Exploring the Implementation of an Internet Based Rehabilitation Programme for HIV adults in a Public Healthcare Centre.

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Declaration

I hereby declare that this research report is my own independent work, and has not been presented for any other degree at any other academic institution, or published in any form.

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Dedications

This is dedicated to my husband Thabo, for your love, unwavering support, patience and mostly for believing in me. To my son, Nathi and daughter, Buhle for your hugs and kisses that let me know that everything is as it should be.

In loving memory of my late grandmother, Lettie. O tlo nna o le mo pelong ya ka.

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1. Introduction

South Africa is regarded to have the most severe HIV epidemic in the world with about 5.51 million people estimated to be infected in 2014 (Statistics South Africa, 2014). Improved access to anti-retroviral (ARV) treatment has resulted in an increase in survival of individuals living with HIV, including those who have milder forms of Human immunodeficiency virus (HIV)-Associated Neurocognitive Disorder (HAND) (Becker *et al.,* 2012). HAND affects 30 to 60% of people living with HIV depending on the stage of the disease (Singh *et al.*, 2010). Although the Highly Active Anti- Retroviral Treatment (HAART) has been shown to reduce HIV cognitive deficits there are some cases that do not respond to the pharmacological treatment. This requires a look at alternative means that can be incorporated into existing interventions to manage the cognitive complaints associated with HIV.

The cognitive deficits associated with HIV are characterized by mental slowness, trouble with memory and poor concentration (Owe-Larsson, Säll, Salamon, & Allgulander, 2009). Attention and working memory have been found to be the most common cognitive functions that deteriorate in individuals living with HIV (Woods, Moore, Weber & Grant, 2009). These cognitive deficits can affect a number of daily activities and productivity in the work environment, including the adherence to the treatment, but accurate identification and appropriate treatments of the deficits is still in its infancy (Becker *et al*., 2012).

The implication of cognitive impairments for daily activities has motivated the development of different kinds of rehabilitation treatments. All these treatments are based on the premise that the brain is susceptible to modification across different ages (Lillard & Erisir, 2011). The growth of cognitive rehabilitation programmes and the growing use of the internet to deliver these has influenced the growth of commercial internet based programmes that offer the flexibility to do cognitive rehabilitation from the comfort of one's home (Rabipour & Raz, 2012). There is effort to produce and prove the effectiveness of such rehabilitation interventions but there is also a greater need to explore the applicability of programmes for deficit associated with particular health conditions (Wilson, 2002).. Computer based working memory rehabilitation programmes are promising effects that can

be generalised to everyday effects and although such effects are still being debated in field there are programmes that are actively being evaluated for efficacy (Klingberg, 2012; Klingberg *et al*., 2005; Brehmer, Westerberg, & Backman, 2012; Rabipour & Raz, 2012; Jaušovec & Jaušovec, 2012).

Given the high rate of HIV, it is likely that there are many people who are presenting with associated cognitive disorders and are experiencing negative impacts on the quality of daily experiences. Hence, it is plausible to think that there is a great need for implementation of interventions, in the form of cognitive rehabilitation, for the large groups that are serviced by public healthcare facilities. However, the feasibility of internet based interventions needs to be explored before large investments are made. Therefore, the aim of this study was describe the challenges and facilitating factors in the process of implementing the CogMed™ Working Memory Training Programme at an HIV clinic for adults living with HIV.

The following chapter presents a short literature review on HIV and associated neurocognitive deficits; understanding working memory using Baddeley's Model; how HIV affect working memory and the internet based rehabilitation programmes including CogMed™. The chapter concludes by introducing the rationale of the study and the research questions. In the third chapter, the method and processes followed for the study are explained. The fourth chapter presents results categorised in the Stages of Use as defined by Chiu & Eysenbach (2010). Discussions with limitations and recommendations associated with the research is presented in the fifth chapter. The final chapter provides a brief conclusion that addresses the research questions. This research attempts to explore the processes of implementing internet based rehabilitation programmes such as CogMed™, in the South African context.

2. Literature Review

2.1 HIV Related Cognitive Deficits

South Africa has an estimated population size of 54 million people (Statistics South Africa, 2014). South Africa is regarded to have the most severe Human Immunodeficiency Virus (HIV) epidemic in the world with 5.51 million people estimated to be infected in (Statistics South Africa, 2014). Acquired Immune Deficiency Syndrome (AIDS) results in the destruction of the immune system and is caused by the HIV. In the public health sector ARV's are started at CD4 count of 350 except in circumstances where there is Tuberculosis (TB), HIV associated Dementia (HAD) (Singh *et al.,* 2010), opportunistic infections or in pregnant women (National Health Department, 2010). About two million people of the country's HIV-infected population were accessing ART in 2012 (Shisana *et al*., 2014).

The survival rate of people living with HIV has improved considerably since the introduction of Highly Active Anti- Retroviral Treatment (HAART) and has changed HIV infection into a chronic "manageable" disease, but HIV-Associated Neurocognitive Disorders (HAND) is still a significant concern for the public health (Owe-Larsson et al., 2009; Woods et al., 2009). About 30 to 60% of people with HIV develop cognitive impairments during the course of the infection which can damage the brain and other parts of the nervous system (Singh, 2012). The damaged immune system can also cause opportunistic infections and cancers that attack the brain, which can lead to cognitive impairments (Woods et al., 2009).

The various neurological complications associated with HIV, include HIV associated neurocognitive disorder (HAND). HAND can be mild to severe, depending on seriousness of symptoms and their impact on daily life and has been divided into three categories according to its severity and the categories were published in 2007 (Owe-Larsson *et al*., 2009). In its least damaging form, symptoms go un-noticed by patients, and it is known as asymptomatic neurocognitive impairment (ANI). ANI mildly affects thinking abilities and is only identified with assessment tools. The person living with ANI and those around them do not notice any symptoms. Minor neurocognitive disorder (MND) affects thinking abilities to a noticeable extent and may mildly interfere with activities of daily living. Severity increases

through mild neurocognitive disorder to its most severe form, HIV associated dementia (HAD) ((Owe-Larsson *et al*., 2009 and Singh, 2012).

Despite the high prevalence rates of HIV infection, relatively few studies have looked at the cognitive functioning of HIV positive patients in African countries (Robertson et al., 2007). South Africa is dominated by HIV-1 Clade C, the more aggressive clade as compared to the developed world, where the infections in the Americas, Europe, Japan and Australia tend to be clade B (Le Vu et al., 2010). While it has been proposed that clade C was less neurovirulent than the more studied clades B, it has recently been suggested that neurocognitive impairment occurs at similar rates in clade C (Signh et al., 2010).

Neuropathology associated with primary HIV infection has a preferentially damaging effect on the basal ganglia, deep white matter, and prefrontal cortex (Owe-Larsson et al., 2009). These brain regions are important to the neural circuitry involved in working memory function and as a result of higher degree of white matter tract in the right hemisphere, holistic and integrated processing is impaired and visuo-spatial functions are affected, whereas verbal processes are largely spared (Woods et al., 2009). However investigations into working memory abilities of individuals infected with HIV have demonstrated difficulties with both visual and verbal working memory tasks (Farinpour *et al.*, 2000) showing a lack of consensus on what areas will be affected by the HIV.

There are a number of studies that have demonstrated that a number of asymptomatic HIV infected individuals may have mild to moderate deficits in memory, information processing speed, and some other specific cognitive domains that are independent of other comorbid factors such as depression (Grassi et al., 1999; Martin et al., 1999; Woods et al., 2009; Stout el al., 2001; Bassel, Rourke, Halman & Smith, 2002; Castellon, Hinkin, Wood, & Yarema, 1998), which suggests that the HIV virus is responsible for the cognitive deficits. The deficits were most apparent in AIDS symptomatic individuals, but it was concluded that the decline may begin during the asymptomatic phase, and the observed cognitive decline may be linked to the decline in every day functioning which can sometimes be observed in HIV-infected individuals that may affect adherence to the HAART regimen treatment which requires 95% adherence for effective treatment (Owe-Larsson *et al*., 2009). The use of

HAART has reduced the cognitive complaints but has not eliminated them and data suggest that persistent cognitive deficits in individuals on HAART may be due to neurological damage sustained before the treatment (Owe-Larsson *et al*., 2009). This suggests that with the large population, about 3 million people in South Africa, that is diagnosed with HIV but are not yet eligible for treatment, there needs to be on going monitoring for HIV related cognitive deficits. Alternative treatment options for deficits that are not responding to HAART treatment also needs to be investigated.

In the early stages of neurocognitive decline there is decreased attention and concentration, psychomotor slowing, reduced speed of information processing, executive dysfunction and working memory impairment. In the later stages there is memory impairment, language problems, visuospatial working memory impairments that can be used to detect early cognitive decline difficulties and apraxia (Woods et al., 2009). If left untreated, HAND can progress and can result in an increased risk for early mortality and often interferes significantly with cognitively demanding activities of daily living such as employment, medication management and driving (Heaton et al., 2010).

Patel and colleagues (2009) suggest that HAART inhibits or delays HIV dissemination in the central nervous system and in the part of the brain where infection has already been established, HAART reduces viral replication in this manner (Patel et al., 2009). However, by its very nature, ARV's are in themselves neurotoxic as even low concentrations of the ARV's have been shown to have adverse effects on the brain (Liner, Meeker & Robertson, 2010; Heaton *et al.,* 2010). Penetration of ARV's into the brain at levels that are needed to effect viral suppression carries the risk of neuronal damage and monitoring of individuals on HAART is important in early detection of damage to the brain (Liner, Meeker & Robertson, 2010).

In clinical settings there is current lack of screening tools for HAND as well as normed assessments for the South African population (Signh *et al*., 2010). There is a need to develop assessment tools to screen patients for HAND, tools that are quick and easy to administer in order to incorporate them as part of a standard HIV treatment plan (Signh *et al*., 2010 & Signh, 2009). Many screening tests have been used to detect HAD, such as the

HIV dementia scale, the Executive Interview, mental alternation tests, the modified Memorial Sloan-Kettering scale, and the International HIV Dementia Scale. These were evaluated to have limited clinical use because they are insensitive to the pick up the milder end of the spectrum of HIV-associated neurocognitive deficits and may need to be adjusted. The following working memory tests were recommended to be used in the South African context: the Digit Span Forward, Digit Span Backward, Trail Making Test A and Trail Making Test B as they can be completed in 15 minutes, require minimal assessor training, and don't need specialized equipment (Signh *et al*., 2010). Although The Automated Working Memory Assessment(AWMA) which was selected for the study does not appear on the list it includes similar tasks to the recommended tests and it is widely used to assess working memory (Alloway, 2007).

South Africa and other sub-Saharan countries follow the WHO guidelines for initiating ARVs in resource constrained settings. People with HAD are eligible to start HAART regardless of CD4 count. The importance of monitoring people with HIV who have not commenced HAART is important in monitoring for HAND and initiating HAART to prevent further cognitive damage (Signh et al., 2010). For populations with known working memory deficits including but not limited to individuals with ADHD, brain injury, cancer, mild cognitive impairment, HIV and learning disabilities, understanding what working memory is, how it impairs cognition, daily functioning and its implications for every day functioning is key to finding interventions that seek to improve working memory (Gathercole & Pickering, 2000).

2.2 Working Memory

Working memory is defined as a system that is dynamic and crucial in areas where attention must constantly move between different sources of information (Baddeley, 2010). The basic definition of working memory is a function that combines the short-term storage with information manipulation or processing capability (Jaušovec & Jaušovec, 2012). The working memory capacity of an individual is reflected in several cognitive activities, which include active maintenance and updating of specific information and goals, as well as in retrieval of important information while ignoring distractions (Miyake et al., 2000).

It is also recognized that working memory has limited capacity, and is capable of only partial retention of past experience, with the degree of retention being dependent on the demands of the task and length of the task being performed (Baddeley, Cocchini, Della, Logie, & Spinnler, 1999). Working memory plays a vital role in the acquisition of original knowledge and problem solving. It is also vital for creating, linking and acting on current goals (Baddeley, et al., 1999). Working memory capacity therefore has important consequences for higher cognitive functioning (Baddeley & Logie, 2007).

Researchers have proposed that working memory capacity is restricted by controlled attention, which is the ability to allocate attention resources despite interference or distraction (Alloway, Gathercole & Pickering, 2006). The theory that is more relevant for working memory training interventions is one that acknowledges contributions from both attention and memory constructs (Unsworth & Engle, 2007).

There are various models of working memory, including the multi component model of Baddeley and Hitch, or the embedded processes model designed by Cowan (Baddeley, 2010). Although the models are different, they all agree on the basic definition of working memory as a function that combines the short-term storage with information manipulation or processing capability (Jaušovec & Jaušovec, 2012). The theoretical framework by Baddeley and Hitch is supported by extensive neuropsychological, neuroanatomical, neuroimaging and factor analytic investigations (Cockcroft, 2011), and will be used as the theoretical background of this study. Research by Baddeley has identified the frontal cortex, parietal cortex, anterior cingulate, and parts of the basal ganglia as involved in working memory. The neural basis of working memory has been derived from lesion experiments in animals and functional imaging on humans (Baddeley, 1996).

The updated Baddeley and Hitch model has four components. The components include the central executive, the phonological loop, visuo-spatial sketchpad and the episodic buffer which was the last one to be added (Baddeley, 2010). The components of Baddeley's (1996, 2010) model include the following four components:

- **The central executive** is responsible for controlling attention and processing of information. It is involved in a number of regulatory functions including retrieval of information from long-term memory. It is responsible for coordinating information between the phonological loop and the visuo-spatial sketchpad.
- **The phonological loop** provides temporary storage for verbal material. Information is repeated over and over again through rehearsing, such as when one tries to remember a person's name and repeats it in their head to commit it to memory. The system is divided into a passive phonological store which temporarily holds speech-like information and a rehearsal system for either vocal or sub-vocal information and responsible for real time maintenance information within the store . The phonological loop prevents the decay of information by continuously articulating, thereby refreshing the information in a rehearsal loop. For example it will maintain a telephone number for as long as one repeats or rehearses the number.
- **The visuo-spatial sketchpad** is specialised in the maintenance and manipulation of visual and spatial information through the manipulation of visual images and the creation of mental maps. The system is divided into two components; the visual cache or passive store responsible for visuo-spatial information and the inner scribe or active rehearsal component which is responsible for maintaining information within the store.
- **The episodic buffer** is a component that is responsible for integrating information across different domains and memory systems into integrated episodes. It can interface with information from perception and long-term memory. The episodic buffer is assumed to have a limited capacity of about four chunks or episodes, and is accessible through conscious awareness.

The temporary storage of information is mediated by the phonological loop and the visuo-spatial sketchpad. The working memory comprises of storage systems in which information flows from the environment, into a series of temporary sensory buffers, which are part of perceptual processes, before being passed on to a limited capacity short-term memory store, which then feeds long-term memory (Baddeley, 2010).

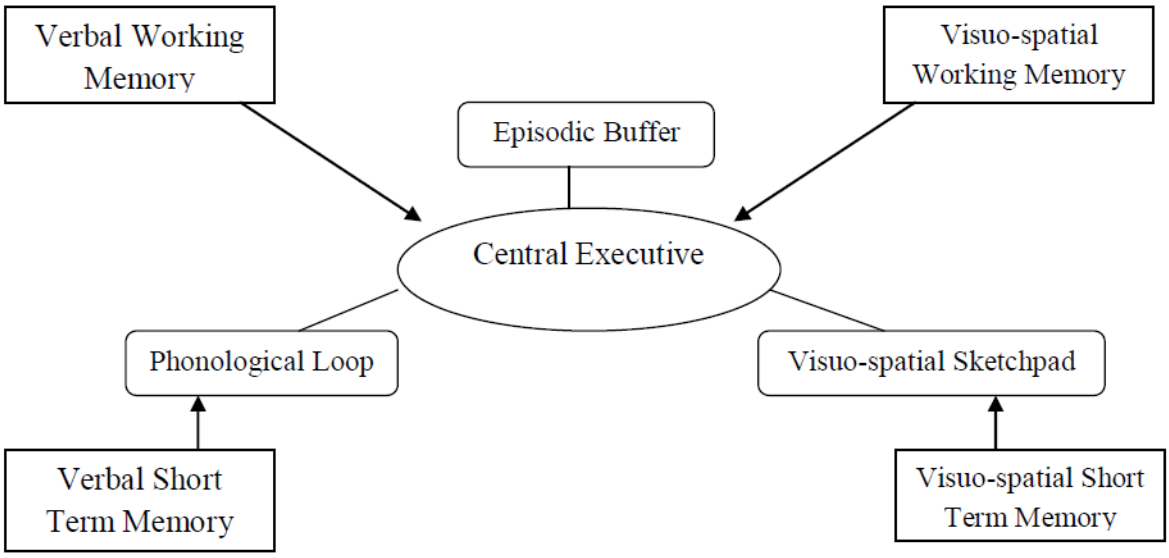
Baddeley's model does not entirely account for the mechanism of working memory and one of the limitations of the model is the concept of decay in short-term memory. If information is not rehearsed, particularly within the articulatory loop, then information may not be recalled. The model suggests that longer words can't be properly rehearsed because of the time restriction, which leads to decay of longer words from the phonological store (Baddeley, 2010). There are experiments that were conducted as reported by Neath & Surprenant (2003) that contradicts Baddeley's model; the experiments demonstrated that longer words did not lead to time related decay suggested that factors other than decay such as the meaning of the word could explain whether a word was encoded and recalled. As such, most models explaining how the brain works use simplified models with components that mostly resemble computer designs but the memory functions are not always as clear cut as modelled and in certain cases cannot explain the experimental data entirely (Neath & Surprenant, 2003). Despite this limitation, Baddeley's model provided an important departure point from previous theories of working memory. It explained that working memory accessed both long and short term memory; used the temporary storage, activated information from long term memory and from the environment (Sternberg, 1996).

The assessment of working memory is still being understood and there are tensions between the working memory model and how it is assessed (Neath & Surprenant, 2003). Baddeley and Hitch's multicomponent model was chosen as the theoretical model for the current study and the Automated Working Memory Assessment (AWMA) is an example of an assessment tool that is based on this model's four components, namely verbal (simple) short-term memory, verbal (complex) working memory, visuo-spatial (simple) short-term memory and visuo-spatial (complex) working memory and it is the only standardized tool for non-expert assessors (Alloway *et al*, 2006; Alloway, Gathercole, Kirkwood, & Elliot, 2008).

Working memory capacity is determined by storage, short-term memory, and processing working memory components which can be measured separately or in combination (Alloway, 2007). Working memory has four constructs that are used to measure the elements of Baddeley's model, as illustrated in Figure 1.

Figure 1

Elements of the working memory and the working memory constructs



The following working memory constructs are measured using the Automated Working Memory Assessment (AWMA):

- Verbal short-term memory, the ability to hold verbal information in mind for a short duration;
- Verbal working memory, the capacity to hold in mind and manipulate verbal information over short duration;
- Visuo-spatial short-term memory, the ability to hold in mind visuo-spatial information for a short duration; and
- Visuo-spatial working, the ability to hold in mind and manipulate visuo-spatial information for a short duration (Alloway, 2007).

The short-term storage components (verbal and visuo-spatial short-term memory) are usually assessed using simple memory span tasks and the processing components (verbal and visuo-spatial working) are typically assessed with complex memory span tasks, which require on-going manipulation and storage of information during presentation, followed by sequential recall (Cockcroft, 2011).

There are numerous questions regarding working memory that remain unresolved and are the subject of continued on-going research. These include the mechanisms for information coding and retrieval, as well as the representation format for different types of information (e.g. verbal or visuospatial) and the control, regulation, function and structure of working memory (Miyake & Shah, 2007). Working memory is regarded as a fundamental function, underlying other executive functions such as reasoning and goal-directed behavior like planning. Researchers have found associations between working memory and general intellectual ability, working memory is known to be a key predictor for academic achievement (Gathercole & Pickering, 2000; Alloway & Gathercole, 2006). Cognitive deficits in the central nervous system of adults with HIV usually include a decrease in sustained attention, a lack of mental flexibility and poor memory (Martin et al., 1999). All these processes are involved in working memory. As a result, the study population targeted HIV positive individuals who would often complain of poor time management, forgetfulness, distractibility, losing track of the topic in a conversation and misplacing things like car keys etc.

In the past it was thought that working memory capacity was fixed, however recent studies have suggested plasticity in the cortex, which may suggest that working memory can be improved (Klingberg, 2010).This could also mean that working memory could be improved through training. The abundance of literature on the function, importance and population groups impacted by deficits in working memory has encouraged the development of interventions in a bid to prove or disprove that working memory can be rehabilitated.

2.3 Internet Based Cognitive Rehabilitation Interventions

Cognitive rehabilitation can be defined as the amelioration of deficits in problem-solving abilities in order to improve functional competence in everyday situations (Wilson 2002). Wilson (2002) argues that the important point about this definition is that, it focuses on functional competence in everyday life showing a move from putting emphasis on drills and exercises and signalling a move to a more individualised approach addressing the everyday manifestations of impairments. Other rehabilitation programmes that can be incorporated

as part of a comprehensive rehabilitation programme include physical exercise, music training, learning a new skill or language, mediation training and therapy (Wass, Scerif, & Johnson 2012) as well as computer based rehabilitation programmes.

Evidence of the brain's ability to adapt has led to a growing industry of commercial brain training interventions. Brain training describes engaging in a specific program or activity that is designed to improve a cognitive skill or cognitive ability through repeated use of the programme over a circumscribed timeframe (Rabipour & Raz, 2012). However, successful cognitive rehabilitation programmes are those that can eventually demonstrate the transference of the training to improvements in daily living (Wilson, 2002) and most of the studies discussed below are not designed to demonstrate transfer of training effects to daily living which limits the usefulness of such interventions and raises questions as to whether investing in such interventions is warranted.

Efficacy of computer based rehabilitation programmes is mainly concerned with proving the effect of the intervention on the area being trained and there is limited focus on the effectiveness and viability of such interventions in the health care facility setting (Wilson, 2002). However the success of an intervention in the clinical setting relies on the uptake and cultural fit in terms of the patient's ability to complete the intervention and the ability of the clinical staff to promote and support the intervention (Khan, Corbett & Ballard, 2014). Identifying these aspects is vitally important in computer applications for rehabilitation. Although several studies have previously focused on the impact of computer based applications on cognitive functions (Kingberg, 2002; Alloway, 2010; Redick, Calvo, Gay, Engle, 2011),only a few of them have analysed the programmes in terms of accessibility and adherence by their end-users (Blanson Henkemans, Rogers & Dumay, 2011) and there is even limited focus on the impact of such programmes in healthcare settings.

Rehabilitation practices have evolved over time and they are now more concerned with the involvement of the patients and their families in setting goals; showing that training interventions translate to improved social functioning; the recognition that effective rehabilitation requires a multi-faceted approach, and also that technology also plays an important role (Wilson & Gracey, 2009). People undergoing rehabilitation rarely have

isolated conditions, they usually have a number of different problems such as emotional, social and behavioural problems (Wilson, 2002). In implementing a rehabilitation programme it is important to work with different stakeholders, assess the need for an intervention, the characteristics of the population, the cultural context, and the administrative and community or administrative characteristics that might affect delivery of the intervention (Castro, Barerrera & Steiker, 2010).

Clinical settings are often faced with lack of resources and this can be exacerbated when the clinic serves a population from low socio-economic background. A study that looked at the rollout of a computer based service in the South African context, highlighted challenges that need to be tackled to achieve successful implementation such as lack of human capital, inequitable access to information, cultural constraints, deficient infrastructure, and budgetary constraints (Maumbe, Oweib, & Alexander, 2008). Computer based interventions bring to the fore the complexity of introducing technology in a community that does not have access to technology and or are computer illiterate (Castro, Barerrera & Steiker, 2010). In addition to concerns of access to resources, computer based interventions can be time-consuming and labour-intensive for both the patient and the healthcare workers. Adequate training and staffing is an important consideration as it will be a critical success factor in successful implementation outside the research environment (Khan *et al*., 2014). Training outside the laboratory setting involves many practical problems that include ensuring compliance over extended periods of training, and as result social support involvement plays a crucial role in playing an oversight role to give feedback as part of the rehabilitation programme.

The effectiveness of the rehabilitation is key to adopting a computer based intervention and there are studies that seek to show the efficacy of the interventions. Jaeggi, Buschkuehl, Jonides & Perrig (2008) proposed that fluid intelligence increased after completing working memory training. The sample consisted of 70 healthy young adults, 35 in intervention and 35 in a no contact control group, who were allocated to four training groups with different training settings. Tests that were used included the dual n-back task Raven's test, and the short version of the Bochumer Matrizen-Test (BOMAT). The researchers noted that working

memory and fluid intelligence shared a “common variance”. There are several criticisms around the methodology of the study, one of which noted that the training tasks employed were similar to the tasks used by the measurement tool and like similar studies, it failed to show the generalisation of the training to everyday living.

Chein & Morrison (2010) conducted a small-scale study involving 42 undergraduates, and 21 of the participants were in a no contact control group. The training protocol had 20 sessions over four weeks. Tests for assessing verbal and spatial short-term memory and verbal and spatial complex memory were used. They demonstrated the effect of an adaptive working memory training programme on capacity, attentional processes, and reading comprehension.

Jaušovec & Jaušovec (2012) reported a large scale study conducted by Owen et al. in 2010 11430 participants completed an internet based training that lasted six weeks. The training focused on different cognitive tasks designed to improve reasoning, memory, planning, visuo-spatial skills and attention. The findings from the study led to the conclusion that, although there were observed improvements in all of the trained cognitive tasks, there was no evidence of the training effects being transferred to tasks that were not trained on, even when those tasks were similar, or to any generalised improvements in the level of cognitive functioning. This study failed to provide evidence of training improving working memory. However, despite these mixed results from various studies, one of the programmes that has promising research support is CogMed™ Working Memory Training.

CogMed™ Working Memory Training is continuing to embark on proving the efficacy of the training intervention on working memory (Kleinberg, 2010; Rabipour & Raz, 2012). Since CogMed™ Working Memory Training was used in this study it is important to review studies that have focused on describing the efficacy of the programme and it’s limitations, particularly since this study will mainly focus on the implementation aspect rather than the efficacy per ser. CogMed™ training involves targeted, repeated performance of working memory tasks, with feedback and rewards based on the accuracy for every trial. The effective training time is 30–40 min per day, five days a week for five weeks which amounts to 15 hours of training. The difficulty of the tasks is adjusted during the training by changing

the amount of information to be remembered so that it is close to the capacity of the participant. It is designed on the premise that working memory training can induce improvements in performance in non-trained tasks that rely on working memory and control of attention. This transfer effect is consistent with training induced plasticity in an intraparietal–prefrontal network that is common for working memory and control of attention. Adaptive training that focuses on control of attention could have similar effects and has shown promising results (Klingberg, 2010). Although it is the ability to adapt and intensity of the training that is believed to underlie the training effect, support from a trained CogMed™ Coach ensures compliance with the CogMed™ protocol, adherence to the training plan (Cogmed, 2012).

Klingberg *et al.* (2005) proposed that the CogMed™ programme had improved the functioning of working memory of children with Attention deficit-hyperactivity disorder (ADHD). The sample consisted of 44 children. Working memory, reason IQ and attention were assessed using the following tests Digit Forward, Span-Board, Raven and Stroop test. The improvements were in respect of the functioning of the visuospatial component of the working memory of subjects using a span-board test and it was concluded that it was possible, that the training effects may transfer to other executive functions such as attention, inhibition and reasoning (Klingberg *et al.*, 2005; Klingberg, 2002).

Another study by Roughan & Hadwin (2011) examined the impact of a CogMed™ programme on measures of working memory, IQ, behavioural inhibition, self-report test and trait anxiety and teacher reported emotional and behavioural difficulties and attentional control and had a three month follow-up. The study comprised of seven participants and eight in a control group. The results showed significantly better measures of IQ, inhibition, test anxiety and teacher-reported behaviour, attention and emotional symptoms, compared with a non-intervention passive control group and group differences were also evident at follow-up. Due to a small sample size they recommended further studies with a larger sample.

Gibson's et al. (2012) study used randomly assigned participants to either a standard or a modified complex span training conditions using CogMed™. The study hypothesized that

CogMed™ does not target secondary memory capacity because the simple span exercises it uses may not allow enough information to be lost from primary memory during training. The author ascertains that potent working memory training interventions would be those that can target both primary and secondary capacities. The main findings showed that secondary memory capacity did not improve, even in the modified training condition and concluded that the potency of span-based working memory interventions cannot be increased simply by converting simple span exercises into complex span exercises (Gibson et al., 2012)

Shipstead, Redick & Engle (2012) argued that controlling for placebo effect was difficult to implement in cognitive training studies since a no-contact control groups does not eliminate the possibility that the trained and control groups were motivated differently to perform at post-test. If the study contained a contact control group, the trained group would receive feedback regarding their performance and be kept motivated throughout the study, whereas non-adaptive control groups that was given a non- adaptive programme which does not challenge them would not receive the motivation required and therefore studies cannot easily be expected to control for placebo effects (Jaeggi *et al*., 2012; Shipstead *et al*., 2012). Jaeggi *et al*. (2012) suggested the use of knowledge-based programmes, which would not have an effect on working memory, to be used for the control group. The control group would be expected to answer questions that increase or decrease in difficulty, in response to participant's performance. They argued that through controlling for motivation as an extraneous variable, the control group would also receive feedback regarding performance improvement and therefore control for the belief that their abilities are improving.

Some of the challenges in designing the studies are to ensure that the measuring tools have appropriate levels of content validity. Kane & Angle (2003) pointed out that some used the Stroop test to measure attention when the evidence does not support the claim that the form of Stroop task used in these studies is related to working memory capacity. Wilson & Gracey (2009) argues that often in rehabilitation interventions cognitive assessment are used as if the aim is to teach participants how to get better scores on the assessment when

in fact what is important is the change in behavioural aspect and she advocates for behavioural assessments to form part of the effectiveness.

Critiques of the studies have raised concerns in the methodology of the studies ranging from not controlling variables adequately, lack of specificity of what proprietary test claims to be testing, small sample size, inadequate specification of "near" and "far" transfer effects or inadequately specified control group (Apter, 2012; Shipstead *et al*., 2012; Hampstead, Gillis, Stringer, 2014). This illustrates that researchers are faced with a myriad of challenges in implementing thesetypes of studies but this is not to say that no effect can be produced (Hulme & Melby-Lervåg, 2012) however ongoing research and reporting on methodological challenges faced in implementation of this rehabilitation programmes can contribute to understanding and enhancing research efforts.

2.3.1 Implementation Process for internet Based Intervention

Compared to pharmaceutical trials, where the intervention often is "prescribed", studies involving computer based interventions are mostly dependent on the participants choosing to stay in the study. This circumstance leads to loss of trial participants in many studies where the intervention is neither mandatory nor perceived as critical to well-being (Chiu & Eysenbach 2010). This study was aimed at understanding factors involved in the implementation process of an internet based intervention. The "Stages of Use" framework developed by Chiu & Eysenbach (2010) and the Andersen's Behavioural Model of Health Service Utilization (BMHSU) (Andersen, 1995), where the two models used to understand the factors that influenced participation and the process of implementing an internet base intervention.

The "Stages of Use" framework, developed by Chiu & Eysenbach (2010), explores usage behaviour in four different stages when family caregivers, who are taking care of patients with dementia, adopt and use internet based services. For this study, the framework is also relevant for participants going through a rehabilitation programme. The Stages of Use framework was developed to highlight the adoption and adherence as a dynamic,

continuous processes occurring in different stages, influenced by different factors to predict participant's progression to the next stage (Chiu & Eysenbach 2010). The four stages are explained below:

- In the **Consideration Stage**, based on information available about the intervention or service, the participant decides whether they will use the service or not. They show acceptance for example by signing a consent form. Participants who felt that the service was easy to use were more likely to consider participating in the study. The stage includes recruitment activities.
- The **Initiation of Use Stage** begins when participants start using the service and make their first login on to the programme. Factors likely to influence if participants will actually use the service or not, despite the initial agreement, are: competing interests, change of interests, lack of time or simply forgetting about it.
- The **Utilization of Service Stage** is reached when participants begin to actively use the service and actively engage in the intervention. In this stage participants choose from one of two paths, attrition or continuation. The decision is influenced by experiences of usefulness of the technology, perceived needs or change in needs. Experiencing positive changes provide motivation for continuing use. If usage is discontinued, the intervention is ended before completion.
- The **Outcome Stage** is reached when participants complete the intervention and complete the post-test assessments and interviews. It was also concluded that motivating users to adhere to an intervention had an indirect impact on the outcomes.

Andersen's BMHSU is the most frequently used theoretical model for predicting and explaining the use of health services, including internet based interventions (Chiu & Eysenbach, 2010). The model consists of three determinant factors: predisposing, enabling, and needs factors. Predisposing factors are factors such as demographics, social structure, and health beliefs. Enabling factors such as access to resources and family support are necessary but not sufficient for participants to use a service. Needs factors must be present for participant. There are two types of needs, the evaluated needs and perceived needs. Evaluated needs are assessed based on the judgment of a healthcare professional and

typically involve objective measures of the users' health status. Perceived needs are subjective opinions of users on the need for service (Andersen, 1995).

The "Stages of Use" framework was used to trace the process from initiation through to completion, and the Andersen's Behavioural Model of Health Service Utilization was used to describe the factors that influence continuation or not of use during the Utilisation of Service Stage. Understanding factors that influence adherence and attrition in internet based interventions can help in improving designs for studies that seek to evaluate the effectiveness of such intervention.

2.4 Rationale of the Study

The increased lifespan of people living with HIV necessitates the investigation of alternative treatment options for dealing with cognitive complaints that are not successfully treated by HAART regimen. The prevalence of the HAND warrants a need for treatment interventions that can contribute to improving people's every day function and in turn improve adherence to medication (Singh *et al.*, 2010). Research has demonstrated that cognitive brain training can be effective in improving cognitive abilities for people across different age groups and a wide range of conditions such as HIV, schizophrenia, stroke survivors with cognitive impairments etc. (Klingberg, 2012; Gathercole *et al.*, 2012). The available literature on Cognitive rehabilitation mainly focuses on the efficacy of computer based programmes but there is very limited focus on the feasibility of such programmes in public health facilities serving low income populations.

Studies, as discussed in the literature review, presented an inconclusive view of the effectiveness of the rehabilitation programmes (Rabipour & Raz, 2012; Wass *et al*., 2012; Apter, 2012; Shipstead *et al*., 2012; Hampstead *et al*., 2014). The implementation of a computer based program for cognitive rehabilitation, especially in a context where there is high demand for treatment but there is lack of services, might be a possible option. However, before incorporating these, normally expensive, systems into the public sector, it is relevant to explore the feasibility and applicability in this particular context. Would it be a

good idea to use computer based programmes for HIV patients in a public hospital that services low income users? With the opportunities that are presented by the use of technology, implementation and adoption of computer based programmes remains a challenge in the country where there is unequal access to resources (Maumbe, Oweib, & Alexander, 2008). In addition to access to resources that are necessary for implementation, the process of implementing such interventions can be plagued by methodological challenges and high attrition rates (Chiu & Eysenbach, 2010; Rabipour & Raz, 2012; Wass *et al*., 2012; Apter, 2012; Shipstead *et al*., 2012).

This study seeks to understand the process of implementing the CogMed™ Working Memory training programme for a group of HIV patients in a South African public outpatient clinic. The research looked at available opportunities and challenges that came with the implementation on an internet based rehabilitation programme focusing on the process from Recruitment/Considerations to the Outcomes Stages.

In order to effectively understand the process of implementing CogMed™ in the public health sector setting, the following question was asked:

2.4.1 Research Questions

What are the challenges and opportunities identified in attempting to implementan internet based program for the rehabilitation of working memory for adults living with HIV at a public healthcare facility in South Africa?

3. Research Method

3.1 Research Aims and Objectives

3.1.1 General Aim

The aim of the study was to describe the challenges and facilitating factors in the process of implementing the CogMed™ Working Memory Training Programme at an HIV clinic for adults living with HIV. The "Stages of Use" framework was followed to explore the implementation process throughout the different stages (Chiu & Eysenbach, 2010).

3.1.2 Research Questions

- What are the factors that influenced participation and attrition in the CogMed™ Working Memory Training Programme from the Recruitment/Consideration through to the Outcomes Stages?
- What are the reported experiences of the participants during the CogMed™ Working Memory Training Programme?
- What are the healthcare worker's reported needs and perception of internet based rehabilitation programmes?
- What is the impact of resource availability on internet based interventions?

3.2 Research Design

Through a qualitative design, the researcher focused on understanding the meaning rather than the measurement of the phenomena (Hussey and Hussey, 1997). The study provided opportunity to understand the process of implementing in internet based intervention in a South African context. The study took an ethnographic approach as the researcher was an active participant in the study (Beker, 2012). The ethnographic approach used in the study takes the view that the purpose of ethnography is interpretive work that is aimed at developing insights into the symbolic meanings of experiences for participants (Beker, 2012). A computer-based intervention was used in order to understand the impact of the

rehabilitation programme in a specific setting, and ethnographic method offered insight into why the effects were produced.

Interviews were conducted at the end of the intervention to assess the experiences of the participants during the intervention and the perception of the healthcare workers regarding internet based cognitive rehabilitation programmes. Participants, including those that had dropped out of the study were invited to interviews to provide feedback on how they have experienced the programme.

3.2.1 Study Site

Two HIV units in public hospitals, serving a large population of HIV patients were selected through convenience sampling. The two hospitals had expressed an interest in introducing cognitive rehabilitation programmes for patients at their clinics. The two hospitals, which will be referred to as hospital A and hospital B, were approached for permission to become the study sites. Both hospitals mainly serve a population with low socio economic backgrounds who cannot afford private health care. Hospital A is located in an affluent suburb whereas hospital B is situated in a township.

3.2.2 Study Participants

Participants included adult HIV patients that participated in the study, healthcare workers from the HIV clinic in hospital A, the researcher and the gatekeepers from hospital A and B. The researcher was involved in enrolling, offering the intervention and providing the coaching to the participants. Those who took part in the intervention; to be referred to as participants; and the healthcare workers that were interviewed will be described in more detail below:

a) Participants

The sample population involved adults who have been diagnosed with HIV and are on ARV treatment at hospital A and are experiencing cognitive complaints. Table 1 shows the demographics' of participants involved in the study at the onset. The study comprised of two females and three males.

Table 1

Participant's (intervention users) demographics

Participant	Age	Sex	HLOE	Employment Status	ARV	Access to computer and internet	Access to Support Coach
A	45	M	Grade 12	employed	1 dose	yes	yes
B	30	M	Grade 12	Employed Shift Worker	1 dose	yes	yes
C	42	M	Diploma	employed	3TC, EFV,TDF	yes	yes
D	29	F	diploma	none	3TC, EFV,TDF	yes	yes
E	36	F	degree	employed	1 dose	yes	no

The study included participants that were receiving ARV treatment and had self-reported cognitive complaints. They were between 20 and 45 years of age. They all had at least a grade 12 education. Their working memory scores ranged from High Average to Extremely Poor, based on the results of the Letter-Number-Sequencing subtest and the AWMA2 pre-test. The participants had daily access to a computer with an internet connection. Four of them had someone who could act as a "support coach" and only one did not have a "support coach". The study excluded participants who had current alcohol or drug abuse, sensory impairments, current neurological opportunistic disease, a history of psychiatric disorders, history of traumatic brain injury and/or HIV related dementia (HAD).

The study used convenience sampling (Kazdin, 2003). Patients from the HIV outpatient clinic at Hospital A were approached while collecting their medication for participation in the study. The researcher had put up posters advertising for research participants who have self-reported mild cognitive complaints and had access to the internet from home or work. During clinic times some of the patients were approached by the researcher or nurses and were asked if they were interested in the study.

b) Informants -Healthcare Workers

The sample population of the healthcare workers comprised of staff members who were employed at the HIV outpatient clinic and were willing to participate. The study used convenience sampling (Kazdin, 2003). Four healthcare workers that were available and willing to participate were interviewed they included a Psychiatrist, nurse, clinic manager, a volunteer counsellor.

3.3 Instruments Used in the Programme

3.3.1 The Intervention: CogMed™ Working Memory Training

CogMed™ Working Memory Training is an internet based working memory rehabilitation program. The programme consists of 25 sessions which are about 30 to 40 minutes long and should be undertaken for five days per week for five weeks. The exercises are on both visuo-spatial and verbal working memory. All tasks involve maintenance of multiple stimuli at the same time, unique sequencing of stimuli order in each trail, and short delays during which the representation of stimuli should be held in working memory.

Participants are allocated exercises that need to be completed in each session. The exercises and levels of difficulty depend on the participant's performance in previous sessions. The training programme has twelve possible exercises that participants can complete during the training.

CogMed™ Administrative Console

The researcher had access to the CogMed™ Administrative Console that provided reports on participant's performance, pause time, completion time, the order of exercises completed, etc. The data was analyzed after sessions, and some of the results were discussed with participants during weekly telephonic coaching sessions.

The CogMed™ Improvement Index

The CogMed™ Improvement Index is a measure of the participant's performance over the course of the program. It is calculated based on the algorithm comprising the average of the best trial on two of the exercises that are consistent throughout the five weeks training. This provides a measure of participant's progress over the course of the program in relation to their initial performance calculated on the third day of participation. Increases in the value of the index represent an improvement in a participant's performance on the program.

The instrument is a subjective indication of improvement. However, given its specific link to the CogMed™ Program and associated tasks, it may provide a useful means of determining program specific improvement.

3.3.2 Pre and Post Assessment Tools

a) Automated Working Memory Assessment 2 (AWMA2)

The Automated Working Memory Assessment 2 (AWMA2) is the first computer based standardised tool to be able to screen for working memory problems. Its main purpose is to identify significant working memory problems in individuals between 5 and 79 years of age. The test has only recently been extended to include adults and therefore there are no studies that have been reported for adults (Pearson, 2012).

The AWMA2 is a computer-based standardised test that assesses verbal short term memory, visuo-spatial short-term memory, verbal working memory and visuo-spatial working memory. The test takes 30 minutes to complete (Pearson, 2012). The administration, scoring and interpretation are fully automated.

A high degree of convergence in performance between the AWMA2 and the WISC-IV Working Memory Index was established in a group of children with average working memory with standard scores > 95 and low working memory with standard scores < 86.

Performance on the digit span test from the Working Memory Index was able to assign correct group membership for 91% of children with low and average working memory (Alloway et al., 2007). For Processing Letter Recall and Mr. X test-retest reliabilities are 0.88 and 00.84 (Alloway et al., 2010).

The AWMA2 test material was designed to be unfamiliar to all participants so that no one can benefit from previously acquired knowledge and the test is reported to be relatively free of bias and socioeconomic influences (Alloway, 2007; Engel, et al. 2008). Therefore the AWMA2 scale can be applied to the South African and international context but has not been normed for the South Africa population. Four of the subscales measuring the working memory construct were be used. See table 2 for the description of the AWMA2 subscales. The working memory components were assessed using the following subscales:

- verbal working memory was assessed by Processing Letter Recall
- visuo-spatial working memory was assessed by the Mr. X task (Alloway,2012).

Table 2

Descriptions of AWMA2 subscales according to Alloway (2011)

Subscale	**Description**
Processing Letter Recall	Participants heard a letter and then had to identify whether a new letter shown on the computer screen matched the letter they heard. They then had to recall the letter/s presented in the correct sequence.
Mr. X	Mr. X is a fictitious cartoon character. The participant is shown a picture of two Mr. X's. The participant identifies whether Mr. X with the blue hat is holding the ball in the same hand as Mr. X with the yellow hat. Then the participant is asked to recall the location of each ball in Mr. X's hand in the right sequence. Mr. X with the blue hat may also be rotated.

b) Letter-Number Sequencing (LNS) subtest from Wechsler Adult Intelligence Scale, 3rd edition (WAIS-III)

The Letter-Number Sequencing subtest from the WAIS-III was used as another measure for assessing working memory. The WAIS III is a pen and paper based test used to test intelligence from the age of 16 until the age of 69.

In the subtest, the participant is presented with a series of numbers and letters in random order. They are then instructed to repeat back the numbers in order first followed by the letters in alphabetical order. For example, if the subject were presented with the string "i-a-5-p-3" the correct response would be "3-5-a-i-p." Lists of two numbers or letters are presented first and list length is increased up to eight numbers or letters. Lists are presented until the individual responds incorrectly to the same list length twice.

The WAIS-III has been normed for the South African population for different age groups, gender, educational level, race and language but norming did not take into consideration the quality of education (Shuttleworth-Edwards, Kemp, Rust, Muirhead, Hartman & Radloff , 2004). However, the Letter-Number Sequencing subtest is relatively free of socio economic influences even in the South African Contect (Engels, et. al., 2008; Shuttleworth-Edwards et. al., 2004). Test –retest reliability of working Memory is .89 and criterion validity was established by correlating WAIS-R and WAIS III.

3.4 Data Collection

In addition to using reports from the CogMed™ Administrative Console for data, the researcher kept a diary with observations and notes when engaging with gate keepers, healthcare workers and the participants throughout the implementation process.

Interviews were completed with participants who took part in the intervention and the healthcare workers as explained below:

a) Interview Questionnaire for Participants

The interviews took a semi structured format focusing on how the participants experienced the content and the context i.e. logistics, coaching, timing, duration, etc. of the CogMed™ intervention programme. The interview schedule had four open ended questions with possible follow up questions. The semi-structured nature of the interview allowed for a deeper understanding of the participants' experiences of the CogMed™ programme as it allowed for the interview to be conducted in an exploratory manner (Liamputtong & Ezzy, 2005).

The open ended questions were designed to encourage the participants' to speak about what was most important to them (see Appendix G). Probing allowed for clarification of responses or further exploration where more information was required. The interview session took about 45 minutes per participant

b) Interview Questionnaire for Healthcare workers

The interviews took a semi-structured format focusing on how the healthcare workers perceive the implementation of the internet based cognitive rehabilitation programme for the patients that receive treatment at the clinic. The interview schedule (see Appendix L) had six questions. The interview session took about 20 minutes per healthcare worker.

3.5 Procedure

The University of the Witwatersrand's Human Research Ethics Committee's (Medical) approval was obtained and a clearance certificate number: M130504 (see Appendix A) was issued before commencement of the study. The researcher requested permission from the hospital (see Appendix B) to approach their out patients at the HIV clinic to participate in the study and explained the potential benefits and risks involved. Permission to involve the participants was obtained from the hospital. Permission to use CogMed™ (see Appendix C)

for research was requested and obtained from the Research Relationship Manager at CogMed™.

Since this study formed part of the academic requirements for a Master's in Clinical Psychology programme the study was limited to twelve months from proposal to report write up stage. Due to high attrition rate and the time limitations on the study, although the protocol approved by ethics was followed for the study, the aim of the study had to be changed to reflect the move from a mixed method design to a qualitative design. After consultation with the supervisor, the study was extended to include perceptions of the healthcare workers. The healthcare workers were interviewed at the last stages of the study. The study followed a process using the four Stages of Use by Chiu & Eysenbach (2010) in order to explore the process of implementing an internet based intervention at a public clinic.

In the Recruitment/Consideration Stage, an advert (see Appendix I) for research participants was posted at the clinic for individuals attending their routine check-up to read. The advert contained the inclusion criteria for participation, room number for immediate consultation with the researcher and contact details for setting up a future appointment. The researcher visited the clinic on Friday mornings and approached patients while they waited for their medicines. Interested participants were briefed on the rationale and requirements of the study. They were made aware of the voluntary nature of participation and their right to withdraw from the study without any fear of being penalised. If participants were interested in being part of the study they were then asked to sign a consent forms (see Appendix D) which spelt out the risks and benefits of involvement in the study. An Information Letter (see Appendix E) explaining the nature of the research and the tasks required was given to the participants and the content of the Information Letter was discussed with each participant.

A biographical questionnaire (see Appendix F) containing information such as age, gender, level of education, home language, drug regimen and access to the internet was completed by the participants. Participants who met the selection criteria were taken through the pre-tests to assess level of working memory. Prior to the start of the study the researcher

received online training on how to administer the CogMed™ programme, coach the participants and to administer the assessments. The researcher also completed the online CogMed™ Working Memory Training programme as part of the accreditation to be a certified CogMed™ Research Coach.

The pre-screening tests were administered by the researcher to establish if the participants were eligible and to establish test baselines. The researcher administered the tests in a quiet room with adequate lighting at a designated area at HIV outpatient clinic at Hospital A. The Letter-Number-sequencing subtest was administered first then followed by the AWMA2 except for the last participant who only completed the LNS subtest.

The participants that were eligible for the study were asked for contact details of a person living with them to act as their "support coach" (see Appendix H). The role of the "support coach" was to monitor and ensure that the participants did their training around the same time every day of the week for five weeks.

An individual introductory meeting to CogMed™ Working Memory training was held with participants to discuss and agree on the training schedule. A demonstration on how to use the programme was provided. The participants were given CD's to set up the CogMed™ Working Memory Training software on their computers. Technical support was provided by the researcher when needed.

In the Initiation and Continuation of Use Stages, daily monitoring of the participants' progress was done by the researcher using the administration module of the CogMed™ Programme. Telephone calls to participants were made if there were any inconsistencies picked up from the results. During the calls suggestions on how to improve performance during sessions were explored with the participants. Weekly coaching telephone calls were made to the participants congratulating them for finishing their week's training, identifying any difficulties and setting targets for the coming week.

In the Outcomes Stage, a week after the completion of the five weeks training, a post follow up assessment session was held with the participants that completed or that dropped out of the study.

The LNS subtest was administered a week after the five weeks training period to the participant who completed the 25 sessions. All participants, including those that dropped out, were invited to an interview session to provide feedback on how they had experienced the intervention. Telephonic interviews were also used to increase chances of participation. Healthcare workers at the HIV outpatient clinic were asked to participate in interviews about their perception of the intervention. If they were interested in participating in interviews they were asked to sign the consent forms (see Appendix K). An information sheet (see Appendix J) explaining the nature of the research and the responsibilities required was given to the healthcare participants and the content of the Information Sheet was discussed with them.

Interviews were held with both participants that completed the intervention and with the healthcare workers about their perception of internet based rehabilitation programmes.

3.5.1 Data Analysis

Data was collected from interacting with gatekeepers, the CogMed™ administrator console, observations, and interviews with participants and healthcare workers during the process of implementing the CogMed™ programme. Analysis of the information from the CogMed™ administrator console was an ongoing process throughout the intervention. The analysed data was used in a feedback loop during the coaching sessions with participants. In addition, the data on the experiences of and observations of engagement in the programme was organised into the Stage of Use and thematic analysis was used to analyse the data. Thematic analysis identifies recurring themes that are important about the data in relation to the research question. The six stages that were followed in the analysis included; becoming familiar with the data collected, generating initial codes, searching for themes,

reviewing themes, finding and naming the themes and then producing the report (Braun & Clarke, 2006).

3.5.2 Ethical Considerations

This research was conducted in accordance with University of the Witwatersrand's Human Research Ethics Committee (Medical) approval and a clearance certificate number: M130504 (see Appendix A) was issued in respect of this project. Healthcare workers' interviews were added to the study to provide more qualitative data due to limited number of participants and high attrition rate for the intervention. Informed consent and information sheet (see appendix K and J) were implemented for the healthcare workers. The study followed guidelines of the Health Professions Council of South Africa's (HPCSA).

Participant's right to both privacy and confidentiality were protected. Confidentiality was assured by ensuring that no person other than the researcher would have direct access to the participant's identifying details, and that all information that could identify the participant would be removed from the research report. Participants were informed that their identifying data would be destroyed once the project had been completed and the research report marked.

However, as the participants needed to be present for the testing, anonymity was not possible. Although data collection was not anonymous, anonymity was guaranteed in the reporting of the results the results. Participants were informed that the research results would be reported in a Masters dissertation, and that group results could also be reported in a journal article. As part of the agreement to source participants from Hospital A and to use CogMed™ Working Memory Training for the study, the findings from the study may be presented to both institutions.

There were no direct monetary benefits to the participants. Participants used their own computer and internet access, and they were made aware of the amount of effort, time, resources and motivation required to take part in this study. The researcher scheduled

appointments to coincide with the days that participants visited the clinic to limit transport and time costs. It should be noted that transport and internet related costs were borne by the participants. Although this study did not provide any reimbursements to the participants, light refreshments were provided during the post and pre-test assessments stage. They were informed that the intervention would not cause any deterioration in their cognitive functioning. The researcher made it clear that the test was meant to the helpful and this test was not an indication of deficiency, rather it was designed to help improve their memory.

There were no physical risks on neuropsychological assessment and rehabilitation. All of the tests that were performed were non-invasive, and only one test was internet-based. Neuropsychological assessments pose the possible risk of psychological discomfort to the participant because they may experience test performance anxiety. The participants did not only feel anxious in their attempt to do 'well' in the assessments and the training, but may have been confronted with a possible deficit in their cognitive performance that they may have not been unaware of or in denial about. This may have caused further anxiety or psychological distress.

If participants experienced distress from participating in the study, they were provided with the contact details for free counselling services and some of the anxieties they experienced during the training was discussed in weekly coaching sessions. Participants were asked to provide feedback on their experiences of the programme in the event that they decided to stop participating in the study. The participants did report distress in participating in the CogMed™ programme but confirmed that it was at a level that they could manage without requiring counselling services and the weekly coaching helped with the motivation.

3.5.3 Self - Reflexivity

In a qualitative study the researcher's own views, beliefs, knowledge and biases may have an influence on quality of the data collected. During interviews the researcher may both assist and hinder the process of co-constructing meanings and it is important for the researcher to be aware of what they bring into the interaction. Self-reflexivity refers to the extent to which the researcher influences the results of the study by the researcher's method of conducting research (Pillow, 2003). It was important for the researcher to be aware of how her race, age, gender, stereotypes about people living with HIV had the potential to affect the research process.

I personally have limited experience working with people living with HIV, and working with them in a research context. I was conscious of the need to be sensitive around how I treated and responded to the participants. I also kept a diary to reflect on my feelings following the interviews with participants and to discuss any issues with the supervisor.

Approaching patients while they waited at the clinic felt like an intrusion on their privacy since HIV is still stigmatised. It was also difficult to approach them and sell the idea of working memory training that required them to spend money in order to complete the training. This was especially difficult with patients who indicated interest in improving their memory, but were unemployed. Some patients thought that there would be remuneration for participating and indicated that they were not available when made aware of the costs associated with the study. The one participant who had access to a computer but did not have access to data for the internet was offered R200 as compensation.

Some of those who enrolled in the study, and did not start the programme made me feel like they only agreed to participate in order to help me out with my research, but when they saw the amount of time required they opted out. Since they felt they had other pressing issues related to living with HIV, somehow they did not see how the programme could benefit them especially since the study was not guaranteed to improve their memory. Most

patients pointed out that failing memory was not really as much a priority for them as it was for the researcher.

During coaching sessions, calling the participants who failed to start the intervention became an uncomfortable process for me. The participants were well aware that it was within their own right to withdraw from the study, but also felt obligated to participate as they had already agreed to start the CogMed™ training programme and they continued to postpone the commencement of their training. Two participants who dropped out after they realised they would not be able to commit to five weeks, were asked to complete at least one session so that they could give feedback on their interaction with the programme, they chose to use their right to withdraw and not participate further. They reported that they felt they had wasted enough of my time and felt like someone else could benefit from the opportunity.

Coaching participants who started the training sessions came with its own challenges. As part of the training, I had gone through the CogMed™ Training Programme and I could relate to how difficult sitting through the training sessions could be and I also experienced how the difficulty of the training affected my motivation to return for further sessions. As such, I was able to identify with the participants' challenges and could relate to their responses to the different tasks that were presented. For one participant the challenges they faced in living with HIV and struggling with unemployment took priority in the coaching sessions as rapport was established with the participants.

As a female researcher, gender dynamics could have also played a role in the attrition rate since all three males that had agreed to participate failed to start the intervention. The HIV stigma continues to play a role in power dynamics and this could have affected the participant's decision to quit the study as participating meant they would be interacting with me on a constant basis. Participants could have possibly felt that their HIV status was at risk of being divulged to other people by participating in the study or that their HIV status was going to be the focus of the study as some point. However, participants' reasons for dropping out were not explored with them.

4. Results

The aim of the study was to describe the challenges and facilitating factors in the process of implementing the CogMed™ Working Memory Training programme at an HIV clinic at a public hospital. The two hospitals that were approached for the study are be referred to as hospital A and hospital B. The themes that arose from the interviews, the observations from interacting with patients, healthcare workers, institutional gate keepers and data from the CogMed™ administration console were organised into the Stages of Use developed by Chiu & Eysenbach (2010) to explore the implementation process throughout the different stages.

4.1 Stage 1: Recruitment/Consideration Stage

4.1.1 Perception of the Need

At the inception of the study, two HIV clinics at two major hospitals that serve a large HIV adult population, had indicated a high prevalence of incidences of HIV comorbid with cognitive symptoms and an interest in finding treatment interventions for the cognitive decline. Both served populations from similar cultural background; however, Hospital A serviced a wider range of population in terms of socio economic status. The main variability was associated with the geographic areas that the two hospitals served.

Hospital A and hospital B were approached with the CogMed™ intervention. Hospital B had completed a diagnostic assessment that evaluated the needs and resources of their patients and had concluded that the CogMed™ offer would not suit them since most of their patients did not have access to computers and the internet at home. At the time, the hospital was already in the process of establishing an onsite rehabilitation centre where their patients would be compensated for transport to travel to hospital; hence, they declined participation at this stage of the study.

In contrast to hospital B, Hospital A gave a go ahead for the intervention. Ethical clearance was obtained from the University's medical research committee and then the proposal was sent to the hospital's research committee for approval. After the approval process then the head of the HIV unit was engaged for finding participants. An arrangement for a computer to be made available for participants to complete their training at the clinic was made. However there were no funds for participant to travel to the clinic for five days a week for five weeks. This limited the study to participants who had access to computers from home or work as only these sub groups were considered for inclusion.

Even though the study was welcomed, as it would help the hospital to understand what might be suitable for their setting, there were still reservations about the suitability of the study. From the beginning of the study, there were concerns of cultural adaptability of the programme considering that most of the patients did not have access to computers but some might have access to smart phones. At the time of the study the programme was only available on computer platform. Healthcare workers raised concerns with finding participants with access to computers and they indicated that they did not believe that an internet-based training programme would work in the clinic context as a majority of the patients they serve do not have access to the internet. When they were asked if they believed that a computer based programme would work in their context this is how they responded:

> "*No, not in the public sector especially not in the clinics. Maybe if it's implemented on cell phones it might work. Since a lot of people have cell phones but don't have access to computers." (Healthcare worker W)*

> *"No, not at the moment. It must take into consideration the community that we work with, we are mainly seeing domestic workers and people who are uneducated. Cell phones can still be a problem because most of the patients we see have very basic phones and no airtime. Manual programmes are still preferred for our community." (Healthcare worker Z)*

Even though the staff at Hospital A indicated that they had reservations about the suitability of the intervention they indicated that beyond the HIV clinic they are doing some limited rehabilitation and they do have a need for cognitive rehabilitation programmes.

> *"There is a need for neuro cognitive rehabilitation for other areas as well for bipolar, schizophrenia. There is a range of deficits that we treat in the clinic." (Healthcare worker W)*

> *"Currently rehabilitation is performed by OT..." (Healthcare worker X)*

All the healthcare workers indicated that they favoured rehabilitation methods which were not computer-based mainly because of challenges to access to computers or clients' low levels of education which made it difficult for them to understand instructions and to feel comfortable with using a computer. The rehabilitation was currently undertaken by Occupational Therapists or psychologists who use paper based activities. They give patients homework that can be checked when they return for their appointments.

> *"We need a programme that will be able to be adapted to our settings. It has to be culturally adaptive. Currently there is unstructured rehabilitation that is happening at the clinic for other patients. We encourage patients to read, play games like sudoku, and exercise to improve memory."(Healthcare worker W)*

> *"If the system meets criteria the clinic can even motivate to buy the programme. " (Healthcare worker W)*

> *"No, not at the moment. It must take into consideration the community that we work with, … Manual programmes are still preferred for our community."(Healthcare worker Z)*

> *"For rehabilitation we can also try to use other senses to stimulate the patients because of their education level." (Healthcare worker Z)*

So, it was observed that although there was a common need for delivering treatment options for cognitive impairment in the public sector, there were contradictory or ambivalent feelings and beliefs concerning whether the delivery mode provided for the purpose of this study would be a suitable option for the particular settings. The healthcare workers concerns were elicited during the interviews that took place after the recruitment stage and perhaps if they were interviewed earlier their input could have helped in improving the recruitment of participants.

Screening for HAND

Complaints about the cognitive deficits are usually not reported by most of patients but sometimes can be noticed by the healthcare workers. The reasons that the patients do not usually complain about their deteriorating memory could be reflecting two issues. Firstly, the dynamics could be as a consequence of patients feeling disempowered and not being aware of what issues to discuss with the healthcare workers. Secondly, the cognitive complaints might be under-reported because patients may want to hide their deficits or even lack the language to explain their experiences. As a result, patents do not complain about their deteriorating memory.

> *"We also serve a disempowered population that doesn't complain...Sometimes they don't want to complain about their memory problems because they want to hide their deficits and other times it's because they are not exposed to what type of information is relevant to discuss with the healthcare workers. There has to be education for the public and not just for diet, sexual behaviour, but for cognitive issues as well, instead of only dealing with more physical presentations during medical check-ups. "(Healthcare worker W)*

> *"The challenges is picking up patients that need rehabilitation. Two out of ten patients do report their memory problems and some of them you can observe that they are having difficulties."(Healthcare worker Z)*

Healthcare workers reported that the clinic has no screening tool for HAND and they don't routinely ask patients about their cognitive problems, which then disempowers the Healthcare professional in identifying the need for intervention.

> *"There are also training challenges in the general, mental health nurses are only trained to pick up HAD. Nurses will also need to know who needs to be referred for cognitive training." (Healthcare worker W)*

> *We would like to get more training, as we have a big role to play and we deal with patients every day. We are at the ground level and we act as the foundation for the clinic." (Healthcare worker Z)*

Besides the lack of normed assessment tools for HAND there was concern about the healthcare workers not having tools for assessing cognitive decline, although the clinic was expecting an HIV health screening tool in the near future that would also include cognitive questions. However, there is an understanding amongst the healthcare workers that the medication will address the cognitive problems and there is a perception that no other assessments/interventions are required for patients on HAART. Some healthcare workers believed that the current medical regime does take care of cognitive deficits, even though literature suggests that the penetration of ARV's into the brain poses a the risk of neuronal damage (Liner, Meeker & Robertson, 2010) and some of the cognitive damage that was experienced before ARV's sometimes does not respond to treatment (Singh *et al.*, 2010). Healthcare workers' understanding of the cognitive deficits in HIV may influence patients' need to seek alternative treatment in addition to ARVs and may even discourage the patients from reporting any cognitive difficulties.

> *"….. they do recover if they take medication correctly. Patients do report memory problems initially but improve when taking medication". (Healthcare worker Y)*

" we have been informed that the new medication does improve memory so treatment targets tissue regeneration and memory rehabilitation programmes might not be priority for HIV patients." (Healthcare worker X)

A lot of cognitive issues are not being identified during the consultations, either due to patients not reporting, or because of Healthcare workers who don't have screening tools or who believe that the medication will be treating the symptoms. Furthermore, the lack of appropriate screening tools that are normed for the South African population increases the difficulties of accurately diagnosing the presence of HAND (Signh *et al*., 2010).

4.1.2 Defining the User

Even though the hospital A serviced high volumes of HIV adult population, and the hospital had perceived a need for providing cognitive rehabilitation for their patients, very few patients were suitable for the study. Details for this will be unpacked in the paragraphs that follow.

Limitations on the Provision of Treatment

a**) Ill Health**

Due to the immuno suppression that is commonly associated with HIV, even for those patients on HAART regimens, the presence of frequent and various illnesses can severely interfere with the person's ability to commit to a time intensive training. Some of the participants were unable to enrol for the study due to ill health during the recruitment stage. During the pre-test assessment one of the participants struggled to follow instruction due to medication he was receiving for an infection. The participant also missed two meetings to install the CogMed™ programme onto his machine, and he was unable to

initiate training due to continued ill-health. Ill patients were advised that they could not participate due to the limited period of the study.

b) HIV Stigma

During the recruitment stage, the researcher had to spent time at the clinic, approaching patients one on one, which forced a disclosure of the seropositive status of the potential participants, which is normally a complex issue for people living with HIV. This raised concerns for the researcher, related to the difficulty of inviting them to take part in the rehabilitation programme and at the same time respecting and honouring their rights to anonymity and privacy. Participants who offered to help find other participants expressed concerns that other people were not as open about disclosing their HIV status. Two of the healthcare workers indicated that part of the inability to attract participants could be a result of issues of confidentiality in relation to HIV.

Finding Potential Participants

Despite the hospital identifying a large number of people presenting with cognitive symptoms the hospital did not have a database with identified potential participants. In the absence of Personal messaging services such as SMS's (short messaging services) WhatsApp or email to invite potential participants, alternative strategies that were more labour intensive had to be employed. Four posters were put up around key areas at the HIV clinic and the researcher visited the clinic once a week for five weeks to do face to face recruitment.

The face-to-face recruitment provided the advantage of the potential participant being able to ask questions and ensuring that the participants were fully informed. At the same time this practice had limited reach and was also open to participants feeling coerced since they may have felt that there was an obligation to help the researcher. HPCSA (2008) research guidelines protects the patients and potential research participants. It states that patients

should not feel coerced to participate in any way. Being a vulnerable population and the association with HIV made the face-to-face approach intrusive for both the patients and the researcher. However, there were few other options. Most of the participants were recruited during the face-to-face recruitment.

Posters gave potential participants the space to consider and think about getting involved without the need to feel pressured or intruded upon but lacked the ability to provide clarity or more information when required. It proved difficult to sell the intervention through posters and only one person responded to the advert. Some referrals were made by healthcare workers who perceived that there was a need for the intervention for the potential participants and the referred participants also had access to resources. Three participants were referred by the healthcare workers. All participants that gave consent to participate had access to internet and they had indicated in their biographical forms that they were comfortable using the internet.

Psychometric assessment of working memory pre-test and post test

a) Selection of the tool

In order to identify those users that could need or potentially benefit from an intervention in working memory, two tests designed to measure this constructs were used for the study. The Automated Working Memory Assessment 2 (AWMA2) and the Letter-Number-Sequencing (LNS) subtest were assessments that were selected to use for pre and post-test to measure the working memory construct. The study included both paper and a computer based assessments for selecting the participants.

Both tests were reported to be relatively free of bias and socioeconomic influences (Engel *et al*., 2008). In addition the LNS was normed for the South African population (Engels *et al.*, 2008; Shuttleworth-Edwards et al., 2004). Therefore both scales can be deemed to be appropriate for the South African context.

b) Using the tests scores to decide inclusion in treatment.

Assessing the potential participant's eligibility for the study using the selected assessment tools presented challenges. There were contradiction in the findings, with the AWMA2 tests suggesting there were deficits and the LNS suggesting there was not. The AWMA2 and LNS subtest gave different results for one of the participant and this raised question of construct validity of the assessment tools. Participant C scored High Average on the LNS subtest as shown in table 3. His AWMA2 scores Visuo Spatial Working Memory and Verbal Working Memory scores were Extremely Poor as shown in table 4. Although Participant D scored Average on the Letter-Number-Sequencing subtest, using the AWMA2 test her Visuo working memory scores was Low while her verbal working memory was Average as shown in table 4. However, participant A scores were consistently low across all the measures.

Table 3

Participant's Pre-test scores for LNS

Participant	Pre-test Raw Score LNS:	Pre-test Scaled Score LNS:	Range
A	5	5	Extremely Low
B	7	7	Low Average
C	12	12	High Average
D	11	10	Average
E	8	7	Low Average

Table 4

Pre-test scores for AWMA2

		Participant A	Participant C	Participant D
Verbal Working Memory	Raw Score	73	65	99
	Percentile Score	4	1	47
	Range	Low	Extremely Poor	Average
Visuo Spatial Working Memory	Raw Score	50	56	72
	Percentile Score	<01	<0.1	3
	Range	Extremely Poor	Extremely Poor	Low

Since both tests were used for acceptance criteria for the intervention, the difference in the assessment scores for LNS subtest and AWMA2 for participant C posed a challenge to the researcher in deciding which of the tests had more validity for assessing working memory since the differences could not easily be accounted for. The lack of South African Norms for the AWMA2 may potentially account for the vast difference between the two test.

c) Mode of Assessment

Whereas using internet based assessment tools provided the advantage of assessing anywhere, anytime with the added benefit of instant results, the disadvantage was lack of continuity when the tool went offline. During the active recruitment stage of the study the AWMA2 scale went offline and two of the participants were not assessed on the AWMA2 scale, reducing the internal reliability of the assessment results to enable the comparisons of all individuals between the different two different assessment tools and amongst the group. This could be an indication that internet based programmes could have availability issues that also may have had implications for the smooth running of the CogMed™ programme for participants without offline capabilities.

There was mixed reports regarding the need for the tool, where healthcare workers that were dealing with the patients on a daily bases felt that current medical regimen was sufficient to address cognitive deficits whereas the clinic gate keepers were open to exploring alternative treatment options for the growing HIV population experiencing cognitive fallout due to HIV. However, computer based rehabilitation programmes remain an option for healthcare facilities that are treating growing numbers of adults with cognitive deficits that includes nut not limited to HIV related cognitive deficits. In the absence of recommended assessment tools and database to identify individuals who need treatment, recruitment of participants relied heavily on face-to-face method and healthcare workers were able to refer patients that had self-reported cognitive symptoms.

4.2 Stage 2: Initiation of Use

During this stage, three out of the five participants that met criteria for inclusion for the study did not initiate the programme and dropped out for various reasons.

Sense of Obligation and Time to Commit

The CogMed™ programme requires that the participants commit to doing exercises five days a week for five weeks. Two of the participants withdrew from the programme before even logging on to the programme. After considering the level of adherence required to complete the training they reported that with their current work commitments they would not be able to adhere to the programme and opted to drop out. The other participant who dropped out at this stage continued to struggle with his health.

With manual rehabilitation programmes that have been run at the clinic, the healthcare workers also expressed that commitment from the patients is a concern. Healthcare workers W and X reported that they used to have a group with set times for meetings but the target group found it difficult to commit to the programme. As a result, they didn't think

this type of intervention would work in the clinic setting and suggested that perhaps it might work for in-patients.

> *"The group comprised of unemployed individuals but they showed a lack of commitment to their health. And maybe because it's a disempowered group. The clinic can offer more to the patients but sometimes the people can't use what is offered some even fail to collect their medication. We are dealing with such issues. "(Healthcare worker W)*

> *We used to have a group and we had set times to meet but the target group was difficult and did not commit. As a result I don't think this type of interventions can work in the clinic setting, maybe for inpatients. "(Healthcare worker X)*

Access to Suitable Training Environment

For participants that began using the programme, they needed an environment that was conducive for cognitive training. An ideal environment for the intervention is a quiet, well-lit room without interruptions. In clinical settings the environment is controlled for other variables that may have an effect on the quality of the intervention, whereas environmental factors such as noise, cell phones ringing and family members interrupting training were often cited as hindrances to a conduce environment in which to do the training.

> *"I always have to wait until the kids are sleeping, otherwise they interrupt me a lot and sometimes it's more difficult to concentrate while they (the children) are watching TV. " (Participant E)*

Environmental factor need to be taken into consideration when considering the implementation of a clinic based programme in a home environment. All participants

undertook their training at home. One participant completed the training in her own bedroom and did not report frequent interruptions during training. However, the other participant experienced many interruptions from her family and at times had to stop to resume at a later time. This is also evident in her long pause times during training.

> *"It's difficult to find suitable time during the day at the office… and my daughter was sick and I had to attend to her and I fell asleep while putting her to bed." (Participant E)*

The sense of obligation, the time and effort that was required to complete the programme influenced the attrition rate at this stage. The dropout rate was high at this stage with two participants citing their work commitment as reasons whereas access to interruption free environment affected the adherence to the training schedule.

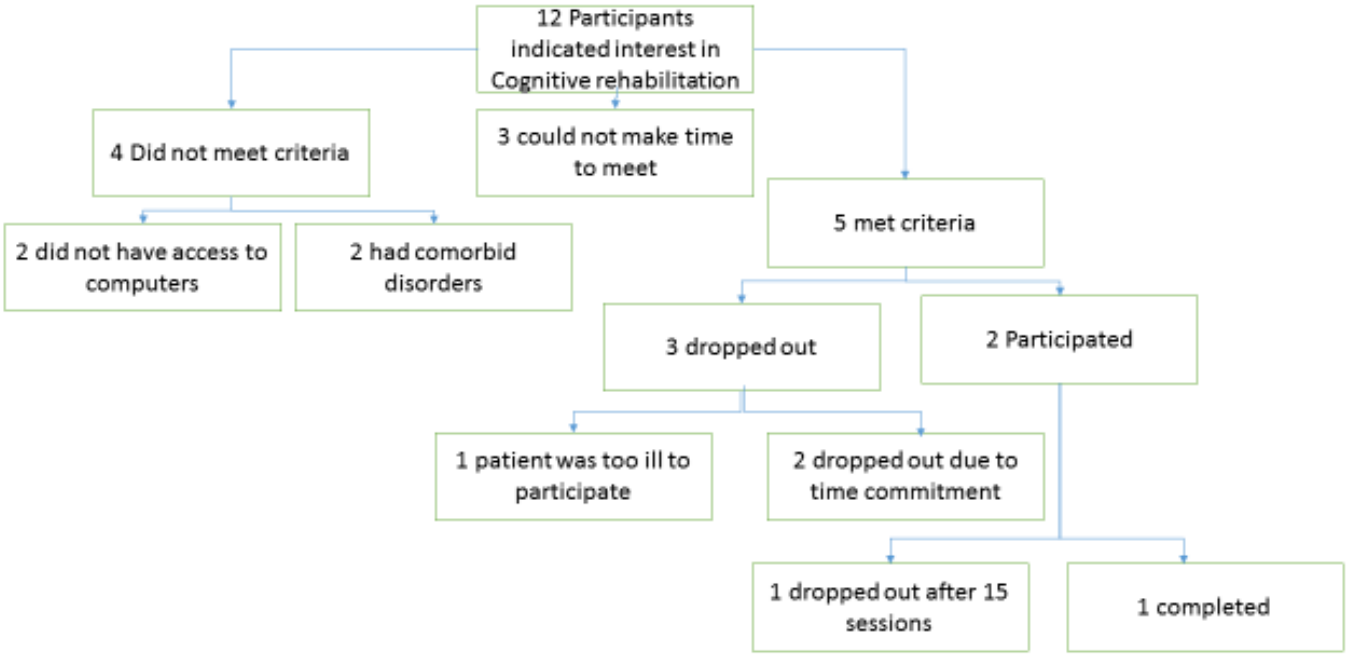
4.3 Stage 3a: Utilisation of Service- Attrition

Attrition

During the recruitment stage, 12 people indicated interest in participating in the study as illustrated in figure 2 below. There were two reasons for disqualifying potential participants, the first was the presence of comorbid disorders, which happened in two cases and the other was a lack of personal computer, which happened in two cases. Three of the participants that indicated interest to participate could not make time to for the selection as they were employed and struggled to get time off work and even struggled to make arrangements outside working hours. In the Consideration Stage, of the five participants that qualified for the study three dropped out before starting the intervention. Two participants reached the Initiation of Use, Utilisation of Service and Outcome Stages. One participant dropped out after 15 sessions due to relocation and only one participant completed the training.

Figure 2

Selection and attrition rate diagram for participants



Ease of Dropout

Part of the informed consent involved making it clear to participants that they had the right to discontinue participation at any time during the study. The easier it is to stop using the program, the higher the non-usage attrition rate will be (Eysenbach, 2005) and when participants were faced with competing external initiatives or activities, they found it easy to choose to dropout. The study did not form part of the treatment plan for participants and there was no obligation to report their progress at the clinic. The participants who dropped

out could have possibly perceived the programme as a non-essential treatment or service and did not have bearing on their physical health. Participation relied on participants' self-efficacy to stay in the programme.

Ease of Use

Training on the CogMed™ programme was provided by the researcher. A demonstration on how to use the CogMed™ programme was provided to participants at the initial meeting. Both Participants D and E found the use of the computer programme relatively easy and did not have any complaints with regards to the user interface. The easy to use interface may have contributed positively to participants continuing to use the intervention.

> *"The exercises were very easy to follow and you'll get the same exercises…" (Participant E)*

> *"I never have problems with the programme, so far I have not experienced any…" (Participant E)*

Perceived Cost versus Perceived Benefit to Participate

For the programme to be effective participants had to complete five training sessions over five weeks. This time had to be incorporated into their daily life schedule as discussed in the Initiation of Use Stage. Even in the Consideration Stage participants often found this as a challenge especially since there was no information related to the effectiveness of the programme during the Recruitment/Consideration Stage. Both participants who dropped out at the Initiation of Use stage were asked to try at least one exercise so that they could give some feedback on how they experienced the programme, but they were unable to make time reporting that they had competing activities.

Participant E reported that the training was too long and sometimes she struggled to make time for the training because of work commitments and family responsibilities whereas participant D found it difficult to incorporate the programme into her daily schedule.

> *"It has been a bit hectic at work and it was difficult to make time… my daughter … was also sick and restless at night. There was just no time…" (Participant E)*

> *"I think they could make it shorter than five weeks…" (Participant E)*

> *"My schedule is quite erratic generally so I didn't have a specific schedule that I kept. I tried to do lessons per day though as was the request but due to the nature of my career … I wasn't able to do so all the time." (Participant D)*

One participant who struggled to commit to the daily training schedule was motivated by the perceived benefits of completing the programme and the promise she had made to the researcher to complete the programme. Even after discussing the possibility of discontinuing the programme she felt that she stood to gain from the training and persevered up until the Outcome stage.

> *"… but I felt like I had committed to the programme and besides I was also motivated because I also wanted to see the end results." (Participant E)*

The ease of dropout influenced the attrition rate with 3 out of five participants qualifying for the study dropping out before even using the programme. The ease of use of the programme improved adherence as participants did not have difficulty engaging with the programme but the perceived time required to participate influenced adherence negatively.

4.4 Stage 3b: Utilisation of Service –Continuation

The themes in this stage are based on the Andersen's Behavioural Model of Health Service Utilization (BMHSU) as it is most frequently used for predicting and explaining the use of health services (Andersen, 1995).

Predisposing Characteristics: to Use the Programme

a) **Gender**

Only females participated in the intervention and all potential male participants dropped out at the Consideration Stage. While internet services studies reported in Bélanger and Carter (2009) concluded that the ability to use computers as well as ethnicity, income, age and education are expected to be a major determinant for people in determining use of computer based services. However while gender is not a determining factor in general. The researcher thought that the male participant dropout rate was due the researcher being female and there could possibly have been issues which may relate to HIV stigma. Another possible reasons that remained unexplored could be that males are generally the breadwinners and may have preferred to be engaged in income generating initiatives as most of the males cited work commitments as a reason for not being able to participate. These thoughts raised the question of how or whether gender could be related to attrition, and further exploration is required.

b) **Social Support**

Social support has been shown to improve adherence to rehabilitation programmes when encouraged as part of the treatment plan (Wilson, 20XX). Participant D reported that the

"support coach" was available to motivate and check if she had completed her daily tasks". It was only one participant who did not have a "support coach" as she was living with her small children and she had to rely on the research coach for motivation.

> *" It helped me a lot to have my buddy … supporting me and motivating me to carry on, on days I did not want to or necessarily felt like it. " (Participant D).*

> "*Coaching helped a lot. I often needed the push to complete the exercises." (Participant E)*

Healthcare workers were aware of the importance of having an integrated approach that includes social support for rehabilitation programmes. One of the healthcare workers pointed out that some of the patients struggle to follow instructions especially when they had just started on new medication. She then indicated that there is a need to have an integrated approach to supporting the patients which will include a social support system that will help with monitoring adherence to training and reporting daily functioning of patients. Healthcare workers emphasized the need to help participants to identify support structures in order to enhance comprehensive care.

> *"… will need to help them identify support structures in order to do comprehensive care. " (Healthcare worker X)*

> *"We will also need to include a support system especially their families." (Healthcare worker W)*

c) **Access to Professional Support and Coaching**

For duration of the study the researcher performed the role of a healthcare worker in providing training and coaching to the participants. In clinical settings the involvement of

the healthcare workers in supporting participants and their caregivers was pointed out to be an important success factor in rehabilitation. Part of being able to provide effective coaching was dependant on being able to monitor the participant's activities so that the performance could be discussed during the coaching sessions.

The success of the programme relies on the weekly coaching which is provided as part of the intervention programme (Kleinberg, 2010). A lot of coaching time went into reassuring the participants that they are doing what they were supposed to be doing and validating their experiences. Both participants who undertook the programme found the coaching to be helpful and they relied on the researcher's coaching to keep motivated.

> *"Coaching helped a lot. I often needed the push to complete the exercises. Some days it was hard and I often didn't feel like doing the exercises." (Participant E)*

At times participants found it difficult to focus on discussing the intervention and wanted to use coaching time for social contact. Coaching Participant D was often a challenge as a lot of time was spent discussing her depression, unemployment status and financial difficulties rather than the programme. It became difficult for the researcher to focus on discussing the details of the programme because when asked about the programme she would be brief and quickly move to talking about her low mood. This could also have been her indication of missing her family and feeling isolated and using this time as an opportunity for catharsis and to find some emotional support, which she acknowledged during some of the coaching sessions.

> *" and I am sorry for taking up your time with all my problems… and I don't like doing this but things haven't been easy…."(Participant D)*

In order to support the participants with the intervention, the healthcare workers reported that allocation of time for the new responsibilities would need to be negotiated with management of the clinic as they are a key success factor in implementing supportive function for the rehabilitation programme.

"… work priorities and time available to commit to the programme in order for the programme to succeed could be a challenge and will need to be taken into consideration when planning." (Healthcare Worker X)

Healthcare workers also reported that their inclusion in terms of them receiving training was important in order to provide a seamless service in supporting the participants. Nurses interact with patients on a daily basis.

"The staff also needs to be trained in order to understand how the programme can serve them better. We should be able to get access to information we need to support the programme and the patients better." (Healthcare worker X)

" We would like to get more training, as we have a big role to play and we deal with patients every day. We are at the ground level and we act as the foundation for the clinic." (Healthcare worker Z)

Although the healthcare workers did not have any experience with CogMed™, they highlighted some features relevant for a computer based rehabilitation intervention. While CogMed™ programme is targeted at working memory only, one of the healthcare workers indicated that if they were to have a system they would need a programme with screening tools and have adaptable programmes that one can choose from

"*…the programme should be able to adapt the training to specific users and be able to select which cognitive areas to focus on*." (Healthcare worker W)

Enabling Characteristics: Access to Resources

Internet based programmes are being implemented in the healthcare sector and access to the internet is a requirement to participate. Out of the five participants that had access to a

computer and the internet, three of them dropped out. As indicated by Andersen's model (1995) enabling factors, such as access to resources, are necessary for participating but they are not sufficient to predict adherence or service use (Andersen, 1995).

All of the participants that qualified to complete the study had access to a laptop and internet data. Only one participant had problems with access to internet data as she was unemployed and this affected her ability to stick to her training schedule. After discussion and agreement with the participant, the researcher organised data for the participant for the duration of the study as data was necessary for participating.

> *"I had limited access to the Internet which was a major challenge". Participant D*

Offline computer capability was favoured for the study since it allowed users access to the programme when there was no connectivity or users had run out of data. Working offline improved user experience since the programme performed at a constant speed without being affected by connectivity interruptions. But limitations on the ability to install applications on one of the participant's laptops meant that the participant could not benefit from the offline capability and experienced speed and interruption issues. The participant experienced challenges with the online version and reported that a couple of times in the middle of the programme she would lose internet connectivity and then struggle to get back on to the programme. The inconsistent access to the internet affected her motivation to access the programme.

> *"Some days I struggled to connect to the internet and it made me feel so, so demotivated." (Participant E)*

Needs Based Characteristics: Perceived Needs Identified by Patient versus Healthcare Worker

The identification of a need by the participant must be present for participant to make use of a service (Andersen, 1995). Most of the participants that were referred by the healthcare

workers ended up withdrawing from the study for various reasons and this could possibly indicate that there may have been a disjuncture in how the patient's perceived their need for rehabilitation as compare to the healthcare workers perceptions, even after it was evaluated that there was a need for the intervention. In the Recruitment/Consideration stage, two participants that were both nominated by clinic staff and whose AWMA2 test results confirmed their evaluated need for the intervention, dropped out before initiating the intervention.

In contrast, participants that had a self-identified need to participate continued to the Outcomes Stage. One participant reported that she had recently become forgetful and was excited at the prospects of an intervention that could help her. She had attributed her forgetfulness to constantly being stressed about her being unemployed and her feeling isolated. The other participant's reason for doing training was that she believed she could benefit from improving her memory as she struggled with her attention.

> *"I am worried about my memory, I keep forgetting where I had placed my keys, cell phone… and could benefit from improved memory…I thought it was related to my stresses in my life…" (Participant D)*

> *"I need something for my memory…..I often forget what I was looking for …but I thought it's because I am a single working mother with small children". (Participant E)*

Participants who were more aware of their perceived need proceeded to the next stages as compared to participants who only had an evaluated need. This is confirmed in the study by Chiu & Eysenbach (2010), as participants who acknowledged their perceived need for the intervention ended up initiating the programme as compared to participants whose perceived needs were identified by the healthcare workers only. Participants' perceived need for participating in the study may have influenced adherence to the intervention.

Using the Anderson's model (1995) the predisposing factors such social support, professional support influenced participant's participation and adherence. More studies are required to determine what influence gender had on participation. The perceived needs by the participants was more likely to improve participation and adherence as compared to the perceived needs by healthcare workers or evaluated needs.

4.5 Stage 4: Outcomes

Observations and Experiences of the Interface

Participants that participated in the intervention had both positive and negative experiences from the programme. The two of them found the programme easy to use, the interface was intuitive and it was easy to follow instructions. The exercises were repeated throughout the training and this facilitating easy interaction with the programme. This is related to the ease of use discussed earlier.

> *"The exercises were very easy to follow and you'll get the same exercises…" (Participant E)*

> *"I have never had issues with the programme, it's fairly easy…no I have not struggles at all most of my issues have nothing to do with the programme. " (Participant E)*

One of the positive aspects of the programme reported by participants was when they were performing well they found themselves using the positive feedback as a confirmation of their preserved cognitive abilities.

> *"I was able to recognise or tap into some of my strengths and it confirmed to me that I was able to see that it is not just remembering dates that I was good at but that I was also good with colours and the order of things as they appeared." Participant D*

"The programme taught me a great deal about my mental health, strengths and capabilities. It managed to put my fears at ease on whether my ARV's were limiting or messing with my memory, ability to remember things." Participant D

During day 11 of the training there are a few new exercises that are introduced in programme. The participants found that the changes made the exercises a bit more "refreshing". They both reported that the change provided new motivation and they hoped that they would be able to tolerate the exercises more as they were previously getting a bit more repetitive.

They could also improve variety so that the tasks looked different every now and then. I liked the change that happened in the middle of the training. It became more interesting. It felt new. "(Participant E)

As the exercises became more familiar, participants also felt that the exercises were monotonous and there was no variety in the way the exercise were presented. One of the participants found that as she was getting used to the programme she reported the exercises tiring and unexciting.

Plus the more I got tired of them there more I got less on the scoreboard which wasn't nice." (Participant D)

The CogMed™ programme has a standardised way of presenting the information in terms of the timing during the exercises (Cogmed, 2012). One participant found the speed of presentation slow. This often happens when people feel that if they are given the information faster, they will be able to retain more and thus avoid the interference created by time.

"I'll get impatient and frustrated with it. Especially the rotating wheel, it will move very slowly and it felt like I will forget everything by the time it stopped….." (Participant E)

Experiencing positive changes provide motivation for continued use (Chiu & Eysenbach, 2010). Even though the programme does not teach cognitive strategies, participants reported having to use strategies in order to improve their performance. It has been hypothesized that the improvement in strategy use may make the task less attention demanding and in turn improve working memory performance (Engle et al., 1999). Both participants reported that they believed that the training improved their memory.

"*I can definitely say that it has helped me with my concentration and to slow down." (Participant E)*

"it felt to her like she was tapping into areas of her brain that she hasn't used in a long time, or didn't even know existed…" (Participant E)

"I know I have been erratic with the exercises, but believe I can see improvements…Yah! Sometimes I do well …" (Participant D)

The study relied on self-reporting from participants for improvements that were noticed in daily living that could have been from the interventions. Participants found that the effects of the training had generalised to other areas in their daily lives and they had attributed the changes to the training.

"But I find I am better at remembering numbers like people's cell phone numbers."(Participant D).

I can tune into my work easily now where in the past I will struggle to sit for more than ten minutes at a time. When I needed to do work, I'll find an excuse to get up

and do something else. I can sit and work until I am done or feel tired. It doesn't feel like a daunting task like it used to. It has helped me to be patient and to finish tasks." (Participant E)

"Yes, it has taught to me to slow down. It has also helped me with slowing down my reading. I find that I now read with more understanding." (Participant E)

"I definitely feel more motivated and focused." (Participant E)

"No, it was definitely from sitting and having to be disciplined in finishing the exercises." (Participant D)

The programme is designed to give participants immediate feedback using sounds and keepingscores. The immediate and constant performance feedback, when negative, was found by the participant to be anxiety provoking and demotivating.

"It was annoying at times cause I wouldn't always get the answers right, particularly the numbers. Numbers have never been my favourites from a young age and to remember a set of eight or more was a nightmare. Plus the more I got tired of them there more I got less on the scoreboard which wasn't nice." (Participant D)

"… plus maybe if it didn't show all the bad scores it could be better but generally it is ok." Participant D

As a way of having to make up strategies to remember things the training effects generalised to everyday living. One for a participant, for example, consequently found herself getting obsessive with patterns. This experience was perceived as negative by the participant.

"I would find myself counting steps as I walk, something that I have never done before. It will feel obsessive how I suddenly looked for patterns…. it got me worried."(Participant E).

The perceived difficulty of the exercises influenced how participants persevered or disengaged with the programme. Participants were likely to avoid activities that they found difficult or leave difficult exercise for last. From observations, when Participant D struggled with the exercises the harder it became for her to resume her next training session. Every time there was a decrease in her CogMed™ index Improvement she took between four to six days before she resumed her training. She took long breaks during the Visuo spatial tasks, such as the Input Module, the Input Module With Lid and the Data Room Tasks. Participant E struggled with the input module exercise and often left it until last or stopped in the middle of the exercise.

Taking breaks between the sessions is recommended as part of the training, but one of the participant's highest active training time was below the average and she completed the exercises without taking a break on two occasions. Her short active training time could indicate her anxiety to complete the exercises as shown in table 5.

Table 5

Training times for participant D

	Min minutes	**Max Minutes**
Training time	27	38
Pause time	0	13
Active training time	33	43

Notes:

Training time = Time it took to complete the training without taking pause time into account

Active training time = training time combined with pause time for a particular session.

Pause time = the total time taken for breaks during a training session

Min minutes = the shortest time it took participant to complete a task

Max minutes = the longest time it took participant to complete a task

i.e. Participant's shortest pause time during her training was 0 minutes and her longest was 13 minutes. Her shortest training session was 33 minutes and her longest was 43 minutes.

The constant increasing in level of difficulty that is required to see improvement meant the programme was perceived as difficult. At times participants reported the training to be hard, time consuming and difficult. The level of difficulty also affected participant E training times.

> *"Frustrating most of the time but I wanted also to know the state of my mental well-being.." (Participant D)*

> *"it was very hard …I think they could make it shorter than five weeks. ..and sometimes it took me more than an hour to complete, and it was too much. It took too long." (Participant E)*

The CogMed™ programme forces the user to take breaks when the participant makes three mistakes in a row. Participant E took longer than average to complete her exercises and the training as shown in table 6 and took longer breaks that participant D. This could indicate that participant D was more anxious, dedicated to completing the exercises and taking as little breaks as required whereas participant E took longer breaks the more she got frustrated with the programme.

Table 6

Training times for participant E

	Min minutes	**Max Minutes**
Training time	37	61
Pause time	1	23
Active training time	34	51

Participant's Performance

For both participants that participated in the programme, their CogMed™ Improvement Index gradually increased during the training sessions as shown in table 7. This demonstrates that there was improvement in the tasks that the participants practiced on.

Table 7

CogMed™ Improvement Indexes for participants

Participant	Start index	Max Improvement	Index Improvement	Number of sessions
D	77	98	21	15
E	73	104	31	25

Participant E is the only participant that completed the 25 days training sessions. Her post test scores for Letter-Number-Sequencing was average (10) which was an improvement from her pre-test score of low average (7) as indicated in table 3. As observed during the assessments, she was more calmer during the post-test as compared to the pre-test and she made more effort in remembering the sequences in LNS subtest. The results could mean that there was a training effect that generalised to the LNS subtest. Since there are no other participant's or controls, extraneous variables cannot be accounted for.

Perception of what Programme Should Offer

Both participants that participated in the intervention and the healthcare workers had pre-conceived ideas of what a rehabilitation programme should look like and what it should offer. The participants responses were based on their interaction with the CogMed™ programme, while the healthcare workers responses were based on their perceptions of what a rehabilitation programme should offer.

Although the healthcare workers did not have any experience with CogMed™, they highlighted some features relevant for a computer based rehabilitation intervention. They highlighted computer access features that will make it easy to manage and support participants.

> *"We will need a full package with options that will allow the patients to do activities from home, even if the activities are manual."* (Healthcare worker W)

"The system must be relevant, in terms of access as well, the staff must be able to monitor progress and the package must be culturally appropriate. " (Healthcare worker W)

One of the key success factors for adoption of an internet based programme is having a culturally appropriate programme for the target population. Cultural adaptations for rehabilitation programmes are effective when applied with certain subcultural groups, but evidence regarding the effectiveness of cultural adaptations has mixed results. (Castro et al 2010). The hospital serves a diverse population and may need to accommodate the different language needs when implementing a rehabilitation programme. The healthcare workers commented that the programme should be diversified in terms of the specific population that they are serving in terms of culture and language.

"It has to include manual programmes and maybe even be translated into other official languages. "(Healthcare worker X).

Initially participants perceived the programme to be "game like" and often struggled with the level of effort required to engage in the programme. Participants had difficulty with motivation in completing the exercises as reflected by the desire to have a programme that provided them with high source of external motivation, such as other computer games that they label as "addictive". Participants often expressed a wish not to be aware of the cognitive effort required to engage in the programme. Since they expressed that the exercises lacked the fun that is commonly associated with playing games, this could potentially indicate that in respect of the training they had a strong external locus of control. People with low motivation and external locus of control tended to have poor adherence and dropped out earlierin such interventions (Blanson Henkemans *et al.,* 2011) and continued motivation was necessary in improving adherence.

“I think if it could be more fun, artistic and engaging like a form of game that doesn't necessarily let your brain know that it is trying to get into your psyche then it would work.” (Participant D)

“I must say, I don’t look forward to doing the exercises, haai! They are not so exciting after a while” (Participant E)

Of the two participants that reached the outcomes stage, only one participant completed the 25 sessions. The user interface was perceived to be easy to use but the difficulty of the tasks was sometimes anxiety provoking which resulted in avoidance of the difficult exercises, affecting adherence negatively. Both healthcare workers and participants had similar perceptions of a programme that would be easy to adhere to, whereas the programme requires people who are motivated and have internal locus of control. Healthcare workers also reported that they would prefer a programme that could be adapted into different languages and provide multiple access points in order to support the dynamic population that they are serving.

5. Discussion

The aim of the study was to describe the challenges and facilitating factors in the process of implementing the CogMed™ Working Memory Training programme at an HIV clinic in the South African context. While the effect of the CogMed™ programme where to be the main deciding factor in selecting the tool for rehabilitation, in order to understand the opportunities and limitations that are presented by implementation of internet based rehabilitation interventions in non-optimal context, it was also important to understand the factors affecting participation and attrition rate through exploring the participant's experiences, the role that resource availability played and the needs and perception of the healthcare workers across the different implementation stages. The discussion describes key results of the study in relation to the literature reviewed and the data generated.

Even though the study was looking at working memory, the study was targeted at participants with HAND, the literature indicates that people with HAND may have impaired working memory, but there is lack of screening tools for HAND which have been recommended to be incorporated as part of the standard of care for people living with HIV/AIDS (Singh, 2009), especially since assessment tools are required to diagnose in the early stages before individuals become aware of impact on every day functioning. Challenges experienced with recruitment of the participants lay in interpreting the working memory score in order to confirm eligibility to participate, amongst other factors. An anomaly in one of the participant's results where he scored High Average in LNS subtest but scored Extremely Low in the AWMA2 posed a threat to internal validity of the assessment tools. The lack of norms for South African adult population for AWMA2 could possibly have contributed to the differences. The lack of normed assessment tools in the South African context is an ongoing concern in building capacity in assessing the diverse population groups found in the country (Foxcroft & Roodt, 2005) and this will also affect the adoption of assessment tools for HAND since South Africa has 11 official languages. The challenges faced by trying to accommodate the diverse and culturally rich community with appropriate

language options for assessment tools (Foxcroft & Roodt, 2005) will also prove challenging for rehabilitation tools.

When healthcare workers do not have access to information and tools to assess HAND they become disempowered to provide an efficient service. Education and training for healthcare workers on HAND, its treatment, monitoring and prevalence will need to be provided in order to support the patients. The perception of some of the healthcare workers that there is not really a need for this kind of intervention for HIV patients as they understood that the pharmacology regiment does address cognitive decline can potentially derail efforts to implement a rehabilitation intervention if patients that may benefit from rehabilitation are not being actively identified. Being able to justify an investment in a rehabilitation tool will be reliant on identification of suitable participants. As part of adopting an internet based programme, healthcare workers will need to be trained in order to be able to dedicate their time and resources in supporting patients. Healthcare workers did indicate that they will need dedicated time out of their current schedules and they will need management support and training so that they are able to support the patients. This was echoed by a study reported by Khan *et al*. (2014) that looked at Healthcare workers who are involved with delivering internet based rehabilitation programmes. The roles and responsibilities will need to be clearly outlined as part of mobilising resources otherwise the programme will not succeed (Khan *et al.,* 2014).

Even though the study was welcomed as a need for rehabilitation for HIV patients was identified at the hospital, there were reservations from healthcare workers about the suitability of the intervention for the targeted population since the majority of the population did not have access to resources. Even though a computer with internet access was made available at the hospital there were no funds for transport to the hospital for the patients considering the duration of the study. Healthcare workers suggested that the programme could work for inpatients but this might be restricted since inpatients are mostly ill and the programme requires healthy participants, unless the programme is used at rehabilitation centres (Sullivan *et al.,* 2015). For future studies, educating patients with cognitive complaints associated with HIV will need to be incorporated into the patient's

treatment plan including patients that have not been initiated on ARV's. This will allow the healthcare workers and the patients to monitor the status and for the patient to be able to report back to the healthcare workers if they notice any deterioration and this will improve the identification of patients that need rehabilitation.

The rehabilitation programme was only made available to participants who had access to a computer and internet. More than 50% of patients who had indicated interested in taking part in the study did not have access to computers. Resources such as computers, internet, access to data and conducive training environment poses a great challenge for successful implementation of a home based internet rehabilitation programme for marginalised communities. Only 40.9% of South African households had at least one member of the family who had access to the internet from home, work, place of study or internet cafés and only 10% of those have direct internet access from home (Statistics South Africa, 2014). Politically, there may be a major concerns regarding the proportion of the target population that will actually be able to use computer based programmes and this raised concerns of whether it is ethical to deploy scarce public sector resources to provide computer based interventions to a limited few (Maumbe *et al.*, 2008). In order to address the dilemma of access to technology, the public health sector may possibly be able to collaborate with other government agencies to use available government resources. Rehabilitation training environments could perhaps be hosted at community centres or schools with internet access provided a suitable training environment can be guaranteed. If efforts to address access to resources are not considered, access to internet based interventions will continue to be limited to a small population with access to resources.

However, there are a number of people who will not be able to use computer based rehabilitation either because of low educational levels, language barriers or lack of computer literacy. In the presence of a multi-faceted approach to rehabilitation, these patients should be able to access other non- computer based services (Wass, Scerif, & Johnson 2012). Besides literacy levels and access to computers, there are cultural differences in communities that influence behaviour to use a computer based intervention that affects the uptake by the community at large such as confidence in the privacy and

security of computer based programme, patient's awareness of the offered services, and confidence to use computers and the Internet (Yildiz, 2007). These issues will need to be addressed during implementation and participants may also need to be provided access to technical computer support and computer training. This study did not assess the number of people who would need computer training before they could participate. This assessment would need to be completed in order to inform if a computer intervention would be suitable for the targeted population.

The Recruitment/Consideration Stage, is likely to be influenced by perceived efforts to use the technology (Chiu & Eysenbach, 2010). Perceived effort to use the technology could have been a factor when participants considered the intervention and gave their consent to participate. All participants indicated in their biographical forms that they had access to the internet and were comfortable with using the internet. However other factors such as motivation and locus of control have been shown to have more influence in participants using such interventions (Blanson Henkemans *et al.,* 2011) and tools to assess those attributes should be considered when assessing suitability for future studies. One of the limitations to the study was the limited assessment tools that were included in the study so as not to burden the participants with long questionnaires or tests, as it has been shown in other studies such as Sullivan *et al.,* (2015) that when participants feel overwhelmed by questionnaires they are more likely to drop out.

All male participants dropped out before initiating the intervention and only female participants completed the intervention which poses a limitation on understanding the effects of gender on participation. This is reported to be a recurring issue in internet based programme research. An attrition study investigating the effects of personal characteristics on the use of an online lifestyle diary conducted by Blanson Henkemans *et al.,* (2011) had no male participants which limited studying the effect of gender and gender related determinants in attrition or efficacy of internet based interventions. A similar study was conducted by a colleague Barberis (2014) using the CogMed™ programme with adults with Schizophrenia in remission who were living in halfway houses. The study included six sample participants that indicated interest and only four qualified for the study. Barberis's (2014)

study was dominated by females. Further studies are required to understand the gender dynamics in internet researches.

In the Initiation of Use stage, in Chiu & Eysenbach's (2010) study, caregivers who had greater technology acceptance were likely to initiate service earlier but in this study the sense of obligation and the reported competing initiatives played a role in participants dropping out or initiating the training. These findings are similar to those of other studies. A study by Sullivan *et al.,* (2015) that looked at cognitive rehabilitation for military personnel had a large number of people declining to participate after considering the amount of time required for the intervention. The high-dosage treatment which is required for the effectiveness of the programme not only affected enrolment, but also appeared to negatively affect adherence to the training. Even though internet based training offers the convenience of completing the training in the comfort of one's home, a suitable training environment is important for improving adherence. Participants who experienced interruptions during training struggled with adhering to the training schedule. Taking part in the intervention also meant the participants had to incorporate the training into their daily routine. In this study participants felt that trying to fit the training into their daily routine was a challenge to adherence whereas in Barberis's (2014) study participants felt that the training provided them with a sense of routine. Interventions with fixed dosage treatment do not fully accommodate an individual patient's needs and such differences have led to a need for a more clinically oriented methods that adapt dosage according to the patient's needs and circumstances (Whyte, Gordon & Gonzalez Rothi, 2009; Wilson, 2009; Hampstead *et al.,* 2014) and adaptable dosages could improve adherence and decrease dropout rates (Sullivan *et al.,* 2015) as participants may feel that they have control over their schedule.

Internet based cognitive training offers several advantages over traditional pencil-and-paper based methods. It eliminates the traveling cost and time for patient as well as allowing healthcare workers access to monitoring patient's progress. However internet based interventions come with challenges of adherence (Eysenbach, 2005). Loss of participants within a computer based intervention carries threats to external and internal validity (Brand

& Jungmann, 2014). Attrition is the net result of those who complete some but not all of the intended intervention exposure, those who complete the intervention but have missing measures, and those who do not engage in the intervention at all (Brand & Jungmann, 2014). The study had a high attrition rate that comprised of 60% participants who did not start the intervention and one participant who stopped using the intervention due to relocation. Eysenbach (2005) while comparing a drug trial and an internet trial, observed that in most drug trials the intervention is "prescribed" for participants, in internet based services usage of the intervention is mostly at the discretion of the participant, allowing the participant to discontinue at any stage of the intervention. He also concluded that for longitudinal studies where the intervention is neither mandatory nor critical to the participants' well-being the attrition rate will be high. The intervention in this study was possibly perceived as not being important to participant's health as the intervention did not form part of the treatment plan at the clinic and participants found it easy to drop out which posed a limitation to the study. In the Utilization of Service Stage, which consists of continuation of use and attrition, there was a high attrition rate since the study conditions made it easy for participants to drop out. Participants who chose to continue using the intervention were driven mainly by a need to see improvements rather technical factors as described in Chiu & Eysenbach (2010) study.

The attrition rate of the participants and the requirement that participants use their own resources when the intervention was perceived as non-essential and there was no guarantee that that they might see improvement from participating, was a limitations to this study. Future projects may need to look at reimbursing participants for the data usage and transport to meetings. In Sullivan *et al.,* (2015) the study recommended that incentives for participating be considered for improving adherence but this may not be suitable in certain contexts as this may be seen as a form of coercion and HSRC research guidelines will need to be followed if funding is made available for such research.

Participants and healthcare workers had perceptions of what the programme should look like and what it should offer. Participants found some of the task very difficult especially the ones that worked on visual and auditory working memory. The CogMed™ programme is designed to adapt to user's performance. This method assumes that as participants

perform at the limit of their ability, then their working memory capacity will increase (Klingberg, 2010). The perceived continued struggle with the task became a demotivating factor for the two participants. The more a participant struggled with the tasks the more likely that adherence was affected and participants took longer to return to the programme, although it was hard to generalise from the two participants Blanson Henkemans et al., (2011) linked these attributes to motivation and locus of control, and observed people with external locus of control, in general, tended to dropout earlier whereas people with an internal locus of control tended to stay in the study longer. Future studies should consider motivation and locus of control factors when selecting participants.

Another perception by healthcare workers of what the programme should offer included a requirement that they would prefer an adaptable programme that would allow for training adaptation to specific users and to be able to select which cognitive areas to focus on whereas CogMed™ is targeted at working memory only (Cogmed, 2012). This suggests that the hospital may find CogMed™ limiting in terms of applicability in the diverse population that they are treating as healthcare workers indicated that beyond the HIV population there were other adult population groups that need cognitive rehabilitation of other kinds. Other rehabilitation options could include compensation strategies training for enabling people to cope in everyday life (Wilson, 2002). A decision to invest in a rehabilitation tool would take into consideration the adaptability of the tool to accommodate the diverse requirements.

One of the Healthcare worker suggested that the design of the programme should not be intense in order to accommodate those participant's that may also have health issues. The perceived difficulty of the programme requires constant monitoring and coaching of participants. This is one aspect of the programme design that is important to manage with participants, and social support and the healthcare worker's involvement appeared important in addressing the anxiety that may be generated by participating in the intervention as this may contribute to the motivation to complete the programme. Coaching is central to the success of the CogMed™ programme and is one of the key success parameters of implementing the programme (Kleinberg, 2010). The intensive and adaptive nature of the programme, increased the perceived difficulty of the tasks that generated a level of anxiety that led to avoidance behaviour which is also reported to be high in

participants who wanted to do well (Beker, 2012) but anxiety could also be related to the concerns of living with HIV (Goldin, 1994). One participant reported that the anxiety extended beyond the training and she found herself obsessed with counting objects. There was a similar theme in a study with schizophrenia participants where the level of anxiety could also have been linked to the paranoia associated with schizophrenia, (Barberis, 2014), but in both studies, the anxiety could also be related to avoidance behaviour of difficulties (Bardeen, Tull, Stevens, & Gratz 2014). Home interventions have been found to be more suitable for children if there is an adult who is doing the monitoring (Kleinberg, 2010) and playing the executive function role for the child, as compared to adults who are expected to do the self-monitoring. Interventions with adults face the challenges that adults are expected to be able to self-manage, but HIV patients have been shown to have difficulties with self-management as they constantly dealing with uncertainties that accompany the diagnosis which may affect adherence (Goldin, 1994). However other studies involving adults without HIV showed a similar trend with participants struggling to adhere to training schedules for other various reasons already discussed (Barberis, 2014; Sullivan *et al.,* 2015; Blanson Henkemans).

For this study, the Outcome of Use Stage focused on factors that affected adherence to the intervention. Some of the factors that were found to improve adherence to the intervention included: continuous personal contact through coaching and programme positive feedback; encouragement from coach and the "support coach". Some of the factors that affected attrition negatively included: having no observable advantages in completing the trial, no financial compensation, the perceived workload and time required to complete and competing initiatives such as work schedules. In order for participants to initiate and adhere to the training it was more important for the patients to have self-identified the need for the intervention as compared to when the needs were only identified by the healthcare workers and this was also a finding in a study conducted Chiu & Eysenbach (2010). Participants who had self-awareness of the cognitive decline were more likely to seek and adhere to treatment (Brand & Jungmann, 2014). This was also the finding in Barberis's (2014) study where participants who were more self-aware of their memory difficulties achieved improved adherence to the training schedule.

Despite HIV being a chronic condition rather than a terminal illness, it is still stigmatised in most communities and for many the psychosocial aspects of living with HIV are a significant determinant of the success of factors such as adherence to treatment regimen and self-management (Goldin, 1994). In this study adherence was mainly affected by competing initiatives. In a similar study adherence was affected by lack of social support for participants with Schizophrenia in remission (Barberis, 2014). One of the limitation to both studies was that the "support coaches" were not involved in providing feedback which would have formed part of the necessary social support for participants. The need to include social support cannot be underestimated in offering a comprehensive rehabilitation programme. Adherence to HAART has been shown to improve when people have social support (Williams, Burgess, Danvers, Malone, Winfield, & Saunders, 2005) and commitment to rehabilitation has shown the same trend as well (Becker *et al.*, 2012).

One of the key components of an effective rehabilitation programme is to demonstrate improvements in everyday living (Wilson, 2002). The individuals that participated in the programme experienced its effects in different ways in their daily lives and they attributed the changes to the CogMed™ programme. Some of the positive aspects experienced by the users was that interface was intuitive and easy. Participants reported training effects that may have generalised to other areas in everyday life such as remembering phone numbers with ease, being more calm and reading with more comprehension. In Barberis's (2014) study, participants also reported positive experiences including improved motivation and concentration in their work and other areas of their lives. The positive experiences that were reported by the participants influenced their motivation to continue with the programme and these subjective experiences had an impact on adherence, even if they did not necessarily translate to improved working memory. In other studies where participants had reported that the training effects had generalised to other areas there was no consensus that the improvements were due to improved working memory because of methodological issues (Klingberg, 2012; Klingberg *et al*., 2005; Brehmer, Westerberg, & Backman, 2012; Rabipour & Raz, 2012; Jaušovec & Jaušovec, 2012; Hampstead *et al*., 2014). In the absence of a "support coach" or a family's observations or perceptions of the

participant's behaviour, it was difficult to evaluate the impact of the training in everyday life and this was a limitation to the study since it relied on self-reported experiences.

While the design of the interface was focused, reported to be easy to use, had limited variability, and was designed to target working memory (Cogmed, 2012) participants reported some negative feedback regarding the interface. One of the negative aspect of the programme was related to the monotonous presentation of the tasks. Participants found the presentation of the tasks lacked the excitement associated with computer games and this affected motivation negatively. The other aspect was related to the negative feedback provided to participants when they were not doing well which increased the levels of anxiety and affected adherence to the training schedule. Programmes that improved compliance need to have usability as a design factor that focuses on avoiding increased levels of anxiety during user feedback, while also motivating the participants even if they are not performing well, and as well, enhance the acceptance of the intervention techniques by their users (Jaspers2009). Future research should use questionnaires for identifying usability of the programme and explore reasons why these deficiencies pose difficulties to participants.

One of the outcome from the study, was that the one participant that managed to complete the intervention, her post-test scores on the LNS subtest showed an increase from Low Average to Average. This indicates that the training effects were translated to the measure being used and or there was improvement in working memory. There was similar finding in Barberis's (2014) study, out of the two participants that completed the intervention there was one that had improved working memory. However, due to sample size and no control participants to control for extraneous variables, the improvements could be due to other factors other than the CogMed™ training i.e. placebo effect, etc. Further research is required to look at the effects of the programme as this was not the focus of this study.

Eysenbach (2005) encourages understanding characteristics of participants that complete the intervention in order to select for or improve factors that promote adherence. The participant that completed the study felt obligated to complete as she had made a promise

to the researcher. The same reasons were put forward in Barberis (2014) study where the two participants that completed the intervention felt it would be an achievement to keep their end of the bargain. This may suggests that participants may have used an external locus of control by relying on the agreement to complete the study (Blanson Henkemans et al., 2011) rather than intrinsic motivation to complete the progamme. However motivation to continue with the programme was a consistent theme throughout the different Stages of Use which was influenced by several factors including coaching, consistent access to the programme, reported positive experiences by participants, and addition of new tasks during training. Once a need by the participant is identified to initiate the intervention motivation is one of the critical success factors required for adherence to the training schedule and to encourage participants to reach the Outcomes Stage.

A strength of the study is that the working memory training was conducted at participant's homes and for out-patient clinics in the public sector this is how the training might actually be implemented if participants are not offered training at the clinics. Therefore, conducting the training at home in this study gave an indication of how the training will work if participants are required to do the training from home. However there are challenges to ensuring adherence to training when participants are completing the intervention at home and, the clinic may want to look at providing the training at the clinic and compensating patients for transport especially for patients who are unemployed and would like to return to work. However Sullivan *et al.'s,* (2015) study was conducted at a military facility and due to the high dosage that required of five days a week at the site, this contributed to attrition. While some authors advocate for individualised dosages for rehabilitation (Whyte *et al*., 2009; Wilson, 2009; Hampstead *et al.,* 2014) to improve adherence, targeted, structured high dosage treatments is recommended for the rehabilitation of working memory on the CogMed™ programme (Kleinberg, 2010). However, there is no consensus on the training dosage in the field of cognitive rehabilitation as compared to other disciplines. Hampstead *et al.* (2014) recommends a dose-response relationship approach to cognitive rehabilitation as computerised programmes can easily be adjusted to accommodate such a requirement.

Tracing the process from the Recruitment/Consideration through to the Outcome Stage provided an opportunity to understand the experiences and perceptions of implementing the study. If resources were to be made available for participants, other factors such as the perceived need for service, motivation, personality traits such as locus of control and social support, are all critical success factors in improving participation.

Limitations and Recommendations

Further research is required to determine whether treatment is effective for adults living with HIV, and whether the improvements that are found are clinically significant and reliable. Future studies should have larger sample size with randomly assigned control group by involving more hospitals to improve the sample size.

There was difficulty faced in collecting data, particularly from participants who dropped out. Future studies should explore integrating the intervention as part of the treatment plan to improve participation in completing follow up interviews.

The role of the 'support coach' is important in providing support and improving adherence for home based computer interventions. Ongoing feedback from 'Support coach' should be incorporated in future research.

Financial reimbursement for internet access could have improved participation and adherence. It is recommended that future research that requires access to the internet should be funded so that participants do not have to incur these expenses.

The AWMA2 tests was developed in foreign contexts, which can affect the psychometric qualities, including the construct validity, reliability, and ecological validity, of the tools when used in the South African context. The psychometric characteristics of the tests should be explored further.

The AWMA2 became unavailable during the recruitment of participants and pre- test for some of the participants, and no AWMA2 post tests were available. Automated tests with offline capabilities are recommended for future studies to allow for continuity in cases of network or tools being taken offline.

The use of the Modified Instrumental Activities of Daily Living scale could have been used for both post and pre-test to provide information about the specific symptoms of cognitive decline, and their impact on activities of daily living. Instead the study had to rely on participants self-report. Due to limited access to the participants, the researcher kept the assessments to a minimum to reduce the level of fatigue when completing assessments. Future studies should include more instruments to assess if the effects are generalised to other areas that affect standard of living.

Internal factors that influence adherence to computer based interventions such as personality traits and locus of control were not controlled for in this study. Future studies should examine these factors.

Ongoing effort to identify patients who need rehabilitation and tracking their memory functions over time could help in identifying participants who may be suitable for such interventions and to improve buy in for future studies.

Both males and females were included in this study, but all males dropped out of the study. Future studies should examine the effects of gender on computer based rehabilitation.

The sample size of the current study was small. This reduces the confidence one can place on the generalisability of the results. It is recommended that future studies increase the size of the samples. This study had very limited number of participants and high attrition rate. Eysenbach (2005) encourages that these types of studies need to be reported as there are challenges in implementing internet based health services in general and attrition data may give clues for real-life adoption problems. It is important to note that despite the above-mentioned limitations, the current research study adds value to current literature and

knowledge base by expanding research on internet based interventions in samples of HIV-positive adults in South Africa and low income context.

6. Conclusion

The prevalence of cognitive decline associated with HIV suggests that there is a large number of people living with HIV that will only enter the public health system after severe cognitive deterioration. Rehabilitation interventions that seek to help patients improve their day to day functioning in order to improve adherence to treatment that require a high compliance rate such as HAART is necessary for patients that have cognitive decline. There are different methods that can be deployed to help the patients with improving their cognitive difficulties including physical exercise.

There are general methodological challenges that are inherent in implementing internet based interventions as evidenced in high attrition rates and understanding factors that affect user's behaviour when engaged in such programmes can contribute to designing studies with improved adherence and lower attrition rates. In order to make inroads in identifying and treating the population that is affected by HAND, quick assessment tools need to be identified that will be suitable for clinic settings and then they also need to be normed for the targeted population to improve internal validity of the tools. Culturally sensitive tools will increase adoption rate of the tests and improve the rate of identifying patients that need treatment instead of relying on self-reporting.

The training needs of the healthcare workers has been identified as crucial for successful implementation of such a programme as they are usually the first and main contact point for the patients. The healthcare workers have identified a need to be trained on the intervention tool in order to support and monitor the participant's progress. They will also need their job descriptions to reflect the role and time required to support the intervention. In addition, the healthcare workers will need training on assessment tools for diagnosing HAND and to be aware of possible treatment interventions that are not catered for by the pharmacological regiments in order to know who to refer for cognitive rehabilitation.

For similar studies where the intervention is not prescribed as part of a patient's treatment plan and it easy for participants to drop out, identification of suitable participants plays a crucial role in improving adherence. The results suggests that an ideal participant is someone who is not ill or is in a functioning healthy state, comfortable with using the internet, has access to resources, has self-identified a need for rehabilitation and has social support. When participants can incorporate the training as part of their daily routine and treatment plan, are self-motivated with internal locus of control, and have the desire to see improvements they are more likely to adhere to the training protocol..

Access to computers and the internet can be a stumbling block in rolling out computer based interventions to communities without access but collaboration with other public agencies can facilitate access to internet resources to prevent further denial of access to services. Programmes with offline capabilities are preferred to offset the unstable internet connectivity in order to improve the user experience. Internet access was a necessity but did not necessarily mean that there would be adherence to intervention. However, further research is required to assess the extent to which the population being served fits the profile of an ideal user, if resources and social support are provided before a financial investment can be made.

The participants reported both positive and negative aspects of participating. The programme interface was intuitive and easy and the training may have generalised to other areas in everyday life such as remembering phone numbers with ease, being more calm and reading with more comprehension. The perceived level of difficulty that is required for the effectiveness of the intervention created anxiety and avoidance behaviour, with one participant reporting being obsessed with counting objects outside the training environment. Coaching was valuable in improving participant's experience and motivation. Social support has been identified as essential in improving adherence and could be used to sustaining motivation, support and to report on participant's behaviour and treatment outcomes for future research.

Internet based interventions can be integrated as part of comprehensive rehabilitation programme for addressing cognitive complaints experienced by individuals on HAART treatment. Some of the outcomes from this research is the recognition that there was an improvement in working memory functioning for the participant that completed the training and there was reported qualitative behavioural improvements for both participants However, further research is needed that explores these improvements in greater detail, using a larger, more diverse sample group.

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Appendix A: Ethics Approval

M130504

R14/49 Ms Lerato Msimanga

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M130504

NAME: (Principal Investigator)	Ms Lerato Msimanga
DEPARTMENT:	Human & Comm Development/Psychology Main Campus/Umthombo Building
PROJECT TITLE:	The Effects and Experience of Working Memory Training Programme on Adults Living with Human Immunodeficiency Virus (HIV)
DATE CONSIDERED:	31/05/2013
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	
APPROVED BY:	Professor PE Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 22/07/2013

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**.

Principal Investigator Signature _____ Date _____

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix B: Permission Letter to Tara Hospital

Psychology
School of Human & Community Development
University of the Witwatersrand
Private Bag 3, Wits, 2050
Tel: 011 717 4503 Fax: 011 717 4559

Tara- The H. Moross Centre Hospital
Chief executive officer: Dr. Florence Otiano
Private Bag X7
Randburg
2125

RE: Permission to Conduct Research Study

Dear Dr. Florence Otiano,

My name is Lerato Msimanga and I am a Master's student at the University of the Witwatersrand. As part of my completion of my Masters degree in Clinical Psychology I am researching "**The Effects and Experience of Working Memory Training Programme on Adults Living with HIV"**. I would like to request permission to conduct a research study at Tara Hospital.

Attention and working memory have been found to be cognitive functions that are affected in individuals living with HIV. The observed working memory impairment may explain decline in every day functioning that is sometimes observed in the individuals living with HIV. Research has shown that cognitive rehabilitation programmes , including computer based programme, can be effective options for improving cognition for people across different age groups and a wide range of conditions e.g. ADHD, schizophrenia, HIV and stroke survivors with cognitive impairments.

Cogmed Working Memory Training is a computer based working memory rehabilitation program. It is administered over 25 sessions. Participants practice both visuo-spatial and verbal working memory exercises for 5 days per week for 5 weeks. Each session lasts about 30- 40 minutes. Daily monitoring of the participant's progress will be done by the researcher using the administration module of the Cogmed Programme and weekly progress reports will be emailed and discussed with participants and their nominated "support coach".

In order to conduct this study, volunteers from the HIV out-patient programme that are willing to participate are required. However, participants must first comply with certain criteria, and all prospective participants will be subjected to a selection process to determine suitability for participation in the study. The assessment tool that will is the Automated Working Memory Assessment (AWMA) to assess working memory. Assessments before and after the Cogmed intervention will be conducted to establish a baseline measure for working memory of each individual participant, and to determine the extent of change brought about by the programme.

Interested participants will be given a briefing, an information letter and a consent form to sign. Due to the nature of the study, I will also recruit a "support coach". This has to be someone living with the participant who can motivate and ensure that the participant does their training around the same time every day of the week. "Support coaches" who agree to participate will also be given cons

The study will follow a single case study design with a maximum of 10 participants that will go through the intervention. It will be conducted over a period of 2 months, expected to start in May and complete in July 2013. All information will be kept confidential in accordance with ethical and professional conduct guidelines and will be obtained by means of biographical questionnaire, interviews and assessments. All data gathered will be analysed to explore the effects of the programme on working memory of the participants. The results will be combined for the project and individual results of this study will remain confidential and anonymous.

Participation in this study is completely voluntary. Volunteers are free to refuse to participate and to withdraw at any time during the study. They will not be penalised or disadvantaged in any way. If the Cogmed intervention is followed as recommended the participant may benefit from improved working memory.

Unfortunately, due to the very limited nature of funding for the project, participants will not be reimbursed for transport, internet and/or other expenses arising in relation to the study. The only direct expenses associated with the study would be transport costs to the hospital for our initial screening and again at the end of the study for the debriefing procedure and minimal internet usage costs.

If approval is granted the following will be requested from the hospital:

- Permission to put up posters to advertise the study and to circulate pamphlets to individuals attending the HIV out-patient programme.
- A suitable space to meet with the patient, the coach and to conduct the pre and post-tests i.e. private office, with a desk, 3 chairs, good lighting.

Commencement of the study will depend on the Medical Ethical Clearance Certificate from the University of the Witwatersrand. This research will contribute to both a body of knowledge on computer-based rehabilitation programmes, as well as to the University of the Witwatersrand and to Clinical Psychologist currently practising in the South African context. On completion of the study you will be informed of the findings through a letter and the research report can be made available to you if so required.

My contact details and those of my supervisor are attached to this form in the event that you may have any further questions or concerns.
Thank you for your consideration,

Sincerely,

Lerato Msimanga
(Clinical Psychology Student)
082 643 1234
Email: otarel.lerato@gmail.com

Aline Ferreira Correia
(Research Supervisor)
011 717 4558
Aline.FerreiraCorreia@wits.ac.za

Appendix C: Permission Letter to Cogmed

Psychology
School of Human & Community Development
University of the Witwatersrand
Private Bag 3, Wits, 2050
Tel: 011 717 4503 Fax: 011 717 4559

Kathryn J. Ralph
Cogmed: Research Relationship Manager
Pearson Clinical Assessment
Upper Saddle River
New Jersey
USA
Kathryn.ralph@pearson.com

RE: Permission to use the Cogmed Working Memory Training to Conduct to a Research Study.

Dear Kathryn J. Ralph

My name is Lerato Msimanga and I am a Master's student at the University of the Witwatersrand. As part of my completion of my Master's degree in Clinical Psychology I am researching "**The Effects and Experience of Working Memory Training Programme on Adults Living with HIV"**. I would like to request permission to use the Cogmed Working Memory Training to conduct a research study at Tara Hospital and or Chris Hani Baragwanath Hosptial.

My research proposal is based on the premise that attention and working memory have been found to be cognitive functions that deteriorate in individuals living with HIV. This study seeks to demonstrate that Cogmed Working Memory Training can be effectively used as a rehabilitation programme for people living with HIV, taking into consideration the South African context.

The research proposal will go through the formal process of the University of the Witwatersrand. The commencement of the study will depend on the approval of the Medical ethical clearance committee from the university and permission from Tara Hospital and Chris Hani Baragwanath Hospital to engage patients in their HIV outpatient. Please see attached research proposal for more information.

The study will follow a single case study design with a maximum of 10 participants that will go through the intervention. The Cogmed training protocol will be followed as recommended by Cogmed**.** This research will be conducted in accordance with the approved research protocol and guidelines of the Health Professions Council of South Africa's (HPCSA) Ethical Guidelines in Health Research.

Prospective participants will be subjected to a selection process to determine suitability for participation in the study. The assessment tool that will be used is the Automated Working Memory Assessment (AWMA) to assess working memory. An assessment before and after the Cogmed intervention will be conducted to establish a baseline for working memory of each individual participant, and to determine the extent of change brought about by the intervention. Interviews will be conducted at the end of the intervention to assess the experience of participating in the programme.

Interested participants will be given a briefing, an information letter and a consent form to sign. Due to the nature of the study, I will also recruit "support coaches". This has to be someone living with the participant who can motivate and ensure that the participant does their training around the same time every day of the week. "Support coaches" who agree to participate will also be given consent forms to sign.

The intervention will be conducted over a period of 3 months, expected to start in May and complete in July 2013. The baseline assessments will be completed in May, and the posts tests are expected to be completed end of June 2013. Due to the limited time for the research study, follow up sessions will not be possible.

If approval is granted to use Cogmed Working Memory Training, requirements as stated in the research license agreement will be observed. The research report with summary data will be submitted to Cogmed before publication.

My contact details and those of my supervisor are attached to this form in the event that you may have any further questions or concerns.

Thank you for your consideration.
Sincerely,

Lerato Msimanga	Aline Ferreira Correia
(Clinical Psychology Student)	(Research Supervisor)
082 643 1234	011 717 4558
otarel.lerato@gmail.com:	Aline.FerreiraCorreia@wits.ac.za

CC. South African Cogmed Representative: Mr. Gerard Finnemore

Appendix D: Participant Information Sheet

Psychology
School of Human & Community Development
University of the Witwatersrand
Private Bag 3, Wits, 2050
Tel: 011 717 4503 Fax: 011 717 4559

Dear Potential Participant

RE: Information Sheet for Participation in the Research Study

My name is Lerato Msimanga and I am a Master's student at the University of the Witwatersrand. As part of my completion of my Masters degree in Clinical Psychology I am researching "**The Effects and Experience of Working Memory Training Programme"**. I would like to invite you to take part this research study.

Research on the effects and the experience that the CogMed™ Working Memory Training Program will have on working memory in individuals with cognitive impairments associated with HIV. In this study we want to learn about the CogMed™ Working Memory Training program, whether or not it will improve working memory in individuals with HIV related cognitive impairments and understand how the participants experienced the programme. This research will not form part of your routine treatment and will require your participation as a separate addition to the other activities you may be engaged in at Tara Hospital.

What is involved in this study?

Your participation in this study will entail the following:

1. Participation in a briefing procedure and screening: This is the procedure that you are currently participating in. During this procedure you will be fully informed of the details of the study and your role in relation to these details. You will also be required to fill out a short demographic questionnaire and complete a tests aimed at assessing your current level of working memory. The test and the demographic questionnaire, will determine whether or not you are a suitable candidate for participation in the study. The entire procedure will take a maximum of 1 hours.

2. Participation in the program: This program will take place over weekdays (Monday to Friday) over a period of five weeks. It will require a maximum of 50 minutes from you each day during which you will be expected to complete a number of activities. You need access to a computer with internet access to access the programme. You will need to return to the after completion of the programme for an interview, debriefing and a final assessment.

3. Finding a "support coach": To participate in this research you need to select a member of your family or somebody who lives with you, to be your "support coach". This person will take on a role aimed at encouraging your continued completion of the working memory

program. I will need to contact the 'support coach" to brief them and provide a short training session on what their role in the project will be.

4. Weekly progress reports will be emailed to you and your "support coach". You will also receive routine telephone calls to discuss progress and provide motivation.

5. Participation in the final test and Debriefing: After you have completed the program you will be required to come back to the hospital for an interview and a final test. This meeting will take up a maximum of 1 hour and will be the last meeting you attend in relation to the study.

What risks are involved in participation?

There will be no direct benefits for participation in the study. There **MAY** result in a positive interaction with regard to the intervention we will be using, however this cannot be guaranteed.

Unfortunately, due to the very limited nature of funding for the project, participants will not be reimbursed for expenses arising in relation to the study. The only direct expenses associated with the study would be minimal internet access and transport costs to the hospital for our debriefing meeting.

Other important information.

Participation is completely voluntary. Withdrawal from participating will involve no penalty or loss of benefits to which you are otherwise entitled. Furthermore, you may discontinue participation at any time without penalty or loss of benefits to which you are entitled.

Every effort will be made to keep personal information confidential. Personal information may be disclosed if required by law.

If results are published it is possible that the group to which you belong will be identified.

If during the study you experience anything that upsets you or makes you feel as though you need to talk to someone you can contact the following place for free counselling services:

The Emthonjeni Community Clinic
Emthonjeni Centre
The University of the Witwatersrand, Johannesburg
011 717 4513

For further information or reporting of study related adverse events.

Lerato Msimanga
(Clinical Psychology Student)
082 643 1234
Email: otarel.lerato@gmail.com

Aline Ferreira Correia
(Research Supervisor)
011 717 4558
Aline.FerreiraCorreia@wits.ac.za

Appendix E: Participant Consent Form

Declaration of Informed Consent For Participation

I,_____(FULL NAME), agree that I have read and understood the letter of informed consent associated with this research project. I fully understand the details of my participation and what this will mean regarding the possible risks of my participation. I hereby consent, in writing, to my participation in this project and am aware that I may at any stage withdraw without any negative implications being associated with my withdrawal.

These include:

- My not being reimbursed for expenses such as transport and internet access.
- That I might become frustrated or upset during the intervention because of the difficulty of the tasks.
- That my participation is voluntary and I may withdraw from the research at any time without any negative consequences affecting me. If I decide to withdraw I will be willing to grant an interview to the researcher give feedback on my experiences of the intervention.
- That my data will be kept confidential and that all information identifying me as a member of the study will be destroyed at its conclusion
- That I have the right not to answer any questions that make me feel uncomfortable.

I hereby consent, in writing, to my participation in this project and am aware that I may at any stage withdraw without any negative implications being associated with my withdrawal.

Signed,

_____ _____

(Print Name) **Signature**
Research Participant **Research Participant**

_____

Lerato Msimanga
Researcher

Appendix F: Biographical Questionnaire

Biographical Questionnaire

Please complete the following questionnaire. All information given will be treated as **strictly confidential.**

Name: _____
Cellphone: _____
Email address:_____
Name of person nominated as coach: _____
Cellphone of person nominated as coach: _____
Email address of nominated coach: _____
Please answer the questions below by placing an X in the appropriate box.

1. Gender: M ☐ F ☐

2. Date of birth? _____(dd/mm/yyyy)

3. Home Language
   - ☐ English
   - ☐ Afrikaans
   - ☐ Zulu
   - ☐ Sesotho
   - ☐ Tswana

Other Please Specify_____

4. Proficiency in English
   - ☐ Very Good
   - ☐ Good
   - ☐ Average
   - ☐ Bad
   - ☐ Very Bad

5. Academic Qualifications:
   - ☐ Grade 10
   - ☐ Grade 11
   - ☐ Grade 12/ Matric
   - ☐ Diploma
   - ☐ Degree

6. Other Please Specify_____

7. How would you describe your current employment status?

- ☐ Employed full time
- ☐ Employed part time
- ☐ Unemployed / Looking for work
- ☐ Student
- ☐ Homemaker
- ☐ Retired

8. Have you ever suffered a traumatic brain injury?

Yes ☐ No ☐

If you answered "Yes", please explain the injury

_____

Please indicate severity of the brain injury:

Low ☐ Medium ☐ High ☐

9. Have you ever been diagnosed as having a learning disability? (E.g. Dyslexia, Dyscalculia)

Yes ☐ No ☐

If you answered "Yes", please explain the nature of the learning disability

_____

10. Have you been diagnosed with a psychiatric disorder?

Yes ☐ No ☐

If you answered "Yes", please provide detail/name of the disorder

_____

11. Do you take alcoholic beverages?

Yes ☐ No ☐

If you answered "Yes", please provide detail below:
Please list alcohol type (beer, whisky, cider etc): _____
Please state number of glass/es you drink:_____ per day/week

12. Do you have a history of drug abuse?

Yes ☐ No ☐

If you answered "Yes", please provide date of last use and the drug name:

_____

13. Are you current on ARV's:

Yes ☐ No ☐

If you answered "Yes", please specify drug regimen _____

14. Generally speaking, how comfortable do you feel using a computer?

☐ Very comfortable
☐ Somewhat comfortable
☐ Not very comfortable
☐ Not at all comfortable

15. How often do you use the Internet?

☐ Once or more a day
☐ A few times a week
☐ A few times a month
☐ Hardly ever
☐ Never

16. Do you have daily access to a computer?

Yes ☐ No ☐

17. Do you have daily internet access?

Yes ☐ No ☐

18. What do you expect to gain from participating in the Cogmed Working Memory Training Programme?

_____
_____
_____
_____
_____

Appendix G: Participants Interview Schedule

The following interview questions were asked and participants were probed to provide answers to both content and context of the CogMed™ intervention:

1. Tell me about your experience with the CogMed™ programme
2. What where the positive aspects of the CogMed™ programme?
3. What where the negative aspects of the CogMed™ programme?
4. What recommendations can you suggest to improve the experience?

Possible follow-up questions included probing to get more information on the ability to stick to the schedule; interaction with a "support coach"; interaction with weekly coaching and monitoring received from researcher; motivation to complete the programme, notice of changes to everyday life; ability to follow instructions from the intervention; ability to perform the tasks; motivation to complete tasks; ability to focus on tasks; the format of the intervention; access to the internet and access to the intervention .

Appendix H: "Support Coach" information sheet and Consent Form

Psychology
School of Human & Community Development
University of the Witwatersrand
Private Bag 3, Wits, 2050
Tel: 011 717 4503 Fax: 011 717 4559

Dear Sir or Madam
Research Supervisor

RE: Consent Form for Participation as a "support coach" in the Research Study

A warm welcome to you,

My name is Lerato Msimanga and I am a Master's student at the University of the Witwatersrand. As part of my completion of my Master's degree in Clinical Psychology I am researching "**The Effects and Experience of Working Memory Training Programme""**. I would like to invite you to participate as a "support coach" for the individual who requested your participation.

What is involved in this study?

Your participation in this study will entail the following:

1. Participation in a telephonic briefing procedure. You will be fully informed of the details of the study and your role in relation to these details. It is expected that the conversation will take no more than 30 min.

2. Supervision of your research participant's engagement with the program used to train working memory. This program will take place over weekdays (Monday to Friday) over a period of five weeks. It will require a maximum of 50 minutes from your participant each day for which you will be expected to ensure that the participant continually and consistently completes the programme at home around the same time every day during the week. Please note that it is required that you live with the participant to fully ensure adequate support.

3. During the research I'll have to your contact details. I will be emailing you weekly progress report of the participant.

What risks are involved in participation?

There will be no direct benefits for participation as a "support coach" in the study.

Other important information.

Participation is completely voluntary. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. However, it may mean that your participant's data be excluded from the study. Furthermore, you may discontinue participation at any time without penalty or loss of benefits to which you are entitled.

Every effort will be made to keep personal information confidential. Absolute confidentiality cannot be guaranteed. Personal information may be disclosed if required by law.

Certain organizations may inspect and/or copy your research records for quality assurance and data analysis. These include groups such as the Research Ethics Committee and the Medicines Control Council.

For further information or reporting of study related adverse events.

Lerato Msimanga
(Clinical Psychology Student)
082 643 1234
Email: otarel.lerato@gmail.com

Aline Ferreira Correia
(Research Supervisor)
011 717 4558
Aline.FerreiraCorreia@wits.ac.za

Declaration of Informed Consent For Participation as a "Support Coach"

I,_____(FULL NAME), agree that I have read and understood the letter of informed consent associated with this research project. I fully understand the details of my participation and what this will mean regarding the possible risks of my participation. I hereby consent, in writing, to my participation in this project and am aware that I may at any stage withdraw without any negative implications being associated with my withdrawal.

Signed,

_____

Support Coach

_____

Lerato Msimanga
Researcher

Appendix I: Advert for Recruiting Participants

Be part of a memory rehabilitation program?

If you are experiencing some of the following symptoms?	**And you meet all the conditions below:**
• Frequently late to work • Often underestimates time required for a tasks • Often loses temper with children and spouse • Forgetfulness • Distractibility • Losing track of the topic in a conversation • Misplacing things like glasses, mobile phone, keys etc	• Currently on ARV treatment at Tara • Between 20 and 45 years of age • You have completed Matric/Grade 12 • You have access to a computer with internet access • You are motivated and can dedicate about 50 minutes of your time to complete computer based exercises for 5 days a week for 5 weeks. 25 sessions will need to be completed from the comfort of your home. A quiet distraction free environment is also highly recommended. • You are available for 2 meetings. First meeting to brief you of the study and complete a computer based screening assessment. Second meeting to do an interview and a final assessment. • Live with someone who can act as you "support coach" to keep you motivated.

If you have answered 'yes' to some of the symptoms and meet all the conditions then you may be eligible to participate in memory rehabilitation research study. The purpose of this research study is to test a memory rehabilitation programme. Benefits may include improved memory but not guaranteed. There is no direct benefit for participating in the study, transport and internet costs will be borne by the participant.

The study is being conducted by Wits University. All information will be kept confidential.
If you are interested, Please sms your name and word 'Memory' to 082 123 1234 and you will be contacted for more information.

Appendix J: Participant Information Sheet for Healthcare Workers

Psychology
School of Human & Community Development
University of the Witwatersrand
Private Bag 3, Wits, 2050
Tel: 011 717 4503 Fax: 011 717 4559

Dear Participant

RE: Information Sheet for Participation in the Research Study

My name is Lerato Msimanga and I am a Master's student at the University of the Witwatersrand. As part of my completion of my Master's degree in Clinical Psychology I am researching "**The Effects and Experience of Working Memory Training Programme"**. I would like to invite you to take part this research study.

Research on the effects and the experience that the CogMed™ Working Memory Training Program will have on working memory in individuals with cognitive impairments associated with HIV. In this study we want to learn about the CogMed™ Working Memory Training programme, whether or not it will improve working memory in individuals with HIV related cognitive impairments; understand how the participants experienced the programme and the implementation process.

Participation in this study is completely voluntary and you may withdraw at any time and there will be no negative consequences. Your participation would consist of a one-on- one interview with me where you will be asked several questions based on the implementation aspect of the rehabilitation programme. You may decide not to answer some of the questions but it would be appreciated for you to answer all the questions to add to the research. Every effort will be made to keep personal information confidential. The interview material and any other identifying documents will be destroyed at the end of the research study. I may use direct quotes from your interview as part of my report. On completion of the study you will be informed of the findings through an email. You can have access to a summarised version of the results of the research by contacting the researcher.

Your participation in this study will be highly appreciated.

Lerato Msimanga
(Clinical Psychology Student)
082 643 1234
Email: otarel.lerato@gmail.com

Aline Ferreira Correia
(Research Supervisor)
011 717 4558
Aline.FerreiraCorreia@wits.ac.za

Appendix K: Consent Form for Healthcare Workers

Declaration of Informed Consent for Interview

I,_____(FULL NAME), agree that I have read and understood the letter of informed consent associated with this research project. I fully understand the details of my participation. I hereby consent, in writing, to my participation in this project and am aware that I may at any stage withdraw without any negative implications being associated with my withdrawal.

These include:

- I may refrain from answering any questions.
- There are no risks or benefits associated with this study.
- The information provided will be kept and dealt with in a confidential manner.
- No information that can identify me or my clients will be included in the research report
- That my data will be kept confidential and that all information identifying me as a member of the study will be destroyed at its conclusion.
- That the researcher might use direct quotes from my interviews in the research report.
- That I have the right not to answer any questions that make me feel uncomfortable.
- The research may also be presented at a local/international conference and published in a journal and/or book chapter.

Signed,

_____	_____
(Print Name)	**Signature**
Research Participant	**Research Participant**

_____

Lerato Msimanga
Researcher

Appendix L: The interview Schedule for Healthcare workers.

The following interview questions were asked to assess the key-respondent's perceptions of implementing a computer based rehabilitation programme in the HIV outpatient clinic:

1. What is your role and responsibilities in this clinic?
2. What is your opinion about cognitive rehabilitation? What do you think it is, what do you think about the potential benefits and risks, who do you think it is aimed for?
3. Do you think a programme with this characteristics (CogMed™, 5 weeks, offsite and online) will work in this context? And why?
4. How do you think the rehabilitation programs must be, to be able to work in the context of this clinic and the patients you see?
5. What do you think is the role of the patients and your role in offering and committing to rehabilitation programmes?