to create an environment for the person on ART as well as their families and other community members to empower themselves.

### **3.5 ANTIRETROVIRAL TREATMENT ROLL- OUT AND ADHERENCE**

This subsection of the article provides a synthesis of literature reviewed and background information on the current status of the HIV and AIDS epidemic, ART, and adherence globally in Sub-Saharan Africa and South Africa.

#### ***3.5.1 Global overview of the HIV and AIDS epidemic, antiretroviral roll-out and adherence***

HIV and AIDS has become one of the most challenging issues globally. The United Nations General Assembly 2011 Political Declaration on HIV and AIDS (UNAIDS Global Report, 2013:4) focused on intensifying efforts to reverse the HIV and AIDS epidemic. At the end of 2012 there were about 35.3 million people infected with HIV worldwide (UNAIDS Global Report, 2013:4). Recent statistics show a number of 36.9 people living with HIV (UNAIDS, 2015:1). The number of new infections worldwide declined. In 2012, 2.3 million people got infected, showing a 33% decline in the number of new infections from 3.4 million in 2001. According to UNAIDS (2015:1), 2 million people became newly infected with HIV in 2014, down from 3.4 million in 2001. The number of people who died from AIDS-related causes in 2012 was 1.6 million worldwide and decreased to 1.2 million in 2014.

The HIV treatment guidelines of the World Health Organisation (WHO, 2013), issued in June 2013, recommended starting treatment when an individual's CD4 count falls below 500 cells /ul. Treatment should be started immediately for HIV positive pregnant women, HIV-positive partners in sero-discordant couples, children younger than five and people with HIV-associated tuberculosis and hepatitis B (UNAIDS Global Report, 2013:4). Globally there has been a rapid increase in access to ART and 9.7 million people in low and middle-income countries had access to HIV treatment at the end of 2012. This is an increase of 1.6 million as from 2011, bringing the global number of people receiving antiretroviral treatment to 10.6 million by December 2012. The 2014 statistics revealed by UNAIDS (2015:1) show an increase to 15.8 million people who receive HIV treatment. Despite considerable progress, global coverage remains low. The increased availability of treatment has dramatically improved survival rates and lowered the incidence of opportunistic infections in people living with HIV and AIDS. A

dramatic reduction in AIDS related mortality has been observed in countries where ART has been made available. The decline in the global annual death rate from 2.5 million in 2005 to 1.6 million in 2012 and 1.2 million in 2014 illustrates the health benefits of scaling up ART access.

### **3.5.2 Adherence to antiretroviral treatment**

Literature addressing issues related to treatment compliance focused on medication compliance. Non-compliance is defined as a patient's resistance to follow the provider's prescriptions for following medication. A patient who chooses not to take medication as prescribed, or follow through with recommended treatment, is defined as non-compliant (Udall, 2004:72). Recently, the term "adherence" had replaced the term "compliance". Adherence has a broader meaning than compliance. Adherence studies acknowledge the vital role of the patient as a partner in the goals and outcomes of treatment. Adherence is thus defined as the "active, voluntary collaborative involvement" of the patient and provider to produce a "desired preventive or therapeutic result" (Udall, 2004:72).

The WHO (2003:3) defined adherence as the extent to which a person's behaviour relating to taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider. Adherence is a complex issue affected by many factors at the medical care system, provider, and patient level. Defining adherence is the first step in understanding barriers to and facilitators of adherence, with the hope of designing effective interventions to enhance adherence (Udall, 2004:72). Characteristics of patients who adhere are independence, intelligence and autonomy. Adhering patients take a more active and voluntary role in defining and pursuing goals for their medical treatment. Ultimately, the concept of adherence recognises that it is the patient who will or will not decide to "deliver his own therapy" (Udall *et al.*, 2004:72).

The introduction of ARV's changed the progression of HIV to AIDS by increasing life expectancy and reduced AIDS related mortality. ART has been shown to successfully decrease viral loads and increase the CD4 cell count. Although ART has many benefits as highlighted by previous research studies, it also poses many challenges. Lack of adherence to ART is one of the main causes for failure of treatment worldwide. Treatment failure is defined as disease progression with a decrease in the CD4 count and an increase in viral load, with the subsequent development of new opportunistic infections. Lack of ART adherence can lead to treatment failure, disease progression and development of drug resistant HIV and AIDS strains. Poor adherence is the major cause of failure to achieve viral suppression with ART regimens. When individuals do not take their medication properly, the drugs are ineffective in inhibiting HIV and reducing the patient's viral load. Therefore, their immune systems will not be able to defend HIV

infection and it will ultimately lead to treatment failure (Hanif *et al.*, 2013:2; Mills *et al.*, 2006:2040; Van Dyk, 2012:90).

Resistance to ART is becoming an increasingly problematic issue and the effectiveness is compromised due to a lack of effective care and support. Resistance to ARVs resulting from poor adherence is severe. Patients that become resistant to the first regimen must be switched to the second regimen which results in a cost increase in the provision of ART (Van Dyk, 2012:90). For example, South Africa adopted a fixed-dose combination formulated of TDF +FTC+EFV as preferred first line ART in April 2013. HIV fixed dose combinations have been promoted to limit the emergence of drug resistance and can lead to improved quality of life, as well as improved adherence (WHO, 2013:77). If patients develop drug resistance, many will need to switch to second line treatments, which is more expensive than first line drugs. If too many people progress to second line treatment, the increased cost will limit access to treatment for many people who could have benefited from first-line treatment. On a social level this will negatively influence economic productivity and will increase the burden on family caregivers, in turn leading to an increased burden on Government to scale-up antiretroviral treatment and reaching more people. Non-adherence to ART is of particular concern in countries that lack capacity to monitor drug resistance and the shortage and expensiveness of second-line regimens.

The WHO (2003) has identified adherence as the most important issue for the scale up of ART programmes. Research studies on ART adherence, indicated variations in ART adherence levels world-wide. For example, a meta-analysis conducted by Mills *et al.* (2006) indicated an adherence level of 55% across North America and a level of 77% for Sub-Saharan Africa. This may suggest that contrary to expectations, adherence rates in Sub-Saharan Africa might be favourable. However, there are no gold standard methods for measuring adherence. Different research studies focus on many indirect ways to measure adherence to ART, for example physician assessment, self-report, pill counts and electronic drug monitoring (EDM) (Gill, 2005:1244; WHO, 2003:4). Most of the studies had been conducted in the more developed countries and there are also only few studies that investigated adherence to ART in resource-poor settings like Sub-Saharan Africa. Previous studies have already highlighted a number of determinants of adherence to ART in low, medium, and high income countries, such as self-efficacy, depression, medication beliefs, alcohol use and misunderstanding prescriptions. Due to increased access to ART there is growing concerns for non-adherence and high rates of patients lost to follow-up (Rosen *et al.*, 2007).

In order to increase adherence to ART, continuous monitoring by community caregivers is needed. Some research studies suggest that the ideal way to ensure and measure adherence would be through a programme modelled after the tuberculosis control strategy. This strategy

involves direct observed treatment (DOTS) which requires a treatment supporter to oversee compliance to the medication regimen for every dose (Lawn *et al.*, 2005:771). Research by Kober and Van Damme (2004:103) suggests task-shifting from specialised to less specialised workers.

### **3.5.3 *The HIV and AIDS epidemic, antiretroviral treatment and adherence in Sub-Saharan Africa***

The presence of HIV infection is currently concentrated in the developing world and 25.8 million people living with HIV are living in Sub-Saharan Africa (UNAIDS, 2015:1). The number of people dying from AIDS-related causes in Sub-Saharan Africa was estimated at 790 000 in 2014 (UNAIDS, 2015:1). During the last decade, access to HIV and AIDS care in Sub-Saharan Africa has been improved by the reduction of the cost of ART and by the implementation of WHO guidelines promoting scaling up by task-shifting from specialised to less specialised health care workers. However, the challenge to achieve high adherence to ART in Sub-Saharan Africa remains high, due to the high number of people infected by HIV and AIDS. Sub-Saharan Africa also experiences other challenges such as patients lost to follow-up, maintaining high adherence rates and to reduce AIDS related mortality.

### **3.5.4 *The HIV and AIDS epidemic and antiretroviral treatment roll-out in South Africa.***

With an estimated 6.4 million people living with HIV and AIDS, South Africa is home to the largest population living with HIV in the world. Over the last decade, the number of new infections declined, yet incidence levels remained high. South Africa has a generalised HIV epidemic driven largely by heterosexual transmission. Data from population-based surveys and sentinel surveillance of pregnant women indicate that the HIV epidemic has reached a plateau, although HIV prevalence rates are rising as a result of an extensive ART programme (UNGASS RSA Progress Report, 2013:12). According to the 2011 National Antenatal Sentinel HIV and Syphilis Prevalence Survey in South Africa (Department of Health, 2012:61), heterosexual transmission indicates a 17.3% prevalence in the general population and an estimated prevalence of 29.5% in the antenatal population. There is a substantial decrease in AIDS related mortality from 350 000 in 2005 to 240 000 in 2012, but mortality remained high in HIV-positive adults who were not on antiretroviral treatment (UNGASS RSA Progress Report, 2013:14). According to statistics from the National Antenatal Sentinel HIV and Syphilis Prevalence Survey in South Africa (Department of Health, 2012:61), 31.2% people were exposed to ART.

South Africa has recognised the importance of an effective response towards HIV and AIDS. The focus of South Africa is to reduce the impact of HIV and AIDS on individuals, families, communities and society. The 2012-2016 National Strategic Plan on HIV, STIs and TB (NSP)

(South African National AIDS Council, 2012:14-15) focuses on the reduction of new HIV infections by at least 50% using a combination of preventative approaches. The NSP also has as its goals to initially have at least 80% of eligible patients on antiretroviral treatment; have 70% of these patients alive and still on treatment five years after initiation; to reduce the number of new TB infections as well as deaths from TB by 50%; ensure an enabling accessible legal framework that protects and promote human rights in order to support implementation of the National Strategic Plan (NSP); and reduce self-reported stigma related to HIV and TB by at least 50%. HIV and AIDS treatment, care, support and prevention are key strategies to address HIV and AIDS in South Africa. As from 2001, to present, political commitment, funding and the scale-up and quality of interventions have increased dramatically through the introduction of ART. The goals of ART are to reduce HIV-related morbidity and mortality, improve quality of life, preserve and restore immunological function, and maximally suppress the viral load.

The ART roll-out has expanded dramatically with approximately 2 150 880 people on HIV treatment. Table 1 gives an outline of statistics for ART for 2011 and 2012 according to the WHO/UNAIDS/UNICEF Global update on HIV treatment (2013). These estimates give an indication of the increase in the number of people on ART. Approximately 780 000 deaths have been averted between 2003 and 2012. The funding of HIV antiretroviral treatment has become more affordable since the introduction of fixed dose antiretroviral comprising of one pill a day. The majority of South Africans in state sponsored ARV treatment will only need one tablet as opposed to, the usual three tablets per day (UNGASS RSA Progress Report, 2013:41).

**Table 3.1: ART coverage and enrolment figures for South Africa 2011 and 2012**

Total number of people receiving ART, 2011	Estimated number of people illegible for ART, 2011	Estimated ART coverage, 2011	Total number of people receiving ART, 2012	Estimated number of people illegible for ART, 2011	Estimated ART coverage, 2012
<b>1 702 060</b>	<b>2 500 000</b>	<b>69%</b>	<b>2 150 881</b>	<b>2 700 000</b>	<b>80%</b>

**Source: WHO/UNAIDS/UNICEF Global update on HIV treatment, 2013**

South Africa experiences manifold challenges regarding antiretroviral treatment. The main challenge is poor adherence attributed to various factors including socio-economic, clinical and socially related factors. Other challenges include insufficient human resources for the implementation of new guidelines. More challenges represent itself in poor working equipment and inadequate infrastructure, contributing to poor staff morale that negatively impact on programme results. There is also loss of patients including patients who do not return for their initial CD4 count and those who do not initiate antiretroviral treatment, despite eligibility. Aspects of treatment are also differentiated along gender lines, and more women tend to take HIV tests than men do. Therefore, the ratio of men to women is relatively low in antiretroviral treatment programmes. Another challenge is the late introduction of patients to treatment, due to late

diagnosis and poor pre-ART programmes partly due to limited staff resources (UNGASS RSA Progress Report, 2013:42-44).

### **3.6 ANTIRETROVIRAL TREATMENT ADHERENCE EMPOWERMENT PROGRAMMES FOR COMMUNITY CAREGIVERS**

This section provides a brief description of projects and training programmes to equip community caregivers with knowledge and skills regarding antiretroviral adherence. These programmes only provide a few examples of the various programmes available. Different programmes focusing on support and empowerment to the community caregiver were assessed. It was found that most programmes are directed towards professionals and only a limited number focuses on the community caregiver. The medical aspects of ART are basically the main focus with limited focus on psychosocial aspects of adherence including the family and community. The projects and training programmes are described below.

#### **3.6.1 The World Health Organisation**

*Integrated Management of Childhood Illness: Manual on Paediatric HIV care and Treatment for District Hospitals* (WHO, 2011). This manual is for use by doctors, clinical officers, senior nurses and other senior health workers who manage HIV-infected children in district hospitals. The manual was developed by the WHO and partners based on evidence based normative guidelines and a thorough review of field experience with HIV/AIDS treatment provision in resource-poor settings.

The main aim of the manual is to contribute to universal access to care, treatment and prevention of HIV and AIDS. The manual consist of two parts. The first part deals with the management of HIV-infected children when they present with common illnesses and opportunistic infections such as coughing or difficult breathing, diarrhoea, fever, malnutrition, anaemia and other haematological manifestations.

Part two consist of HIV specific management, including antiretroviral therapy as well as chronic care such as diagnosis of HIV infection in infants and children, routine care of HIV-exposed and infected children, antiretroviral therapy, nutritional support, pain management and disclosure and psychosocial support.

#### **3.6.2 Salvation Army**

*Guidelines for establishing community-led antiretroviral treatment through a human capacity development approach* (Salvation Army, 2005). This manual was developed by the Salvation Army in 2005. Components of the manual include, drug management, training and learning for

ART documentation and measurement, as well as partnerships with regard to ART and adherence.

### **3.6.3 Project PAL**

*Buddy training manual for staff* (Project Pal, 2005). This manual was developed as part of a research project on enhancing antiretroviral adherence. The focus is on training peer educators as part of the treatment team. The manual is of significance with regard to social support and offers valuable information.

### **3.6.4 Southern African AIDS Trust**

*This training manual focuses on community mobilisation and empowerment for improved access to care, support and treatment* (South African AIDS Trust, 2014). This training manual was developed in 2014 and aims to mobilise and empower communities by improving access to care, support and treatment for people living with HIV and AIDS. The manual focuses on antiretroviral treatment, stigma, resource mobilisation, and leadership for improved access to care.

### **3.6.5 International Associations of Providers of AIDS care/Pan African Health Organisation/ World Health Organisation**

*Peer education trainer's manual*. This training manual was developed in 2014. The purpose of this training programme is to increase the knowledge and skills of HIV positive adolescents and young people to live physically and emotionally healthy. The training is to be conducted by peer educators (International Associations of Providers of AIDS care/ Pan African Health Organisation/World Health Organisation, 2014).

### **3.6.6 Horizons/Population Council International Centre for Reproductive Health Coast Province General Hospital Mombasa Kenya**

*Adherence to antiretroviral therapy in adults: A guide for trainers* (Horizons/Population Council International Centre for Reproductive Health Coast Province General Hospital Mombasa Kenya: 2004). The training manual was developed by the Horizons Program of the Population Council, The International Centre for Reproductive Health and the Coast Province General Hospital for the antiretroviral therapy programme in Mombasa, Kenya. The adherence training manual has been designed for health workers in ARV programmes. This training manual contains information on adherence, patient preparation for adherence and adherence counselling.

### **3.6.7 Harlem Adherence to Treatment Study, Harlem Hospital**

*Peer support for HIV treatment adherence: a manual for Program Managers and Supervisors of peer workers* (2003). The manual has been developed by Harlem Adherence to Treatment Study, Harlem Hospital. The manual focuses broadly on aspects of peer educators and includes aspects like adherence support, training of peer educators, supervision and support of peer educators and evaluation of peer programmes.

### **3.6.8 SAFAIDS**

The organisation focus on different programmes, including, *antiretroviral treatment skills and knowledge notebook for community workers in Southern Africa; HIV prevention, treatment, care and support: A training package for volunteers; Training manual for service providers to support children's HIV treatment literacy in communities*. SAFAIDS in collaboration with the American Jewish World Services (AJWS) and Firelight Foundation have developed this regional children's HIV treatment literacy toolkit. The primary aim of the toolkit is to support children living positively with HIV or on ART, and to support their parents, caregivers and others in their circle of care. A training manual for service providers to support children's HIV treatment literacy in communities is a part of this toolkit. The modules include HIV in children and families, children living with HIV: paediatric antiretroviral treatment and healthy practice, support of children, teamwork in service provision, optimising entry information and retention in HIV care; and ART adherence for PLWHIV. Other manuals of SAFAIDS includes an antiretroviral treatment skills and knowledge notebook for community workers in Southern Africa and a training package for volunteers on HIV prevention, treatment and care and support ( SAFAIDS, 2006a).

### **3.6.9 International HIV/AIDS Alliance**

*Community engagement for antiretroviral treatment: Participatory tools and activities for civil society organisations working with people with HIV*. This manual was developed in 2006. The manual is aimed at providing accurate information for lay people. It focuses on the basic information on HIV and ARV treatment, starting ARV treatment, ARV treatment information and how to provide it, adherence to ARV treatment, ARV treatment follow-up, changing ARV treatment, ARV treatment differences between men and women, living with ARV treatment, ARV treatment for children, ARV prevention of mother to child transmission, the role of CBOs in supporting people on ARV treatment (International HIV/AIDS Alliance, 2006).

### **3.6.10 International Association of Physicians in AIDS Care/National Minority AIDS Council**

*A train the trainer manual for extending peer educators role to patient navigation.* The purpose of this training program is to address the need for peer educators to actively engage with people living with HIV and AIDS in enhancing entry into HIV care, promoting ART adherence and facilitating long-term retention in HIV care. This manual focuses on, the role of peer educators, peer educators engagement in HIV care, adherence, drug resistance, HIV treatment, improving retention in care, the role of peer educators in implementing the entry into and retention in care and antiretroviral adherence guidelines. The conclusion is that there are many empowerment programmes with regard to ART. However, more intervention programmes addressing the psychosocial needs of patients on ART need to be developed (International Association of Physicians in AIDS care/ National Minority AIDS Council, 2012).

## **3.7 MOTIVATION FOR EMPOWERMENT OF COMMUNITY CAREGIVERS WITH REGARD TO ART SUPPORT**

Numerous studies have confirmed that the level of support received from family members and close social networks strongly influences individuals behaviours and decisions regarding treatment. This section will focus on the potential role of the community caregiver regarding ART specifically looking at the implementation of the IMB model for increased self-regulation and self-efficacy.

### **3.7.1 History and evolving of community caregivers in South Africa**

Lay or community based workers, have emerged as part of broader cross-sectoral responses to HIV and AIDS as well as job creation initiatives. Over the last decade in South Africa, a rapid growth in programme activities for the comprehensive response to HIV and AIDS, have been responsible for the emergence of a large lay/volunteer worker infrastructure. It began in the late 1990s with state support to non-governmental organisations employing home and community based carers. The 1990s also saw the training of lay counsellors to promote voluntarily HIV testing and DOTS supporters for the TB programme (Schneider *et al.*, 2008:180).

Community workers are also part of the Comprehensive Care, Management and Treatment Programme (SANAC, 2012) governing antiretroviral access. Recent years have seen a significant shift in international thinking, back towards large-scale deployment of lay or community health workers after a rapid expansion in HIV and AIDS funding and programmes and renewed interest in child survival (Dewing *et al.*, 2014-63). The aim was to address the health worker shortage for the scale-up of antiretroviral treatment. In 2006, the WHO proposed task-shifting, and the training of community health workers, as core ideas in its AIDS and Health

workforce plan (Callaghan *et al.*, 2010:2). The massive training of community based workers was identified as a quick win for achieving the millennium development goals.

The term community caregiver is commonly used in other countries. A major area of interest of this literature review was to identify the role of the community caregiver with regard to ART adherence. In the context of general health worker shortages, community members have taken on care roles where care is not available. Home community based caregivers refer to paid and unpaid volunteers who provide services to clients with chronic illnesses, within the context of their families and communities (Department of Health, 2010). Different research studies, identified many terms for those who work in the community and carry out one or more functions related to care and support services. Terms used include treatment supporter, adherence support worker, lay counsellor, health promoters, community health advisors, outreach educators, community health representatives, peer health promoters and peer health educators (Schneider *et al.*, 2008:180). Community caregivers represent the most formalised end of a continuum of community participation around HIV and AIDS, from treatment literacy training programmes for people living with HIV and AIDS to members of their social network volunteering to be TB or ART treatment buddies and participation in rights-based activist networks.

The term used for this literature review is *community caregiver* also referred to as *caregivers*. According to literature reviewed, home based care volunteers, or community caregivers are community members who are trained to provide ART adherence counselling and to perform a wide range of home based care activities. The literature review has demonstrated that little research has been performed on the contributory role of this community support towards ART adherence of patients.

### **3.7.2 Community caregivers and the scale-up of ART**

The task-shifting to lay community caregivers is increasingly suggested as a potential strategy to overcome the barriers to sustainable antiretroviral treatment scale-up in high HIV-prevalence resource limited settings and to overcome the human resource shortage (Bedelu *et al.*, 2007:465; Kober & Van Damme, 2004:4; Wouters *et al.*, 2012:3). The WHO (2008:7) defines task-shifting as *the rational redistribution of tasks among health work force teams. Specific tasks are given to health workers with shorter training and fewer qualifications to make more use of the fewer human resources for health.* Wouters *et al.* (2012:3) state that recently health systems research has increasingly explored the potential benefits of two types of task-shifting, namely the shifting of tasks to lay community providers (type iii), and counsellors and people living with HIV and AIDS themselves (type iv).

Inherent to present day ART delivery models, are the following issues: scaling-up ART in low-income countries with a high AIDS burden, faced with a continuously growing caseload of people to be maintained on long-term ART; and shortage of and skewed distribution of the health workforce. The future caseload of people on ART critically depends on the number of people started on ART annually and the survival of those already on ART (Van Damme, *et al.*, 2008:2109). The countries with the weakest Human Resources of Health (HRH) base (expressed as PLWHA per doctor or per qualified health worker) are those that reached the lowest ART coverage (WHO, 2011:3). For example, according to the Operational Plan for South Africa, one doctor, two professional nurses, one pharmacist and a dietician are responsible for treating and managing 500 patients. The target of the South African programme is to have 1 million people on ART in the public sector by 2015. The shortage of human resources decrease expansion of ART, and reduces both the quality and quantity of time spent with each patient.

Staffing shortages cripple a facility's ability to provide psychosocial support and follow-up programmes essential to adherence. Pre-counselling and supportive adherence counselling are potential facilitators of adherence, but personnel shortages make these programmes impractical. Furthermore, insufficient human resources place more stress on the few staff available, causing fatigue and a decrease in motivation. The shortage of health personnel constitutes a massive problem in reaching this target in the near future. According to Schneider *et al.* (2006:20) a reorganisation of human resources is drastically needed.

### **3.7.3 Challenges community caregivers face**

There are limited studies looking at the impact caregiving has on caregivers. Studies done by De Saxe Zerden (2006:42-43) and Singh *et al.* (2011:840) focused on challenges with regard to community caregivers. The researchers found that caregivers often experience negative consequences of HIV stigma, feel highly burdened and experience mental and physical health problems due to the demands of their jobs.

People with HIV and AIDS and those close to them are subjected to numerous stressors that can impact their mental health. These stressors include fear and anxiety following the initial disclosure of their status and confusing medical treatment regimens; the prospect of a series of medical problems; and the sadness and grief of having a foreshortened future. The burden of care usually manifest in caregivers experiencing stress and burnout. Burnout is when a person display physical and emotional exhaustion as a result of caring for others. Caregiver support is lacking. A study done in Lusikisiki in the Eastern Cape by Mango (2004) to evaluate the use of psychological services by individuals living with HIV and AIDS and their communities revealed that there was little psychological support for family, friends and communities of people living with HIV and AIDS as much support is directed towards the patient.

Caregivers often feel stigmatised, because they work with HIV and AIDS patients. Research studies found the following factors to contribute to stigma. Caregivers often feel that they have to hide their caregiving jobs from family and friends. This secrecy often results in feelings of loneliness, isolation and a lack of support from their social network. Because caregiving is a demanding job, caregivers may also experience a huge degree of burden. Caregivers often have to do physically exhausting tasks, such as bathing and feeding the patients. Lastly, caregivers face the emotional stress of losing loved ones or others they deeply care for, due to AIDS. Loss often is an unrecognised stressor for caregivers. Consequently caregivers suffer increased burnout, depression, physical health problems and stress related problems. Understanding how to minimise the effects of caregiving are essential for the well-being of the community caregiver. Efforts to improve the level of adherence require a collaborative approach involving the patient, community, social and health workers as well as policy makers to find ways to address the structural and environmental constraints.

### **3.8 OVERVIEW OF THE ROLE OF THE COMMUNITY CAREGIVER IN ART ADHERENCE**

This section explores literature regarding the specific role of the community caregiver in ART adherence as well as proposed recommendations regarding caregivers role in ART support.

#### **3.8.1 *Facilitators for adherence***

To define the role of the community caregiver in ART adherence of patients the focus must firstly be on the facilitators for adherence as identified by different research studies mentioned in this literature review. Different studies highlight the facilitators for good adherence including, acceptance of HIV-status and disclosure, self-motivation to adhere to medication, self-efficacy and ability to adhere to ART, belief in the efficacy of treatment, ARV pre-treatment health state, the need to care for others, perceived availability of social support, an effective adherence counselling programme and attention to psychosocial problems.

#### **3.8.2 *Changing needs of people living with HIV and AIDS***

There is a need for psychosocial support to patients on ART. A person diagnosed as HIV infected will undergo considerable psychological distress. The main concern for those who test positive, include the need for social, peer and psychological support, access to medical care and treatment, disclosure and planning for the future. Anger, fear depression and denial are common initial reactions to an HIV-positive result. In addition, the person has been diagnosed with a condition that carries stigma, fear and discrimination. For this reason the report on the global HIV and AIDS epidemic has included psychosocial support for the PLHWHIV and their families on its list for essential services. A review of the literature regarding the needs of people living with HIV and AIDS reflect the following: physical needs, including assistance with the

physical care of the patient; cleaning; income generating projects, like vegetable gardens; emotional support; love; time to rest; transport and food. The needs of the people living with HIV and AIDS have changed with the advent of ART from basic physical care to more wide ranging care and support needs on a structural level (nutritional and economic) and a psychosocial level.

### **3.8.3 The changing role of the community caregiver after the introduction of ART**

Recent literature suggest that a shift has been observed in the type of services provided by community caregivers, from services with a strong focus on nursing care to more comprehensive care and support services and programmes. In Table 3.2 the researcher gives her own summary of proposed roles and responsibilities of community caregivers in terms of the IMB model based on the literature reviewed, which can assists with the development of intervention strategies to support patients on antiretroviral treatment.

**Table 3.2: Summary of roles and areas for empowerment for community caregivers**

<b>Information</b>	<b>Areas for empowerment</b>
	<ul style="list-style-type: none"> <li>✓ Record keeping and link clients to facilities</li> <li>✓ Conduct assessment of the patient circumstances</li> <li>✓ Facilitate information sessions regarding HIV and AIDS and antiretroviral treatment and adherence</li> <li>✓ Information on psychosocial problems</li> </ul>
<b>Motivation</b>	<ul style="list-style-type: none"> <li>✓ Facilitate a support system regarding disclosure</li> <li>✓ Counselling on acceptance of HIV status</li> <li>✓ Pre-treatment counselling sessions</li> <li>✓ Adherence counselling</li> <li>✓ Support for mental health needs of patients</li> <li>✓ Support and monitor adherence</li> <li>✓ Help the patent to set goals, and to develop a positive attitude, self-efficacy and commitment</li> <li>✓ Motivation sessions on psychosocial needs</li> <li>✓ Run HIV support groups</li> <li>✓ Tracking clients who defaulted and encourage to continue with treatment</li> </ul>
<b>Behavioural skills</b>	<ul style="list-style-type: none"> <li>✓ Facilitate skills development programmes for families e.g. physical care of patient, psychosocial support</li> <li>✓ Link to material assistance and nutritional support</li> <li>✓ Skills building on social support networks and communication</li> <li>✓ Empowering regarding income-generating activities</li> <li>✓ Sessions on decision making and behaviour change programmes</li> </ul>

The study in Zambia and South Africa by Caregivers Action Network (2013:14) found that with regard to ART, caregivers have now a role in record keeping; linking of clients to services provided at facility level; health promotion activities; tracking clients living with HIV and AIDS on treatment; encouraging defaulters to resume treatment and educating family members on how to support their relatives to adhere to ART. Some caregivers reported additional roles, such as counselling community members, testing individuals for HIV, and linking those living with HIV to treatment centres.

Other interventions that are important for adherence include couple and group counselling; education about adherence; address the low level of health literacy; address gender inequalities working with employers; poverty relief; disability grants; bridging the cultural divisions; reducing stigma and addressing mental health needs; oral and written patient monitoring; family interventions; reduction of stigma; assistance with disclosure; changing attitudes and beliefs concerning HIV and substance and drug use, depression; patient participation; improving decision making skills; information sharing and emotional support through support groups; community education and treatment literacy; counselling on ART, early recognition of possible drug reactions, nutritional supplementation and palliative care; communication as well as vocational and income generating activities (Dewing *et al.*, 2014:65; Skhoshana *et al.*, 2006:22; Uldall *et al.*, 2004:76; WHO, 2003:31; Zacharia *et al.*, 2009:552).

Community caregivers are also actively involved in HIV prevention programmes. They provide advice to community members and family members on HIV and AIDS. According to research, the provision of ART for reducing the spread of HIV is rapidly gaining momentum and there is substantial evidence that effective ART can prevent the transmission of HIV between sexual partners. Further, research around pre-treatment preparation for ART represents a gap for urgent attention. As ART treatment programmes continue to grow, there is increasing interest in the community based management of ART for expanding capacity.

Researchers has shown that retention in South Africa's national ART programme has deteriorated over time and as more people have enrolled in care. Their review shows that cognitive, behavioural and mixed interventions including emotional support, can be effective at improving treatment adherence. However, intensive interventions directed towards the individual can be difficult to implement in practice in Southern Africa due to large numbers of patients and restricted financial and human resources. As discussed, people on ART face numerous barriers to adherence and retention in care, including fear of disclosure, the experience and fear of side effects, migration and depression, food insecurity, financial constraints, drug-stock-outs, long distances to clinics and long patient waiting times. Adherence and retention in care depend to some extent on personal motivation which is likely to be affected by whether treatment is perceived to be of benefit to oneself or others.

### **3.9 DISCUSSION**

HIV and AIDS has become a major challenge and influence the lives of an estimated 6.4 million people in South Africa. Previous studies found that one of the main reasons for increased ART scale-up and adherence of patients on ART is the shortage of human resources. According to the literature review making use of lay community caregivers is a potential strategy to overcome the barriers to sustainable antiretroviral treatment scale-up in high HIV-prevalence settings with limited resources. Community caregivers fulfil a wide range of services in the context of HIV and AIDS and the provision of ART changed the role of the community caregiver as well as services rendering to people living with HIV and AIDS.

Another goal of this review was to evaluate intervention strategies in terms of the IMB model. Certain interventions were proposed, with special focus on the role of the community caregiver in antiretroviral treatment of patients. This review highlighted the importance of community caregivers in the context of HIV and AIDS services. Community caregivers are also seen as an extension of services rendered by professionals and is seen as a valuable support system for ART scale-up and improved adherence of patients on ART. Therefore, it would be imperative to give consideration to community caregivers as a social support system to improve ART adherence of patients.

### **3.10 RECOMMENDATIONS**

Based on the review the following recommendations can be made:

- Based on the roles of the community caregivers, social workers can develop programmes for their skills development.
- Research is needed on how the community perceives the services of the community caregiver in the context of ART support.
- Evaluation studies should be done with regard to the impact of the services of community caregivers.
- It is recommended that research should be done regarding ART empowerment programmes for community caregivers.

### **3.11 CONCLUSIONS**

According to the literature review, community caregivers are a valuable support system to expand ART provision and to support adherence of patients. Information from this research can guide social workers to develop intervention programmes for community caregivers. Such programmes should focus on development of capacities to promote human and community well-being, and can be developed in the framework of the IMB model with a focus on information, motivation and skills development.

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## ARTICLE 3

### THE PERCEPTIONS OF COMMUNITY CAREGIVERS WITH REGARD TO ANTIRETROVIRAL TREATMENT ADHERENCE OF PATIENTS: A PHENOMENOLOGICAL STUDY.

Mokwele, R.M and Strydom, H (Mokwele, R.M. is a PhD student and Social Worker at the Department of Social Development (North-West Province) and Strydom, H is a Professor in Social Work at the North-West University (Potchefstroom Campus) and a researcher in COMPRES (Community Psychosocial Research Unit).

#### **Abstract**

HIV and AIDS caused millions of deaths and immense suffering throughout the world. Although there is no cure, existing treatment has transformed this disease into a manageable chronic illness. However, successfully treating HIV and AIDS requires high levels of adherence to prescribed medications. Relatively little is known about the experiences and psychosocial challenges that community caregivers of HIV and AIDS Home Community Based care programmes experience regarding antiretroviral treatment (ART) adherence of patients. The objectives of this article is to identify challenges of community caregivers with regard to antiretroviral treatment adherence of patients, to explore and understand social support in the context of community care and to identify the needs of community caregivers for empowerment programmes. A phenomenological approach was adopted to explore the perceptions of community caregivers with regard to ART adherence of patients. Focus group interviews were conducted with community caregivers who were purposively sampled from three organisations. Participants also made narrative reflections regarding their experiences and challenges regarding ART adherence of patients in the journals they kept. The focus group data were transcribed and analysed through qualitative data analysis methods. The study findings suggest that social support is important for ART adherence of patients. The conclusion was made that community caregivers are important to support patients with regard to ART adherence. The study also found that community caregivers are faced with many psychosocial challenges with regard to ART adherence of patients. Therefore, interventions to support community caregivers to facilitate ART adherence of patients should be strengthened.

#### **4.1 INTRODUCTION**

South Africa has the largest number of people living with HIV and AIDS in the world. In 2012, 240 000 South Africans died of AIDS-related causes. However, many lives have been saved through a massive scale-up of antiretroviral treatment in the last few years (WHO, 2013). At the

end of 2012 an estimated eighty percent of people with HIV and AIDS received antiretroviral treatment in South Africa. There is a growing concern about antiretroviral treatment adherence, the development of drug-resistant HIV and drug failure (Kagee, 2011: 413; Van Dyk, 2012:1). Social support structures is important for patients adherence to ART (Dahab *et al.*, 2008:4; Kagee *et al.*, 2011:85; Nachega *et al.*, 2006:128). The effects of HIV and AIDS have had a devastating effect on communities in South Africa. Little is known about the experiences and role of community caregivers regarding HIV and AIDS antiretroviral treatment in South Africa, and the integration into other systems. It is therefore imperative to explore the challenges experienced by community caregivers in order to get a better understanding of the problem. This article consists of a discussion of the research methodology and the research findings. Twenty community caregivers, male and female, participated in focus groups. Participants also made narrative reflections in journals regarding their perceptions. The study describes participants perceptions of antiretroviral treatment adherence of patients and their needs with regard to a social work empowerment programme. The study concludes by giving recommendations for a social work empowerment programme for community caregivers.

## **4.2 AIM OF THE STUDY**

This study aimed to explore and describe the perceptions of community caregivers with regard to antiretroviral treatment adherence of patients and a social work empowerment programme to enhance their skills to facilitate the adherence of HIV and AIDS patients on antiretroviral treatment.

## **4.3 RESEARCH METHODOLOGY**

### **4.3.1 Research paradigm**

A qualitative approach was used to explore the perceptions of community caregivers with regard to antiretroviral adherence of patients and a social work empowerment programme to facilitate adherence of patients on antiretroviral treatment. According to Botma *et al.* (2010:190) and Niewenhuis (2009:50) the fundamental purpose of qualitative research is to collect rich descriptive data on a particular phenomenon with the intention to gain an understanding of what is being observed or studied. It therefore focuses on how individuals and groups view and understand the world and constructs meaning out of their experiences.

### **4.3.2 Research design**

Niewenhuis (2009:70) refers to research design as a plan or strategy comprising the underlying philosophical assumptions, specification of the selection of respondents, data gathering techniques to be used and the data analysis to be done. The research adopted a

phenomenological design. Phenomenology focuses on people's subjective experiences and interpretation of the world. According to Fouché and Schurink (2011: 316), the purpose of a phenomenological approach is to understand the issue or topic from the everyday knowledge and perceptions of specific respondents or subgroups.

### 4.3.3 Participants

The sampling technique used for this research was purposive sampling. The sample size was determined by saturation. Greeff (2011:367) defines saturation as the process when data become repetitive or no new ideas come to the front. The exact amount of focus groups to be used when using this methodology could not be planned in advance. It evolved during the research process.

The sample determined inclusion criteria for the participants. The criteria included the following:

- Male and female home community based caregivers;
- Active involvement in service delivery to patients on antiretroviral treatment;
- Serving home community based care programmes in Potchefstroom (Bambanani Youth Project, Baptist Children's centre and Hospice Emmanuel Loving Angels);
- At least one year experience working with HIV and AIDS patients on antiretroviral treatment; and
- Ability to communicate in Tswana, Afrikaans or English.

Exclusion criteria were:

- Community caregivers who worked for less than one year at any of the organizations; and
- Inability to communicate in Tswana, Afrikaans or English.

A total of sixteen participants took part in four focus group sessions. Table 4.1 shows the details of the participants in each of the focus groups.

**Table 4.1: Focus group participants**

Focus group name	No of females	No of males	Total number in group
Baptist Children's centre	4	0	4
Emmanuel Hospice Loving Angels	3	1	4
Bambanani Youth Project- group 1	2	2	4
Bambanani Youth Project- group 2	2	2	4
<b>TOTAL</b>	<b>11</b>	<b>5</b>	<b>16</b>

#### **4.3.4 Research Settings**

The participants were selected from three home community based care centres, namely Baptist Children's Centre, Bambanani Youth Project and Emmanuel Hospice Loving Angels. The goal of these organisations is to provide home based care services for people living with HIV and AIDS. Services provided by these centres include home visits and lay counselling.

#### **4.3.5 Procedure**

Permission to conduct the research was obtained from the managers of the home community based care (HCBC) centres. They also assisted with the selection of the participants for the study. A meeting was scheduled at the three facilities for an introductory session. The sessions took part in the hall of each of the organisations. The halls were private and comfortable for the participants. At this meeting, participants were orientated on the nature of the research and processes as well as their willingness to take part in the study. Each participant also received a document which contained relevant information on the purpose and procedures of the study. Willing participants were asked to give written consent to participate in the research. Questions and doubts were answered before they signed the consent form. The process was facilitated by the principle researcher and two assistants who were previously caregivers within the community based care centres. Appointments for focus groups were scheduled with the participants. Journals were distributed to the participants at the initial meeting to capture their experiences regarding patients and antiretroviral treatment. The journals were collected after a month.

#### **4.3.6 Data collection**

In qualitative research data is collected using different techniques, such as participant observation, semi-structured interviews, focus groups, field notes, memos, documents, reports and diaries. Data obtained from qualitative research methods aimed to explore the ways in which people construct social reality and the inherent meanings attached to these realities (Botma *et al.*, 2010:190; Niewenhuis, 2009:50). For the purpose of this study, data was collected using focus groups. These groups explored community caregivers' perceptions of patients' adherence to antiretroviral treatment and a social empowerment programme to facilitate patients' adherence to antiretroviral treatment. Community caregivers reflected their narratives regarding ART adherence of patients in journals. The focus group sessions were transcribed, data was analysed and notes were made during and at the end of the sessions.

##### **4.3.6.1 Focus groups**

The focus group schedule was pre-tested by means of a pilot study with six participants in a focus group to make sure the questions were relevant and understandable to the participants.

These participants were excluded from the main study. The schedule was adjusted based on the feedback from the focus group. Since participation with six members in the group did not produce the expected optimal participation, it was decided to decrease the number of participants per focus group from six to four participants, in order to increase participation.

Bryman (2008: 475) and Greeff (2011:348) describe focus groups as group interviews and a means of better understanding how people feel or think about an issue, product or service. Focus groups are especially useful when the knowledge about the research question is inadequate and elaboration is required. Participants are selected, because they have certain characteristics in common that relate to the topic of the focus group. According to Smith (2009:118), focus groups offer significant advantages in terms of empowerment and representing shared ideas and norms more effectively. The aim of the focus groups in this study was to explore the views of the participants regarding patients' adherence to ART. Four focus groups, consisting of four community caregivers per focus group were conducted. Altogether sixteen caregivers took part in the focus groups. The focus group questions were developed from the literature review. Each focus group followed an interview guide with open ended questions. This lasted for more or less 1.5 hours. Recordings were done by means of a tape recorder after permission was obtained from the participants. The researcher also trained two assistants to help with the transcribing process. They were trained on confidentiality and had to sign a contract.

#### **4.3.6.2 Journals**

By means of journal descriptions and narrative storytelling, participants described their experiences regarding adherence of patients. According to Alaszewski (2006) the aim of journals in social research is for participants to narrate their thoughts about a certain phenomenon, giving them the opportunity to return to the written text and supplement it with additional thoughts or information. The instructions for journal views were pre-printed in the journals and were collected after a month. Questions included, How do you as a community caregiver experience your work in the community with regard to patients on antiretroviral treatment?; Describe your daily challenges with your patients on antiretroviral treatment?; Based on your daily experiences, why do you think patients are not adhering to antiretroviral treatment?; What services do you render in the community for people on antiretroviral treatment and how do people in the community view your services?; How do you work with other support systems in the community and how do they see your service?; What support and training do community caregivers need to assist them with their work with patients on antiretroviral treatment?. Twelve participants reflected and narrated their experiences in the journals.

#### **4.3.7 Trustworthiness of the study**

Trustworthiness is a term used within qualitative research in order to describe the strength of the claims to knowledge the researcher is making. Trustworthiness can be established through the marshalling of evidence (Hammond & Wellington, 2013:147). The methods of trustworthiness proposed by Lincoln and Guba (in Babbie & Mouton, 1998:276) were utilised during this research. The aspects of credibility, transferability, dependability and confirmability were taken into account. The following methods were used to increase trustworthiness of the study:

##### **4.3.7.1 Credibility**

The researcher ensured credibility of the study through the following measures: Triangulation was achieved through the use of different methods, namely journals and focus groups. According to Smith (2009:65) triangulation will achieve greater confidence in research findings and greater depth of analysis. A pilot study was executed to test the focus group interview schedule. Focus group sessions were tape recorded and detailed notes were made of the sessions by two transcribers. Transcriptions of the focus group sessions were done after each focus group session. The biases, views, beliefs and opinions of the researcher were bracketed by maintaining an open mind approach.

##### **4.3.7.2 Transferability**

Transferability refers to the degree to which the findings of one's inquiry can apply beyond the boundaries of the project (Schurink *et al.*, 2011:397). This was done by establishing the degree of similarity in the respondents' views with other literature on the same subject. The researcher described the research process in the final report with sufficient detail and precision in order to enable other researchers to judge whether the results are transferable to other contexts.

##### **4.3.7.3 Dependability**

Dependability addresses the consistency or congruency of the results (Babbie & Mouton, 1998:278). Dependability considers the process of data collection, data analysis and theory generation, and is often evidenced by an audit trail of the data collection procedures. Theoretically at least, another researcher could follow the steps taken in the original study. The researcher described the data collection procedure in detail in the final report.

##### **4.3.7.4 Confirmability**

Confirmability is generally taken as a measure of how well the findings are supported by the data. The researcher did an audit trail of the audio recordings, focus group schedule, field notes

as well as themes that were developed. The auditing trail allows for understanding what was discovered and how it was discovered (Schurink *et al.*, 2011:422).

#### **4.3.8 Ethical aspects**

Hammond and Wellington (2013: 58) defines ethics as a moral principle or a code of conduct that actually governs what people do. It is concerned with the way people act or behave. Strydom (2011:114) defines ethics as %a set of moral principles that are suggested by an individual or group, are subsequently widely accepted, and offer rules and behavioural expectations about the most correct conduct towards experimental subjects and respondents, employers, sponsors, other researchers, assistants and students+. Ethical clearance for this study was granted by the ethics committee of the North-West University with the number NWU-00130-14-S1. The following ethical principles were followed.

##### **4.3.8.1 Potential harm to participants**

It is the researcher's ethical obligation to protect respondents against any form of physical discomfort that may emerge from the research project (Strydom, 2011:115). Since the topic was focused on HIV and AIDS matters, a cautious approach had to be followed to protect participants against emotional harm. The researcher informed the participants beforehand about the potential impact of the investigation. They were also offered counselling sessions if needed.

##### **4.3.8.2 Informed consent and voluntary participation**

According to Moule and Hek (2011:37) obtaining informed consent implies that all possible or adequate information on the goal of the investigation, the procedures that will be followed during the investigation, possible advantages, disadvantages and danger to which respondents may be exposed to as well as the credibility of the researcher, will be discussed with the potential participants. Before the onset of data collection, aspects pertaining to anonymity, confidentiality and privacy were discussed with the participants. This information was included in the consent form in order to allow for participants to make a voluntary and thoroughly reasoned decision about their participation. They were also made aware of the fact that they could withdraw without reason from the investigation at any time before data analysis and they were assured that they would not be discriminated against or penalised in any way. The transcribers involved signed a confidentiality contract.

##### **4.3.8.3 Confidentiality**

Alston and Bowles (2007:21) view the right to privacy as taking into account the respondent's personal privacy and identity while handling information in a responsible manner. The researcher ensured the anonymity of participants. However, only partial anonymity could be ensured during the focus group sessions. Information was coded for reasons of anonymity. All

information of the participants regarding the focus groups, were kept safe by the researcher. All focus group sessions took place in a private hall at the different centres.

#### **4.3.9 Data analysis**

Qualitative data analysis involves making sense of text and image data. It involves preparing data for analysis, conducting different analyses, understanding the data, representing the data and making an interpretation of the larger meaning of the data. Creswell's data analysis spiral process indicates that, instead of a linear approach, the process moves in analytic circles (Creswell, 2009:183.) The data analysis comprised of, planning for recording the data, data collection and preliminary analysis, managing the data, reading and writing memos, generating categories and coding the data, testing emergent understandings and searching for alternative explanations, interpretation and developing typologies (Creswell, 2013:182).

Methods of presenting the data and collection and recording of data were prepared before going into the field. Collection and recording of data was carried out through focus group discussions. The narratives in journals were already in textual format suitable for analysis. The data consisted of field notes and tape recordings. Information was sorted into different types. Data obtained from the focus group sessions through the tape recordings were transcribed and organised. The researcher read through all the transcribed data to get a general sense of the information and converted the data from the files into sentences for analysis.

Data were described and classified, and interpreted and categorised for identification of similarities. Thereafter the data was organised according to different themes. Additional extracts resulting from the narratives in the journals were checked against the themes that emerged from the focus group discussions to identify new themes. Emerging themes were revised until no further themes could be identified. The researcher also identified patterns of meaning held by participants and reduced this to sub-themes. The researcher sought for explanations and identified similarities from the views of the participants. These explanations and similarities were then compared before describing them. The researcher presented data in the findings by means of narratives, themes, sub-themes and quotes from the focus groups and the journals, supported by the literature. The following main categories as set out in table 4.2 were identified.

#### **4.4 FINDINGS**

**Table 4.2: Themes and sub-themes regarding the experiences and challenges of community caregivers regarding patients' antiretroviral treatment adherence**

<b>Category A: Psychosocial challenges and ART adherence of patients</b>	
<b>Themes</b>	<b>Sub-themes</b>
<b>Theme A1: Behavioural challenges</b>	▪ Alcohol and drug abuse

	<ul style="list-style-type: none"> <li>▪ Risky sexual behaviour</li> <li>▪ High risk behaviour is prevalent with the youth</li> </ul>
<b>Theme A2: Psychological challenges</b>	<ul style="list-style-type: none"> <li>▪ Feelings of hopelessness</li> <li>▪ Anger and non-acceptance of HIV status</li> <li>▪ Patients lack motivation</li> </ul>
<b>Theme A3: Physical challenges</b>	<ul style="list-style-type: none"> <li>▪ Patients experience difficulties with self-regulation and self-efficacy</li> <li>▪ Knowledge and beliefs regarding physical complications of ART</li> </ul>
<b>Theme A4: Social challenges</b>	<ul style="list-style-type: none"> <li>▪ Cultural and traditional practices and beliefs influence the patients adherence to ART</li> <li>▪ Discrimination and stigma influence adherence to ART</li> <li>▪ Non-disclosure as a barrier to ART adherence</li> </ul>
<b>Theme A5: Socio-economic challenges</b>	<ul style="list-style-type: none"> <li>▪ Lack of food influence ART adherence</li> <li>▪ Social grants as a barrier to ART adherence</li> <li>▪ Unemployment as a barrier to ART adherence</li> <li>▪ Transportation as a barrier to ART adherence</li> </ul>
<b>Category B: Social support in the context of community care for ART adherence</b>	
<b>Theme B1: Social support</b>	<ul style="list-style-type: none"> <li>▪ The community caregiver as support system</li> <li>▪ The community as support system</li> <li>▪ The family as support system</li> </ul>
<b>Category C: ART interventions and empowerment programmes for community caregivers</b>	
<b>Theme C1: ART Interventions</b>	<ul style="list-style-type: none"> <li>▪ Behavioural interventions</li> <li>▪ Psychological interventions</li> <li>▪ Interventions on a physical level</li> <li>▪ Social interventions</li> <li>▪ Socio-economic interventions</li> </ul>
<b>Theme C2: Empowerment programmes</b>	<ul style="list-style-type: none"> <li>▪ Behaviour change programmes</li> <li>▪ Psychological empowerment</li> <li>▪ Educational empowerment</li> <li>▪ Social support empowerment</li> </ul>

#### **4.4.1 Category A: Psychosocial challenges and ART adherence of patients**

Category A focuses on psychosocial challenges with regard to ART. The analysis revealed a number of psychosocial dimensions influencing ART adherence. According to Wouters *et al.* (2014:146), merely initiating life-saving ART in all eligible HIV and AIDS patients is not sufficient. As a chronic illness, HIV and AIDS require life-long treatment adherence, and thus sufficient attention to the psychosocial dimensions of care and support needs of community caregivers to encourage ART adherence of patients.

- **Theme A1: Behavioural challenges**

The data that emerged in relation to behavioural challenges are divided into three sub-themes, namely alcohol and drug abuse, risky sexual behaviour, and high risk behaviour in relation to the youth. These are being presented in the discussion to follow.

- **Sub-theme A1.1: Alcohol and drug abuse**

According to literature studies, high risk behaviour like abuse of alcohol and other drugs have been associated with poor or no adherence to ART (Coetzee *et al.*, 2011:148; Morojele *et al.*, 2014:522). Community caregivers stated the following about alcohol abuse: *“The main problem is alcohol...If you tell them (patients) to stop drinking alcohol they will say it is my life and I know I will die...and that is not good.”* Some studies have demonstrated that the majority of respondents took medication, even when they drank alcohol (Rao *et al.*, 2007:31).

Community caregivers confirm this and said: *“Some patient’s repeat the same mistakes... my client defaulted because she does not take the pills when she is drinking alcohol...Most of them (patients) they abuse alcohol...So they don’t have time for their medication.”* This was echoed by another respondent who said: *“Because of alcohol abuse the patient will go to bed drunk...They don’t want to drink the pills the next day...It causes them to default.”*

ART and non-adherence may be associated with the chaotic lifestyle of people who abuse drugs and alcohol (Coetzee *et al.*, 2011:148). One of the respondents describes it as follows: *“When my patient drinks, her boyfriend gets abusive...He beats her up in front of the children...The client does not want to listen to advice...She does not have ID and the children do not have birth certificates.”*

Based on the narrative reflections alcohol seemed to be a major factor for patients' non-adherence to ART. However, community caregivers are of the opinion that the problem is spiralling out of control and describe it as follows: *"They (the patients) drink alcohol all the time...They don't want to listen to advice to stop drinking."* Researchers are in consensus that appropriate interventions that will target the risk that alcohol use increases the risk for HIV infection, should be developed and implemented.

➤ **Sub-theme A1.2: Risky sexual behaviour**

In many instances, substance abuse may lead to sexual risky practices and health compromising behaviour. A study done by Hahn *et al.* (2011:5) on alcohol's effect on the HIV epidemic in Sub-Saharan Africa indicated that alcohol consumption is associated with risky sexual behaviour and an increased risk of HIV-infection. Alcohol consumption reduces a person's ability to make informed choices concerning safer sex and protection from HIV infection (Inungu & Karl, 2006:4). The following quotations describe the problem from the view of the community caregivers. *"Some girls participate in unprotected sex knowingly and spread the virus...They say they cannot die alone...In that way they are spreading the virus...If you take part in unprotected sexual activities you will not drink your medication regularly."* Other respondents stated that: *"They (men) will use the girls and give them drugs (Tik) to sleep with them and spread the virus. They say nothing will happen because they who are HIV-positive will live longer than other people."*

➤ **Sub-theme A1.3: High risk behaviour is prevalent with the youth**

Community caregivers indicated that high risk behaviour is especially prevalent among the youth. They said: *"The youth take drugs and ART on its own is a drug... The youth drink alcohol and take medication or take medication and then go out to drink...It is very dangerous for the body...It is a risk and they can die."* In this regard, Heyer and Ogunbanjo (2006:8); Matchtinger and Bangsberg (2006:9) and WHO (2003:28) claim that younger, non-white persons in a lower income bracket, with lower literacy levels and with unstable housing, are usually associated with non-adherence in resource poor countries. According to the previous literature research, age was found as a predictive factor with adolescents, who struggle to adhere to ART, compared to adults. This is consistent with the findings of this research study. The above findings also confirm that appropriate interventions, targeting the risk of alcohol use and high-risk sexual behaviour, which increases the risk for HIV infection, should be developed and implemented. From these narrative reflections, it can be concluded that the youth especially engage in high risk behaviour.

• **Theme A2: Psychological challenges**

From this study, it is evident that psychological problems manifest itself in different ways as expressed by the following quotation: *"Some patients who drink medication want to get well but*

*inside they are wounded.*+ Studies by Nakimuli-Mphungu *et al.* (2012:2115) and Yeyi *et al.* (2014:1485) found that people with HIV and AIDS are subjected to numerous stressors that can impact their mental health leading to depression.

➤ **Sub-theme A2.1: Feelings of hopelessness**

According to Nakimuli-Mphungu *et al.* (2012:2115), depression is associated with feelings of hopelessness with the loss of will to care for the self. Based on the responses of the community caregivers, depressive behaviour of patients is a major barrier for optimal adherence to medication. The following was said: *“Some patients they don’t see why they should take treatment because they don’t get cured.”*

➤ **Sub-theme A2.2: Anger and non- acceptance of HIV status**

Anger and non-acceptance of HIV-status was particularly perceived by community caregivers as a major barrier to adherence of patients to medication. Most caregivers agreed that individual acceptance of HIV positive status is required for optimal adherence to ART. However, patients experienced difficulty accepting their HIV status as expressed by the following statement. *“Patients cannot accept their status...”*

They said: *“They (patients) are angry of taking pills every day... they want their life back before they were drinking the pills.”* Interventions are needed, since it influences their ability to take their medication as required from them. Other community caregivers stated the following: *“Many patients who are on antiretroviral treatment don’t accept that they are sick and they don’t take their medication as described...For example when they take medication at 8h00 in the morning, they make it 10h00 and that is not good, because the treatment will fail.”*

➤ **Sub-theme A2.3: Patients lack motivation**

According to community caregivers, lack of self-motivation lead to low ART adherence as one focus group participant explained: *“The patients have a lack of motivation... They are not positive... They don’t have self-motivation... They will say I will die at any time.”* Others expressed it in this way: *“Some patients who drink medication are ignorant, because when you check it, by the end of the day they did not take the pills... They have the information and the knowledge, but they are just ignorant.”*

According to WHO (2003:146), how patients experience the psychological impact of ART differs and impacts their motivation for taking drugs. This can either facilitate, or undermine ART adherence. A person’s motivation to adhere as prescribed is influenced by the value the person places on treatment and the confidence he or she has to follow instructions as indicated. A person on treatment may choose to adhere or not to adhere based on his or her understanding of the risks and benefits of the prescribed treatment regimen. When the value of the treatment for a person’s daily functioning is pointed out during routine checkups, motivation is enhanced.

- **Theme A3: Physical challenges**

Physical challenges emerged as difficulties with regard to self-regulation, knowledge and beliefs with regard to the physical complications of ART. The participants highlighted the following challenges:

- **Sub-theme A3.1: Patients experience difficulties with self-regulation and self-efficacy**

Heyer and Ogunbanjo (2006:7) explain self-efficacy as a person's belief in his or her ability to take the medication as prescribed, to manage their condition. Self-efficacy or the sense of being empowered to change factors affecting one's life also affects adherence behaviour. However this seems to be problematic as experienced by the respondents. They stated: *"Sometimes they (the patients) ask you to go with them to the clinic so they can understand...they ask caregivers to go and explain their problem to the health care workers at the clinic."*

- **Sub-theme A3.2: Knowledge and beliefs regarding physical complications of ART**

A person's knowledge and beliefs about HIV and AIDS and ART can influence adherence (Miller *et al.*, 2010:50; Nachega *et al.*, 2005:198; WHO, 2003:99). Community caregivers stated that patients' fears and beliefs regarding the physical complications of ARVs and the treatment discourage them from taking the medication. They stated that patients have different beliefs regarding the treatment, which influences their adherence to treatment. For example they say: *"Some patient's belief if they take ART, they are going to be malformed...Sometimes they don't go to the clinic."* Community caregivers reported a lack of self-esteem of the patients because of the side-effects. Some community caregivers reported the following: *"They (the patients) said ARV gives side effects like glands so they don't want to go to the clinic because of that."* Literature confirms that for patients without proper education and support side effects may be so severe that they may discontinue their treatment in favour of more immediate relief. Therefore, people on antiretroviral treatment must be educated about the potential adverse side effects they may experience and be advised on how to handle it (Hardon *et al.*, 2006:289; WHO, 2003:98).

- **Theme A4: Social challenges**

Cultural and traditional practices and beliefs, discrimination and stigma as well as non-disclosure are social factors that influence adherence from the perspectives of the community caregivers as discussed below.

- **Sub-theme A4.1: Cultural and traditional practices and beliefs influence the patient's adherence to ART**

Participants were asked to discuss culture in terms of how it might influence adherence of patients. Denial about the existence of HIV disease and denial about a HIV positive diagnosis as illustrated in the studies of Dahab *et al.* (2008:3) and Aspeling and Van Wyk (2008:6) were also reflected by community caregivers as a major problem. According to community caregivers, patients indicated that they would rather revert to traditional medication. *“Some patients will use medication from the traditional healers... It is not good for them.”* Other patients prefer not to take the medicine or use both, which will compromise their health like expressed in the following statement:

*“Others say that ARV’s is not for them... They say they belief in traditional medication to heal them... Some of the patients use both”... Patients have beliefs that ART has complications and feel that traditional medicine is better.”*

Patients will not take their treatment, because they do not believe that HIV is the cause of their illness. They believe they were bewitched and that the HIV virus has nothing to do with their illness. According to community caregivers more patients are resorting to explanations for their sickness, such as witchcraft. Community caregivers echoed this in statements like the following: *“The patients don’t want to find out that they are HIV positive. They say it is witchcraft...They are not HIV positive.”*

➤ **Sub-theme A4.2: Discrimination and stigma influence adherence to ART**

Fear of being stigmatised and not disclosing HIV status, are factors that negatively influences adherence in Sub-Saharan Africa (Frank & Duncan, 2009:4; Inungu & Karl, 2006:2; Nachega *et al.*, 2005:200). Participants revealed that patients are affected by stigma at home and in the community. This affects their adherence to ART. Many patients experience fear of being recognised as an AIDS patient and do not want to access services due to stigma. This is summarised by community caregivers as follows: *“Some patients don’t go to the clinic, because they are afraid of stigma, so they don’t collect medication at all... They say that other people notice that you get medication from the clinic, because they group people at the clinic.”*

This is supported by literature studies which found that stigma can, among other things discourage people from being tested, impede access to treatment and other health care services, undermine adherence to treatment and discourage disclosure (Inungu & Karl, 2006:2). Respondents agreed that as patients do not feel accepted, this may lead taking the medicine secretly. Some respondents perceived the integration of ART with other health services as exposing them to the likelihood of being stigmatised. *“Some patients are going to the hospital and are worried about who will see them going there...Some of them say the caregivers must fetch the medication for them.”*

➤ **Sub-theme A4.3: Non-disclosure as a barrier to ART adherence**

One important psychosocial factor facilitating ART adherence is the patients' decision to disclose to others their HIV status and need for ART. Patients who disclose their status to others close to them do not have to take their pills secretly. Secrecy is something that can result in treatment defaults. Non-disclosure emerged as a barrier to adherence. When the patients are in a state of denial it is difficult to disclose to others and medicine are hidden from friends and family as experienced by community caregivers who said: *"You will find that some patients will hide their medication from the family."* Failure to disclose could be because of fear of stigma, fear of being discriminated against and abandonment. Respondents stated that: *"At home the patients are stigmatised and are blamed for being HIV-positive...family members will say to the patient if you were not irresponsible you would not have been HIV-positive... It is mostly stigmatisation from home which makes it difficult for patients to take their pills."* Others stated: *"Some patients are also ignorant, because they don't want their partners to know their HIV status."* This confirms the study by Vu *et al.* (2012:136) who found a lack of disclosure of patients' HIV status to their partners.

- **Theme A5: Socio-economic challenges**

Lack of food, social grants, unemployment and transportation came out as challenges for adherence of patients to ART.

- **Sub-theme A5.1: Lack of food influence ART adherence**

In this study, lack of food was cited as a main problem and affected adherence. According to the community caregivers food complicated adherence and lead to non-adherence. Community caregivers experienced that patients have a lack of food: *"As a caregiver sometimes when I visit a patient they are alone...they don't have food and they cannot take medication."* Others stated that: *"Most of the times they (patients) complain about not having food and cannot take the medication...When they see us they want food parcels...Now we are busy helping them with food gardens so that the patient can adhere to ART."*

Literature, (Kagee *et al.*, 2011:85; Skovdal *et al.*, 2011:303; Tuller *et al.*, 2010:780) confirms that socio-economic factors play a substantial role in people's decisions about their health. Patients who struggle with food, and attending monthly consultations are less likely to adhere and therefore more likely to experience opportunistic infections (Hardon *et al.*, 2006:9; Kagee *et al.*, 2011:4). Recent research studies confirm the importance of nutrition in ART adherence. Patients receiving food assistance had higher adherence than patients who did not receive nutritional support.

- **Sub-theme A5.2: Social grants as a barrier to ART adherence**

Research studies also found that disability grants are sometimes the only source of income for some people on ART. Research done by Kagee *et al.* (2011:86) and Leclerk-Madlada

(2006:251) found that the qualifying criteria for the disability grant for people on ART poses a major challenge. Community caregivers reflected the following: *“Poverty also makes the patients not to drink the medication...They don’t have much to eat...Also others do not even receive the grant.”*

Some caregivers are concerned that some patients do not want to drink the medication because they are scared they will lose the grant. This is described in expressions like the following: *“Some patients don’t want to drink the pills... they want to default so they can get the disability grant.”* However, some community caregivers regard the grant as having a positive effect for improving the life circumstances of patients. They stated: *“Some patients don’t misuse the grant... If they don’t have the grant they will apply for the grant.”* However, some patients are of the opinion that the grant cannot fulfil all their needs: *“Some of the patients say the grant does not help, because it is too little.”*

➤ **Sub-theme A5.3: Unemployment as a barrier to ART adherence**

Community caregivers stated that patients are not in a position to work, because of their condition. *“This influences them negatively...“They can’t work....They only rely on grants.”* Others said that patients reported that taking the medication influence their ability to work. They stated: *“Some patients say you can’t work and also drink medication, because it is difficult to do so...You forget about the pills.”* Research studies done by Barnighausen *et al.* (2007:8) and Coetzee *et al.* (2011:148) revealed that loss of a job and wages is of great concern for patients on antiretroviral treatment. Individuals with employment may have to choose between attending clinic and paying rent or feeding their children and therefore do not disclose their status to the employer.

➤ **Sub-theme A5.4: Transportation as barrier to ART adherence**

Two of the most commonly reported ART-related expenses across sub-Saharan Africa are transportation and additional food requirements (Kagee *et al.*, 2011:85; Skovdal *et al.*, 2011:303; Tuller *et al.*, 2010:780). The study by Kagee *et al.* (2011:85), on structural barriers to ART adherence in South Africa, found problems with regard to access to transport as a major barrier. In this study, transportation was established as a barrier for both community caregivers and the patients. Community caregivers described the problem as follows: *“Sometimes the clinic does not have medication so they refer you to the local chemist, but that time you don’t have transport.”*

#### **4.4.2 Category B: Social support in the context of community care for ART adherence**

Community caregivers regarded social support as important for adherence. The following emerged from the study:

- **Theme B1: Social support**

Availability of social support is crucial for good adherence to ART. This subsection will highlight the important role played by social support. These issues are presented under support from the community caregiver, community and family support. For this study social support in HIV infection may also be described as the assistance offered to HIV-positive persons by their social network as opposed to a professional and is often associated with improved health outcomes (Ncama *et al.*, 2008:1758; Yeji *et al.*, 2014:1483).

The study by Gilbert and Walker (2009:1127) found that adherence rates are increased by significant others. People who live alone and who have poor social networks are less likely to be adherent (Heyer & Ogunbanjo, 2006:8). According to Nachega *et al.* (2006:129) short-term support patients in their early stages of ART should be assisted with regard to physical adjustment. This requires physical and emotional support. Long-term support should focus on empowered living, meaning having the necessary motivation, support and knowledge to sustain adherence.

➤ **Sub-theme B1.1: The community caregiver as support system**

The shortage of human resources prevents the provision of much needed additional adherence support to patients (Van Damme *et al.*, 2008). Sustainable treatment strategies thus require the mobilisation of additional human resources. Researchers assessed the impact of adherence support interventions on a wide range of ART outcomes in resource-limited settings characterised by a prevalence of HIV. These research initiatives suggested that the support provided by community based caregivers could significantly improve ART outcomes and is much needed in the assessment of adherence support interventions (Wouters *et al.*, 2012; Wouters *et al.*, 2014:14).

The community caregiver plays an important role in home community based care. This came to light through expressions by community caregivers. According to community caregivers they are viewed as an important support system at community level and stated that: *“Some patients were bedridden... but when they are well they will remember you, because you stood by the patient and are valued as important in the patient’s life.”* Caregivers stated that the patients and community acknowledge the important tasks that they play in supporting HIV positive patients on ART. Some of the community caregivers’ narrative reflections are that: *“Some patients have a lack of support... The treatment has side-effects... The patients don’t have support...Some only have children in the house... The children don’t know how to help them... Some of them are still small...They look to us caregivers for support...If you go through the side-effects you need somebody to support you and take you to the clinic.”* This is consistent with the findings of the study by Cornett (2008:58) in Uganda, where it was found that some patients only have children as a treatment supporter and they are alone at home.

The community caregivers carry out a wide range of activities, assisting people in need of care in their communities. The role of community caregivers include linking the community with resources and service, spreading health information, mobilising people to determine their health needs, raising awareness about disease, identifying and treating minor illnesses and acting as agent for change and development. One community caregiver reflected in the journal: *“Some patients don’t have care...so I give them support so that they feel accompanied by someone and not feel alone.”*

There was general consensus that the services of the community caregiver enhance ART adherence and assist that patients understand the importance of adhering to their treatment. Caregivers described their duties as follows: *“We make sure they get the medication. If necessary we collect the medication for them at the clinic... The clinic gives us a list of the defaulters and we go and look for them... Sometimes we come along with the card and get the medication.”* Community caregivers specified other services rendered: *“We assist them (the patients) not to forget to drink their pills...We do lay-counselling... “We tell them about the treatment and adherence.”* Most of the services are in line with the services of the community caregiver as outlined in the studies by Wringe *et al.* (2010), Weidle *et al.* (2006), The Caregivers Action Network report, South Africa (2013) and Zacharia *et al.* (2009).

Community caregivers stated that there are also other factors in the community that affects them. Some respondents spoke about the demands of the job. They stated: *“Some caregivers take medication late... You can promise patient to bring information... Then you take your own time to come back to the client...Caregivers have high workload...There are factors affecting them not to do their job properly”.*

The patients sometimes display aggressive behaviour and rejection towards the caregiver. The rejection is displayed by chasing the caregiver away when he or she visits. Caregivers stated the following: *“Some patient’s don’t want us to visit them”* and *“Sometimes they chase us away.”* Community caregivers also report about the relationship with patients. Some has a good relationship, others not. As stated by one community caregiver in the journal. *“I don’t have good relationship with my client...He is very angry...Sometimes he chases me away.”* Others feel saddened and emotional because of the circumstances of their patient and expressed their own feelings towards their situation: One respondent wrote in the journal *“You suffer as well, because seeing someone who is sick is sad... I wish I can do more so that I can save them.”* I also realise that: *“Firstly I have to accept myself ....than I can talk to other people.”*

With regard to caregivers’ association with other services in the community, they stated: *“We work hand in hand with the counsellors and refer the cases that we cannot deal with....we are working with the community health workers...they supply us with medication and we take the medication to the patients who are not able to go to the clinic.”* This confirms literature that

states that personnel shortages impact negatively on the implementation of ART programmes and insufficient human resources place more stress on the limited staff available (Schneider *et al.*, 2006:20); Van Damme, *et al.*, 2008:2109).

As reflected in this study, community caregivers experience challenges with regard to the demands of the work they are doing in the community. Some researchers (De Saxe Zerden., 2006:42-43; Singh *et al.*, 2011:840) have demonstrated that caregivers often experience negative consequences of HIV stigma, feel highly burdened and experience mental and physical health problems because of the demands of their jobs. It is therefore clear that interventions in this regard are needed.

➤ **Sub-theme B1.2: The community as support system**

Community members appreciate the work done by caregivers and see them as role models in the community by helping patients to recover and live a normal life as well as seeing patients survive. Overall community caregivers felt that they are well accepted in their communities which can be illustrated by the following: *“The patients and others in the community know us and know that we check how they take the medication.”*

Community caregivers agreed that an increase acknowledgment and information of the HIV problem in the community has made it easier for them regarding service delivery. The community is well sensitised about HIV and AIDS. Perceptions of the community towards community caregivers regarding facilitating ART adherence are important. The following narrative statements indicated the experience of community caregivers in view of their day to day tasks in rendering services to the community. *“The best support comes from the community... the community is the best motivator for them (the patients) to adhere to their medication...the community has changed. Now they have the information... Workshops brought changes to the community... not only for the caregivers.”*

➤ **Sub-theme B1.3: The family as support system**

The family plays an important role in adherence. According to researchers, family support, communication between family members, parental involvement, family dysfunction, stable living situations are factors that determines adherence. In a family where there is poor communication and little support, especially with regard to HIV positive children, it influences adherence negatively. Families must therefore be included in discussions to improve adherence (Bhana *et al.*, 2014:8).

HIV and AIDS care and support activities extend well beyond the needs of the HIV positive person and often include dynamics including the whole family (Wouters *et al.*, 2014:146). According to community caregivers, family members sometimes demonstrate negative attitudes, and refuse to provide care for a family member with AIDS. A number of challenges were

reported by community caregivers. The lack of family support was described as a big challenge. Community caregivers said: *“The family is not supportive... Support should start with the family, sometimes the family is there other times not.”*

Participants also said that patients experience discrimination from their families. *“You know some family will blame you... The family will normally say that the patient lived an irresponsible life... It is because of this and that you became HIV-positive.”* One participant stated in the journal: *“The families don’t care as much for the patient.... They leave them in the bedroom, alone with food and water...they don’t spend so much time with them...antiretroviral patient need support, love and care... All we (caregivers) do is to be with them for couple of hours, but the family spends so much time with them and is not caring for them.”*

However, they agreed that family support plays an integral part in a patient’s adherence to ART. It is crucial that the family members take part in caring for the patients and are aware and have an understanding of the patient’s treatment regimen so that they can help remind the patient about when to take medication. This will assist the community caregivers who often feel that families have shifted their caring role to the caregiver.

#### **4.4.3 Category C: ART interventions and empowerment programmes for community caregivers**

Interventions regarding ART are very important for the patient and the community caregiver. The following emerged from the study.

- **Theme C1: ART Interventions**

Community caregivers regarded behavioural interventions focused on alcohol abuse, risky sexual behaviour and HIV and AIDS prevention and life skills programmes as important. These issues are discussed below.

- **Subtheme C1.1: Behavioural interventions**

The following behavioural interventions were mentioned by the participants in the study:

- **Alcohol abuse**

Community caregivers proposed certain intervention strategies with regard to ART adherence of patients. Community caregivers agreed that alcohol abuse should be addressed. They stated: *“We should address the problem of alcohol.... We need to teach people to adhere so they should not drink...We should advise them on the dangers of using alcohol and medication at the same time.”*

- **Sexual behaviour change, life skills and prevention programmes**

Efforts aimed at preventing the spread of HIV are at the core of many HIV responses strategies. Prevention strategies seek to bring about behavioural change by encouraging people to learn their HIV status, to take precautions not to transmit HIV to others if they are positive and to protect themselves against HIV infection if they are negative. From the caregivers responses it is evident that sexual behaviour change programmes are needed in the community. They stated: *"We want programmes on abuse, prevention and life skills programmes."*

- **Sub-theme C1.2: Psychological interventions**

The following psychosocial interventions emerged from the study:

- **Emotional care**

According to community caregivers, patients are in need of emotional support. More emotional support programmes should be offered. Based on literature, motivation is associated with adherence-related behavioural skills and these skills directly predicts adherence to ART (WHO, 2003:141). Community caregivers in this study see motivation as an empowerment tool. Community caregivers said: *"We must teach them that there is life after HIV and AIDS and they must drink their pills"*. Motivation must be at the core of all programmes. Another intervention is to start support groups. They summarise it as follows: *"We must open support groups...By opening up support groups you bring different people together so they can learn from each other so they can share problems from hearing others."* However, support groups do have some disadvantages and caregivers said: *"We also wanted to start with the support groups, but they (patients) don't tell the family they are HIV-positive...You will see the sister, aunt or brother come with them to support them...Then they will be afraid that that person will find out that they have the disease... They also say the other family members will ask why they are going to the group."* Kagee (2011) proposed in his interventions that addressing mental health needs is important for improved ART adherence.

- **Sub-theme C1.3: Interventions on a physical level**

Interventions on a physical level included information about ART as well as support for the patient regarding self-efficacy.

- **Information about ART and administering of treatment**

According to community caregivers there is a lack of education on ART. They stated: *"There is less education about the treatment ...that is why patients default...There must be more information on medication."* Based on the UNGASS RSA Progress Report (2013), lack of information regarding ART is one of the challenges. Remarks from the community caregivers show intervention is needed. Community caregivers are in consensus that the community and patients should be empowered regarding ART adherence. Caregivers feel that patients must be

trained on how to administer treatment. Educating the community and the patient about ART is essential. Educational programmes on ART will promote efficacy of the patient and also make families and the community more involved in the care of the patient. Information about disease progression and treatment are less prevalent in these initiatives and is one of the challenges highlighted in the UNGASS RSA Progress Report (2013).

- **Self-efficacy**

The term self-efficacy represents a person's confidence in his or her ability to achieve a specific goal in a specific situation. According to the self-efficacy theory (Kalichman, 2008:683), one is competent and capable of accomplishing a specific behaviour such as adherence. Patients must be trained to go to the clinic and talk about their illness and ART with health personnel. Community caregivers found that patients do not want to take responsibility for their own treatment. They stated: *"Some patients will throw the pills away...You will teach them not to do it, because they drink the pills for themselves and not for the caregiver."*

- **Sub-theme C1.4: Social interventions**

The need for social support as well as family support was regarded as important interventions on a social level.

- **Need for social support structures**

Social support is a critical aspect of living with HIV and AIDS to improve the patient's quality of life, therefore higher social support is associated with higher ART adherence. Studies done in Uganda by Gilbert and Walker (2009:1127) and Cornett (2008:58), regard social networks as important. This is supported by the views of community caregivers who regard a social support network as highly important to people on ART. They stated that: *"If people care for you the person will feel loved and drink the medicine to survive."*

- **Need for family support**

The effects of family dynamics on physical and mental health have been studied for many years. Only a few studies (Rotheram-Borus *et al.*, 2010; Wouters *et al.*, 2014) explored the potential role family dynamics have in the impact of peer adherence support on clinical treatment outcomes. The study outcomes demonstrated interaction affect between peer adherence support and levels of family functioning. The studies associate better family functioning with better quality of life and better adherence levels. According to these studies, it is vital to explore ways to ensure the training of peer adherence supporters, enabling them to adequately tailor their activities to different family contexts. Training should include family counselling and family skills.

Community caregivers indicated a need for the implementation of family empowerment programmes. They stated: *"Support must come from the family...we must teach the family how*

*to care for the patient.*” These interventions are in line with previous research studies, such as the qualitative interview study of Sanjabo *et al.* (2008) in Zambia. In this study, patients and health care providers said that disclosure is a critical factor, usually linked to the support they receive from their families.

➤ **Sub-theme C1.5: Socio-economic interventions**

The following socio-economic interventions were proposed by the participants:

○ **Food security and social security programmes**

According to community caregivers, food security programmes is a facilitator for optimal adherence to ART. Research studies confirm the importance of nutrition in antiretroviral treatment adherence (Hardon *et al.*, 2006:9; Kagee *et al.*, 2011:4; Nachega *et al.*, 2006:131). According to WHO (2013:179) nutritional support increase the success of ART. Research studies also found that disability grants are sometimes the only source of income for some people on ART (Kagee *et al.*, 2011:86; Leclerk-Madlada, 2009:251). Community caregivers agreed that they should assist patients with application for social grants. They said: *“We must assist with application for grants.”*

○ **Support programmes for income generating activities**

Income generating projects were seen as an important strategy as stated by community caregivers who said: *“We must start more food gardens so that patients can adhere to taking medication.”* This is consistent with the findings of Campbell *et al.* (2011) stating that ART patients are in need of income generating programmes.

● **Theme C2: Empowerment programmes**

Proposed empowerment programmes focused on behaviour change programmes, psychological empowerment programmes, educational programmes and social empowerment programmes.

➤ **Sub-theme C2.1: Behaviour change programmes**

Empowerment programmes focused on the following.

○ **Knowledge and skills regarding alcohol and drug intervention**

Community caregivers felt they lacked skills regarding alcohol and drug abuse interventions. The caregivers expressed their worry and need for information regarding general precautions when dealing with alcohol abuse as follows: *“We want programmes on alcohol and drug abuse and life skills for the youth about drugs...We need to be trained on alcohol. It is not easy to stop alcohol abuse.”*

➤ **Sub-theme C2.2: Psychological empowerment programmes**

Emotional empowerment programmes were seen as a high priority and included the following:

○ **Emotional empowerment programmes**

Caregivers expressed their need for information and general knowledge on how to deal with the emotional aspects of the patients as follows: *“We also don’t know how to handle the anger and need training on anger of the patients”*. Another community caregiver said: *I would appreciate if I can get training how to handle people’s anger and frustration”*. Others mentioned: *“How do you deal with that person, because of the mental illness? They are mentally ill because they do not drink the pills and they become mentally unstable.”*

○ **Lay counselling**

Respondents mentioned a need for empowerment programmes on lay- counselling. They said: *“We want more training on lay counselling.”* This will enable caregivers to support the patient to disclose their HIV-positive status if they wish to do so. They are of the opinion that they cannot give support if the family member does not disclose his status to other family members. It is important to capacitate patients and the family on how to cope amidst stress and difficult life circumstances. They must be taught about hope, optimism, problem solving skills, coping abilities and healthy lifestyles. Literature supports this outlook on lay counselling, such as a study by Cornett (2008) in Uganda illustrating the value of counselling for people on ART for improved adherence.

➤ **Sub-theme C2.3: Educational programmes**

Social and health education focusing on a healthy lifestyle as well as education regarding ART were seen as a priority by the participants.

○ **Social and Health education**

It was made clear that community caregivers need knowledge on basic ART. One participant said: *“I want to know everything about the drugs and make them understand why they have to take the medication.”* They also stressed the importance of teaching patients about a healthy life style and one respondent said: *“Patients need to be given information on how a healthy and responsible lifestyle.”* Another participant said: *“I want training on the side effects of ART. The patients fight with us that we don’t understand their situation...Maybe if I have more information I will convince them.”*

➤ **Sub-theme C2.4: Social empowerment programmes**

Another important area for information and skills development focused on empowerment programmes. The following family empowerment programmes were proposed by the community caregivers:

- **Family empowerment programmes**

Family support is a valuable contributor to support the patient on ART. Families have fears with regard to social stigma and isolation, contagion, and fear of abandonment as illustrated in this study. Family and friends often need much counselling and teaching to be able to care for someone at home. It is often the community caregiver who assists the family with this. Participants regarded family support as very important. A citation of another participant shed more light on the importance of the involvement of the family: *“The family must get counselling and information on how to deal with the person who is HIV-positive.”*

Another respondent said: *“The family must accept the HIV-status of the patients and not be judgmental... We must teach them how to treat the HIV positive person...We must do home based care to train the family, because they are scared to get infected.”* Family members need to be trained on HIV...*They are ignorant when coming to things of HIV and AIDS...We need to teach the family how to deal with it.”* Community caregivers expressed their need for skills development regarding relationship building with the patient and between the patient and his family. They said: *“The family must get counselling and information on how to deal with the person who is HIV-positive. They are in agreement that: “We can also teach them how to monitor the patient; how to bath them and how to give them the medication...The family must accept and not be judgmental...We must teach them how to treat the HIV positive person.”*

#### **4.5 DISCUSSION**

The present study applies a qualitative approach to explore community caregivers' experiences and challenges regarding patients on ART. Based on the themes generated, the challenges concerning ART in this research support previous research literature regarding ART adherence challenges. As seen in this study, community caregivers perceived many challenges regarding ART adherence of patients. In particular these challenges can be described as those relating to high risk behaviour, health beliefs, social problems, socio-cultural challenges and socio-economic challenges.

The use of alcohol has been associated with poor adherence. Motivation and self-efficacy were highlighted as main facilitators for adherence to ART. Failure to disclose leads to non-adherence as the patient has to seek ways to secretly take the medicine. Socio-economic factors such as a lack of food influence adherence of patients to ART. According to this study, cultural beliefs play a role in the patients' knowledge of ART and can negatively impact adherence to ART. The study showed that community caregivers are a much needed form of support to patients on ART. They proposed interventions with regard to ART adherence of patients. The findings of this qualitative research highlight the need for interventions concerning

ART adherence for community caregivers and can inform the design of interventions to promote ART adherence.

#### **4.6 LIMITATIONS OF THE STUDY**

- Qualitative research is context-specific and the findings of this study cannot be generalised to other settings.
- The study was limited to only three home community based care organizations. This means that the results of this study may not be applicable to other settings and different factors may be identified that influence adherence of patients, as well as needs for empowerment programmes.
- Some new data may arise when the same research is conducted in other home community based care facilities however, similar studies need to be undertaken regarding community caregivers and ART adherence of patients.

#### **4.7 RECOMMENDATIONS.**

Based on the research findings, the following recommendations can be made:

- The challenges of community based caregivers regarding ART adherence is important for future research and the development of community based ART interventions.
- Studies to explore the psycho-social challenges regarding ART adherence should be encouraged.
- Research on community based interventions for ART adherence should be enhanced
- The use of community caregivers in ART services is seen as a valuable strategy to support adherence of people on ART, therefore more research is needed regarding ART empowerment programmes for community caregivers.

#### **4.8 CONCLUSIONS**

Four main conclusions arise from the findings of this research. These include:

- The explorative qualitative research suggested that adherence is influenced by many psycho-social factors and is important for the development of community based ART interventions.
- The role of community caregivers was seen as vital in supporting patients on antiretroviral treatment. The supporting role of the community caregiver came out strongly in this research and they should be involved in programmes of a psychosocial nature.
- The results showed many psychosocial challenges with regard to ART and it is evident that interventions regarding these issues are needed.

- Further guidance, support, skills development and training are needed to provide and enhance the development of community caregivers with regard to ART support.

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## ARTICLE 4

### DEVELOPMENT OF AN EMPOWERMENT PROGRAMME FOR COMMUNITY CAREGIVERS TO FACILITATE PATIENT'S ADHERENCE TO ANTIRETROVIRAL TREATMENT

Mokwele, R.M and Strydom, H

Mokwele, R.M. is a PhD student and Social Worker at the Department of Social Development (North-West Province) and Strydom, H is a Professor in Social Work at the North-West University (Potchefstroom Campus) and a researcher in COMPRES (Community Psychosocial Research Unit).

#### **Abstract**

Literature have indicated that adherence to antiretroviral treatment (ART) has become a significant issue which increased with ART roll-out. Adherence to antiretroviral treatment poses a great challenge, especially in the absence of a cure. Presently ART is the only available option that offers the possibility of dramatically reducing HIV and AIDS-related morbidity and mortality, while improving the status of people living with AIDS. Communities take more responsibility for the care of people living with HIV and AIDS. The task-shifting to lay community caregivers is increasingly suggested as a potential strategy to overcome the barriers to sustainable antiretroviral treatment scale-up in high HIV-prevalence resource limited settings and to overcome the human resource shortage. With the realization of the central role played by community caregivers regarding adherence and the success of ART this article focuses on the development of a social work empowerment programme for community caregivers to facilitate patients adherence to antiretroviral treatment.

#### **Key words**

Antiretroviral treatment, community caregiver, HIV and AIDS, empowerment, systems theory

#### **5.1 INTRODUCTION**

The overall goal of this qualitative study was to develop an empowerment programme for community caregivers to facilitate patients adherence to antiretroviral treatment. Literature and programmes studied focused mainly on the health aspects and not necessarily the psychosocial aspects of ART adherence. It is important that the psychosocial factors, that may influence ART adherence of patients be addressed.

According to WHO (2013:5) many lives have been saved through a massive scale-up of antiretroviral treatment in the last few years. Recent studies have indicated that people living

with HIV and AIDS should be empowered towards self-management of their illness. Self-management is an essential component of early treatment. This includes equipping individuals with skills and resources they need to make changes in their behaviour and teaching them about lifestyle and health decisions which may delay disease progression and maximize quality of life. There is increased interest during the past decade in the role of community based educational and self-management programmes aimed at adherence (Mahungu *et al.*, 2009; Wouters *et al.*, 2012).

The study of Kabore *et al.* (2010) focus on the role of community caregivers with regard to empowering patients towards self-management and includes home based care, nutritional advice drug literacy, training, prevention education, management of ART side -effects and general treatment guidance. Research by Van Damme *et al.* (2008) have indicated that overburdened health staff often have difficulty in conveying the practical skills required for practicing a more patient-centered and less technical model of patient care that is aimed at empowering people living with HIV and AIDS for informed day-to-day decision making.

This article focuses on the empowerment of community caregivers by means of a social work empowerment programme through group work. According to Zastrow (2010:45), group work seeks to facilitate the intellectual, emotional, and social development of individuals through group activities. The information-motivation-behavioural skills model (IMB model) and systems theory has been influential for the empowerment programme. The focus is on empowerment of the caregivers through information, motivation and skills building to attend to patients on ART. Elements common to all models of empowerment includes individual empowerment through personal development, collective empowerment through validation of individual experiences, raising consciousness, and social action. According to the systems theory the focus is on the person-and- situation as an interrelated whole. A person is viewed as an integral part of his or her life situation (Compton *et al.*, 2005: 24). In the systems theory we strive to understand the interaction between a client and other social systems. For the purpose of this study, systems are seen as the patient, community and the community caregiver.

## **5.2 PROBLEM STATEMENT**

Lack of adherence to ART is one of the main causes for failure of treatment worldwide. The shortages of human resources have been a problem in ART roll out and support for people on ART in resource-limited settings. Due to the scarcity of social workers, the assistance of lay councilors is needed to attend to patients on antiretroviral treatment, especially with regard to adherence. The impact of HIV and AIDS on a psychosocial level as found by Wessels (2003) is mainly associated with psychological conditions such as depression, stigma, rejection, discrimination and social indicators such as poverty, financial burdens, high prevalence of

orphans, substance abuse and the availability of support systems. In order to increase adherence to ART, efforts need to be made to ensure continuous monitoring through ART adherence support accomplished through the use of community caregivers.

Community caregivers provide psychosocial support and lay counselling, education on HIV prevention and provide care and treatment to people living with HIV and AIDS. Community caregivers also conduct home visits to trace patients who have missed appointments or to provide adherence support, as well as assist with issues such as disclosure, HIV and AIDS prevention, stigma reduction, and improving adherence to care and treatment of which also impact negatively on them. The need for an empowerment programme was identified to strengthen the knowledge and skills of community caregivers regarding psychosocial support for patients on antiretroviral treatment to equip caregivers with knowledge of self-care and to enhance their support to patients on ART. The ultimate goal caregivers' insights and care will enhance patients' ability to understand, and adhere to their medication regimen. There is also a need to educate the community and families about ART and adherence.

This empowerment programme focused on a group work empowerment approach. Empowerment programmes are essential for community caregivers working with patients on ART, therefore they need to be knowledgeable, and empowered to assume the role of enabler through the support of the social worker. With regard to this study, the researcher's aim was to answer the following question: *What should the content be of a social work empowerment programme for caregivers regarding the adherence of patients on antiretroviral treatment?*

### **5.3 AIM AND OBJECTIVE**

This study was aimed at designing an empowerment programme for community caregivers to facilitate patients' adherence to antiretroviral treatment (ART). The literature and qualitative needs assessment identified many psychosocial challenges regarding patients' adherence to ART. It is important that the psychosocial challenges regarding ART adherence be addressed and community caregivers be equipped through the development of knowledge and skills.

### **5.4 RESEARCH METHODOLOGY**

#### **5.4.1 Research design**

This study focused on the intervention research model. According to De Vos and Strydom (2011:475) intervention research is an applied action taken by a social worker or other helping agent, usually in concert with a client or other affected party, to enhance or maintain the functioning and well-being of an individual, family, group, community or population. De Vos and Strydom (2011:476) divides the intervention research model into six phases, namely, problem

analysis and project planning, information gathering and synthesis, design, early development and pilot testing, evaluation and advance development and dissemination. Phase 1 of the research focused on a literature study which revealed information based on the overall challenges with regard to antiretroviral treatment. Phase 2 focused on a phenomenological study to explore community caregivers' experiences and challenges with regard to patients' adherence to ART and needs regarding an empowerment programme. Phase 3 of the research which is the aim of this article focuses on the development of a social work empowerment programme and on design, early development and pilot testing as set out in the intervention research model.

#### **5.4.2 Participants**

The programme was pilot tested with six community caregivers. A session was presented to them and they had to give their inputs on the programme. Eight social workers of the Department of Social Development were purposely selected to participate in the evaluation of the programme. The opinions of both community caregivers and social workers were collected to be integrated in the final empowerment programme. The inclusion criteria for the purposive sample include the following.

- Male and female home community based caregivers;
- Active involvement in service delivery to patients on antiretroviral treatment;
- Serving home community based care programmes in Potchefstroom (Bambanani Youth Project, Baptist Children's Centre and Hospice Emmanuel Loving Angels);
- At least three months experience working with HIV and AIDS patients on antiretroviral treatment;
- Ability to communicate in English, Afrikaans or Tswana.
- Social workers must have working experience as a coordinator of the HIV and AIDS programme for at least one year; and
- Both male and female.

Potential respondents were recruited by the researcher by means of selection through the databases of the home community based care centres and the Department of Social Development.

#### **5.4.3 Data collection**

A draft of the suggested empowerment programme was given to respondents. During phase one, six community caregivers participated in a focus group session to give inputs regarding the social work empowerment programme. The inputs were used to determine the effectiveness in terms of the practicality of the programme and the adaptability to various contexts of the

intervention as well as to identify which elements of the prototype may need revision. Phase two focused on a peer review with eight social workers giving inputs in the preliminary empowerment programme. These social workers were involved in the HIV and AIDS programme of the Department of Social Development, North West Province. Semi-structured interviews according to a schedule were used. They were asked to rate the content relevance and make suggestions for the improvement of the social work empowerment programme. The questions for the semi-structured interviews were developed after the literature review of phase one and the focus group sessions of phase two of the research. The experiences of and feedback of social workers on the suggested empowerment programme were followed up during semi-structured telephonic interviews. Due to the geographical distance between the researcher and the different participants, it was not possible to conduct individual interviews with the participants.

#### **5.4.4 Data analysis**

Creswell's data analysis process was used to identify themes and to conduct further planning. The data analysis comprised of planning for recording the data, data collection and preliminary analysis, managing the data, reading and writing memos, generating categories and coding the data, testing emergent understandings and searching for alternative explanations, interpretation and developing typologies (Creswell, 2013:182). The data was analysed manually. The participants were allowed to give their views from their own experiences in practice. Their views and opinions of the methods and content of the preliminary empowerment programme were taken into account in order to make adaptations to the empowerment programme.

- **The trustworthiness of qualitative data**

The methods of trustworthiness proposed by Lincoln and Guba (in Babbie & Mouton, 1998:276) were utilised, namely credibility, transferability, dependability and confirmability.

#### **5.4.5 Ethical aspects**

The ethical aspects were taken into consideration and included: Potential harm to participants (Strydom, 2011:115); Justice (Botma *et al.* 2010: 19); Confidentiality (Alston and Bowles, 2007:21) and benefits (Botma *et al.*, 2010:21).

- **Justice**

According to Botma *et al.* (2010: 19) justice means that participants should be treated fairly. No new intervention procedures or techniques that have not been described in the information brochure form should be executed. No information was gathered without the knowledge of the

participants. Informed consent was obtained from the participants (caregivers and social workers).

### ➤ **Confidentiality**

The identity of each participant will be protected. The researcher will be sensitive to the rights of participants and ensure their anonymity, adhere to their right to self-determination and treat all information in a responsible, confidential manner. Community caregivers and social workers will be assured of the confidentiality of the study.

### ➤ **Benefits**

Botma *et al* (2010:21) state that benefits to the participants arise when the participants receive the intervention being studied. In this study the researcher is of the opinion that the caregivers benefited from the empowerment programme as a means of self-development. The social work empowerment was also seen as useful by the social workers. This clearly showed that the benefits outweighed the risk of the study. Community caregivers could also gain insight into their own emotions through the focus group discussions and their participation in the empowerment sessions.

## **5.5 THE SOCIAL WORK EMPOWERMENT PROGRAMME**

### **5.5.1 Rationale and theoretical basis**

The development of the empowerment programme for community caregivers to facilitate patients' adherence to ART was informed by the literature and empirical results studied and obtained through this study. From the literature review it became clear that there are limited empowerment programmes available for community caregivers focussing on the psychosocial issues of patients enabling caregivers to attend to the psychosocial needs of patients on ART.

The rationale of this study was that ART is a challenge for community caregivers. The purpose of this programme therefore was to address the need for community caregivers to actively support people living with HIV and AIDS (PLWHIV) in enhancing antiretroviral treatment (ART) adherence. The programme also aims to empower the community caregiver regarding self-care. Community caregivers are engaged with PLWHIV in their communities. This empowerment programme aims to enhance their knowledge and skills with regard to psychosocial care to PLWHIV. Upon successful completion of this programme, it was envisaged lead to the improvement of the circumstances of families, groups and communities by increasing their personal, interpersonal, socio-economic and political strengths. Empowerment is therefore defined as the process of helping individuals, families, groups and communities to increase their personal, interpersonal and socio-economic and political strengths and to develop

influence toward improving their circumstances+ (Zastrow, 2010:52). According to Du Bois and Miley (2005:54), empowerment is a process of releasing the potential and strength of social systems and discovering and creating resources and opportunities for promoting effective social functioning in client resolution of problems, issues and needs

Hepworth *et al.* (2002:438) define empowerment as enabling groups or communities to gain or regain the capacity to interact with the environment in ways that enhance resources to meet their needs, contribute to their well-being potential and life satisfaction and provide control over their lives. This definition of empowerment supports the overall goal of the study, namely to empower community caregivers to render social intervention services to people living with HIV and AIDS on antiretroviral treatment to enhance adherence. Social workers have the responsibility to empower those who are engulfed by the weight of their circumstances. This is related to the strengths perspective, which focuses on the strengths of every individual, group, family or community. It is the social worker who believes in the patients' strengths and guide them to begin the climb toward transformation and growth (Zastrow 2010:52).

By means of systems theory, social workers intervene by looking at a holistic view of people and their environment and bringing the concept of person-in-environment back into perspective (Compton *et al.*, 2005: 24). The systems theory according to Toseland and Rivas (2012:57) attempt to understand the group as a system of interacting elements. Therefore groups are in constant interaction with their environment (Toseland & Rivas 2012:5; Zastrow, 2010:351).

### **5.5.2 Group work as method of empowerment**

According to the literature review, patients' adherence to ART challenges poses challenges to community caregivers. A social work empowerment programme was developed according to the needs of the community caregivers. This programme was based on the focus group sessions and the literature reviewed on challenges regarding ART of patients. In working with group members, such as community caregivers working with patients on ART, the social worker focuses on each individual's strengths and resources to help them resolve the difficulties they experience in their daily lives. The social worker should identify the strengths of group members in order to use such strengths effectively emphasising the clients' resources, capabilities, support systems, and motivation to meet challenges to overcome adversity. This approach does not ignore the existence of social problems, individual disease or family dysfunction. It emphasises the clients' strengths that are used to achieve and maintain individual and social well-being (Zastrow, 2010:52).

According to Toseland and Rivas (2009:12), group work can be defined as an approach that is goal-directed in small groups, aimed at accomplishing tasks and meeting their socio-emotional needs. The activity is directed towards individual members in a group and the group as a whole

within a system of service delivery. In other words, group work is a method used by the social worker who is applied to a group process, dynamics, and mutual relationships and programme media. Corey and Corey, (2002:92-93), Toseland and Rivas (2009:16-17) and Zastrow, (2010: 76-81), identified the following advantages of group work:

- Better problem-solving potential in groups, where there is an exchange of ideas and the development of new approaches to a problem or issue;
- The experience of commonality, where similar interests and goals can be shared in a group;
- Group therapy provides help and mutual support for group members and is therapeutic because members share their experiences and knowledge;
- Groups with social action are important vehicles in facilitating the empowerment of individual group members;
- Groups are convenient, efficient and cost-effectiveness;
- The group increases the members self-esteem, social integration and sense of control;
- The group can develop and strengthen community networks;
- The group dynamics help people to discover and enhance their strengths.

According to Toseland and Rivas (2010:261) programme activities are a medium through which the functioning of members can be assessed in areas such as interpersonal skills, ability to perform daily activities, motor coordination, attention span, and the ability to work cooperatively. Programme activities can therefore be seen as any strategy with relevant procedures and a certain time-frame aimed at accomplishing a particular objective. The procedure for selecting programme activities is as follows:

- Specify programme activities that are consistent with the group purposes and goals.
- Specify the objectives of the programme activity;
- Specify programme activities that can be performed, given the available facilities, resources and the time;
- List potentially relevant programme activities, based on the members' interests, motivation, age, skills level, physical and mental state and attention span;
- Classify programme activities into:
  - Characteristics of the activity;
  - Physical requirements of the activity;
  - Coordination and strengths;
  - Social requirements of the activity, e.g. interactional, verbal and social skills;
  - Psychological requirements of the activity, e.g. expression of feelings, thoughts and motives.

Programme activity that is best suited to achieve the objectives specified should be selected. For the selection of the programme activities, appropriate programme activities were selected based on the findings and recommendations of the literature review and the phenomenological study with the community caregivers. In this way the needs of the group members corresponded with the potential programme activities (Roux 2002:186; Toseland & Rivas, 2010:261). In selecting members for the social work empowerment programme, the relevant programme activities were taken into account as well the members' willingness to participate in the programme, their age, physical and mental or psychological state, their level of literacy and their concentration span. The content of the full programme is presented in table 4.1. The methods of teaching used in programme implementation included the following:

**Group participation**-It is evident that people learn best, when they participate in the learning rather than be passive observers. Reinforced learning leading to behavioural change is best accomplished through the active participation of the learner. The ultimate goal, of this process is to empower members so that they can take charge of their lives, both inside and outside of the group. The social workers therefore show their beliefs in members' strengths (Zastrow: 2010:78).

**Group discussion**-The group discussion is a purposeful discussion under the guidance of a social worker in which all the members of the group are involved in order to promote their social functioning. This method is useful when group members feel comfortable with one another and individuals are not hesitant to speak. Group discussions expose group members to the beliefs, values and practices of others. One of the best ways to encourage group discussions is through problem posing and problem solving. In this instance one give group members a case study or a scenario to analyse and discuss (Zastrow: 2010:78).

**Story-telling and sharing ones experiences**-These can be effective methods of learning. People like to hear about the experiences of others, and often find that they can relate to these experiences. Fictional stories are also helpful in sharing important messages.

#### **Role play and stimulation**

Role playing is a technique in social work where reality is simulated with a view to enable the group members to develop insights, learn skills, cope with feelings and to practice, interpret and modify modes of behaviour (Toseland & Rivas, 2010:105; Zastrow: 2010:80).

**Visual aids**-Posters, photographs pictures, overhead projection, slide presentations videos and works of art can all be powerful educational tools. Discussions can be guided by means of such aids. For example, the group can be asked what the visual aid meant to them, what they liked or disliked about it and what they found disturbing and helpful.

**Learning aids**-Flip charts, fact sheets, flesh charts, wall charts and drawings done by the group or others, diagrams tables and graphs provide clear and easy access to information. These aids can be used to stimulate group discussion. For example, questions such as what does the drawing tell you; or what is missing from this information can promote discussion.

## 5.6 The suggested social work empowerment programme

**Table 4.1: The suggested social work empowerment programme**

<b>Session</b>	<b>Topic</b>	<b>Programme activities</b>
<b>Session 1</b>	Welcoming and Introduction to empowerment programme	Welcoming Measuring scale Post-test Ice breaker Group discussion Contracting
<b>Session 2</b>	ART and adherence	Group exercise Presentation Brainstorm Group discussion
<b>Session 3:</b>	The community caregiver and psychosocial and adherence support	Group exercise Presentation Case study Group discussions
<b>Session 4:</b>	Communication and lay counselling	Group exercise Presentation Group discussions Role play
<b>Session 5:</b>	Providing psychosocial and adherence support	Group exercise Presentation Group discussions Assessment tools Case study
<b>Session 6:</b>	Disclosure	Group exercise Presentation Group discussions Case study
<b>Session 7:</b>	Mental health and substance abuse	Group exercise Presentation Group discussions Case study Role play

<b>Session 8:</b>	Positive and healthy Living	Group exercise Presentation Group discussions Role play Evaluation Termination Completion of measuring scale
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### **5.6.1 Session 1: Welcoming and introduction to the empowerment programme**

#### **5.6.1.1 Session Content**

- Welcoming and introduction to the empowerment programme;
- Goals and objectives of the empowerment programme;
- Establish ground rules.

#### **5.6.1.2 Session objectives**

- To help participants to get to know each other and help them feel more comfortable;
- Become familiar with goals, objectives of the empowerment programme;
- To explain the content of the sessions;
- To become aware of their own expectations, assumptions and concerns about their role as caregivers;
- To complete the measuring scales and pre-test.

#### **5.6.1.3 Session activities**

##### **➤ Introduction to empowerment programme**

This session is designed to help participants get to know one another and to help them feel more comfortable sharing personal feelings and experiences. Participants are asked to stand in a circle. Each person should state their name, and the meaning of their name, the name of the organisation where they work and a description of their work. This is used as an ice-breaker to set a welcome and positive atmosphere of warmth and acceptance. The introduction serves as a starting point for interaction to get to know and to feel at ease with one another. It also helps to develop group cohesion (Toseland & Rivas, 2009:74-75). After the introduction session, participants are asked to deliberate questions in exercise 1 in a large group based on concerns regarding people living with HIV and AIDS and general observations in the community regarding people on antiretroviral treatment. Participants are allowed 10-15 minutes for feedback on the discussion and responses are written on a flip chart. Next, they are asked to deliberate on the questions in exercise 2 in a large group, based on what are your attitudes regarding people

living with HIV and AIDS and ART?+and %What do you think is your general knowledge and skills with regard to HIV and AIDS and ART?+They are allowed 10-15 minutes for feedback on discussion and responses will be written on a flip chart.

➤ **Goals and objectives of the empowerment programme**

The goals and objectives as well as the purpose of the empowerment programme, are outlined after which the content and structure are discussed. Contracting takes place during this session. According to Toseland and Rivas (2009:171) contracting usually results from the dynamic interaction of the social worker and the group members during the beginning stage of the group. The facilitator provides an overview of the core knowledge and skills that participants are expected to have by the end of the programme as well as an overview of the sessions of the empowerment programme.

➤ **Expectations and ground rules**

Participants are informed that the facilitator want to create a space for learning and personal growth. In order to do that, however, the participants must come to some agreements about the ground rules they will follow to ensure the confidentiality and well-being of all the participants. Thereafter ground rules are discussed for implementation during the sessions. Aspects like the place of meetings, the duration as well as the days on which the groups will gather are finalised. Participants also give an indication of their learning expectations and the competencies they want to achieve based on the following questions %What skills do you want to acquire at the end of this empowerment programme; %Why is the improvement of your knowledge and skills necessary to enhance service delivery to the patient on ART?+The group is asked to fill out an expectations sheet at the beginning and end of the sessions. Participants are allowed twenty minutes to complete their expectation sheet.

## **5.6.2 Session 2: ART and adherence**

### **5.6.2.1 Session Content**

- Antiretroviral treatment;
- Adherence to antiretroviral treatment.

### **5.6.2.2 Session objectives**

- To discuss antiretroviral treatment;
- For participants to have a common understanding of the challenges regarding ART adherence.

### **5.6.2.3 Session activities**

#### **➤ Discussion on antiretroviral treatment**

As a large group participants are asked to brainstorm and think about the following questions: What are ARVs, and who qualifies for ART? This is to test their knowledge and will also serve as an ice-breaker to the session. Next, a presentation will be done regarding antiretrovirals and antiretroviral treatment which focuses on the criteria for starting ART and people's eligibility for ART as well as how the drugs work (Evian, 2003:275-290; Van Dyk, 2005:70-87). The next discussion focuses on adherence. Adherence is the term used to describe the patient's behaviour of taking drugs correctly, in the right dose, with the right frequency and at the correct time. A critical aspect of adherence is the patient's involvement in deciding how and when to take the drugs (Harlem adherence to treatment study, 2003:34; Uldall *et al.*, 2004:74; WHO, 2003). Participants are asked as a large group to brainstorm the challenges that clients experience regarding ART adherence. Thereafter the discussion will be clarified by sharing the information in the information sheet, focusing on the difference between clients that adheres to ART and clients not adhering to ART and how caregivers will know when the patient adheres or not to medication. The reasons for non-adherence are outlined with a focus on psychological factors, mental factors, behavioural factors, physical factors, social factors, factors linked to treatment and factors linked to professionals and structures as identified by Coetzee *et al.* (2011:148); Morojele *et al.* (2014:522); Rao *et al.*, (2007:31) and SAFAIDS (2007:19-23). The discussion also focuses on the skills that patients need to be able to adhere to treatment and why treatment support is necessary (Project Pal, 2005:14). Participants will break into small groups and brainstorm on a list of possible challenges that people experience with regard to ART adherence using a case study as an example for practical examples and to improve problem solving skills of the participants.

### **5.6.3 Session 3: The community caregiver and psychosocial and adherence support**

#### **5.6.3.1 Session Content**

- The importance of psychosocial support;
- Psychosocial support services that community caregivers can render.

#### **5.6.3.2 Session objectives**

- To discuss the importance of psychosocial support;
- To discuss the community caregiver as social support system;
- To discuss the psychosocial services caregivers can provide.

### **5.6.3.3 Session activities**

#### **➤ Discussion on the importance of psychosocial support**

As an introduction, caregivers have to brainstorm their understanding of psychosocial support (Blom & Blemridge, 2003:381-390; Gilbert and Walker, 2009:1127; Van Dyk, 2005:145-149). With regard to ART adherence, psychosocial support addresses the psychological, social, and adherence needs of patients, their partners, families, and children. They are also asked to discuss the community caregiver as social support system, and the psychosocial services caregivers can provide. Thereafter, the facilitator does a presentation on psychosocial support. The focus is on the following: What is psychosocial support, what is the importance of psychosocial support and the community caregiver as a social support system. In order to fulfil their tasks, community caregivers must have knowledge, skills and the right attitude. The participants will break into small groups and will be asked to provide definitions of knowledge, skills and attitude, using the information sheet. Thereafter participants will write their ideal knowledge, skills and attitude regarding psychosocial support on small pieces of paper. Thereafter the groups will give feedback and a review of what was discussed in the small groups. The facilitator will do a presentation on knowledge, skills and attitude and examples appropriate for community caregivers to facilitate patients' adherence to ART. The next discussion focuses on why patients need support and interact with other networks. Participants will divide into pairs and take turns practicing how to assess the effectiveness of the other persons' networks. Questions that need to be asked, are: Who are part of these networks? Is regular support provided? How can each one enhance their social support network? The facilitator will lead a discussion on why social support is important.

#### **➤ Psychosocial support services community caregivers can render**

The next discussion focuses on the types of support services community caregivers can render. Community caregiver will discuss their role with regard to psychosocial support to PLWHIV. Thereafter the information in the information sheet will be shared with them focussing on types of support, including the following: Informational support, affirmational support and emotional support (Project Pal, 2005:34; SAFAIDS, 2007:65). The following services can be provided by community caregivers, which include positive living and life skills courses to help PLWHIV come to terms with their HIV status and provide information and skills to gain control over their lives. Lay counselling to help PLWHIV accept their HIV status and prepare for possible repercussions of visibility. Counsellors can refer PLWHIV to other activities and to training to develop their capacity for further involvement. The value of support groups are discussed as well as the types of support groups. The Department of Social Development (2010a) defines a support group as "a formal organised group where participants who are experiencing similar life challenges and problems come together to share their experiences, find strategies to cope and deal life challenges. Support groups are purposeful groups, formed to achieve certain goals. Support

groups empower and support people at various levels, namely spiritual physical and psychological levels, depending on the groups objectives.+

#### **5.6.4 Session 4: Communication and lay counselling**

##### **5.6.4.1 Session content**

- Building relationships with clients;
- Communicating with and counselling children and adolescents;
- Lay counselling skills;
- Listening and learning skills;
- Motivational interviewing and the counselling session.

##### **5.6.4.2 Session objectives**

- To discuss how to build a relationship with clients;
- To discuss communication and lay counselling skills;
- To discuss the basic principles of lay counselling;
- To discuss the counselling process.

##### **5.6.4.3 Programme activities**

###### **➤ Building relationships with clients**

As introduction, participants are asked the following questions:

- Their understanding of what a trust relationship means;
- Some things a community caregiver can do to build trust with clients;
- How do they think their clients feel when they visit them (are they scared, angry, sad);
- How might these feelings affect the clients trust and relationship with the community caregiver?
- Why a trusted relationship is important for improved ART adherence of patients?

The discussion will be clarified by sharing the information in the information sheet as a presentation. The focus is on the following: The factors that influence building a relationship with the client; the emotions clients experience when they seek for help; and what the community caregiver can do to build a relationship with the client (Van Dyk, 2005:176-177). Participants are led through an exercise, which gives them an opportunity to discuss and practice some skills required for building relationships and trust with clients. Participants are asked to review the case study. Two community caregivers are asked to role play the case study. Upon completion of the role play, a discussion is facilitated by the presenter asking the following questions:

- What do you think the client was experiencing in this situation?;
- How did the community caregiver try to build a relationship and trust with the client?

➤ **Communicating with and counselling children and adolescents**

Another point of focus of this session is communicating with and counselling children. A brief presentation and discussion focuses on how the community caregiver can improve communication with children; how does the community caregiver communicate with adolescents; and how can communication with children and adolescents be improved.

➤ **Lay counselling skills**

A discussion is facilitated regarding lay counselling and activities to improve lay counselling skills of caregivers. A discussion follows focusing on what is a counsellor; the values of a counsellor; why do we counsel people; the mistakes in counselling (Evian, 2003:198; Knott, 2003:51-79; Van Dyk, 2005:173-192).

➤ **Basic listening and learning skills-**

The last activity focuses on basic listening and learning skills based on Egans model and the client-centred counselling approach as set out by Dewing *et al.* (2013:207), including the following:

- ✓ Skill 1: Use helpful non-verbal communication.
- ✓ Skill 2: Actively listen and show interest in the client.
- ✓ Skill 3: Ask open-ended questions.
- ✓ Skill 4: Reflect back what the client is saying.
- ✓ Skill 5: Empathise -Show that you understand how the client feels.
- ✓ Skill 6: Avoid judging words.
- ✓ Skill 7: Help the client set goals and summarize each counselling session.

Participants divide into groups of three. Each small group will identify a counsellor and a client. A listening skill is allocated to each group. Each group will choose a scenario, have a discussion and role play based on the scenario. Community caregivers will discuss each of the seven skills in their different groups, and explain why each is important for lay counselling.

➤ **Motivational interviewing and the interview**

Community caregivers will focus on motivational interviewing and practice the interview process through case studies.

• **Family counselling**

Participants must discuss the following in small groups:

- ✓ Their understanding of family counselling;
- ✓ Why is it important to include the whole family in ART matters.

The discussion will be clarified by sharing the information in the information sheet as a presentation with focus on content that did not come up during the discussion. The presentation

will focus on what the role of the family is regarding ART; why is family empowerment regarding HIV and AIDS and ART important; the difference between counselling of the individual versus the family; what are the principles of family counselling; and the structure of a family counselling session (Van Dyk, 2005:229-230). Participants will do an exercise based on the case study to practice counselling the family.

### **5.6.5 Session 5: Providing psychosocial support services**

#### **5.6.5.1 Session content**

- The needs of clients regarding psychosocial and adherence support;
- Assessing psychosocial support needs.

#### **5.6.5.2 Session objectives**

- To discuss the needs of clients regarding psychosocial support for enhanced adherence;
- To identify strategies to improve psychosocial and adherence support;
- To discuss and practice on how to do an adherence assessment;

#### **5.6.5.3 Programme activities**

##### **➤ The needs of clients regarding psychosocial and adherence support**

Group members start with a group exercise on the needs of people living with HIV and AIDS. The focus of the discussion is on the psychosocial support needs of patients. The different types of stigma and discrimination towards PLWHIV are discussed, namely, felt stigma; enacted stigma and self-stigma (Inungu & Karl, 2006:2; Project Pal, 2005:44-45). The causes and effects of stigma and discrimination and how to address it through community based interventions are discussed. For the group exercise, participants divide into two groups and each small group identify how they will address stigma using the case study. One group will focus on community based interventions and the other group will focus on individual intervention. Participants will give feedback after the discussion. Responses are captured on a flip chart.

##### **➤ Assessing Psychosocial Support Needs**

The discussion also focuses on, the psychosocial support needs of patients how a psychosocial assessment is done. The adherence assessment tool is used as guideline in the discussion. Participants will divide into three small groups. A case study will be assigned to each group. Each group will review their assigned case study and identify the important issues in relation to the assessment tool and discussing how they would use the psychosocial assessment tool with their patients (Marston, 2003:122-123; Project Pal, 2005:44-45).

## **5.6.6 Session 6: Disclosure**

### **5.6.6.1 Session content**

- Disclosing to family partners and friends;
- Disclosure and children.

### **5.6.6.2 Session objectives**

- To discuss the methods for disclosing to family partners and friends;
- To learn how to identify negative disclosure experiences.

### **5.6.6.3 Programme activities**

#### **➤ Introduction to the session**

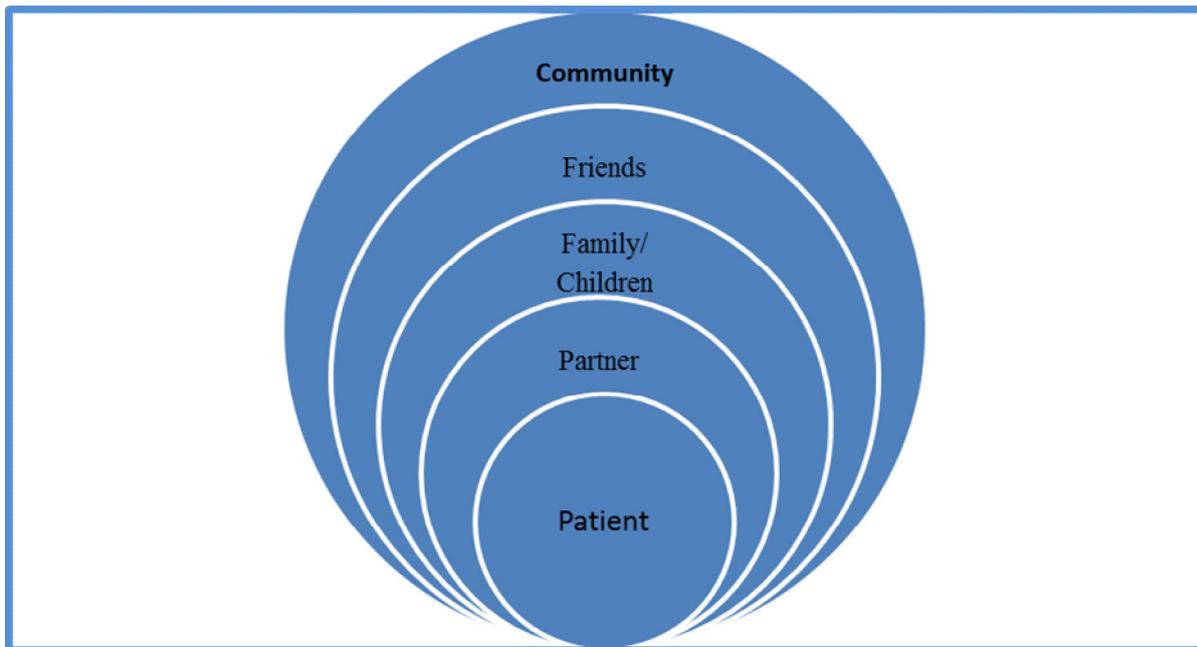
Participants start the session by discussing what disclosure is and why it is important for people living with HIV and AIDS (Nachega *et al.*, 2006:131; International Association of Providers of AIDS care (IPAC)/Pan African Health Organization/ World Health Organization, 2014:15-23).

As a large group participants share the following:

- ✓ Their understanding of what disclosure is and why it is important;
- ✓ The benefits of disclosure;
- ✓ The disadvantages of disclosure.

Participants are asked to do the exercise based on the case study. The facilitator will do a presentation on disclosure, the advantages of disclosure, the disadvantages of disclosure, and decisions about disclosure (International Association of Providers of AIDS care (IPAC)/Pan African Health Organization/ World Health Organization, 2014:194; SAFAIDS, 2006a:34).

These are discussed using the disclosure circle in figure 4.1. The process of disclosure is then discussed within the group followed by some group exercise about disclosure strategies through case studies and role plays. The last point of discussion is disclosure and children and how it should be addressed with a focus on the Children's Act (Children's Act 38 of 2005).



**Figure 4.1: Disclosure circle (International Association of Providers of AIDS Care/Pan American Health Organisation/World Health Organisation: 2014)**

### **5.6.7 Session 7: Mental health, substance abuse and ART**

#### **5.6.7.1 Session content**

- Mental health and people living with HIV and AIDS;
- Substance abuse.

#### **5.6.7.2 Session objectives**

- To identify their own beliefs and attitudes about mental illness and people living with HIV and AIDS;
- To discuss the categories of mental illness;
- To discuss how to recognize when a client may have a mental illness, determine the need for follow up care, and provide appropriate referrals for mental health services;
- To discuss substance abuse and how it can effect adherence to ART.

#### **5.6.7.3 Programme activities**

##### **➤ Mental health and people living with HIV and AIDS**

The session starts with a group exercise on mental health and a presentation by the facilitator. After the presentation, group members discuss mental health, what it is and its influence on ART. Participants discuss how factors such as mental health and substance abuse can prevent

people from taking medications properly; how to recognise these problems; how they may interfere with adherence; and how to refer people for help. The discussion starts by defining mental health and mental illness. Participants brainstorm responses to the following questions: What is mental health; what is mental illness; how do mental illnesses differ from psychosocial problems; and what causes mental illness (WHO, 2006). Thereafter participants do an exercise. The facilitator discuss the following regarding mental health: What is mental health; causes of mental health problems; other factors affecting PLWHIV that contributes to mental health problems; other mental health conditions; recognising the signs of mental illness; telling if someone is depressed; and possible signs and symptoms of anxiety disorders. Psychosocial correlates related to mental health outcomes included family relationships, social support, coping styles and HIV-related worry and stressors. Other problems were identified that can influence mental health (DuBois & Miley, 2010:343; International Association of Providers of AIDS care (IPAC)/Pan African Health Organization/ World Health Organization, 2014:56-58; WHO, 2006).

The session also focuses on intervention strategies that caregivers can implement to identify and assist with mental health problems. Community caregivers do some role plays and brainstorm activities based on their circumstances in the community regarding mental health.

#### ➤ **Substance abuse**

The session starts with a group activity. Participants divide into two groups and discuss the signs and symptoms of substance abuse and what the community caregiver can do about it. A presentation follows on substance abuse focussing on possible signs and symptoms of alcohol and substance abuse (Du Bois & Miley, 2010:344) and intervention strategies from the community caregiver. The facilitator then leads a discussion around substance use and focus on the following: Does drug and alcohol use influence adherence and how; what is the caregivers role towards the clients in the community regarding alcohol use?

### **5.6.8 Session 8: Positive and healthy living**

#### **5.6.8.1 Session content**

- Positive and healthy living;
- Burnout and self-care.

#### **5.6.8.2 Session objective**

- To discuss the different aspects of positive and healthy living;
- To discuss prevention programmes;
- To discuss strategies regarding self-care.

### 5.6.8.3 Programme activities

#### ➤ **Positive and healthy living**

Group members starts with a group exercise on healthy living. They brainstorm activities on their understanding of healthy living. They discuss positive and healthy living and the different aspects thereof, such as good nutrition and exercise, a positive mind-set, prevention and to care for yourself as caregiver. Participants then brainstorm how patients can keep themselves healthy on ART. Participants are asked to discuss the aspects of positive and healthy living, namely nutrition, a positive mind-set, prevention and care for the self and also discuss each topic one by one by way of group activities. The group discussion focuses on the aspects of positive living such as like how to keep healthy while on ART.

Participants have discussions regarding the healthy food groups and food hygiene, because individuals with a good nutritional status are more likely to be successful with the treatment response (Department of Social Development, 2010b; International AIDS Alliance, 2006:82; Van Dyk, 2005:101-102). Access to a balanced diet is crucial for people living with HIV and AIDS in order to comply with medication requirements. A healthy diet may delay the progression and initiation of treatment by helping to maintain the immune systems resistance against infections.

#### ➤ **ART and prevention**

Participants make a diagram or drawing showing the links between HIV care, support, treatment and prevention and discuss prevention activities (SAFAIDS, 2006b: 23; Van Dyk, 2005:373-378). Each group shares their results. The facilitator facilitates a group discussion about what has been learned from the activity and focus on the following:

- HIV prevention aims to prevent the transmission of HIV and re-infection. HIV care support and treatment aims to improve the quality of life of people with HIV;
- HIV prevention can lead to increased HIV counselling and testing, which in turn can lead to broader and quicker access to treatment for people with HIV and AIDS;
- HIV prevention can reduce the stigma and fear around HIV and AIDS, which in turn improves the quality of life for people living with HIV and AIDS as they become more accepted and understood in their families and communities (DuBois & Miley, 2010, 322-323);
- Good care and support activities include advice on condom use to prevent unwanted pregnancies, mother-to-child-transmission, primary infection and re-infection;
- Through HIV Counselling and Testing (HCT), people can learn about HIV-prevention if they are HIV positive, get advice on how to live safely with the virus and plan for the future.

A group discussion also focus on: learning to live positively with HIV and AIDS; having a positive mindset; believing in yourself; setting life goals and finding out more about HIV and

AIDS and ART. The last activity focuses on burn out and self-care (Van Dyk, 2005:323-331). Participants discussed the signs of burn out in terms of their work environment, following these guidelines:

- At times the patient might direct strong emotions to you. Often they do not mean to hurt you and are just generally frustrated with their own situation;
- Try to allow the sick person to express his/her feelings and frustrations freely. Try not to over react to the persons emotions. Try to find out if there is something they need and how you can help;
- The caregiver's role can be very demanding. Thus caregivers may have times when they are tired, angry and disinterested in caring for the sick person. These are normal reactions and you should not feel guilty but try to find out a way to manage your reaction; and
- The signs that can help you recognize burn out are:
  - ✓ Irritability;
  - ✓ Fatigue;
  - ✓ Disturbed sleeping;
  - ✓ Poor concentration;
  - ✓ Avoiding the patient and sending someone else to care for the patient;
  - ✓ Emotional numbness, lack of joy;
  - ✓ Alcohol and drug abuse.

Community caregivers do role plays and discuss case scenarios on how to best care for themselves in their work environment. This session also focuses on conclusion of the social work empowerment programme. The post-test and evaluation of the programme are done during this session.

## **5.7 RESULTS OF THE PILOT TESTING AND PEER REVIEW OF THE SOCIAL WORK EMPOWERMENT PROGRAMME**

Six community caregivers and eight social workers from the department of social development took part in the evaluation of the draft empowerment programme. The aim of this evaluation was to receive inputs from community caregivers and social workers who deal with patients on ART. The researcher wanted to confirm the applicability and user friendliness of the empowerment programme. Here follows some responses from the community caregivers and social workers:

- The empowerment programme gives guidance regarding education of community caregivers;
- The empowerment programme is holistic at meeting the needs of patients on ART;
- It will be nice to have a programme to train community caregivers;
- We will be able to empower people living with HIV and AIDS;

- The programme cover most aspects of patients on ART and even the families;
- The problems addressed are the problems that patients in the community experience;
- The programme will be helpful for the community caregivers.

These inputs were valuable to finalise the empowerment programme. The proposed empowerment programme proved to be a potentially helpful tool for community caregivers based on the responses from the caregivers and social workers. During the testing process of the proposed empowerment programme, it became clear that the programme follows a holistic approach, to cover most aspects of psychological support to patients on ART. From the feedback on the prototype empowerment tool, adjustments could be made.

## **5.8 DISCUSSION**

Group work is a very useful, helpful and effective method and tool for empowering community caregivers to facilitate patients' adherence to ART. By means of the systems theory, social workers intervene by looking at a holistic view of people and their environment. Group work seeks to facilitate the intellectual, emotional, and social development of individuals through group activities. The purpose of this programme was to address the need for community caregivers to actively support people living with HIV and AIDS (PLWHIV) in enhancing antiretroviral treatment (ART) adherence. Upon successful completion of this programme, it was envisaged that the caregivers will be able to effectively apply the relevant knowledge and skills to support patients on ART. The group work programme focused on different aspects of service delivery to the patient on ART. It also dealt with empowerment and how to help the patient to interact with the environment in ways that enhance resources to meet his needs, and to help the caregiver to contribute to the patient's well-being potential. The programme also focused on empowering community caregivers to render social intervention services to patients on ART.

## **5.9 RECOMMENDATIONS**

- The psychosocial challenges of patients on ART should be addressed through empowerment of community caregivers;
- Empowerment should be addressed through group work;
- Social workers have to be knowledgeable on all aspects of HIV and AIDS as well as antiretroviral treatment to be able to empower community caregivers;
- The client should be the basis of information regarding their needs for empowerment programmes;
- Community caregivers play an important role regarding community based educational and self-management programmes aimed at adherence;
- Continuous empowerment sessions to community caregivers should be facilitated by social workers.

## **5.10 CONCLUSIONS**

Community based educational and self-management programmes aimed at adherence are important. It is important to identify the psychosocial challenges and needs of patients on ART. The conclusion from this study can be drawn that group work is a means of empowering caregivers to facilitate patients' adherence to ART. Group work is a very useful, helpful and effective method for empowerment of community caregivers to facilitate patients' adherence to ART. Social workers are knowledgeable with regard to issues of HIV and AIDS and ART and can fulfil the role as enabler to empower support systems in the community.

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NORTH-WEST UNIVERSITY  
YUNIBESITI YA BOKONE-BOPHIRIMA  
NOORDWES-UNIVERSITEIT  
POTCHEFSTROOM CAMPUS

**ANTIRETROVIRAL TREATMENT AND ADHERENCE: AN EMPOWERMENT PROGRAMME  
FOR COMMUNITY CAREGIVERS**

**R.M. MOKWELE**

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## **6.1 INTRODUCTION**

At the end of 2012 there were about 35.3 million people infected with HIV worldwide. Globally there has been a rapid increase in access to Antiretroviral treatment (ART) in the last few years, and 9.7 million people in low and middle-income countries had access to HIV treatment at the end of 2012. Despite considerable progress, global coverage remains low, with only 34% of the 28.3 million people eligible for treatment receiving antiretroviral treatment. Lack of adherence to ART is one of the main causes for failure of treatment worldwide. The shortages of human resources have been a problem in ART roll out and support for people on ART in resource-limited settings. In order to increase adherence to ART, efforts need to be made to ensure continuous monitoring through ART adherence support, which can be accomplished through the use of community caregivers. Community caregivers provide psychosocial support and lay counselling, education on HIV prevention and provide care and treatment to people living with HIV and AIDS. Community caregivers also conduct home visits to trace patients who have missed appointments or to provide adherence support. They also assist with issues such as disclosure, safer sex, stigma reduction, improving adherence to care and treatment which also impact negatively on them. This empowerment programme was developed to strengthen the knowledge and skills of community caregivers with regard to psychosocial support for patients on ART, to equip community caregivers with regard to self-care and to enhance their support to patients on ART. The aim for this programme is that the insights and care that community caregivers provide will enhance the patients' ability to understand, and adhere to their medication regimen. There is also a need to educate the community and families about ART and adherence to treatment. This empowerment programme will follow a group work empowerment approach.

## **6.2 PURPOSE OF THE EMPOWERMENT PROGRAMME**

The purpose of this programme is to address the need for community caregivers to actively support People Living with HIV and AIDS (PLWHIV) in enhancing ART adherence. The programme also aims to empower the community caregiver regarding self-care. Community caregivers are engaged with PLWHIV in their communities. This empowerment programme aims to enhance their knowledge and skills with regard to psychosocial care to PLWHIV. Upon successful completion of this learning intervention, the caregivers will be able to effectively apply the relevant knowledge and skills to support people on ART.

## **6.3 LEARNING OUTCOMES**

After completion of this empowerment programme caregivers will:

- know the goals and objectives of the empowerment programme;

- be able to understand adherence and the challenges regarding adherence;
- be able to understand psychosocial and adherence support;
- be able to implement basic communication and lay counselling skills;
- be able to understand their roles as community caregivers with regard to psychosocial and adherence support to people on antiretroviral treatment;
- be able to understand and give disclosure support;
- have an understanding of mental health and substance abuse and how it affects adherence; and
- have an understanding of healthy living and prevention programmes to support healthy living for people on ART as well as care for themselves.

#### 6.4 PRESENTATION METHODS

<p><b>Facilitator presentations</b>-An introduction to place the content in broader context</p>	
<p><b>Individual exercise</b>-These exercises are to be completed so that you can apply the learning principles and skills learned</p>	
<p><b>Group activity</b>-This exercise must be discussed within groups</p>	
<p><b>Case studies</b>-The groups will discuss the case study</p>	

#### 6.5 OVERVIEW OF EMPOWERMENT SESSIONS

The empowerment programme includes 8 sessions, each with its own learning objectives. Each session focuses on different parts of discussion topics.

Session 1: Welcoming and introduction to the empowerment programme.

Session 2: ART and adherence.

Session 3: The community caregiver and psychosocial and adherence support.

Session 4: Communication and lay counselling skills.

- Session 5: Providing psychosocial support services.
- Session 6: Disclosure.
- Session 7: Mental health, substance abuse and ART.
- Session 8: Positive and healthy living.

## SESSION 1

### WELCOMING AND INTRODUCTION TO THE EMPOWERMENT PROGRAMME

#### 1. Session content

Part 1.1: Welcoming and introduction to the empowerment programme

Part 1.2: Goals and objectives of the empowerment programme

Part 1.3: Establish ground rules

#### 2. Session purpose and objectives

- to help participants to get to know each other and help them feel more comfortable;
- become familiar with goals, objectives of the empowerment programme;
- to explain the content of the sessions; and
- become aware of their own expectations, assumptions and concerns about their role as caregivers.

#### 3. Session time: 2 hours 30 minutes

<b>Methodologies</b>	<b>Material</b>
Facilitator presentation	Participant hand-out
Large group discussions	Pen and pencils
Small group discussions	Flip chart and markers/or
Case study	Tape /adhesive putty
Brainstorm	

## Part 1.1: Welcoming and introduction to the empowerment programme

### Learning outcomes

#### After completing this activity, participants:

- will know more about the trainers and other training participants;
- had been sharing their attitudes, skills and knowledge regarding PLWHIV, HIV and AIDS and ART.

#### Presentation guide

1. Ask participants to stand in a circle. Each person should state their names, and the meaning of their names, the name of the organisation where they work and a description of their work.
2. After the introduction session, ask them to deliberate on the questions in *exercise 1* in a large group. Allow for 10-15 minutes for feedback on discussion and write responses on a flip chart.
3. Next, ask them to deliberate on the questions in *exercise 2* in a large group. Allow for 10-15 minutes for feedback on discussion and write responses on a flip chart.



#### Interactive Exercise # – Brainstorming questions (20--30 minutes)

*What are your concerns regarding people living with HIV and AIDS?*

*What are your general observations in the community regarding people on antiretroviral treatment?*



#### Interactive Exercise #– Brainstorming questions (20-30 minutes)

*What are your attitudes regarding people living with HIV and AIDS and ART?*

*What do you think is your general knowledge and skills with regard to HIV and AIDS and ART?*



## Part 1.2: Goals and objectives of the empowerment programme

### Learning outcomes

#### After completing this activity, participants will:

- become familiar with the goals and objectives of the empowerment programme;
- have an understanding of the training objectives; and
- have shared their expectations and set ground rules for the programme.

#### Presentation guide

1. Provide an overview of the goals and objectives of the empowerment programme.
2. Provide an overview of the core knowledge and skills that participants are expected to have by the end of the programme.
3. Provide an overview of the sessions of the empowerment programme.



#### ❖ Information sheet

##### 🌈 Goals of the empowerment programme

The goal of this programme is to address the need for community caregivers to actively support PLWHIV in enhancing antiretroviral treatment (ART) adherence. Community caregivers are engaged with PLWHIV in their communities. This empowerment programme aims to enhance their knowledge and skills with regard to psychosocial care to PLWHIV. Upon successful completion of this learning intervention, the caregivers will be able to effectively apply the relevant knowledge and skills to support people on ART.

##### 🌈 Learning outcomes

After completion of this empowerment programme caregivers will:

- be able to understand the challenges regarding ART adherence;
- be able to understand psychosocial and ART adherence support;
- be able to understand their roles as community caregivers with regard to psychosocial and adherence support to people on antiretroviral treatment;
- be able to implement basic communication skills;
- be able to implement basic counselling skills;
- be able to understand and give disclosure support;
- be able to implement interventions for the family;

- have an understanding of mental health and substance abuse and how it affects adherence; and
- have an understanding of healthy living and prevention programmes to support healthy living for people on ART.

### **Overview of empowerment sessions**

The empowerment programme includes 8 sessions, each with its own learning objectives. Each session focuses on different parts of discussion topics.

Session 1: Welcoming and introduction to the empowerment programme

Session 2: ART and adherence

Session 3: The community caregiver and psychosocial and adherence support

Session 4: Communication and counselling skills

Session 5: Providing psychosocial and adherence support services

Session 6: Disclosure

Session 7: Mental health, substance abuse and ART

Session 8: Positive and healthy living

## Part 1.3: Expectations and ground rules

### Learning outcomes

#### After completing this activity, participants:

- had been sharing their expectations and set ground rules for the programme sessions.

#### Presentation guide

1. Ask participants with regard to their expectations for the empowerment programme and the core competencies that they want to achieve. Use *Annexure 1* for this exercise.
2. Discuss the ground rules with participant
3. Write all ground rules on the flipchart



#### Interactive exercise # – Brainstorming questions (20-30 minutes)

*What skills do you want to acquire at the end of this empowerment programme?*

*Why is the improvement of your knowledge and skills necessary to enhance service delivery to the patient on ART?*



## SESSION 2

### ART AND ADHERENCE

#### Session Content

Part 2.1: Antiretroviral treatment

Part 2.2: Adherence to antiretroviral treatment

#### 1. Session purpose and objective

- to discuss antiretroviral treatment; and
- for participants to have a common understanding of the challenges regarding ART adherence

#### 2. Session time: 2 hours 30 minutes

<b>Methodologies</b>	<b>Material</b>
Facilitator presentation	Participant hand out
Large group discussions	Pen and pencils
Small group discussions	Flip chart and markers/or
Case study	Tape /adhesive putty
Brainstorm	

## Part 2.1: Antiretroviral treatment

### Learning outcomes

#### After completing this activity, participants will:

- have an understanding of antiretroviral treatment.

#### Presentation guide

1. As a large group ask participants to brainstorm ART

*What is ARV's?*

*Who qualify for ART?*

2. Clarify the discussion by sharing the information in the attached information sheet as a presentation (focus on content that did not come up during the discussion)



#### ❖ Information sheet

##### 🚩 What do we know about ART?

- ART stands for antiretroviral treatment.
- ART involves a combination of antiretroviral (ARV) drugs.
- ART is not a cure for HIV and AIDS.
- While on ART, PLWIV can still transmit HIV and can still become re-infected with HIV.
- ARVs are taken for life.
- Not all people with HIV need to begin ART.
- Decrease the amount of HIV in your blood (your viral load), slowing HIV progression.
- Increase the number of CD4 cells in your blood (your CD4 count), protecting you from opportunistic infections.

##### 🚩 When does a person start ARV?

- Patient's readiness to take ARVs.
- Psychological barriers.
- The patient's potential for adherence to ARVs
- The existence of other illnesses like TB.

## How does ARV's work?

- HIV drugs work by slowing the virus's ability to make billions of copies of itself.
- HIV drugs can reduce your viral load to such a low level it cannot be detected by laboratory tests (which is referred to as an undetectable level).
- To get the most benefit from HIV treatment you must take your HIV drugs properly, which is known as adherence.

## Part 2.2: Adherence to antiretroviral treatment

### Learning outcomes

#### After completing this activity, participants will:

- have an understanding of the challenges regarding ART adherence

#### Presentation guide

1. As a large group ask participants to brainstorm the challenges that clients experience regarding ART adherence.
2. Clarify the discussion by sharing the information in the attached information sheet as a presentation (focus on content that did not come up during the discussion).



#### ❖ Information sheet

##### 🧩 What is adherence?

**Adherence** is the term used to describe the patient's behaviour of taking drugs correctly, in the right dose, with the right frequency and at the correct time. A critical aspect of adherence is the patient's involvement in deciding how and when to take the drugs.

#### 🧩 How will you know when the patient adheres to medication?

##### *Difference between clients that adheres to ART and clients not adhering to ART*

###### *Client 1-adheres to ART*

- taking ARV's correctly, as prescribed, even if the person feels healthy; and
- not taking any breaks from treatment.

###### *Client 2-Not adhering to ART*

- miss one or many appointments at the hospital or health centres, lab, or pharmacy;
- not following the care plan;
- missing one or more doses of medicine;
- stopping medicine for a day or many days (taking a treatment 'break');
- missing whole days of treatment;
- taking or giving medicines at the wrong times;
- not reducing risk taking behaviour; and
- not observing the dietary instructions.

### ✚ **What happens when a person doesn't adhere to the antiretroviral treatment plan?**

- the CD4 count will drop and the person will start getting more opportunistic infections;
- it is more likely that the person will pass HIV to others (during unprotected sex, for example);
- the person might become depressed or de-motivated due to illness or physical deterioration;
- poor adherence leads to virologic failure, evolution of drug resistance and subsequent immunologic and clinical failure;
- the person can develop resistance to one or all of the drugs, meaning that the drugs will not work anymore even if they are taken correctly again;
- the person may have to start taking a new regimen or second-line ARV;
- incomplete viral suppression;
- continued destruction of the immune system-cd4 cell counts;
- disease progression;
- emergence of resistant viral strains;
- limited future treatment options; and
- higher cost to the individual and ARV programme.

### ✚ **What are the reasons for non-adherence?**

#### ***Emotional/psychological:***

- depressive state, emotional breakdown;
- low self-esteem; and
- denial if a person wants to forget that they are infected by the HIV virus, they tend to not want to take drugs as they remind them of HIV and AIDS.

#### ***Mental factors:***

- inability to understand and remember prescriptions, dosage timetables, etc. (these abilities can be linked to the level of literacy and education); and
- lack of belief in the effectiveness of the treatment (perceptions of medicine in general).

#### ***Behavioural factors:***

- possible difficulties in organising and managing personal time (for example, in relation to work schedules);
- reactions to side effects and other constraints of the treatment; and

- the consumption of substances such as alcohol or drugs which can affect the administering of the treatment

***Physical factors:***

- For an HIV positive asymptomatic person, the treatment can be perceived as the start of the illness. The side effects of antiretroviral drugs are perceived as the first signs of AIDS.
- For a symptomatic person, the disappearance of opportunistic infections and other pathologies can give the impression of being cured and no longer requiring the treatment.

***Social factors:***

- Situations in which the person taking the treatment must hide away to take their drugs (in the family, at the workplace, with friends, etc.);
- stigmatisation, discrimination, rejection, social isolation;
- the level of support from the family circle, in general and when taking the treatment;
- lack of financial resources and greater priorities for survival;
- caring for other ill people, children in particular; and
- the failure of the treatment for a person within the family circle can affect a person's belief; and in the effectiveness of their own HIV treatment.

***Factors linked to the treatment:***

- The failure of the treatment for a person within the family circle can affect a person's belief in the effectiveness of their own HIV treatment.
- Large number of doses per day: The larger the number of doses, the more complicated the treatment is to take, in particular for PLWHIV taking other medication (preventive and/or interceptive treatments for opportunistic infections and other pathologies). It is often thought that more than two doses of drugs per day lead to poor observance.
- Side effects: The greater the number of side effects or adverse reactions, the more difficult it is to take the treatment
- Unsuccessful treatment: If a person thinks that the illness is progressing despite the treatment, they are less motivated to take the drugs.

***Factors linked to professionals and structures:***

- a lack of knowledge and training on the part of healthcare professionals in relation to HIV treatments; and

- A lack of clear information on the elements like dosage, effects and effectiveness of the drugs, possible side effects, lack of availability and active listening for the person on treatment

#### ✚ **What necessary skills do patients need for adherence?**

##### ***To adhere, clients must:***

- believe they can do it (self-efficacy);
- feel psychologically well;
- not abusing substances;
- get the support they need;
- integrate their regimen into their lifestyle;
- problem-solving skills to accommodate the changes in routine and schedules; and
- understand the regimen and the importance of not skipping doses

#### ✚ **Why is treatment adherence support necessary?**

- Because HIV is a virus, and because the virus can change so much and so quickly, it doesn't take many missed doses for the virus to change enough so that the drugs used to treat it don't work anymore. This is called drug resistance and it is the reason that adherence to HIV medications is so important.

#### **Interactive exercise#– Group exercise (10-15 minutes)-Small group discussions**

Have participants break into small groups and brainstorm a list of possible challenges that people experience with regard to ART adherence. Use *case study 1* as an example.



#### **Case study #**

Adam is working in the local factory of his town. Currently he is on ART and experiences difficulties to take his pills. He also does not trust his family members at home.



## SESSION 3

### THE COMMUNITY CAREGIVER AND PSYCHOSOCIAL AND ADHERENCE SUPPORT

#### 1. Session Content

Part 3.1: The importance of psychosocial support

Part 3.2.: Psychosocial support services that community caregivers can render

#### 2. Session purpose and objectives

- to discuss the importance of psychosocial support;
- to discuss the community caregiver as social support system, and
- to discuss the psychosocial services caregivers can provide.

#### 3. Session time: 3 hours

<b>Methodologies</b>	<b>Material</b>
Facilitator presentation	Participant hand-out
Large group discussions	Pen and pencils
Small group discussions	Flip chart and markers/or
Case study	Tape /adhesive putty
Brainstorm	

## Part 3.1: The community caregiver and psychosocial support

### Learning outcomes

#### After completing this activity, participants will:

- have an understanding of psychosocial support and the importance of psychosocial support; and
- understand their role as a social support system.

#### Presentation guide

1. Ask participants in a large group to brainstorm psychosocial support
2. Discuss the community caregiver as social support system
3. Discuss the role of the community caregiver with regard to psychosocial support to PLWHIV



#### ❖ Information sheet

##### 🚦 What is psychosocial support?

###### **Definition of psychosocial support:**

“**Psycho-**” refers to the mind and soul of a person (involving internal aspects, such as feelings, thoughts, beliefs, attitudes, and values).

“**Social**” refers to a person’s interactions with others, social attitudes, values (culture), and the influence exerted by one’s family, peers, school, and community.

**Psychosocial support**-With regard to ART adherence, psychosocial support addresses the psychological, social, and adherence needs of patients, their partners, families and children.

##### 🚦 What is the importance of psychosocial support?

- HIV affects all dimensions of a person’s life: physical, psychological, social, and spiritual.
- A person who has just learn his/her HIV-status may need support in understanding and adjusting to this information, as well as planning for what is going to happen next.

- Psychosocial support can help clients and caregivers cope with HIV and enhance their own and their children's quality of life.
- It can help with the disclosure process.
- It can create opportunities to provide patients with information.
- It can help clients gain confidence in themselves and their skills.
- It can help build a trusting relationship between the client and the lay counsellor.
- It can prevent more serious mental health issues from developing.
- Psychosocial wellbeing is related to better adherence to HIV care and treatment.
- It can provide people (or link people) with needed social, housing, and legal services.
- It can help people mentally and practically prepare for difficult circumstances.

 **The community caregiver as a social support system**

Research has shown that people who have a lot of support from other people are more likely to take their medications. An important task of a community caregiver is to be a source of support for PLWHIV. There are different types of social support that the community caregiver can assist with.

▪ **Definition of community caregiver**

The community caregiver is the first line of support between the community and various health and social development services. He/she plays a vital role in supporting and empowering the community members to make informed choices about their health and psychosocial well-being and provides on-going care and support to individuals and families who are vulnerable due to chronic illness and living circumstances.(Department of Social Development, 2010).

*In order to fulfil their tasks,  
community caregivers must have  
knowledge, skills and the right  
attitude:*

**Interactive Exercise # – Group exercise (10-15 minutes)-Small group discussions**



1. Have participants break into small groups and ask participants to provide definitions of knowledge, skills and attitude, using the information sheet.
2. Ask participants to write the ideal knowledge, skills and attitude regarding psychosocial support on small pieces of paper and stick them to the appropriate circle on the flipchart.
3. Have group feedback and review what was discussed in the small groups.

▪ **Knowledge**

Knowledge means an understanding of information and ideas. It is important for psychosocial support because it allows caregivers to understand what is going on, to reassure the person seeking help, and to suggest the most appropriate plans. It is important that knowledge is kept up to date so that it can be the basis for providing the best possible care, support and treatment.

▪ **Skills**

Skills mean knowing how to do something. They might relate to technical work (such as how to prescribe medicines) or ~~people~~ people+work (such as how to support a person with HIV to communicate their psychosocial support needs). Some of the most essential skills for providing psychosocial support include: *listening, planning, taking action.*

▪ **Attitudes**

Attitudes describe how individuals view issues and other people. Appropriate attitudes are vital for people involved in psychosocial support work. For example, if a person is open and genuine, rather than condemning or pitying people with HIV, it will encourage people to come forward for help, take care of them and avoid feeling overwhelmed. It is also important for people involved in providing psychosocial support to be respectful and accepting of socially marginalised people like sex workers, prisoners, homosexuals and people using drugs.

## Examples of knowledge, skills and attitude

Knowledge	Skills	Attitude
<b>HIV</b> <b>Nutrition</b> <b>Health education</b> <b>Positive living</b> <b>ART</b>	<b>Counselling</b> <b>Communication</b> <b>Listening</b> <b>Planning</b> <b>Follow-up and referral</b> <b>Training</b>	<b>Acceptance</b> <b>Compassion</b> <b>Respect and non-judgment</b> <b>Honesty</b> <b>Positive and encouraging</b>

### 🚦 Why do clients need support and link with other networks?

First, let's consider your own sources of support. We call this your own **social network or social support system**. This may be your partner or spouse, your friends and family, maybe even neighbours, anyone you come in contact with. These people are your social network. Some of you will be able to think of many people, others just a few, and some of you may have no one regular person in your social network.

### Interactive exercise # – Small group discussion

Divide into pairs and take turns practicing how to assess for the other person's social networks. Who is in them? Is regular support provided? How can each one enhance their social support network?



### 🚦 What is the value of social support?

- **People trust those in a similar situation.**

PLWHIV have the opportunity to discuss their personal circumstances in a safe environment with someone who relates to their situation.

- **Improved adherence:**  
Community caregivers can support the adherence of PLWHIV to care and treatment because they may have a deeper understanding of what the client is experiencing.
  
- **Community participation:**  
Community caregivers can play a role in community mobilization, decreasing stigma and increasing support for PLWHIV.
  
- **Empowerment of individuals:**  
Community caregivers can increase the confidence of PLWHIV enabling them to make good decisions and take action.
  
- **Task shifting and saved time:**  
Community caregivers can help free up the time of doctors, nurses, and social workers by providing basic education and counselling.
  
- **Increased access:**  
Community caregivers can start groups that are otherwise difficult to start and maintain by professionals due to lack of time. Community caregivers can follow up with clients who have missed appointments for ART.

## Part 3.2: Psychosocial support services community caregivers can render

### Learning outcomes

#### After completing this activity, participants will:

- have an understanding of psychosocial support services that the community caregiver can give

#### Presentation guide

1. Discuss the role of the community caregiver with regard to psychosocial support to PLWHIV
2. Use the information in the information sheet



#### ❖ Information sheet

#### 🚩 What type of support can the community caregiver give?

##### ▪ Informational support

Informational support is suggestions or information about what has worked for you or others.

*“Sounds like your medications are making you very sick. Do you think you should call the clinic to ask someone about this?”*

##### ▪ Affirmational support

Affirmational support is words of encouragement that increase the patientsq belief in themselves and their abilities.

*“You took all your medications since we last talked? That’s great! I knew you could do it.”*

##### ▪ Emotional support

Emotional support includes empathy, support, understanding, listening and caring.

*“I know. It is really hard being on these medications. I understand you feel like quitting*

## **What services can be given to PLWHIV?**

### ▪ **Positive living and life skills courses**

These courses can help PLWHIV come to terms with their HIV status and provide information and skills to gain control over their lives.

### ▪ **Lay counselling**

*Counselling* helps PLWHIV accept their HIV status and prepare for possible repercussions of visibility. Counsellors can refer PLWHIV to other activities and to training to develop their capacity for further involvement. *Counselling skills will be discussed in session 4.*

### ▪ **Support groups**

*“A support group is a formal organized group where participants who are experiencing similar life challenges and problems come together to share their experiences, find strategies to cope and deal life challenges. Support groups are purposeful groups, formed to achieve certain goals. Support groups empower and support people at various levels, namely spiritual physical and psychological levels, depending on the group’s objectives” (Department of Social Development, 2010).*

In the context of HIV and AIDS, support groups can empower PLWHIV by building their self-esteem and preparing them to be open about their HIV status. A support group can provide a chance for people to talk freely, in confidence, and be listened to and encouraged. It may sometimes challenge members’ attitudes, but in a safe and supportive environment. To form a support group it is important to be clear about why you want to get together. Some groups may be formed simply for members to have a place to talk to each other and share feelings and experiences. Other groups of people may join together to work towards a common goal or need such as providing information about HIV. Support groups can:

- help people feel that they are not isolated and alone with their problems;
- provide a way to meet people and make friends;
- help individuals to become more confident and powerful;
- make links between people from different backgrounds and increase understanding and tolerance;
- help to share resources, ideas and information, for instance about the latest available treatments or local support services; and
- make others in the community more aware of the situation facing people in the group by increasing the visibility of people living with HIV.

### ✚ What types of support groups are there?

#### ▪ Adolescent support groups

Adolescents Living with HIV and AIDS (ALHIV) may want to form their own support groups to discuss some of the special challenges they face. These groups may involve recreational activities (sports, crafts, drama, etc.) as well as time for discussion. It is best if they are led by an adolescent enrolled in care and treatment, such as an adolescent peer educator.

#### ▪ Young mothers support groups

Young mothers living with HIV and those with HIV exposed or HIV-infected children may want to have their own support group. Young mothers support groups can provide needed psychosocial and emotional support and can help mothers understand and access key HIV and Prevention of Mother-to-Child-Transmission (PMTCT) services. These groups can also address concerns specific to mothers, such as safer infant feeding, care of HIV-exposed babies, and the importance of adherence to PMTCT and ART services.

#### ▪ Couples support groups

Couples, including discordant couples as well as those where both partners are living with HIV, may wish to form support groups. Couples can share common concerns and challenges, and can support each other to live positively with HIV.

#### ▪ Post-test clubs

These groups are for anyone who has been tested for HIV; they do not require participants to disclose their status. They often focus on promoting HIV information and education in the community and they also provide a social environment for members to meet each other and to discuss important issues, such as how to stay negative, being in a discordant relationship, etc.

### ✚ What topics that can be incorporated into support group meetings?

- positive living; adherence; disclosure; prevention; dealing with stigma; mental health problems; dealing with dying and the death of a friend or family member.

#### **Interactive Exercise # 3 – Small group discussion**

Divide into two groups and discuss the following:

*What do you think is the main challenges faced when establishing and maintaining support groups?*

*How can it be addressed?*



## SESSION 4

### COMMUNICATION AND LAY COUNSELLING

#### Content

- Part 4.1: Building relationships with clients
- Part 4.2: Communicating with and counselling children and adolescents
- Part 4.3: Lay counselling skills
- Part 4.4: Listening and learning skills
- Part 4.5: Motivational interviewing and the counselling session

#### Session purpose and objectives

By the end of this session, participants will be able to:

- understand communication and counselling skills;
- understand the basic principles of counselling; and
- understand the counselling process.

#### Module time: 4 hours

<b>Methodologies</b>	<b>Materials</b>
Facilitator presentation	Participant hand-out
Large group discussions	Flip chart
Small group discussions	Pen and pencils
Case study	
Role play	

## Part 4.1: Building relationships with clients

### Learning outcomes

#### After completing this activity, participants will:

- have an understanding of how to build a relationship with clients

#### Presentation guide

1. As a large group ask the participants to share the following:

*their understanding of what a trust relationship mean,;*

*some things a community caregiver can do to build trust with clients;*

*how do they think their clients feel when they visit them (are they scared, angry, sad)*

*how might these feelings affect the client's trust of and relationship with the community caregiver?*

*explain why a trusted relationship is important for improved ART adherence of patients?*

2. Clarify the discussion by sharing the information in the attached information sheet as a presentation (focus on content that did not come up during the discussion)

3. Lead participants through the exercise, which will give them an opportunity to discuss and practice some skills required for building relationships and trust with clients.



#### ❖ Information sheet

##### 🚩 What factors influence building a relationship with the client?

PLWHIV may have a variety of personal concerns related to their diagnosis, to disclose of their HIV-status, to feelings of isolation and to coping with a chronic condition. In order to provide them with support and information, community caregivers must first establish trust and build a relationship with the client. Establishing trust with a client can be difficult because of the following:

- their self-confidence, relationships, social skills and general thinking;
- they may feel fearful, embarrass or uncomfortable; they may be reluctant to disclose personal information, because they fear being isolated;
- they may have concerns about confidentiality, which will impact their willingness to discuss personal issues, therefore confidentiality must be a priority;
- the person is not comfortable sharing his feelings;
- they may feel that other people don't have time or do not understand;

- they may feel that people will make them feel guilty for not taking their medication or other people may reject them;
- they fear that they will lose confidentiality; and
- they may feel that they are too busy, stubborn or unworthy.

#### **What emotions do clients experience when they seek help?**

- *shy*, needing to discuss personal matters;
- *embarrassed* that they are seeking assistance;
- *worried* that someone will see them and tell other people;
- *anxious* about their health condition;
- *afraid* that they might die;
- *resistant* to receiving help or rebellious because of the fear of the unknown;
- *unsure* of how to ask for help; and
- *hopeful* that community caregivers can provide them with assistance to live a more comfortable and normal life.

#### **What can the community caregiver do to build a relationship with the client?**

- treat everyone equally and with respect;
- be open to their questions and need for information;
- do not use judgmental words or body language do not talk by scolding, shouting, blaming or getting angry;
- use words and language that they can understand;
- if sensitive issues are being discussed, make sure that conversations are not seen or overheard by others;
- reassure them that anything they say will be kept confidential, this means that you will not tell other people any information about clients, including what they say or that they are living with HIV;
- clients may be reluctant to disclose personal information if other family members are present; you as a caregiver should assure them that information entrusted with you will not be shared unless the client gives his or her permission;
- allow enough time for clients to become comfortable enough during the visit to ask questions and express concerns;
- show an understanding of and empathize with the clients situation and concerns; try to put yourself in his or her shoes;
- understands that clients might be uncomfortable; be reassuring when responding to them. Explain that you *are here to help.*

- Reassure clients that their feelings and experiences are normal; and
- be honest and admit when you do not know the answer to a question.

**Interactive exercise #: Establishing a relationship and building trust with the client**



1. Ask participants to review the case study.
2. Ask two community caregivers to role play the *case study* as a community caregiver and the other the role of the client.
3. Upon completion of the role play, facilitate a discussion by asking the following questions:  
*What do you think the client was experiencing in this situation?*  
*How did the community caregiver try to build a relationship and trust with the client?*

**Case study #**

Portia is 24 years old and recently found out that she is HIV infected. She disclosed her HIV-status to her sister and told her that she is using ARV. Afterwards they had a big fight. Although she trusted her sister in the past, she is worried that her sister will disclose her HIV-status to family members and others now that she is angry with her. How will you handle the situation?



## Part 4.2 Communicating with and counselling children and adolescents

### Learning outcomes

#### After completing this activity, participants will:

- have an understanding of communication with children and adolescents.

#### Presentation guide

1. Remind participants that communication and counselling will be different for each client. For example, communicating with and counselling older clients are very different from communicating with younger children.



2. Ask participants the following questions:

*How would communication with an 11-year-old differ from that with a 30 year-old?*

3. Record responses on a flip chart and fill in using the content below.

#### ❖ Information sheet

#### 🚩 How can the community caregiver improve communication with children?

- It is important to think about ways to help the child tell his or her problem.
- Younger children need time to feel safe and to trust. Sometimes children are afraid to talk to adults. Starting the session by doing something together, like playing a game, for example drawing something. When the child has done this, he or she will be able to tell you more about what he/she has drawn.
- Do not expect them to instantly begin talking. Allow plenty of time and be patient. They may feel scared.
- Explain things in simple terms. Use verbal and non-verbal communication, for example a simple touch and a smile can sometimes communicate much more than many well-thought out words.
- Just because the child is not asking questions does not mean that he or she is not thinking about what is being said.
- Do not force the child to share immediately. Positively reinforce their efforts to express themselves.
- If a child is rude or aggressive, remember that this behaviour may not be directed at you. He or she may be feeling angry with adults in general for treating him or her badly or for letting him or her down. Be patient and don't take it personally.

### ✚ How does the community caregiver communicate with adolescents?

- Begin by establishing relationship with the adolescents;
- Ask questions about the client's home, family, school and even hobbies before moving onto more sensitive topics like adherence to medication and disclosure;
- Ask indirect questions: initially, ask about the behaviour of peers and friends rather than ask direct questions about the client's own behaviour, for example: *"Do any of your friend's peers know that they drink medication?"*
- Reduce stigma around an issue by normalizing the issue, for example: An adolescent who is living with HIV may feel embarrassed seeking help to deal with different issues, but you can reduce stigma and feelings of shame by saying: *"I have a number of young people who are also living with HIV. I'm here to help you."*
- Encourage peer support: Encourage adolescents to discuss issues with peers who are also infected with HIV - either one-to-one or in groups. Peer support helps adolescents realise that they are not alone in dealing with the types of problems they have. They may not respond to adults who tell them to take their medication every day, but they might listen to a peer who tells them the same thing.

### ✚ How can communication with children and adolescents be improved?

**Storytelling or reading together:** The community caregiver could read or tell a story during a group or individual counselling session. After finishing the story, the community caregiver can ask questions to lead the discussion.

**Journaling:** Encourage for example adolescent clients to keep a journal or diary. The journal is a place adolescents can write about what is happening in their lives and how they feel about it (for example, *"Last week I felt.....because...."*).

**Drawing:** Encourage clients to draw a picture of their families or their homes. The community caregiver should then ask questions about the drawing to show interest and encourage expression:

*"Tell me about your drawing."*

*"What happened here?"*

*"How did you feel then?"*

**Letter writing:** Encourage adolescent clients to write letters to friends or family members about what is happening or how they are feeling

**Doing something fun:** Do something fun while you are talking. This could include playing a game, playing cards, taking a walk, pursuing a hobby (making a toy, knitting, hand sewing, etc.), or playing a sport. Young people often feel more comfortable talking when discussion is secondary to something else they are doing

## Part 4.3: Lay counselling skills

### Learning outcomes

#### After completing this activity, participants will:

- have an understanding of counselling and counselling skills

#### Presenting steps

1. Ask participants the following:

*What is a counsellor*

*What are the values of a counsellor?*

*What is counselling?*

*Why do we counsel people?*

*What does counselling include? What does it not include?*

*Discuss common counselling mistakes.*

*How does counselling for children and adolescents differ for counselling adults?*

2. Share the presentation on counselling and communication.



#### ❖ Information sheet

##### ✚ What is a counsellor?

A counsellor is someone who helps people to think more deeply about their lives and their problems. This can help people feel happier and more satisfied with their life. A counsellor will listen carefully. He or she will help people find solutions to their problems.

##### ✚ What are the values of a counsellor?

- understanding, trying to be understanding, putting yourself in the client's shoes;
- non-judgmental, does not judge the actions or behaviours of the client, showing respect for the client's decisions, demonstrating that their primary concern is with what the client feel about their own actions;
- respectful and caring-believing in the client's value as a human being, no matter what they do or have done and showing that they have confidence in the client's ability to solve his/her own problems when he/she has the resources and support;
- genuine, are real with the client, using language and body language that are not fake;
- takes responsibility for what they say and do;
- is a good listener;
- has patience;

- likes people;
- think about his/her own feelings and values;
- can keep information confidential; and
- knows what he or she cannot do.

### ✚ **What is counselling?**

Counselling is a two-way communication process that helps people look at their personal issues, helps them to make decisions and helps them in planning how to take action.

### ✚ **Why do we counsel people?**

- to help them talk about, explore, and understand their thoughts and feelings;
- to help them work out for themselves what they want to do and how they want to do it;
- counselling is a way of working with people to understand how they feel and to help them decide what they think is best to do in their specific situation;
- the role of community caregiver is to support and assist the client's decision-making process;
- community caregivers are not responsible for solving all of the client's problems;
- ultimately, it is the responsibility of the client to make his or her own decisions and then to carry them out.

<b><i>Counselling is:</i></b>	<b><i>Counselling is not:</i></b>
<ul style="list-style-type: none"> <li>▪ establishing supportive relationships;</li> <li>▪ having conversations with a purpose (not just chatting);</li> <li>▪ listening carefully;</li> <li>▪ helping people tell their stories without fear of stigma or judgment;</li> <li>▪ giving correct and appropriate information;</li> <li>▪ helping people make informed decisions;</li> <li>▪ helping people exploring options and alternatives;</li> <li>▪ helping people to recognize and build on their strengths;</li> <li>▪ helping people develop a positive</li> </ul>	<ul style="list-style-type: none"> <li>▪ solving another person's problems;</li> <li>▪ telling another person what to do;</li> <li>▪ making decisions for another person;</li> <li>▪ blaming another person;</li> <li>▪ interrogating or questioning another person;</li> <li>▪ judging another person;</li> <li>▪ preaching to or lecturing another person;</li> <li>▪ making promises that cannot be kept;</li> <li>▪ imposing one's own beliefs on another person; and</li> <li>▪ providing inaccurate information.</li> </ul>

<p>attitude toward life and to become more confident;</p> <ul style="list-style-type: none"> <li>▪ respecting everyone's needs, values, culture, religion, and lifestyle; and</li> <li>▪ being willing to trust clients' feelings and decisions, which may be the right ones for them at that time, given their particular situation.</li> </ul>	
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**✚ What are the common counselling mistakes?**

- not allowing enough time for counselling, which can make it hard for the client to take in all the information and react to it;
- conducting counselling in a non-private space, like in a corridor or waiting area, or allowing interruptions during the counselling session;
- controlling the discussion instead of allowing the client to control it and giving him or her time to ask questions and express his or her feelings and needs;
- judging the client by making inappropriate statements;
- preaching to the client by telling him or her how to behave or how to lead his or her life, for example, saying: *“you never should have lived a irresponsible lifestyle, now you are HIV- positive”*;
- labelling the client ;
- not accepting the client's feelings;
- advising the client before he or she has enough information or before he or she has had enough time to arrive at his or her own solution;
- interrogating by asking accusatory questions, for example questions that start with *“why...?”* encouraging dependence · increasing the client's need for the community caregivers' guidance; and
- trying to get the client to accept new behaviour by flattery or fakery; *“%know you are a good girl and will take your ARV as I have requested.”*

## Part 4.4 Basic listening and learning skills

### Learning outcomes

#### After completing this activity, participants will:

- have an understanding of the basic listening and learning skills

#### Presentation guide

Discuss each of the 7 skills, one at a time, and explain why each is important for quality counselling.



#### ❖ Information sheet

##### 🚩 Skill 1: Use helpful non-verbal communication

Non-verbal communication refers to all aspects of a conversation that convey information without the use of words. This includes messages conveyed through gestures, gaze, posture and facial expressions. Non-verbal communication reflects people's attitudes. We are often not aware of what our body language says, but our body language tells others what we really feel. Sometimes your body will give one message and your words will give a different message. When you listen to somebody, it is important that your body language and your words should give the same message.

#### ▪ Positive body language for counsellors

Have a **relaxed posture**-. Do not move around quickly or chat nervously.

Have an **open posture**. Crossing your legs or arms can signal that you are not listening what the client is saying.

**Leaning forward** toward the client (not too much) is a sign of involvement

Look at the person you are talking to. Culturally appropriate **eye contact** should be maintained to communicate interest. Never stare or glare at the client.

**Sitting squarely** facing another person shows involvement. If for any reason this may be considered threatening, then sitting to the side is also an option.

## Skill 2: Actively listen and show interest in the client

Another way of showing that you are interested and want to encourage a client to talk is by using gestures like nodding and smiling, responses like “*Mmm*” or “*Aha*,” and skills like clarifying and summarizing. These behaviours show that the community caregiver is actively listening to the client. They also invite the client to relax and talk about him or herself.

**Clarifying:** Clarifying prevents misunderstanding and helps sort out what has been said. For example, if the client says: “*All my friends will abandon me if they find out I have HIV!*” the community caregiver could say, “*Tell me more about why disclosing to your friends is a concern for you.*”

**Summarising:** Summarising means pulling together the themes that have come up during a counselling discussion so the client can see the whole picture. Summarising helps ensure that the client and the health worker understand each other.

### ***Example of actively listening and showing interest:***

**Client:** “*Yesterday one of my friends saw me and wanted to know what I was doing at the clinic at the green group. You know they group the patients at the clinic.*”

**CC:** “*Yes. That is not nice. What would you like to do to make this situation better?*”

## Skill 3: Ask Open-ended questions

**Open-ended questions** begin with words like “*how*,” “*what*,” “*when*,” “*where*,” or “*why*.”

For example:

“*Are you taking your ARVs?*”

“*Can you tell me more about how you take your ARVs?*”

“*How many times in the past week have you taken your ARVs?*”

Open-ended questions help clients explain their feelings and concerns, and they also help counsellors to get the information they need to help clients make decisions.

**Closed-ended questions** start with words like “are you?” “did he?” “has she?” or “do you?”, and usually only require a “yes” or “no” answer.

An example of a closed-ended question is “Do you use your ARV?” Closed-ended questions are good for gathering basic information at the start of a counselling or group education session. However, they are less helpful in getting at how the client is really feeling.

#### **Skill 4: Reflect back what the client is saying**

"Reflecting back," also referred to as paraphrasing, means repeating back what a client has said in order to encourage him or her to say more. Try saying what the client has said, but in a slightly different way. For example, if a client says, “*I can't tell my family about my HIV-status,*” the community caregiver could reflect back by saying, “*It sounds like talking to your family is not something that you feel comfortable doing right now.*” After the client confirms that this is accurate, the community caregiver could then say, “*Let's talk about that some more.*”

Reflecting back shows that the community caregiver is actively listening, and it helps the community caregiver understand the client's feelings.

#### **Skill 5: Empathise-Show that you understand how the client feels**

Empathy is when one person is able to comprehend (or understand) what another person is feeling. Empathy is not the same as sympathy. Sympathy implies that you pity or feel sorry for the other person. Showing empathy helps encourage clients to discuss issues further. For example, if a client says, “*I just can't tell my partner that I have HIV!*” the community caregiver could respond by saying, “*It sounds like you might be afraid of your partner's reaction.*”

#### **Skill 6: Avoid judging words**

Judging words are words like: *right, wrong, well, badly, good, enough, and properly*. If a health worker uses judging words when asking questions, adolescent clients may feel that they are in the wrong or that they need to respond in a certain way to avoid disappointing the counsellor.

### **Examples of using judging words**

**CC:** *“Did you take your medicine correctly (or properly)?”*

**Client:** *“I think so.”*

**CC:** *“Didn’t you understand what I told you about taking your medicine?”*

### **🚩 Skill 7: Help the client set goals and summarise each counselling session**

Toward the end of a session, the counsellor should work with the client to come up with next steps and to summarize the session:

**Develop “next steps”:** The community caregiver could initiate this part of the discussion by saying, *“Okay, now let’s think about the things you will do this week based on what we talked about.”* To help the client develop a more specific plan, the community caregiver could ask:

- *“What do you think might be the best thing to do?”*
- *“What will you do now?”*
- *“How will you do this?”*
- *“Who might help you?”*
- **Summarise the client’s plan and review next steps:**
- The community caregiver could say, *“I think we’ve talked about a lot of important things today. (List main points.) We agreed that the best next steps are the following.”*
- **Give the client a chance to ask questions.**
- **Make referrals**, if needed.
- **Make an appointment for return visit:** Discuss when the client will return and make sure he or she has an appointment.

#### **Interactive Exercise #: Practice listening and learning skills**

##### **Small group work**

Split up participants into groups of three.

Ask each small group to identify a counsellor, and a client.

Allocate a listening skill to each group

Ask each group to choose a scenario, have a discussion and role play based on the scenario.



## Part 4.5: Motivational interviewing and the counselling session

### Learning outcomes

#### After completing this activity, participants will:

- have an understanding of motivational interviewing and the counselling session

#### Presentation guide

Discuss each of the seven skills, one at a time, and explain why each is important for quality counselling.



#### ❖ Information sheet

#### 🚦 Motivational interviewing

#### ▪ Key components of motivational interviewing

<b>Expressing empathy</b>	Understand and be aware of and be sensitive to the thoughts and experiences of the patient.
<b>Supporting self-efficacy</b>	Supporting the patient with the sense that an individual can identify and meet one's needs and goals.
<b>Avoiding argumentation and resistance</b>	Listening to the patient's resistance to change. Working collaboratively with the patient to develop his/her input regarding the treatment plan.
<b>Discovering discrepancies</b>	Helping patients identify discrepancies between their current behaviour and desired future behaviour

## The counselling session

### ▪ **Engagement-Establishing the relationship**

- The room should be a quiet place that has doors that close and where there will be no interruptions.
- Introduce yourself; say your name and explain your role and the length of time you have together.
- Ask the client to introduce her or himself.
- Explain that what is discussed will be kept confidential.
- Ways to begin a counselling session:

*“Can you tell me why you came here today?”*

*“Where would you like to start?”*

### ▪ **Contracting-Understanding the problem**

- Let the client talk about the thoughts, feelings, and actions around her or his issues or problems.
- Use the seven essential counselling skills.
- Help the client decide which issues or problems are the most important to talk about during the session.

### ▪ **Supporting decision-making**

- Support the client to make her or his own decisions on next steps.
- The lay counsellor can help the client explore the options, but it is ultimately the client's decision to make

### ▪ **Termination-Ending the session**

- Summarize what was discussed during the session.
- Review the client's next steps.
- Give the client a chance to ask questions.
- Make referrals, if needed.
- Discuss when the client will return and make sure she or he has an appointment.

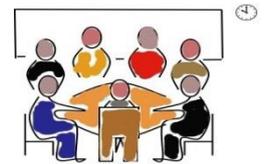
### Interactive exercise #: Practice the counselling session

Divide participants into groups of three.

Ask each small group to identify a counsellor, and a client.

Allocate a listening skill to each group

Ask each group to choose a scenario, have a discussion and role play based on the scenario.



### Case study #

Moos tell you that he is very worried that his family and friends at school will find out that he is HIV infected. He also does not drink his ARV $\text{\$}$ . *How do you counsel Moos?*



## Part 4.6: Family counselling

### Learning outcomes

#### After completing this activity, participants will:

- have an understanding family counselling

#### Presentation guide

1. Ask participants to discuss in two small groups the following:

*their understanding of family counselling; and  
why is it important to include the whole family in ART matters.*



Clarify the discussion by sharing the information in the attached information sheet as a presentation (focus on content that did not come up during the discussion)

2. Ask participants to do exercise 1 based on the case study.

#### ❖ Information sheet

##### ✚ What is the role of the family with regard to ART?

- health care;
- ensure that a responsible member of the family supports the person with HIV to take drugs and live positively, including psychosocial and spiritual support;
- be aware of whether the person is improving or not and take action to seek further help if necessary;
- live positively as a family with a life style which will prevent the transmission of HIV and encourage the person with HIV to continue with prevention measures;
- drug management;
- ensure that drugs are collected regularly and kept safe;
- directly observe drug treatment as per treatment schedule;
- adherence of treatment and follow-up appointments;
- pattern of nutritious intake and exercise; and
- monitor whether the person is improving or not.

##### ✚ Why is family empowerment regarding HIV and AIDS and ART important?

- HIV affects the whole family;
- HIV counselling is usually provided by lay counsellors;

- families living with AIDS are often very poor with little or no income, it is important that the whole family receives care.

### ✚ What is the difference between counselling of the individual versus the family?

Individual empowerment	Family empowerment
Focus on individual needs	Focus on needs of all the family members
Counsellor must be empathic	Counsellor must be empathic and impartial
Counsellors role more non-directive	Counsellor role more directive
Counsellor talks more	Counsellor talks less and listen more
Advocate role	Referee role each person gets a change
Focus on individual	Focus on relationship between individuals

### ✚ What are the principles of family counselling?

- joining with all the members of the family is important and avoids perceptions of favouritism;
- encourage the family members to look at each other as they speak and not just look at you, the counsellor;
- ask a question and encourage each family member to answer;
- focus on the here and now, avoid getting bogged down in long histories and get hooked into one person's issues;
- acknowledge all points of view and do not listen for too long to any one person; If one person dominates the session:
- try to include the other family members in the discussion;
- ask the other family members if they had similar experiences or feelings;
- ask a question to the other family membership acknowledges the other family member, but subtly leads away from the dominant speaker;
- ask the other family members how they feel about the issue being discussed;
- sometimes declare a subject that is very controversial and which causes a lot of arguments off limits;
- affirm and acknowledge difference. Families do not have to agree on everything;
  - use problem solving skills;
  - where are they now, where do they want to go?;
  - how will they achieve this?; and
  - Rebuild faith and trust.

## What is the structure of a family counselling session?

- start by introducing yourself;
- And say what the aim of the session is
- describe briefly what family counselling is;
- tell the family members how long the session will be;
- get some basic ground rules for the session;
- ask the family members to introduce themselves;
- introduce the basic issues for the session
- gets agreement from family member regarding issues for discussion?;
- acknowledge each person for his/her contribution as they speak;
- summarizes what had been said regularly; and
- towards the end of the session, ask family members to think of the way forward.

### Case study # –Family problem

Maureen used to monitor Gopolang's ART medication. However she became ill. Gopolang had missed some doses. Lerato leave early for work and can't monitor Gopolang's medication. Pule is unreliable because of his drinking habits. How can the family find a solution for the problem?



### Family counselling role play #

The facilitator will be the counsellor and four participants will be the family members. Maureen is the grandmother of the family. She is 75 years old; she looks after her positive grandson, Gopolang. Lerato is the daughter of Maureen. She works at the shoe factory. She lives in the same household. Pule is the 30 year old son of Maureen. He is unemployed. He drinks a lot and also smoke marijuana. He also lives in the household.



## SESSION 5

### PROVIDING PSYCHOSOCIAL SUPPORT SERVICES

#### Content

Part 5.1: The needs of clients regarding psychosocial and adherence support

Part 5.2: Assessing psychosocial support needs

#### Session purpose and objective

**By the end of this session it is expected that the community caregiver will:**

- understand the needs of clients regarding psychosocial support for enhanced adherence;
- identify strategies to improve psychosocial and adherence support; and
- knows how to do an adherence assessment.

**Module time: 2 hours**

<b>Methodologies</b>	<b>Materials</b>
Facilitator presentation	Participant hand-out
Large group discussions	Flip chart
Small group discussions	Pen and pencils Flip chart and markers
Case study	Tape or Bostik (adhesive putty)
Role play	Small sheets of paper

## Part 5.1: The needs of clients regarding psychosocial and adherence support

### Learning outcomes

#### After completing this activity, participants will:

- have an understanding of the needs of clients regarding psychosocial support and adherence

#### Presentation guide

Ask participants to discuss in a large group what the needs of clients are regarding psychosocial and adherence support



1. Divide participant into two groups and do the *exercise*
2. Focus on stigma and ask participants to brainstorm the following.  
*What is stigma?*  
*What is discrimination?*
3. Record the responses on a flip chart and discuss the information in the information sheet.
4. Next, ask participants to brainstorm some examples of stigma and discrimination that they have observed taking place against PLWHIV in the community.
5. Record responses on a flip chart.
6. Facilitate a discussion by asking the following questions:  
*How can PLWHIV deal with stigma and discrimination?*  
*What can the community caregiver do to reduce stigma and discrimination against PLWHIV?*

#### ❖ Information sheet

#### 🚩 What are the psychosocial support needs of patients?

- discussing feelings and concerns about their HIV status and the effects it has on their own and their family's lives;
- empathy and acceptance from partner and family members;
- support in understanding and coming to terms with their HIV status;
- peer support from other HIV-positive people;
- methods to disclose their HIV status to their partner and other family members;
- methods to encourage their partner and other family members to test and enrol into care and treatment programmes;
- support for positive living;
- support regarding HIV prevention;

- access to community-based organizations and support groups;
- need for nutrition support for self and family;
- access to social grants and income-generating activities;
- support for mental health; and
- support regarding substance abuse.

#### ✚ **How can the community caregiver improve psychosocial support to PLWHIV?**

- identify strategies to support PLWHIV in dealing with stigma and discrimination;
- recognize psychosocial challenges among PLWHIV and provide support and referrals;
- conduct a psychosocial assessment with PLWHIV to better determine their specific psychosocial needs and the types of support they need; and
- provide PLWHIV with ongoing psychosocial support services, including referrals.

### ***Overview of stigma and discrimination***

#### ✚ **What is stigma?**

- stigma is defined as an undesirable or discrediting attitude directed towards an individual with a certain attribute thereby reducing that individual's status in the eyes of society;
- having a negative attitude toward people one thinks are not "normal" or "right";
- labelling or seeing a person as inferior (less than or below others) because of something about him or her, for example, labelling and not value PLWHIV or people associated with PLWHIV.

#### ✚ **What kinds of stigma are there?**

**Felt stigma**-refers to real or imagined fear of societal attitudes and potential discrimination arising from a particular undesirable attribute or disease such as HIV or association with a particular group.

**Enacted stigma**-refers to the real experience of discrimination, for example the disclosure of one's HIV status can result in loss of a job, health benefits or social ostracism based on real or perceived HIV status.

**Self-stigma**-refers to self-blame, where people may feel they are being judged by others so they isolate themselves. PLWHA practice self-stigma and isolate themselves from their friends, families and communities; this can be viewed as a survival strategy such as when someone denies his/her risk of infection or fails to disclose his/her HIV status in order to avoid being ostracized.

#### ✚ **What are the examples of stigma?**

- name calling, finger pointing;
- teasing, ridicule, labelling, blaming, shaming, judging;
- making assumptions, rumour, gossiping;
- neglecting, rejecting, isolating, separating;
- not sharing utensils, hiding, staying at a distance;
- harassment, physical violence, abuse.

#### ✚ **What are the causes of stigma?**

- to be able to effectively address stigma it is important to identify the causes and this will differ from society to society or community to community. Key causes of Stigma are:
  - morality;
  - poor health care;
  - poverty;
  - gender;
  - government policy;
  - fatalism;
  - media; and
  - ignorance.

#### ✚ **What is discrimination?**

**Discrimination:** Treating someone unfairly or worse than others because he or she is different (for example, because a person has HIV).

#### ✚ **What are the different forms of discrimination?**

- facing violence at home or in the community;

- not being able to attend school;
- being kicked out of school;
- not being able to get a job;
- being isolated or shunned from the family or community;
- not having access to quality health or other services;
- being rejected from a church, mosque, or temple;
- police harassment;
- verbal discrimination, for example gossiping, taunting, or scolding;
- physical discrimination, for example insisting a person use separate eating utensils or stay in a separate living space; and
- stigma and discrimination deter access to HIV prevention, care, and treatment services for many people; stigma and discrimination can prevent people living with HIV, including adolescents, and their families from living a healthy and productive life.

#### **What are the effects of stigma and discrimination?**

- discrimination keep PLWHA from accessing care, treatment, counselling, and community support services (because they want to hide their status);
- cause a great deal of anxiety, stress, and/or depression;
- make PLWHA feel isolated and as if they do not belong to the community;
- result in poor adherence to medications;
- make it difficult for people to tell their partner(s) their status;
- make it difficult for people to discuss safer sex with partners;
- make it hard for parents to disclose their own HIV-status to their children and also for caregivers to tell HIV-infected children their HIV diagnosis;
- discourage people from taking ARVs or accessing other HIV services; and
- prevent people from caring for PLWHA in their family, in the community.

#### **How can one deal with stigma and discrimination?**

- **Stigma reduction strategies**

The way in which individuals discover and disclose their HIV status to others as well as the way they cope with their HIV status is influenced by cultural and community beliefs and values regarding causes of illness, learned patterns of responses to illness, social and economic contexts and norms.

### **Community based interventions**

Community caregivers can play a crucial role in helping identify the different types of stigma and raising awareness about the damage and pain that stigma and discrimination bring through the following actions:

- awareness campaigns;
- information dissemination; and
- advocacy and involvement of the community, government, religious leaders and the private sector.

### **Interventions aimed at PLWHA**

- withdrawing;
- avoiding situations;
- ignoring stigmatisers;
- joining support groups;
- counselling;
- sharing experiences with peers, family and friends;
- fighting back;
- going public;
- talking to stigmatisers;
- self-assertiveness; and
- build self-esteem.

#### **Interactive Exercise #: Addressing stigma**

1. Divide participants into groups of two.
2. Ask each small group to identify how they will address stigma using the case study.
3. One group will focus on community based interventions and the other group will focus on individual intervention.
4. Participants will give feedback after the discussion.



#### **Case study #: Addressing stigma**

Martha is HIV positive. She has two children. She has been recently divorced from her husband. When she got sick, she also learned that her husband felt sick and he was positively tested for HIV. She is worried of what the community will say about the situation, because she already heard rumours.



## Part 5.2 Assessing psychosocial support needs

### Learning outcomes

#### After completing this activity, participants will:

- have an understanding of how to assess the psychosocial support needs of clients.

#### Presentation guide

1. Review *the Psychosocial Assessment Tool*

2. Ask participants to divide into pairs and give them about 15 minutes to review and practice using the psychosocial assessment tool.

Ask them to switch roles so that each participant has a chance to administer at least some parts of the psychosocial assessment tool.

3. Ask participants to discuss the following questions :

*What do you think of this Psychosocial Assessment Tool?*

*How did you feel using the tool? What was challenging?*

*How could you use this tool with patients?*



#### ❖ Information sheet

##### 🚧 How does one do a psychosocial assessment?

- emphasize that all information will be kept confidential and private;
- conduct the assessment in a space that has privacy;
- respect the dignity and worth of the client;
- use good listening and learning skills, as discussed in session 4;
- be positive and encourage and praise throughout the assessment;
- allow the client to express his or her views and to describe his or her experiences;
- respect the client's ideas and solutions to problems;
- do not judge; make the client feel comfortable instead of fearful of being punished or judged;
- offer to include caregivers and/or family members in input into the assessment as needed and agreed upon by the client while simultaneously protecting the confidentiality of information;
- keep good records; always keep a copy of the psychosocial assessment in the client's file.

## Adherence needs assessment

Directions: Community caregivers can focus on the following when they do an assessment.

For each problem rated 1 or 2, you need to help the patient determine how exactly this interferes with adherence.

(Adopted from Project Pal, Buddy Training Manual)

*Rate each of the following as:*

*0 = not a concern 1 = probably a concern 2 = definitely a concern*

- Prior experience with adherence to medications was not successful.
- Inadequate knowledge about regimen, including names of drugs, dosing and special dietary instructions.
- Belief system: those medications don't work, that the danger of not taking them is minor that it's not necessary to take them consistently, no knowledge of resistance.
  - *Explain the benefits of medication, the dangers of missing even a few doses, how; and how*
  - *Resistance can develop and lead to entire classes of drugs not working, how the regimen is their best chance.*
- Low confidence or self-efficacy in own ability to take medications.
  - *Offer affirmation support, encourage even small steps toward adherence.*
- Side effects: does not know what to expect or how to get help, feeling sick from side effects without adequate medical care to address them, not aware that side effects usually subside substantially after the first few weeks.
  - *Encourage patient to contact clinic staff, share hand-outs, and provide hope that the side effects can be managed.*
- Does not have good relationship with primary provider or other clinic staff.
  - *Encourage patient to talk to providers about what they want and need in the relationship; mention that it is possible sometimes to switch providers.*
- Does not have a fairly routine daily schedule with appropriate spaced and environmentally cued times for doses. Have no plans for disruptions (i.e., travel or changing work schedule, unexpected stays away from home).

- *Help patient devise a reasonable daily schedule or learn to make plans for disruptions such as having extra doses on person or at work.*
- Discomfort with disclosure of HIV status (especially to co-workers or people living in home and whether this interferes with adherence.
  - *Help patient assess whether it would be better to disclose or, if not, what strategies are available to work around stigma and secrecy.*
- Unstable living conditions or inadequate housing, food, financial resources, transportation, childcare, insurance or other immediate life needs which are more pressing than HIV adherence.
  - *Refer*
- Is experiencing untreated psychological distress or impairment.
  - *Refer to social workers if necessary, encourage them to seek treatment, explain how this interferes with adherence.*
- Has untreated alcohol or other substance use problems leading to chaotic lifestyle or other impediments to adherence.
  - *Refer to social workers, encourage them to seek treatment, explain how this interferes with adherence*
- Is isolated, has an inadequate social support network.
  - *Asses patients' networks that are helpful and encourage patient to seek them out for support, educate about other available sources of support such as groups and social/religious organisations*
- Reasons reported for missing medication doses: Other barriers the caregiver is aware of or concerns or fears that might interfere with adherence (i.e. Domestic violence, other physical illness or disability)
  - *Refer*

### Interactive Exercise # – Small group discussion



1. Divide participants into three small groups.
2. Assign each group one of the case studies below.
4. Ask each small group to review their assigned case study and to identify the important issues in relation to the assessment tool.
5. Recording key points on flip chart and discussing how they would use the Psychosocial Assessment Tool with their client.

### Case study #



A 17-year-old woman named Tebogo tested positive for HIV six months ago. She is currently caring for her three younger sisters with the help of her grandmother. She is so busy that she has missed a couple of appointments at the ART clinic. Her partner is the only one who knows she is HIV-positive, but he himself has not been tested. *How do you proceed with Tebogo today?*

- *What would your plan be for the current session with Tebogo? What would you discuss?*
- *How would you document your session and the next steps you agree upon with Tebogo?*
- *What is your role as a lay counsellor in helping Tebogo?*
- *Would you provide any referrals for Tebogo? If yes, describe how would you document this and find out if she went where she was referred to?*

### Case Study #



Tshepiso is married and has four children. She was referred to the ART clinic because her CD4 count was 200. When you visit Tshpeiso, she says that she went to the ART clinic, but left because there was a long queue and people were gossiping about her. She decided she does not want to take any ARV medications and is feeling fine.

- *What kind of adherence support does Tsepiso needs?*
- *What kind of psychosocial support do you think Tsepiso needs?*

## SESSION 6

### DISCLOSURE

#### Content

Part 6.1: Disclosing to family partners and friends

Part 6.2: Disclosure and children

#### Session purpose and objective

By the end of this module, participants will:

- be familiar with methods for disclosing to family partners and friends; and
- know how to identify negative disclosure experiences.

#### Session time: 3 hours

<b>Methodologies</b>	<b>Materials</b>
<ul style="list-style-type: none"><li>• Facilitator presentation</li><li>• Large group discussions</li><li>• Small group discussions</li><li>• Case study</li><li>• Role play</li></ul>	<ul style="list-style-type: none"><li>• Participant hand-out</li><li>• Flip chart</li><li>• Pen and pencils</li></ul>

## Part 6.1: Disclosing to family partners and friends

### Learning outcomes

#### After completing this activity, participants will:

- have an understanding of how to disclose

#### Presentation guides

1. As a large group ask the participants to share the following:  
*their understanding of what disclosure is and why is it important;*  
*the benefits of disclosure; and*  
*the disadvantages of disclosure.*



Clarify the discussion by sharing the information in the attached information sheet as a presentation (focus on content that did not come up during the discussion).

2. Ask participants to do the exercise based on the case study.

#### ❖ Information sheet

##### 🚩 Should I disclose?

You may have just learned that you are HIV-positive or you may have known for some time. There are going to be situations in your life where you are going to have to decide whether or not to share your HIV-status or assisting someone to share his/hers. This is not always an easy decision to make. Disclosing your HIV-status can be one of the most frightening things to do.

##### 🚩 What is disclosure and why is it important?

- Disclosure means telling someone something about yourself that they don't already know. HIV-disclosure means that you tell somebody else that you are HIV-positive. Disclosure is when a person tells one or more people about his or her HIV status.
- Disclosure is an on-going process, meaning that a person may first want to disclose to only one person and then, over time, disclose to others. It is not a one-time event and clients need on-going support during the whole process, including preparing to disclose to another person and follow-up support after they have disclosed.

### **What are the disadvantages of disclosure?**

- Client may be blamed by partner or family for bringing HIV into the household.
- Client's partner, family, or friends may reject, abandon, or distance themselves from her/him.
- Client may lose the financial support of a working partner.
- Client may face discrimination in the community.
- Client may face discrimination at work, including possibly losing her/his job.
- Others may make assumptions about the client's sexuality, promiscuity, or lifestyle choices.
- Client's children may face rejection at school or in the community.
- Client may face physical violence.

### **What are the benefits of disclosure?**

- Disclosure can ensure that friends and family members can provide the kind of emotional and practical support that is helpful when living with HIV.
- Living with a secret can influence your self-confidence and lead to depression and anxiety.
- Finding a loving and supportive person to talk about your experience living with HIV and AIDS can be useful.
- Most of the time there is no need to inform employers, teachers or school administrators about your HIV-status, but in some cases it might be helpful if you need to explain why you have to go to appointments with service providers to help you live well with HIV.
- Some people decide at a certain point in their lives that they will be very open about their HIV-status.
- Being open about one's status can be a way of taking the shame and stigma out of living with HIV stigma.

### **What are the disadvantages of disclosure?**

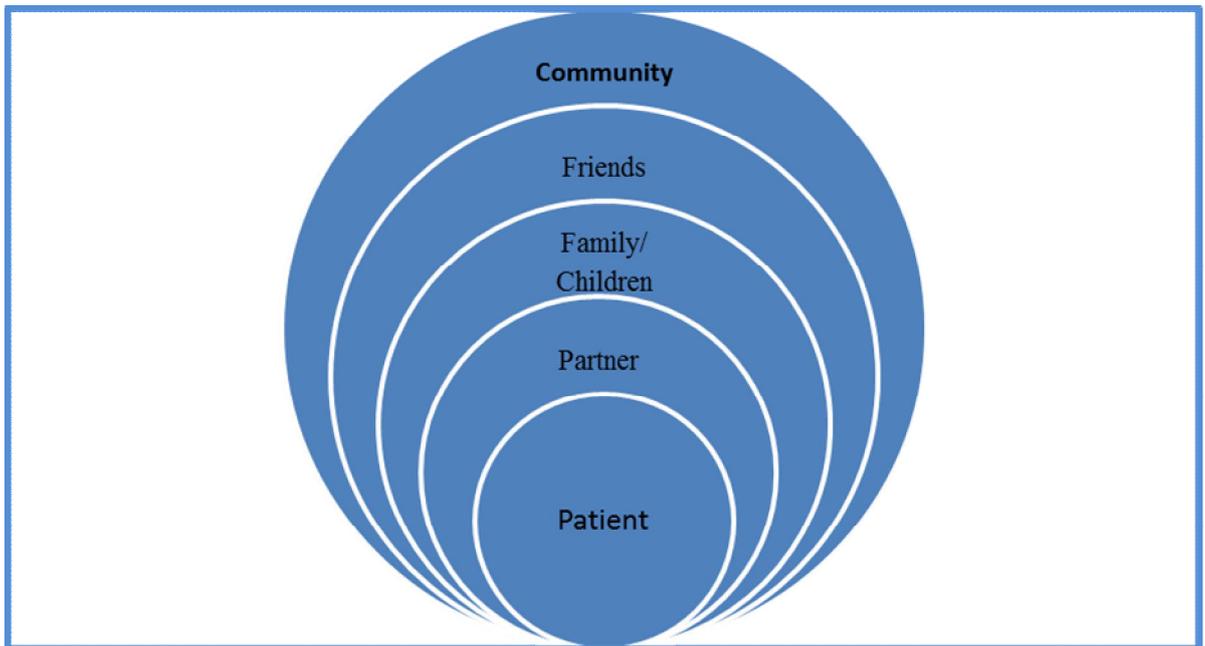
- Being so open about your HIV-status can be disadvantaged.
- It can take away your control of who knows your HIV-status, how they found out and what they know about your personal story.
- Disclosing places you at risk of rejection and discrimination, and it can also jeopardize your social life, your work or school life.

- For those who find out they are infected while in primary relationships with another person there are different considerations.
- First it is possible that their partners are HIV-positive and don't know their status.
- If their partners are not HIV-positive then steps must be taken to reduce the risk of HIV transmission.
- If like many people with HIV and AIDS you prefer to disclose your HIV-status to some people and not to others, there are some things you should consider.

### **How do I decide about disclosure?**

- A good way to understand disclosure and to help people decide who they will disclose to is by creating a disclosure circle with clients.
- The centre of the circle is the client himself/herself.
- The next circle is a person or people the person is very close to, such as a mother, sibling, or partner.
- The next circle includes larger groups of people that the person is not as close to, such as people at work or others in the community.
- There can be many layers to a client's disclosure circle.
- Each layer of disclosure represents a process in itself . preparing for disclosure, the disclosure process, and on-going conversations after disclosure. Remember that the conversation does not end after disclosure.
- The goal is not that all people will eventually disclose to all of the people in their disclosure circle. Instead, the disclosure circle gives lay counsellors a way to discuss with clients.

**Figure 1: Disclosure circle:** International Association of Providers of AIDS Care/Pan American Health Organisation/World Health Organisation: 2014)



#### ✚ Why disclosing?

- Ask yourself why this particular family member or friend or partner needs to know your HIV-status.
- Do you need their emotional or practical support?
- Does keeping your HIV-status a secret feel like it will harm the closeness that you share with your family member, friend or partner?
- What do you hope to get out of making this disclosure? Are you hoping for emotional support? Unconditional love? Concern? Are you hoping that they will be able to offer you practical support, such as giving you money or a place to live, or help with things like getting to the doctor or paying for medication? What do you expect their reaction might be?
- Understanding your hopes and expectations before making a disclosure about your HIV status is very important as it can affect what you say, and when you say it.

#### ✚ General helpful approach to disclosure counselling:

- Use good communication and counselling skills.
- Discuss the advantages and disadvantages of disclosure specific to the client's life.
- Help the person to identify barriers and fears about disclosure.

- Explore possible options to overcome specific barriers.
- Encourage the client to take the time needed to think things through.
- Talk about sexual partners who need protection from HIV infection.
- Identify sources of support.
- Support clients to make their own decisions about disclosure.

#### **What should be disclosed?**

- It's important to determine what you want to tell them. Are there details you want to keep to yourself, even if they ask? Have you thought about how much they might want to hear from you?
- Remember that you've possibly had at least a little bit of time to get used to the fact that you are HIV positive. The person you tell might also need some time to come to terms with it. This can affect how much you tell them at first.
- Do you want to get into how you became infected? Are you prepared to discuss this?
- In some cases, especially for gay men and transgender women, coming out about their HIV status may mean coming out about their sexuality or gender identity.
- For those who've injected drugs, coming out about HIV may mean coming out for the first time about drug use. How much does the person you are telling already know about these things? How might knowledge of these things affect how they treat you or feel about you?
- Telling a primary partner may result in disclosing that you have had sex with other partners, or used injection drugs.
- Sometimes you might have had unprotected sex with a new partner before telling them your HIV status. Disclosing this information can risk your emotional and physical well-being. For this reason, it is important to think carefully about when, where, and what to discuss.
- One of the most challenging things about disclosure is that it isn't always possible to predict how people are going to react to you.
- Those expected to have negative judgments have sometimes been incredibly loving and supportive.
- Unfortunately, the opposite sometimes happens and people we think will be supportive can react negatively.
- Disclosure always carries at least some risk, and it's best to remember this when considering what to tell.

## Tips on disclosure

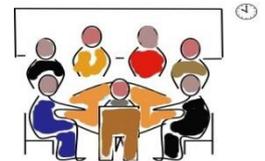
- In most situations you can take time to consider who to tell and how to tell them.
- Keep it simple. You don't have to tell the person every detail.
- Consider whether there is a real purpose for you to tell this person or if you are simply feeling anxious and want to dump your feelings.
- Having feelings of uncertainty is normal.
- Your friend, family member, or sex partner may have strong feelings when learning about your HIV status and might want support as well.
- There's no perfect roadmap for disclosure. Trust your instincts, not your fears.

## When and where to disclose?

- Wait until you know that you and the person have free time and can talk uninterrupted for at least 20 or 30 minutes, or even longer.
- Consider privacy.
- If at all possible, make sure that other people won't interrupt you while you're talking.
- Generally, you will have time to make the decision about when to tell a friend, family member, or a new romantic partner.

### **Interactive Exercise #**

Ask participants to divide into two groups and discuss the scenario in the case study and come up with disclosure strategies



### **Case study #**

Sharon is HIV positive and started taking ARVs. She did not disclose to anyone her HIV-status or that she is on ART, because she is ashamed of what others will say. Help Sharon explore and prepare to begin her disclosure process.



## Telling a current partner

- One of the most difficult people to tell about our HIV status is a person we've had sex with, or shared injection equipment with.

- This is especially true if we knew our status before we had sex or used drugs with them.
- This may be shocking news to them.
- For this reason, it can be very helpful to reach out first to a very trusted friend or counsellor to talk through what we want to say and how we want to say it, as well as to prepare for a potentially emotional and negative reaction.
- Another useful tool is to write out what you want to say in the form of a letter.
- In some cases, it can be good to give your partner that letter in person and ask them to read it before you talk.
- This can allow you to get out the most important information before the person begins reacting.
- Honesty is important in any relationship, but your own well-being is also important. Think ahead about what you suppose your current or former partner might do, and act accordingly.

#### **Telling a friend or family member**

- Very close friends and family members may also have their own emotional reaction.
- For some it might be a shock that you have engaged in behaviours that put you at risk for HIV.
- Some may be ignorant about HIV and about people who are infected.
- In some cases, the negative reaction may be simply based on the grief your friend or family member might feel about the news.
- It is important to be prepared to let your friend or family member have space for their own reaction.

#### **Interactive Exercise # – Role-Play (20 minutes)**

- Ask participants to do a role play on how to disclose to a family member.
- Give participants about 8-10 minutes to conduct their role-play.



When this is complete, ask the group as a whole to discuss their experiences with the role-play, how it relates to their own fears or personal experiences and how they feel they have learned to respond to negative reactions to disclosure

## Part 6.2: Disclosure and children

### Learning outcomes

#### After completing this activity, participants will:

- have an understanding of how disclosure affects children.

- **Presentation guides**

- 1. As a large group ask the participants to discuss the following:
- *disclosure and children; and*
- clarify the discussion by sharing the information in the attached information sheet as a presentation (focus on content that did not come up during the discussion).



- **What about disclosure and children?**

How is telling a child that he or she is living with HIV different from an adult disclosing his or her own HIV status?

- **What must be considered with regard to disclosure of the HIV status of children?**

- the needs, feelings, and beliefs of the child;
- the needs, feelings, and beliefs of the parents or caregivers;
- the age and developmental stage of the child;
- the specific family situation of the child;
- how the parents or caregivers communicate with the child;
- the level of peer support the child has;
- the child's level of functioning in school; and
- the child's interest and activities.

- **What are some of the reasons adults (including health care workers) do not want to tell children about their HIV status?**

- Sometimes they do not know where to start. There may be concerns about how other children will react or how the HIV infected child will feel.
- They fear that disclosing will cause harm to the child.
- They fear that disclosing will reduce the child's will to live.
- They fear that disclosing will make the child think he or she is not normal.
- They have the belief that children are supposed to be happy, and that knowing they have HIV will make them no longer enjoy their childhood.

- They are afraid that the child's or family member's HIV status will be revealed by accident.
- Children are not always good at keeping secrets.
- Children may not understand the stigma attached to HIV.
- They want to protect the child from social stigma, discrimination, and rejection.
- They feel guilty that the child is HIV infected.
- They are not comfortable talking about taboo subjects, such as sex, with children.
- They have difficulty coping with their own illness, or that of loved ones.
- As a result of traditional family coping strategies, such as silence around death and illness, limited open communication and denial as a coping strategy.
- they believe that children are too young to understand how complicated health is.

#### ✚ **What are the reasons to disclose a child's HIV status?**

- Children have a right to know about their own health care;
- Children who have not been disclosed to may:
  - have frightening or incorrect ideas about their illness;
  - feel isolated and alone;
  - learn their HIV status by mistake; and
  - have poor adherence.
- Children often want and ask to know what is wrong. Children are observant, smart, and curious. They often know much more than we adults think.
- Children may already suspect their HIV status but are keeping it a secret or waiting for an adult to talk to them about it.
- Children may have fears about their HIV status, especially if one or both of their parents has died.
- The later a child is told about his or her status the more difficult it will be for the child to accept.
- When children learn about their status directly from their caregivers, it can provide comfort and reassurance. Too often, children overhear health care workers and caregivers talking about their health as if they are not in the room.
- Children who know their HIV status can take an active role in their care and treatment plan and, when old enough, take steps to live positively and prevent new infections.
- Orphaned or other vulnerable children may wonder why they have lost a parent or been rejected by the family. They need to know the truth.

## ✚ What types of disclosure are there?

### ***Partial disclosure:***

- giving a child information about his or her illness without using the actual words %HIV+ or %AIDS+;
- should start at an early age (and definitely by age 5);
- helps move the disclosure process forward and prepares the child for full disclosure later on;
- is an effective strategy to help caregivers who do not yet feel ready to use the terms %HIV+ and %AIDS+ or for caregivers of young children who are not ready for full disclosure;
- is part of a process in which caregivers gradually move toward full disclosure;
- is useful for building a context in which full disclosure can be more meaningful for the child.

### ***Full disclosure:***

- telling a child specifically that he or she is HIV infected and giving him or her information about what this means, including that the child will need lifelong HIV care and treatment;
- is easier for the child if they have been partially disclosed to over time, understand some basics about their health and their care and medicines and have received ongoing support throughout the disclosure process.

## ✚ Assisting families with disclosure:

### ***Pre paring Families***

- **Asking and discussing the following questions can help determine what kind of support the caregivers need:**

*What do they think is important to communicate to the child?*

*What do they think will be the hardest part of the disclosure process?*

*What do they think will be the hardest questions to answer?*

- **Educating Families**

- Acknowledge that disclosure is very difficult.
- Affirm the parents or caregiver's commitment to disclosing to the child.
- Answer any questions about paediatric HIV the family may have.
- Help families think about what questions the child might ask.
- Help plan how the child will receive support after disclosure.

## **Planning for disclosure**

### ▪ **When and where will disclosure start?**

- Ideally when the child is in a comfortable place, such as at home.
- Start by playing with the child, or talking about the child's day.
- Disclosure should not happen immediately after the family has learned about the child's status. There needs to be some time for the family to get used to the idea and to come to terms with the child's status.
- Disclosure should not happen at the same time as another important event, such as a birthday, graduation, etc.
- Who will lead the conversation and what is the person's relationship to the child?
- The best person to tell a child about his or her HIV status is usually a parent or caregiver.
- Will there be other people involved, for example, if the child becomes angry and withdrawn or has questions that the caregiver may have trouble answering?
- How will the conversation be started?
- At this time, is the goal partial or full disclosure?
- How will the caregivers provide support to the child after disclosure?
- How will they continue the disclosure process for example if they are partially disclosing?
- What anxieties does the family have and what can help reduce this anxiety?
- What support does the family need?
- Make sure to ask about all of the child's caregivers to make sure everyone has the same messages and knows how and when the child will be disclosed to.
- Encourage disclosure to brothers and sisters of the child living with HIV; they can be a very important source of support for the child.
- Disclosure is more than telling a child his or her HIV status.
- Disclosure is an on-going process.
- Caregivers should talk about health issues with children at an early age, including giving simple explanations about illness to young children. This is called partial disclosure.
- Younger children, particularly if they are sick, are more interested in what will happen to them in the near future they need comfort and assurance.
- When to say HIV+ varies with the child and the family, but most children should know they have HIV as soon as they have developed the emotional maturity to understand what this means.

### **Tips when dealing with children and disclosure**

- Many of the listening and learning skills discussed in session 3 apply to children as well as adults.
- Always give the child correct information. Never lie to the child.
- Remember there are legal issues related to disclosure.
- The main objective of the Children's Act is to give effect to children's constitutional rights.

### **What does the Children's Act says regarding HIV disclosure to children?**

- The Children's Act says that every child has the right to confidentiality regarding his or her HIV status.
- The Act says that every child has the right to participate in decisions about his or her health, to access a range of information about his or her health, and to access a range of health services.
- The HIV status of a child may be disclosed with the consent of the child, if the child:
  - -is 12 years of age or older; or
  - -is under the age of 12 years and of sufficient maturity to understand the benefits, risks, and social implications of such a disclosure
- The HIV status of a child under the age of 12 years who is not of sufficient maturity to understand the benefits, risks, and social implications of disclosure may be disclosed with the consent of:
  - the parent or caregiver (regardless of whether the parents are alive or dead);
  - a designated child protection organization arranging the placement of the child, such as Child Welfare or the Department of Social Development;
  - the superintendent or person in charge of a hospital, if the child has no parent or caregiver and if there is no designated child protection organization arranging the placement of the child;
  - a children's court, if consent is unreasonably withheld; if disclosure is in the best interests of the child; or if the child or the parent or caregiver of the child is incapable of consenting to such disclosure.
- The HIV status of a child may be disclosed without consent in the following circumstances:
  - If the disclosure is within the scope of that person's powers and duties in terms of the law;
  - If it is necessary to carry out an obligation in the Children's Act during legal proceedings in which disclosure is necessary for those proceedings.

**Case study # – Role-Play (20 minutes)**

Itumeleng is a 12-year-old female orphan who lives with her maternal aunt and uncle. Her aunt, Matshepo, monitors her ARV medication and reports very good adherence. When asked to consider disclosure of HIV status, Matshepo was tearful. She stated that she knew this day would come and would like to discuss the options with her husband before making final decisions



## SESSION 7

### MENTAL HEALTH AND SUBSTANCE ABUSE

#### Content

Session 7.1: Mental health and people living with HIV and AIDS

Session 7.2: Substance abuse

#### By the end of this session, the community caregiver will be able to:

- identify their own beliefs and attitudes about mental illness and people living with HIV and AIDS;
- know the categories of mental illness;
- recognize when a client may have a mental illness, determine the need for follow up care, and provide appropriate referrals for mental health services; and
- understand substance abuse and how it can affect adherence to ART.

**Module time: 3 hours**

<b>Methodologies</b>	<b>Materials</b>
Interactive trainer presentation	Flip chart and markers
Values clarification	Tape or Bostik (adhesive putty)
Large group discussion	Participants should have a copy of their
Brainstorming	Participant manuals.
Small group work	
Case study	
Role play	

## Part 7.1 Mental Health and people living with HIV and AIDS

### Learning outcomes

#### After completing this activity, participants will:

- have an understanding of mental health of people living with HIV and AIDS

#### Presentation guide

1. Inform the participants that we talked before about how factors such as mental health and substance use can prevent people from taking medications properly. Today we are going to talk about these in more detail, including how to recognize these problems, how they may interfere with adherence, and how to refer people for help. 
2. Discuss the definition of mental health and of mental illness. Start by asking participants to brainstorm responses to the following questions:  
*What is mental health?*  
*What is mental illness?*  
*How do mental illnesses differ from psychosocial problems?*  
*What causes mental illness?*
3. Discuss the content in the information sheet below.
4. Ask participants to do *exercise 1*.

#### ❖ Information sheet

##### 🚦 What is mental health?

Mental health refers to your emotional, psychological and social well-being. It is an important part of staying healthy when living with HIV. Your mental health affects how you think, feel and act. It also helps determine how you handle stress, relate to others and make choices.

##### 🚦 What causes mental health problems?

- a family history of mental health problems and other genetic factors;
- stressful life events or psychosocial reasons, including trauma, sexual and physical abuse, neglect and illness; and
- psychological factors such as unhealthy thinking patterns and trouble managing feelings.

### ✚ How other factors affecting PLWHA contribute to mental health problems?

- cognitive impairment, dementia and psychosis as a result of viral infection of the brain;
- depression and anxiety due to the negative impact of illness on the person's life;
- alcohol and drug use;
- psychiatric side effects of ARVs;
- social difficulties faced as a result of discrimination;
- disclosure;
- dealing with loss and death;
- loss of employment;
- difficulties to access services; and
- changes in physical appearance.

### ✚ What are the other mental health conditions?

Mental illness (or mental disorder) is characterized by the presence of the following over time:

- anxiety disorder;
- mood disorders; and
- personality disorders.

*Remember, a mental health disorder may have been already a problem for a person before they had HIV.*

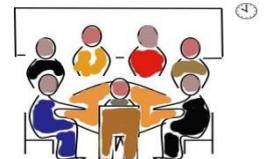
#### **Interactive Exercise # – Group exercise (10-15 minutes)**

Ask participants to brainstorm responses to and discuss these questions:

*What are the most common mental illnesses among people living with HIV and AIDS?*

*What are some local terms used in your community for these conditions/illnesses?*

*Why is addressing mental health and mental illness important to the care of people living with HIV and AIDS?*



## ❖ Information sheet

### 🚩 How does one recognise signs of Mental Illness?

Diagnosing a specific mental illness can be difficult and requires specialized training. However, community caregivers should know the signs that a serious mental illness may be present and know how to refer the client for further assessment and care.

#### ▪ Use a client's recent and past history

##### **Recent history:**

- A client may self-report symptoms of mental illness or a client suffering from a mental illness may not be aware that something is wrong or may be too afraid to talk about it.
- Concerns about the changes brought about by possible mental illness may be initially expressed by a client's family members, other adults, or peers.
- The community caregiver who knows the client well may also notice these changes over time. For example:
  - The client has shown a dramatic change in behaviour and/or a major decrease in psychosocial functioning (e.g., used to be friendly, but now only wants to be alone; used to be calm, but is now behaving in a violent way).
  - the client has been saying things that do not seem plausible (e.g., "my family members are
  - trying to poison me," "voices are telling me that I'm a bad person," etc.)

##### **Somatic symptoms:**

- Mental illness, especially depression and anxiety disorders, affect the mind and body and, when severe, are routinely accompanied by physical (or somatic) complaints.
- These may include: fatigue, headaches/migraines, abdominal pain/gastrointestinal problems, backaches, difficulty breathing, changes in appetite and weight, changes in sleep patterns, and chest pains.

#### ▪ Review the client's clinical and ART history:

- If signs of possible mental illness are observed or reported, community caregivers should review the client's HIV history, recent changes in disease status, and ART regimen (including any dosing or medicine changes) to determine if they are contributing to changes in the client's mental health.

- While rare, some ARVs can have side effects that may contribute to mental health problems. In these cases, drug changes may need to be considered for clients with new onset mental health problems.

***Past history:***

- Many mental illnesses are persistent or recurrent, and some can begin in early childhood. The client or an accompanying family member or friend may report past events that suggest the presence of a mental illness. These include the following:
  - past psychiatric hospitalization;
  - past use of psychotropic medication (any medication capable of affecting the mind, emotions, and behaviour);
  - history of severe behavioural disturbances; and
  - history of mental illness in the family (e.g., depression, schizophrenia)
- **Make observations during routine visits (and ask caregivers' about their observations)**
- Community caregivers can make observations about the following during their routine visits with clients, which may alert them to the existence of a possible mental illness:
  - **Appearance and presentation:** The client's hygiene and grooming are poor; the client comes across as frightening or frightened; the client looks depressed.
  - **Attitude and behaviour:** The client is restless, belligerent, uncooperative, the client is making threats, is unwilling/unable to speak, and is behaving in odd and unusual ways.
  - **Mood and emotions:** The client looks or seems to be frightened, sad or angry.
  - **Speech, thinking and perception:** The client is speaking very rapidly or overly loudly or softly; is saying things that make no sense; is saying things that are unlikely to be true (e.g. my grandmother is poisoning me); is reporting hallucinations (hearing or seeing things that are not there).
  - **Level of alertness and orientation:** The client is having trouble staying alert and attentive; is drowsy; is confused about things like where he or she is and what time of day it is.
  - **Social and intellectual skills:** The client does not have the verbal, behavioural, and/or social skills that would be expected of someone his or her age.

## **Mental Illness: Signs and symptoms and tips for community caregivers.**

### ▪ **Depression**

*Everyone feels down, sad, or depressed once in a while. Many people living with HIV/AIDS report feeling down at one time or another. Research has shown that women tend to report being depressed more than men and about one out of every four people become severely depressed at some point in their lives.*

### **How can you tell if someone is depressed?**

- change in appetite;
- inability to sleep;
- low energy and fatigue;
- loss of interest or pleasure in previously enjoyed activities;
- feelings of worthlessness;
- diminished ability to think or concentrate;
- recurrent thoughts of death; and
- suicidal thoughts.

### **What can the community caregiver do?**

- Refer client to trained counsellor or other mental health provider, peer support group and group/individual therapy, if available.
- Ask about alcohol and drug use.
- Review the client's HIV history, recent changes in disease status, and ART regimen (including any dosing changes or new medications).
- If depression is severe, does not improve, or worsens, refer client to a mental health provider if the following happen:
  - they indicate they might hurt themselves or another person, or if they show any evidence of self-harm;
  - their families cannot cope with them anymore;
  - they are thinking about, threatening, or have attempted to kill themselves
  - if suicidal, ensure immediate safety and refer to professionals.

## **Anxiety disorders**

### ***Possible signs and symptoms of anxiety disorders***

- cannot eat;
- cannot breathe or has frequent shortness of breath;
- panic attacks (may include shaking, sweating, fast heartbeat, difficulty breathing);
- tingling in the hands or feet;
- chronic headaches;
- trouble sleeping; nightmares;
- cannot concentrate on anything;
- feels jumpy, stressed out, or restless;
- feels overwhelming sense of worry; and
- fearful of participating in normal activities.

## **What can the community caregiver do?**

- Refer client to peer support group and group/individual therapy, if available.
- Teach client relaxation techniques and explore other coping mechanisms to manage anxiety.
- Review the client's HIV history, recent changes in disease status, and ART regimen (including any dosing changes or new medications).
- If anxiety is severe, interferes with the client's functioning, and/or does not improve or worsens over time, refer client to a mental health provider.

## **Severe mental illness**

### ***Possible signs and symptoms of severe mental illness***

- bizarre delusions;
- auditory or visual hallucinations (client reports hearing or seeing things);
- paranoia;
- agitation;
- suspiciousness;
- hostility; and
- exaggerated sense of self.

 **What can the community caregiver do?**

- Review the client's HIV history, recent changes in disease status, and ART regimen (including any dosing changes or new medications).
- Refer to a psychiatrist or other mental health professional for assessment and treatment.

## Part 7.2 Substance abuse

### Learning outcomes

#### After completing this activity, participants will:

- have an understanding of substance abuse and how it affects mental health and ART.

#### Presentation guide

1. Ask participants to divide into two groups.
2. Ask them to discuss the signs and symptoms of substance abuse and what the community caregiver can do about it.



#### ❖ Information sheet

#### 🚩 Alcohol and substance use disorders

##### ***Possible signs and symptoms of alcohol and substance***

- sudden changes in personality without another known cause;
- loss of interest in favourite hobbies, sports, or other activities;
- sudden decline in performance or attendance at school or work;
- changes in friends and reluctance to talk about new friends;
- deterioration of personal grooming habits and personal hygiene;
- difficulty paying attention or forgetfulness;
- sudden aggressive behaviour, anger, nervousness, or giddiness;
- increased secretiveness, heightened sensitivity to being asked questions; and
- sudden changes or unexplained problems with adherence to medications or missed appointments

#### 🚩 What can the community caregiver do?

- provide general education and counselling on risk reduction and behaviour change;
- for example, assess the safety of the client and others while client is under the influence of alcohol or drugs (if operating a motor vehicle, having sex, etc.) and provide risk reduction counselling;
- provide referrals for individual and group counselling and treatment (e.g. Alcoholics Anonymous);

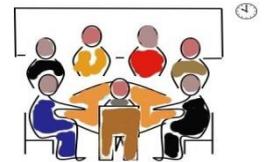
- review the client's HIV history, recent changes in disease status, and ART regimen (including any dosing changes or new medications);
- screen for alcohol misuse and drug use and abuse upon initial intake and whenever suspected, based on medical history, reports from family/partner, client's behaviour in the clinic, or findings from psychosocial assessments; and
- be patient and accepting of the client's situation; recovery can be a gradual process.

### **Interactive Exercise # –Large group discussion**

Lead a discussion around substance use.

*Does drug and alcohol use influence adherence and how?*

*What is your role towards your clients in the community regarding alcohol use?*



## SESSION 8

### POSITIVE AND HEALTHY LIVING

Content

Part 8.1: Healthy living

Part 8.2: Burnout and self-care

#### **Session purpose and objectives**

By the end of this module, participants will be able to:

- understand the different aspects of positive and healthy living;
- understand and know how to implement prevention programmes; and
- come up with strategies to care for themselves

Session time: 3 hours

Methodologies	Materials
<ul style="list-style-type: none"><li>• Facilitator presentation</li><li>• Large group discussions</li><li>• Small group discussions</li><li>• Case study</li><li>• Role play</li></ul>	<ul style="list-style-type: none"><li>• Participant hand-out</li><li>• Flip chart</li><li>• Pen and pencils</li></ul>

## Part 8.1: Healthy living

### Learning outcomes

**After completing this activity, participants will be able to:**

- have an understanding of the aspects of positive and healthy living.

#### **Presentation guide**

1. Inform the participants that positive and healthy living have different aspects and can include good nutrition and exercise, a positive mindset prevention and to care for yourself as caregiver.
2. Ask participants how patients can keep themselves healthy on ART?
3. Ask participants to discuss the aspects of positive and healthy living, namely nutrition positive mindset, prevention and care for the self.
4. Discuss each topic one by one by way of group activities and fill in with the information in the information sheet.



#### ❖ **Information sheet**

##### 🚩 **How does one keep him/her self-healthy on ART?**

- Practice safe sex while on ART. Even if you are on ART, you can still infect your partner with HIV. When you have sex with someone who is HIV-positive, you can get a new infection. New infections can weaken your immune system. You could also get a new HIV virus that is resistant to the current ARV medication. This will increase the viral load in the body. Always use a condom when you and your partner have sex to protect you and your partner from new infections
- Eat the right foods. Fruit and vegetables. These foods helped to fight sicknesses. Beans, lentils, meat, chicken, fish, milk, eggs. These foods help to build the body and keep us strong
  - Cut down on alcohol and smoking. Alcohol can make you forget to take your medication. It can also make you eat less. Try to cut down or stop drinking. Smoking causes chest infections. It also makes people eat less.
  - Exercise your body. It is helpful to exercise your body. It is good to keep active and busy.
  - Get support from other people. Join a support group. Speaking openly is important. It helps you to take your medicines properly

- Treat any disease or problems. Go to clinic when you are sick. Go for regular check-ups. Don't take other medication when on ART. Traditional medication cannot be taken with ART

### What is healthy nutrition?

#### Presentation guide

1. Ask participants to give a definition of good nutrition.
2. Ask participants to give different groupings for nutrition (proteins, carbohydrates, fats, vitamins, minerals and water).
3. Ask participants what the body does with nutrients and the role of each other.
4. Ask participants to define the six food groups
5. Discuss what people eat in a normal day.
6. Does it include all food groups?
7. Ask participants to write a draw what would be a better meal.



#### ▪ **Healthy food**

Food can be sorted into six groups. A healthy meal is made up of at least one food from each of the six groups with plenty of clean water.

<p><b>Vegetables</b></p> <p>Provide minerals, vitamins, water &amp; fibre-protects the body from illness: leafy greens, pumpkin, squash, carrots</p>	<p><b>Fruits</b></p> <p>Contain carbohydrates, vitamins &amp; water-gives energy and protect the body from illness: banana, Pawpaw, guava, mango, orange, pineapple</p>
<p><b>Staples</b></p> <p>Provide carbohydrates,-gives power and energy to the body: grains, maize, sweet potatoes, rice, yam, cassava, potato, sorghum, oats</p>	<p><b>Meat</b></p> <p>Protein-builds and repairs the body: meat, fish, eggs, milk,</p>
<p><b>Fats</b></p> <p>Also gives power and energy to the body: oil, butter and margarine, fatty meat and</p>	<p><b>Legumes and nuts</b></p> <p>Protein and carbohydrates-builds &amp; repair the body and protects it from illnesses: soya beans, sugar beans, groundnuts, tree nuts, fish, sunflower seeds</p>

## **Food hygiene**

- Cook all food well before eating.
- Wash all fruits and vegetables in clean water before eating.
- Boil water before drinking, if it is not clean.

## **ART and prevention**

Ask participants to make a diagram or drawing showing the links between HIV care, support and treatment and HIV prevention.

Ask each group to share their results.

Facilitate a group discussion about what was learned from the activity.



- HIV prevention aims to prevent the transmission of HIV and re-infection. HIV care support and treatment aims to improve the quality of life of people with HIV.
- HIV prevention can lead to increased HIV counselling and testing, which in turn can lead to broader and quicker access to treatment for people with HIV and AIDS.
- HIV prevention can reduce the stigma and fear around HIV and AIDS, which in turn improve the quality of life for people living with HIV and AIDS as they become more accepted and understood in their families and communities.
- Good care and support activities include advice on condom use to prevent unwanted pregnancies, mother-to-child-transmission, primary infection and re-infection.
- Through HCT, people can learn about HIV-prevention; if they are HIV positive they can be given advice on how to live safely with the virus and plan for the future.

## **Learn to live positively with HIV and AIDS**

Positive living is a term used by people living with HIV and AIDS to describe steps used by people living with HIV and AIDS and aids that enhance their lives and increase their health.

## **Having a positive mind**

If you think you will deal with your HIV infection and ART, you will live a long and healthy life. When you believe that you can do this, then you will also be willing to do things that will help you to stay healthy and strong.

## **Believe in yourself**

Love yourself. Remember that you are valuable, important and worthy. Think about the many ways that you are useful to your family and friends, work and the community. Remind yourself that you are an important person because *%am the breadwinner in the family+, %am getting an education which will enable me to help other people better themselves+, %am helping other people with HIV to cope with it". %am a mother and my children need me to guide and support them as they grow". "I am father and my children need my protection, care and love and they need me to support them to get a education+, %can share my experience with the community and help them prevent getting infected". "I can encourage other people to get an HIV test and know their status so that they can live positively and avoid infecting other people". %have good farming skills and can use them to continue producing crops for our family and community'...* And think of the many other ways in which you are important and useful.

## **Setting goals for living**

Why must you go on living?

Write down all the reasons why you need to go on living and why you should stay healthy and strong. This could be:

- I have children to protect, nurture and care for.
- I want to complete my education and further education.
- I am very good at the work that I do and my employer needs me.

## **Set your goals**

- I will live longer so that I can see my children grow and protect them from the dangers of life.
- I will get the education that I have always wanted.
- I will get the promotions at work.
- I will eat healthy food and exercise regularly to stay physically strong.
- I will continue with doing things I enjoy.

## **Welcoming good – kicking out bad**

Think positive (good) thoughts only. Avoid negative (bad) thoughts because they will reduce your mental powers and weaken your immune system . making you sick.

### **Telling someone**

To help you live positively you also need some support and encouragement from people who truly love and care for you.

### **Finding out more about HIV and AIDS and ART**

Get more information about HIV and AIDS and ART. The more you know about HIV and ART, the better you can use the information to stay healthy and strong. But remember that not all information you get is true. Make sure you check the information you get with different people working in the area of HIV and AIDS or health workers (nurses, doctors, or peer educators, community caregivers).

## Part 8.2 Burnout and self-care

**After completing this activity, participants will:**

- have an understanding of burnout and strategies to care for themselves

### **Presentation guide**

1. Ask participants to discuss burnout.
2. Ask them to discuss the signs of burnout.
3. Ask participants to brainstorm ways in which they can care for themselves.



**Community caregiving is at times very stressful and difficult especially when supporting clients on ART**

**Community caregiving can affect our psychosocial well-being**

- **Working as a caregiver is not easy and requires a lot of attention, time and energy. You should pay attention to yourself and take care of your own health and adopting appropriate behaviour**

❖ Information sheet

### **What is stress and burnout?**

- Stress denotes the experience of feeling overwhelmed by physical, intellectual and emotional demands.
- The high level of stress that you accumulated stress that you experience as a community caregiver, is likely to negatively influence your resilience.
- Burnout is physical, emotional and mental exhaustion.

### **What are the symptoms of stress and burnout?**

- At times the patient might direct strong emotions to you. Often they do not mean to hurt you and are just generally frustrated with their own situation.
- Try to allow the sick person to express his/her feelings and frustrations freely. Try not to over react to the persons emotions. Try to find out if there is something they need and how you can help.

- The caregiver's role can be very demanding, so caregivers may have times when they are tired, angry and disinterested in caring for the sick person. These are normal reactions and you should not feel guilty but you should try to find a way to manage them.
- The signs that can help you recognize burn out are the following:
  - Irritability;
  - Fatigue;
  - poor sleeping;
  - poor concentration;
  - emotional numbness, lack of joy; and
  - alcohol and drug abuse

#### **How do I take care of myself so I can effectively respond to people on ART?**

- Define for yourself what is meaningful and valued in caregiving.
- Divide task into manageable parts, ask others to help and encourage self-care by the patient.
- Be aware of what causes stress and avoid it.
- Share your problems and feelings with other caregivers, family members and friends.
- Be aware that you can't do everything yourself and you can need help.
- Try to take regular breaks from caring for the sick person. Try to do something refreshing and manage time for activities which are not related to caregiving.
- Do something outside the patient home, such as joining social gatherings, visiting friends
- Take time to rest. Try to find somebody who can replace you for periods of time
- Use relaxation techniques.
- Take care of your own health.

**ANNEXURE A**



**Expectations for the training**

You will get much more out of this programme if you take some time to think about the things you would like to achieve as a result of the empowerment programme

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In order to achieve this I intended to:

Learn the following:

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Apply the following:

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Implement the following:

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**Signed:**

\_\_\_\_\_  
**Date**

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**ARTICLE 5**  
**EVALUATION OF AN EMPOWERMENT PROGRAMME FOR COMMUNITY CAREGIVERS  
TO FACILITATE PATIENT'S ADHERENCE TO ANTIRETROVIRAL TREATMENT**

Mokwele, R.M and Strydom, H (Mokwele, R.M. is a PhD student and Social Worker at the Department of Social Development (North-West Province) and Strydom, H is a Professor in Social Work at the North-West University (Potchefstroom Campus) and a researcher in COMPRES (Community Psychosocial Research Unit).

***Abstract***

The aim of this article was to evaluate the effectiveness of a social work empowerment programme for community caregivers to facilitate patients' adherence to antiretroviral treatment. For the purpose of this research, an experimental and comparison group were formed comprising of twelve caregivers each. The comparison group received both the pre-test, post-test and post-post-test at the same time as the experimental group, but did not receive the treatment. The effectiveness of the programme was evaluated by means of the Personal Multi-Screening Inventory (PMSI). Evaluation according to this measuring scale took place on three occasions: before the group started, at the end of the last group session and one month after the last group session. At the end of the group sessions, the social work empowerment programme was evaluated by all the group members. The programme was analysed and the results of the measurements indicates that the community caregivers were empowered through the programme and that such an empowerment programme is needed.

**7.1 INTRODUCTION**

The need for the development of an empowerment programme through group work (Toseland & Rivas, 2012:389; Zastrow, 2010:45), was identified to strengthen the knowledge and skills of community caregivers with regard to psychosocial support of patients on antiretroviral treatment (ART). This programme was developed and implemented. The programme was evaluated by means of the Personal Multi-Screening Inventory (PMSI) to establish the impact thereof on community caregivers. The results of the Personal Multi-Screening Inventory (PMSI) as well as the questionnaires on knowledge skills and attitude and the results of the schedule regarding the impact of the social work empowerment programme will be discussed in this article.

**7.2 PROBLEM STATEMENT**

Despite recent international efforts to upgrade (ART), only 34% of the 28.3 million eligible people in low-and middle-income countries are receiving ART (UNAIDS Global Report, 2013:46). However, progress had been made and at the end of 2014, 36.9 million people were

infected with HIV and 15.8 million people in low-and middle-income countries were receiving antiretroviral treatment (ART) in 2014 (UNAIDS, 2015:1).

One of the main constraints in achieving universal ART coverage is the limited human resources available to treat HIV and AIDS. Research studies by Kabore *et al.* (2010), Schneider *et al.* (2006) and Van Damme *et al.* (2008) have indicated that overburdened health staff often have difficulty in conveying the practical skills aimed at empowering people living with HIV and AIDS for informed day-to-day decision making. Insufficient human resources causes stress to the limited staff available, leading to fatigue and a decrease in motivation (Schneider *et al.*, 2006:20). The need for the development of a social work empowerment programme was identified to strengthen the knowledge and skills of community caregivers regarding psychosocial support for patients on ART to equip caregivers with self-care, knowledge and to enhance their support to patients on ART.

This article focuses on the measurement of the psychosocial functioning of community caregivers after the presentation of the social work empowerment programme. According to Zastrow (2010:45) group work seeks to facilitate the intellectual, emotional, and social development of individuals through group activities. In social work, there has been a move towards accountable and empirically validated practice (Toseland & Rivas, 2005:389). Evaluation and measuring are essential in obtaining information on the effects of a single intervention on the individual or total group experience (Toseland & Rivas, 2005:389). By means of the social work empowerment programme, the psychosocial functioning of the community caregivers was evaluated before they started the social work empowerment programme, at the end of the programme as well as one month after the programme.

### **7.3 RESEARCH QUESTION**

For the purpose of this article the research question to be answered is:

Can the presentation of a social work empowerment programme be effective in empowering community caregivers to facilitate patients' adherence to antiretroviral treatment?

### **7.4 AIM OF THE RESEARCH**

The aim of the research and this article was to implement and evaluate a social work empowerment programme for community caregivers to facilitate the adherence of patients on antiretroviral treatment.

## **7.5 RESEARCH METHODOLOGY**

The intervention research model was used. According to De Vos and Strydom (2011:476) the intervention research model is divided into six phases, namely, problem analysis and project planning, information gathering and synthesis, design, early development and pilot testing, evaluation and advance development and dissemination. Phase four of the research focuses on the aim of this article namely, the implementation and evaluation of a social work empowerment programme for community caregivers to facilitate patients' adherence to ART.

### **7.5.1 Research design**

The study focused on experimental research (Fouché *et al.*, 2011:145) and the quasi experiment was chosen (Botma *et al.*, 2010:114). Quasi-experimental designs assist the researcher to test for casual factors where it is difficult to implement a true experiment. According to Fouché *et al.* (2011:148), a quasi-experimental design has some, but not all of the requirements of an ideal experiment. The comparison group pre-test-post-test design was chosen in order to determine how the programme will affect the experimental group by comparison of pre- and post-test results.

For the purpose of this research, an experimental and comparison group were formed comprising of twelve caregivers each. The caregivers in the experimental group received the empowerment programme while the comparison group did not participate in the programme. The comparison group received both the pre-test, post-test and post-post-test, at the same time as the experimental group, but did not receive the treatment (Rubin & Babbie, 2011:271-278).

### **7.5.2 Participants**

The type of sampling chosen for this research was simple random sampling. According to Babbie (2010:189) with simple random sampling, each individual case in the population has an equal chance of being selected for the sample. For the purpose of this study, 24 community caregivers were purposively selected for the experimental and comparison groups. Both groups consisted of twelve community caregivers working with patients on ART.

The sample determined inclusion criteria for the participants. The criteria included the following:

- Male and female home community based caregivers with at least more than three months experience working with HIV and AIDS patients on antiretroviral treatment;
- Active involvement in service delivery to patients on antiretroviral treatment;
- Serving home community based care programmes in Potchefstroom (Bambanani Youth Project, Baptist Children's Centre and Hospice Emmanuel Loving Angels);
- Ability to communicate in English, Afrikaans or Tswana.

Exclusion criteria were:

- Community caregivers who worked for less than three months at any of the organisations; and
- Inability to communicate in Tswana, Afrikaans or English.

In quasi-experiments, assignment to treatment or control status may be determined by self-selection or administrator decision. Selection to the groups was based on age, sex and years of experience. Therefore, no absolute assurance could be given that the two groups would exactly be the same, however, all possible measures were taken to select the two groups as similar as possible regarding age, sex, years of experience in care giving, etc (Rubin & Babbie, 2011:271-278). Table 7.1 gives a summary of the demographic characteristics of the experimental and comparison group that were based on biographical information such as age, gender, home language, qualifications and working experience.

**Table 7.1: Demographic characteristics of community caregivers**

Experimental group (n=12)			Comparison group (n=12)		
Variable	Frequency	%	Variable	Frequency	%
Gender			Gender		
Male	3	25	Male	3	25
Female	9	75	Female	9	75
Age			Age		
22-28	9	75	22	6	50
29-35	2	16.66	29-35	3	25
36-42	1	8.33	36-42	3	25
Language			Language		
Sesotho	3	25	Sesotho	2	16.66
Tswana	9	75	Tswana	6	50
Afrikaans	-	-	Afrikaans	3	25
Xhosa	-	-	Xhosa	1	8.33
Qualifications			Qualifications		
Grade 12	5	41.66	Grade 12	7	58.33
Grade 11	4	33.33	Grade 11	3	25
Grade 10	3	25	Grade 10	2	16.66
Experience			Experience		
1 year	3	25	1	4	33.33
2 years	4	33.33	2	3	25
More than 3 years	5	41.66	More than 3 years	5	41.66

### **7.5.3 Data collection**

For the purpose of this study, quantitative and qualitative research were used. Barker (2003: 354) defines quantitative research as follows: "Systematic investigations that include descriptive or inferential statistical analysis." Examples are experiments, survey research and investigations that make use of numerical comparisons. According to Delpont and Roestenburg (2011:181) the selection of data collection methods for a quantitative approach can include questionnaires, indexes and scales. The Personal Multi-Screening Inventory (PMSI) of the Perspective Training College was used in the research to measure the personal functioning of the community caregivers before and after the presentation of the programme, based on the following areas, positive psychosocial functioning, negative psychosocial functioning, emotional functioning, self-perception, interpersonal functioning, spiritual functioning and physical functioning. This is a standardised questionnaire, which is valid and reliable as proposed by Botma *et al.* (2010:174).

A self-developed questionnaire based on knowledge, skills and motivation developed by the researcher, measured the three dimensions of the caregivers (both experimental and comparison group). This was based on the information, motivation and behaviour skills model (IBM) for community caregivers to acquire the information, skills and motivation to attend to patients on ART. After a baseline measurement, an intervention programme was conducted with only the experimental group, followed by a post-test with both experimental and comparison groups. A final post-post-test was conducted with both experimental and comparison groups one month after the intervention (empowerment programme). All sessions incorporated elements of information, motivation and behavioural skills.

A self-structured schedule was used as the qualitative measure in this study to evaluate the success of the social work empowerment programme.

### **7.5.4 Research procedure**

Permission to conduct the research was obtained from the managers of the home community based care (HCBC) centres. They also assisted with the selection of the participants for the study. Before the first group session, the experimental and comparison group members completed the measuring scale of the Perspective Training College. The same measurement was repeated on both groups after the presentation of the empowerment sessions and a post-test was done one month after completion of the empowerment sessions. The empowerment programme was implemented and evaluated by the group members in the experimental group by means of a self-administered schedule as an additional measure.

### **7.5.5 Data analysis**

Data from the Personal Multi-Screening Inventory (PMSI) scale was processed by a computer programme of the Perspective Training College. The self-developed questionnaire based on knowledge, skills and motivation that was developed to measure the three dimensions of the caregivers (of both the experimental and comparison group) was processed by the researcher. The schedule was also used to evaluate the success of the social work empowerment programme. The qualitative data from the self-administered schedule was analysed manually by the researcher by means of the constant comparative method (Poggenpoel, 1998:338-339). This method includes the following steps: comparing units applicable to each category; integrating categories and their properties; delimiting the construction and writing the construction

### **7.5.6 Reliability and validity of quantitative data.**

- **Reliability**

Reliability refers to the consistency of the measure achieved. The researcher must be in a position to provide proof of the reliability of the instrument. Reliability was achieved by ensuring consistency in data collection through the data collection tools, (questionnaires). Content-related reliability was achieved through the use of self-developed questionnaires to collect detailed information from participants, (Botma *et al.*, 2010:177).

- **Validity**

Validity indicates whether the conclusion of the study are justified, based on the design and interpretation. Criterion validity was implemented, whereby the scores obtained in one measurement could be accurately compared with those obtained with a more direct or already validated measure of the same phenomenon. Content validity was achieved by ensuring that the data collection instruments measured what it is supposed to measure (Botma *et al.*, 2010: 174).

### **7.5.7 The trustworthiness of qualitative data**

The methods of trustworthiness proposed by Lincoln and Guba (in Babbie & Mouton, 1998:276) were utilised, namely credibility, transferability, dependability and confirmability.

### **7.5.8 Ethical aspects**

Hammond and Wellington (2013:58) defines ethics as: ~~an~~ a moral principle or a code of conduct that actually governs what people do. It is concerned with the way people act or behave.+ Ethical permission was obtained from the ethics committee of the North-West University,

Potchefstroom Campus with the number NWU-00130-14-S1NWU. The following ethical measures were taken during the research.

- The researcher ensured that the environment where sessions were conducted was relaxed. Participants were granted breaks if they required so.
- They were informed that they would be referred for appropriate counselling if they experienced emotional discomfort as sensitive issues were discussed.
- The researcher acknowledged the rights of participants and ensured their anonymity, adhered to their right to self-determination and treated all information in a responsible, confidential and respectful manner (Alston & Bowles, 2007:21). All information regarding the empowerment sessions was kept private.
- The researcher acted professional, tactful, honest and neutral at all times. The researcher respected the views and opinions of the participants and restrained herself from making value judgments.
- According to Strydom (2011:126) a highly scientific investigation will not be viewed as research unless the findings of the study are introduced to the reading public in written form. The researcher compiled the report as accurately and objectively as possible containing all essential information. Shortcomings and errors were admitted and all due recognition should be given to sources consulted.
- The researcher undertook to release the findings in such a manner that utilisation by others was encouraged, since that would be the ultimate goal of the research project.
- Information regarding the study will be made available to the participants in their own language through feedback information sessions after the completion of the study.

#### **7.5.9 Limitations of the study**

- This study was conducted in one geographical area and makes it difficult to generalise its results to other geographical areas.
- Only a selected number of participants were used.
- The quantitative measuring instrument might have been a challenge for the participants, due to the length of the questionnaire.
- The programme was implemented over a period of eight weeks. The conclusion can be drawn that the programme should be implemented over a longer time span with shorter sessions and time must be given to community caregivers to practice and internalise what they have learned.
- Selection to the groups was based on age, sex and years of experience. However, some other important criteria, e.g. marital status were overlooked, which formed an important part of the quantitative measuring instrument.

## **7.6 EVALUATION THROUGH A SOCIAL WORK EMPOWERMENT PROGRAMME**

### **7.6.1 *The nature of evaluation in group work***

According to Toseland and Rivas (2009:12), group work can be defined as an approach that is goal-directed in small groups, aimed at accomplishing tasks and meeting their socio-emotional needs. The activity is directed towards individual members in a group and the group as a whole within a system of service delivery. In other words, group work is a method used by the social worker, which is applied to a group process, dynamics, and mutual relationships and programme media.

An empowerment- based practice evaluation such as a group work programme is a process of helping individuals, families, groups and communities (Barker, 2003:141). A group work empowerment programme enables them to increase their personal, interpersonal, socio-economic and political strengths. Toseland and Rivas (2009:390) view the benefits of evaluation for social workers who implement group work are as follows:

- The social worker can assess the progress of the group members and determine whether the group and the programme have accomplished the agreed purpose.
- Evaluation can help social workers in improving their leadership skills.
- Evaluation can examine the cost-effectiveness of group work services.
- Evaluation can satisfy the social workers curiosity and professional concern about effects of specific interventions they perform while working with a group.
- Social workers can systemise and turn into practice, those covert hypo-these processes that they routinely engage in.

### **7.6.2 *The social work empowerment programme***

#### **7.6.2.1 *Composition of the groups***

In quasi-experiments, assignment to treatment or control status may be determined by self-selection or administrator decision. Selection to the groups were based on age, gender and years of experience, to select the two groups as similar as possible regarding age, sex, years of experience in caregiving, (Rubin & Babbie, 2011:271-278). The experimental as well as the comparison group in this study were composed of twelve caregivers (nine female and three male). The group worker needed to be able to identify common demographic characteristics and to work towards group cohesion, therefore diversity issues such as age, gender or socio-cultural factors needed to be taken into account (Toseland & Rivas, 2012:165).

### 7.6.2.2 Frequency, duration and content of sessions

According to the results of the needs assessment, the programme was developed based on subjects for eight sessions. The empowerment programme took place over a period of eight weeks. The sessions took place on a weekly basis. The duration of each session was two hours with a fifteen minute break in between. The full programme is presented in table 7.2.

**Table 7.2: Social work empowerment programme**

<b>Session</b>	<b>Topic</b>	<b>Programme activities</b>
<b>Session 1</b>	Welcoming and introduction to empowerment programme	Welcoming Measuring scale Post-test Ice breaker Group discussion Contracting
<b>Session 2</b>	ART and adherence	Group exercise Presentation Brainstorm Group discussion
<b>Session 3:</b>	The community caregiver and psychosocial and adherence support	Group exercise Presentation Case study Group discussions
<b>Session 4:</b>	Communication and lay counselling	Group exercise Presentation Group discussions Role play
<b>Session 5:</b>	Providing psychosocial support services	Group exercise Presentation Group discussions Assessment tools Case study
<b>Session 6:</b>	Disclosure	Group exercise Presentation Group discussions Case study
<b>Session 7:</b>	Mental health and substance abuse	Group exercise Presentation

		Group discussions Case study Role play
<b>Session 8:</b>	Positive Living and healthy living	Group exercise Presentation Group discussions Role play Evaluation Completion of measuring scale

## 7.7 RESULTS OF THE RESEARCH

The results will be done according to the Personal Multi-Screening Inventory (PMSI) and the analysis on knowledge, skills and attitude (quantitative measures) and the qualitative measuring instrument.

### 7.7.1 Results of the Personal Multi-Screening Inventory (PMSI) instrument:

The Personal Multi-Screening Inventory (PMSI) questionnaire which was selected, include, positive/negative psychosocial functioning, emotional functioning, self-Perception, interpersonal functioning, spiritual functioning, and physical functioning. The measurement took place before, and after the implementation of the programme a post-post-test was done. The following results represent an average of twelve respondents from the experimental group and twelve respondents from the comparison group.

#### 7.7.1.1 Positive psychosocial functioning

The positive psychosocial functioning area is divided into three main categories, namely expectation, achievement and satisfaction which in turn are divided into internal functioning (ISS) and behaviour (GBS). The mentioned six indicated areas were used to measure the positive psychosocial functioning.

#### Positive psychosocial functioning

0-30%: Under activated, unable to rationalize.

31%-72%: Under activated, needs attention

73%-79%: Warning area

80%-95%: Optimally activated

95%-100%: Over activated, out of touch with reality

**Table 7.3: Analysis of positive psychosocial functioning of experimental group (n=12) and comparison group (n=12)**

Measurement	Experimental group (n=12)			Comparison group (n=12)		
	Pre	Post	Post-post	Pre	Post	Post-post
EXPECTATION-IIS	79%	60%	63%	74%	59%	59%
EXPECTATION-GBS	81%	57%	70%	70%	63%	58%
ACHIEVEMENT-IIS	71%	59%	65%	66%	54%	59%
ACHIEVEMENT-GBS	76%	56%	65%	71%	58%	58%
SATISFACTION-IIS	75%	58%	69%	69%	57%	56%
SATISFACTION-GBS	75%	56%	65%	73%	63%	61%
Average score	76%	57.6%	66%	70.5%	59%	58.5%

- **Expectation: Inner Interactive Scale**

The experimental group measured at 79% for the pre-assessment compared to 74% of the comparison group. After presenting the programme the positive psychosocial functioning of the experimental group measured 60% and increased to 63% for the post-post-test, while the comparison group score declined to 59% for both the post and post-post-test. This measurement indicated that participants in both groups fluctuated between feelings of optimism and hopefulness about the future focused on positive elements in their circumstances. However, according to a research study by Van Dyk (2007:49-66) on occupational stress experienced by care workers working in the HIV and AIDS field, the severity and intensity of the HIV epidemic is often perceived as overwhelming by carers since it involves whole families, including children, who are often suffering severe financial hardships and other problems with the potential to influence their hopes and optimism. Although a decline from the baseline measurement for both groups, it can be concluded that the empowerment programme yielded positive results for the experimental group to make them hopeful and optimistic about the future and to focus on the positive elements in their circumstances on a personal level and regarding their working environment.

- **Expectation: General Behaviour Scale**

The positive psychosocial functioning of the experimental group measured at 81%, for the pre-assessment, indicating that it was optimally activated. Respondents' behaviour showed that they were fully developed in this area and did not need much intervention. The comparison group measured at 70%, indicating that their positive psychosocial functioning was under

activated and needed attention. However, experimental groups post measurement showed a decline to 57% for the post-test and 63% for the post-post-test compared to the comparison group measurement of 63% and 58% for the post-post-test. The experimental group measurement increased again to 70% during the post-post-test. These measurements show significant variances for both groups. This also points to uncertainty based on the ability to help others and encourage others. However, the empowerment programme had a slightly positive affect for the experimental group and they did develop qualities of helping others to be successful and to encourage them, to show others that they care and have faith in them, to act calmly, to deal positively with problems and to support others. As Van Dyk (2007:50) states: "A lack of capacity to give compassionate care, development of a negative self-image and the belief that it is not possible to make a difference must be prevented at all cost." In this regard, community caregivers need continuous professional support for development in this area.

- **Achievement: Inner Interactive Scale**

The experimental group measured at 71% for the pre-assessment compared to 66% of the comparison group. According to the analysis, this indicated that they needed development to improve qualities of goal-setting, self-motivation, desire to grow and improve, perseverance to complete difficult tasks, and taking responsibility for their behaviour and success. The post test results revealed that the experimental group measured 59% for the post test and the comparison group measured 54%, which still indicated that they needed development in this area. This area also showed significant fluctuation between the measurements and the results might point to overwhelming tasks based on their work environment. The study in South Africa by Caregivers Action Network (2013:14) found that caregivers experience an increase in tasks especially with the expansion of ART. Caregivers now have the role of record keeping; linking clients to services provided at facility level; health promotion activities; tracking clients living with HIV and AIDS on treatment; encouraging defaulters to resume treatment and educating family members on how to support their relatives to adhere to ART. Other additional roles include counselling community members, testing individuals for HIV, and linking those living with HIV to treatment centres. This supported the views of previous research by (Simpson, 2006) indicating that a high workload involved too many patients to attend to, too much to do and little time to rest. It can thus be concluded that high workload influences the achievement ability of caregivers. After the presentation of the programme the positive psychosocial functioning of the experimental group measured 65% for the post-post-test. Although still under activated there was a slight improvement from the post-test to the post-post-test compared to the comparison group score of 54% for the post test and 59% for the post-post-test. This indicated that this area still needed attention and intervention strategies to address for both groups.

- **Achievement: General Behaviour Scale**

The experimental group measured 76% which indicates a warning area. The comparison group measured 71%, indicating that this area was under activated and needed attention. After the presentation of the programme the positive psychosocial functioning of the experimental group measured 56% and increased to 65% for the post-post-test, while the comparison group declined to 58% for both the post and post-post-test. Although the experimental group showed an improvement with the post-post measurement, the fluctuations in measurements lead to the conclusion that respondents of both groups experienced challenges with regard to the following qualities in their behaviour: organisation, self-confidence and drive. This indicated that continuous professional assistance to develop these qualities is needed.

- **Satisfaction-Inner Interactive Scale**

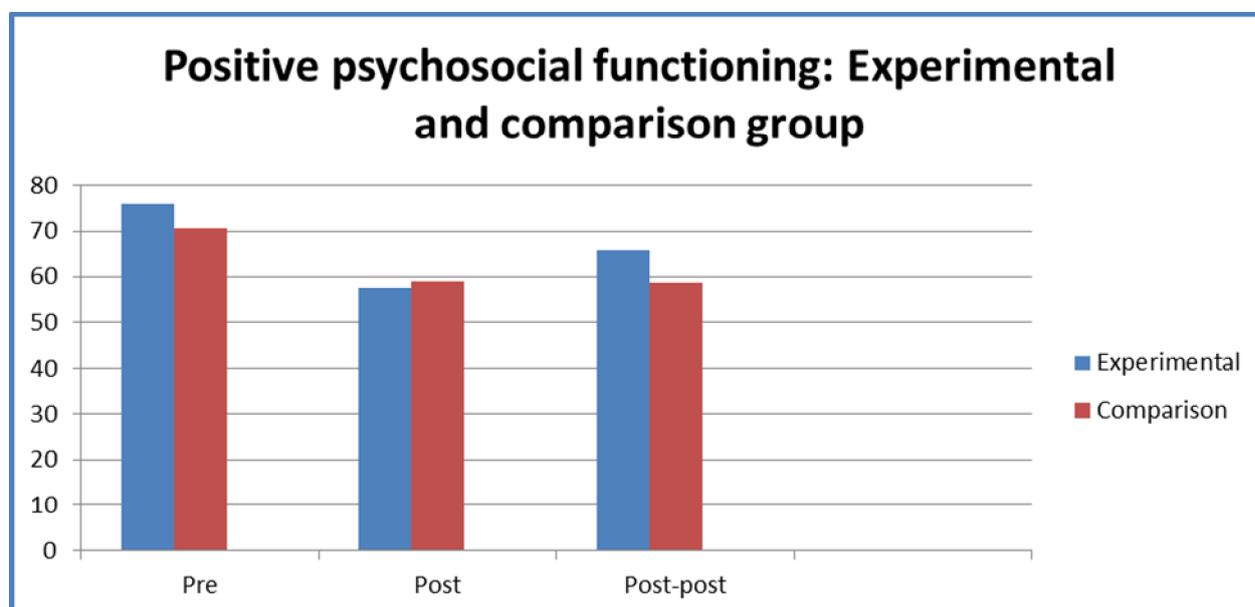
The experimental group measured 75% and indicated a warning area. The comparison group measured 69%, indicating that this area was under activated and needed attention. Characteristics of this area include: satisfaction with one's circumstances, humour, positive use of free time, interaction with others, happiness, friendliness and peace of mind. Previous research studies (Shobede, 2011; Simpson, 2006; Singh, 2011 & Van Dyk, 2007) had indicated that caregivers have little time or energy for self-care neglecting nutrition, exercise, socialisation and sleep leading to physical ailments. The demands of caring for patients and their families may also lead to social isolation. After the presentation of the programme the positive psychosocial functioning of the experimental group measured 58% and increased to 69% for the post-post-test, while the comparison group decreased to 57% for the post test and 56% for the post-post-test. The conclusion can be drawn that although respondents of the experimental group improved slightly, both groups experiences difficulty with regard to this area and will need continuous professional intervention.

- **Satisfaction: General Behaviour Scale**

The experimental group measured 75% and the comparison group measured 73%, which indicated a warning area. After the presentation of the programme the positive psychosocial functioning of the experimental group measured 56% and increased to 65% for the post-post-test, while the comparison group decreased to 63% for the post test and 61% for the post-post-test. The conclusion can also be drawn that respondents of the experimental group's ability to develop qualities to make use of their free time and enjoy life in a responsible manner did slightly improve based on the scores. However, the results based on respondents' behaviour indicated a lack of humour, use of free time, interaction with others and pleasure of life.

**Table 7.4: Differential changes for positive psychosocial functioning over intervention**

	Differential change over intervention (pre and post test)	Differential change post-test and post-post-test	Differential change pre-test and post-post-test
EG			
Positive psychosocial functioning	-18.4%	8.4%	-10%
CG			
Positive psychosocial functioning	-11.5%	0.5%	12%



**Graph 7.1: Positive psychosocial functioning: Experimental and comparison group**

Table 7.4 illustrates the differential changes over the intervention based on the average score for positive psychosocial functioning as illustrated in graph 7.1. In general, the positive psychosocial functioning of the experimental group measured at an average of 76%, for the pre-assessment, indicating a warning area. This indicates a decline of -18.4% during the intervention which represents a decline with regard to positive psychosocial functioning. The post measurement showed the positive psychosocial functioning, with regard to the experimental group at 57.6%. The differential change between the post-test and the post-post-test shows an increase of 8.4%, indicating an improvement in psychosocial functioning from the post-test to the post-post-test. The results of the post-post test revealed an average of 66%, and showed a differential change of -10% between the pre-test and post-post-test. In summary the

conclusion can thus be made that for the experimental group most improvement occurred between the post and post-post measurements. The comparison group measured at 70.5%, indicating that their positive psychosocial functioning was under activated and needed attention. The post-test of the comparison group measured at 59% (a differential change of 11.5%). Between the pre-test and the post-test, the comparison group scored 58.5%. Although the idea was for the experimental group to have an optimally positive psychosocial functioning with the implementation of the empowerment programme, the results shows a fluctuation between measurements in all six areas, with an improvement only in the post-post-test but, a decline from the baseline measurements. The conclusion can be drawn that community caregivers had new insights regarding their positive psychosocial functioning because of the empowerment sessions. This indicates that they still need intervention with regard to positive psychosocial functioning.

#### **7.7.1.2 Negative psychosocial functioning**

The negative psychosocial functioning area is divided into three main categories, namely stress, helplessness and frustration, which in turn are divided into internal functioning (ISS) and behaviour (GBS). Six indicated areas, as illustrated underneath, were used to measure the negative psychosocial functioning of the respondents.

##### **Negative psychosocial functioning**

0%-5%: Under activated, out of touch with reality.

6%-21%: Optimally activated

22%-28%: Warning area

29%-70%: Over activated, needs attention

71%-100%: Over activated, unable to rationalize

**Table 7.5: Analysis of negative psychosocial functioning for experimental (n=12) and comparison group (n=12)**

	Experimental			Comparison		
	Pre-	Post	Post-post	Pre-	Post	Post-post
STRESS-IIS	40%	42%	34%	33%	38%	39%
STRESS-GBS	34%	41%	38%	33%	36%	40%
HELPLESSNESS-IIS	27%	43%	32%	30%	35%	38%
HELPLESSNESS-GBS	34%	32%	33%	32%	40%	28%
FRUSTRATION-IIS	31%	42%	33%	34%	40%	38%
FRUSTRATION-GBS	27%	34%	27%	26%	36%	34%
Average	32%	39%	32%	31%	37.5%	36%

- **Stress: Inner Interactive Scale**

The pre-test score with regard to negative psychosocial functioning for the experimental group was 40% and 33% for the comparison group, which indicated that it was over activated and needed attention. This means that community caregivers had high stress levels and they did not respond positively to the demands of their environment. Too much stress, nervousness, overload, burn-out, worry and fatigue was part of their daily functioning based on the pre-assessment. According to UNAIDS (2008b:15), caregivers who work with HIV and AIDS patients are faced with enormous psychological and physical challenges in providing care, which may result in burn out. Burn out is defined as %emotional exhaustion, depersonalisation and a sense of low personal accomplishment that occur amongst individuals working with people.+Burnout results from a discrepancy between the demands of the job and the ability of the worker to meet these demands. The research studies by HIV and AIDS Treatment in Practice (HATIP) and Van Dyk (2007:62) found that care workers have to continually deal with fatigue, depression, unresolved grief and burnout.

Care workers battle with bereavement, overload, over identifying with their patients, fear of exposure to HIV, and finding it difficult to cope with their own and patientsqstigmatisation and confidentiality issues. This indicates that stigma not only has consequences and impact negatively on the patient, but also the community caregivers who experience challenges with regard to stigma in their working environment (WHO, 2003:139). According to Ogden (2006: 335), due to HIV stigma, caregivers may be closed off from social support at a time they need it most. The post measurement showed the same results for both groups 42% for the experimental group and 38% for the comparison group and still stayed in this category of 34% for the experimental and 39% for the comparison group. Although the experimental group

improved slightly from the post-test to the post-post-test, the results indicates that that despite the programme, they still experience challenges to handle problems like overload, worry and fatigue and needed professional assistance.

- **Stress: General Behaviour Scale**

The pre-test score for the experimental group was 34% and 33% for the comparison group. The post test showed a score of 41% for the experimental and 36% for the comparison group. The post test revealed a score of 38% for the experimental and 40% for the comparison group. This still showed that this area was over activated and needed attention. Behaviour that characterise this area include anxiety and physical symptoms of headaches which is an indication that they could not manage the behavioural elements of stress in a responsible way and acted in uncertain, moody and panicky ways. According to the UNAIDS (2008a) report, managing stress in HIV and AIDS caregivers is not an event, but a process during which everyday stressors and anxieties are to be addressed. If not, these stressors, gradually undermine the carersqmental and physical health. Therefore through this research it is concluded that community caregivers need to be assisted to learn to address their stress in a positive manner.

- **Helplessness: Inner Interactive Scale**

The pre-test score for the experimental group was 27%, which indicated a warning area. The result of 30% for the comparison group indicated that this area was over activated and needed attention. However, the post test showed a score of 43% for the experimental and 35% for the comparison group, which still indicated a need for improvement. A research study done by De Saxe Zerden (2006:42-43) found that 69% of caregivers felt sad about patient related issues and feel helpless when it comes to addressing the problems. This sense of helplessness may be due to inadequate expertise to deal with PLWHIV, increased workload and coping with inadequate resources. Trauma was also reported by 70% of the respondents in a study by Mathebula (2006) which explores the challenges faced by caregivers at the Muslim AIDS Programme. This trauma happens because of the experiences due to loss to death. The post-post-test revealed a score of 32% for the experimental and 38% for the comparison group. Although the experimental group improved slightly between the post-test and the post-post-test, the results still showed that this area was over activated and needed attention. This indicated that this area did regressed for both groups and their inner experience were less positive, characterised by feelings of down-heartedness, uselessness and senselessness.

- **Helplessness: General Behaviour Scale**

The pre-test score for the experimental group was 34% and 32% for the comparison group which indicated that it was over activated and needed attention. The post test showed a score of 32% for the experimental and 40% for the comparison group. In this regard, the experimental group improved slightly during the intervention. However, the post-post-test revealed a score of

33% for the experimental and 28% for the comparison group. This still showed that this area needed attention. These results showed that respondents experienced challenges with regard to goal orientation, motivation and were less positive.

- **Frustration: Inner Interactive Scale**

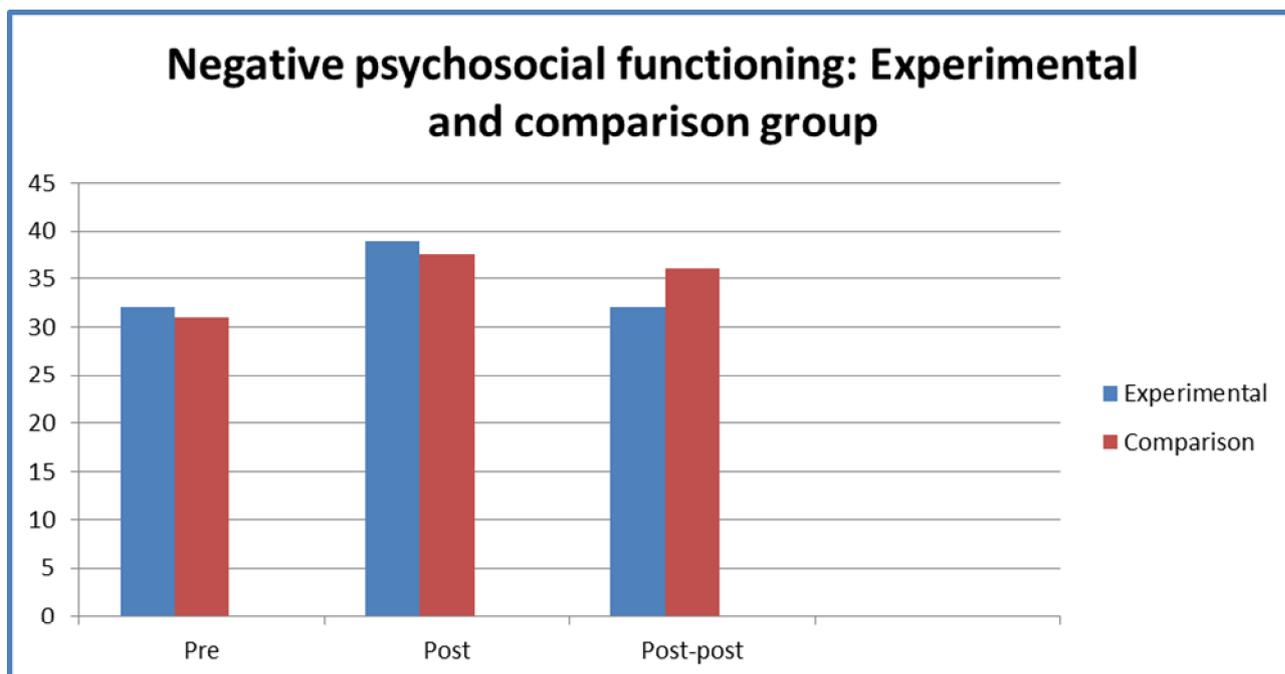
The score for the experimental group for the pre-assessment was 31% and 34% for the comparison group which indicated that it was over activated and needed attention. The post test showed a score of 42% for the experimental and 40% for the comparison group. The post-post-test revealed a score of 33% for the experimental and 38% for the comparison group. This indicated that the experimental group was slightly better, with a downward move, however still in the over activated area. This indicated that their capacity to handle anger, irritation and impatience improved slightly from the post-to the post-post-test.

- **Frustration: General Behaviour Scale**

The score for the experimental group pre-test was 27%, which indicated a warning area and 26% for the comparison group. The post test showed a score of 34% for the experimental and 36% for the comparison group, which showed that this was over activated and needed attention. The post-post-test revealed a score of 27% for the experimental group and 34% for the comparison group. The measurement for the experimental group was thus stable which might indicate an improvement. This indicated that the experimental group was slightly better, with a downward move, compared to the comparison group score of 34%. This indicated that community caregivers ability to control them when angry and to make other people feel secure, improved. It can be concluded that the experimental group was equipped to manage their anger effectively and showed development in this area.

**Table 7.6: Differential changes for negative psychosocial functioning**

	<b>Change over intervention (Pre-and post-test)</b>	<b>Differential change post-test and post-post- test</b>	<b>Differential change pre-test and post-post-test</b>
EG			
Negative psychosocial functioning	-7%	7%	0%
CG			
Negative psychosocial functioning	-6.5%	0.5%	1.5%



**Graph 7.2: Negative psychosocial functioning: Experimental and comparison group**

Based on the differential changes over intervention as indicated in table 7.6 and the average scores as indicated in graph 7.2, the pre-test average score for negative social functioning for the experimental group was measured at 32%, which indicated that it was over activated and needed attention. An increase in the post assessment to 39% still showed an over activation that needed attention, however the post-post assessment decreased again to 32%, which showed an improvement with regard to negative psychosocial social functioning. Compared to the experimental group, the comparison group scored 31% for the pre assessment, 37.5% for the post assessment and 36% for the post-post assessment. Based on the assessments, it showed that the experimental group improved slightly better compared to the comparison group from the pre assessment to post-test (intervention phase). While the experimental group improved with 7%, the comparison group only improved with 1.5%. Thus, the differential changes indicate that the empowerment programme had a slight positive effect on the experimental group. However, the results correlates with analysis of Van Damme (2008:211) which found that there is now overwhelming evidence that in countries like Sub-Saharan Africa, hit hardest by HIV and AIDS, care workers has to cope with ever increasing higher workloads, resulting in growing emotional and physical stress.+

### 7.7.1.3 Emotional functioning

The emotional functioning is divided into seven areas, namely dependency, paranoia, anxiety, memory loss, disturbing thoughts, senselessness of existence and suicidal thoughts. These seven indicated areas were used to measure the emotional functioning of the respondents.

## Emotional functioning

0%-16%: Optimally activated

17%-21%: Warning area

22%-70%: Over activated, needs attention

71%-100%: Over activated, unable to rationalise

**Table 7.7: Analysis of emotional functioning of experimental (n=12) and comparison group (n=12)**

	Pre	Post	Post-post	Pre	Post	Post-post
DEPENDENCY	38%	48%	34%	38%	48%	43%
PARANOIA	34%	46%	35%	33%	41%	45%
ANXIETY	23%	37%	27%	22%	29%	32%
MEMORY LOSS	23%	35%	27%	21%	35%	32%
DISTURBING THOUGHTS	23%	42%	29%	26%	37%	39%
SENSELESSNESS OF EXSISTENCE	22%	44%	41%	36%	46%	47%
SUICIDAL THOUGHTS	20%	38%	25%	15%	36%	38%
Average	26%	41%	31%	27%	39%	39%

- **Dependency**

Indicative of this area is the ability to cope with life and to handle problems effectively without support of something else. The measurement for the experimental pre-test was 38%, which indicated that it was over activated and 38% for the comparison group. This implicated that they needed development in this area. The post-test measured 48% for the experimental, and 48% for the comparison group, which still showed that it was over activated and needed attention for both groups. The pos-post test revealed a measurement of 34% for the experimental and 43% for the comparison group. This indicated that the experimental group improved, compared to the comparison group measure of 43% which decreased from the post to the post-post-test. The conclusion can therefore be drawn that the experimental groups ability to handle pressure and problems effectively improved from the pre-test to the post-post-test.

- **Paranoia**

The pre-test measurement for the experimental group was 34%, and 33% for the comparison group which indicated that it was over activated and needed development. This measurement

was an indication that both groups had the perception that people are talking behind their back and were out to get them or trying to hurt them. The post test showed a score of 46% for the experimental and 41% for the comparison group, which still showed that it was over activated and needed attention for both groups. The post-post test revealed a score of 35% for the experimental and 45% for the comparison group and was still over activated. The conclusion can therefore be drawn that community caregivers need to be developed in this area.

- **Anxiety**

Behaviour that is characteristic of this area includes fear or becoming afraid easily. The pre-test measurement for the experimental group was 23%, which indicated that it was over activated and needed development and 22% for the comparison group. The post test showed a measurement of 37% for the experimental and 29% for the comparison group, which still showed that it was over activated and needed attention for both groups. Research by De Saxe Zerden (2006:42) indicated that fear of family and fear of HIV and AIDS play a major role in the emotional functioning of caregivers. They have to cope with their own fears of becoming HIV positive and fears of their clients with regard to disclosure issues. Fears also manifest itself through the lack of knowledge of HIV and ART. Most caregivers personal exposure and experience of HIV was high. Most of them knew someone or had someone in their personal lives that had HIV. The post-post test revealed a score of 27% for the experimental and 32% for the comparison group. This indicated that the experimental group was slightly better, but, still over activated compared to the comparison group measurement of 32%.

- **Memory loss**

The pre-test measurement for the experimental group was 23%, and 21% for the comparison group. This indicated that community caregivers displayed signs of memory loss and experienced challenges with remembering important activities. The post-test measured 35% for the experimental, and 35% for the comparison group, which still showed that it was over activated and needed attention for both groups. The post-post test revealed a measurement of 27% for the experimental and 32% for the comparison group. This indicated that the experimental group was slightly better, but still over activated compared to the comparison group measurement of 32%, indicating that the area needed attention.

- **Disturbing thoughts**

Disturbing thoughts points to ideas and thoughts that disturb the individual. The measurement for the experimental group pre-test was 23%, and 26% for the comparison group which indicated that it was over activated and needed attention. The post test showed a measurement of 42% for the experimental group and 37% for the comparison group, which still showed that it was over activated and needed attention for both groups. It can be concluded that both groups

showed a regression from the baseline measurement. It can also be concluded that they are aware now of what disturbing thoughts are and could do introspection.

- **Senselessness of existence**

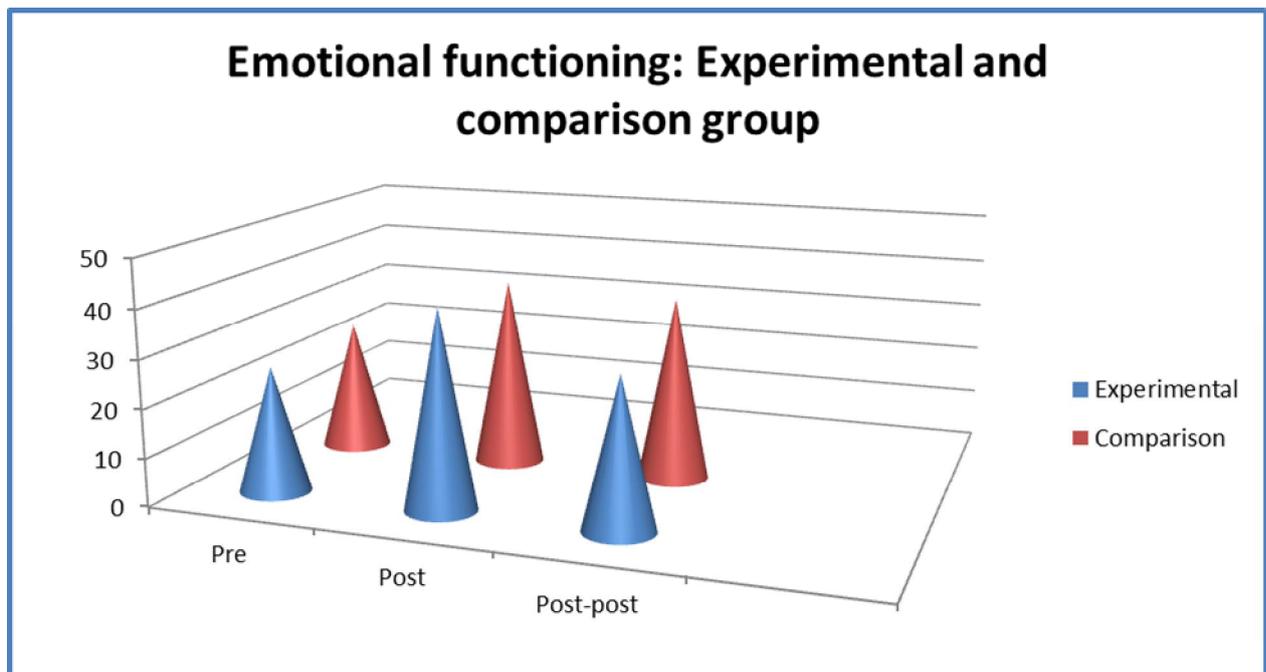
The pre-test measurement for the experimental group was 22%, which indicated that it was over activated and needed attention and 36% for the comparison group. Senselessness of existence points to whether one has a purpose in life, have dreams and the ability to help to make the world a better place. The post test showed a measurement of 44% for the experimental and 46% for the comparison group, which still showed that it was over activated and needed attention for both groups. The post-post test revealed a measurement of 41% for the experimental and 47% for the comparison group. This indicated that the experimental group was slightly better in the post-post-test, but still over activated.

- **Suicidal thoughts**

The pre-test measurement for the experimental group was 20%, which indicated a warning area and 15 % for the comparison group which means it was optimally activated. The post test showed a higher measurement of 38% for the experimental and 36% for the comparison group. Both groups regressed from the baseline measurement. This showed that this area was over activated and needed attention in both groups. This was surprisingly high for the post test for both groups. The pos-post test revealed a measurement of 25% for the experimental and 38% for the comparison group. This indicated that the experimental group showed a lower score in the post-post-test, but, regressed from the initial baseline assessment.

**Table 7.8: differential changes for emotional functioning**

	<b>Change over intervention (Pre-and post-test)</b>	<b>Differential change post-test and post-post-test</b>	<b>Differential change pre-test and post-post-test</b>
Experimental group			
Emotional functioning	16%	-11%	5%
Comparison group			
Emotional functioning	-12%	0%	12%



**Graph 7.3: Emotional functioning: Experimental and comparison group**

Based on the differential changes over intervention on the average score for emotional functioning (table 7.8 and graph 7.3), the following conclusions can be drawn:

The pre-test average score for emotional functioning for the experimental group was measured at 26%, which indicated that it was over activated and needed attention. An increase in the post assessment to 41% still showed an over activation that needed attention. Emotional challenges with regard to frustration and memory loss were identified among caregivers. This concurs with previous research of Simpson (2006) which found that caregivers experience frustration due to poor family support, or patients that do not accept them and poor working conditions. However, the post-post assessment decreased again to 31%, with a differential change of 10% compared to the 0% of the comparison group, which showed an improvement from the post-test to the post-post-test with regard to emotional functioning. However this area was still over activated and needed attention. Compared to the experimental group, the comparison group scored 27% for the pre assessment, and 39% for the post and post-post assessment. Based on the assessments, it could be seen that the experimental group showed a greater improvement compared to the comparison group. However, many challenges were observed with regard to emotional functioning of community caregivers that influence their daily functioning negatively. This is in line with previous findings (Simpson, 2006; UNAIDS, 2000, UNAIDS, 2008b). It can therefore be concluded that they need continuous professional assistance.

#### 7.7.1.4 Self-perception

Self-perception is divided into three areas, namely inner insecurity, guilt feelings and lack of self-worth. These three indicated areas were used to measure the self-perception of the respondents.

##### Self- Perception

0%-20%: Optimally activated

21%-25%: Warning area

26%-70%: Over activated, needs attention

71%-100%: Over activated, unable to rationalise

**Table 7.9: Analysis of self-perception for experimental (n=12) and comparison group (n=12)**

	Pre	Post	Post-post	Pre	Post	Post-post
INNER INSECURITY	35%	39%	32%	34%	40%	34%
GUILT FEELINGS	22%	36%	22%	19%	36%	28%
LACK OF SELF-WORTH	19%	18%	20%	17%	36%	33%
Average	25%	31%	25%	23%	37%	32%

- **Inner insecurity**

During the pre-measurement the experimental group had a percentage of 35% and 34% for the comparison group indicating that it was over activated and needed attention. This indicated that community caregivers experienced insecurity in relationships and were afraid that they will be hurt emotionally. They felt threatened by circumstances and were afraid of future failure and rejection. The post-test showed a measurement of 39% for the experimental and 40% for the comparison group, which still showed that it was over activated and needed attention for both groups. The pos-post test revealed a measurement of 32% for the experimental group and 34% for the comparison group. This indicated that the results have dropped for the experimental group from the pre-test to the post-post-test, which suggest the social work empowerment programme had improved their inner security.

- **Guilt feelings**

The pre-test measurement for the experimental group was 22%, and 19% for the comparison group. This indicated that community caregivers did not have guilt feeling with regard to their

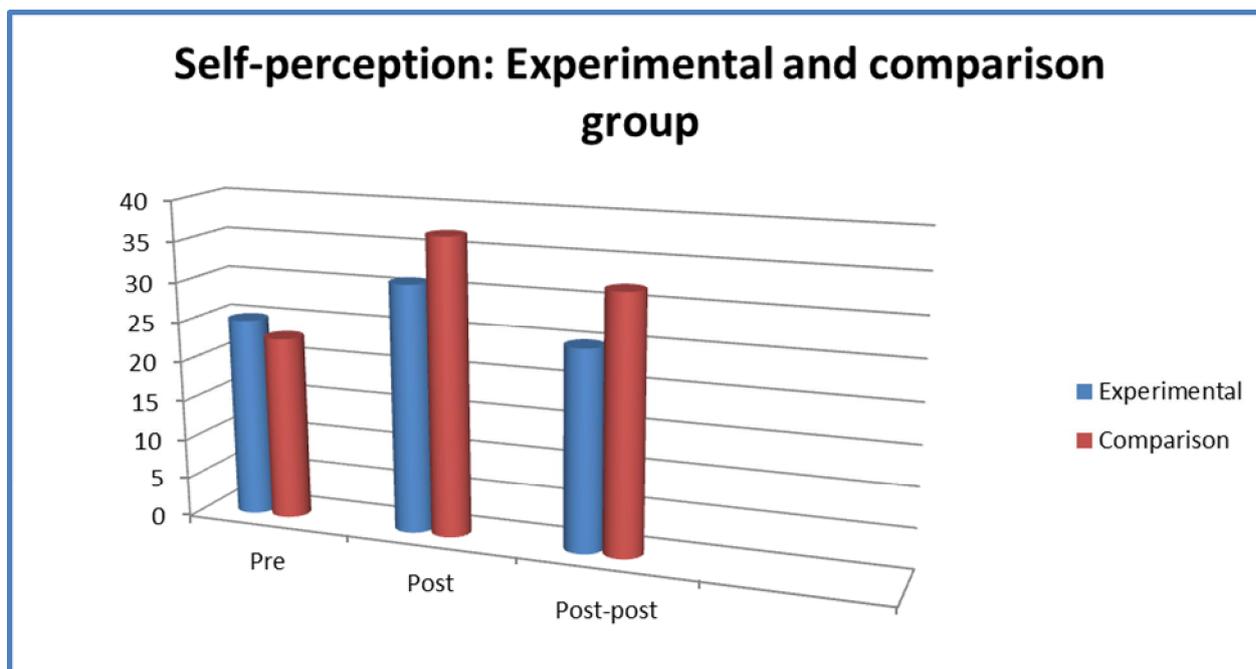
ability to manage themselves responsibly and did not accept blame for everything that went wrong. However an increase in the measurement to 36% for both the experimental and the comparison groups indicated that development in this area was needed. The post-post test revealed a score of 22% for the experimental and 28% for the comparison group. The score from the pre-test to the post-post-test was thus stable for the experimental group.

- **Lack of self-worth**

Indicators of self-worth include to feel good about one self and to experience oneself as someone important and special. The measurement for the experimental group pre-test was 19%, and 17% for the comparison group. This measurement was positive and indicated that community caregivers did not need any development in this area. The post-test measurement of 18% for the experimental group indicates a positive change over the intervention period. In contrast, the comparison group measurement increased to 36%, which indicated a difference of 18% for the post-test. The post-post-test revealed a score of 20% for the experimental and 33% for the comparison group. Therefore the conclusion can be drawn that the community caregivers from the experimental group did not experienced major problems in this area.

**Table 7.10: Differential change for self-perception**

	<b>Change over intervention (Pre-and post- test)</b>	<b>Differential change post-test and post-post-test</b>	<b>Differential change pre-test and post-post - test</b>
EG			
Self-perception	6%	-6%	0%
CG			
Self-perception	14%	-5%	9%



**Graph 7.4: Self-perception: Experimental and comparison group**

In general as set out in table 7.10 and graph 7.4, the pre-test average score for self-perceptions for the experimental group was measured at 25%, which indicated that it was over activated and needed attention. An increase in the post assessment to 31% still showed an over activation that needed attention. However the post-post assessment decreased again to 25%, showing an improvement with regard to self-perception. This was however still in the warning area, but with a differential change of -6%. Compared to the experimental group, the comparison group scored 23% for the pre assessment, and 37% for the post-test and 32% for the post-post assessment. Based on the assessments, it showed that the experimental group improved better compared to the comparison group especially during the intervention phase which showed a differential change of 6% for the experimental group and only 5% improvement for the comparison group. While the experimental group was stable at 25% at the post-post-test, the comparison group's score increased to 32%.

#### **7.7.1.5 Interpersonal functioning**

Interpersonal functioning is divided into eight areas, namely social support, relationship with child, relationship with partner, relationship with mother, relationship with father, relationship with family, relationship with friends and relationship with colleagues. These eight indicated areas were used to measure the interpersonal functioning of the respondents.

## Interpersonal functioning

0%-30%: Under activated, unable to rationalize

31%-63%: Under activated, needs attention

64%-68%: Warning area

69%-100%: Optimally activated

**Table 7.11: Analysis of interpersonal functioning for experimental (n=12) and comparison group (n=12)**

	Pre-	Post	Post-post	Pre	Post	Post-post
SOCIAL SUPPORT	97%	100%	100%	86%	92%	25%
RELATIONSHIP WITH CHILD	100%	100%	100%	55%	65%	35%
RELATIONSHIP WITH PARTNER	100%	13%	75%	38%	50%	29%
RELATIONSHIP WITH MOTHER (STEP)	90%	95%	95%	70%	50%	55%
RELATIONSHIP WITH FATHER (STEP)	70%	60%	55%	0%	35%	50%
RELATIONSHIP WITH FAMILY	75%	89%	89%	57%	89%	39%
RELATIONSHIP WITH FRIENDS	68%	68%	68%	29%	21%	39%
RELATIONSHIP WITH COLLEAGUES	78%	11%	44%	42%	47%	58%
Average	85%	55%	78%	47%	56%	41%

- **Social support**

This research has indicated that community caregivers rely heavily on social support in the form of family structures. These findings correlate with other research findings. The pre-test score for the experimental group with regard to social support was 97%, which indicated that it was optimally activated and did not need attention and 86% for the comparison group. The post test showed a score of 100% for the experimental, and 92% for the comparison. The pos-post test revealed a score of 100% for the experimental, and a surprising 25% for the comparison group. This indicated that the experimental group was functioning optimally with regard to social support. This means that they could rely on a special person for support when in need and who is a source of comfort. The conclusion can be drawn that the empowerment programme was successful based on the post intervention score of the experimental group.

- **Relationship with child**

A stable relationship with children was seen as an important form of support for community caregivers. The score for the experimental pre-test was 100%, which indicated that it was optimally activated and did not need attention. The score of 55% for the comparison group indicated that they needed intervention with regard to relationship building with their children. The post test showed a score of 100% for the experimental, which showed it was still optimally activated and the comparison group scored 65%, which indicated a warning area. The post-post test revealed a score of 100% for the experimental and 35% for the comparison group. This indicated that the experimental group functioned optimally with regard to their relationships with their children. They could share and do things together with their children and have a stable relationship.

- **Relationship with partner**

Relationship with partners also formed a cornerstone for optimal functioning for community caregivers. The pre-test measuring of 100% for the experimental group is an expression of the value of partner support. However, the measurement of 38% for the comparison group indicated a strong need for development. This might be due to the selection of the groups since this did not form part of the selection criteria for the groups. Not all respondents reported that they were in a relationship with a partner, especially respondents from the comparison group. The post-test showed a score of 13% for the experimental group, indicating this area was under activated. It can be concluded that the experimental group had post knowledge about relationships and relationship building from the empowerment sessions and their relationships therefore was measured against what was learnt. The comparison group scored 50%, which indicated it was under activated. However, the pos-post test revealed a score of 75% for the experimental and 29% for the comparison group. This indicated that the experimental group was functioning optimally and was more realistic about their relationship with their partner and the relationship was based on honesty, fun and trust.

- **Relationships with mother (step)**

As seen in this research, relationship with the mother was viewed as important. The pre-test score for the experimental group was 90%, which indicated that it was optimally activated and did not need attention and 70% for the comparison group. The post test showed a score of 95% for the experimental, and 50% for the comparison. The pos-post test revealed a score of 95% for the experimental and 55% for the comparison group. This indicated that the experimental group was functioning optimally with regard to relationship with the mother. They could do things together and share a relationship based on trust and honesty.

- **Relationship with father (step)**

The pre-test score for the experimental group was 70%, which indicated that it was optimally activated and did not need attention and 0% for the comparison group. The post-test showed a score of 60% for the experimental and 35% for the comparison group. The pos-post-test revealed a score of 55% for the experimental and 50% for the comparison group. This indicated that this area was under activated and regressed from the pre-test to the post-post-test especially for the experimental group. This even worsened during the intervention. It can be concluded that the decrease in scores indicated that they learned more about relationships in the groups and could evaluate this relationship more realistically. This pointed to broken relationships with the father figure, which lack honesty and trust. This might also point to an absent father figure.

- **Relationship with family**

Relationship with family measured 75% for the experimental group pre-test and 57% for the comparison group. The post-test showed a positive after intervention change regarding family relationships. The post test showed a score of 89% for the experimental, and 89% for the comparison. However, the post-post test revealed a score of 89% for the experimental and 39% for the comparison group. This indicated that the experimental group was functioning optimally with regard to relationship with the family since the score increased during intervention. This indicated the empowerment programme was effective to empower community caregivers to enrich their family support systems, and to enhance their relationship that is built on trust and honesty.

- **Relationship with friends**

Relationship with friends scored 68% for the experimental group pre-test and 29% for the comparison group. The post test showed a score of 68% for the experimental, and 21% for the comparison group. The pos-post test revealed a score of 68% for the experimental and 39% for the comparison group. In contrast, this indicated that the experimental group was stable in terms of relationships with friends which meant that they could rely on their friends and have a relationship based on trust and honesty.

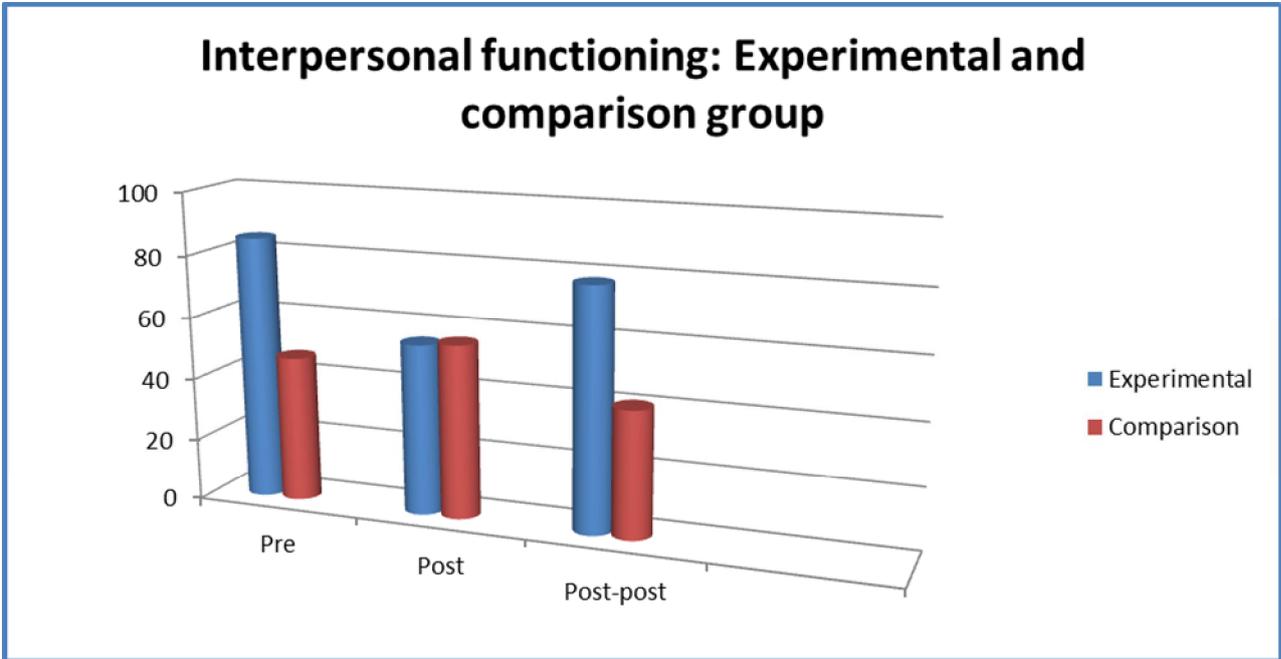
- **Relationship with colleagues**

Relationship with colleagues scored 68% for the experimental group pre-test and 29% for the comparison group. The post-test showed a drastically lower score of 11% for the experimental group. The score of the experimental group increased again during the pot-post-test to 44% which indicated that it was under activated. This fluctuation in scores can be attributed to the fact that the obtained knowledge on relationship gave them a chance to evaluate their relationship with their friends realistically. The comparison group post-test revealed a score of 47% and 58% for the post-post-test. In contrast to the experimental group, the lower score

indicated that they might experience challenges with regard to relationship building with colleagues.

**Table 7.12: Differential change for interpersonal functioning**

	Change over intervention (Pre and post-test)	Differential change post-test and post- post-test	Differential change pre-test and post-post- test
EG			
Interpersonal functioning	-30%	23%	-7%
CG			
Interpersonal functioning	9%	15%	-6%



**Graph 7.5: Interpersonal functioning: Experimental and comparison group**

In general as set out in table 7.12 and graph 7.5, the pre-test average score for interpersonal relationships for the experimental group was measured at 85%, which indicated optimal interpersonal functioning. The post-assessment score decreased to 55% indicating that it was under activated and needed attention. The post-post assessment increased again to 78% (an increase of 23%), showing an improvement with regard to interpersonal functioning, however, only between the post-and post-post-test, with a decrease from the original baseline measurement. Compared to the experimental group, the comparison group scored 47% for the pre-assessment, 56% for the post-test and 41% for the post-post assessment. The assessment showed that their inter-personal functioning was under activated and needed development. Based on the assessments, it showed that the experimental group improved better compared to

the comparison group. However, the experimental group also started off better during the pre-assessment. It might be that they gained more insight with regard to interpersonal relationships.

### 7.7.1.6 Spiritual functioning

The following scores represent the scoring on spiritual level.

#### Spiritual functioning

0%-30%: Under activated, unable to rationalise

31%-75%: Under activated, needs attention

76%-80%: Warning area

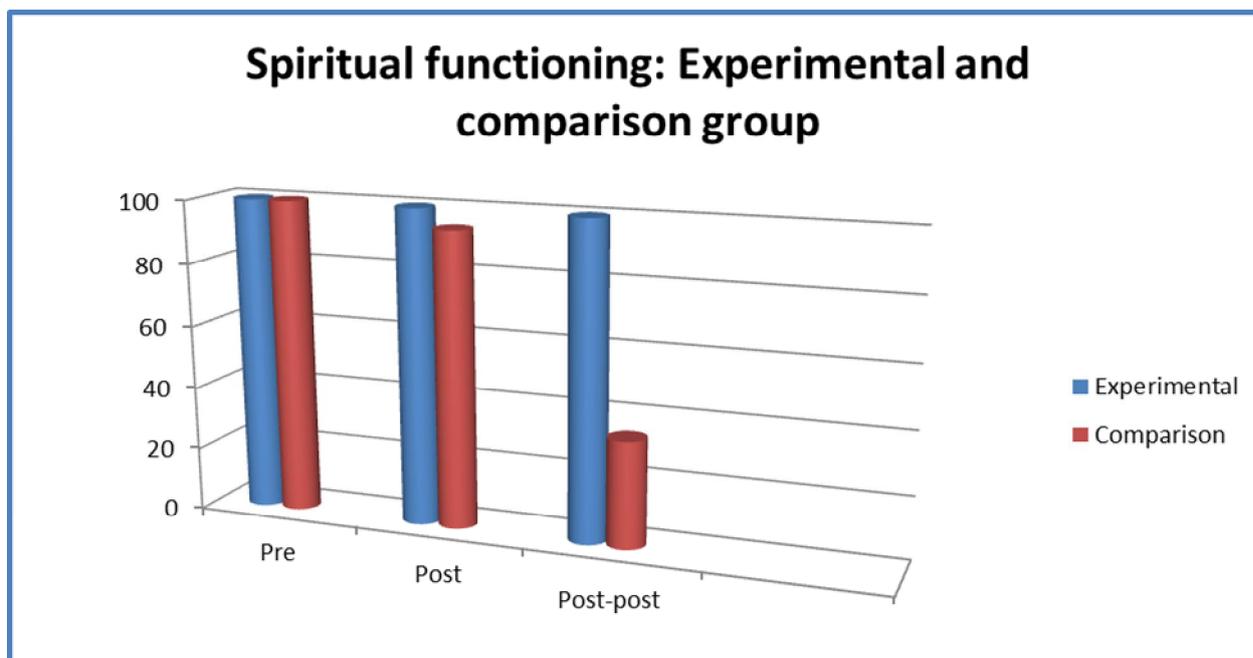
81%-100%: Optimally activated

**Table 7.13: Analysis for spiritual functioning for experimental (n=12) and comparison group (n=12)**

	Pre	Post	Post-post	Pre-	Post	Post-post
RELATIONSHIP WITH GOD	100%	100%	100%	100%	94%	34%

**Table 7.14: Differential change for spiritual functioning**

	Change over intervention (Pre and post-test)	Differential change post-test and post-post-test	Differential change pre-test and post-post-test
EG			
Spiritual functioning	0%	0%	0%
CG			
Spiritual functioning	-6%	-60%	-66%



**Graph 7.6: Spiritual functioning: Experimental and comparison group**

In general as set out in table 7.14 and graph 7.6, the pre-test average score for spiritual functioning for the experimental group was constantly at 100% for the pre-, post-and post-post-test, which indicated that they function optimally. Compared to the experimental group, the comparison group scored 100% for the pre-assessment, and 94% for the post-test and 34% for the post-post assessment. Their assessment showed that their spiritual functioning were under activated and needed development. Based on the assessments, it showed that the experimental group improved slightly better compared to the comparison group.

#### **7.7.1.7 Physical functioning**

The score card represents the scores for physical functioning.

#### **Physical functioning**

0%-31%: Under activated, unable to rationalise

31%-67%: Under activated, needs attention

67%-74%: Warning area

74%-100%: Optimally activated

**Table 7.15: Analysis of physical functioning for experimental (n=12) and comparison group (n=12)**

	Pre-test	Post-test	Post-post-test	Pre-test	Post-test	Post-post-test
BODY IMAGE	63%	69%	64%	68%	58%	64%
SEXUAL SATISFACTION	45%	41%	52%	66%	56%	53%
Average	54%	55%	58%	67%	57%	59%

- **Body image**

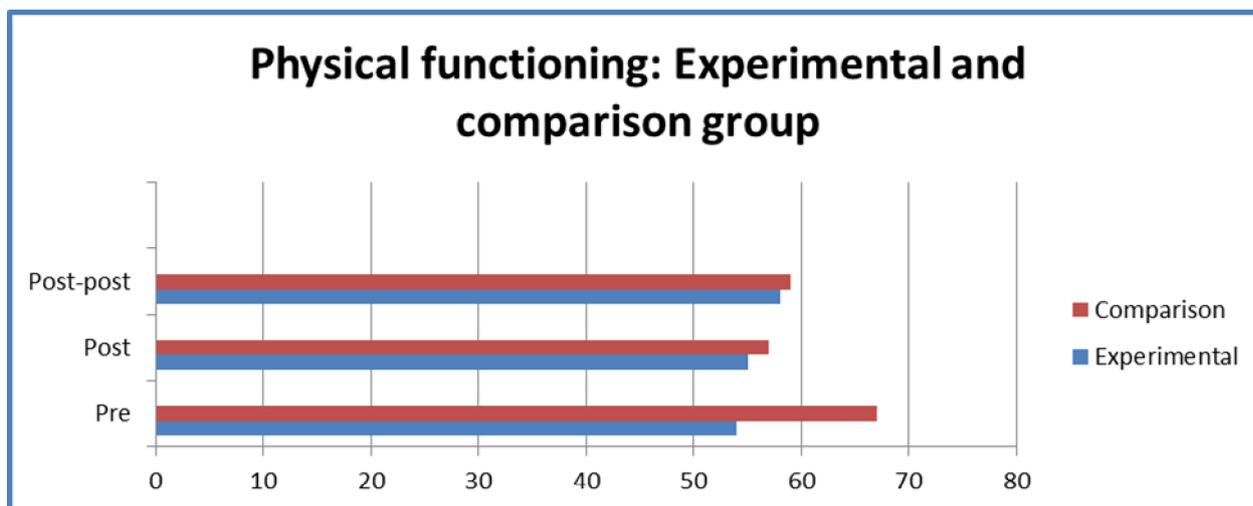
The pre-test score for the experimental group with regard to body image was 63% which indicated that it was under activated and needed attention. The comparison group scored 68%. The post test showed an increase to 69% for the experimental group which means their feelings regarding their body improved, compared to a lower score of the comparison group (58%). However the score of the experimental group decreased again to 64% during the post-post-test, but still shows an overall increase from the pre-test to the post-post-test compared to the decrease in the post-post-test of the experimental group from 68% in the pre-test to 64% in the post-post-test.

- **Sexual satisfaction**

The pre-test score for the experimental group with regard to sexual satisfaction was 45% which indicated that it was under activated and needed attention. The comparison group scored 66%. The post-test showed a decrease to 41% for the experimental group compared to the score of 56% for the comparison group. However, the score of the experimental group increased again to 52% during the post-post-test, but still shows an overall increase from the pre-test to the post-post-test compared to the 53% of the comparison group. This means that the comparison group did slightly better. This may be attributed to the composition of the groups.

**Table 7.16: Differential change for physical functioning**

	Change over intervention (Pre-and post- test)	Differential change post-test and post-post-test	Differential change pre-test and post-post-test
EG			
Physical functioning	1%	3%	4%
CG			
Physical functioning	-10%	2%	-8%



**Graph 7.7: Physical functioning for experimental and comparison group**

In general as set out in table 7.16 and graph 7.7, the pre-test average score for physical functioning for the experimental group was 54% for the pre-test, 55% for the post-test and 58% for the post-post-test. All three scores indicated that this area was under activated and needed attention. Compared to the experimental group, the comparison group scored 67% for the pre-assessment, 57% for the post-test and 59% for the post-post assessment. Their assessment also showed that their physical functioning were under activated and needed development. As mentioned, these differences in scores can be attributed to the composition of the groups. Those caregivers in relationships as well as married respondents could answer this question more comfortably compared to single respondents.

### **7.7.2 Analysis of the knowledge, skills and motivation (attitude) assessments**

The next section focused on the assessment of the knowledge, skills and motivation (attitude) of the community caregivers.

#### **7.7.2.1 Knowledge**

The first focus was on knowledge of the caregivers, which was measured using a two point scale as follows: True or false. The questionnaire focused on general facts about HIV and AIDS and antiretroviral treatment (ART). For items where the assertion was correct, the question was scored as correct if the respondent selected %true+ for questions 1, 2, 4 and 5 and false for question 3. For knowledge, each correct response to one of the five items was valued as one, while incorrect or no response answers were valued as zero. These scores were then converted to percentages. Lastly an average was calculated for the pre-, post-and post-post-test scores.

**Table 7.17: Correct answers on knowledge for experimental and comparison groups**

Knowledge statement	Experimental group (n=12)			Comparison group (n=12)		
	Pre-test	Post-test	Post-post test	Pre-test	Post-test	Post-post- test
	%			%		
1. ART decrease the number of CD4 cells in the body ( <i>true</i> )	100	100	100	100	91.66	91.66
2. Antiretroviral treatment is not a cure for HIV and AIDS ( <i>true</i> )	91.66	100	91.66	83.33	83.33	83.33
3. ART decrease the number of CD4 cells in the body ( <i>False</i> )	75	33.33	25	50	50	33.33
4. People should be counselled about antiretroviral (ARV) drugs ( <i>true</i> )	91,66	100	100	100	100	100
5. People taking ARV should not take part in high risk behaviour ( <i>true</i> )	100	83.33	100	100	91.66	100
<b>Average</b>	<b>91.66</b>	<b>83.33</b>	<b>83.33</b>	<b>86.66</b>	<b>83.33</b>	<b>81.66</b>

Table 7.17 shows the results of both groups in percentages (pre-test, post-test and-post-post-test). The table specifically demonstrates the percentages of the correct responses on each of the knowledge items listed. There is little difference in knowledge for the experimental and comparison groups at the baseline. Both the experimental (91.66%) and comparison group (86.66%) had relatively high scores. By contrast, the experimental and comparison groups showed a decline on the overall score for the knowledge items from baseline pre-test to post-test. The experimental group's knowledge stayed at 83.33%, while the comparison group declined to 81.7%. The results showed an improvement over the period of the intervention for four of the five items.

In general, the participants showed a significant improvement in their knowledge across the three measurements, for all items, except for one of the items. Significant differences were found for only one of the 5 items.

### 7.7.2.2 Skills

The community caregivers' skills were assessed, using a multiple question format. Multiple answers could be selected. They could choose any response to the questions listed. Questions were based on every day work with the client and the ability of the community caregiver to know

the situation. Questions were also based on the content of the empowerment programme. Questions were asked in general to reflect the level of skills that participants acquired before during and after the sessions. For skills, each correct response to one of the five items was valued as one, while incorrect or no response answers were valued as zero. These scores were then converted to percentages. Lastly an average was calculated for the pre-, post- and post-post test scores.

Table 7.18 shows the results of both groups based on percentages on the correct answers (pre-test, post-test and-post-post-test). The pre-test average score of the experimental group was 23.33% compared to the 25% of the comparison group. However during the post-test, the experimental groups score increased to 76.66% compared to the comparison group score of 30%. This represents a 46.66 differential change for the experimental group after intervention. The post-post test score for the experimental group was measured at 78.33% compared to the comparison group score of 30%, which indicates a 48.33 differential change between the experimental and the comparison group after the intervention.

**Table 7.18: Correct answers on skills for experimental and comparison groups**

Knowledge statement	Experimental group (n=12)			Comparison group (n=12)		
	Pre-test	Post-test	Post-post test	Pre-test	Post-test	Post-post test
	%			%		
6. Issues to discuss when counselling people on antiretroviral treatment	16.66	50	75	33.33	41.66	33.33
7. Other topics to discuss while counselling HIV-positive clients	25	75	91.66	16.66	16.66	16.66
8. What listening skills to use when counselling the patients	8.33	50	66.66	25	33.33	41.66
9. What psychosocial support services to give	50	91.66	91.66	25	33.33	33.33
10. How will the community caregiver tell if a patient is depressed	16.66	33.33	66.66	25	25	25
<b>Average</b>	<b>23.33</b>	<b>76.66</b>	<b>78.33</b>	<b>25</b>	<b>30</b>	<b>30</b>

### 7.7.2.3 Motivation (Attitude)

The next focus was on motivation (attitude) of the caregivers, which was measured using a four point scale as follows: Agree, somewhat agree, somewhat disagree and disagree.

Questionnaire items in this section established the general motivation in terms of general views and opinions of caregivers regarding ART. The question focused on general day-to-day experiences and beliefs of caregivers regarding HIV and AIDS and ART issues. Based on the literature and empowerment programme, five motivation (attitude) questions were developed. These questions were designed to establish the personal level of motivation of the community caregiver to attend to patients on ART. The responses to these items established the personal motivation of the caregivers to attend to ART. If the response was in the affirmative (agree) for questions 12, 14 and 15 and negative (disagree) for question 11 and 13 it indicated a high motivation level. Table 7.19 and 7.20 represent a frequency distribution of the respondents' general attitudes on HIV and AIDS and ART by using a pre-test, post-test and post-post-test.

**Table 7.19: Frequency distribution of the respondents' motivation (attitude) to HIV and ART: Experimental group**

Motivational (attitude statements)	Pre-test				Post test				Post-post test			
	Agree	Somewhat agree	Somewhat disagree	Disagree	Agree	Somewhat agree	Somewhat disagree	Disagree	Agree	Somewhat	Somewhat disagree	Disagree
11. Telling people about risk behaviour is enough to change behaviour.	10	1	1	0	9	2	0	1	2	1	0	9
12. Comfortable providing services to HIV positive people	10	2	0	0	9	1	1	1	9	3	0	0
13. At risk of becoming infected with HIV working with PLWHA	1	0	1	10	3	1	2	6	2	3	0	7
14. It's important to counsel people about antiretroviral treatment	11	1	0	0	9	1	0	2	12	0	0	0
15. People can improve their life quality through antiretroviral treatment	11	1	0	0	11	1	0	0	12	1	0	0
<b>TOTAL</b>	<b>43</b>	<b>5</b>	<b>2</b>	<b>10</b>	<b>41</b>	<b>6</b>	<b>3</b>	<b>10</b>	<b>36</b>	<b>8</b>	<b>0</b>	<b>16</b>

**Table 7.20: Frequency distribution of the respondents' motivation (attitude) to HIV and ART: Comparison group**

Motivational (attitude statements)	Pre-test				Post test				Post-post test			
	Agree	Somewhat agree	Somewhat disagree	Disagree	Agree	Somewhat agree	Somewhat disagree	Disagree	Agree	Somewhat	Somewhat disagree	Disagree
16. Telling people about risk behaviour is enough to change behaviour.	10	1	1	0	5	1	4	7	1	1	2	8
17. Comfortable providing services to HIV positive people	10	1	1	0	9	1	2	0	11	1	0	0
18. At risk of becoming infected with HIV working with PLWHA	3	1	0	8	4	1	2	5	2	0	0	9
19. It's important to counsel people about antiretroviral treatment	11	1	0	0	9	0	3	0	11	1	0	0
20. People can improve their life quality through antiretroviral treatment	12	0	0	0	10	0	2	0	12	0	0	0
<b>TOTAL</b>	<b>46</b>	<b>5</b>	<b>2</b>	<b>8</b>	<b>39</b>	<b>3</b>	<b>13</b>	<b>5</b>	<b>47</b>	<b>3</b>	<b>0</b>	<b>9</b>

Most community caregivers of the experimental and comparison group (83.33%) agreed during the pre-test that telling people about risk behaviour is enough to change behaviour. The post-post-test revealed that the experimental group showed more knowledge and 75% disagreed with the statement, since they had more knowledge of programmes and interventions for people on ART, compared to the 66.66% of the comparison group. Most caregivers from the experimental group and comparison group felt comfortable providing services to HIV positive people, with equal scores of 83.33% for the pre-test, 75% for the post test and 91,66% during the post-post-test measurement. This measurement shows that the experimental group showed

the most improvement. They acquired knowledge and skills did have an impact on their attitude towards their work and patients on ART.

In general, based on the scores, the conclusion can be drawn that the experimental group showed a positive improvement with regard to knowledge, skills and attitude. These results can be attributed to the presentation of the social work empowerment programme. However, this assessment was not based on standardised assessment scales, but could give an indication of development in the experimental group.

## 7.8 QUALITATIVE EVALUATIONS OF THE PROGRAMME

A schedule was designed by the researcher to evaluate the effectiveness of the programme. This schedule was completed at the beginning of the empowerment sessions and at the last session of the social work empowerment programme. Only the experimental group participated in the evaluation of the social work empowerment programme (n=12). The data was processed by means of the constant comparative method of Lincoln and Guba (1985) as described by Poggenpoel (1998:338-339).

Pre-and post-test-test questions

Pre-test questions and responses	Post-test questions and responses
<p>What will an empowerment programme to facilitate patients adherence to ART mean to you?</p> <ul style="list-style-type: none"> <li>• <i>I will be able to help vulnerable families to handle HIV and ART</i></li> <li>• <i>I will be learning more about ART treatment and how to deal with people who live with HIV and AIDS</i></li> <li>• <i>I will learn more about counselling</i></li> <li>• <i>I will be able to help people</i></li> <li>• <i>How to maintain confidentiality</i></li> <li>• <i>I want to know listening skills</i></li> </ul>	<p>What did the empowerment programme to facilitate patients adherence to ART mean to you?</p> <ul style="list-style-type: none"> <li>• <i>It meant a lot to me. It made me realise many things about ART, like how to eat, behave and talk about yourself to others</i></li> <li>• <i>It means to me that there can be hope for my community</i></li> <li>• <i>It meant that a community member with HIV is still my community member</i></li> <li>• <i>It meant that people empowerment is good</i></li> </ul>
<p>My expectations for this empowerment programme are</p> <ul style="list-style-type: none"> <li>• <i>How to be able to deal with HIV treatment</i></li> <li>• <i>Knowing more about psychosocial support</i></li> <li>• <i>Know about treatment adherence counselling</i></li> </ul>	<p>My expectations for this empowerment programme were?</p> <ul style="list-style-type: none"> <li>• <i>To learn the importance of ART</i></li> <li>• <i>How to deal with ART treatment</i></li> <li>• <i>How to communicate with the community and to do lay counselling</i></li> </ul>

<ul style="list-style-type: none"> <li>• <i>Know about communication programmes</i></li> </ul>	
<p>What do you want to learn from the empowerment programme?</p> <ul style="list-style-type: none"> <li>• <i>How I can support people living with HIV and AIDS</i></li> <li>• <i>I want to know the risk of not taking ART</i></li> <li>• <i>I want to improve my communication skills</i></li> <li>• <i>I want to improve my psychosocial skills</i></li> <li>• <i>I want to learn about the side effects of ART</i></li> <li>• <i>I want to learn counselling that must not affect my emotions</i></li> <li>• <i>I am easily affected other peoples' problems and I want to learn how to handle stress</i></li> <li>• <i>What happen when a client default on medication</i></li> </ul>	<p>What did you learn from the empowerment programme?</p> <ul style="list-style-type: none"> <li>• <i>I have learned skills and a lot of personal knowledge</i></li> <li>• <i>I have learned it is not good to stigmatise people</i></li> <li>• <i>I have learned the importance of taking ARV</i></li> <li>• <i>I learned a lot about psychosocial support groups</i></li> <li>• <i>I have learned how to deal with stress and how to eat healthy</i></li> <li>• <i>I have learned how to live with HIV and AIDS</i></li> </ul>
<p>What do you want to learn or experience to improve your relationship with patients on ART?</p> <ul style="list-style-type: none"> <li>• <i>How to communicate with a client who take ARV</i></li> <li>• <i>Who must take treatment and how must they take the treatment</i></li> <li>• <i>I want to learn more about community care giving</i></li> <li>• <i>I can support people living with HIV and AIDS</i></li> </ul>	<p>What did you learn or experienced to improve your relationship with patients on ART?</p> <ul style="list-style-type: none"> <li>• <i>I can now understand their feelings</i></li> <li>• <i>I must not neglect people living with HIV</i></li> <li>• <i>Confidentiality is important for the patient</i></li> <li>• <i>To teach them how to live positively</i></li> <li>• <i>I must have an open relationship with my patients and give them time to talk to me</i></li> </ul>
<p>What changes do you want to see with regard to your knowledge, skills and motivation/attitude</p> <ul style="list-style-type: none"> <li>• <i>I want to implement this, because I saw many people who want help for counselling</i></li> <li>• <i>There are many people who want protection I will be able to go back to the community and give them information so that they can change negative behaviour</i></li> <li>• <i>I want to open more support groups</i></li> <li>• <i>I want to implement my communication</i></li> </ul>	<p>What changes did you see with regard to your knowledge, skills and motivation/attitude</p> <ul style="list-style-type: none"> <li>• <i>My behaviour towards my patient improved</i></li> <li>• <i>It changed my patient well-being</i></li> <li>• <i>I have seen a lot of potential for the programme after implementing the things I have learned</i></li> <li>• <i>The change is that now I can live positively with my disease and also my family and clients</i></li> <li>• <i>I can now empower my clients</i></li> </ul>

<p><i>skills</i></p> <ul style="list-style-type: none"> <li>• <i>I want to encourage patients to take their medication regularly</i></li> </ul>	
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In general, community caregivers who participated in the group work empowerment sessions valued the programme. They indicated that it increased their knowledge on ART and made them more hopeful, with regard to service delivery. They could improve their skills and gain knowledge and skills on how to deal with specific challenges regarding ART. Based on their responses, they had pre-expectations of the empowerment programme which was met to empower them. This newly acquired knowledge and skills influenced their attitude to patients on ART positively. Their relationship with the patients was enhanced and they felt that they were now in a position to empower their patients.

## 7.9 DISCUSSION

The purpose of this programme was to address the need for community caregivers to actively support people living with HIV and AIDS (PLWHIV) in enhancing antiretroviral treatment (ART) adherence. Upon successful completion of this programme, it was envisaged that the caregivers will be able to effectively apply the relevant knowledge and skills to support patients on ART. Group work is a very useful, helpful and effective method and tool for empowering community caregivers to facilitate patients' adherence to ART. The group work programme focused on different aspects of service delivery to the patient on ART to empower community caregivers to render social intervention services to patients on ART.

The programme was evaluated using the Personal Multi-Screening Inventory (PMSI) questionnaire which include, positive/negative psychosocial functioning, emotional functioning, self-perception, interpersonal functioning, spiritual functioning and physical functioning. The measurement took place before and after the implementation of the social work empowerment programme and a post-post-test was done. Based on the results, the conclusion could be drawn that community caregivers showed a need for development with regard to positive psychosocial functioning in all six indicated areas. With regard to negative psychosocial functioning, they only showed significant improvement with regard to stress (interactive scale), helplessness (general behaviour scale), and frustration (general behaviour scale). However, the average scores showed a stable measurement from the pre-test to the post-post-test. The results also indicated that community caregivers needed development in the areas of memory loss, paranoia, disturbing thoughts, senselessness of existence and suicidal thoughts. This emphasise that community caregivers need more guidance with regard to positive and negative psychosocial functioning as well as emotional functioning which was identified as a limitation of the

empowerment programme. In future more emotional support should be incorporated in the intervention programme.

The area of self-perception yielded positive results in the following three areas: inner security, guilt feelings and lack of self-worth. Community caregivers measured the best development in the area of interpersonal relationships. However they indicated a need for development in the area of relationship with father, partner and colleagues. These discrepancies in measurement could be attributed to absence of fathers, no relationship with father, no guidance with regard to interpersonal colleague relationships and the fact that some caregivers were not in relationships. Spiritually they functioned optimally. However, the results indicated they needed development in the area of physical functioning. The contexts that contribute to vulnerability on the emotional level when implementing intervention programmes must be taken into account. The intervention programme may only yield meaningful outcomes if the emotional, work and environmental challenges the community caregivers face, are also considered.

In general with regard to the PMSI some other factors may have influenced the accuracy of information. This assessment could have been mentally challenging because of the length of the questionnaire and the pre-knowledge of the groups, resulting in repeated or no answering of some questions and not reflecting carefully on the questions, which might have influenced the respondents' genuine emotions. Respondents may have underreported on some areas like sexual satisfaction and partner relationship which may have influenced the accurateness of some information. The results could also have been affected by the composition of the groups that did not take into account the marital status of respondents, for example.

One of the factors contributing to the poor development in some areas could also have been attributed to the length of the empowerment programme especially with regard to emotional aspects. It can therefore be concluded that the programme must be implemented over a longer time span with shorter sessions and time must be given to community caregivers to practice and internalise what they have learned. However, it can be regarded as positive that respondents developed significantly with regard to items covered in the empowerment programme for example, the handling of stress, family relationships and involvement in ART. The assessment on knowledge, skills and attitude showed significant development, however none standardised measurement scales were used in this regard.

## **7.10 RECOMMENDATIONS**

- Community caregivers play an important role with regard to community based educational and self-management programmes aimed at adherence, which should be enhanced.
- A lack of psychological support was observed with regard to community caregivers and it is recommended that they receive continuous emotional support. The programme should

incorporate emotional issues. Stress management and motivational programmes should be implemented for community caregivers.

- More research studies should be conducted regarding the psychosocial support of community caregivers.
- Measuring instruments should be less complicated and should take into account the educational level of respondents.
- The programme should be implemented over a longer time span with shorter sessions and time must be given to community caregivers to practice and internalise what they have learned.

## **7.11 CONCLUSIONS**

This article argues that an intervention based on a social work empowerment programme for community caregivers would be effective in developing the skills of community caregivers to facilitate patients' adherence to antiretroviral treatment. The goal of the social work empowerment programme was to give information, to equip them with skills that may influence caregivers' attitude or motivation positively. The conclusion from this study can be drawn that community based educational and self-management programmes aimed at adherence are important for community caregivers and group work is an empowering method for caregivers to facilitate patients' adherence to ART. The research results showed that in order to achieve meaningful and sustainable results, the emotional and work environment of the community caregiver must be taken into account. Previous research highlighted some emotional and work related factors that influence optimal functioning of the community caregiver. Intervention programmes should therefore include aspects of emotional and occupational empowerment sessions. Future studies should be undertaken including larger samples of community caregivers that include measurement of the psychosocial functioning of community caregivers.

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## SECTION C

### SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

#### 8.1 INTRODUCTION

This section provides a summary and evaluation of the research, and offers conclusions and recommendations derived from the research. The overall goal of the study formulated will be evaluated, as well as the objectives, the research question, literature review and results of the empirical research. By the end of 2014, the number of people living with HIV increased to 36.9 million and an estimated 25.8 million are living in Sub-Saharan Africa (UNAIDS, 2015:1). The number of people dying from AIDS-related causes in Sub-Saharan Africa is estimated at 790 000 in 2014. With the expansion of ART, an estimated 15.8 million people living with HIV and AIDS were receiving ART at the end of 2014 (UNAIDS, 2015:1).

The main constraint in achieving universal ART coverage is the limited human resources available to treat HIV and AIDS as indicated by previous research studies by Kabore *et al.* (2010), Schneider *et al.* (2006) and Van Damme *et al.* (2008). Based on previous research and this research study, insufficient human resources can cause stress to the limited staff available (Schneider *et al.*, 2006:20). Therefore, through this research it was investigated in which way community caregivers can assist to empower patients towards self-management and to give treatment guidance.

The need for the development of an empowerment programme through group work (Zastrow, 2010:45; Toseland & Rivas, 2012:389), was identified to strengthen the knowledge and skills of these community caregivers with regard to psychosocial support for patients on antiretroviral treatment. This programme was developed and implemented. Finally it was evaluated by means of the Personal Multi-Screening Inventory (PMSI) and other measurements like a self-developed questionnaire based on knowledge, skills and attitude (motivation) as well as a qualitative schedule, to evaluate the impact of the programme.

#### 8.2 RESEARCH METHOD AND DESIGN

The research followed a mixed method approach and particularly the multiphase mixed method in which both qualitative and quantitative methodology was used (Creswell & Plano Clark, 2011:5). The intervention research model of Rothman and Thomas (1994) was used as described by De Vos and Strydom (2011:476). The intervention research model is divided into six phases, namely, problem analysis and project planning, information gathering and synthesis,

design, early development and pilot testing, evaluation and advance development and dissemination.

### **8.2.1 Problem analysis and project planning**

The research project started with a search for relevant information and was conducted at the Ferdinand Postma Library, North-West University, Potchefstroom Campus, using local as well as international databases and was structured to include journals, books and electronic journals. An information search through the Internet was also done through EBSCO Host and Google Scholar. This assisted to formulate the research problem which was identified as relevant.

### **8.2.2 Information gathering and synthesis**

This phase focused on a systematic literature review of factors that influence adherence of patients to antiretroviral treatment (Article 1). A literature study was also done regarding ART scale-up and the role of the community caregiver (Article 2).

A qualitative approach was used to explore the perceptions of community caregivers with regard to antiretroviral adherence and a social work empowerment programme to facilitate adherence of patients on antiretroviral treatment (Botma *et al.*, 2010:190; Niewenhuis, 2009:50). The qualitative research design was phenomenology (Fouché & Schurink, 2011: 316), as the research focused on describing what participants have in common as they experience a phenomenon (Article 3).

### **8.2.3 Design**

This phase of the research focused on the development of a social work empowerment programme for community caregivers and focused on design, early development and pilot testing as set out in the intervention research model (De Vos & Strydom, 2011:476). Phase 1 of the research focused on a literature study which revealed information based on the overall challenges with regard to antiretroviral treatment. Phase 2 focused on a phenomenological study to explore community caregivers' experiences and challenges with regard to patients' adherence to ART and needs regarding an empowerment programme. This information was used to develop the social work empowerment programme.

### **8.2.4 Early development and pilot testing**

The social work empowerment programme was pilot tested (Article 4). A draft of the suggested social work empowerment programme was given to respondents. During phase one, six community caregivers participated in a focus group session to give inputs regarding the social

work empowerment program to determine its effectiveness in terms of the practicality of the programme and the adaptability to various contexts of the intervention and to identify which elements of the prototype may need to be revised. Phase two focused on a peer review with eight social workers involved in the HIV and AIDS programme from the Department of Social Development, North West Province to give inputs in the preliminary empowerment programme. Telephonic semi-structured interviews according to a schedule were used due to the geographical distances between the researcher and the respondents. Social workers rated the content relevance and made suggestions for the improvement of the social work empowerment programme.

### **8.2.5 Evaluation and advanced development**

This phase focused on the evaluation of the social work empowerment programme (Article 5). The study focused on experimental research. According to Fouché *et al.* (2011:145) the idea of an experiment in social science research, is that two comparison groups are set up. The quasi experiment was chosen (Botma *et al.*, 2010:114). The comparison group pre-test-post-test design was chosen.

The type of sampling chosen for this research was simple random sampling. According to Babbie (2010:189) with simple random sampling, each individual case in the population has an equal chance of being selected for the sample. The experimental and comparison group consisted of 12 community caregivers each. Selection to the groups was based on age, sex and years of experience, therefore, no absolute assurance could be given that the two groups would exactly be the same however, all possible measures were done to select the two groups as similar as possible regarding age, sex, years of experience in care giving, etc (Rubin & Babbie, 2011: 271-278).

The Personal Multi-Screening Inventory (PMSI) of the Perspective Training College was used in the research to measure the personal functioning of the community caregivers before and after the presentation of the programme, based on the following areas; positive psycho-social functioning, negative psycho-social functioning, emotional functioning, self-perception, interpersonal functioning, spiritual functioning and physical functioning.

A self-developed questionnaire based on knowledge, skills and motivation was developed by the researcher, to measure the three dimensions of the caregivers (both experimental and comparison group).

A self-structured schedule was used as the qualitative measuring instrument in this study to evaluate the success of the social work empowerment programme.

### **8.2.6 Dissemination**

The information of this study was prepared to be disseminated through publishing articles in accredited journals. One article has been submitted for publication at Social Work. Another two articles has been submitted for publication. The researcher also intends to publish the remaining two articles in accredited journals.

## **8.3 RESEARCH QUESTIONS**

Through this research the researcher sought to answer the following overall research question:

*How can community caregivers be empowered to facilitate the adherence of patients on antiretroviral treatment?*

This overall research question was answered through this research, by means of the literature review on the challenges of ART for patients and the role of the community caregiver in ART. The qualitative study also shed light on the daily experiences of community caregivers regarding ART of patients. The programme evaluation gave some insights that are valuable for future research and programme development. The sub questions focused on the following:

### **Question 1**

*What are the factors that influence patients' adherence to ART?*

To answer the question, a detailed literature review was done on the factors influence patientsq adherence to ART.

### **Question 2**

*What is the role of the community caregiver regarding ART adherence?*

The literature review on the role of the community caregiver regarding ART adherence of patients, shed light on this research question.

### **Question 3**

*What are the perceptions of community caregivers regarding ART adherence of patients?*

For the purpose of this study it was found appropriate to explore the perceptions of the community caregivers, since they work on a daily basis with patients on ART. The perceptions of the community caregivers were established through qualitative research and described in detail in Article 3. Through this phenomenological study, they could share their experiences regarding ART of patients, in order to establish a deeper understanding of the problem. The

research identified factors like alcohol abuse and family support as factors that can influence adherence of patients to ART.

#### **Question 4**

*What are the perceptions of community caregivers with regard to a social work empowerment programme to enhance their skills to facilitate antiretroviral adherence of patients?*

Based on this question, the goal was to explore ways of getting information from the community caregivers to give suggestions for a social work empowerment programme. From the phenomenological study, the community caregivers could give inputs in the development of a social work empowerment programme to facilitate patients' adherence to ART.

#### **Question 5**

*What should the content of a social work empowerment programme be for caregivers regarding the adherence of patients on antiretroviral treatment?*

From the literature review and the qualitative research, valuable information was gathered that assisted in the development of the social work empowerment programme. Social workers were also included to give their views on the programme through a peer review (Article 4).

#### **Question 6**

*Can the presentation of a social work empowerment programme be effective in empowering community caregivers to facilitate patients' adherence to antiretroviral treatment?*

The social work empowerment programme was evaluated by means of the Personal Multi-screening Inventory which was found to be an effective measuring scale. The results of the quantitative research indicated that a social work empowerment programme can be effective in empowering community caregivers to facilitate patients' adherence on ART. Chapter 5 gives a detailed description of the findings.

## **8.4 AIM AND OBJECTIVES OF THE RESEARCH**

### **8.4.1 Aim**

The aim of the research was to implement and evaluate a social work empowerment programme for community caregivers to facilitate the adherence of patients on antiretroviral treatment. The aim was achieved through the literature review, as well as the qualitative and quantitative research. Based on the literature review and the qualitative research, the programme could be developed, implemented and evaluated. The results of the research

showed that community caregivers could be empowered through the social work empowerment programme.

#### **8.4.2 Objectives of the research**

*To do a literature study to explore the factors that influence patients' adherence to ART.*

To reach this objective, an extensive literature study was done about the challenges regarding antiretroviral treatment of patients.

*To do a literature study on the role of the community caregiver regarding ART adherence of patients.*

For this a literature study was done on the role of the community caregiver regarding ART of patients.

*To explore and describe the perceptions of community caregivers with regard to the underlying psychosocial factors affecting antiretroviral adherence of HIV and AIDS patients.*

In pursuing this objective a qualitative phenomenological study with 16 community caregivers was done to gain insight into the perceptions of community caregivers regarding ART of patients.

*To explore and describe the perceptions of community caregivers with regard to a social work empowerment programme to enhance their skills to facilitate the adherence of HIV and AIDS patients on antiretroviral treatment.*

Through the qualitative research the needs of community caregivers with regard to a social work empowerment programme was established in order to reach this objective.

*To develop a social work empowerment programme for community caregivers.*

This objective was realised by designing a social work empowerment programme for community caregivers to facilitate patients' adherence to ART.

*To implement and evaluate the effectiveness of the social work empowerment programme for community caregivers.*

For this the social work empowerment programme was implemented and evaluated with a presentation of a detailed discussion in Article 5 on the quantitative and qualitative findings.

## **8.5 CENTRAL THEORETICAL STATEMENT**

The central theoretical statement for the research was formulated as follows:

*A social work empowerment programme for community caregivers will enhance their skills to facilitate adherence of patients on antiretroviral treatment.*

This research confirmed that a social work empowerment programme plays an important role in empowering community caregivers to facilitate patients' adherence to ART.

## **8.6 LITERATURE REVIEW AND EMPIRICAL RESEARCH**

The next section focuses on the literature review based on the articles and empirical research and will be presented in terms of a summary, conclusions and recommendations.

### **8.6.1 Article 1: Factors that influence adherence to antiretroviral treatment of patients: a literature review**

#### **8.6.1.1 Summary**

The aim of the literature study in Article 1 was to explore factors that influence adherence to antiretroviral treatment of patients in order to develop ART intervention programmes. This review followed a systems approach. A social-ecological framework (Compton *et al.*, 2005:24) was used for the exploration of barriers and facilitators to sustained treatment adherence of persons on ART. An overview was provided on the factors which influence adherence to antiretroviral treatment of patients. The review highlighted factors on an individual level, namely socio-demographic factors, high risk behaviours, psychological factors and condition and treatment related factors, knowledge, beliefs and understanding of treatment and treatment fatigue, motivation and self-efficacy. This followed a detailed discussion on social networks, including family support and social support and how it impacts on adherence of patients. Community based factors that influenced adherence included HIV and AIDS stigma, discrimination and disclosure issues and factors based on socio-economic status. Socio-cultural factors included cultural and religious factors. Services related factors focused on the health care system, the health care provider and the accessibility of ART services.

#### **8.6.1.2 Conclusions**

- This review systematically discussed the factors associated with ART adherence through a social-ecological framework.

- The focus was on five categories, namely individual factors, social networks, community based factors, socio-economic status, socio-cultural factors and services related factors. This study emphasised a number of factors that contribute to non-adherence to ART.
- The review suggests that adherence is influenced by many psycho-social factors and in order to develop ART interventions, it is necessary to consider the challenges regarding antiretroviral treatment.

### **8.6.2 Article 2: Antiretroviral roll-out and adherence: the role of the community caregiver.**

#### **8.6.2.1 Summary**

This literature review explored the value of social support from the community caregiver regarding adherence of patients. The focus was on the promotion and maintenance of health by means of socio-environmental and behavioural changes through empowerment programmes for improved self-regulation and self-efficacy of the patient. Such programmes include information, motivation and behavioural skills development. This article applied the systems theory with a focus on, the patient on ART, and the community caregiver. The literature review focused on (1) the role of the community caregiver in antiretroviral treatment programmes; (2) empowerment programmes for community caregivers; and (3) recommendations with regard to the role of the community caregiver in antiretroviral treatment in context of the information, motivation and behavioural skills model. This literature review proved to be of value for the development of a social work empowerment programme for community caregivers to facilitate patients' adherence to antiretroviral treatment.

#### **8.6.2.2 Conclusions**

- According to the literature review, community caregivers are a valuable support system to expand ART provision and to support adherence of patients.
- Information from this research can guide social workers to develop intervention programmes for community caregivers.
- Such programmes should focus on development of capacities to promote human and community well-being, and can be developed in the framework of the IMB model with a focus on information, motivation and skills development.

### **8.6.3 Article 3: *The perceptions of community caregivers with regard to antiretroviral treatment adherence of patients: a phenomenological study.***

#### **8.6.3.1 Summary**

This study aimed to explore and describe the perceptions of community caregivers with regard to antiretroviral treatment adherence of patients and a social work empowerment programme to enhance their skills to facilitate the adherence of HIV and AIDS patients on antiretroviral treatment. This study used a qualitative approach with a phenomenological design. Four focus group discussions were facilitated with 16 community caregivers to gain insights with regard to antiretroviral treatment of patients and a social work empowerment programme. The results of these focus group discussions assisted with the development of the social work empowerment programme. This information was essential, because it addressed the needs of the community caregivers with regard to empowerment on how to facilitate patients' adherence to ART.

#### **8.6.3.2 Conclusions**

- The explorative qualitative research suggested that adherence is influenced by many psycho-social factors and is important for the development of community based ART interventions.
- The role of community caregivers was seen as vital in supporting patients on antiretroviral treatment. The supporting role of the community caregiver came out strongly in this research and they should be involved in programmes of a psychosocial nature.
- The results showed many psychosocial challenges with regard to ART and it is evident that interventions regarding these issues are needed.
- Further guidance, support, skills development and training are needed to provide for and enhance the development of community caregivers with regard to ART support.

### **8.6.4 Article 4: *Development of an empowerment programme for community caregivers to facilitate patient's adherence to antiretroviral treatment***

#### **8.6.4.1 Summary**

This study was aimed at designing an empowerment programme for community caregivers to facilitate patients' adherence to antiretroviral treatment (ART). The literature and qualitative needs assessment identified many psychosocial challenges with regard to ART adherence of patients. In this article an outline is given for the social work empowerment programme. The key elements of the programme are described, with aspects of the implementation and facilitation thereof.

#### **8.6.4.2 Conclusions**

- Community based educational and self-management programmes aimed at adherence are important.
- It is important to identify the psychosocial challenges and needs of patients on ART.
- The conclusion from this study can be drawn that group work is a means of empowering caregivers to facilitate patients' adherence to ART.
- Group work is a very useful, helpful and effective method for empowerment of community caregivers to facilitate patients' adherence to ART.
- Social workers are knowledgeable with regard to issues of HIV and AIDS and ART and can fulfil the role as enabler to empower support systems in the community.

#### **8.6.5 Article 5: Evaluation of an empowerment programme for community caregivers to facilitate patients' adherence to antiretroviral treatment**

##### **8.6.5.1 Summary**

The aim of this article was to evaluate the effectiveness of a social work empowerment programme for community caregivers to facilitate patients' adherence to antiretroviral treatment. For the purpose of this research, an experimental and control group were formed comprising of 12 caregivers each. The control group received both the pre-test, post-test and post-post-test, at the same time as the experimental group, but did not receive the treatment. The effectiveness of the programme was evaluated by means of the Personal Multi-Screening Inventory (PMSI), self-developed questionnaire on knowledge, skills and attitude (motivation) and a self-developed qualitative schedule. Evaluation according to the PMSI and knowledge, skills and attitude questionnaire took place on three occasions, namely before the group started, at the end of the last group session and one month after the last group session. The qualitative measurement took place before and after the group sessions. The research indicated that the community caregivers were empowered through the programme and that such an empowerment programme is needed. However challenges with regard to the psycho-social functioning of community caregivers were identified that needed attention.

##### **8.6.5.2 Conclusions**

- This article argues that an intervention based on a social work empowerment programme for community caregivers would be effective in developing the skills of community caregivers to facilitate patients' adherence to antiretroviral treatment.
- The goal of the programme was to give information, to equip them with skills that may influence their attitude or motivation positively.

- The conclusion from this study can be drawn that community based educational and self-management programmes aimed at adherence are important for community caregivers and group work is an empowering method for caregivers to facilitate patients' adherence to ART.
- The research results showed that in order to achieve meaningful and sustainable results, the emotional and work environment of the community caregiver must be taken into account.
- Previous research highlighted some emotional and work related factors that influence optimal functioning of the community caregiver.
- Intervention programmes should therefore include aspects of emotional and occupational empowerment sessions. Future studies should be undertaken which should include larger samples of community caregivers and should include measurement of the psychosocial functioning of community caregivers.

## **8.7 RECOMMENDATIONS**

### **Recommendations regarding the literature review**

- From the literature review it is clear that research to explore the psychosocial challenges regarding ART adherence should be encouraged.
- The use of community caregivers in ART services is seen as a valuable strategy to support adherence of people on ART, therefore more research is needed regarding ART empowerment programmes for community caregivers.
- Furthermore, based on the literature review it is recommended that research on community based interventions for ART adherence should be enhanced.

### **Recommendations regarding the findings of the empirical research**

- Social workers need to do more research with regard to ART support and the role of the community caregiver to enable caregivers to render more support services.
- Knowledge of the challenges of community based caregivers regarding ART adherence is important for future research and the development of community based ART interventions.

### **Recommendations regarding the social work empowerment programme**

- The psychosocial challenges of patients on ART should be addressed through empowerment of community caregivers.
- Empowerment should be addressed through group work.
- Social workers have to be knowledgeable on all aspects of HIV and AIDS as well as antiretroviral treatment to be able to empower community caregivers.
- The client should be the basis of information regarding their needs for empowerment programmes.

- Community caregivers play an important role with regard to community based educational and self-management programmes aimed at adherence, therefore continuous empowerment sessions to community caregivers should be facilitated by social workers
- A lack of psychological support was observed with regard to community caregivers and it is recommended that they receive continuous emotional support. Support programmes should incorporate emotional issues. Stress management and motivational programmes should also be implemented for community caregivers.
- Measuring instruments should be less complicated and should take into account the educational level of respondents.
- The social work empowerment programme must be implemented over a longer time span with shorter sessions and time must be given to community caregivers to practice and internalize what they have learned.

## **8.8 CONCLUDING REMARKS**

There is a great need for the programme and further research is needed to support community caregivers on continuous basis rather than one programme presentation. The programme should be implemented on a regular basis. The programme will also be presented to the comparison group and the experimental group will be followed up to establish further needs.

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**SECTION E: ANNEXURES**

**PERMISSION FOR RESEARCH (HOSPICE AMANUEL LOVING ANGELS ): ANNEXURE A**



**HOSPICE EMANUEL LOVING  
ANGELS**

Cell nr: 081 432 1799  
Fax: 018 297 6656  
Mantop: Ima & de Ploos

**REG NO: 119-387 NPO**

Primary Address  
63 Blommetje Street  
Promosa  
Pretoria

11 Sept. 11

**TO: R M MOKWELE**

**RE: PERMISSION FOR RESEARCH**

Emmanuel Hospice is a Non-Profit making organization registered with Social Development under section 21, the intention is to assist the community.

Our Organization is based in Promosa and we cater for 100 Orphans and Vulnerable Children in and around Promosa area (Est 7, Baipol, Akale Park and Informal Settlement). We also take care of the sick patients where we provide them with Home Based Care Service. We have a total of 16 care workers in our organization who volunteers to care for CVC and terminally ill patients.

I am a student at the North West University. I hereby would like to ask permission to do research with the community caregiver's organization.

**Purpose of the study**

The purpose for the study is to develop a social empowerment program for community caregivers to facilitate HIV/AIDS patient's adherence to antiretroviral treatment. HCSplce was chose a participant for the research due to the work at the community.

I would like to have a group discussion with the community caregivers and they also have to complete questionnaires and participate in program that will be presented to them.

Your permission for the study will be highly appreciated

Yours truly

Ria Du Ploos  
Project Manager



**PERMISSION FOR RESEARCH (BAMBANANI YOUTH PROJECT): ANNEXURE B**

**BAMBANANI YOUTH PROJECT**



11650 Madikizela Street  
Extension 7  
Potchefstroom  
2531  
NPO: 025 381  
Cell No: 073 788 6005

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Ms Roslind Mokwele  
North West university  
Potchefstroom

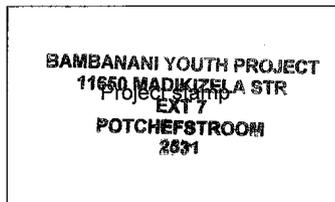
Re: Permission for research

We as Bambanani Youth Project give permission to Ms R Mokwele to do research with the community caregivers of the organization.

Wishing you good luck with your research.

Project Manager

*A. K. Moeng*  
.....  
Ms A. Moeng



PERMISSION FOR RESEARCH (BAPTIST CHILDREN'S CENTRE): ANNEXURE C



4587 MADI STREET, IKAGENG  
PO BOX 1249 POTCH 2531  
TEL: 018-295-0316  
FAX 018 295 – 2910

REG: 019-791-NP

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BOARD MEMBERS: Mrs. Q Khumalo, Mrs. M Mahlaule, Ms. J. Motlogeloa, Ms. S. Gaduka,  
Ms J. Motlogeloa, Mrs. O. Marite Ms. Mr. K Loate, Rev. S.B Ndebele., Ms. V.T Vana, and Ms. M. Ntheledi  
and Ms. J. Dikane

6<sup>TH</sup> September 2014

Ms. R.M Mokwele  
North West University.  
Potchefstroom Campus.  
Potchefstroom.

Re: Permission for Research.

Greetings in the name of our Lord Jesus Christ.

We hereby give permission for you to do research on the programme for community caregivers to facilitate adherence to Antiretroviral treatment. We believe that the programme will assist our caregivers to provide better services to our community. Should there be a need for you to want to see any of our beneficiaries, we also grant you permission to do so. As an organisation we would like to receive feedback on the progress of your research at the end of the research.

We wish you success in your research programme.

Yours Partner in the fight against HIV and AIDS pandemic.

Rev. S.B Ndebele  
Project Manager

## ANNEXURE D: ETHICS APPROVAL



NORTH WEST UNIVERSITY  
YUNIBESITH YA BOKONE-BOPHIRIMA  
NOORDWES-UNIVERSITEIT  
POTCHEFSTROOM CAMPUS

Private Bag X6001, Potchefstroom  
South Africa 2520

Tel: 018 299-1111/2222  
Web: <http://www.nwu.ac.za>

Prof H Strydom  
Social Work

Faculty of Health Sciences  
Tel: 018-299 2092  
Fax: 018-299 2088  
Email: [Minnie.Greeff@nwu.ac.za](mailto:Minnie.Greeff@nwu.ac.za)

24 October 2014

Dear Prof Strydom

**Ethics Application: NWU-00130-14-S1 "The development and evaluation of a programme for community caregivers to facilitate HIV and AIDS patient's adherence to antiretroviral treatment"**

All ethical concerns have been addressed and ethical approval is granted until 30/06/2016.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Minnie Greeff'.

Prof Minnie Greeff  
Health Research Ethics Committee Chairperson

Original details: Prof Minnie Greeff(10187308) C:\Users\113210572\Documents\ETEX\2014 ETHICS\NWU-00130-14-S1 (H Strydom-RM Molwale) - Approval letter.docm  
24 October 2014

File reference: 9.1.5.3

## ANNEXURE E: CONSENT FORM FOR COMMUNITY CAREGIVERS TO PARTICIPATE IN FOCUS GROUP SESSIONS AND JOURNAL DESCRIPTIONS



NORTH-WEST UNIVERSITY  
YUNIBESITI YA BOKONE-BOPHIRIMA  
NOORDWES-UNIVERSITEIT  
POTCHEFSTROOM CAMPUS

### **Title of the research project**

The development and evaluation of a social empowerment programme for community caregivers to facilitate the adherence of patients to antiretroviral treatment.

**Reference number: NWU-00130-14-S1**

### **Principle investigator:**

Roslind Mokwele

### **Dear Community caregiver**

I am Roslind Mokwele. I am a PhD student (Social Work) at the North-West University (Potchefstroom Campus). You are hereby invited to participate in a research study to explore the perceptions of community caregivers with regard to a social empowerment programme to facilitate the adherence of patients on antiretroviral treatment. In order to decide whether you are going to participate in the study, I would like to give you the following information for you to be able to make an informed decision. I would like you to read the information which will explain the details of the project and how you could be involved. You are welcome to ask the researcher any questions regarding the project.

### **Purpose of the study**

- The purpose of the study is to develop a social work empowerment programme for community caregivers to facilitate HIV and AIDS patients' adherence to antiretroviral treatment.
- The study will be conducted in Potchefstroom and will involve three Home Community Based care organizations, namely Baptist Children's centre, Emmamnuul Hospice Loving Angels and Bambanani Youth Project.
- At least three focus groups will be conducted with community caregivers to explore their perceptions with regard to the facilitation of adherence of HIV and AIDS patients to antiretroviral treatment.

- The social work empowerment programme will be pre-liminary evaluated by means of a focus group and peer reviews by social workers for inputs to be able to make adaptations if necessary.
- Community caregivers will take part in a quasi-experiment to evaluate the social work empowerment programme.

### **Selection for participation**

- You have been invited to participate because of your knowledge of working with patients with HIV and AIDS to give information regarding this topic.
- You also complied with the following selection criteria: Male or female community caregiver; actively involved in service delivery to HIV and AIDS patients from the Home Community based Care programme in Potchefstroom (Bambanani Youth Project, Baptist Children's centre and Hospice Emmanuel Loving Angels); have at least one year experience working with HIV and AIDS patients on antiretroviral treatment; able to communicate in English.

### **Duration and location**

The study will take place at Baptist Children's centre. Focus group sessions will take about 1 hour and 15 minutes on three different occasions. The presentation of the empowerment programme to the community caregivers will be sessions of one day each at least once a week.

### **Responsibilities**

On agreement to participate in the study, you will be expected to take part in focus group; dairies your daily experiences of working with patients on antiretroviral treatment in a journal.

### **Risk/Discomfort**

The risks in this study are minimal since the focus will be on the community caregivers' perceptions and programme development. It might happen that you will experience emotional distress when participating in the focus group sessions. Should you experience any emotional distress I will refer you to an appropriate counsellor. It might also happen that some members will be uncomfortable to talk in front of others, or feeling less valuable in the group, that may create a feeling of uneasiness. Group rules will be set to limit loss of anonymity in group facilitation.

## **Voluntary participation**

You as participant can decide whether you want to participate in the research or not. You do not have to take part in the study, and your refusal to participate will involve no penalty or loss of rights to which you are entitled. You may withdraw from the study at any time and without fear of losing any services or benefits to which you are entitled.

## **Confidentiality**

The loss of partial anonymity in the focus groups will be addressed through the set of group rules. Any information obtained from you as participant in the focus group sessions will be handled as confidential way and will only be made known with your consent. The identity of each participant will be protected. All information will be coded and no personal information that will be able to identify you will be mentioned in the research. I would like to record the information of the focus group sessions to be able to capture all the valuable information. This information will only be used for research purposes. Only I, the transcribers and the supervisor will have access to the recorded information. All recorded information will be stored in a safe place during and after the research and only the researcher and the supervisor will have access to the tape recordings. The researcher will sign a contract of confidentiality with the transcribers of the focus groups.

## **Benefits**

There are certain benefits for you as participant regarding this study. Your contribution will add to the knowledge regarding social work services to HIV and AIDS patients on antiretroviral treatment. You as community caregiver will be able to gain insight into your own emotions through the focus group discussions. As community caregiver you will be empowered through the presentation of an empowerment programme to improve your psycho-social functioning as caregiver to HIV and AIDS patients. You will also benefit from the social work empowerment programme as a means of self . development.

## **Cost**

There will be no cost to you as a result of your participation in this study. You will receive no payment for participation. Refreshments will be provided during the focus group sessions.

## **Payment**

Please be aware that there will be no payment for participation in the research.

## Questions and feedback regarding the research

The findings of the research will be made available to you on request and it will be shared with you in your own language.

All other questions and inquiries regarding the research can be directed to:

Researcher: Ms. Roslind Mokwele cell no 0795226879

Project leader: Professor H. Strydom, tel no 018 299 1677

Human Research Ethics Committee: Ms. C. van Zyl tel no 018 299 2094

## Declaration by participant

The above-mentioned information was presented to me in (Tswana/English/Afrikaans) and I the participant is familiar with this language or was translated to me. I was given the opportunity to ask clarifying questions and am satisfied with the response to the questions. I have been informed about the nature of the research and the risks and benefits. I have also read the information about the research study and understand the content thereof. I had enough time to read and ask questions. I hereby give my permission to take part in the study.

I \_\_\_\_\_ age \_\_\_\_\_ hereby voluntarily consent to my participation in the research.

Signed \_\_\_\_\_ at \_\_\_\_\_ on  
(date) \_\_\_\_\_ 2015

\_\_\_\_\_  
Signature of community caregiver Date

\_\_\_\_\_  
Signature of person obtaining consent Date

\_\_\_\_\_  
Signature of witness Date

## ANNEXURE F: FOCUS GROUP DISCUSSION SCHEDULE



NORTH-WEST UNIVERSITY  
YUNIBESITI YA BOKONE-BOPHIRIMA  
NOORDWES-UNIVERSITEIT  
POTCHEFSTROOM CAMPUS

### FOCUS GROUP DISCUSSIONS

#### Schedule

#### Objectives

1. Determine knowledge, beliefs and attitudes regarding ART.
2. Explore social support given to people living with HIV and AIDS in the communities.
3. Explore perceptions of factors affecting adherence to ART.
4. Explore and get suggestions from community caregivers for improving patients adherence to ART.
5. Explore the needs of the community caregivers with regard to a empowerment programme to facilitate patients adherence to antiretroviral treatment.

#### Content

1. Introduction session (community caregivers introduce themselves age, married, children, how long and how are you involved in HIV and AIDS activities in your community?)
2. What do you know about ART activities (what is it and the current service of practice in ART. Where do people obtain ART in area?)
3. What are your perceptions, beliefs, attitudes with regard to HIV and AIDS treatment? Criteria for starting ART etc. What are the reasons for the perceptions? What does ART adherence mean to you?
4. How does the community experience your services with regard to HIV and AIDS support.
5. Do ART patients face any problems with adherence to their medication? Explore.
  - a. Demography (age, sex, education, socio-economic status, occupation, marital status).
  - b. Information, knowledge, self-efficacy, Motivation.
  - c. Beliefs, attitude toward ART.
  - d. Support from family, community. (What does support mean to the caregiver, How does the community see support from them).
  - e. Behaviour skills (Pill taking, scheduling, adherence aids).

- f. Service quality (trust to health provider, interaction provider/client, facility and equipment).
  - g. Regimen, simplicity, toxicity, disruption of daily activities.
  - h. Disease stage (mental and health status).
  - i. Structural factors such as cost, distance, time to health facility, lack of finances, nutrition
  - j. Risk behaviours such as alcohol and drug abuse.
  - k. What other factors influence adherence of patients.
- 
- 6. What activities take place at the moment in your community to help people to adhere to ART? Explore on existing strategies to improve adherence.
  - 7. What should be done more to assist people assist people to adhere to ART?
  - 8. What do you as a caregiver need with regard to training to facilitate patients adherence to ART (Areas where you feel you need training on).
  - 9. Do you have any questions or need any clarity.
  - 10. Conclusion, thank participants.

**ANNEXURE G: CONSENT FORM FOR COMMUNITY CAREGIVERS TO PARTICIPATE IN  
FOCUS GROUP SESSIONS FOR THE PILOT TESTING OF THE SOCIAL WORK  
EMPOWERMENT PROGRAMME**

**Title of the research project**

The development and evaluation of a social empowerment programme for community caregivers to facilitate the adherence of patients to antiretroviral treatment.

**Reference number: NWU-00130-14-S1**

**Principle investigator:**

Roslind Mokwele

**Dear Community caregiver**

I am Roslind Mokwele. I am a PhD student (Social Work) at the North-West University (Potchefstroom Campus). You are hereby invited to participate in a research study to explore the perceptions of community caregivers with regarding to a social empowerment programme to facilitate the adherence of patients on antiretroviral treatment. In order to decide whether you are going to participate in the study I would like to give you the following information for you to be able to make an informed decision. I would like you to read the information which will explain the details of the project and how you could be involved. You are welcome to ask the researcher any questions regarding the project.

**Purpose of the study**

- The purpose of the study is to develop a social work empowerment programme for community caregivers to facilitate HIV and AIDS patients adherence to antiretroviral treatment.
- The study will be conducted in Potchefstroom and will involve three Home Community Based care organizations, namely Baptist Children's centre, Emmamannual Hospice Loving Angels and Bamabanani Youth Project.
- At least three focus groups will be conducted with community caregivers to explore their perceptions with regard to the facilitation of adherence of HIV and AIDS patients to antiretroviral treatment.

- The social work empowerment programme will be pre-liminary evaluated by means of a focus group and peer reviews by social workers for inputs to be able to make adaptations if necessary.
- Community caregivers will take part in a quasi-experiment to evaluate the social work empowerment programme.

### **Selection for participation**

- You have been invited to participate because of your knowledge of working with patients with HIV and AIDS to give information regarding this topic.
- You also complied with the following selection criteria: Male or female community caregiver; actively involved in service delivery to HIV and AIDS patients from the Home Community based Care programme in Potchefstroom (Bambanani Youth Project, Baptist Children's centre and Hospice Emmanuel Loving Angels); have at least one year experience working with people living with HIV and AIDS; able to communicate in English.

### **Duration and location**

The study will take place at Baptist Children's centre. Focus group sessions will take about 1 hour and 15 minutes on three different occasions. The presentation of the empowerment programme to the community caregivers will be sessions of one day each at least once a week for approximately ten weeks.

### **Responsibilities**

On agreement to participate in the study, you will be expected to take part in focus group sessions to assist with the evaluation of the pre-liminary social work empowerment programme.

### **Risk/Discomfort**

The risks in this study are minimal due to since the focus will be on the community caregivers' perceptions and programme development. It might happen that you will experience emotional distress when participating in the focus group sessions group. Should you experience any emotional distress I will refer you to an appropriate counsellor. It might also happen that some members will be uncomfortable to talk in front of others, or feeling less valuable in the group, that may create a feeling of uneasiness. Group rules will be set to limit loss of anonymity in group facilitation.

## **Voluntary participation**

You as participant can decide whether you want to participate in the research or not. You do not have to take part in the study, and your refusal to participate will involve no penalty or loss of rights to which you are entitled. You may withdraw from the study at any time and without fear of losing any services or benefits to which you are entitled.

## **Confidentiality**

The loss of partial anonymity in the focus groups will be addressed through the set of group rules. Any information obtained from you as participant in the focus group sessions will be handled as confidential way and will only be made known with your consent. The identity of each participant will be protected. All information will be coded and no personal information that will be able to identify you will be mentioned in the research. I would like to record the information of the focus group sessions to be able to capture all the valuable information. This information will only be used for research purposes. Only I, the transcribers and the supervisor will have access to the recorded information. All recorded information will be stored in a safe place during and after the research and only the researcher and the supervisor will have access to the tape recordings. The researcher will sign a contract of confidentiality with the transcribers of the focus groups.

## **Benefits**

There are certain benefits for you as participant regarding this study. Your contribution will add to the knowledge regarding social work services to HIV and AIDS patients on antiretroviral treatment. You as community caregiver will be able to gain insight into your own emotions through the focus group discussions. As community caregiver you will be empowered through the presentation of an empowerment programme to improve your psycho-social functioning as caregiver to HIV and AIDS patients. You will also benefit from the social work empowerment programme as a means of self . development.

## **Cost**

There will be no cost to you as a result of your participation in this study. You will receive no payment for participation. Refreshments will be provided during the focus group sessions.

## **Payment**

Please be aware that there will be no payment for participation in the research.

**Questions and feedback regarding the research**

The findings of the research will be made available to you on request and it will be shared with you in your own language. All questions and inquiries regarding the research can be directed to:

Researcher: Ms. Roslind Mokwele cell no 0795226879

Project leader: Professor H. Strydom, tel no 018 299 1677

Human Research Ethics Committee: Ms. C. van Zyl tel no 018 299 2094

**Declaration by community caregiver**

The above-mentioned information was presented to me in (Tswana/English/Afrikaans) and I the participant is familiar with this language or was translated to me. I was given the opportunity to ask clarifying questions and am satisfied with the response to the questions. I have been informed about the nature of the research and the risks and benefits. I have also read the information about the research study and understand the content thereof. I had enough time to read and ask questions. study.

I \_\_\_\_\_ age \_\_\_\_\_ hereby voluntarily consent to my participation in the research.

Signed at \_\_\_\_\_ on (date) \_\_\_\_\_ 2015

\_\_\_\_\_  
Signature of community caregiver Date

\_\_\_\_\_  
Signature of person obtaining consent Date

\_\_\_\_\_  
Signature of witness Date

ANNEXURE H: PERMISSION FOR RESEARCH: DEPARTMENT OF SOCIAL  
DEVELOPMENT



social development

Department:  
Social Development  
North West Provincial Government  
REPUBLIC OF SOUTH AFRICA



Private Bag X 6  
Mmabatho, 2735  
Provident House Building  
MMABATHO

**HUMAN CAPITAL MANAGEMENT**

Tel: +27 (18) 388 2867  
Fax: +27 (86) 691 8369  
E-mail: pmathe@nwpg.gov.za

Mrs R.M Mokwele  
North West University  
**Mmabatho**  
2735

Dear Madam

**Subject : Request For the Permission to conduct research within the  
Department**

Your correspondence dated 30<sup>th</sup> June 2014 on the above subject is hereby acknowledged with thanks.

Kindly note that your request to conduct research within the organisation has been approved by the Acting Head of Department and you can proceed with your research immediately. The relevant office will be informed accordingly.

For further enquires please do not hesitate to contact Mr A Mokgwasa or Ms P Mathe at 018 388 2867/ 1600.

Wishing you all the best in your endeavour.

Thank you,

**Mr A Mokgwasa**  
**Acting Director: HCM**

Lefapha la Tihabololo ya Loago ♦ Department van Maatskaplike Ontwikkeling





## **ANNEXURE I: CONSENT FORM FOR SOCIAL WORKERS TO PARTICIPATE IN PEER REVIEWS**

### **Title of the research project**

The development and evaluation of a social empowerment programme for community caregivers to facilitate the adherence of patients to antiretroviral treatment.

**Reference number: NWU-00130-14-S1**

### **Principle investigator:**

Roslind Mokwele

You are hereby invited to participate in a research study to explore the perceptions of community caregivers with regarding to a social empowerment programme to facilitate the adherence of patients on antiretroviral treatment. In order to decide whether you are going to participate in the study I would like to give you the following information for you to be able to make an informed decision. I would like you to read the information which will explain the details of the project and how you could be involved. You are welcome to ask the researcher any questions regarding the project.

### **Purpose of the study**

- The purpose of the study is to develop a social work empowerment programme for community caregivers to facilitate HIV and AIDS patients' adherence to antiretroviral treatment.
- The study will be conducted in Potchefstroom and will involve three Home Community Based care organizations, namely Baptist Children's centre, Emmamannual Hospice Loving Angels and Bambanani Youth Project.
- At least three focus groups will be conducted with community caregivers to explore their perceptions with regard to the facilitation of adherence of HIV and AIDS patients to antiretroviral treatment.
- The social work empowerment programme will be pre-liminary evaluated by means of a focus group and peer reviews by social workers for inputs to be able to make adaptations if necessary.

- Community caregivers will take part in a quasi-experiment to evaluate the social work empowerment programme.

### **Selection for participation**

- You have been invited to participate because of your knowledge of working with patients with HIV and AIDS to give information regarding this topic.
- You also complied with the following selection criteria: Social worker, male or female and have at least one year experience working with people living with HIV and AID as coordinator of the HIV and AIDS programme.

### **Responsibilities**

On agreement to participate in the study, you will be expected to take part in semi-structured interview sessions. This is to evaluate and to get your inputs regarding the social work empowerment programme in order to make adaptations to the programme.

### **Risk/Discomfort**

It might happen that you will experience emotional distress regarding your work with HIV and AIDS patients when participating in the interview sessions. Should you experience any emotional distress I will refer you to an appropriate counsellor.

### **Voluntary participation**

You as participant can decide whether you want to participate in the research or not. You do not have to take part in the study, and your refusal to participate will involve no penalty or loss of rights to which you are entitled.

### **Confidentiality**

Any information obtained from you as participant during the interview sessions will be handled as confidential and will only be made known with your consent. The identity of each participant will be protected. All information will be coded and no personal information that will be able to identify you will be mentioned in the research. I would like to record the information of the interview sessions to be able to capture all the valuable information. This information will only be used for research purposes. Only myself, and the supervisor will have access to the recorded information of the interviews. All recorded information will be stored in a safe place during and after the research and only the researcher and the supervisor will have access to the tape recordings.

## **Benefits**

There are certain benefits for you as participant regarding this study. Your contribution will add to the knowledge regarding social work services to HIV and AIDS patients on antiretroviral treatment.

## **Cost**

There will be no cost to you as a result of your participation in this study.

## **Payment**

Please be aware that there will be no payment for participation in the research.

## **Questions regarding the research**

The findings of the research will be made available to you on request.

All questions and inquiries regarding the research can be directed to:

Researcher: Ms. Roslind Mokwele cell no 0795226879

Project leader: Professor H. Strydom, tel no 018 299 1677

Human Research Ethics Committee: Ms. C. van Zyl tel no 018 299 2094

## **Declaration by social worker**

The above-mentioned information was presented to me in (Tswana/English/Afrikaans) and I the participant is familiar with this language or was translated to me. I was given the opportunity to ask clarifying questions and am satisfied with the response to the questions. I have been informed about the nature of the research and the risks and benefits. I have also read the information about the research study and understand the content thereof. I had enough time to read and ask questions.

I \_\_\_\_\_ age \_\_\_\_\_ hereby voluntarily consent to my participation in the research.

Signed at \_\_\_\_\_ on (date) \_\_\_\_\_ 2015

\_\_\_\_\_  
Signature of community caregiver

\_\_\_\_\_  
Date

---

Signature of person obtaining consent

---

Date

---

Signature of witness

---

Date



## ANNEXURE J: INTERVIEW SCHEDULE FOR SOCIAL WORKERS.

Interview schedule-Social Workers

Please answer the following questions as completely as possible.

### Section A:

#### 1. Gender

Male		Female	

#### 2. Your Social Work experience (Cross only one)

1-5 years	
6-10 years	
11-15 years	
16-20 years	
21-25 years	
26-30 years	
More than 31 years	

#### 3. Your highest qualification

Diploma Social Work	
BA Social Work	
Honns Social Work	
MA Social Work	
PhD Social Work	
Other	

**4. What challenges do you experience regarding antiretroviral treatment of patients?**

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**5. What do you think should be the role of the Social Worker in supporting community caregivers to facilitate patients' adherence to antiretroviral treatment?**

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**6. What are your comments with regard to the developed programme?**

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**7. What is else do you think should be included in the programme?**

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**8. Any other remarks?**

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Ms R.M. Mokwele

PhD student

Social Work Division

North-West University (Potchefstroom campus)

## **ANNEXURE K: CONSENT FORM FOR COMMUNITY CAREGIVERS TO PARTICIPATE IN QUASI-EXPERIMENT**

### **Title of the research project**

The development and evaluation of a social empowerment programme for community caregivers to facilitate the adherence of patients to antiretroviral treatment.

**Reference number: NWU-00130-14-S1**

### **Principle investigator:**

Roslind Mokwele

### **Dear Community caregiver**

I am Roslind Mokwele. I am a PhD student (Social Work) at the North-West University (Potchefstroom Campus). You are hereby invited to participate in a research study to explore the perceptions of community caregivers with regarding to a social empowerment programme to facilitate the adherence of patients on antiretroviral treatment. In order to decide whether you are going to participate in the study I would like to give you the following information for you to be able to make an informed decision. I would like you to read the information which will explain the details of the project and how you could be involved. You are welcome to ask the researcher any questions regarding the project.

### **Purpose of the study**

- The purpose of the study is to develop a social work empowerment programme for community caregivers to facilitate HIV and AIDS patients adherence to antiretroviral treatment.
- The study will be conducted in Potchefstroom and will involve three Home Community Based care organizations, namely Baptist Children's centre, Emmamual Hospice Loving Angels and Bambanani Youth Project.
- At least three focus groups will be conducted with community caregivers to explore their perceptions with regard to the facilitation of adherence of HIV and AIDS patients to antiretroviral treatment.

- The social work empowerment programme will be pre-liminary evaluated by means of a focus group and peer reviews by social workers for inputs to be able to make adaptations if necessary.
- Community caregivers will take part in a quasi-experiment to evaluate the social work empowerment programme.

### **Selection for participation**

- You have been invited to participate because of your knowledge of working with patients with HIV and AIDS to give information regarding this topic.
- You also complied with the following selection criteria: Male or female community caregiver; actively involved in service delivery to HIV and AIDS patients from the Home Community based Care programme in Potchefstroom (Bambanani Youth Project, Baptist Children's centre and Hospice Emmanuel Loving Angels); have at least 3 months experience working with people living with HIV and AIDS; able to communicate in English.

### **Duration and location**

The study will take place at Baptist Children's centre. The presentation of the empowerment programme to the community caregivers will be sessions of one day each at least once a week.

### **Responsibilities**

On agreement to participate in the study, you will be expected to take part in a quasi-experiment, whereby 12 community caregivers will form an experimental group and 12 community caregivers will form a comparison group. The community caregivers from the experimental group will receive training sessions based on the empowerment programme. The comparison group will not receive the training, together with the experimental group, but only at a later stage.

### **Risk/Discomfort**

The risks in this study are minimal. However it might happen that you will experience emotional distress when participating in the empowerment sessions when discussing items. Should you experience any emotional distress I will refer you to an appropriate counsellor. It might also happen that some members will be uncomfortable to talk in front of others, or feeling less valuable in the group, that may create a feeling of uneasiness. Group rules will be set to limit loss of anonymity in empowerment sessions.

**Voluntary participation**

You as participant can decide whether you want to participate in the research or not. You do not have to take part in the study, and your refusal to participate will involve no penalty or loss of rights to which you are entitled.

**Confidentiality**

The loss of partial anonymity in the empowerment sessions will be addressed through the set of group rules. Any information obtained from you as participant in the empowerment sessions will be handled as confidential and will only be made known with your consent. The identity of each participant will be protected. All information will be coded and no personal information that will be able to identify you will be mentioned in the research. I would like to record the information of the empowerment sessions to be able to capture all the valuable information. This information will only be used for research purposes. Only myself, and the supervisor will have access to the recorded information. All recorded information will be stored in a safe place during and after the research and only the researcher and the supervisor will have access to the tape recordings.

**Benefits**

There are certain benefits for you as participant regarding this study. Your contribution will add to the knowledge regarding social work services to HIV and AIDS patients on antiretroviral treatment. You as community caregiver will be able to gain knowledge on HIV and AIDS and antiretroviral treatment of patients through the social work empowerment programme. As community caregiver you will also be empowered through the presentation of an empowerment programme to improve your psycho-social functioning as caregiver to HIV and AIDS patients. You will also benefit from the social work empowerment programme as a means of self-development.

**Cost**

There will be no cost to you as a result of your participation in this study. You will receive no payment for participation. Refreshments will be provided during the empowerment sessions.

**Payment**

Please be aware that there will be no payment for participation in the research.

The findings of the research will be made available to you on request and it will be shared with you in your own language.

**Questions and feedback regarding the research**

The findings of the research will be made available to you on request and it will be shared with you in your own language.

All questions and inquiries regarding the research can be directed to:

Researcher: Ms. Roslind Mokwele cell no 0795226879

Project leader: Professor H. Strydom, tel no 018 299 1677

Human Research Ethics Committee: Ms. C. van Zyl tel no 018 299 2094

**Declaration by community caregiver**

The above-mentioned information was presented to me in (Tswana/English/Afrikaans) and I the participant is familiar with this language or was translated to me. I was given the opportunity to ask clarifying questions and am satisfied with the response to the questions. I have been informed about the nature of the research and the risks and benefits. I have also read the information about the research study and understand the content thereof. I had enough time to read and ask questions. I hereby give my permission to take part in the study.

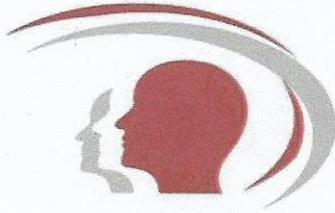
I \_\_\_\_\_ age \_\_\_\_\_ hereby voluntarily consent to my participation in the research.

Signed at \_\_\_\_\_ on (date) \_\_\_\_\_ 2015

\_\_\_\_\_  
Signature of community caregiver Date

\_\_\_\_\_  
Signature of person obtaining consent Date

\_\_\_\_\_  
Signature of witness Date



**Perspective  
Training College**

**Perspektief  
Opleidingskollege**

**Potchefstroom  
South Africa**

PO Box 20842 Posbus  
Noordbrug, Potchefstroom, 2522

7 Grietjie Street / Straat 7  
Dassierand, Potchefstroom, 2531

Tel +27 18 293 1416  
Fax 0866 921 322

E-mail / E-pos:  
[perspektief@lantic.net](mailto:perspektief@lantic.net)

Besoek ons webwerf:  
Visit our website:

[www.perspectivetrainingcollege.com](http://www.perspectivetrainingcollege.com)

Lede / Members:  
AC Faul & AJ Hanekom

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CK 1992/029890/23

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Standard Bank Potchefstroom  
Branch Code: 052838  
Account Number: 012380040

***Personal Multi-Screening  
Inventory (PMSI)***

***Persoonlike Multi-Sifting  
Inventaris (PMSI)***

***Questionnaire / Vraelys***

**Comprehensive Personal  
Assessment**

**Omvattende Persoonlike  
Assessering**

## Personal Multi-Screening Inventory (PMSI)

### About your PMSI Profile

#### Confidentiality

We want you to know that the personal information you share will remain just that, personal. Your confidentiality will be respected.

#### Purpose

The PMSI is designed to improve the quality of your life by evaluating your present functioning and making recommendations for the future. For the report to be accurate, all questions need to be answered to the best of your ability.

#### A few Suggestions

Answer the questions as quickly and as honestly possible. Do not speculate too long before you answer. This is not a test and there are no right or wrong answers. The first answer that comes to mind is usually the correct one.

#### Procedure

- Mark the relevant number on the answer sheet, by encircle the number.
- Check to be sure you have answered every question.
- If a specific question is not applicable, please encircle the **X** on the answer sheet.

#### Example

I am full of life

If your answer is **often**, encircle **4**

## Persoonlike Multi-Sifting Inventaris (PMSI)

### Oor u PMSI Profiel

#### Vertroulikheid

Ons wil hê u moet weet dat die persoonlike inligting wat u met ons deel persoonlik bly. U vertroulikheid sal beskerm word.

#### Doel

Die PMSI is ontwerp om kwaliteit van u lewe te verhoog deur u huidige funksionering te evalueer en aanbevelings vir die toekoms te maak. Vir die verslae om akkuraat te wees moet al die vrae na die beste van u vermoë beantwoord word.

#### 'n Paar Voorstelle

Antwoord die vrae so vinnig en eerlik moontlik. Moenie te lank oor 'n antwoord dink nie. Dit is nie 'n toets nie en daar is geen regte of verkeerde antwoorde nie. Die eerste antwoord wat in u gedagtes opkom, is normaalweg die korrekte een.

#### Prosedure

- Merk die relevante nommer op die antwoordblad, deur die nommer te omring.
- Maak seker u het elke vraag geantwoord.
- Indien 'n spesifieke vraag nie op u van toepassing is nie, omsirkel die **X** op die antwoordblad.

#### Voorbeeld



Ek is vol lewe

Indien u antwoord **dikwels** is, trek 'n sirkel om **4**.

1 2 3 ④ 5

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Perspektief Training College, PO Box 20842, Noordbrug 2522

Tel +27 18 297 3716, Fax +27 18 297 4775, E-mail [perspektief@lantic.net](mailto:perspektief@lantic.net)

**Personal Multi-Screening Inventory (PMSI)**  
**Persoonlike Multi-Sifting Inventaris (PMSI)**

**Questionnaire / Vraelys**

Mark the relevant item on the answer sheet, using the following numerical scale:

Merk die betrokke item op die antwoordblad deur die volgende skaal te gebruik:

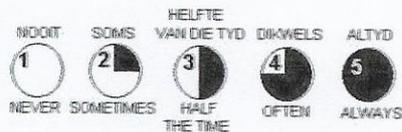


I feel rejected.	1	Ek voel verwerp.
I maintain the belief that things will turn out fine.	2	Ek behou geloof dat dinge goed sal afloop.
I act in a tense way.	3	Ek tree gespanne op.
I feel frustrated.	4	Ek voel gefrustreerd.
I have willpower.	5	Ek het wilskrag.
I get head aches and/or other aches as a result of tension.	6	Ek kry hoof- en/of ander pyne as gevolg van spanning.
I am hopeful about my future.	7	Ek is hoopvol oor my toekoms.
I feel as tense as a tightly coiled spring.	8	Ek voel so gespanne soos 'n opgewende veer.
I have stopped laughing.	9	Ek het opgehou om te lag.
I feel life is unfair.	10	Ek voel die lewe is onregverdig.
I avoid people.	11	Ek vermy mense.
I feel people demand too much from me.	12	Ek voel daar word te veel eise aan my gestel.
I take action to solve my problems.	13	Ek neem aksie om my probleme op te los.
I feel panicky.	14	Ek voel paniekerig.
I find it difficult to get started.	15	Ek sukkel om aan die gang te kom.
I find it difficult to keep up the pace.	16	Dit is vir my moeilik om die pas vol te hou.
I feel powerless to do anything about my circumstances.	17	Ek voel magteloos om iets aan my omstandighede te doen.
I act in a listless way.	18	Ek tree lusteloos (sonder energie) op.
I feel satisfied with the standard of my life.	19	Ek voel tevrede met die standaard van my lewe.
I act without any purpose.	20	Ek tree doelloos op.
I become entangled in arguments.	21	Ek raak in argumente betrokke.
I take control of my problems.	22	Ek neem beheer van my probleme.
I act panicky when I experience stress.	23	Ek tree paniekerig op wanneer ek spanning ervaar.
I create an unpleasant atmosphere when I feel frustrated.	24	Ek skep 'n onaangename atmosfeer wanneer ek gefrustreerd voel.
I show my frustrations to others.	25	Ek wys my frustrasies aan ander.
I feel good about the course my life is taking at present.	26	Ek voel goed oor die huidige verloop van my lewe.
I am downhearted.	27	Ek is terneergedruk.
I feel irritated.	28	Ek voel geïrriteerd.

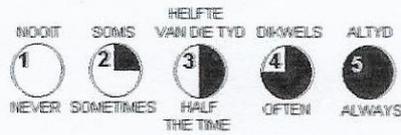


I get what I want by making others feel too threatened to oppose me.	29	Ek kry my sin deur ander mense te bedreig te laat voel om my teen te staan.
I socialise with others.	30	Ek verkeer sosiaal met ander.
I feel cheerful.	31	Ek voel opgewek.
I become embittered.	32	Ek raak verbitterd.
I only do the minimum.	33	Ek doen net die minimum.
I feel angry.	34	Ek voel kwaad.
I act disordered when I experience stress.	35	Ek tree verward op wanneer ek spanning ervaar.
I encourage others because I believe things will turn out well.	36	Ek praat ander moed in want ek glo alles sal goed gaan.
I manage life with a smile.	37	Ek hanteer die lewe met 'n glimlag.
I am goal oriented.	38	Ek is doelgerig.
It is important to me to work hard.	39	Dit is vir my belangrik om hard te werk.
I feel satisfied with my present accomplishments.	40	Ek voel tevrede met dit wat ek tans bereik.
People can see from my actions that I am afraid.	41	Mense kan uit my optrede sien dat ek bang is.
I feel prevented from reaching my objectives.	42	Ek voel verhinder om my doelwitte te bereik.
I achieve little.	43	Ek bereik min.
I act unproductively.	44	Ek tree onproduktief op.
I feel down-in-the-dumps.	45	Ek voel neerslagtig.
I complete what I set out to do.	46	Ek maak klaar met dit waarmee ek begin.
I hurt others feelings before they can hurt me.	47	Ek maak ander se gevoelens seer voor hulle dit dalk aan my doen.
I behave in a nervous manner.	48	Ek tree senuweeagtig op.
I enjoy my relationships.	49	Ek geniet my verhoudings.
I plan events in such a way that life is a joy to me.	50	Ek beplan my lewe só, dat ek dit geniet.
I manage life from a negative point of view.	51	Ek hanteer die lewe vanuit 'n negatiewe gesindheid.
I am successful.	52	Ek is suksesvol.
I act without enthusiasm.	53	Ek tree sonder entoesiasme op.
I keep calm by remaining positive.	54	Ek behou kalmte deur positief te bly.
I take initiative when things need to be done.	55	Ek neem inisiatief wanneer dinge gedoen moet word.
Stress gives me muscular tension.	56	My spiere trek saam as gevolg van spanning.
I feel overstressed.	57	Ek voel oorspanne.
My behaviour towards others shows that I have faith in them.	58	My gedrag teenoor ander wys dat ek in hulle glo.
I act with uncertainty.	59	Ek tree onseker op.
I worry.	60	Ek bekommer my.
I have a high energy level.	61	Ek het baie energie.





I look forward to the future.	96	Ek sien uit na die toekoms.
I adapt to bad things that happen to me in a positive way.	97	Ek verwerk die slegte dinge wat met my gebeur op 'n positiewe manier.
I spend time on hobbies.	98	Ek spandeer tyd aan stokperdjies.
I do things that I enjoy.	99	Ek doen dinge wat vir my lekker is.
I wish I could just run away from it all.	100	Ek wens ek kan van alles af weghardloop.
I have perseverance.	101	Ek het deursettingsvermoë.
I communicate positive feelings towards others.	102	Ek kommunikeer positiewe gevoelens aan ander.
I feel like giving up.	103	Ek voel lus om moed op te gee.
I act calmly because all will be well.	104	Ek tree rustig op want alles sal goed gaan.
I feel joyful.	105	Ek voel vrolik.
I feel lonely.	106	Ek voel eensaam.
I refrain from participating in activities.	107	Ek weerhou my van enige deelname aan aktiwiteite.
I lose self-control when I become angry.	108	Ek verloor beheer wanneer ek kwaad word.
I am at ease in my relationships with others.	109	Ek is gemaklik in my verhoudings met ander.
I am friendly.	110	Ek is vriendelik.
I listen to others when they talk about their problems.	111	Ek luister na ander wanneer hulle oor hulle probleme praat.
I act moodily.	112	Ek tree buierig op.
I focus on the positive aspects in my circumstances.	113	Ek fokus op die positiewe aspekte in my omstandighede.
I have little hope for my future.	114	Ek het min hoop vir my toekoms.
I keep on working until I am satisfied.	115	Ek hou aan werk totdat ek tevrede is.
My thoughts are frightening to me.	116	My gedagtes maak my bang.
I find it difficult to get bad thoughts out of my mind.	117	Ek kry slegte gedagtes moeilik uit my kop.
I wake up at night feeling afraid.	118	Ek word snags wakker in 'n toestand van vrees.
I think about committing suicide.	119	Ek dink daaraan om selfmoord te pleeg.
People stare at me.	120	Mense staar my aan.
The only way to end my shame is to end my life.	121	Die enigste manier om my skaamte te verberg, is om my lewe te beëindig.
I find it difficult to handle problems without the support of something.	122	Dis vir my moeilik om probleme te hanteer sonder dat iets my ondersteun.
I forget important phone numbers.	123	Ek vergeet belangrike telefoonnommers.
I have frightening nightmares.	124	Ek het vreesaanjaende nagmerries.
People are trying to make me look foolish.	125	Mense probeer om 'n gek van my te maak.
I have difficulty remembering basic things.	126	Ek vind dit moeilik om basiese dinge te onthou.
I have disturbing thoughts.	127	Ek het ontstellende gedagtes.
Horrible thoughts rush into my mind.	128	Aaklige gedagtes kom by my op.



People who are supposed to be my friends are out to stab me in the back.	129	Mense, wat veronderstel is om my vriende te wees, is daarop uit om my in die rug te steek.
I break out in cold sweats.	130	Ek kry koue sweetaanvalle.
I think about ending my life.	131	Ek dink daaraan om 'n einde aan my lewe te maak.
I prefer something to support me when things go wrong.	132	Ek verkies dat iets my moet ondersteun wanneer dinge verkeerd loop.
Life is worthwhile.	133	Die lewe is die moeite werd.
I think I shall find peace when I take my own life.	134	Ek dink ek sal vrede vind wanneer ek my eie lewe neem.
I feel panic stricken.	135	Ek voel paniekbevange.
I can feel people watching me.	136	Ek kan aanvoel dat mense my dop hou.
I help make the world a better place.	137	Ek help om van die wêreld 'n beter plek te maak.
I have ideas and thoughts that disturb me greatly.	138	Ek het idees en gedagtes wat my baie ontstel.
I experience anxiety.	139	Ek beleef angs.
People spy on me.	140	Mense hou my dop.
It is useless for me to continue living.	141	Dit is nutteloos om aan te hou lewe.
I find it difficult to keep up the pace without the help from something else.	142	Dis vir my moeilik om die pas vol te hou sonder die hulp van iets anders.
I forget where I put things that I use daily.	143	Ek vergeet waar ek dinge wat ek elke dag gebruik, neersit.
I have a dream for my life.	144	Ek het 'n droom vir my lewe.
Disturbing ideas come to me.	145	Ontstellende gedagtes kom by my op.
I overcome obstacles in my life.	146	Ek kom struikelblokke in my lewe te bowe.
I think about my final plans for ending my life.	147	Ek dink aan die finale planne om my lewe te neem.
I forget personal information.	148	Ek vergeet persoonlike inligting.
People talk about me behind my back.	149	Ander mense skinder van my.
People are "out to get me".	150	Mense is daarop uit om my te benadeel.
I make a difference in life.	151	Ek maak 'n verskil in die lewe.
Life is difficult to handle on my own.	152	Dis moeilik om die lewe op my eie te hanteer.
People are trying to hurt me.	153	Mense probeer my seermaak.
I have a purpose in life.	154	Ek het 'n doel in die lewe.
Everyone would be better off if I was dead.	155	Dit sal vir almal beter wees as ek dood is.
I like it when something helps me to handle pressure.	156	Ek hou daarvan wanneer iets my help om druk te hanteer.
I find it hard to manage life without the support of something else.	157	Dis vir my moeilik om die lewe te hanteer sonder die ondersteuning van iets anders.
I know why I live.	158	Ek weet hoekom ek lewe.
I have strange thoughts.	159	Ek het vreemde gedagtes.
People talk about me.	160	Mense praat oor my.



I forget important things about my work or school.	161	Ek vergeet belangrike dinge omtrent my werk of studies.
I think about horrible things.	162	Ek dink aan aaklige goed.
My life is over and I may as well end it.	163	My lewe is verby en ek kan dit net sowel beëindig.
I am dependent on the support of something else.	164	Ek is afhanklik van die ondersteuning van iets anders.
I need something to cope with life.	165	Ek het iets nodig om die lewe te kan hanteer.
I think about different ways that I could kill myself.	166	Ek dink aan verskillende maniere om myself dood te maak.
I find it difficult to remember more than one instruction.	167	Ek vind dit moeilik om meer as een opdrag te onthou.
I am stricken with a sense of paralysing fear.	168	Ek word platgeslaan deur 'n gevoel van verlamende vrees.
My memory seems to fail me.	169	Dit lyk asof my geheue my in die steek laat.
People try to cause me trouble.	170	Mense probeer my in die moeilikheid bring.
My agony is too great for me to continue living.	171	My lyding is te veel om aan te hou leef.
I worry about the horrible thoughts that I have.	172	Ek is bekommerd oor die aaklige gedagtes wat ek het.
I learn from my previous experiences.	173	Ek leer uit my vorige ervarings.
I become so afraid that I can hardly move.	174	Ek word só bang dat ek skaars kan beweeg.
I feel worthless.	175	Ek voel nikswerd.
I live with self-reproach.	176	Ek leef met selfverwyf.
I become scared.	177	Ek raak bang.
I am afraid of the future.	178	Ek is bang vir die toekoms.
I feel threatened by my current circumstances.	179	Ek voel bedreig deur my huidige omstandighede.
I am afraid to fail.	180	Ek is bang om te misluk.
I blame myself.	181	Ek veroordeel myself.
I find it difficult to accept myself.	182	Ek sukkel om myself te aanvaar.
I feel unimportant.	183	Ek voel onbelangrik.
I feel like a failure.	184	Ek voel soos 'n mislukking.
Everything is my fault.	185	Alles is my skuld.
I feel I deserve punishment.	186	Ek voel ek verdien straf.
I feel I am a hopeless person.	187	Ek voel ek is 'n hopelose mens.
I feel ashamed of myself.	188	Ek voel skaam vir myself.
I am afraid that I will be hurt emotionally.	189	Ek is bang ek gaan emosioneel seerkry.
I feel guilty.	190	Ek voel skuldig.
Feelings of guilt control my life.	191	Skuldgevoelens beheer my lewe.
I am afraid people will reject me.	192	Ek is bang mense sal my verwerp.
My circumstances make me feel uncertain.	193	My omstandighede laat my onseker voel.



## Interpersoonlike Funkisionering / Interpersonal Functioning

Complete this section with regard to your interpersonal functioning. Mark the relevant item on the answer sheet, using the above-mentioned numerical scale:

Voltooi hierdie afdeling met betrekking tot u interpersoonlike funksionering. Merk die betrokke item op die antwoordblad deur die bostaande skaal te gebruik:

### Verhouding met Vriende / Relationship with Friends

My friends and I do things together.	194	Ek en my vriende doen dinge saam.
I can be honest with my friends.	195	Ek kan eerlik wees met my vriende.
My friends bail me out when I am in trouble.	196	My vriende help my wanneer ek in die moeilikheid is.
My friends share their secrets with me.	197	My vriende deel hul geheime met my.
My friends and I have fun together.	198	Ek en my vriende het 'n lekker tyd saam.
I share my secrets with my friends.	199	Ek deel my geheime met my vriende.
I trust my friends.	200	Ek vertrou my vriende.

### Verhouding met Gesin / Relationship with Family

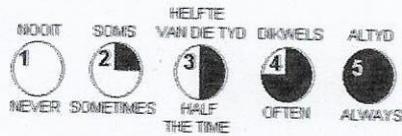
Complete this scale if you are part of a family		Voltooi hierdie skaal indien jy deel van 'n gesin is.
I share my feelings with my family members.	201	Ek deel my gevoelens met my gesinslede.
I receive guidelines from my family members.	202	Ek ontvang leiding van my gesinslede.
Our family spends time together.	203	Ons gesin bring saam tyd deur.
I can be honest with my family members.	204	Ek kan eerlik wees met my gesinslede.
My family bails me out of trouble.	205	My gesin help my wanneer ek in die moeilikheid is.
I share my secrets with my family members.	206	Ek deel my geheime met my gesinslede.
I can share what happens to me with my family.	207	Ek kan vir my gesin vertel wat met my gebeur.

### Verhouding met Ma (Stiefma) / Relationship with Mother (Stepmother)

I share my secrets with my mother/stepmother.	208	Ek deel my geheime met my ma/stiefma.
My mother/stepmother and I do things together.	209	Ek en my ma/stiefma doen dinge saam.
I spend time with my mother/stepmother.	210	Ek bring tyd saam met my ma/stiefma deur.
My mother/stepmother and I have fun together.	211	Ek en my ma/stiefma het 'n lekker tyd saam.
I share my feelings with my mother/stepmother.	212	Ek deel my gevoelens met my ma/stiefma.

### Verhouding met Pa (Stiefpa) / Relationship with Father (Stepfather)

My father/stepfather and I do things together.	213	Ek en my pa/stiefpa doen dinge saam.
I spend time with my father/stepfather.	214	Ek bring tyd saam met my pa/stiefpa deur.
I share my secrets with my father/stepfather.	215	Ek deel my geheime met my pa/stiefpa.
I share my feelings with my father/stepfather.	216	Ek deel my gevoelens met my pa/stiefpa.
My father/stepfather and I have fun together.	217	Ek en my pa/stiefpa het 'n lekker tyd saam.



### Verhouding met Maat / Relationship with Partner

Complete this scale if you are in a romantic relationship with someone.		Voltooi hierdie skaal indien jy in 'n romantiese verhouding met iemand staan:
My partner and I have fun together.	218	Ek en my maat het 'n lekker tyd saam.
I share my secrets with my partner.	219	Ek deel my geheime met my maat.
I can be honest with my partner.	220	Ek kan eerlik wees met my maat.
I share my feelings with my partner.	221	Ek deel my gevoelens met my maat.
My partner and I do things together.	222	Ek en my maat doen dinge saam.
I spend time with my partner.	223	Ek bring tyd saam met my maat dour.

### Verhouding met Kind / Relationship with Child

Complete this scale if you have children. Complete this scale either with regard to your children in general, or with regard to the child you have the worst relationship with.		Voltooi hierdie skaal indien jy kinders het. Voltooi die skaal met betrekking tot jou kinders in die algemeen, of met betrekking tot die kind met wie jy die slegste verhouding het.
I spend time with my children	224	Ek bring tyd deur saam met my kinders.
My children and I have fun together.	225	Ek en my kinders het 'n lekker tyd saam.
My children share their secrets with me.	226	My kinders deel hulle geheime met my.
My children strive to be like me.	227	My kinders wil graag soos ek wees.
My children and I do things together.	228	Ek en my kinders doen dinge saam.

### Verhouding met Kollegas / Relationship with Colleagues

Complete this scale if you are currently employed		Voltooi hierdie skaal indien jy tans in 'n werksituasie staan.
My colleagues treat me with respect.	229	My kollegas behandel my met respek.
My colleagues criticize me.	230	My kollegas kritiseer my.
My colleagues irritate me.	231	My kollegas irriteer my.
I get along with my colleagues.	232	Ek kom met my kollegas oor die weg.
My colleagues make me feel part of the team.	233	My kollegas laat my deel van die span voel.
My colleagues talk behind my back.	234	My kollegas skinder van my.
My colleagues frustrate me.	235	My kollegas frustreer my.
My colleagues let me down.	236	My kollegas laat my in die steek.
My colleagues support me.	237	My kollegas ondersteun my.

### Social Support / Sosiale Ondersteuning

I can rely on a special person for support.	238	Daar is 'n spesiale persoon op wie ek kan staatmaak vir ondersteuning.
There is a special person that respects me.	239	Daar is 'n spesiale persoon wat my respekteer.
There is a special person that cares for me.	240	Daar is 'n spesiale persoon wat vir my omgee.
I can count on a special person when things go wrong.	241	Ek kan op 'n spesiale persoon staatmaak wanneer dinge verkeerd loop.



**ANNEXURE M: PRE-TEST/POST-TEST ASSESSMENT TOOL FOR COMMUNITY  
CAREGIVERS ON KNOWLEDGE, SKILLS AND MOTIVATION (ATTITUDE)**

**Code:** \_\_\_\_\_

**Date:** \_\_\_\_\_

**The following questions deal with knowledge, skills and motivation/attitude towards HIV and AIDS patients.**

**PART 1: Knowledge**

Instructions: For each of the following statements, circle either **true** if you agree or **false** if you disagree.

1. HIV-positive people have the same rights as those who are HIV-negative.

True/False

2. Antiretroviral treatment is not a cure for HIV and AIDS.

True/False

3. ART decrease the number of CD4 cells in the body.

True/False

4. Prior to starting antiretroviral therapy (ART), people should be counselled about antiretroviral (ARV) drugs.

True/False

5. People who are taking ARV drugs should not use not take part in high risk behaviours like alcohol and drug abuse

True/False

## **PART 2: Skills**

6. What particular issues should community caregivers discuss when counselling people on antiretroviral treatment
  - a. That combining alcohol with ART is best
  - b. The availability of family support
  - c. The location and logistics of available care and treatment
  
7. What other topics should community caregivers discuss while counselling HIV-positive clients?
  - a. The fact that it is not necessary to use condoms if both partners are HIV positive
  - b. Considerations in disclosing HIV status
  - c. The availability of support systems (e.g., family, community, social, legal, nutritional, or child health services)
  
8. What listening skills will you use when you counsel the patient?
  - a. Don't use non-verbal communication
  - b. Actively listen and shows interest in the client
  - c. Ask open-ended questions
  
9. What psychosocial support services can the community caregiver give?
  - a. lay counselling
  - b. Support groups
  - c. None of above
  
10. How will the community caregiver tell if a patient is depressed?
  - a. Change in appetite
  - b. Feelings of worthlessness
  - c. Low energy and fatigue

### **PART 3: Motivation (Attitude)**

Instructions: Tick one response for each of the questions below. There is no right or wrong answer to these questions.

11. I believe that telling people that certain behaviours put them at risk for HIV infection or other sexually transmitted infections (STI s) is generally enough to cause them to change their behaviour.

Agree    Somewhat agree    Somewhat disagree    Disagree

12. I am comfortable providing health information lay counselling and other services to HIV positive people

Agree    Somewhat agree    Somewhat disagree    Disagree

13. I believe that I am at high risk of becoming infected with HIV while working with people living with HIV and AIDS.

Agree    Somewhat agree    Somewhat disagree    Disagree

14. I believe that it is important to counsel people with HIV about antiretroviral treatment

Agree    Somewhat agree    Somewhat disagree    Disagree

15. I believe that people can improve their life quality through antiretroviral treatment

Agree    Somewhat agree    Somewhat disagree    Disagree



## ANNEXURE N: EXPECTATIONS FOR EMPOWERMENT PROGRAMME

1. What will an empowerment programme to facilitate patients adherence to ART mean to you?

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2. My expectations for this empowerment programme are?

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3. What do you want to learn from the empowerment programme?

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4. What do you want to learn or experience to improve your relationship with patients on ART?

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5. What changes do you want to see with regard to your knowledge, skills and motivation/attitude?

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**ANNEXURE O: POST- EXPERIENCES REGARDING EMPOWERMENT PROGRAMME**

1. What did the empowerment programme to facilitate patients adherence to ART mean to you?

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2. My expectations for this empowerment programme were?

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3. What did you learn from the empowerment programme?

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4. What did you learn or experienced to improve your relationship with patients on ART?

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5. What changes did you see with regard to your knowledge, skills and motivation/attitude after the implementation of the empowerment programme?

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