Exploring the acceptability of a visual intervention to improve paediatric adherence to antiretroviral therapy in South Africa

by
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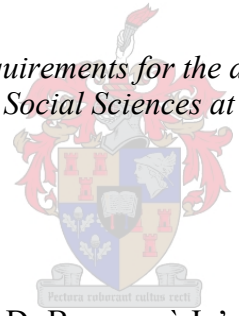

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DECLARATION

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ABSTRACT

Near-perfect levels of adherence are required by children five years and younger on ART in order to achieve optimal treatment outcomes. Caregivers of children on ART are fundamental in ensuring their child achieves high levels of adherence, as they are responsible for administering medication to the child. Caregivers require the necessary adherence-related information, motivation, and behavioural skills to ensure their child remains adherent to ART. However, these components are often affected by caregiver, child, and medication regimen characteristics, as well as contextual and healthcare related factors. Whilst there are a number of children who are non-adherent to ART, effective interventions targeted at this age group are not available. Visual interventions, such as the Petrie device demonstration developed in accordance with the IMB-model, has shown potential in enhancing medication adherence, and may be appropriate for use with caregivers of children on ART.

In this study, I explored the acceptability of the Petrie device demonstration with caregivers of young children on ART. Participants included in the study were eleven caregivers to children five years and younger on ART, attending outpatient clinics within the City of Cape Town Municipality, South Africa. Data describing participants' understanding and beliefs of their child's diagnosis and treatment, medication knowledge, and adherence-related factors were collected using questionnaires. Interviews and a brief questionnaire were used to determine how participants reacted to the device after seeing it. The quantitative data was analysed using descriptive analyses Thematic analysis was used to analyse the qualitative data.

Participants reported high levels of adherence despite experiencing various barriers to adherence. The Petrie device demonstration was found to be acceptable to participants. The demonstration increased adherence-related knowledge and motivation, which led to some participants suggesting changes in medication administration behaviour that they intended to implement. As the demonstration may prove effective in enhancing adherence to ART, future research should be conducted to determine the efficacy of the device in doing so. Whilst the

demonstration appears suitable for use as part of routine clinical practice, aspects of implementation and feasibility require further work.

OPSOMMING

Om optimale behandelingsuitkomste te bereik, word byna perfekte vlakke van nakoming vereis van kinders vyf jaar en jonger op ART. Versorgers van kinders op ART is van noodsaaklike belang om te verseker dat hul kind hoë vlakke van nakoming bereik, aangesien hulle verantwoordelik is vir die toediening van medikasie aan die kind. Versorgers benodig die nodige nakomingsverwante-inligting, -motivering en -gedragsvaardighede om te verseker dat hul kind ART getrou neem. Alhoewel, hierdie komponente word dikwels beïnvloed deur versorger, kind, en medikasie-regime eienskappe, sowel as kontekstuele en gesondheidsorg verwante faktore. Alhoewel daar 'n aantal kinders is wat nie ART getrou neem nie, effektiewe ingrypings wat op hierdie ouderdomsgroep gerig is, is nie beskikbaar nie. Visuele ingrypings, soos die Petrie-apparaat demonstrasie wat ontwikkel is in ooreenstemming met die IMB-model, het potensiaal gewys om medisyne-nakoming te verbeter, en mag toepaslik wees vir gebruik by versorgers van kinders op ART.

In hierdie studie het ek die aanvaarbaarheid van die Petrie-apparaat demonstrasie met versorgers van jong kinders op ART ondersoek. Deelnemers wat in die studie ingesluit was, was elf versorgers van kinders vyf jaar en jonger op ART, van buitepasiënte klinieke binne die Stad Kaapstad Munisipaliteit, Suid-Afrika. Data wat die deelnemers se begrip en oortuigings van hul kind se diagnose en behandeling beskryf, asook medikasie kennis en nakomings-verwante faktore, is ingesamel deur middel van vraelyste. Onderhoude en 'n kort vraelys was gebruik om te bepaal hoe deelnemers gereageer het op die toestel nadat hulle dit gesien het. Die kwantitatiewe data is geontleed deur beskrywende analise. Tematiese analise is gebruik om die kwalitatiewe data te ontleed.

Deelnemers het hoë vlakke van nakoming gerapporteer ten spyte van verskeie faktore wat die potensiaal gehad het om nakoming negatief te beïnvloed. Die Petrie-apparaat demonstrasie was aanvaarbaar gevind deur deelnemers. Die demonstrasie het nakomingsverwante kennis en motivering vermeerder, wat gelei het tot sommige deelnemers wat veranderinge in medikasie-administrasiegedrag voorgestel het, wat hulle beplan om te implementeer. Aangesien die demonstrasie effektief kan wees om die nakoming aan ART te verbeter, moet toekomstige

navorsing gedoen word om die doeltreffendheid van die apparaat te bepaal. Alhoewel die demonstrasie skynbaar geskik is vir gebruik as deel van roetine kliniese praktyk, benodig aspekte van implementering en uitvoerbaarheid verdere ondersoek.

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LIST OF ACRONYMS

ABC	Abacavir
AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral
CCTA	Cardiac computed tomography angiography
CD4	Cluster of differentiation 4
CLWH	Children living with HIV
DBS	Dried blood spots
EFV	Efavirenz
EID	Early infant detection
HIV	Human immunodeficiency virus
HREC	Health Research Ethics Committee
IAC	Intensive adherence counselling
IMB	Information-Motivation-Behavioural Skills Model
LMIC	Low and middle-income countries
LPV/r	Lopinavir/ritonavir
MEMS	Medication event monitoring system
MTCT	Mother-to-child transmission
NNRTIs	Non-nucleoside reverse-transcriptase inhibitors
PDA	Personal digital assistant
PIs	Protease inhibitors
PLWH	People living with HIV
PMTCT	Prevention of mother-to-child transmission
PrEP	Pre-exposure prophylaxis
RCT	Randomised control trial
SDT	Self-determination theory

SMS	Short message service
StatsSA	Statistics South Africa
STI	Sexually transmitted infection
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV and AIDS
UNICEF	United Nations Children's Fund
USA	United States of America
VF	Virological failure
VL	Viral load
WHO	World Health Organisation
3-D	Three dimensional
3TC	Lamivudine

GLOSSARY

Active visualisation	A form of visual intervention intended to show patients the internal processes of their illness, and its treatment.
Adherence	The extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a healthcare provider.
Adherence counsellors	Lay health personnel or clinic nurses that provide voluntary counselling and testing, pre-ART initiation education training, psychosocial support and adherence counselling services to ART users in the public healthcare system.
ART	The daily use of a combination of HIV medicines to treat HIV infection, usually including three difference medication types.
ARV	The medications used to treat HIV.
Caregiver	The individual responsible for administering ART to the child and/or attending clinic visits on behalf of the child (usually the biological parent, legal guardian, or a relative).
Petrie device demonstration	An active visualisation device developed to demonstrate the necessity of adherence to ART and PrEP.
Primary caregiver	The individual responsible for administering ART to the child and/or attending clinic visits on behalf of the child (usually the biological parent, legal guardian, or a relative).
Visual interventions	Interventions incorporating visual imagery.

CHAPTER 1

INTRODUCTION

Introduction and Background

For children with HIV, adherence to antiretroviral therapy (ART) is a complex phenomenon. Paediatric patients on ART rely on a caregiver to administer their medications. The reliance on a caregiver for medication administration may complicate adherence, as the child's caregiver may not possess the necessary knowledge or skills regarding treatment (Amico & Orrel, 2012; Arage, Assefa, & Kassa, 2014; Coetzee, Kagee, & Bland, 2016b; Haberer & Mellins, 2009), the child may have multiple caregivers (Elsland et al., 2018; Haberer & Mellins, 2009; Reda & Biadgilign, 2012), or the caregiver may simply forget to administer the child's medications (Haberer & Mellins, 2009; Smith, Gengiah, Yende-Zuma, Upfold, & Naidoo, 2016). Moreover, paediatric adherence to ART may be obstructed by medication regimen related factors (Biru et al., 2016; Buchanan et al., 2012; Campbell et al., 2012; Reda & Biadgilign, 2012), contextual factors (Vreeman, Wiehe, Pearce, & Nyandiko, 2008; Williams, Van Rooyen, & Ricks, 2016), and healthcare system related factors (Dewing et al., 2012a; Dewing et al., 2012b; Williams et al., 2016). Such complicating factors occurring in paediatric adherence to ART are indicative of the need for methods to promote medication compliance. However, very few interventions have improved adherence to ART amongst children five years and younger with HIV (Bain-Brickley, Butler, Kennedy, & Rutherford, 2011, Nasuuna et al., 2018; Ferrand et al., 2017). The aim of the present study was to assess the acceptability of a visual intervention designed to improve paediatric adherence to ART.

HIV/AIDS: Figures

As of 2017, an estimated 36.9 million [31 100 000 - 43 900 000] people were living with HIV globally (Joint United Nations Programme of HIV and AIDS [UNAIDS], 2017). Eastern and Southern Africa accounted for the areas worst affected, with 19.6 million people living with HIV (PLWH) found in this area (UNAIDS, 2017). Of the global population living with HIV, 7.2 million people are in South Africa (UNAIDS, 2017). Furthermore, HIV/AIDS has a significant impact on children – in 2017, 1.8 million [1 300 000 - 2 400 000] children (<15 years) were reported to be

living with HIV globally (UNAIDS, 2017). In South Africa, 280 000 [220 000 - 370 000] children under the age of 15 were living with HIV in 2017 (UNAIDS, 2017).

Paediatric HIV

The progression of paediatric HIV is much more rapid than the progression of HIV in adults (Saloojee & Violari, 2001). As HIV undermines the functioning of an individual's immune system, children who are HIV-infected are more prone to opportunistic infections (B-Lajoie et al., 2016; Purcell, Downing, Kaharaza, & Bunnel, 2006; Saloojee & Violari, 2001; Walakira, Ddumba-Nyanzi, & Kaawa-Mafigiri, 2014). Such opportunistic infections often progress more aggressively (Saloojee & Violari, 2001) and may be more difficult to treat, as the child's immune system is unable to provide immunity or defence against the infection. These infections may also be recurrent (Saloojee & Violari, 2001) or chronic (Walakira et al., 2014). It has also been found that children with advanced HIV-infection may experience neurocognitive and motor deficits (Ruel et al., 2012). Without ART approximately one third of children infected with HIV will die by the age of one year, and half by the age of two years (Newell et al., 2004).

Prevention of mother to child transmission. The majority of HIV-infections amongst children can be attributed to mother-to-child transmission (MTCT); in South Africa almost all HIV-infected children acquire HIV vertically (Walakira et al., 2014). Prevention of mother-to-child transmission (PMTCT) has therefore been prioritised. Whilst PMTCT has been successful, with the rate of MTCT in South Africa at 2.6% in 2016 (Goga et al., 2016), there were still 13 000 [11 000 - 22 000] children newly infected with HIV in South Africa in 2017 (UNAIDS, 2017). Thus, whilst prevention should remain of key concern and additional efforts should be made to scale-up these services, there is a significant need to ensure that HIV-infected children receive adequate treatment and care.

Paediatric Adherence to ART

Since the introduction of ART, HIV is now considered a manageable condition. ART allows children to achieve better health outcomes, such as suppressed viral load (VL), increased CD4 count, and improved immune functioning, thereby decreasing child mortality (Purcell et al., 2006).

Non-adherence to ART allows the virus to replicate, and may result in the virus developing resistant strains, and virological failure (VF) occurring (Shafer et al., 2007). A study conducted in the South African context found the probability of VF amongst children was 19.3% after 3 years (Davies et al., 2011). Another study conducted in South Africa found that the probability of VF in children was 19.1% after a median duration of 1.5 years on ART (Fairlie et al., 2016). Children on first-line treatment regimens who experience treatment failure, as evidenced by a consistently raised VL count (>1000 copies/millilitre) despite good adherence, may then need to switch to a second-line regimen (Department of Health South Africa, 2015). The decision to switch to a second-line regimen, or third-line regimen in the case of those who fail second-line treatment, must be made in consultation with an expert physician.

In order to achieve treatment success, individuals with HIV need to have a high level of adherence to ART (Harberer & Mellins, 2009). The Department of Health South Africa (2015) states that the adherence goal is >95% of doses taken by the patient. In the case of paediatric patients, children are usually prescribed three syrup medication formulations each with specific dosing requirements, which have to be taken at twelve-hour intervals. However, children five years and younger on ART are not responsible for their own medication administration. Medication administration in the case of paediatric patients is most often the responsibility of the child's caregiver (usually the biological parent, legal guardian, or a relative).

Factors Influencing Paediatric Adherence

As indicated, responsibility for medication administration amongst paediatric patients on ART lies with the child's caregiver. Caregiver responsibility for medication administration can influence adherence in various ways. To begin, the caregiver's commitment to the child's adherence is of great importance. Caregiver permanence is also influential (Campbell et al., 2012), as studies have shown that having multiple caregivers or a change in caregivers is associated with poor adherence (Coetzee, Kagee, & Bland, 2015; Elsland et al., 2018; Haberer & Mellins, 2009; Reda & Biadgilign, 2012, Smith et al., 2016). Caregiver inconsistency can lead to confusion amongst caregivers if medication doses are altered, particularly if there is a lack of communication amongst

the caregivers responsible. An additional factor that is crucial to adherence is caregiver knowledge and understanding of their child's medication regimen. It has been found that poor knowledge of medication regimen is associated with non-adherence (Amico & Orrel, 2012; Arage et al., 2014; Haberer & Mellins, 2009). Moreover, should caregivers hold negative beliefs about their child's treatment, adherence can be negatively impacted (Haberer & Mellins, 2009; Perez & Leroy, 2009; Reda & Biadgilign, 2012). Additionally, caregivers may forget to administer medications (Arage et al., 2014; Biru et al., 2016; Buchanan et al., 2012; Smith et al., 2016). Furthermore, children who are aware of their status may be more adherent, as they themselves may be more motivated to adhere (Arage et al., 2014; Lesch et al., 2007; Müller, Bode, Myer, Stahl, & Van Steinbüchel, 2011; Vreeman et al., 2009). However, most paediatric patients are not aware of their status, as parents usually view children below the age of five as too young to be informed of their condition (Lesch et al., 2007, Vreeman, Gramelspache, Gisore, Scanlon, & Nyandiko, 2013).

Additional factors complicating medication adherence are due to the prescribed regimen itself. The complexity of medication regimens (Campbell et al., 2012; Reda & Biadgilign, 2012) and dealing with difficult to use syrup formulations (Haberer & Mellins, 2009) may impact adherence. Furthermore, the taste of the medication, specifically its bitterness, may also lead children to refuse or spit up medications (Biru et al., 2016; Buchanan et al., 2012; Campbell et al., 2012; Coetzee et al., 2015; Coetzee et al., 2016b; Elsland et al., 2018; Reda & Biadgilign, 2012).

Contextual factors may also impact paediatric adherence. Socioeconomic factors, such as being able to afford transport to the clinic may be influential, as this could affect clinic attendance (Arage et al., 2014; Haberer & Mellins, 2009; Mafune, Lebese, & Nemathaga, 2017; Williams et al., 2016). Additionally, stigma and discrimination may also affect adherence to treatment. Caregivers may feel the need to hide the child's medication due to the fear of stigma, resulting in delay or failure to administer medications due to the presence of others (Coetzee et al., 2015; Müller et al., 2011; Williams et al., 2016). Moreover, community support and understanding has been found to have a positive impact on adherence (Campbell et al., 2012). In contrast, should

caregivers experience stigma and discrimination, they may not access treatment altogether for their child (Williams et al., 2016).

The healthcare system itself also influences paediatric adherence to ART. Issues within the clinic, such as long waiting times, lack of compassion and unapproachability showed by clinic staff may disrupt adherence (Williams et al. , 2016). Studies on adherence counselling within the South African context have found that at some sites, the training received by counsellors has been inadequate and limited (Coetzee et al., 2015; Dewing et al., 2012b). Additionally, within an already overburdened healthcare system, not all sites have adequate facilities to conduct counselling sessions which, coupled with high patient load, may lead to rushed sessions (Dewing et al., 2012a).

Interventions to Enhance Adherence

Given the complexity of paediatric adherence it is not surprising that few interventions exist to support medication adherence. Further, available interventions to enhance chronic medication adherence have been found to be complex in nature and ineffective (Niewlaat et al., 2014). Bain-Brickley et al. (2011) identified four interventions, both randomised control trials (RCTs) (Berrien, Salazar, Reynolds, & McKay, 2004; Wamalwa et al., 2009) and non-randomised trials (Funck-Bretano et al., 2005; Müller, Myer, & Jaspan, 2009), that aimed to enhance adherence amongst HIV-infected individuals younger than 18 years of age. The study conducted by Berrien et al. (2004) employed a home-based nursing programme, intended to enhance caregiver knowledge of the child's HIV-infection, medication, and adherence to medication. This study showed potential in improving paediatric adherence to ART, with improvements in adherence levels and VL. Medication diaries (Wamalwa et al., 2009), different ART regimens (Müller et al., 2009), and a peer-support group for adolescents (Funck-Bretano et al., 2005) did not demonstrate improved adherence to ART. A recent intervention conducted by Ferrand et al. (2017) found that a structural support intervention delivered by healthcare workers to caregivers resulted in increased viral suppression amongst children on ART. Further, Nasuuna et al. (2018) found that an intensive adherence counselling (IAC) intervention programme was ineffective in improving rates of viral suppression. It should be noted that none of these interventions specifically targeted children five

years and younger. This is a period during which adherence is complicated primarily due to the child's reliance on the caregiver for medication administration. Thus effective intervention, targeted at the caregiver of the child, is needed to support and improve paediatric adherence to ART.

Visual Models

The current evidence base for visual interventions is still very limited (Jones & Petrie, 2017; Jones et al., 2018; Williams, Anderson, Barton, & McGhee, 2012), yet it is a field that is showing promise in enhancing illness understanding, and adherence to medications in patients with acute or chronic illnesses. Visual stimuli have been found to influence both cognitions and emotions, which in turn may influence behaviour (Williams et al., 2012). Additionally, images have been found to be more memorable than verbal messages (Gardener & Houston, 1989), which may result in longer-term impact. A review conducted by Houts, Doak, Doak, & Loscalzo (2006) indicates that adding pictures to either written or verbal information can increase patient attention, understanding, recall, and adherence. Furthermore, images may be particularly helpful to patients who have a low level of literacy (Houts et al., 2006; Jones & Petrie, 2017). Interventions relevant to those with low levels of literacy may be particularly relevant in the South African context, where a sizeable portion of the population are illiterate (Statistics South Africa [StatsSA], n.d.b).

Active visualisation. Active visualisation is form of visual intervention which is intended to illustrate to patients the internal processes of their illness, and its treatment (Jones & Petrie, 2016). Such interventions can include animations and physical demonstrations (Jones & Petrie, 2017; Jones et al., 2018). Promising results using an active visualisation intervention has been seen in a previous study conducted by Perera, Thomas, Moore, Faasse, and Petrie (2014), who developed an intervention using a smartphone application incorporating active visualisation designed to enhance adherence to ART amongst adults with HIV. The findings of Perera et al. (2014) indicate that providing participants with a visual representation of the mechanisms of ART may be effective in enhancing adherence.

The Petrie device. The Petrie device is an active visualisation model, designed to improve adherence to ART (Jones & Petrie, 2017). The Petrie device is a Perspex model resembling the

torso of the human body, which aims to illustrate to patients how HIV is controlled in the body when medication is taken daily as prescribed. To demonstrate this, a series of chemicals (representing the virus) and effervescent tablets (representing ART tablets) are dropped into the model to create dynamic colour changes in the body of the model. A clear liquid solution in the body demonstrates to viewers that the medication is controlling viral replication, whereas a pink liquid solution illustrates to viewers that when they are non-adherent to ART, the virus is able to replicate. Through altering the pH balance of the solution in the Petrie device, individuals are shown what the effects of ART are on the virus through a simple, yet effective demonstration. Jones and Petrie (2017) indicate that the device may be of greatest use to individuals with low-health literacy, making abstract medication related concepts more concrete, and easier to understand. The device was implemented in an RCT with non-adherent adolescents and adults in the Western Cape, South Africa, and resulted in increased adherence amongst the intervention group, as evidenced by decreased VL (Jones et al., 2018).

Rationale

Near-perfect adherence to ART is necessary for children with HIV to achieve optimal health outcomes. In what is now considered a treatable and manageable chronic illness, it is crucial that adherence to ART is addressed from an early age to slow disease progression, and decrease infant and child mortality. Furthermore, as children progress into adolescence and adulthood, having promoted adherence from a young age may assist in aiding individuals to continue to maintain high levels of adherence throughout life. Therefore, efforts to improve adherence amongst this age group are critical for patients' health outcomes.

As evidenced, adherence to treatment is crucial amongst paediatric patients. Whilst there are various barriers to adherence to ART in children five years and younger, few effective interventions addressing adherence amongst children in this age group exist. The Petrie device, developed by Jones and Petrie (2017) may provide a means for healthcare professionals to aid caregivers in understanding the mechanisms of ART. The implementation of the model within the South African setting targeted at adolescents and adults on ART was found to be successful in improving

adherence (Jones et al., 2018). However, as the field of active visualisation is still in its infancy, further research is still required to determine the acceptability, feasibility and efficacy of such models.

Aims and Objectives

The aim of this study was to determine the acceptability of a visual intervention using the Petrie device (further referred to as the Petrie device demonstration) amongst caregivers of children with HIV, who are receiving ART. Acceptability, as defined by Bowen et al. (2009, p.3), refers to "how the intended individual recipients […] react to the intervention".

The objectives for the study were:

1) To examine caregivers' thoughts on and opinions of the Petrie device demonstration, specifically relating to information, motivation, and behavioural skills.
2) To determine whether caregivers felt the Petrie device demonstration is appropriate to implement with others, specifically in a clinic setting.
3) To explore caregivers' thoughts about future implementation of the demonstration, and suggested changes.

Overview of Chapters

In Chapter 2, I provide an overview of the current literature regarding PMTCT, ART for paediatric patients, adherence, and factors influencing adherence, as well as research relating to visual models and interventions, active visualisation, and the Petrie device. The theoretical framework of the present study is also discussed in this chapter.

In Chapter 3, I describe the methodology of the present study, including the research design, participant selection, the questionnaires and the semi-structured interview schedule used, the Petrie device demonstration, and the data collection procedure. I also outline the quantitative and qualitative data analysis methods used, after which I discuss the issue of trustworthiness in qualitative analysis, and relevant ethical considerations.

In Chapter 4, I present demographic information on the study participants, as well as relevant sample characteristics. Included here are participant beliefs and understanding of their

child's diagnosis and medication, participants' knowledge of the child's ART regimen, disclosure of the child's HIV status to others, caregiver consistency, self-reported adherence, and barriers faced by participants in achieving medication compliance. I then present quantitative data regarding participants' experiences of the Petrie device demonstration. Lastly, I discuss the qualitative thematic analysis findings of the study, with reference to the four main themes identified in the data, and the necessary subthemes, with the use of illustrative quotations.

In Chapter 5, I discuss the study findings. Here, I examine adherence and related factors of the study sample in relation to relevant literature. Further, I also discuss the study findings in terms of the three study objectives. The limitations of the present study are also addressed, and recommendations for future work are provided.

CHAPTER 2

LITERATURE REVIEW

Introduction to Chapter

In this chapter I provide an overview of the literature regarding paediatric HIV and adherence to ART, as well as the interventions available to enhance medication adherence. To begin, PMTCT and the number of new paediatric HIV-infections are discussed. Second, paediatric initiation on ART, follow-up, and typical medication regimens are presented. Third, paediatric adherence to ART is addressed, namely looking at its importance, the levels of adherence currently being seen in this population group, and factors influencing adherence that are experienced by caregivers and children. Fourth, the adherence counselling system is discussed. Fifth, I provide evidence on the available interventions to enhance chronic medication adherence and adherence to ART, highlighting the need for novel interventions to improve ART medication compliance that are suitable within the South African context. Sixth, visual interventions and the potential contributions thereof to the field are discussed. An overview of the Petrie device demonstration is also presented. Finally, the theoretical framework employed in the present study is discussed.

PMTCT and New Paediatric HIV Infections

The scale up of PMTCT services can be considered as one of the greatest achievements in the sphere of public healthcare (United Nations Children's Fund [UNICEF], 2017). Since 2008, the South African Department of Health has implemented a rapid increase in the PMTCT and early infant detection (EID) services available, exemplifying the focus on the prevention of new HIV infections (National Department of Health South Africa, 2015). When considering PMTCT in the context of other low and middle-income countries (LMIC), Armenia, Cuba, Belarus, and Thailand have eliminated MTCT, of which Cuba was the first to do so in 2015 (World Health Organisation [WHO], 2017).

In 2017, the number of children living with HIV (CLWH) under 15 years of age in South Africa was estimated to be 280 000 [220 000 - 370 000] (UNAIDS, 2017). The number of new infections in this age group was approximately 13 000 [11 000 - 22 000] (UNAIDS, 2017).

Coverage of pregnant women receiving ART for PMTCT was high in 2017 (>95% [82 - >95]), and an estimated 53 000 [44 000 - 86 000] new infections were averted (UNAIDS, 2017). High levels of coverage and the number of new infections averted due to PMTCT is illustrative of country level success in the PMTCT scale up, in a setting that is high in HIV-prevalence (Goga et al., 2015).

However, UNICEF (2017) indicates that there is a slowing in the pace of global progress when it comes to PMTCT. UNICEF estimate that at current progress rates, the 2020 Super-Fast-Track Target of 20 000 newly infected children will not be met, with instead an estimated 100 000 new infections projected globally in 2020. A study conducted by Goga et al. (2016) indicates that as of 2016, whilst MTCT was at 2.6% in South Africa, the national target of <2% at 6 weeks postpartum was not yet achieved. Additionally, by extrapolating the results of their study, Goga et al. (2016) state that the number of infant infections is still above the global validation targets of ≤50 per 100 000 live births.

Furthermore, Maskew et al. (2018) conducted a study in South Africa in which they found that despite the introduction of 'Option B', a less complex ART regimen for PMTCT in contrast to 'Option A', it was estimated that less than 50% of women would reach 80% adherence during the final months of pregnancy. Additionally, they found that many women only commence with a PMTCT regimen late in pregnancy, around 22 weeks. Moreover, more than a third of participants attended their first antenatal care visit and initiated a PMTCT medication regimen less than 16 weeks before their estimated delivery date.

Whilst the coverage of PMTCT in South Africa is high, there are still a significant number of pregnant women who are non-adherent and/or not accessing PMTCT care, and as such a number of infants are still vertically infected. Therefore, retention in HIV-related treatment for paediatric patients, particularly adherence to medications, is of great importance.

Paediatric Initiation on ART and Follow-up

According to the Universal Test and Treat guidelines, all children with HIV, regardless of CD4 count, are offered ART treatment, prioritising those with a CD4 count of ≤350 (Department of Health South Africa, 2016). As presented in the *National Consolidated Guidelines for the*

Prevention of Mother-to-Child Transmission of HIV (PMTCT) and the Management of HIV in Children, Adolescents and Adults (Department of Health South Africa, 2015), the child is then initiated on one of two regimens (see Typical Dosing Regimens), depending on the child's age and weight. After initiating ART, the child is seen monthly for a follow-up session to monitor the child's condition. Once the child has stabilised, they are then seen every three to six months for follow-up sessions. The child's VL and CD4 count is recorded at 6 months and 1 year after initiating ART, after which it is monitored at 12-month intervals.

Typical Dosing Regimens

Paediatric ART regimens have far more complex dosing requirements than those of adults. Whilst adults are generally required to take a single dose of medication or a combination of various pills each day, infants and young children are usually prescribed a combination of three liquid medications to be taken at twelve-hour intervals. Additionally, these liquid formulations each require specific, accurate measurements (see Table 2.1). The National Guidelines (Department of Health South Africa, 2015) indicate children younger than three years, or those older yet weighing less than 10kgs are prescribed a medication regimen of Abacavir (ABC), Lamivudine (3TC), and Lopinavir/ritonavir (LPV/r). Children between 3 and 10 years, weighing more than 10kgs are prescribed a regimen of ABC, 3TC, and Efavirenz (EFV). It should be noted here that children who initiated ART with a regimen of ABC/3TC/LPV/r, must remain on the same regimen at age 3.

The dosing requirements are adjusted according to the weight of the child, as can be seen in Table 2.1. For example, a child weighing between 5 and 7kgs would be on a regimen of ABC/3TC/LPV/r. The typical prescribed doses for a child in that weight group would be 3ml ABC + 3ml 3TC + 1.5ml LPV/r, administered twice daily.

Table 2.1.

ARV Dosing Chart

<table>
<tr><th>Weight (kg)</th><th>Abacavir (ABC)</th><th>Lamivudine (3TC)</th><th>Efavirenz (EFV)</th><th>Lopinavir/ritonavir (LPV/r)</th></tr>
<tr><td><3</td><td colspan="4">Consult with a clinician experienced in paediatric ARV prescribing for neonates (<28 days of age) and infants weighing <3kg</td></tr>
<tr><td>3-3.9
4-4.9</td><td>2ml bd</td><td>2ml bd</td><td rowspan="3">Avoid using when <10kg or <3 years: dosing not established</td><td>1ml bd</td></tr>
<tr><td>5-5.9
6-6.9</td><td>3ml bd</td><td>3ml bd</td><td rowspan="2">1.5ml bd</td></tr>
<tr><td>7-7.9
8-8.9
9-9.9</td><td>4ml bd</td><td>4ml bd</td></tr>
<tr><td>10-10.9

11-13.9</td><td>Choose only one option
6ml bd OR 2x60mg tabs bd</td><td>Choose only one option
12ml od OR 4x60mg tabs od</td><td>6ml bd</td><td>12ml od</td><td>200mg nocte (1x200mg cap/tab)</td><td>2ml bd</td></tr>
<tr><td>14-16.9

17-19.9</td><td>8ml bd OR 2.5x60mg tabs bd</td><td>5x60mg tabs od OR 1x300mg tab od OR 15ml od</td><td>½x150mg tab bd OR 8ml bd</td><td>1x150mg tab od OR 15ml od</td><td rowspan="2">300mg nocte: (200mg cap/tab + 2x50mg cap/tab)</td><td>Choose one option:
-2.5ml bd
-100/25mg paeds tabs: 2 bd
-200/50mg adult tabs: 1 bd</td></tr>
<tr><td>20-22.9

23.-24.9</td><td>10ml bd OR 3x60mg tabs bd</td><td>1x300mg tab + 1x60mg tab od
1x300mg tab + 2x60mg tabs od</td><td>1x150mg tab bd OR 15ml bd</td><td>2x150mg tab od OR 1x300mg tab od OR 30ml od</td><td>Choose one option:
-3ml bd
- 100/25mg paeds tabs: 2 bd
- 200/50mg adult tabs: 1 bd</td></tr>
<tr><td>25-29.9

30-34.9

35-39.9

>40</td><td>1x300mg tab bd</td><td>2x300mg tabs od OR 1xABC/3TC 600/300mg tab od</td><td>1x150mg tab bd</td><td>2x150mg tabs od OR 1x300mg tab od OR 1xABC/3TC 600/300mg tab od</td><td>400mg nocte: (2x200mg caps/ tabs)

600mg tab nocte</td><td>Choose one option:
- 3.5ml bd
- 100/25mg paeds tabs: 3 bd
- #200/50mg adult tabs: 1 bd
+ 100/25mg paeds tabs: 1 bd
Choose one option:
- 4ml bd
- 100/25mg paeds tabs: 3 bd
- #200/50mg adult tabs: 1 bd
+ 100/25mg paeds tabs: 1 bd
Choose one option:
- 5ml bd
- 200/50mg adult tabs: 2 bd</td></tr>
</table>

Note. Kg=kilograms; ml=millilitres; mg=milligrams; tab=tablet; cap=capsule; bd=twice daily; od=once daily; paeds=paediatric. Adapted from "Paediatric Dosing Chart for Children", Department of Health South Africa, 2015, *National Consolidated Guidelines for the Prevention of Mother-to-Child Transmission of HIV (PMTCT) and the Management of HIV in Children, Adolescents and Adults*, p. 129. Copyright 2014 by the Department of Health, Republic of South Africa.

Such a medication regimen requires the caregiver to accurately measure the necessary dose amounts and administer these to the child at given times, namely at 12 hour intervals. Additionally, some of the antiretrovirals (ARVs) have specific guidelines for administration and storage. For example, LPV/r is best taken with food as this increases absorption, and ideally this formulation should be refrigerated. Alternatively, LPV/r can be kept in a cool (<25 ºC) place in the house for 42 days (Department of Health South Africa, 2015).

Paediatric Adherence to ART

Adherence is defined by the WHO (2003, p.17) as, "the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a healthcare provider". With regards to ART, individuals therefore need to take the correct amount of ARV pills or liquid formulations as prescribed. In the case of children five years and younger, responsibility for medication administration lies with the caregiver of the child. High levels of adherence to ART are of great importance in order to maximise clinical effectiveness amongst paediatric patients. The South African Department of Health (2015) states that the adherence goal is >95% of doses taken, indicative that excellent adherence levels should be aimed for amongst individuals on ART.

The Importance of Paediatric Adherence to ART

Adherence to ART can result in a supressed VL, enabling persons undergoing treatment to maintain improved levels of health (i.e. fewer opportunistic infections), and greater overall immune functioning (Volberding, 2008) in what was previously considered a life-threatening condition. However, as mentioned, non-adherence to ART allows the virus to replicate, and may result in the virus developing resistant strains (Shafer et al., 2007). When the virus is resistant to treatment, VF takes place. VF is evidenced by a VL count of >1000copies/ml, despite good adherence (Department of Health South Africa, 2015). The course of action after treatment failure must be determined in consultation with an expert physician. Once a child has failed first-line treatment, a second-line treatment regimen is initiated. If a child then fails second-line treatment, referral to an expert physician is required for consideration of how and whether to proceed with a third-line

treatment regimen. It has been found that acquired medication resistance to ART is prevalent among children in South Africa (Davies et al., 2011; Fairlie et al., 2016). Davies et al. (2011) conducted a study with a cohort of 5485 South African children recruited from seven paediatric programmes. The study found that the probability of VF after three years was 19.3%. A study conducted by Fairlie et al. (2016) found that of the 7053 children included in the study, 19.1% developed VF, after a median duration of 1.5 years of ART.

There are limited treatment options available for paediatric patients, and, as indicated, initiation on third-line treatment needs to be carefully considered and motivated. For children to develop resistant viral strains in such early stages of treatment reduces the treatment options available to them in later life, which can result in further complications.

Levels of Adherence in Reality

Achieving near-perfect adherence to ART is complex and challenging, especially within the context of a life-long treatment programme. Further, measuring adherence to ART is also complex and challenging. At present, various measures are available to assess paediatric adherence to ART, namely subjective measures such as proxy (i.e. caregiver) or self-report, and objective measures, such as medication return, pharmacy records, clinic attendance, directly observed therapy, and medication event monitoring system (MEMS) data.

VL remains the gold standard for assessing treatment success in this age group. For VL testing, plasma specimens are preferred (WHO, 2016). However, data on VL are not always available due to the testing intervals in VL follow-up (Department of Health South Africa, 2015). Additionally, inappropriate handling of plasma specimens for the purpose of VL monitoring can be problematic (Costenaro et al., 2014). Further, in resource-limited settings inadequate infrastructure may prevent routine VL testing (WHO, 2016). In such settings dried blood spot (DBS) specimens can be used to assess VL (WHO, 2016). This method of VL assessment has been found to have "acceptable sensitivity and specificity for identifying virological failure" (WHO, 2016, p. 133).

Among children on ART, it is evident that in the South African context, adherence rates are highly variable. For example, a study by Elsland et al. (2018), conducted in a semi-urban clinic in

the Western Cape, South Africa, used medication return to determine adherence amongst a sample of children (ages 2.1 to 12.9 years). By calculating the percentage of medication taken, based on the number of pills or the volume of liquid formulations returned, the study reported that adherence levels amongst the sample were between 20.3 and 54.7%. The low adherence levels evidenced by medication return contrast quite starkly with self-report measures used in the same study, which reported adherence levels between 79.6 and 89.1%. The findings reported by Elsland et al. (2018) evidence that self-report measures tend to overestimate levels of adherence, which may be due to social desirability bias (Fisher, 1993) and/or recall bias (Raphael, 1987). In contrast, a study conducted with a paediatric cohort (age range 6 months to 13 years) in rural KwaZulu-Natal, South Africa (Smith et al., 2016), found that adherence levels were greater than 85% throughout a two-year follow-up, as measured by medication return. As such, medication return may be a more accurate measure of adherence. For example, Davies, Boulle, Fakir, Nuttal and Eley (2008) reported that medication return was associated with viral response, evidencing the increased level of accuracy in determining adherence achieved by this method.

However, medication return is not without issues. Martin et al. (2009) report that families may forget to bring all necessary medication bottles back to the clinic. Further, patients may even discard medications before clinic attendance so as to appear to be adhering to the medication regimen (Jimmy & Jose, 2011), evidencing that removing the correct number of doses does not necessarily mean that the patient follows the prescribed regimen (Lam & Fresco, 2015). Moreover, employing a medication return measure does not allow for examination of any patterns of adherence (Lam & Fresco, 2015).

MEMS may provide a more reliable measure of adherence amongst caregivers and children on ART (Martin et al., 2009). This method of electronic drug monitoring allows for the recording of exact dates and times of medication bottle openings. Wisepill, a wireless pill container, is an example of MEMS. This device submits a cellular signal when opened (Haberer et al., 2010). Wisepill however is developed for use with individuals on a tablet-based ART regimen, and therefore may not be applicable to children five years and younger. It should be noted regarding

MEMS data, that the opening of a medication bottle does not always correspond to the intake of medications (Martin et al., 2009). Further, patients may take the incorrect dose amount, which would not be recorded by such a measure (Jimmy & Jose, 2011). Additionally, malfunctioning of MEMS devices may lead to loss of data (Martin et al., 2009; Stringer et al., 2018). Additionally, such devices are costly (Martin et al., 2009), which poses a challenge in resource-limited settings.

Further, studies have been conducted to determine whether antiretroviral concentration in hair samples is a feasible measure of adherence (Hickey et al., 2014). Such methods are relatively low cost, and are able to quantify drug exposure over time, allowing researchers to predict virologic response. However, in the South African context, the use of such methods to measure adherence may be challenged due to cultural beliefs and superstitions around providing samples of hair for research (Coetzee, Kagee, Tomlinson, Warnich, & Ikediobi, 2012). It is evident that measuring adherence is problematic in the absence of convenient, affordable, and accurate measures.

Whilst there are clearly various difficulties with measuring adherence, the studies by Elsland et al. (2018) and Smith et al. (2016) indicate that whilst there are disparities in adherence levels amongst children on ART with some patients achieving high levels of adherence, the adherence goal of >95% of doses taken is not being achieved. Additionally, a review conducted by Fox & Rosen (2015) regarding retention of paediatric patients found that there was an 86% retention at 24-months amongst South African cohorts. Whilst this retention rate is significantly higher than Mozambique for example, with a retention rate of 62% at 24 months, it is indicative of a number of children who are not adherent to or simply not accessing treatment. Furthermore, UNAIDS (2017) estimated that only 58% [45 - 77] of children younger than 15 years of age living with HIV in South Africa are receiving ART. Therefore, within the South African context, there are evidently a number of paediatric patients who are not accessing treatment for HIV, and/or are non-adherent.

Factors Influencing Paediatric Adherence

Clearly adherence to treatment remains a key issue in the care of HIV patients, and is considered by Rabkin and Chesney (1999) as the Achilles Heel of treatment success. Issues with adherence are prevalent among paediatric patients on ART, as there are various factors that influence adherence.

Such factors can be viewed in terms of child/caregiver factors, medication regimen characteristics, context factors, and healthcare system factors.

Child/caregiver factors. Adherence behaviour in paediatric patients is more complex than that of adults (Haberer & Mellins, 2009). This complexity is in large part due to the fact that young children on ART are not responsible for their own medication administration. The responsibility for medication administration lies with a caregiver, who therefore plays a significant role in the adherence of the child. Reliance on a caregiver for medication administration results in a number of complicating factors.

One of the initial experiences that could result in non-adherence to ART or not accessing treatment at all, is the shock and disbelief experienced by caregivers when receiving the child's diagnosis. This is particularly true for biological mothers, who may experience guilt over vertical transmission. Williams et al. (2016) report that these emotions experienced by the caregiver could result in denial, which may lead to the caregiver avoiding the clinic, and therefore not accessing treatment for the child or themselves (if HIV-infected).

Clearly the caregiver's commitment to the child's adherence is important. Campbell et al. (2012) indicate that it is important for the child's adherence that they have a permanent treatment partner. Due to the caregiver's crucial role in the child's treatment, it is important that the caregiver is constant, responsive, and attentive (Rapoff, 2010; Rochat, Mitchell, & Richter, 2008), as well as nurturing and sensitive to the child's emotional and physical needs (Black et al., 2016; Richter et al., 2016). As such, having multiple caregivers or a change in caregivers is associated with poor adherence (Coetzee et al., 2015; Elsland et al., 2018; Haberer & Mellins, 2009; Reda & Biadgilign, 2012, Smith et al., 2016). If multiple individuals are involved in medication administration, this can result in confusion amongst caregivers if medication doses are altered, particularly if there is a lack of communication amongst the caregivers responsible. However, the impact of multiple caregivers on adherence has not been conclusively established (Haberer et al., 2011). In the context of multigenerational living in South Africa (Amoateng, Heaton, & Kalule-Sabiti, 2007), additional caregivers may in fact provide support for the primary caregiver, similar to a treatment supporter

(Nachega et al., 2005; Nachega, Mills, & Schechter, 2010; Nakamanya, Mayanja, Muhumuza, Bukenya, & Seeley, 2018).

The caregiver's knowledge and understanding of the child's treatment also plays a role in paediatric adherence to ART. Poor knowledge of the child's medication regimen is associated with non-adherence (Amico & Orrel, 2012; Arage et al., 2014; Haberer & Mellins, 2009). Additionally, caregiver beliefs regarding the child's treatment may influence adherence. A positive impact on adherence is caused by the child's parent or caregiver holding positive beliefs about the efficacy of the child's medication regimen (Simoni et al., 2007). For example, in a review conducted by Reda and Biadgilign (2012), belief that the treatment has a positive impact on quality of life of the patient was associated with higher adherence levels. The findings of Reda and Biadgilign (2012) echo previous reports by Perez and Leroy (2009) who indicate that the caregiver's perception of and belief in the efficacy of medications played an important role in adherence.

One of the most commonly self-reported barriers to adherence occurring at the caregiver level is forgetting to administer medications (Arage et al., 2014; Biru et al., 2016; Buchanan et al., 2012; Smith et al., 2016). Caregivers forgetting to administer medications illustrates the importance of medication reminders, which have been associated with improved adherence (Biru et al., 2016). In addition to this, it has been reported that medication adherence is higher if the child's HIV-status has been disclosed to them (Arage et al., 2014; Vreeman et al., 2009). Children may refuse to take the medication (Walakira et al., 2014), and disclosure to the child may in turn influence the child's motivation to adhere (Müller et al., 2011). However, it is recommended that children are disclosed to in a manner that is developmentally appropriate (Lesch et al., 2007). The guidelines developed by the WHO (2011), recommend that children who are of school-going age (6 to 12 years) should be disclosed to. In contrast, younger children should be told of their status "incrementally" (p.12), in a manner that is appropriate to their cognitive and emotional development. Most paediatric patients five years and younger are not aware of their status, as caregivers may believe that the child is too young to understand (Vreeman et al., 2013). Caregivers have been found to be more likely to

disclose the child's status to older children, typically those older than 10 years (Madiba & Mokgatle, 2017; Vreeman et al., 2013).

Medication regimen characteristics. Further complicating factors to paediatric adherence to ART are due to treatment-related issues. As indicated, in the absence of fixed dose combinations, children on ART are usually prescribed a combination of three syrup formulations, which must be administered at twelve-hour intervals. Each of the prescribed formulations have particular dose requirements. The complexity of medication regimens for paediatric patients has been found to be associated with non-adherence (Campbell et al., 2012; Reda & Biadgilign, 2012). Further, difficulty to incorporate medication regimens into daily routine may also prove problematic (Matsui, 2007).

Moreover, dealing with liquid medication formulations poses a barrier to adherence in its own right. Syrup formulations may be difficult to use (Haberer & Mellins, 2009), with such medication regimens requiring caregivers to accurately measure dose amounts and administer these more frequently than adult regimens require. A study by Coetzee et al. (2016b) found that caregivers lacked the necessary skills which would have assisted in accurate measurement of medications, such as dose checking, and removing the bubbles in the syringes used to measure the medications. Such issues with medication measurement could lead to caregivers not administering the correct dosages to the child. Furthermore, if the caregiver perceives the medication to be difficult to administer, this may also lead to lower levels of adherence (Elsland et al., 2018). A recent study conducted by Engelbrecht, Mukina, Green, and Skinner (2018), implemented an adherence simulation exercise with clinicians, either doctors or nurses, involved in paediatric HIV management. As a component of the simulation, participants were required to adhere to an allocated medication regimen, administering liquids representing the prescribed medications into a sink. Whilst one may assume clinicians would not report issues commonly experienced by caregivers due to their involvement in the field of healthcare, participants experienced difficulty in handling the syringes and medications, indicating that they often spilled the medications. Additionally, participants indicated that keeping time in administering the medications was an issue, and found

that this disrupted daily routine. Such a simulation highlights the barriers to paediatric adherence in terms of complex and difficult to administer medication regimens.

In addition to the aforementioned barriers, one of the primary issues with ART formulations for children is their palatability. The taste of the syrup formulations poses a significant barrier to adherence. Palatability has been found to be an issue in medication adherence by a number of studies (Biru et al., 2016; Buchanan et al., 2012; Campbell et al., 2012; Coetzee et al., 2015; Coetzee et al., 2016b; Elsland et al., 2018; Reda & Biadgilign, 2012). Campbell et al. (2012) reported that taste posed such an issue to medication administration that caregivers resorted to bribing children with juice so that they would take the medicines. The taste of LPV/r has been specifically noted as problematic, with recommendations to increase palatability including coating the child's mouth with peanut butter, dulling taste buds with ice, or administering sweet foods immediately after the dose (Child and Adolescent Committee of the SA HIV Clinicians Society in collaboration with the Department of Health, 2013). Such taste-masking attempts can be difficult for caregivers in resource-scarce settings. In light of such issues with palatability of syrup formulations, it is no surprise that children on tablet only regimens are more adherent (Elsland et al., 2018). The Department of Health (2015) in fact recommends that children be switched from syrup-based medications to a tablet or capsule based regimen as soon as possible.

Context-related factors. There are various contextual factors which influence adherence to ART. Vreeman et al. (2008) discuss the important role that socioeconomic context plays in adherence, which is emphasised by caregivers indicating that they struggle to afford transport to the clinic (Arage et al., 2014; Haberer & Mellins, 2009; Williams et al., 2016). This may lead to caregiver-child dyads forgoing clinic appointments. Therefore, accessibility of healthcare services, particularly in terms of their proximity to the caregiver and child, are influential in the access of treatment and adherence.

Stigma and discrimination may also influence adherence to treatment. Should caregivers not disclose the child's status to the family, they may feel the need to hide the child's medications, and the caregiver therefore not administering or delaying administration of medications due to the

presence of others (Coetzee et al., 2015; Müller et al., 2011; Williams et al., 2016). Caregivers may then also not be able to use the visibility of the medications as a reminder to administer it to the child (Marhefka et al., 2008). Stigma and discrimination may also result in caregivers not accessing healthcare services, and therefore, not accessing treatment for the child (Williams et al., 2016). The role of stigma in non-adherence is further emphasised in the finding that reduced stigma is predictive of increased viral suppression (Müller et al., 2011). Additionally, Campbell et al. (2012) report that community understanding and support is a facilitating factor in paediatric adherence to ART.

Healthcare system factors. Williams et al. (2016) indicate that caregivers experience various issues occurring within the healthcare system, which may lead to avoidance of accessing clinics. Long waiting times at clinics are reported as a barrier to access, with caregivers indicating that they have to wait hours at the clinic, sometimes having to take an entire day off work. For some, this may result in a loss of income. Additionally, it was found that caregivers felt that staff at the clinics showed a lack of compassion for caregivers and patients (Williams et al., 2016), and formed a possible barrier to accessing healthcare services. Furthermore, caregivers experienced healthcare staff to be unapproachable and unsympathetic, and felt that they did not have enough time with clinic staff to be able to access all the information that they felt was needed (Williams et al., 2016). As indicated, a lack of knowledge regarding the child's treatment regimen could result in non-adherence. The problematic relay of information to caregivers is echoed in a study by Coetzee et al. (2015), in which adherence counsellors report that they felt caregivers are provided with too much information regarding their child's diagnosis and treatment over a very short space of time.

Adherence Counselling

In light of the current barriers to adherence, it is of great importance that steps are taken in order to promote medication compliance, particularly within the healthcare sector where the majority of caregivers receive treatment-related information. One of the primary strategies currently employed by the South African Department of Health is that of individual counselling following diagnosis, which is delivered by lay counsellors and nurses. As the caregiver is the treatment partner of the

child, it is important to provide psychosocial support to the individual responsible for the child's medication administration. Adherence counselling begins at the time of the child's diagnosis (Department of Health South Africa, 2015). At this point it is key that the caregiver is thoroughly educated on HIV, and that the child's treatment plan and follow-up is discussed. It is important that caregivers are counselled as to how to administer their child's medication(s), and that they are able to monitor possible side-effects that may be experienced by the child, as well as cope with challenges to adherence (Western cape Government Health, 2018). Adherence counselling sessions are conducted monthly for the first three months, after which they are conducted on a quarterly basis. During these sessions, medication adherence needs to be promoted, providing the caregiver with adherence tools, knowledge, and the skills necessary to ensure that the child achieves medication compliance (Remien et al., 2013). These sessions are intended to provide caregivers with an opportunity to have an open discussion with the counsellor, in which they are able to ask questions.

Studies have found that there are various flaws in the current adherence counselling provided. To begin, in a study conducted in rural South Africa, the training received by adherence counsellors was found to be inadequate and limited (Coetzee et al., 2015). Additionally, in a study conducted by Dewing et al. (2012b) in the Western Cape, South Africa, not all of the participating counsellors had taken part in two of the courses required to practice as HIV counselling and testing (HCT) counsellors, namely a 10 day HIV/AIDS/STI/TB Information Course, and a 10 day intensive counselling course. This indicates that not all counsellors have completed the necessary training. The variability in training that is experienced within the South African context may mean that adherence counsellors are not sufficiently equipped to monitor patient adherence, and counsel those who experience treatment failure. Counsellors require further training (Kagee, 2013), and increased supervision and support (Coetzee, Kagee, & Bland, 2016a; Dewing et al., 2012b; Petersen, Fairall, Egbe, & Bhana, 2014) to adequately carry out their role.

The context within which adherence counselling takes place is also worthy of consideration. Within an already overburdened healthcare system (Coetzee et al., 2016a; Crowley & Stellenberg,

2014; Hunter et al., 2017; Mathibe, Hendricks, & Bergh, 2015) counsellors often do not have dedicated spaces within which to conduct counselling sessions. Dewing et al. (2012a) report that counsellors indicated that there were either none or too few rooms in which to conduct sessions. The study, conducted in Cape Town, South Africa, found that at a particular site counsellors were in fact sharing a room whilst conducting sessions. Furthermore, the lack of a dedicated space means that counsellors are also limited in the time that they can spend with a patient (Dewing et al., 2012a). The short length of counselling sessions is also reported by Coetzee et al. (2016b) who conducted a study in rural KwaZulu Natal, South Africa, citing the average length of sessions as 8.1 minutes in their study. Short counselling sessions may occur due to high patient load, with counsellors feeling "pressured to get through the pile of folders belonging to patients waiting to see them" (Dewing et al., 2012a, p. 1291). The rushed nature of counselling sessions is also noted by counsellors themselves, some of whom feel that caregivers are provided with too much information over a short period of time (Coetzee et al., 2015). Additional observations in counselling sessions note that counsellors were engaged in administrative tasks during the session (Coetzee et al., 2016a).

The counselling techniques employed may also prove problematic in terms of promoting adherence. Whilst counsellors possess the necessary knowledge regarding HIV and treatment, Dewing et al. (2012b) note that not all of the counsellors participating in their study treated the patients with respect and positive regard. Instead, counsellors were found to express judgement regarding the behaviour of the patient, which was patronising, reinforcing the counsellors role as an authority figure. In turn, this positions the patient in a passive and dependant role in terms of problem-management in treatment. Such findings are similar to that of Williams et al. (2016) who report that caregivers found that clinic staff lacked compassion when dealing with caregivers and patients.

Interventions to Address Paediatric Adherence

In addition to the barriers to adherence faced by paediatric patients and caregivers, issues with the current adherence counselling system highlight the significant need for evidence-based

interventions that will assist in increasing medication compliance amongst paediatric patients on ART. Amico and Orrel (2012) provide recommendations as to how interventions can attempt to support adherence to ART through means such as increasing access to and monitoring treatment, simplification of medication regimens, and education. Assisting individuals on ART with skills, tools, and social support are also of importance. Patient-centred care and responsive healthcare systems is also emphasised. The following section will examine interventions developed to enhance chronic medication, not necessarily specific to HIV, as well as those developed for use with ART specifically.

Chronic Medication Adherence Interventions

Attempts to support adherence to chronic medication have received attention in research. A review conducted by Nieuwlaat et al. (2014) included 182 RCTs not specific to paediatric patients, of which 17 were found to have a low risk of bias. Conditions addressed in these studies included cardiovascular disease or cardiovascular risk, chronic obstructive pulmonary disease, diabetes, HIV/AIDS, hypertension, and psychiatric disorders. These studies involved enhanced support from healthcare professionals, peers, and families, as well as daily treatment support. In an attempt to address multiple barriers to adherence, the studies reported on were complex in nature. Moreover, despite the effort and resources that went into the studies, they were not very effective – of the seventeen studies, eight studies showed no improvement in either adherence or clinical outcome. Two of the included studies (Lester et al., 2010; Simoni et al., 2009) will be further discussed in the following section, due to their focus on ART adherence.

Additionally, a review conducted by Dean, Walters, and Hall (2010) found that studies incorporating both educational and behavioural components in interventions targeting medication adherence amongst children (ages 9 months to 19 years) were more likely than interventions reliant on an educational component alone to improve adherence. The review included studies that improved medication compliance targeted children and adolescents with asthma (Smith, Seale, Ley, Shaw, & Bracs, 1986; Bonner et al., 2002), epilepsy (Shope et al., 1980), juvenile rheumatoid arthritis (Rapoff et al., 2002), tuberculosis (Hovell et al., 2003), and participants who had just

undergone a renal transplant (Fennell, Foulkes, & Boggs, 1994). Improved adherence was evidenced by missed doses as reported in an interview (Hovell et al., 2003), self-report questionnaire (Bonner et al., 2002; Smith et al., 1986), blood testing (Fennel et al., 1994; Shope et al., 1980), or MEMS data (Rapoff et al., 2002).

ART Adherence Interventions

There have been various interventions developed to address the issue of medication adherence amongst individuals, specifically adults, on ART. In the previously mentioned review conducted by Nieuwlaat et al. (2014), two studies addressing adherence to ART were included. Simoni et al. (2009) made use of peer support and pager messaging strategies with adults (ages 19 to 60 years), in Seattle, United States of America (USA), which did not show improved adherence to ART as measured by electronic drug monitors (EDM) and self-report. In contrast, the study conducted by Lester et al. (2010) in Kenya, was found to have significantly improved adherence to ART as measured by self-report, as well as improved rates of viral suppression. This study employed a short message service (SMS) support system. In a similar study conducted in the USA by Dowshen, Kuhns, Johnson, Holoyda, & Garofalo (2012), an intervention using SMS medication reminders with a sample of adolescents and young adults (ages 14 to 29) was found to significantly improve self-reported adherence, illustrative of the potential that reminder strategies can play in improving adherence. The findings of Lester (2010) and Dowshen et al. (2012) are reiterated in a review conducted by Kanters et al. (2017), who reported that SMS-based interventions were superior to standard care, particularly in LMIC settings due to the ability to reach a large number of individuals at a relatively low cost. These findings contrast with a review conducted by Chaiyachati et al. (2014), which indicated that studies employing reminder devices did not produce significant results. Additionally, techniques such as cognitive behavioural interventions, education, treatment support, and directly observed therapy showed potential, but did also not produce noteworthy effects (Chaiyachati et al., 2014).

Interventions Targeted at Children on ART

It is evident that whilst a number of interventions have been developed to support adherence to ART in adults, significantly less work has been done in the field of children. A review conducted by Bain-Brickley et al. (2011) found that a number of studies, employing methods such as directly observing therapy, cellphone reminders, pill swallowing, and education and support interventions, showed promise, yet were not evaluated properly. Their review yielded only four control trial interventions, randomised and non-randomised, intending to improve the adherence of children to ART, which will be discussed here.

Of the four interventions included by Bain-Brickley et al. (2011) only one demonstrated an effect on adherence. Berrien et al. (2004) implemented a home-based nursing programme with patients and caregivers in Connecticut, USA. The study consisted of eight home visits intending to provide the caregiver with knowledge and skills to improve adherence, which took place over a three month period. The average age of patients in the study was 10 years (range 1.5 to 20 years). As measured by pharmacy medication refill records after completion of the intervention, this intervention showed a significant improvement in adherence levels of the intervention group in comparison with the control group. Furthermore, whilst changes in VL were found in the intervention and the control group, those in the control group were not noteworthy. However, the sample size was small, with only 35 participants.

In contrast, the other interventions reported on showed no effect on adherence levels of participating children. Funck-Bretano et al. (2005) implemented a peer support group for adolescents at a clinic in Paris, France, over a two-year period. The study found changes in VL suppression, which, whilst not significant, illustrate that perception of illness can perhaps improve medical outcomes. This was evidenced by decreased concerns about illness, and lowered negative perception of treatment in the intervention group. Müller et al. (2009) conducted a study with South African children, in which they compared different ART regimens, specifically boosted protease inhibitors (PIs) and nonnucleoside reverse-transcriptase inhibitors (NNRTIs). The mean age of children in the sample was 5.1 months. Neither regimen showed an effect on adherence levels of

participants as evidenced by MEMS data. Finally, Wamalama et al. (2009) implemented a strategy which required caregivers of Kenyan children on ART to use medication diaries. The mean age of the children in this study was 4.7 years. This study did not have any impact on adherence, as measured by self-report questionnaires, or clinical outcomes, such as CD4 and VL count.

Further studies have recently been conducted in the field. A retrospective cohort study by Nasuuna et al. (2018) aimed to determine whether a nationally implemented IAC programme for children and adolescents (ages 9 months to 19 years) in Uganda would improve viral suppression. Individuals who had a VL >1000 copies/ml, indicative of VF, were required to attend three IAC sessions at monthly intervals, after which VL follow-up was conducted. In the case of children, these sessions were conducted with the caregiver if the child was five years or younger, or with the caregiver and the child, if the child was between six and 15 years. Older adolescents could elect to have the counselling sessions without the caregiver present. The study found that of the children with VF, only 23% were virally suppressed after completing all three IAC sessions. It should be noted that the national programme on which this study reported conducts medication resistance testing only on those failing second-line regimen treatment. Therefore, medication resistance may have played a role in the rates of viral suppression amongst the cohort.

A recent study, employing a community-based support intervention for caregivers of 334 children and adolescents on ART in Zimbabwe, found increased viral suppression in participants in the intervention group (Ferrand et al., 2017). This study involved structured support visits by trained community healthcare workers over a period of eighteen months, to caregivers of children between 6 and 15 years newly diagnosed with HIV. Sessions involved providing caregivers with knowledge, support, and resources. Such a study illustrates that an intervention of this nature has the potential to assist in achieving better treatment outcomes for young people on ART.

It is evident that effective adherence interventions incorporate some kind of educational and support component for the patient and/or caregivers (Berrien et al., 2004; Ferrand et al., 2017). As evidenced, paediatric adherence to ART may be complicated by various caregiver-related factors, such as caregiver knowledge of and beliefs regarding treatment. Moreover, caregivers have been

found to experience difficulty with complex dosing requirements, and do not always possess the skills to administer the child's medication accurately. Interventions such as those reported by Müller et al. (2009) and Wamalama et al. (2009) do not address such barriers to adherence faced by caregivers and children, which may result in interventions of this kind being ineffective in improving adherence. Educational interventions, such as the intervention employed by Berrien et al. (2004) which attempts to assist caregivers to children on ART develop the necessary skills to accurately administer the child's medications, may be particularly effective amongst caregivers of children under five years. However, the small sample size of this study (N=35) is problematic. As indicated by Bain-Brickley et al. (2011) various methods are available that do show promise in enhancing adherence to ART amongst children, yet these have not been properly evaluated. The intervention by Ferrand et al. (2017), which intended to provide caregivers with knowledge and support, was found to be effective in improving adherence as evidenced by viral suppression. However, the child age range in this study was 6 to 15 years, and did not target caregivers of children five years and younger. The study by Berrien et al. (2004) was not targeted specifically at caregivers of children under five years either, as children between 1.5 and 20 years were included. Therefore, whilst a small number of the interventions available for children on ART do show promise in providing techniques to improve adherence, the studies are not specifically targeted to improve the adherence of children five years and younger. This emphasises the need in research and practice for interventions tailored specifically to this age group, and calls for interventions which aim to enhance caregiver knowledge and understanding, as well as improve medication administration skills.

Visual Interventions

A field that is showing great promise in enhancing medication adherence is the use of visual media. There is an increasing preference for the use of visuals in healthcare interventions, yet the evidence base is limited and still in its infancy (Williams et al., 2012). Visual interventions are cost effective and easy to understand, which may have resulted in their increasing popularity. Despite the novelty of the field, the use of visual imagery in healthcare has the potential to enhance patient

understanding of illness and treatment, and improve medication compliance (Houts et al., 2006). The potential of this type of intervention is in part because it allows an abstract concept to be demonstrated in a very real, and physical manner. Through engaging with something concrete, the visual imagery presented is likely to have a significant impact on the patient (Williams et al., 2012).

The use of visual imagery is powerful and effective for a number of reasons – it can evoke an emotional response in a patient which may result in behaviour change (Houts et al., 2006), and it can be said to have an effect on memory that is longer lasting than words alone (Gardener & Houston, 1989). The use of visual materials, resulting in mental imagery, increases rumination, creating a longer term impact of the visual presented to the patient (Williams et al., 2012). Furthermore, in addition to enhancing understanding, by aiding communication the use of pictures can promote positive interactions between patients and healthcare staff (Williams et al., 2012), which may in turn influence adherence.

Combining visual imagery with words, be it written or spoken, may also be an effective intervention tool to employ. A review conducted by Houts et al. (2006) indicated that visual imagery, particularly when combined with words, increases attention and recall. Katz, Kripalani, and Weiss (2006) corroborate these findings, indicating that when visual imagery is used in combination with words, it increases patients understanding of medication instructions. Therefore, the use of visual imagery and words can be considered as more effective than either used in isolation (Mayer & Sims, 1994).

Additionally, interventions employing visual imagery may be particularly relevant to individuals with low levels of literacy (Houts et al., 2006; Jones & Petrie, 2017). According to StatsSA (n.d.b) (http://www.statssa.gov.za/?page_id=737&id=4) the youth literacy rate (ages 15-34) in South Africa is 93.9%, whereas the adult literacy rate (ages 35-64) is 79.3%. Moreover, 6% of the population has received no schooling whatsoever. Therefore, visual interventions may be well suited for use in the South African context where a sizeable portion of the population are illiterate, and/or have not received formal schooling.

Interventions Employing Visual Imagery

There have been various studies in the field of healthcare which employ visual imagery interventions. Devich, Ellis, Waltham, Broadbent, and Petrie (2014) made use of a diagnostic test of the cardiac computed tomography angiography (CCTA) to determine patients' perceived value thereof. Through allowing patients to view the structures and blood vessels of the heart, this tool assisted in addressing patients' understanding, as well as their behavioural intentions with regards to seeking healthcare, and motivation to do so. The importance of seeing the internal workings of an illness is reiterated in a study by Harrow, Wells, Humphris, Taylor, and Williams (2008), which found that the imagery conveyed to women with breast cancer of their illness, either through scans or verbal metaphors provided by their healthcare practitioner, influenced women's illness experiences. Therefore, by providing patients with either an image of their cancer or a visual descriptor, patients may be able to gain a better understanding of both their illness and the treatment.

The use of physical models to explain illness and/or treatment is also a field showing promise. A study conducted by Stephens et al. (2015) used 3-D printed bones in an attempt to improve treatment initiation among patients with osteoporosis. The use of the models resulted in greater emotional affect, as well as a greater understanding of the condition. Additionally, an increased number of individuals in the intervention group initiated a relevant medication regimen. Jones, Fernandez, Grey, and Petrie (2017) also used 3-D models of bones with osteoporosis, as well as animations of the condition with a sample of individuals at risk for developing the disease to determine whether the two mediums had differing effects. It has been reported that animations can assist patients in understanding complex ideas more easily (Ainsworth, 2008). The study by Jones et al. (2017) found no significant difference between the visual mediums, with both strategies altering beliefs and treatment motivations amongst the targeted group.

Visual interventions have also been used in studies regarding medications. Karamanidou, Weinman, and Horne (2008) used a physical demonstration to illustrate the mechanism of phosphate-binding medication amongst a group of individuals with end-stage renal disease, for

whom phosphate control is an important goal of treatment. The study made use of a transparent, plastic container, shaped like the human stomach, as well as a phosphate-binder and a phosphate solution. The demonstration showed a significant change in patients' understanding of the medication, as well as beliefs regarding treatment. However, the demonstration showed no effect on adherence.

Pictograms have also become a preferential method of communicating important information about medications to patients. Dowse and Ehlers (2005) incorporated pictograms into medicine labels, illustrating instructions for use. The intervention was delivered with a group of individuals attending an outpatient clinic, who had been prescribed a short-course of antibiotics. Individuals participating in the study were Xhosa-speaking, with low literacy levels. The use of pictograms resulted in increased adherence amongst patients, as well as better understanding of medication instructions, illustrating the ability of visual imagery to assist in the communication of information to patients with low literacy. A study conducted by Yin et al. (2008) employed a pictogram-based intervention in an attempt to decrease errors made in the administration of liquid medications to children by caregivers. As previously mentioned, the measuring and administration of such medication formulations poses a barrier to adherence for children to whom they are prescribed. The intervention intended to provide caregivers with knowledge of the medication dosages, the length of treatment, as well as the preparation and storage of medications. Yin et al. (2008) found fewer errors in dose accuracy, as reported by caregivers during an interview and through direct observation. Adherence levels were greater amongst participants in the intervention group as measured by self-report and medication return. Caregiver knowledge of the medications prescribed to the child was also increased.

Visual Imagery in ART Interventions

Visual interventions have also been used in studies related to ART adherence. Brock and Smith (2007) conducted a study with adults initiating or on ART, incorporating a personal digital assistant-based (PDA) video intervention. The video provided patients with information which would aid in increasing self-efficacy regarding medication taking, and enhance patients' beliefs that

they were able to adhere to the medication regimen. Directly after being shown the video, participants showed significant improvements in knowledge of HIV and medication. At the follow-up session, patients also showed great improvements in self-reported adherence. Whilst the study design was quasi-experimental, with no control condition, the study does illustrate the ability of visual imagery to influence patient knowledge of medications, and adherence.

An intervention implemented by Perera et al. (2014) employed a smartphone application intended to enhance adherence to ART. Participating adults on ART were recruited from an outpatient clinic in Auckland, New Zealand. Participants were either provided with a standard or augmented version of the application. The augmented application provided patients with real time information regarding medication intake, and its effect on the participants' levels of immune protection. The use of the augmented application resulted in increased levels of self-reported adherence, as well as decreased viral load. Participants who made use of additional components of the augmented application were also found to possess a greater understanding of their illness, and the importance of their medications. This study illustrates the potential of improving adherence by providing patients with personalised health-related imagery. The aforementioned studies evidence the promise of interventions incorporating visual media in the field of ART adherence.

Petrie Device Demonstration

A particular field showing promise within visually based interventions is that of active visualisation. Active visualisation is a means of illustrating to participants the internal process of an illness or treatment in a way that is engaging, and accessible (Jones & Petrie, 2017). Such a demonstration takes a concept that may be difficult for a patient to understand, and by interpreting it in a visual manner, allows patients to understand how their medication works, and the importance of taking it. The interventions discussed by Karamanidou et al. (2008) and Perera et al. (2014) are both examples of active visualisation, providing the patient with a visual representation of what is taking place in the body when taking medication. The Petrie device demonstration, an active visualisation device as reported on in Jones and Petrie (2017) and Jones et al. (2018), was developed in order to demonstrate to participants the necessity of adherence to ART and pre-

exposure prophylaxis (PrEP), a preventative measure for individuals who are at high risk of contracting HIV. The device is a transparent Perspex container, shaped as a human torso. Through altering the pH of the solution inside the device, the colour is changed, which illustrates to participants the effects of adherence and non-adherence to ART or PrEP on the body. The demonstration attempts to provide a clearer and more effective explanation of the effects of treatment behaviour in comparison to information that patients may have been previously exposed to. Further discussion of the Petrie device and how it works is provided in Chapter 3.

The Petrie device was implemented in an RCT in the Western Cape, South Africa, with a sample (N=111) of individuals older than 15 years who were non-adherent to ART (Jones et al., 2018). The study aimed to assess the efficacy of the demonstration in improving adherence to ART. The study found significant improvements in VL in individuals who had received the intervention, as opposed to those who received standard care alone. However, this study was limited by the lack of available VL data for the sample, due to the absence of routine VL monitoring and limited clinical records. Additionally, the researchers were not able to take into account other medical issues that may have affected VL, as this information was not available. However, the demonstration appeared to be acceptable to participants, as it was reported as being easy to understand, interesting, and motivating. Jones et al. (2018) provide initial evidence that an active visualisation demonstration can assist in improving adherence to ART, and thereby result in greater treatment success, as evidenced through decreased VL. In light of the lack of suitable and effective interventions for paediatric patients, an adaptation of the Petrie device demonstration may prove useful for the population group in question. However, no research has been done to determine whether such an intervention is acceptable to caregivers of children five years and younger on ART.

Theoretical Framework

The present study is conceptualised in terms of the Information-Motivation-Behavioural Skills (IMB) model of adherence to antiretroviral therapy (Fisher, Fisher, Amico, & Harman, 2006). This theory suggests that behaviour change is dependent on information, motivation, and behavioural skills. Thus, adherence to ART is reliant on sufficient information about adherence to the prescribed

medication, motivation to adhere, and behavioural skills to perform the necessary tasks. More specifically, adherence-related information and motivation work through behaviour skills to affect adherence to ART. The following section will examine the three concepts employed in this model individually, namely information, motivation, and behaviour skills. Use of this model in studies examining adherence, as well as interventions employing this model will be discussed. Finally, the use of the model in the present study will be discussed.

Information

The first component of the IMB-model by Fisher et al. (2006) is information. In order for an individual to be adherent to ART, they need to have an accurate and comprehensive understanding of their HIV-diagnosis, the treatment plan, medication regimen dosing requirements, potential side effects of medication, and the required level of medication adherence. Possessing the necessary adherence-related information will assist individuals in achieving adherence to ART. Moreover, Fisher et al. (2006) indicate that, related to information, individual beliefs or heuristics may impact adherence related decisions. The example used by Fisher et al. (2006) ("If I'm feeling OK, I must be taking enough medication" [p.463]) indicates that should a person hold incorrect heuristics regarding adherence, this may negatively impact adherence.

With regard to paediatric patients, it was evidenced in the literature that caregiver knowledge and understanding of the child's ART influences adherence. Poor caregiver knowledge of medication regimen is associated with lower adherence (Amico & Orrel, 2012; Arage et al., 2014; Haberer & Mellins, 2009). It is also important to note here that, in a study conducted by Williams et al. (2016), caregivers to children on ART felt that they were not able to access the necessary information from healthcare staff. Therefore, providing caregivers of children on ART with the needed information may prove particularly useful in improving adherence to ART.

Motivation

The second component of the IMB-model is motivation, which specifically speaks of individual motivation and social motivation. An individual's motivation to adhere to their medication regimen is crucial in achieving medication compliance. Motivation depends on an individual's attitude

towards medication adherence, which is determined by their beliefs regarding the efficacy of ART. Those who hold positive beliefs regarding the efficacy of medications present with higher levels of adherence. Simoni et al. (2007), Perez and Leroy (2009), and Reda and Biadgilign (2012) indicate that adherence is positively impacted by the caregiver holding positive beliefs about the efficacy of ART. This is particularly true of caregivers to children on ART. Such beliefs are a form of intrinsic motivation as described in self-determination theory (SDT) (Deci & Ryan, 1985; Hamrin, Sinclair, & Gardener, 2017). However, individuals do not necessarily possess intrinsic motivation, as this type of motivation generally relates to the motivation to engage in behaviours that are enjoyable or challenging, which may not be the case with medication adherence. Therefore, it is more likely for individuals on medications to possess extrinsic motivation, specifically integrated motivation. This type of motivation means that individuals are more likely to adopt a behaviour if the outcome is valued. In the case of caregivers to children on ART, the caregivers desired outcome is for the child to be healthy, which medication adherence would allow. Further, realisation of the efficacy of the medication may in turn lead individuals to develop intrinsic motivation (Hamrin et al., 2017).

Social support is also key in improving adherence motivation. Fisher et al. (2006) indicate that an individual's perception of support from others can have an impact on motivation to adhere. The applicability of this to paediatric patients is illustrated by Campbell et al. (2012), who indicate that community understanding and support may aid in improving adherence to ART amongst children. Caregivers who experience stigma and discrimination may feel that they lack social support, which may lower adherence-motivation.

Behavioural Skills

The individual's adherence-related behavioural skills are also key in improving adherence to ART. Behavioural components include an individual's ability to administer medications, and incorporate medication administration into daily routine. According to Fisher et al. (2006) the behavioural skills component of the IMB-model includes both objective abilities, as well as the individual's perceived self-efficacy to employ adherence-related behavioural skills.

As was evidenced by Coetzee et al. (2016b) not all caregivers have the necessary skills to administer medications to their child. Caregivers do not check the accuracy of doses, or remove the bubbles from syringes, to ensure that the measurements are precise. Moreover, caregivers have been found to perceive paediatric ART regimens as difficult to administer (Elsland et al., 2018). Perceived difficulty of administration could lead to lower perceptions of self-efficacy to administer the medications, which in turn could result in lower levels of adherence. It is therefore key that caregivers are provided skills and tools to ensure that they are able to administer medication as prescribed (Amico & Orrel, 2012).

Use of the IMB-Model in Research

Factors of the IMB-model, namely information, motivation, and behavioural skills as discussed above, have been both theoretically and empirically linked to adherence. Studies conducted by Amico, Toro-Alfonso, and Fisher (2005), Amico et al. (2009), Norton et al. (2010), Rongkavilit et al. (2010), and Smith, Fisher, Cunningham, and Amico (2012) used the IMB-model to understand adherence amongst various population groups. These studies showed that adherence and adherence-related barriers could be explained by using this model. For example, Amico et al. (2009) examined ART adherence amongst a sample of HIV-positive adults in Mississippi, USA. The study found that those who possessed adherence-related knowledge, experienced social support, and held positive beliefs about adherence had improved adherence-related behavioural skills, and as such higher levels of self-reported adherence. Similar findings were reported by Amico et al. (2005) who studied adherence of adults with HIV to ART in Puerto Rico.

Further, the IMB-model has been used in interventions to address prevention of HIV (Fisher, Fisher, Bryan, & Misovich, 2002), as well as adherence to ART (Fisher et al., 2011). Fisher et al. (2002) implemented a school-based intervention with minority high school students in Connecticut, USA. The study implemented a classroom intervention, peer-based intervention, and a combined intervention, all of which intended to provide participants with HIV prevention information, motivation, and behavioural skills. The classroom intervention had significant effects on HIV preventative behaviours, such as condom use during sexual intercourse, immediately after

the interventions. Furthermore, this effect was maintained after one year. Fisher et al. (2011) employed the IMB-model in a computer administrated ART adherence support intervention, LifeWindows. This intervention was employed as part of routine clinical care with adults on ART. In the study, the barriers experienced by participants in terms of information, motivation, and behavioural skills were assessed. Participants were then offered a targeted intervention to address the issues reported. This intervention was found to improve adherence amongst patients, illustrating that interventions informed by the IMB-model are effective in enhancing adherence to ART.

Use of the IMB-Model in the Present Study

The Petrie device demonstration used in this study focuses on the first two components of the IMB-model model, specifically providing the caregiver with information, and motivation. The Petrie device demonstration clearly shows caregivers the importance of the child adhering to ART. The demonstration aims to increase caregiver understanding of the importance of ART adherence by providing caregivers with necessary information. Moreover, through illustrating to the caregiver the importance of ART, and showing the effect of adherence/non-adherence on the child's body, the demonstration may alter caregivers' perceptions regarding the efficacy of treatment. Increasing caregivers' belief in the efficacy and necessity of treatment may then motivate the caregiver to ensure that their child consistently adheres to ART. Through providing information and motivation, the demonstration may in turn influence the caregiver to implement behavioural change in administration of the child's ART (i.e. employ adherence-related behavioural skills). As such, the present study aimed to determine the acceptability, namely how participants reacted to the intervention, of the Petrie device demonstration, which is intended to enhance paediatric adherence to ART by providing caregivers with information and motivation for their child to adhere.

Summary of Chapter

A review of the literature shows that whilst PMTCT has been effective within South Africa, there are still a number of children who are vertically infected with HIV. Therefore, adherence to treatment is of crucial importance so as to ensure that treatment success is achieved for those living with HIV. However, there are various barriers and complicating factors in the adherence of children

to ART, resulting in adherence levels that are not meeting the target goal (>95%) in this population group. Yet, despite the need for interventions to address this, there is a lack of effective strategies to enhance adherence amongst paediatric patients.

Visual interventions are showing promise in the field of medication adherence. Success has been found in enhancing adherence to ART using such strategies, one of which is the Petrie device demonstration, an active visualisation device. The theoretical framework of the present study, the IMB-model was discussed in detail, and a description was provided of how it was used in the study. The present study adapted the Petrie device demonstration, and aimed to determine its acceptability amongst caregivers of children five years and younger on ART. The following chapter will outline the methodology used in the current study.

CHAPTER 3

METHODOLOGY

Introduction to Chapter

According to Bowen et al. (2009), the implementation of evidence-based interventions which have been "rigorously evaluated and found to be both efficacious and effective" (p.452) is the goal towards which the field of health promotion and illness prevention should strive. Feasibility studies are therefore of great importance in determining whether an intervention should be further tested to determine its efficacy (Bowen et al., 2009). One aspect of focus in a feasibility study is that of acceptability, which allows the researcher to determine how intended recipients reacted to the intervention (Bowen et al., 2009). Understanding how participants react to an intervention allows researchers to adapt the protocol as necessary for use in RCTs. Qualitative research in particular has been identified as useful in addressing questions of acceptability (O'Cathain et al., 2015). A qualitative methodology provides a means by which researchers are able to gain an in-depth understanding of participants' reactions to a particular intervention, which, if well-conducted, can make an important contribution in determining the feasibility of a particular intervention (O'Cathain et al., 2015).

Below, I outline the aims and objectives of the present acceptability study using the Petrie device demonstration, with caregivers of children five years and younger on ART. I then provide a detailed description of the research design, sampling, and recruitment process, after which I provide a detailed description of the research setting and procedure. I then discuss the instruments and demonstration, including a section on the language used in both. I then provide a description of the data collection and analysis procedure. I then elaborate on the steps undertaken to ensure trustworthiness in this qualitative study. Finally, I address the ethical considerations pertinent to the present study.

Research Aims and Objectives

In the present study I aimed to determine the acceptability of a visual intervention, more specifically the Petrie device demonstration, amongst caregivers of children five years and younger with HIV who are receiving ART.

The objectives for the proposed study were:

1) To examine caregivers' thoughts and opinions of the Petrie device demonstration, specifically relating to information, motivation, and behavioural skills.
2) To determine whether caregivers felt the Petrie device demonstration is appropriate to implement with others, specifically in a clinic setting.
3) To explore caregivers' thoughts about future implementation of the demonstration, and suggested changes.

Research Design

An exploratory qualitative research design was used, in order to gain a more comprehensive understanding (Bless, Higson-Smith, & Sithole, 2013) of caregivers' opinions of the visual model. As conceptualised by Stebbins (2001), exploratory research allows for the description and understanding of a given phenomenon, which is particularly useful when little or no knowledge is available on the topic. As mentioned, the field of visual interventions is still in its infancy, with the current project being the first study to assess the acceptability of the Petrie device demonstration amongst caregivers to children on ART. Therefore, in allowing for a detailed and insightful examination (Stebbins, 2001) of this little studied intervention, an exploratory research design was most appropriate for use in the present study. Additionally, a qualitative methodology is particularly suitable for an exploratory research design, as it enables an in-depth examination of the phenomena under study. Qualitative research is particularly useful, as it incorporates an individual's perspective, usually in their own words, providing the researcher with insights from those experiencing a particular phenomenon themselves (Zvonkovic, Sharp, & Radina, 2012). Use of a qualitative methodology allowed for a rich examination of caregivers' reactions to the demonstration, which would perhaps not have been achieved with a purely quantitative

methodology. As the current study aimed to determine the acceptability of the Petrie device demonstration, with change over time not assessed, a cross-sectional design was also most suitable.

Quantitative data, in the form of questionnaires, was also collected. However, the study was not a mixed methods study, as the participant responses to the quantitative questionnaires were used to understand the sample characteristics in terms of participants' understanding and beliefs of their child's diagnosis and treatment, as well as adherence and reported barriers to medication adherence. Additionally, a brief quantitative assessment of participants' experience of the demonstration used in the study was employed for methodological triangulation. This quantitative assessment was used in a "complementary" (Patton, 1999, p. 1193) manner, and allowed for greater trustworthiness in determining caregiver's reactions to the demonstration. This methodological triangulation is further discussed below (see Trustworthiness).

Sampling and Recruitment of Participants

Caregivers were recruited from two healthcare facilities in the Western Cape. It should be noted that the names of the facilities have been concealed both here and in the approval documents included in the appendices (see Appendix A and Appendix B for site approval letters) so as to avoid stigmatisation of participants. A combination of convenience and purposive sampling was used in the study. Convenience sampling is a non-probability sampling technique, involving the selection of subjects based on their accessibility and proximity to the researcher (Bless, Higson-Smith, & Sithole, 2013). Convenience sampling was used in the selection of the data collection sites, as these healthcare facilities were selected based on their accessibility and proximity to the researcher. However, it should be noted that the recruitment sites are healthcare facilities that serve a large proportion and diverse population of individuals seeking healthcare in the region. Further information on the sites is provided below (see Research Setting). Purposive sampling allows the researcher to identify and select potential participants who can be deemed as 'information-rich' (Palinkas et al., 2015) due to their expertise or knowledge of a particular phenomenon. Purposive sampling was used to identify caregivers who met the study's eligibility criteria, which were as follows:

- Participants in the study were caregivers to children five years and younger on ART.
- The caregiver was defined as the individual who regularly attends clinic visits with the child (attended >1 clinic visit with the child since the child has been on ART) and/or is involved in administering the medication to the child at home.
- Caregivers must willingly give consent to participating in the study.
- Caregivers need to be competent in either English or Afrikaans as a first or second language.
- Caregivers must be 18 years of age or older.
- Neither the caregiver nor the child must require urgent medical attention.

In accordance with the research proposal approved by Stellenbosch University's Health Research Ethics Committee (HREC) (Reference number: S17/09/182), and so as not to disrupt normal clinic processes, I did not directly approach possible participants for recruitment. As recommended by and arranged with the two facilities in question, possible participants were identified for recruitment based on the age of the child as indicated on the front of the child's clinic file. I did not access the information within the files. Clinic files of children 5 years or younger on ART were flagged for recruitment by me. I did so by reviewing the front cover of the files of children who were booked for consultations that day in order to determine the age of the child. If the child was 5 years or younger, I placed a purple coloured Post-it note on the front of the child's file to indicate to the healthcare practitioner that the caregiver be referred for participation in my study. The text on the Post-it note read "REFERRAL: Participation in study using visual demonstration to explain how child's medicine works". The room in which sessions were conducted was also written on the Post-it note for ease of reference. Caregivers whose children's files were flagged by me were then referred for participation by the healthcare practitioner following the child's clinic consultation.

Description of Participants

A sample of eleven caregivers to children five years and younger on ART were recruited for the study. One additional participant was excluded, as they did not complete the study. This participant

completed the first three questionnaires, and left to see the doctor prior to the demonstration portion of the session, after which they did not return.

Research Setting

Participants were drawn from two public healthcare facilities in the City of Cape Town municipality, in the Western Cape, South Africa. The City of Cape Town area, according to the Western Cape Government (Western Cape Government, 2017), was home to an estimated 4 055 580 people in 2016. Moreover, within this municipality, there are wide socioeconomic disparities. According to the census data obtained in 2011 (StatsSA, n.d.a) (http://www.statssa.gov.za/?page_id=993&id=city-of-cape-town-municipality), it was reported 13.7% of households had no monthly income, with 36% of households in the municipality living below the poverty line of less than R3500 income per month. The unemployment rate at the time was reported as 23.9%. Additionally, formal dwellings only accounted for 78.3% of residences, with a large number of informal settlements in the area. Of the households in the municipality, 3.7% do not have electricity for lighting, and 8.8% do not have access to on site sanitation facilities. The recruitment and data collection sites therefore service a diverse population group within the area. A description of each healthcare facility follows below.

Infectious Diseases Clinic (IDC) at Site A

The IDC at Site A was a recruitment and data collection site of the present study. Site A is located in Somerset West, outside of Cape Town. This health district services the towns of Somerset West, Strand, Gordon's Bay, and other smaller areas. Through the IDC, an outpatient section of the hospital, Site A provides a full ART service. Consultations for paediatric patients take place on a Thursday, during which caregivers and children are able to see a doctor, and then collect the necessary medications from the hospital pharmacy. Sessions of the present study took place in the Pharmacy Counselling Room, located in the pharmacy section of the clinic where patients collect their medications. Both the IDC and the pharmacy are on the ground floor. The IDC services approximately 170 children up to 18 years of age. Of the eleven participants in the present study,

eight were recruited from Site A, out of a total of 48 patient files flagged for referral for participation at this facility.

Infectious Diseases Clinic (IDC) at Site B

The IDC at Site B was a recruitment and data collection site of the present study. Site B is located in Bellville, in Cape Town. As a tertiary healthcare facility, patients are referred from primary or secondary healthcare facilities. The hospital services a drainage area in the province, providing services to individuals from various communities. Site B operates an IDC, including a full ART service. Here, children and caregivers are able to see a doctor, and collect medication(s). Sessions for the current study took place in a room which attempts to provide a recreational space for children at the hospital. The room is located on the same floor as the IDC, down the hall from the doctor's consultation rooms. After their clinic session, caregivers and children need to collect their medicine(s) from the hospital pharmacy. The IDC is located on the 8th floor of the hospital, whereas the pharmacy is on the ground floor. Site B's IDC provides services to approximately 250 children up to 18 years of age. Three participants were recruited from Site B, out of a total of 52 patient files flagged for referral.

Paediatric Patients' Follow-Up Procedure

The follow-up, i.e. clinic attendance following diagnosis and initiation on ART, of paediatric patients is similar at both sites, as doctors from Site B's IDC are also responsible for seeing and treating paediatric patients at Site A's IDC. It should be noted that whilst the follow-up procedure is similar, it is also dependent on each individual patient. Children who have recently started ARVs initially attend the clinic monthly for between four and six months, after which they come every two to four months for follow up appointments or to collect their medications. Children under one year of age attend the clinic more regularly than older children, as their medications require adjustments according to weight more often. Older children and adolescents attend the clinic every four months. Once patients have seen the doctor, they then proceed to the pharmacy to collect their medications.

Research Procedure

Prior to commencement of the study, I received ethical clearance from Stellenbosch University's Health Research Ethics Committee (HREC reference number: S17/09/182) (see Appendix C for ethical approval). Further, I obtained permission to conduct this research from the Western Cape Department of Health (see Appendix A and Appendix B for site approval letters). Several meetings were held with hospital management to procure permission for recruitment and data collection. Both healthcare facilities were approached in the planning phases of the project. Following ethical approval from HREC and permission from the Western Cape Department of Health, meetings with the relevant contact persons at each of the hospitals were held to make the necessary arrangements regarding recruitment and data collection.

To recruit participants, I flagged clinic files (based on the age of the child), indicating the possibility for referral, and the nature of the project. At the end of the child's clinic session, the doctor or healthcare professional would then refer the caregiver for participation in the study.

Sessions were conducted at both facilities in private rooms. Whilst the children brought to the healthcare facility by the caregivers were not active participants in the study, i.e. the contact session was targeted at the caregiver and questionnaires and the interview were completed by the caregiver, the child was present during the contact session. Therefore, I set up child-friendly activities in the room, including colouring books, and a puzzle mat.

Caregivers were provided with a brief explanation of the study and what would be expected of them if they consented to participate. I took field notes regarding reasons for declining to participate, which are included below (see Data Collection). Caregivers (hereafter referred to as participants) who met the eligibility criteria and were interested in participating were informed about the nature of the study, and the risks and benefits of participation using informed consent procedures (see Appendix D for the participant information leaflet and consent form). It was also indicated to participants that participation in the study was entirely voluntary, and that they could withdraw at any time. Furthermore, participants were assured of the confidentiality of their responses, and that all data obtained would remain anonymous. Participants were provided with the

option to have the information leaflet and consent form, as well as the questionnaires, read to them. The steps then followed in data collection after participants had provided written informed consent are illustrated in Figure 3.1 below.

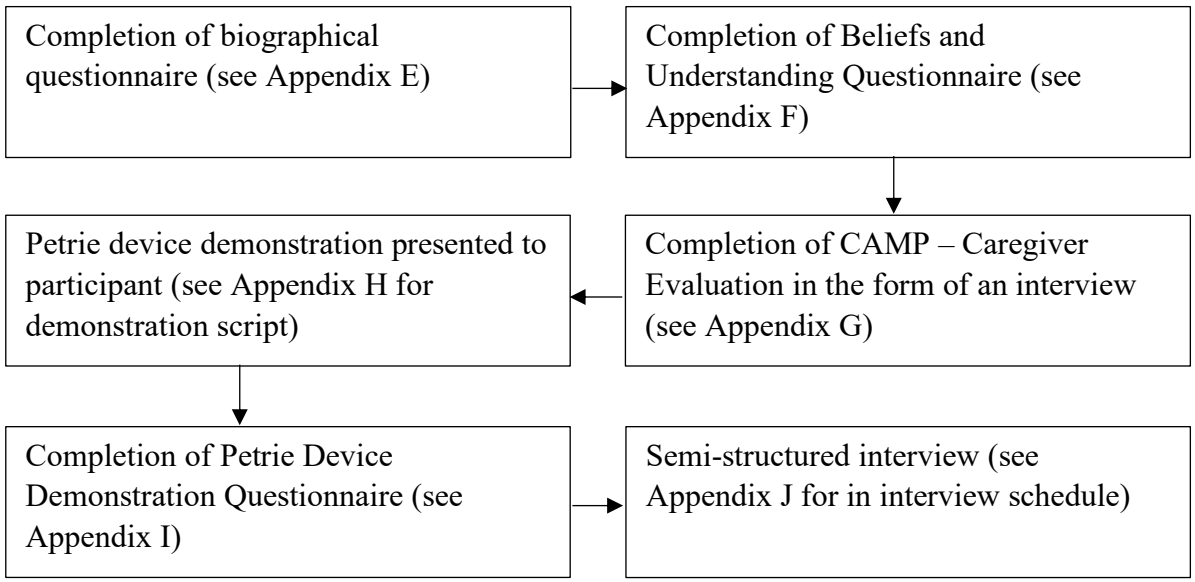

Figure 3.1. Data collection procedure.

Participants began by completing a biographical questionnaire (see Appendix E for the biographical questionnaire) regarding themselves and the child they had brought to the clinic (see Instruments for a description of each of the questionnaires used in the study). Participants then completed two questionnaires: a study specific Beliefs and Understanding Questionnaire (See Appendix F), and the Comprehensive Adherence Measurement for Paediatrics (CAMP) - Caregiver Evaluation (see Appendix G). The former consisted of questions regarding the participants' beliefs and understanding of the child's diagnosis and medication, which required participants to rate their responses on a scale of 0 to 10. Participants could elect to read and fill in these questionnaires themselves or have them read out loud and their verbal responses recorded on the questionnaires by me. The CAMP - Caregiver Evaluation obtained information regarding medication administration and barriers to adherence, and was administered to all participants in the form of an interview, in which I filled in participant responses.

Following the completion of the questionnaires, participants were presented with the Petrie device demonstration which was demonstrated to them following a standard script (see Appendix H for demonstration script). The demonstration lasts approximately 15 minutes, and explains the effects of adherence and non-adherence to ART on the body. After the demonstration, participants completed a short questionnaire regarding their experience of the Petrie device demonstration (see Appendix I), in which they were required to rate their responses to the questions on a scale of 0 to 10. Participants then participated in a semi-structured interview (see Appendix J for interview schedule), regarding their thoughts and opinions of the visual model they had just been presented with. Interviews were audio recorded by the researcher with permission from the participants. The total length of sessions ranged between 52 and 88 minutes long.

Instruments

Biographical Questionnaire

The biographical questionnaire (see Appendix E) obtained information regarding the caregiver's age, ethnic group, gender, language, place of residence, social class, education, and current employment. The participants were also asked whether they were on any medication, and if so, what medication were they currently taking. This question was used to determine participants' familiarity with medication usage, as well as whether they themselves were on ART. The relationship between the participant and the child was also ascertained (i.e. whether the caregiver was the biological parent, relative, or guardian of the child). Participants were also required to indicate whether they were the individual who regularly brings the child to the clinic since treatment initiation, as well as whether they regularly administer the child's medication, whilst the child has been on ART.

The questionnaire also included items regarding the child, such as their age, gender, and place of residence. Information regarding the date of the child's HIV-diagnosis, length of time on ART, as well as the child's knowledge of their HIV-status was also obtained in this questionnaire.

Beliefs and Understanding Questionnaire

This study-specific questionnaire (see Appendix F) aimed to assess the participant's beliefs and understanding regarding the child's HIV-diagnosis and treatment. The questionnaire was adapted from the original used in the study with adults (Jones et al., 2018), so as to be relevant to the population group of the present study. For example, a question such as "How long do you think your HIV infection will continue?" was reworded as "How long do you think your child's virus infection will continue?". Participants were required to rate their responses on a scale from 0 to 10. The options for the previous example question ranged from 0 ("A very short time") to 10 ("Forever"). Participants were reminded prior to completion of the questionnaire that there are no right or wrong answers to the questions – a correct answer is one that is true for them.

CAMP – Caregiver Evaluation

The Comprehensive Adherence Measurement for Paediatrics (CAMP) – Caregiver Evaluation (see Appendix G), was developed by Vreeman et al. (2015) in order to identify questionnaire items that best predicted paediatric adherence to ART. The CAMP is a caregiver-report questionnaire, containing 48 items. Items included in the questionnaire were determined by literature review, expert panel consultation, and qualitative work (Vreeman et al., 2015). Questionnaire items included knowledge of the medicines currently taken by the child, late and missed doses, adherence barriers, social barriers, household characteristics, and a visual analogue scale to determine the number of doses taken in the past week. Items included in this questionnaire were thoroughly evaluated in the study conducted by Vreeman et al. (2015) in Kenya. For the purposes of the present study, six items were removed from the questionnaire, the questions of which were as follows:

- "Are you currently enrolled in AMPATH nutrition program? □Yes □No"
- "Imagine I could give you 5 cows now OR I could give you 8 cows in 5 years. This is not a real situation; this is a hypothetical situation to imagine. Which would you prefer? □ 5 cows now □ 8 cows in 5 years"
- "We want to know whether you agree or disagree with this statement: 'I will sometimes give something up now so that I will get something better in my future.' An example is: 'I will

not slaughter my cow for meat this year so that my cow could have a calf next year, and then I could slaughter 2 cows.' Do you: □ Strongly disagree □ Disagree □ Neither agree nor disagree □ Agree □ Strongly agree"

- "Where do you get your water for drinking? □ Piped (outside) □ Piped (in home) □ Borehole □ River/stream/lake □ Other _____"
- "Do you boil your drinking water? □ Yes, always □ Yes, sometimes □ No

  If no, use other treatment? □ Yes, always □ Yes, sometimes □ No"
- Visual analogue scale determining how many medication doses were missed in the mornings and evenings over the past week

These items were removed due to their lack of relevance for the participant group and/or the purpose of the current study. The visual analogue scale was removed as this information is already obtained earlier in the questionnaire. I obtained permission to use this questionnaire from the developers (see Appendix K).

Petrie Device Demonstration Questionnaire

The Petrie Device Demonstration Questionnaire is a 6-item questionnaire, assessing participant's experiences of the Petrie device demonstration (see Appendix I). Items such as "How helpful was the demonstration in helping you understand your child's medication?" required participants to rate their responses on a scale of 0 to 10 (e.g. 0 "Not at all helpful", 10 "Extremely helpful"). This questionnaire was adapted from a questionnaire used in the parent study with adults.

Semi-Structured Interview

In order to obtain an in-depth understanding regarding participant's experiences and thoughts of the Petrie device demonstration, participants were asked to take part in a semi-structured interview. The interview schedule (see Appendix J) was developed in consultation with the interview schedule used in the parent study, and was formulated in line with the IMB-model (Fisher et al., 2006). The model suggests that behavioural change (adherence to ART) is dependent on information, motivation, and behavioural skills to perform the necessary tasks. As such, the interview included questions regarding the information provided by the model (e.g. "Did you learn anything from

seeing the demonstration?"), motivation (e.g. "Has the demonstration changed the way that you feel/think about your child's virus and the medication that they need to take?"), and behavioural skills ("Do you think, after seeing the demonstration, that you will do anything differently when you give your child their medication? What would you change or not change?"). Questions regarding the utility, feasibility, and implementation of the Petrie device demonstration were also included in line with the objectives of the study.

Petrie Device Demonstration

The Petrie device is an active visualisation model, designed to improve adherence to ART. It is a Perspex model designed to resemble the torso of the human body (see Figure 3.2 and Figure 3.3), which aims to illustrate to patients how HIV is controlled in the body when medication is taken daily as prescribed.

Through altering the pH balance of the solution in the Petrie device, individuals are shown what the effects of ART are on HIV. The Petrie device demonstration follows a standardised script (see Appendix H) adapted from the demonstration script used in the parent study. The demonstration takes approximately 15 minutes, and was presented to participants in either English or Afrikaans depending on their language preference.

The demonstration is designed to illustrate to participants what takes place over a twelve-day period in which medication is adhered/not adhered to. In order to illustrate the passing of time, a calendar is used in the demonstration to convey to the viewer on which days medication is adhered to, or not adhered to. The device begins with a pink solution (dilution of sodium hydroxide and water, mixed with the pH indicator Phenolphthalein) inside the device (see Figure 3.2 Image A). The pink colour indicates the HIV virus can replicate. 'Medication', a dilution of acetic acid in water, is then added to the model (see Figure 3.2 Image B), which changes the pH balance, resulting in the liquid changing to clear (see Figure 3.2 Image C and Image D). The clear liquid indicates that the presence of medication is controlling viral replication.

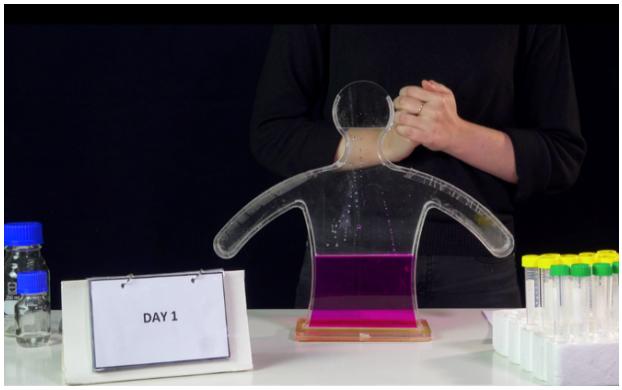

Image A

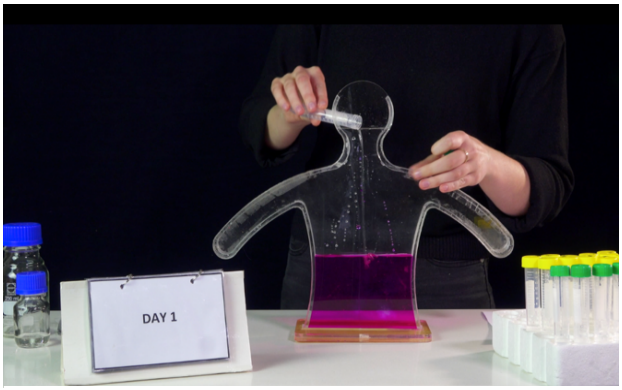

Image B

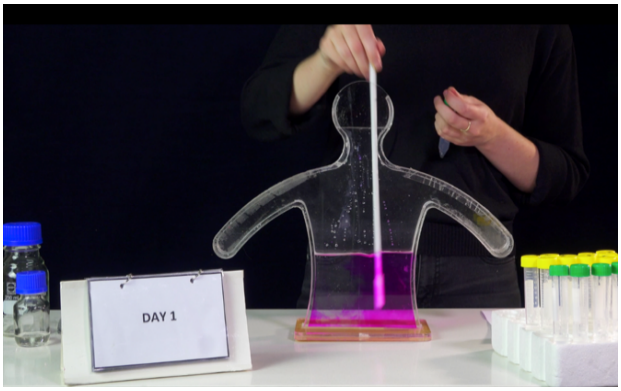

Image C

Image D

Figure 3.2. Demonstration of medication adherence.

Image E

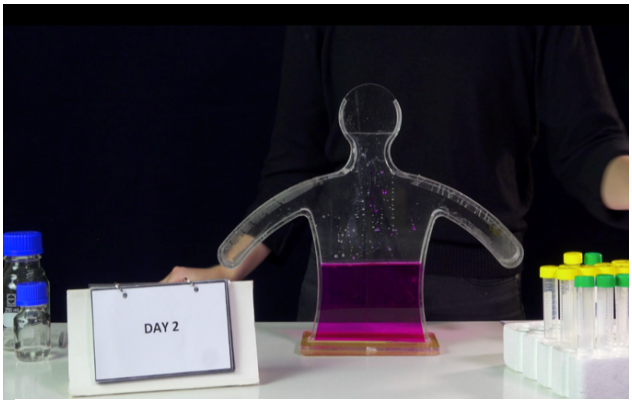

Image F

Figure 3.3. Demonstration illustrating need for medication every day.

In order to illustrate to participants that the virus is always present in the body, at the beginning of each 'day' as conveyed by the calendar, a dilution of sodium hydroxide in water, intended to represent the HIV virus, is then added to the model (see Figure 3.3 Image E). This alters

the pH, changing the liquid to pink (see Figure 3.3 Image F). This illustrates to participants that medication needs to be taken every day.

To demonstrate non-adherence, the 'virus' solution is added to the model, without the addition of 'medication' solution, increasing the concentration of sodium hydroxide. This is used to demonstrate the effects of non-adherence over a short period (i.e. missing two doses), and over a longer period. In demonstrating short term non-adherence, when 'medication' is added to the model again, the liquid will not immediately return to clear, and will instead lighten the solution inside the model. The solution will only return to clear after 'medication' has been added for two 'days' subsequent to the last missed 'dose'. In demonstrating the effects of long-term non-adherence, once 'medication' is added to the model again, the solution in the model does not lighten and remains a deep pink colour.

Adaptation of the Petrie Device Demonstration

The Petrie device demonstration used in the parent study used effervescent Asproclear tablets (i.e. aspirin) to affect colour change when 'medication' was added (see Appendix L for the chemistry used in the parent study). However, as most children between the ages of 0 and 5 however are on a syrup-based medication regimen, the use of tablets was not appropriate to use in an intervention targeted at caregivers of paediatric patients. The chemistry of the model used in the present study was adapted by me to incorporate a liquid 'medication' solution prior to commencement of the study (see Appendix M for the chemistry used in present study) in consultation with two staff members from Stellenbosch University's Process Engineering Department.

Language Used in Instruments and Demonstration

Sessions were conducted in either English or Afrikaans, as I am fluent in both languages. The biographical questionnaire, beliefs and understanding questionnaire, CAMP – Caregiver Evaluation, and the interview schedule were translated from English into Afrikaans by Stellenbosch University's Language Centre, with emphasis on ensuring that they were written in everyday language so as to be as accessible to participants as possible. The Petrie Device Demonstration

Questionnaire and demonstration script were adapted from the Afrikaans versions used in the parent study.

Due to the age group of the children taking part in the study (five years and younger), most of the children (N=10, 90.91%) were unaware of their HIV-status. To avoid inadvertent disclosure during the session, the term 'virus' was used instead of HIV in the questionnaires, demonstration, and interview.

Data Collection

Following the research procedure as described above, recruitment and data collection was conducted from 7 March to 31 July 2018. I was present at Site B's Hospital's IDC on Tuesdays, and at Site A's IDC on Thursdays. The intended sample size of the study was 20 to 30 participants, however, over the course of data collection recruitment was slow. I flagged 100 patient files for referral to participate. Of those referred to me, 71 caregivers did not have any contact with me at all, and 17 caregivers declined to participate. Those who declined to participate cited various reasons. Of the caregivers who declined to participant, most indicated that they did not have time to participate in the study (*n*=8, 47.05%), as they had other commitments such as needing to get to the pharmacy, or see another healthcare professional at the clinic. Three caregivers (17.64%) indicated that they did not have time as they needed to return to work after bringing their child to the clinic. Additionally, a small number of caregivers (*n*=2, 11.76%) stated that they needed to get to their transport from the clinic, and therefore could not take part. Two caregivers (11.76%) indicated that they did not usually attend clinic visits with the child, nor did they administer the child's medication. One caregiver felt that they already had the knowledge that the demonstration would provide, and therefore did not want to take part. Finally, one caregiver declined to participate as they were not comfortable with either English or Afrikaans.

Twelve caregivers consented to participate, one of which was excluded from the study as they did not complete the full session, with a final sample size of eleven caregivers. Data was collected and analysed concurrently. As evidenced slow recruitment and time constraints contributed to the small sample size. The possible range of responses to the interview questions was

fairly narrow, and thus we feel that we were able to reach data saturation. Saturation occurs when no new themes are being identified. However, there is the possibility that with a larger sample size, further themes could have been identified in the data.

Quantitative data analysis

Participant responses to the biographical questionnaire, Beliefs and Understanding Questionnaire, CAMP – Caregiver Evaluation, and Petrie Device Demonstration Questionnaire were recorded using Microsoft Excel for Mac[1]. I checked the recorded data for accuracy, after which the data were then imported into IMB SPSS Statistics[2] for analysis. The dataset was cleaned and checked for parametric assumptions of normality. A descriptive analysis was run to determine frequencies and measures of central tendency. The results of the Beliefs and Understanding Questionnaire, the CAMP – Caregiver Evaluation, and the Petrie Device Demonstration Questionnaire are included in Chapter 4.

Qualitative data analysis

I used thematic analysis (Braun & Clarke, 2006) to analyse the qualitative data inductively. Thematic analysis is a form of qualitative data analysis, providing a method of "identifying, analysing, and reporting patterns (themes) within data" (Braun & Clarke, 2006, p. 79), allowing for a rich, detailed analysis. Inductive thematic analysis provides a method of analysis in which the researcher has freedom in determining what is important in the data and what constitutes a theme, as the researcher is not operating within a pre-existing coding, or theoretical framework. The themes identified are therefore driven by the data. Once the data analysis has been conducted, the researcher can then return to the literature, in order to interpret the data within a particular theoretical context.

Qualitative research can be criticised as allowing for an " 'anything goes' " approach in data analysis (Antaki, Billig, Edwards, & Potter, 2002, para. 6), as the flexible approach may lead to inconsistencies and a lack of coherence in the analysis (Nowell, Norris, White, & Moules, 2017).

[1] Version 16.5 (180709). Copyright © Microsoft.
[2] Version 25, 64-bit edition. Copyright © IBM Corporation and its licensors 1989, 2017.

However, thematic analysis, as conceptualised by Braun and Clarke (2006), provides a step-by-step approach to thematic analysis, enabling transparency in the analysis process, allowing the researcher to make their method of analysis explicit. It includes six phases, namely: "familiarising yourself with your data" (1); "generating initial codes" (2); "searching for themes" (3), "reviewing themes" (4); "defining and naming themes" (5); and "producing the report" (6) (Braun & Clarke, p. 87). Table 3.1 contains a summary of the six phases identified by Braun and Clarke (2006).

The software programme ATLAS.ti for Mac[3] was used to assist in the data analysis process. Below I outline how each phase of the data analysis was conducted in line with the phases set out by Braun and Clarke (2006), as well as indicating how ATLAS.ti was used in this process.

Phase 1: Familiarising yourself with your data

This phase involved the transcribing, translation, and repeated reading of the interview transcripts. After data collection and prior to transcribing, I would listen to the interview to ensure that I was familiar with the language, style, and content of the audio recording. I then transcribed the recording verbatim, after which I listened to the recording again, and reviewed the transcript in order to ensure accuracy. After the transcribing was complete, I read through each interview again.

As the majority of the interviews (N=8, 72.2%) were conducted in Afrikaans, a significant portion of time was spent translating interviews from Afrikaans to English after initial transcription. I reviewed the translations numerous times in order to ensure that the content and meaning of what participants had said had not been altered. It should be noted that language use errors were not corrected in the transcribing and translation process, in order for the written text to remain true to what the participant had said, and not potentially alter the meaning thereof in any way.

Once all interviews were transcribed and translated where necessary, the transcriptions were imported into ATLAS.ti. During the re-reading of the transcripts, I made use of ATLAS.ti's memo function in order to note what participants were saying and particular points of interest, as well as to generate initial code ideas. During this process I had already begun to form ideas of possible themes based on the ideas prevalent in the data.

[3] Version 8.2.4 (599). Copyright © 2013-2018 ATLAS.ti Scientific Software Development GmbH.

Table 3.1

Phases of Thematic Analysis.

Phase	Description of the process
1. Familiarising yourself with your data:	Transcribing the data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking in the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Note. Adapted from "Using Thematic Analysis in Psychology" by V. Braun and V. Clark, 2006, *Qualitative Research in Psychology, 3*, p. 87. Copyright 2006 Edward Arnold (Publishers) Ltd.

Phase 2: Generating Initial Codes

I created a list of initial code ideas, in order to create as much structure in the analysis process from early on, which allowed for a systematic analysis. I then began the first round of coding, coding all relevant quotations. During this process codes were added to and removed from the initial list, and altered as necessary.

Phase 3: Searching for Themes

During this phase of the analysis codes were organised into four broad candidate themes, relating to the caregiver's role, the demonstration, HIV and treatment, and implementation of the

demonstration. Codes were grouped using the code group manager function in ATLAS.ti in order to organise the data into potential themes. Codes were also colour coded to indicate the broad theme of which they formed a part. During this phase, codes were merged and altered in order to refine and make the analysis more cohesive. Redundant codes were refined or removed. The coding was reviewed during this process by my supervisor.

Phase 4: Reviewing Themes

In order to review the themes, two levels of review were conducted. Level 1 involved reviewing all the coded extracts for each theme, in order to determine whether the coded data formed a "coherent pattern" (Braun & Clarke, 2006, p. 91) in relation to the theme under which they were grouped. After reading through the extracts for each theme, it was evident that three of the candidate themes, namely the caregiver role, the demonstration, and implementation of the demonstration, needed to be further refined and sorted into subthemes. Once I was satisfied with the first level of review, I continued to the second level. The final review of the themes involved determining whether the identified themes accurately reflect the meanings present in the entirety of the data set.

Phase 5: Defining and Naming Themes

Once I was satisfied that the themes identified represented the data, I named the themes and subthemes. The naming of the themes was an iterative process, beginning in phase 3. As indicated, four themes were identified in the data, namely, (1) Reactions to 'seeing' the Petrie device demonstration, (2) Responsibilities as caregiver, (3) Thoughts on HIV and treatment, and (4) Future implementation of the Petrie device demonstration. Of these themes, Thoughts on HIV and treatment was the only theme to not be further organised into subthemes.

Phase 6: Producing the Report

The final phase involves presenting the results of the analysis, having selected compelling extracts from the data to illustrate the themes. The findings of the study are presented in Chapter 4. It should be noted that in reporting on the findings, all participants were assigned pseudonyms.

Trustworthiness in Qualitative Research

The trustworthiness of qualitative research is often questioned, and it is suggested by Shenton (2004) that this is because issues of reliability and validity cannot be addressed in the same manner as in quantitative research. Furthermore, the flexible approach allowed by qualitative thematic analysis, as employed in the present study, lends itself to various criticisms, as were discussed. Therefore, qualitative researchers must be able to show that data collection and analysis has been conducted in a manner that is "precise, consistent, and exhaustive" (Nowell et al., 2017, p. 1) by recording in a systematic manner the methods used, and disclosing these in enough detail. This allows the reader to audit the analysis conducted by the researcher (Koch, 1994), and determine the trustworthiness thereof. Guba (1981), and Guba and Lincoln (1981) provide a set of criteria for ensuring and assessing trustworthiness of naturalistic inquires, including qualitative research. The authors identified four key components, namely credibility, transferability, dependability, and confirmability. These criteria will be discussed individually below in relation to the data analysis of the present study.

Credibility. Credibility is the first criteria addressed by Guba (1981), and Guba and Lincoln (1981). This refers to the fit or congruence between the respondents views (reality), and the interpretations of the researcher (findings) (Tobin & Begley, 2004). Credibility can be ensured by conducting member checks (Guba, 1981). One means of conducting member checks is to ask research participants clarifying questions during the interview process (Shenton, 2004). In the present study, I made sure to ask such questions if (i) what a participant said was unclear, and (ii) in order to ensure that I had an accurate understanding of their responses. Additionally, encouraging participants to be honest during the data collection process can assist with credibility (Shenton, 2004). Through creating a comfortable rapport with participants in the present study, and reminding them that there were no right or wrong answers to posed questions, I attempted to elicit data that was as true to reality as possible.

Additionally, credibility can be addressed by employing methodological triangulation and investigator/analyst triangulation. Patton (1999) indicates that studies using only one method of data

collection are more vulnerable to the errors tied to that particular mode of enquiry. In order to mitigate this to an extent, a short questionnaire (see Appendix I for Petrie Device Demonstration Questionnaire) was used to provide a quantitative measure of participants' reactions to the demonstration. This was used to contextualise the qualitative findings. Furthermore, as indicated, analyst triangulation is important to ensure credibility, as it can assist in reducing bias that may arise as a result of a single individual analysing the data. In the present study my research supervisor reviewed my qualitative data analysis in order to ensure that my interpretation was congruent with what the participants were reporting.

Transferability. Transferability refers to the generalisability of a study's findings. However, naturalistic modes of enquiry, such as qualitative methods, do not strive to make claims of applicability, and therefore should rather aim to provide a rich description of the phenomena at hand (Guba, 1981). In the present study, I attempted to do so by employing purposive sampling, a method recommended by Guba (1981), to identify participants that fit the study's eligibility criteria, and that would be able to provide a rich account of the phenomenon of study. Additionally, I was able to collect "thick' descriptive" (Guba, 1981, p. 86) data by describing the study sites, collecting demographic information on the sample, assessing participants understanding and beliefs of the child's diagnosis and medications, and employing a comprehensive measurement of adherence. These measures allowed for an in-depth description of the context and experiences of the study's participants.

Dependability. Dependability refers to the extent that the findings of a study are consistent and replicable. It is argued however that this may be hard to achieve in qualitative research, due the changing nature of the phenomena under study (Shenton, 2004), and is therefore perhaps not relevant to the field (Guba & Lincoln, 1981). Yet, such issues must still be addressed, and it is thus crucial that the methods employed in qualitative studies are reported on in detail (Shenton, 2004), ensuring that the steps taken in research are logical and well documented (Tobin & Begley, 2004). In the present study, I thoroughly documented the research plan and execution thereof, making explicit the methods used in data collection and analysis, as was presented in this chapter.

Confirmability. In research, the objectivity of a study is of key concern (Guba & Lincoln, 1981). Therefore, the researcher must strive to ensure that the results reported are reflective of the experiences and views of the participants, and are not the result of the predispositions of the researcher (Shenton, 2004, p. 72). According to Guba and Lincoln (1981), this is achieved when the criteria of credibility, transferability, and dependability have all been met. Additionally, in addressing the issues of confirmability, the researcher must acknowledge their positionality within the research and provide a description of their experiences (Koch, 1994). Koch (1994) specifically recommends keeping a journal of one's experiences whilst conducting research. Moreover, Patton (1999) indicates that the researcher should provide information regarding their training and preparation.

When beginning this research project, I had just completed my Bachelor of Arts Honours degree in Psychology. I was relatively inexperienced in the field of the current research study, yet had completed a qualitative research project as a component of my Honours degree. In order to prepare for the current study, I read extensively on research in the field of paediatric HIV and visual interventions. Moreover, I sat in on sessions conducted as part of the parent study (reported on in Jones et al., 2018), ensuring that I was familiar with the original study protocol and demonstration. As indicated, I did not have much research experience at the time of study commencement, yet I attempted to mitigate this by preparing thoroughly for data collection, ensuring that I was familiar with the study protocol, practicing the demonstration numerous times, and familiarising myself with the measures used.

During data collection I took field notes of my experiences at the sites and in sessions conducted with participants, in order to be able to reflect thereon, particularly in terms of how I assumed participants may have perceived me. I was aware of the fact that I was an 'unfamiliar face' to participants, who were accustomed to dealing with the regular clinic staff and doctors. I noted that some participants assumed that I was a doctor and referred to me as such during the sessions. Moreover, whilst most of my participants were older than me, they appeared to view me as an authority figure. Patton (1999) notes that the presence of a researcher may create a "halo effect" (p.

1202), which could cause participants to behave in a certain way, and perhaps "show off" (p. 1202). In the particular study, participants' assumption that I was a doctor may have led to inflated levels of self-reported adherence, or participants not providing an honest account of their experiences, based on the information they may have assumed that I was hoping to obtain.

Ethical Considerations

Informed Consent Procedures

As indicated, all participants provided written informed consent prior to commencement of the session, indicating that they understood the study, and what the research procedure would entail. The research procedure was explained to potential participants prior to participation (see Appendix D for the Information Leaflet and Consent Form). I emphasised that participation was voluntary, and that the participant could withdraw from the study at any point, even if they had provided their consent to participate initially. Participants were also ensured that they would remain anonymous, and that their identity would be protected. In order to ensure this, I assigned all individuals a participant identity number (001 – 011), after which I assigned each participant a pseudonym for the purpose of reporting the findings. All data was entered into an anonymised database, stored in a password-protected file on a private computer. Moreover, all hard-copy data, such as completed questionnaires, were kept in a locked cabinet in an office in the Department of Psychology at Stellenbosch University.

Beneficence

One of the important principles in research is ensuring that the welfare of the participant is maintained, and that the research is of benefit to the participant in some way. Whilst the benefits of this demonstration for participants have not been determined, it could be assumed that providing the participant with greater knowledge and understanding of their child's medication regimen may be beneficial to participants. Additionally, whilst this study entailed no risks of which myself or my supervisor were aware of, we were mindful that the child's HIV-diagnosis may be a sensitive topic for participants. Therefore, prior to commencement of the session, all participants were informed that should they feel distressed during or after the session, I would refer them to a registered

counsellor at their healthcare facility (see Appendix D for Information Leaflet and Consent Form). However, no participants indicated the need for referral, and appear to have found the experience positive and useful, as will be further discussed in Chapter 4.

Summary of Chapter

In this chapter, I provided a thorough account of the research design, including the sampling strategies and recruitment of participants. A description of the research setting was also provided, examining the municipality which the two healthcare facilities formed a part of, as well as the sites themselves. The research procedure was described in detail, and the instruments used were discussed individually. Data collection was addressed, with a brief examination of recruitment success, based on files flagged, and field notes that I had kept during the research process. The quantitative data analysis was outlined, after which I provided a thorough examination of the thematic analysis used to analyse the qualitative data. I addressed issues of trustworthiness in qualitative studies, and stated how such concerns had been addressed in the research process and write-up thereof. Lastly, I addressed necessary ethical considerations of the research.

CHAPTER 4

RESULTS

Introduction to Chapter

In the following chapter, I present the findings of the present acceptability study. To begin, the demographics of the sample are outlined, including information on both the participant, and the child that the participant had brought to the clinic. Secondly, key participant characteristics are discussed, in order to provide greater understanding of the participants included in the study. This section provides an overview of relevant information, such as participant understanding of and beliefs about the child's diagnosis and medication. Moreover, participant knowledge of the child's ART regimen is examined, as is disclosure to others, caregiver consistency, self-reported adherence, and barriers to adherence that are experienced by the participant and the child. Thirdly, in order to triangulate the qualitative data, participants' responses to a brief questionnaire regarding their experience of the Petrie device demonstration are presented. Finally, the qualitative findings of the study are reported, examining the themes and subthemes identified in the data, with the use of illustrative quotations.

Sample Demographics

As can be seen in Table 4.1, the sample of the current study consisted of eleven participants(N=11) (i.e. caregivers to children five years and younger on ART), the majority of whom were female (n=10). All participants were assigned pseudonyms for the purposes of reporting the findings. Participant pseudonyms, and relevant individual participant characteristics are presented in Table 4.2.

Participant age ranged from 18 to 64 years, with the mean age being 40.1 years (SD=16.6). Most participants indicated that they were of a lower socioeconomic status, with four describing their social class as lower class, and three stating they were working class. A further three participants described themselves as middle class, with only one participant stating that she formed part of the highest socioeconomic grouping, namely 'higher class'.

Table 4.1.

Sample Demographics

Characteristics	*N*=11
Age of caregiver (Years) (Mean; Range)	40.09; 18 – 64
Caregiver gender	
Male	1
Female	10
Race	
Black	2
Coloured	9
Caregiver SES	
Lower	4
Working	3
Middle	3
Upper middle	0
Higher	1
Highest level of education of caregiver	
Grade 7	1
Attended high school, but did not matriculate	7
Matric	2
Tertiary	1
Employment	
Unemployed	4
Employed	4
Pensioner	3
Relationship to the child	
Biological mother	5
Grandmother	2
Grandfather	1
Aunt	1
Foster mother	1
Great-grandmother	1
Regular attendance of child's clinic visits	11
Regular administration of child's medications	10
Caregiver medications	
None	3
Yes	8
- *ARVs*	3
- *High blood pressure medication*	3
- *High blood pressure and diabetes medications*	1
- *Does not know*	1
Age of child (Months) (Mean; Range)	30.45; 10 – 60
Child gender	
Male	5
Female	6
Time since initiation on ART (Months) (Mean, Range)	19.81; 3 – 36

Table 4.2.

Participant Characteristics

PID	Pseudonym	Age	Caregiver medication	Relationship to the child	Child characteristics
001	Nina	18	Does not know	Biological mother	1 year old daughter, on ART for 1 year
002	Maria	63	High blood pressure	Grandmother	10 month old grandson, on ART for 3 months
003	David	63	High blood pressure	Grandfather	4 year old grandson, on ART for 2 years
004	Akhona	23	None	Foster mother	3 year old foster daughter, on ART for 3 years
005	Lerato	32	ARVs	Biological mother	5 year old son, on ART for 3 years
006	Jennifer	44	None	Grandmother	2 year old granddaughter, on ART for 2 years
007	Samantha	39	ARVs	Biological mother	14 month old daughter, on ART for 1 year
008	Gloria	38	High blood pressure	Aunt	23 month old nephew, on ART for 23 months
009	Louisa	30	None	Biological mother	2 year old son, on ART for 1 year
010	Vanessa	64	High blood pressure, diabetes	Great-grandmother	3 year old great-granddaughter, on ART for 2 years
011	Angeline	27	ARVs	Biological mother	4 year old daughter, on ART for 1 year

Most participants had attended high school, yet did not matriculate (*n*=7). Two participants had matriculated, one of whom went on to complete tertiary education studies. Most of the sample reported that they were not currently employed (*n*=7), of whom half were pensioners. Additionally, a large portion of participants (*n*=8) indicated that they were currently on a prescribed medication regimen, of whom three were on ART. It should be noted here that five participants reported being the biological mother of the child they had brought to the clinic, yet only three participants reported being on ART.

Almost all participants (*n*=10) were biologically related to the child that they had brought to the clinic, with only one participant having no biological relation to the child at all, indicating that she was the child's foster mother. All participants regularly attended clinic visits with the child in their care, i.e. the participant had attended more than one clinic session since the child initiated ART. However, Vanessa, whose 3 year old great-granddaughter had been on ART for 2 years,

indicated that she did not always administer the child's medications, and that the responsibility was shared between herself (the great-grandmother) and the child's mother.

Of the children brought to the clinic, five were male, and six were female. The mean age of the children was 30.5 months (SD=16.5), with the youngest child aged 10 months, and the oldest 5 years. The mean length of time that the children had been on ART was 20 months (SD=10.6), ranging between 3 and 36 months. Additionally, almost all of the children were not aware of their HIV-status, with only one of the children (age 3 years, on ART for 3 years at the time of the interview) having been disclosed to. It is interesting to note that this child was in foster care (i.e. the participating caregiver, Akhona, was her foster mother).

Sample Characteristics

In the section below, I provide descriptive information about particular participant characteristics, including data regarding participants' understanding and beliefs of their child's HIV-diagnosis and medication, knowledge of their child's ART regimen, whether the child's status had been disclosed to others, caregiver consistency, self-reported adherence, and barriers to adherence reported by the participant. This data provides a greater understanding of the study participants in terms of the aforementioned factors, and assists in contextualising the qualitative data.

Beliefs and Understanding of Child's Diagnosis and Medication

All participants completed the Beliefs and Understanding Questionnaire (see Appendix F) prior to the presentation of the Petrie device demonstration. As discussed previously (see Chapter 3), this questionnaire required participants to rate their responses to each item on an 11-point Likert-type scale, ranging from 0 to 10, with the appropriate anchors. The mean responses are reported below.

Participants in the present sample reported a 'moderate' understanding of their child's HIV-infection (M=6.45, SD=3.39). This level of understanding demonstrates that whilst participants felt they had some understanding of their child's illness, they were cognisant of the fact that their knowledge and understanding of their child's illness was limited and insufficient.

Additionally, participants felt that their child's illness was serious (M=7.09, SD=4.59), yet indicated that they felt it did not have a particularly great effect on their child's life (M=4.73,

SD=3.98). A large number of participants (*n*=8) believed that their child's virus would continue forever (selecting a score of '10 (Forever)' on the Likert-type scale). However, David, whose 4 year old grandson had been on ART for 2 years at the time of the interview, felt that it would only continue for a moderate length of time (selecting a score of 6). Gloria, whose 23 month old nephew had been on ART for almost two years at the time of the interview, indicated that her child's HIV-infection would continue for a very long time (selecting a score of 9). Participants were evidently concerned about their child's illness (M=8.27, SD=3.17), and indicated that it negatively affected their emotions (i.e. made them feel scared, angry or upset), (M=6.09, SD=4.7). In contrast, the impact on the child's emotions was reported as being very small (M=1.09, SD=2.47). Participant's also indicated that children did not experience a large number of symptoms from their virus (M=3.64, SD=3.75), and an even smaller number from their medication regimen were experienced (M=1.82, SD=3.09).

Participants felt that there was a large amount of control over their child's virus (M=8.4, SD=2.5), meaning that that participants believed that there were things that could be done to assist the child with their illness. Participants felt that the child's medications were helpful in keeping their child healthy (M=8.91, SD=2.3). Participants reported that the medications were absolutely necessary for the child (M=9.55, SD=1.51), and participants were motivated for their children to adhere to their ART regimen (M=8.91, SD=3.02). However, participants showed concern regarding the life-long use of these medications (M=6.18; 4.62). Moreover, participants reported that it was somewhat difficult for their child to adhere to their prescribed medication regimen (M=5.73, SD=4.98), meaning that participants experienced issues in administering medications, and ensuring that the child is adherent. It should be noted that this last item was reverse scored, with the relevant anchors (0 = Extremely difficult, versus 10 = Not difficult at all).

ART Regimen Knowledge

Participant medication knowledge was assessed using the CAMP – Caregiver Evaluation (see Appendix G). Participants were asked to name the medications given to their child, the amounts of each medication given, and the times at which medications had to be administered. Participants in

the present study did not report complete medication knowledge. Of the participants in the study, 54.55% indicated that they knew how many types of medications their child took, as well as the dosages and times of day to administer these. However, no participants were able to name their child's medications. Nina, whose 1 year old daughter had been on ART for a year, indicated that she possessed no medication knowledge whatsoever.

Disclosure to Others

Almost all participants (*n*=9) reported that they had disclosed their child's status to other family members, and friends, as reported on in the CAMP – Caregiver Evaluation (see Appendix G). Moreover, the child's status was disclosed to other members of the household in all cases.

Caregiver Consistency

Caregiver consistency was examined in the CAMP – Caregiver Evaluation (see Appendix G) by determining how many morning and evening doses in a seven-day week the participant (as opposed to another household member or individual outside of the home) administered the child's medications. The modal number of morning doses administered within a week by participants was 7 (SD=1.7), ranging between 2 and 7. The modal number of evening doses administered within a week by participants was 7 (SD=1.75), ranging from 2 to 7. In a large number of cases (*n*=8), the participating caregiver was solely responsible for medication administration. Three participants indicated that they shared medication responsibility with another individual. One participant, Akhona, reported that she administered medication four times a week in the mornings and evenings, sharing this responsibility with another foster mother. Jennifer, whose 2 year old granddaughter had been on ART for almost 2 years at the time of the interview, indicated that she was responsible for administering medications twice a week in the mornings and evenings, and shared the responsibility with the child's father, and another relative who lived outside of the home. A third participant, Vanessa, indicated that she shared medication responsibility with the child's mother, and only administered five morning-doses a week. Only one participant, Nina, indicated that frequent changes in caregivers posed a problem to adherence.

Self-Reported Adherence to ART

Adherence to ART was examined using the CAMP – Caregiver Evaluation (see Appendix G). Here participants were asked to indicate if their child had missed any medication doses in the past day (Item 20), in the past three days (Item 21), in the past seven days (Item 31a, Item 31d), and in the past month (Item 22). Self-reported adherence was high in the present study, with all participants indicating that their child missed no doses in the day prior to the session, and that no doses were missed in the past three days. Whilst most participants (*n*=9) reported that their child missed no doses in the past seven days, two participants, Nina and Louisa, reported that their children missed two doses altogether over the course of the past week. Whilst almost all participants (*n*=10) reported 100% adherence (no doses missed) over the past month, Angeline, whose 4 year old daughter had been on ART for 1 year at the time of the interview, indicated that her child missed four doses in the past month, achieving an adherence level of 93.33%. It can be seen from the data presented here (e.g. two participants reporting two missed doses during the past week, yet reporting no missed doses in the past month), that participant's reported adherence was at times inconsistent with what had been indicated elsewhere in the questionnaire.

It should be noted here that five participants made use of medication reminders, such as administering medications at meal times, using time as a reminder, or taking evening medications at the same time as specific television programmes.

Reported Barriers to Adherence

The CAMP – Caregiver Evaluation (see Appendix G) allowed for a thorough examination of adherence-related issues, particularly barriers to adherence that are experienced by the child and the caregiver. The questionnaire included a number of items which required participants to read through a list of medication administration issues, and tick those that applied to themselves and/or the child (see Appendix G, Items 23, 24, 25, 26, and 28). The results of these questions, and others in the questionnaire relating to medication adherence barriers are presented in Table 4.3.

It is evident that a number of barriers to adherence were experience by participants, specifically relating to child and caregiver factors, issues with the medication regimen, community-

Table 4.3.

Barriers to Medication Adherence Reported by Participants

Barriers to medication adherence	Number of participants reported (*N*=11)
Caregiver-related	
Forget to administer medications as too busy	1
Forget to administer medications on time	5
Have difficulty administering medications on time	5
Did not understand the medication instructions	1
Not always present/were away from home	2
Did not think the medications were helping	1
Thought the child needed a break from the medicines	1
Concerned medications would result in side effects	2
Thought other things were more urgent	1
Felt discouraged or lost hope	3
Child-related	
Often experience difficulties in getting child to take medications	4
Child was not aware of their status, asked many questions	1
Child did not understand the medication instructions	1
Child refused to take the medicines	3
Child felt better	1
Medication regimen	
Child indicated medicine was too bitter	4
Child experienced problems with one of the formulations	4
Medication ran out before next clinic appointment	1
Difficulty administering medications if not given with food	1
Community-related	
Did not want others to see medications administered to child	2
Felt the need to hide child's medications	2
Delayed medication administration due to presence of others	1
Discouraged by neighbours/friends/family to administer medications	1
Feared discrimination and isolation	1
Others did not believe medications were necessary for the child	1
Transport	
Lack of money for transport to clinic	4
No transport available to clinic	1

related barriers, and transport issues. Four caregivers indicated that they often experienced difficulty in getting their child to take the medications. Participants also struggled with keeping time in administering medications; either they forgot to administer the medications on time (*n*=5), or

they experienced difficulty in administering the medications on time (*n*=5). Further, a portion of participants (*n*=3) indicated they lost hope or felt discouraged. Some participants (*n*=3) indicated that their child would refuse to take the medications. Participants (*n*=4) participants reported that their child experienced difficulties with one of the medication formulations, specifically due to the bitterness thereof. Further, a small number of participants also felt that they had to hide the child's medications (*n*=2), and that they did not want others to see ART medications being administered to the child (*n*=2). An additional barrier to adherence reported by participants was a lack of money to pay for transport to the clinic (*n*=4).

Petrie Device Demonstration Questionnaire

As previously indicated, this questionnaire (see Appendix I) required participants to rate their responses to five items on an 11-point Likert-type scale, ranging from 0 to 10, with the relevant anchors. The mean responses are reported here.

Participants found the Petrie device demonstration useful in assisting them to understand their child's virus (M=8.73, SD=3), and their child's medication regimen (M=9.098, SD=2.4). Additionally, participants felt the demonstration was interesting (M=9.73, SD=0.91). The demonstration also made participants feel particularly motivated to administer their child's medications (M=8.91, SD=3.01). Participants reported that the demonstration did make them feel somewhat anxious about the child's virus (M=6.09 SD=4.48) and medication (M=6.09 SD=4.48).

Qualitative Thematic Analysis Findings

As previously indicated, semi-structured interviews were conducted with participants (see Appendix J for interview schedule) after they were presented with the Petrie device demonstration. Four primary themes and nine sub-themes were identified in the data (see Table 4.4), which will be discussed individually below.

Table 4.4.

Summary of Themes

Theme	Subtheme
1) Reactions to 'seeing' the Petrie device demonstration	1.1) The benefits of 'seeing'
	1.2) Cognitive shifts as a result of 'seeing'
	1.3) The importance of 'seeing'
2) Responsibilities as caregiver	2.1) Responsibility to remain motivated
	2.2) Responsibility to change behaviour
	2.3) Responsibility to disseminate new information
3) Thoughts on HIV and treatment	(None)
4) Future implementation of the Petrie device demonstration	4.1) Where to use the device?
	4.2) Who should present the device?
	4.3)What changes should be made to the demonstration?

Theme 1: Reactions to 'Seeing' the Petrie Device Demonstration

Participants' reactions to the demonstration was one of the primary themes that emerged in the data. The responses have been grouped into three subthemes, namely 1) The benefits of 'seeing', 2) Cognitive shifts as a result of 'seeing', and 3) The importance of 'seeing'. These subthemes will be elaborated on below.

Subtheme 1.1: The benefits of 'seeing'. Participants seemed to have had a positive experience taking part in the study. Four participants said that they were glad to have taken part. For example, Gloria said "I am glad I came to see this, and I made time to come and watch this". Maria, whose 10 month old grandson had been on ART for 3 months at the time of the interview, stated "I am glad that I could learn something today". Samantha, whose 14 month old daughter had been on ART for 1 year at the time of the interview, expressed that she was "grateful" for the opportunity to see the demonstration and to meet the researcher.

Participants also experienced the demonstration itself in a positive way, describing it as "wonderful" (Jennifer), providing the participant with "good things" (Nina). Maria said that she was "impressed" by the demonstration. The demonstration was also described by two participants, Gloria and Vanessa, as "very interesting". Moreover, the demonstration was motivating for two

participants. For example, Maria said, “I feel motivated that I can give him (her child) a life”. For Lerato, whose 5 year old son had been on ART for 3 years at the time of the interview, the demonstration was “encouraging”.

The usefulness of the demonstration was also emphasised by participants. Four participants described the demonstration as being helpful in some way, with one participant indicating that the demonstration should be “out everywhere, at clinics and the hospitals […] because it helps a lot” (Vanessa). The idea that the demonstration could be used to help others was reiterated by two other participants. Louisa, the biological mother to a 2 year old boy who had been on ART for 1 year at the time of the interview, said: “You must just show it to more people. Show hospitals. So people can see the importance of the virus. Many people don’t understand it, like I didn’t understand it.” Here Louisa clearly articulates the value of seeing the demonstration in improving her understanding of HIV.

Angeline suggested that the demonstration might be particularly useful to newly diagnosed patients, and those who do not have a good understanding of the medications. She stated:

> Yes, because I think when you, when anybody finds out, finds out you have HIV, you’re confused. You don’t know, there are so many questions you want to ask […] Because I think at some clinics they don’t explain it well to the to, to the patient. And that’s why some of the patients they stay away. They don’t want to take this, they embarrassed about it. And all of those things. So I think it would make a huge difference at the hospital. (Angeline)

However, some participants experienced negative emotions as a result of seeing the demonstration, indicating that it made them “scared” (David), and “worried” (Jennifer, Gloria). Gloria indicated that the feeling of worry she felt was caused by concerns over what may happen to her child if he does not adhere to his medications. Additionally, for Jennifer, the demonstration brought up painful memories of how her own daughter, the biological mother of her granddaughter, had died from HIV/AIDS. Seeing the demonstration made her think of that experience, which she described as a struggle: “And how your child suffered, it’s a great struggle. To now suddenly get sick, and not get out of bed again. And leave your small child behind. It is awful.”

Subtheme 1.2: Cognitive shifts as a result of 'seeing'. The demonstration provided participants with knowledge and understanding of both the child's HIV-diagnosis and their treatment. The knowledge gained by participants had an empowering impact. For example, Akhona stated, "I am feeling good because I know I have the knowledge now". Both Samantha and Gloria described the demonstration as 'eye opening' and explained that it assisted them in realising the importance of their child's medications. Louisa stated that after seeing the demonstration she understands "it is a must, the child must get it (ART)". Gloria too stated that "this thing (the demonstration) did really let me realise how important the medicine is, and what's really going on with the virus". Angeline explained how after seeing the demonstration, she understood the importance of adherence, and that she must administer the medications, even if the palatability thereof is an issue. She stated that:

> Because I thought with the bitterness of the medicine, what, what difference is it going to make, because the HIV cells are still there. They always tell you 'well, the cells are sleeping', but, it, I saw it today, it actually does help. […] Before I thought, um, okay the medicine is, this is the medicine, you can't see anything so, I'm sure a day won't, a day you skip won't change anything. (Angeline)

Angeline also indicated that she felt had she seen the demonstration shortly after receiving the child's diagnosis, that she would have "had a clear mind", and stated, "I would have known a lot that I know now that I didn't know back then". She reported that the demonstration provided her with information, which would have been useful had she received it shortly after her child had been diagnosed. She also spoke about her own experiences with HIV, and being told of her diagnosis:

> If they showed me – because I had many questions that I didn't know if they would give me an answer. They only said 'well, um, you're gonna take medicine for the rest of your life'. That's it. That's what happened when I found out I have HIV. So she's – I didn't show any emotions. Um, so the sister asked me 'are you alright', I said 'yes, I'm fine'. So, so, the only thing that I ask her is 'so, up until when do I take my medicine?'. And she said 'no, you taking it for the rest of your life'. That's it. (Angeline)

In Angeline's experience of how HIV and treatment were previously explained to her by healthcare staff, she felt that the clinic staff may have not have been able to answer her questions regarding her diagnosis, and that if she had been shown this demonstration after her own diagnosis, she would perhaps have received more information. Angeline addressed her experience of not receiving the 'full story' or all information necessary from clinic staff, and how this demonstration could have been useful in providing the necessary knowledge.

Information and caregiver knowledge was also evidenced as necessary for adherence. Understanding how the medication works in the child's body, and its effect on HIV is important because it is "good to know why to give your child's medicine" (Nina). Maria stated that previously "I just gave it for the child", but after seeing the demonstration, "it also does me good to think I can help". Knowing what the medication is "in aid of" (Vanessa) is important for caregivers to adequately fulfil their role in the child's medication adherence.

Three participants reported that seeing the demonstration had influenced their view of their own medications. These were Gloria, Lerato and Angeline. Gloria was prescribed medication for high blood pressure, and had indicated in the interview that at times she takes a "break" from her medication regimen. However, after seeing the demonstration she realises her "break is not a good break", and that she felt "very guilty that I am not drinking my medicine". Lerato and Angeline were both on ARVs at the time of the interview. Lerato said that the demonstration gave her "hope that I am going to live long life". Angeline indicated that seeing the demonstration, and realising the importance of adherence made her feel "guilty" about skipping medication doses, stating that "going forward, no, I can't miss anything, straight head", indicating the possible effect of the demonstration on her own future adherence.

Subtheme 1.3: The importance of 'seeing'. Through active visualisation, the demonstration allowed participants to see the effects of adherence and non-adherence to ART in a concrete way. The ability to see what happens in the body was addressed by six participants. Gloria indicated that the demonstration "shows you exactly what happens to you if you miss a dose, and it shows you exactly how you can help yourself again if you take your medication". The colour

change technique used to demonstrate the effects of adherence and non-adherence was also referred to specifically by four participants. Lerato stated that "I felt happy when the water is going clear", and Angeline indicated that she was "amazed" by the colour change, and felt that "it demonstrates that the medicine actually works". The importance of this active visualisation technique used in the demonstration was also mentioned by two participants, Gloria and Louisa, who stressed how important it is to see something in order to understand it. For example, Louisa said that "a person will never know something if you don't see something".

Theme 2: Responsibilities as Caregiver

The responsibilities of the caregiver were discussed by participants specifically in terms of 1) Responsibility to remain motivated, 2) Responsibility to change behaviour, and 3) Responsibility to disseminate new knowledge. These three subthemes are discussed below.

Subtheme 2.1: Responsibility to remain motivated. Participant responses evidenced the importance that caregivers remain motivated in their role. The role played by the caregiver in the child's adherence to ART, and the importance of this was addressed by five participants. Nina acknowledged her role in administering the child's medication, stating, "I must not miss the medicine". The importance of the caregiver's role was emphasised by Maria, who said "I can give him (the child), uh, a life", indicating how important her role is in ensuring the child remains healthy. The importance of the caregiver role in adherence was echoed by Gloria, who stated, "if I don't give him the medication, I then want him to be sick". This participant also drew attention to the fact that the child cannot adhere to medications by himself, stating that "it (the demonstration) also makes me aware that I must be aware to give him his medicine, because he cannot use it by himself".

Participants also spoke about how in the child-caregiver relationship, the child needs to be put first. Maria indicated that administering the child's medication is "not for me, but it is for him (the child)". Gloria also discussed how in one of the questionnaires she had completed as part of the study, it was questioned whether any meals are missed by the child, and whether medication is not

given due to lack of food to give with medications (CAMP – Caregiver Evaluation, Items 15 and 16). She stated:

> And so, like when I listened to the questions, people don't want to give it because they don't have food in the house. To just eat a sandwich is quick, I mean, you have something in your stomach, you can drink your medicine. But it is more important to drink your medicine. You can maybe drink your medicine now, and then in ten minutes 'okay, give me something to eat now, I feel a bit', and you feel the medicine, that nauseous, and now eat a little bit. Or you can look at the child, 'no but I now gave him medicine on an empty stomach, okay let me make provision if I do not have'. It doesn't make you a bad person to go ask someone else. It makes you a bad person to not ask, to not give that child anything. (Gloria)

Gloria reported that if a child cannot take medications without food, as the caregiver, one should ask others for something for the child to eat. She also indicates in the quote above, that the child and their adherence should be prioritised.

Participants also stated that they were confident about their role, and motivated for their child to adhere. Maria stated that her child has a "long life ahead of him", and that it "makes me feel good to keep him (her child) healthy". Two other participants, David and Lerato, both demonstrated future oriented thinking. David indicated that medication adherence is absolutely necessary, as "he (the child) will stay healthy, live longer". Lerato stated, "I know it (medication) is working, my child is going to live long life". In the sample, four participants, Maria, Akhona, Jennifer, and Vanessa, indicated that they felt "good" about administering their child's medication. Jennifer said that when she thinks about giving medication to her child, "it feels good to give it because it helps her". Angeline attributed the positive feeling about medication administration to the effect of the medicine on the child, stating, "This is gonna be okay. The medicine is actually helping".

Subtheme 2.2: Responsibility to change behaviour. Four participants indicated that after seeing the demonstration they would implement behavioural changes in medication administration. Lerato stated that if she leaves her child, i.e. she is absent and not able to administer her child's

medications, she will ensure that there is another individual who will administer the child's medication, emphasising that in future she will "make sure" that her child will get medication if she is not available to administer it. Two participants, Gloria and Angeline, indicated that administering medications at a regular time had been an issue for them previously. However, after seeing the demonstration both indicated that they would change their medication administration behaviour to ensure that their children received medication at regular times. Gloria said that she specifically struggled with administering the medications on time on the weekend, and that they will "have to find another way so that he (the child) can drink his medicine at a regular time". She also stressed the importance of not administering doses late, stating, "it mustn't be an hour – maybe five minutes, ten minutes, maybe at the longest twenty minutes." She reiterated that she will "put more into those times of him, make sure the times are regular for him". Angeline also stressed the importance of administering the medications on time: "I think I would just think about the times that I give it. And based on keeping specific times that I would be available to give. I think that would make a huge difference."

The importance of adherence to ART despite potential barriers was also stressed by participants. One participant, Maria, alluded to the potential impact of HIV-related stigma, and how one must continue to administer medication despite this, stating that she had learnt from seeing the demonstration to "just go on daily, and to not be scared of other people, and to just carry on. It's – it's, like I said, it's not about me and you, it is about him (the child)." Gloria also spoke of the stigma attached to her child's illness, stating that "people will talk about you, in your community, will show you the finger and so on". One participant, Angeline, indicated that the palatability of the medication, specifically the bitterness thereof, was an issue. She had previously thought that if her daughter missed "a day" of medication because of this, that it "won't change anything", yet realised that the medication does in fact have an effect, and must be adhered to. As such, Angeline indicated that, despite the taste of the medications, she will ensure that her daughter takes the necessary medications as prescribed, which she had not previously done. Louisa stated that in administering her child's medication in future, she would "do everything differently", indicating a significant

change in her medication administration behaviours. She indicated that sometimes her child would spit out the medication and she would not redose, yet now, "when he spits I must give it again". Louisa also indicated that her child would refuse medications, which would make her "tired" and "hopeless", yet she indicated that now she "will try harder". It should be noted here that seven participants said that they would not change any aspect of their medication administration.

Subtheme 2.3: Responsibility to disseminate new information. Three participants indicated that they would share what they had learnt during the session with others. One participant stated, "I am now going to tell people" (Maria), and another said, "I will tell others that they taking medicine, how it works" (Lerato). Vanessa, who shares responsibility for administering the child's medications with the child's biological mother, indicated that she will stress to her the importance of the child adhering to ART, stating, "I can tell the mom I learnt this at the hospital and it is a must that you don't miss a day of your child's medicine".

Theme 3: Thoughts on HIV and Treatment

Participants spoke about their thoughts of their child's diagnosis and treatment, particularly the seriousness of HIV as a lifelong condition, how ART is able to help, and therefore why treatment is so important. Four participants spoke about the seriousness of HIV, and the potential consequences thereof. David described HIV as "dangerous because it can, it actually makes, can cause death". Two further participants spoke of the possibility of mortality, particularly if the child does not adhere to ART. Akhona stated, "the virus is going to go up if she (the child) doesn't drink and it is going to, she is going to die". This sentiment was echoed by Angeline who said that "if she (the child) doesn't take the medicine, well, then my thoughts on when is she dying could be sooner". Two participants also discussed the fact that there is no cure available for HIV, emphasising the seriousness thereof. Gloria had indicated that she believed her child's HIV was not a life-long infection. However, after seeing the demonstration she stated, "You don't get rid of the virus. You have to do with it every day, every second of your life that you breathe is the virus there for you". Angeline reiterated this, yet also spoke of how administering medication can assist in keeping the

virus under control, stating, “I learnt that the virus will always still be in there. But it’s up to you how you give the medicine, how you keep it under control”.

All participants emphasised the importance of ART in keeping the child healthy. Vanessa stated, “You can have a normal life even if you have it and if you use your medicine in the right, uh, manner”, indicating the importance of ART in assisting the child to live a normal life. Maria stressed the importance of administering the child’s medication every day, and the effect of non-adherence on the child’s immune system stating:

> I must give it every day, and, and, how the sickness will be kept under control if I, and if it is not given, then does the child, it makes him sicker, and makes his immune system, makes it completely confused and confused (Maria).

Three further participants also drew attention to the effect of adherence/non-adherence, emphasising the importance of ART. Akhona stated that without medication, one will be ill more often, stating, “You have to drink your medication when you’re sick, don’t refuse, because you’re going to get sick more”. Samantha stressed the importance of ART in maintaining one’s health, stating that “they (others with HIV) must use their medication, and must not get behind with their medications, because it’s their own health”. Jennifer spoke of how adherence to ART can assist in lowering one’s risk of death due to HIV/AIDS. Her daughter (the child’s biological mother) died from HIV/AIDS related causes, which she spoke of in the interview. She said that “it is painful to see how people die from this sickness when they could have avoided it”.

Theme 4: Future Implementation of the Petrie Device Demonstration

Participants were asked questions pertaining to the implementation of the Petrie device demonstration in the future. Participant responses can be divided into three subthemes, namely, 1) Where to use the device?, 2) Who should present the device?, and 3) What changes should be made to the device?. Each subtheme is further discussed below.

Subtheme 4.1: Where to use the device?. Participants were asked where they felt the demonstration could be presented to others. Nine of the study participants indicated that the demonstration should be used in clinics and hospitals. Angeline said hospitals and clinics would be

where patients and/or caregivers are most accessible, stating that such sites would be "where you get the most patients". Samantha stated that the demonstration should be presented in "private" individual sessions.

However, Gloria was adamant that the demonstration should not be presented in clinics, due to judgement and stigma that may accompany the decision to view the demonstration:

> At the clinic, I would say two sided. Because at the clinic there are lots of different types of people, and you don't want the eyes on you. You don't want the eyes to see you listen to these talks. No, then tomorrow they say, then they know my status. So, and yes, I understand what they say, doctors and patients have that... But still as a person, we have our things together. It sounds like it would be suitable for mothers. But you will still get those mothers that will walk out. You are going to get those that walk out because 'don't come and teach me about certain things because nothing is wrong with my child and I'. And ever, like is in those questionnaires, to say yes, how will the virus have an impact on his life. People will about you, in your community, will show you the finger and so on. (Gloria)

From the excerpt above, it is clear that Gloria felt that if the demonstration were to be presented in clinics or hospitals individuals would choose to not participate. Gloria felt that the best place for implementation would be in churches in the community, stating:

> And when it's in a church, a close- knit church perhaps, and it is spoken about these things, people can feel more safe, because you feel in the house of God, and then you can say anything. You can lay your problems out. […] We so look forward to going to church. And there you will go sit and listen, you won't stand out. (Gloria)

It is clear that Gloria felt that should the demonstration be presented in churches as people would be more inclined to take part as they would not feel judged, because church is a place of safety. Two further participants, Maria and Jennifer, indicated that the demonstration should be presented in the community. Jennifer specifically said that the demonstration should be presented on farms "so that people can see what this sickness is about". However, two participants spoke of the disadvantages of presenting the demonstration in communities. Gloria indicated that people will

not wish to take part should the demonstration be presented in a community hall for example, as this may result in stigma, stating, “If in a community hall, you will get lots of people that will stand out”. Angeline said that should the demonstration be delivered in communities, that “people won’t go by themselves” as some may be “embarrassed” or think “no, I’m not gonna do that, it’s not for me”.

Subtheme 4.2: Who should present the device?. Participants were also asked what type of person they felt should deliver the demonstration, to determine whether there were any particular role or characteristic preferences held by participants. To begin, seven participants said that the demonstration could be used in standard clinic sessions with a paediatrician. Further, four participants stressed the importance of the presenter being someone who is able to communicate clearly. In addition to this, the language ability of the potential presenter was deemed by participants as important and Louisa stated, “You explained it very well, you speak my language”. Additional characteristics identified by participants as important of the potential presenter of the device included someone who is friendly, understanding, and non-judgemental (Louisa), educated on the topic (Jennifer), and someone who is “open” (Gloria). Gloria further described the ideal presenter of the demonstration as a “go-getter”. She said that when it comes to talking about HIV “everyone is an ostrich that sticks their head in the sand”, indicating that people do not want to talk about this topic. Therefore, the ideal presenter, according to Gloria, is someone who is “motivated” to talk about HIV with patients and caregivers.

Two participants, David and Louisa, had no preferred presenter role, such as doctor or nurse, with Louisa stating that it “doesn’t matter who the person is who does it, so long as it gets shown”. Three participants, Nina, Jennifer and Vanessa, indicated that doctors should present the demonstration to others. Jennifer, and Vanessa stated that clinic nurses would also be suitable candidates to deliver the demonstration. Angeline however stated that clinic sisters specifically should not present this demonstration to others. Angeline and Jennifer both indicated that individuals from universities should present the demonstration. It should be noted here that when asked about the type of person who should present the demonstration, six participants expressed a

preference for me, the original researcher who had conducted the sessions with the participants of the present study.

Subtheme 4.3: What changes should be made to the device?. While almost all participants did not have suggested changes for the demonstration or the model, one participant, Angeline, suggested that perhaps a face could be added to the device itself, stating, "Give him eyes". Another participant, Gloria, added that the demonstration should perhaps be presented to caregivers on a regular basis, stating, "maybe this should be done daily, or once a week, or once a month, just to make people aware".

Summary of Chapter

In this chapter I presented the findings of the present study. I began by outlining the sample demographics, after which I presented relevant sample characteristics. Here I discussed participants understanding and beliefs of their child diagnosis and medication, medication regimen knowledge, whether the child's status had been disclosed to others, caregiver consistency, self-reported adherence, and barriers to adherence reported by the participant. It was presented that participants felt that they did have some understanding of their child's illness, yet they did not possess complete medication knowledge, as evidenced by no participants being able to name their child's medications. They deemed HIV as a serious, life-long condition, which had an impact on the participants' emotions. Participants also indicated that medications were absolutely necessary and helpful, and were thus motivated for their child to adhere. Participants reported that their child's status had been disclosed to others in the household, as well as family members and friends. Whilst caregiver consistency was high in the present sample, there were instances where multiple individuals were responsible for the child's medication administration. Various barriers to adherence were reported by participants, specifically relating to child and caregiver factors, issues with the medication regimen, community-related barriers, and transport issues, evidencing that participants experienced difficulties in administering and adhering to the prescribed ART regimen. However, self-reported adherence was high in the present study, with almost all participants (n=10) reporting 100% adherence (no doses missed) over the past month.

Quantitative data regarding participants' experiences of the Petrie device demonstration was presented. This data illustrated that participants found the demonstration useful in assisting them to understand their child's HIV-diagnosis and medication regimen. Moreover, the demonstration was deemed to be interesting to participants, and made participants feel motivated to administer their child's medications. Participants did report that the demonstration did made them feel somewhat anxious about their child's illness and medication.

Finally, in the qualitative thematic analysis findings, four main themes were identified, namely, (1) Reactions to 'seeing' the Petrie device demonstration, (2) Responsibilities as caregiver, (3) Thoughts on HIV and treatment, and (4) Future implementation of the Petrie device demonstration. Participant reactions to the demonstration emphasised the benefits, knowledge gained, and importance of 'seeing' the demonstration. Caregiver responsibilities to remain motivated, change behaviour, and disseminate new information were discussed in relation to the second theme. In discussing their thoughts on HIV and treatment, participants spoke of the seriousness of HIV, and the importance of ART. The final theme, namely future implementation of the Petrie device demonstration, presented participants' thoughts regarding the ideal setting and presenter for presenting the demonstration, and changes that should be made to the demonstration. The findings presented in this chapter will be discussed in light of the relevant literature in the following chapter.

CHAPTER 5

DISCUSSION AND CONCLUSION

Introduction to Chapter

The findings of the interview data demonstrated that the Petrie device demonstration was acceptable to caregivers of children five years and younger on ART. Participants in the present study found the demonstration beneficial, and experienced cognitive shifts as a result of seeing it. Moreover, the active visualization component of the demonstration was important for participants. Participants also reported that the demonstration made them motivated for their child to adhere, to change medication administration behaviours, and disseminate the information that they had learnt to others. Participants also spoke of the seriousness of HIV, and the importance of their child's medication, as was emphasised in the demonstration. Considerations of feasibility and implementation were also addressed by participants.

In this chapter I will begin by discussing the medication adherence achieved by children in the study sample, specifically in relation to factors which may influence adherence. As the demonstration is concerned with adherence to ART, it is important that these factors are addressed here. Secondly, the findings of the study will be discussed in terms of the three study objectives to illustrate acceptability. The objectives of the present study were (1) To examine caregivers' thoughts and opinions of the Petrie device demonstration, specifically relating to information, motivation, and behavioural skills, (2) To determine whether caregivers feel the Petrie device demonstration is appropriate to implement with others, specifically in a clinic setting, and (3) To explore caregivers' thoughts about future implementation of the demonstration, and suggested changes. Finally, the limitations of the present study, and recommendations for future research will also be addressed.

Adherence and Related Factors

In the present study, high levels of adherence were reported by participants. All participants but one reported 100% adherence over the past month at the time of participation. The participant whose child missed four doses over the past month achieved adherence of approximately 93%, which,

whilst below the target for adherence (>95% doses taken) (Department of Health South Africa, 2015), is still high.

The adherence levels reported in the present study are higher than previous studies conducted with children in the South African context (Elsland et al., 2018; Smith et al., 2016). Smith et al. (2016) found adherence levels greater than 85% over a two-year follow-up as measured by medication return amongst a sample of children ages 6 months to 13 years. Elsland et al. (2018) reported adherence levels between 20.3 and 54.7% as measured by medication return amongst a sample of children ages 2.1 to 12.9 years. However, using a self-report measure in the same study found different results, with reported adherence levels between 79.6 and 89.1%. The findings reported in the present study and by Elsland et al. (2018) evidence the potential pitfalls of self-report measures. Whilst the sample size of the present study was small, the range of adherence levels reported is still higher than those reported by Elsland et al. (2018) and Smith et al. (2016) using medication return. Vreeman et al. (2008) indicate that caregiver reports of adherence could be subject to social desirability bias or recall bias. Caregivers may feel the need to "project a favourable image to others" (Fisher, 1993, p. 303), meaning that responses regarding their child's adherence on self-report measures may be inflated to reflect what the caregiver feels is the correct or socially acceptable response (i.e. social desirability bias). Moreover, recall bias may result in caregivers intentionally selecting information to report, which can lead to an "embroidery" of personal history (Raphael, 1987, p. 167), which, in turn, may lead participants to overestimate levels of adherence achieved. These biases are further evidenced in the present study by some participants providing differing estimates of adherence depending on the questions posed.

Objective measures of adherence, such as medication return and MEMS data, may therefore provide a more accurate account of adherence. However, these measures do not necessarily correspond to the intake of medications, or correct dose amounts being administered (Jimmy & Jose, 2011; Martin et al., 2009). As indicated, VL remains the most accurate measure for assessing treatment success amongst young children on ART. However, VL data are not always available due to the testing intervals in VL follow-up (Department of Health South Africa, 2015). Further, to

employ such a measure in adherence research would require additional blood to be drawn at specific intervals, which is painful for children, and costly.

Lam and Fresco (2015) suggest the use of a multi-measure approach, employing more than one existing measure. By using multiple measures of adherence, the strengths of one measure used can compensate for the weaknesses of another, which can assist in providing more accurate measures of adherence. A study conducted with adults in the South African context used medication return and self-report to measure adherence (Wu et al., 2014). Using these two methods in combination was found to be a strong predictor of VF. Moreover, these methods are cost effective, and therefore suitable for use in resource-limited settings. The employment of a combination of medication return and self-report may prove useful in future work.

It is interesting to note that whilst most participants were solely responsible for medication administration, two participants reported sharing the responsibility with another individual or multiple individuals. Despite studies having reported that caregiver inconsistency may lead to poor adherence (Coetzee et al., 2015; Elsland et al., 2018; Haberer & Mellins, 2009; Reda & Biadgilign, 2012; Smith et al., 2016), the reported levels of adherence were high in the present study, particularly amongst those who reported caregiver inconsistency (100% of doses taken over the past month at the time of interview).

Yet, it should be noted that the influence of multiple caregivers on adherence cannot be conclusively stated (Haberer et al., 2011). Participants in the present study who reported sharing medication responsibilities were grandmothers, and shared this task with other family members such as a biological parent. In South Africa, there is a preference for multigenerational living, particularly in African and Coloured communities (Amoateng et al., 2007). This results in care for children within a multigenerational household often being shared with at least one other individual, such as a grandparent. Further, within the South African context, it is recommended that to improve adherence a treatment 'buddy' should be encouraged (Department of Health South Africa, 2015). Whilst this treatment supporter should be someone who has shared experiences (Department of Health South Africa, 2015), the supporter can also be a family member or friend (Nachega et al.,

2010). Treatment supporters have been deemed important in maintaining adherence to ART amongst adults (Nachega et al., 2005; Nakamanya et al., 2018). In the case of children, sharing the task of medication administration with another individual may in fact provide the caregiver with support, which is influential in improving adherence (Fisher et al., 2006). However, in order to positively influence adherence, it is key that the treatment supporter be included in education sessions (Nachega et al., 2005). In doing so, barriers posed by misinformation, confusion, or lack of communication between caregivers can be mitigated.

Barriers to adherence reported by participants in the present study were similar to those reported in the literature. Participants struggled with forgetting to administer medications, and specifically struggled to remember to administer medications on time. Various studies indicate that forgetting to administer medications is one of the most common issues experienced in paediatric adherence to ART (Arage et al., 2014; Biru et al., 2016; Buchanan et al., 2012; Smith et al., 2016). This barrier can be mitigated by employing medication reminders, which have been found to increase medication adherence amongst children (Biru et al., 2016). However, some participants in the present study who made use of reminder techniques, such as administering medications at meal times, reported that they nonetheless experienced issues with forgetting to administer medications on time.

Moreover, caregivers have been found to forget to administer medications when there are no visible cues to act as a reminder (Marhefka et al., 2008). Caregivers may feel the need to hide medications, due to concern about others seeing or recognising the medicines, and the fear of subsequent stigma. Keeping medications out of site for this purpose can lead to caregivers forgetting to administer medications on time, or all together. Some participants in the present study reported that they did not want others to see them administer ARVs to the child, which led them to hide or delay administering medications. Some participants reported they felt the need to hide medications despite the fact that all participants had disclosed the child's HIV-status to other members of the household. Caregiver reluctance to administer medications in front of others has been reported in the literature (Coetzee et al., 2015; Coetzee et al., 2016b; Müller et al., 2011;

Williams et al., 2016). Such a finding is indicative that support and understanding from other members of the household and the community can assist caregivers in administering medications as prescribed, and improving adherence (Campbell et al., 2012).

As indicated, caregiver knowledge and beliefs about the efficacy of the child's medication regimen is influential in determining adherence (Fisher et al., 2006). Higher levels of adherence have been found amongst caregivers who believe that their child's medication regimen is effective in helping them to remain healthy (Perez & Leroy, 2009; Simoni et al., 2007; Reda & Biadgilign, 2012). One participant in the present study expressed the belief that she had felt the medications were not helping the child. Another participant indicated that she had felt it would not make a difference if doses were skipped. It should be noted that only the latter participant reported lowered rates of adherence (93% of doses taken over the past month at the time of the interview). Participants expressed that they did not possess complete knowledge of their child's medication regimen, with all participants unable to name their child's medications. Lenahan et al. (2013) indicate that the ability to name one's medications is a key aspect of optimal health. The study by Lenahan et al. (2013) conducted with patients with hypertension, found that the ability to name medications was associated with greater health literacy, and greater medication adherence. This underscores the finding by Fisher et al. (2006) that individuals on ART need a comprehensive and accurate knowledge of their medication regimen. In the case of paediatric ART, this means the caregiver requires complete and correct knowledge of the child's medication regimen.

Participants also reported difficulty with administration of medications due to the palatability thereof, indicating that one prescribed medication formulation was problematic. Issues with palatability have been noted in a number of studies as a barrier to adherence (Biru et al., 2016; Buchanan et al., 2012; Campbell et al., 2012; Coetzee et al., 2015; Coetzee et al., 2016b; Elsland et al., 2018; Reda & Biadgilign, 2012). One participant in the present study indicated the taste of the medication led her to sometimes skip her child's doses as she felt it would not make a difference if they were missed, and another indicated that her child would spit up doses.

Affordability of transport to the clinic has been reported in the literature as a barrier to adherence (Arage et al., 2014; Haberer & Mellins, 2009; Williams et al., 2016). Clinics are inaccessible to caregivers should they not have the financial means to travel there. This proved an issue for participants in the present study, with a portion indicating that at times they had been unable to afford transport to the clinic. Lack of financial means to travel to the clinic could have perhaps led caregivers to miss the child's clinic appointments, however, whether this occurred was not assessed in the present study.

Further, it should be noted that whilst no participants reported issues with the healthcare system in the quantitative measures, one participant did discuss this in the interview portion of the study. She reported that she had felt that clinic staff would have been unable to answer her questions regarding both her and her child's diagnosis, and indicated that she had not received all the necessary information. This is consistent with the finding reported by Williams et al. (2016), which indicated that caregivers felt that they were unable to access all the information needed from clinic staff. Coetzee et al. (2016) indicate that the content provided to caregivers in adherence counselling sessions is severely lacking. However, the standard of counselling sessions was not deemed as insufficient by caregivers in another study (Coetzee et al., 2015), who in contrast felt that the sessions were "adequate" (p. 317), and that they felt comfortable asking counsellors for assistance. As indicated, caregiver knowledge is of key importance to adherence, and calls for further measures, such as the visual model employed in the present study, to provided caregivers with the information necessary.

Determining the Acceptability of the Petrie Device Demonstration

As stated, the aim of the present study was to determine the acceptability of a visual intervention using the Petrie device demonstration amongst caregivers of children with HIV, who are receiving ART. In keeping with the definition of Bowen et al. (2009), acceptability was defined as how recipients of the intervention reacted to it. In order to determine the acceptability of the Petrie device demonstration, three study objectives were outlined, namely examining caregivers' thoughts and opinions of the demonstration, determining whether caregivers felt the device is appropriate to

implement with others, specifically in a clinic setting, and exploring caregivers' thoughts about future implementation and suggested changes. The findings of the present study will be discussed below as pertaining to the three study objectives.

Objective 1

The first objective of the present study was to examine caregivers thoughts and opinions of the Petrie device demonstration, as relating to information, motivation, and behavioural skills. In accordance with the IMB-model (Fisher et al., 2006), if caregivers to children on ART possess the necessary information, are motivated for their child to adhere, and have the necessary behavioural skills to achieve adherence, the child is more likely to maintain high levels of adherence over time. The findings below show how each of these components are complicated in the sample. Moreover, the effect of the demonstration on these key determinants of adherence is discussed. It should be noted that as the study did not follow a pre-test and post-test design, we cannot state for certain that changes in information and motivation occurred. Further, as no follow-up was conducted as part of this study, we cannot determine whether these factors were maintained over time, or that participants in fact implemented behavioural changes.

Information. According to Fisher et al. (2006), accurate and comprehensive knowledge regarding diagnosis and treatment is needed to facilitate adherence to ART. More specifically, individuals require an understanding of what HIV is, why medication is necessary, how treatment works, the benefits of treatment, and possible side effects that may occur as a result of treatment (Department of Health South Africa, 2015). This information is generally obtained by caregivers in adherence counselling sessions. During such sessions the counsellor is required to discuss with the caregiver the child's diagnosis, ensure the caregiver understands the child's medication regimen, and address the importance of adherence and the consequences of non-adherence (Remien et al., 2013). As such, the counsellor ideally serves as an information resource to caregivers, discussing issues that may be experienced in adherence, as well as suggesting means to obtain the necessary adherence support (Remien et al., 2013). However, as evidenced, the content of adherence counselling sessions is often lacking (Coetzee et al., 2016a). Whilst it is key that caregivers are

equipped with adherence-related knowledge, as informational sources adherence counsellors and clinic staff should be provided with the necessary support themselves to ensure that they are effective in providing adherence support to caregivers.

As was indicated, prior to seeing the Petrie device demonstration, participants reported that their understanding of their child's HIV-infection was lacking and incomplete, which has been found in the literature to negatively impact adherence (Amico & Orrel, 2012; Arage et al., 2014). This lack of caregiver knowledge was evidenced in the present study by two participants reporting that they believed their child's HIV-infection would not continue forever prior to seeing the demonstration. This may indicate that these participants had believed their child's virus could be cured. The belief that ART can cure HIV has been reported amongst adults with HIV in a study conducted in South Africa (Nachega et al., 2005), and may prove problematic as individuals who hold such a belief may discontinue treatment when they feel 'better' (Dahab et al. 2008; Muessig et al., 2015). Further, as indicated, no participants were able to name the medications prescribed to their child, which has been found to have an impact on chronic medication adherence and health outcomes (Lenahan et al., 2013). Whilst almost two thirds of participating caregivers were able to state how many medications their child was prescribed, the dose amounts, and times to be administered, the gap in caregiver knowledge may prove problematic to future adherence.

The demonstration was key in providing participants with knowledge and understanding, which may prove crucial in enhancing or maintaining current levels of adherence achieved by the study sample. By providing a clear, visual explanation of the effects of medication intake, the information provided in the demonstration assisted participants in understanding their child's diagnosis, and emphasised to participants the importance of the child achieving high levels of adherence to ART. The knowledge gained by participants was empowering, and they themselves were able to recognise the importance of information in fulfilling their role as a caregiver. The importance of imparting knowledge to caregivers is evidenced by Yin et al. (2008) who found that by using a visual demonstration to provide caregivers with comprehensive and accurate information regarding medication dosing and administration instructions, caregivers were able to improve levels

of dose accuracy achieved. In receiving the necessary medication administration-related information, caregivers were better able to adequately fulfil their role. The importance of knowledge for caregivers was emphasised by participants in the present study reporting that the demonstration could help others on ART or caregivers to children on ART, which was reiterated by three participants indicating that they would disseminate the new knowledge they had gained to others.

It is also interesting to note that the information and understanding provided to participants extended to and influenced how three of those on chronic medications viewed and understood their own adherence. In particular, participants realised the importance of adherence to medications. Whilst participants on ART themselves experienced this cognitive shift, it is noteworthy that this was experienced by another participant who was prescribed medication for high blood pressure and was at times non-adherent. A review conducted by Abegaz, Shehab, Gebreyohannes, Bhagavathula, and Elnour (2017) found that, of the participants included in the review, almost half were non-adherent to antihypertensive medications. Moreover, 83.7% of those who presented with uncontrolled blood pressure were non-adherent. The Petrie device, in demonstrating non-adherence to ART, shows caregivers how VL increases when medication intake does not occur. In the case of hypertension, when one is non-adherent to antihypertensive medication, blood pressure increases. Such similarities may have affected the present study's participant, and led her to link what she had learnt in the demonstration to her own chronic medication. This speaks to the implications that this type of active visualisation demonstration has for other chronic illnesses.

Further, Fisher et al. (2006) speak of adherence-related heuristics, which may influence decision making in adherence compliance. In the present study, it was evidenced that the demonstration shown to participants has the potential to alter such heuristics. One participant previously thought that, because HIV is always present in the body and the effects of medication cannot be seen immediately, it would not make a difference if medications were skipped. This finding relates to the conceptualisation of HIV as a sometimes "silent virus" (Wilson, Hutchinson, & Holzmer, 2002, p. 1314), in which patients with HIV may be relatively symptom free, and the

effects of medication adherence cannot be physically seen. This may lead individuals to skip medication doses if they feel healthy (Muessig et al., 2015). The participant in the present study expressed that seeing how ART works in the body to keep HIV under control changed this belief. This is consistent with a study by Karamandiou et al. (2008), which found that use of an active visualisation demonstration explaining the mechanism of phosphate-binding medication amongst patients with end-stage renal disease, changed patients understanding of medications and beliefs about treatment.

Motivation. Motivation, both individual and social, is critical in enhancing adherence to ART (Fisher et al., 2006). Individual motivation specifically relates to the attitude of the individual towards medication adherence, which is determined by beliefs regarding the efficacy of ART. In the case of caregivers to children on ART, this theory would postulate that children will be more adherent should caregivers believe the child's medication regimen is effective in treating and managing HIV. Such beliefs are a form of intrinsic motivation as described by SDT (Deci & Ryan, 1985; Hamrin et al., 2017). Positive beliefs about medication efficacy have been found in the literature to improve adherence to ART (Haberer & Mellins 2009; Perez and Leroy, 2009; Reda & Biadgilign, 2012; Simoni et al., 2007).

Prior to seeing the demonstration, it was evident that participants felt that the prescribed medications were effective, as they reported ART was absolutely necessary in keeping the child healthy. Moreover, participants reported that they were motivated for their child to adhere to the prescribed regimen. However, some of the sample reported that they had previously felt the medications were not working, and also expressed concern about the side effects and long-term use of medications. Worries about side effects and long-term use of medications have been reported in the literature (Biadgilign et al., 2011), however, such concerns have been found to be outweighed by caregiver belief in the necessity of medication (Abongomera et al., 2017), which was stressed to participants of the present study in the demonstration.

Seeing the demonstration motivated participants for their child to adhere to ART. Experiencing something in a visual, concrete way, can evoke an emotional response in a patient

(Houts et al., 2006), which may increase motivation. Moreover, motivation for the child to adhere was evidenced by participants exhibiting future-oriented thinking, expressing that the potential of the child to live a long, healthy life as a result of adherence was motivating. This motivation described by participants links the SDT conceptualisation of integrated motivation. The concept of integrated motivation states that individuals are more motivated to adopt a behaviour if they value the outcome thereof (Deci & Ryan, 1985; Hamrin et al., 2017). In the case of participants in the present study, caregivers place value on the outcome of adherence due to the impact thereof on the child's health. This may then influence them to adopt adherence-related behavioural skills. Moreover, some participants stated that seeing the demonstration had altered their beliefs regarding the efficacy of medications, and that they now understood the importance of adherence. The belief in the efficacy of the medications may in turn increase caregivers' intrinsic motivation for their child to adhere to ART, which is key in ensuring medication adherence (Hamrin et al., 2017). Further, participants were motivated by the importance of their role in ensuring their child was adherent, and understood that in the caregiver-child relationship, the child's adherence needs to be prioritised. This echoes the findings of Olds, Kiwanuka, Ware, Tsai, and Haberer (2015), which described how caregivers would forgo their own needs for the benefit of the child, such as going without food so that the child could eat.

An individual's perception of support from others is also influential in motivation to adhere to ART (Fisher et al., 2006). Whilst participants in the present study reported that the HIV-status of the child was disclosed to other members of the household, as well as family and friends, it is clear that social motivation may have been low for some participants. A lack of support from and stigmatisation by family and friends has been reported by caregivers of children with HIV in the literature (Mafune et al., 2017; Williams et al., 2016). Participants in the present study reported that they felt the need to hide or delay administering medications as they did not want others to see them giving the child ARVs. The fear of stigma and discrimination may have lead participants to feel that others should not see them administering medications, which corresponds with research findings (Coetzee et al., 2015; Müller et al., 2011; Williams et al., 2016). Moreover, one participant reported

that they were discouraged by others to administer medications, as other did not feel the medications were necessary, which evidences a lack of support to fulfil their role as a caregiver to a child with HIV. Such findings may prove problematic for future adherence amongst the sample, as it has been reported in the literature that children of caregivers who experience support and understanding are more likely to achieve high levels of adherence (Campbell et al., 2012). After seeing the demonstration, one participant spoke of how one must continue to administer medications and ensure the child is adherent despite other people. Whilst increased social motivation was not assessed as a part of the present study, by realising the importance of adherence participants may be motivated to disclose to others, or to continue to fulfil their role as caregiver and ensure their child is adherent to ART despite possible stigma.

Behavioural skills. Behavioural skills are an important component of adherence to ART (Fisher et al., 2006). Caregivers must be able to administer medications, and incorporate medication administration into daily routine (Matsui, 2007). It should be noted that dose accuracy and measurement was not assessed in the present study, and therefore I cannot state conclusively whether participants possessed all the necessary skills to administer medications such as understanding the measurement tools, dose checking or removing bubbles form syringes (Coetzee et al., 2016b).

Participants did report however, that they had found it difficult for the child to adhere to the prescribed medication regimen. The perception of medication regimens as difficult to administer has been found to negatively impact adherence (Elsland et al., 2018). One of the issues with medication administration expressed by participants is that they had experienced difficulty administering medications on time, struggling to incorporate it into their daily routine. Medication regimens that are simple, and easy to incorporate into daily routine are the most beneficial to adherence (Matsui, 2007). Yet, it has been evidenced that paediatric ART regimens are complex in terms of the number of medications prescribed, dose amounts, and dosing schedule (National Department of Health, 2015), and therefore caregivers may struggle to adapt to such a regimen. However, after seeing the demonstration participants indicated that they would employ measures to

ensure that they administer medication regularly, such scheduling medication administration at specific times.

Participants also reported that they had experienced problems with one of the medication formulations due to the taste thereof. Issues with palatability have been reported on extensively in the literature (Biru et al., 2016; Buchanan et al., 2012; Campbell et al., 2012; Coetzee et al., 2015; Coetzee et al., 2016b; Elsland et al., 2018; Reda & Biadgilign, 2012). One participant reported that she would sometimes let her child skip doses due to the bitterness thereof, and another indicated that her child would spit up medication. After seeing the demonstration this participant indicated that she would be sure to re-administer the medication to her child should he spit up medication in the future, evidencing that she understands the importance of her child taking all prescribed doses of medication.

Objective 2

The second objective of the present study was to determine whether participants felt that the device was appropriate to use with other caregivers, specifically in a clinic session. Participants felt that the demonstration would be beneficial to others, both caregivers and individuals on ART, as it would provide knowledge and understanding of HIV and treatment, indicative that participants deemed the demonstration as acceptable, and applicable to others. It should be noted here that the demonstration made participants somewhat anxious about their child's HIV and treatment. This was found in the study conducted by Jones et al. (2018) using the Petrie device, and can be attributed to the demonstration exposing the participant to the threat and consequences of treatment failure. Whilst this may appear problematic for implementation with other caregivers, this anxiety seemed to be mitigated by participant belief in the efficacy of treatment and motivation for their child to adhere.

Further, almost 70% of the sample reported that the demonstration could be used in standard clinic sessions with a paediatrician. However, whilst this may seem feasible to participants, the context of the current healthcare system needs to be taken into account. With high patient loads, requiring paediatricians to deliver such a demonstration is not feasible. In order to cope with the

increasing demand for treatment, the decision was made in 2009 to decentralise ART services to primary healthcare (PHC) facilities. PHC facilities are challenged to deliver high quality services within a healthcare system that is lacking infrastructure and trained healthcare professionals, and is facing an ever increasing demand for healthcare services (Crowley & Stellenberg, 2014; Mathibe et al., 2015).

In general, task shifting takes places as a process of decentralisation (Crowley & Stellenberg, 2014). Within the context of adherence to ART, lay-counsellors and nurses have assumed some of the load in ensuring patients maintain adherence to ART through adherence counselling. As paediatricians have limited time, and in some settings are not readily available, adherence counsellors may be best positioned to deliver an intervention of this kind. Conversely, adherence counselling sessions have been deemed as not strong enough to support adherence to ART (Dewing et al., 2012a). However, lay counsellors are disadvantaged in their ability to support adherence to ART due to variable training (Dewing et al., 2012b), and the lack of adequate support and supervision received by counsellors themselves (Coetzee et al., 2016a; Dewing et al., 2012b; Petersen et al., 2014). Once counsellors have received initial training, they are generally "left on their own to identify and address adherence problems with the patient" (Remien et al., 2013, p. 1980). Such a lack of support and supervision may lead to counsellors being ill-equipped to provide adherence-related support to patients. However, with adequate training and supervision (Kagee, 2013; Petersen et al., 2014) adherence counsellors have the potential to be valuable adherence agents in the lives of patients, and may be the most suitable individuals to deliver such an intervention.

Objective 3

The third objective of the present study was concerned with examining caregivers thoughts about the future implementation of the device, and what changes could be made to the demonstration. Participants in the study specifically addressed where they thought the demonstration should be delivered in future work, and who should present it.

More than 80% of the sample reported that the demonstration could be delivered in clinics and hospitals, as this is where patients are accessible. However, as mentioned, implementing such an intervention within the healthcare system, particularly in PHC facilities, may prove problematic. In KwaZulu Natal, some clinics were not even adequately equipped to provide the necessary ART services (Crowley & Stellenberg, 2014). With South Africans accessing clinic services at an ever increasing rate, PHC facilities may not have sufficient space to accommodate and attend to all patients (Hunter et al., 2017), let alone implement an intervention such as the Petrie device demonstration.

Moreover, as evidenced in the present study recruitment rates were slow, with only a small number of caregivers forming part of the study sample. One of the most common reasons cited provided for choosing to not participate was that caregivers did not have time. Long waiting times at clinics have been reported as an issue for caregivers (Williams et al., 2016), which may dissuade potential participants from spending additional time at the clinic. Whilst potential participants reported various reasons for declining to participate, the small sample size may also relate to the stigma that could accompany participation in such a study. One participant spoke of how taking part in such a study in the clinic may lead people to assume one's HIV status. Fear of being judged as HIV-positive has been reported as a barrier to participation in HIV vaccine trials (Dhalla & Poole, 2011; Richardson et al., 2017). The same participant suggested presenting the demonstration in churches within communities, as this would provide a safe space for individuals to view the demonstration, where they may perceive less stigma. Campbell et al. (2007) report that churches are a suitable setting for health promotion interventions due to their stability as respected and credible social institutions within the community. Churches provide members with an enduring social group (Taylor & Chatters, 1988). As such, church-based social networks are likely to be sources of both spiritual and emotional support from members of the congregation (Krause, Ellison, Shaw, Marcum, & Boardman, 2001). Thus, the social networks and support provided by members of churches (Campbell et al., 2007) may reduce the fear of stigma experienced by caregivers who wish

to view the demonstration. However, presenting the demonstration in a church does not take into account multi-religious communities. Religious belief was not assessed as part of the present study.

Participants had various suggestions as to who should present the demonstration. Participants suggested that doctors or nurses could present the demonstration, indicative that participants approve of such a demonstration being delivered as part of routine clinical practice. However, as discussed above with regard to the second objective of the present study, paediatricians may not be in a position to deliver such a demonstration, due to high patient load in a system where infrastructure and time are lacking (Crowley & Stellenberg, 2014; Mathibe et al., 2015). In contrast, one participant indicated that she felt clinic nurses would not be suitable candidates to deliver the intervention. In this participant's experience, clinic staff had not provided her with all the necessary information regarding her own and her child's diagnosis. This may be due to pitfalls in the adherence counselling system, as a result of insufficient training and a lack of supervision provided to counsellors (Coetzee et al., 2016a; Dewing et al., 2012b; Petersen et al., 2014; Remien et al., 2013). Further training and supervision may enable counsellors to provide the necessary adherence-related support to caregiver-child dyads, and implement such an intervention.

Further, participants suggested that the future presenter must be someone who is friendly, understanding, motivating, and educated on the topic of HIV and treatment. Moreover clear explanations and language proficiency was important.

Almost all participants felt that no changes needed to be made to the demonstration. One participant proposed that the model itself could be given eyes, suggesting that the model could be made more realistic. Moreover, one participant suggested that the demonstration should be delivered to caregivers regularly so as to further increase knowledge and understanding. As such booster sessions may be a valuable avenue to explore in addition to the initial contact session. Such sessions can be seen as 'refreshers' that occur after the intervention, provided weeks or months apart, reiterating the primary content of the intervention (Lochman et al., 2014). By reinforcing the content, booster sessions may enhance memory retention, which, coupled with the long lasting effect of visual imagery (Gardener & Houston, 1989; Williams et al., 2012), may prove particularly

useful in enhancing adherence-related knowledge and motivation amongst caregivers to children on ART.

Limitations and Recommendations

The findings of this study present the experiences and opinions of a small number of caregivers to children on ART within the City of Cape Town municipality. Due to the small sample size (N=11), the findings cannot be generalised. Moreover, whilst the sample were diverse in terms of age, SES, education, and relationship to the child, only one male caregiver took part. Therefore, a larger and more diverse sample would have allowed the acceptability of the demonstration to be stated more conclusively. However, whilst the findings of the current study are not generalisable, the study findings may still be transferable to other caregiver-child dyads who are presented with the Petrie device demonstration. In an effort to ensure transferability I provided thick descriptive data of the study context, as well as of the participants and their experiences.

Further, the participants of the study may be biased in motivation. As participants were made aware of the length of the contact session and consented to participate even after the long wait at the clinic, it can be said that these participants may have been more motivated caregivers. As motivation is a key component of the IMB model, the potential bias of the present sample must be taken into account.

Whilst the purpose of the Petrie device demonstration is to improve adherence to ART, the efficacy of the demonstration was not assessed in the present study. Change in diagnosis and treatment-related knowledge and beliefs post-intervention was not assessed, nor was change over time. Moreover, change in adherence as a result of viewing the demonstration was not evaluated. Further follow-up would have allowed me to assess the impact of the demonstration, particularly in terms of adherence. However, the purpose of the present study was to assess acceptability, and therefore determining the efficacy of the demonstration was not necessary. Moreover, attempts to determine the efficacy of the demonstration in enhancing adherence may have proved problematic in the context of the present study as participant retention may not have been high, as evidenced by caregiver reluctance to take part in the present study, and slow recruitment rates that are unrelated

to the acceptability of the demonstration. Further work is needed to determine the ideal implementation setting for such a demonstration. However, it is evident that this demonstration shows promise in its ability to enhance medication adherence. Therefore, further research is required to determine whether a visual intervention of this kind is effective in enhancing paediatric adherence to ART. Conducting a pilot study measuring change in adherence over time as determined by a multi-measure approach, would provide preliminary data as to the efficacy of the demonstration in enhancing adherence to ART.

However, the feasibility of implementing the device poses an issue to further work. Whilst participants indicated that the demonstration would be appropriate to use in a clinic setting, the preparation and delivery thereof may prove problematic. The demonstration requires complex chemistry in order to affect the colour change used to illustrate adherence/non-adherence. The necessary solutions and adequate facilities are required to prepare the various components needed for the intervention. Moreover, preparing the solutions requires specific training, is time consuming, and requires space for storage. The space needed to store the solutions, particularly if they need to be transported to a clinic for use as they were in the present study, means there is a limit as to how many patients can see the demonstration on a given day. Whilst this was not an issue in the present study due to slow rates of recruitment, if such a demonstration were to be delivered as part of routine practice, the storage of solutions would become an issue. In the setting of an overburdened healthcare system, the implementation of such an intervention would prove difficult. It is unlikely that clinics have the facilities, time, or space required for the preparation and delivery of such an intervention. In order to use the demonstration in the healthcare setting ‘kits’ of pre-prepared solutions would be required. However, the feasibility of the current demonstration should not lead to complete disregard of the study findings.

It is evident that the active visualisation technique used in the demonstration was acceptable to caregivers, and may prove effective in enhancing paediatric adherence to ART. Therefore, adaptation of the demonstration in its current form may be required. Work by Perera et al. (2014) found that an active visualisation smartphone intervention providing persons on ART with real

time, visual information regarding their level of immune protection as a result of medication intake was effective in increasing adherence, and decreasing VL. However, the SES of participants may have been influential in determining the acceptability of a smartphone-based intervention. By adapting the intervention in its current concrete form into an animation to be presented on a smartphone or tablet computer device, the Petrie device demonstration may be more feasible to implement in various settings, not only in clinics. This would require further work in adapting the demonstration, as well as determining whether the animation version is more or less acceptable than a physical demonstration.

Conclusion

Adherence to ART is key in ensuring optimal health outcomes for children five years and younger with HIV. Caregivers of children on ART are fundamental in ensuring their child achieves high levels of adherence. However, caregivers require the necessary adherence-related information, motivation, and behavioural skills to ensure their child remains adherent, and these components are often disrupted. Active visualisation devices explaining the effects of medication adherence, such as the Petrie device demonstration, provide caregivers with adherence-related knowledge and motivation, which in turn may assist caregivers in conceptualising behavioural strategies to ensure improved levels of adherence. The Petrie device demonstration was found to be acceptable to caregivers, and appears suitable for use as part of routine clinical practice. However, aspects of implementation, such as the preferred setting, still need to be determined and requires further work. Moreover, feasibility of the demonstration in its current form is problematic, and adaptation of the demonstration into an animation may be appropriate. The findings of this research indicate that such an intervention has the potential to enhance paediatric adherence to ART, and further work should be conducted to determine the efficacy thereof.

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APPENDICES

Appendix A: Approval to Conduct Research at Site A

Western Cape Government
Health

STRATEGY & HEALTH SUPPORT
Health.Research@westerncape.gov.za
tel: +27 21 483 0866 fax: +27 21 483 9895
5th Floor, Norton Rose House, 8 Riebeek Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: WC_201711_015
ENQUIRIES: Dr Sabela Petros

Stellenbosch University

Faculty of Medicine and Health Sciences

Francie Van Zijl Drive

Tygerberg Hospital

Cape Town

7505

For attention: Ms Melissa Bradshaw, Dr Bronwyne Coetzee

Re: **Exploring the acceptability of a visual intervention to improve paediatric adherence to antiretroviral therapy.**

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.

Please contact following people to assist you with any further enquiries in accessing the following sites:

[redacted] **Dr Werner Viljoen** **021 850 4704**

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

3. In the event where the research project goes beyond the estimated completion date which was submitted, researchers are expected to complete and submit a progress report (**Annexure 8**) to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

4. The reference number above should be quoted in all future correspondence.

Yours sincerely

DR A HAWKRIDGE

DIRECTOR: HEALTH IMPACT ASSESSMENT

DATE: 21/11/2017.

Appendix B: Approval to Conduct Research at Site B

Western Cape Government
Health

[redacted]
REFERENCE:
Research Projects
ENQUIRIES: **Dr GG Marinus**
TELEPHONE:**021 938 5752**

Ethics Reference: **S17/09/182**

TITLE: Exploring the acceptability of a visual intervention to improve paediatric adherence to antiretroviral therapy.

Dear Melissa Bradshaw

PERMISSION TO CONDUCT YOUR RESEARCH AT [redacted]

1. In accordance with the Provincial Research Policy and [redacted] Hospital Notice No 40/2009, permission is hereby granted for you to conduct the above-mentioned research here at [redacted]

2. Researchers, in accessing Provincial health facilities, are expressing consent to provide the Department with an electronic copy of the final feedback within six months of completion of research. This can be submitted to the Provincial Research Co-Ordinator (Health.Research@westerncape.gov.za).

DR GG MARINUS
MANAGER: MEDICAL SERVICES

DR D ERASMUS
CHIEF EXECUTIVE OFFICER
Date: 15 December 2011

Administration Building, Francie van Zijl Avenue, Parow, 7500 Private Bag X3, Tygerberg, 7505
tel: +27 21 938-6267 fax: +27 21 938-4890 www.capegateway.gov.za

TYGERBERG HOSPITAL

Ethics Reference: **S17/09/182**

TITLE: Exploring the acceptability of a visual intervention to improve paediatric adherence to antiretroviral therapy.

BY _____

An authorized representative of [redacted]

NAME Dr DS Erasmus

TITLE CEO

DATE 15 December 2017

Appendix C: Ethical Approval

UNIVERSITEIT STELLENBOSCH UNIVERSITY

Approved

New Application

25/10/2017

Project ID #: 1502

HREC Reference #: S17/09/182

Title: Exploring the acceptability of a visual intervention to improve paediatric adherence to antiretroviral therapy

Dear Melissa Bradshaw,

The **New Application** received on 26/09/2017 was reviewed by members of the **Health Research Ethics Committee (HREC)** via Minimal Risk Review procedures on 25 October 2017 and was approved.

Please note the following information about your approved research protocol:

Protocol approval period: This project has been approved for a period of one year from the date of this approval letter.

Please remember to use your project reference number (1502) on any documents or correspondence with the HREC concerning your research protocol.

Translation of the consent document/s to the language/s applicable to the study participants should be submitted.

Please note that this decision will be ratified at the next HREC full committee meeting. HREC reserves the right to suspend approval and to request changes or clarifications from student applicants. The coordinator will notify the applicant (and if applicable, the supervisor) of the changes or suspension within 1 day of receiving the notice of suspension from HREC. HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:

Please note a template of the progress report is obtainable on https://applyethics.sun.ac.za/Project/Index/1640 and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Helene Visser at City Health (Helene.Visser@capetown.gov.za Tel:+27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions please visit: https://applyethics.sun.ac.za/Project/Index/1640

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely,

Francis Masiye,

HREC Coordinator,

Health Research Ethics Committee 2.

Federal Wide Assurance Number: 00001372

Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2015 (Department of Health).

INVESTIGATOR RESPONSIBILITIES

Protection of Human Research Participants

Some of the responsibilities investigators have when conducting research involving human participants are listed below:

- Conducting the Research: You are responsible for making sure that the research is conducted according to the HREC approved research protocol. You are also responsible for the actions of all your co-investigators and research staff involved with this research.
- Participant Enrolment: You may not recruit or enrol participants prior to the HREC approval date or after the expiration date of HREC approval. All recruitment materials for any form of media must be approved by the HREC prior to their use. If you need to recruit more participants than was noted in your HREC approval letter, you must submit an amendment requesting an increase in the number of participants.
- Informed Consent:You are responsible for obtaining and documenting effective informed consent using **only** the HREC approved consent documents, and for ensuring that no human participants are involved in research prior to obtaining their informed consent. Please give all participants copies of the signed consent documents. Keep the originals in your secured research files for at least fifteen (15) years.
- Continuing Review:The HREC must review and approve all HREC approved research protocols at intervals appropriate to the degree of risk but not less than once per year. There is **no grace period**. Prior to the date on which the HREC approval of the research expires, **it is your responsibility to submit the continuing review report in a timely fashion to ensure a lapse in HREC approval does not occur.** If HREC approval of your research lapses, you must stop new participant enrolment, and contact the HREC Office immediately.
- Amendments and Changes:If you wish to amend or change any aspect of your research (such as research design, interventions or procedures, number of participants, participant population, informed consent document, instruments, surveys or recruiting material), you must submit the amendment to the HREC for review using the current Amendment Form. You **may not initiate** any amendments or changes to your research without first obtaining written HREC review and approval. The **only exception** is when it is necessary to eliminate apparent immediate hazards to participants and the HREC should be immediately informed of this necessity.
- Adverse or Unanticipated Events:Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research-related injuries, occurring at this institution or at other performance sites must be reported to the HREC within **five (5) days** of discovery of the incident. You must also report any instances of serious or continuing problems, or non-compliance with the HREC's requirements for protecting human research participants. The only exception to this policy is that the death of a research participant must be reported in accordance with the Stellenbosch University Health Research Ethics Committee Standard Operating
  Procedures www.sun25.sun.ac.za/portal/page/portal/Health_Sciences/English/Centres%20and%20Institutions/Research_Development_Support/Ethics/Application_package. All reportable events should be submitted to the HREC using the Serious Adverse Event Report Form.
- Research Record Keeping: You must keep the following research-related records, at a minimum, in a secure location for a minimum of fifteen years; the HREC approved research protocol and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence from the HREC.
- Reports to the MCC and Sponsor: When you submit the required annual report to the MCC or you submit a required report to your Sponsor, you must provide a copy of that report to the HREC. You may submit the report at the time of continuing HREC review.
- Provisions of Emergency Medical Care: When a physician provides emergency medical care to a participant without prior HREC review and approval, to the extent permitted by law, such activities will not be recognized as research nor will the data obtained by any of such activities be used in support of research.
- Final Reports: When you have completed (no further participant enrolment, interactions, interventions or data analysis) or stopped work on your research, you must submit a Final Report to the HREC.
- On-Site Evaluations, MCC Inspections, or Audits: If you are notified that your research will be reviewed or audited by the MCC, the Sponsor, any other external agency or any internal group, you must inform the HREC immediately of the impending audit/evaluation.

Appendix D: Participant Information Leaflet and Consent Form

Participant Information Leaflet and Consent Form

TITLE OF THE MASTERS RESEARCH PROJECT:
Exploring the acceptability of a visual intervention to improve paediatric adherence to antiretroviral therapy
RESEARCHER: Melissa Bradshaw
SUPERVISOR: Dr Bronwyne Coetzee
ADDRESS:
Department of Psychology, Stellenbosch University
CONTACT NUMBER:
Melissa Bradshaw (021) 808 2857/Dr Bronwyne Coetzee (021) 808 3979

You are being invited to take part in a research project, conducted by a masters student from Stellenbosch University. Please take some time to read the information in this leaflet, which will explain the details of this project. Please ask the researcher any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.
This study has been approved by the **Health Research Ethics Committee at Stellenbosch University (S17/09/182)**.

WHAT IS THIS RESEARCH ALL ABOUT?

In this study we are interested in understanding your experiences of a visual demonstration, which will explain your child's antiretroviral therapy (ART) to you. This study will be taking place at two hospital sites, and we will invite 20 to 30 people to take part in the study. If you agree to take part in this study, we would ask you to complete three questionnaires. Thereafter, you will be presented with a demonstration, after which you will be asked to complete a final questionnaire, and an interview. With your permission, we would like to voice record this interview. The total time taken up by this session would be approximately an hour and a half.

Your participation in this study will not prevent you from receiving your usual medical services. The information we obtain from your participation will be anonymized (neither your nor your child's names will be used) and your personal information will be kept confidential. Participation is not compulsory. You may withdraw from the study at any time.

WHY HAVE I BEEN INVITED TO PARTICIPATE?

You have been invited to take part in this study because you are the caregiver of the child that you have brought to the clinic. This means that you attend regular clinic sessions with the child and/or administer their medication. Your child is between the ages of 0 and 5 years, and is currently receiving chronic medication, specifically antiretroviral therapy (ART).

WILL I BENEFIT FROM TAKING PART IN THIS RESEARCH?

There are no direct benefits associated with participating in this study. However, your participation in this research is likely to generate knowledge that will benefit other caregivers and their children receiving chronic medication in future.

ARE THERE IN RISKS INVOLVED IN MY TAKING PART IN THIS RESEARCH?

There are no known risks to participating in this study. Should you have any concerns do not hesitate to contact the researcher. Should you feel distressed whilst completing the questionnaires or being interviewed, please tell the researcher who will refer you to the registered counsellor or psychologist at your healthcare center. If you feel distressed after the session then please contact the researcher who will refer you to the registered counsellor or psychologist at your healthcare centre, or contact the Health Research Ethics Committee.

WHO WILL HAVE ACCESS TO MY OR MY CHILD'S MEDICAL RECORDS?

We will not access you or your child's medical records.

WILL I BE PAID TO TAKE PART IN THIS STUDY AND ARE THERE ANY COSTS INVOLVED?

No, you will not be paid to take part in the study. There will be no costs involved for you, if you do take part.

IS THERE ANY THING ELSE THAT I SHOULD KNOW OR DO?

- If you feel distressed please contact the researcher (Melissa Bradshaw) at 021 808 2857, who will refer you to the registered counsellor or psychologist at your healthcare centre.
- If you would like more information about this study please contact the researcher (Melissa Bradshaw) at 021 808 2857 or the research supervisor (Dr Coetzee) at 021 808 3979.
- You can contact the Health Research Ethics Committee at 021 938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.
- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I …….. agree to take part in a research study entitled *Exploring the acceptability of a visual intervention to improve paediatric adherence to antiretroviral therapy.*

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurized to take part.
- I may choose to leave the study at any time and will not be penalized or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

I consent to [*please tick the necessary boxes*]:

- … taking part today
- … the use of a voice recorder during the interview session

Signed at (*place*) ..... on (*date*) …….. 201…..

……

Signature of participant

Declaration by researcher

I *(name)* …….. declare that:

- I explained the information in this document to ……..
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above

Signed at (*place*) ..... on (*date*) …….. 201…..

……

Signature of investigator

Inligtingsblad en Toestemmingsvorm vir Deelnemers

TITLE VAN DIE MEESTERS NAVORSINGSPROJEK:
Exploring the acceptability of a visual intervention to improve paediatric adherence to antiretroviral therapy
NAVORSER: Melissa Bradshaw
NAVORSINGSTUDIELEIER: Dr Bronwyne Coetzee
ADRES:
Departement van Sielkunde, Stellenbosch Universiteit
KONTAK NOMMER:
Melissa Bradshaw (021) 808 2857/Dr Bronwyne Coetzee (021) 808 3979

Ons nooi jou om deel te neem aan ’n navorsingsprojek van ’n magisterstudent van die Stellenbosch Universiteit. Lees asseblief die inligting in hierdie inligtingsblad deeglik deur, want dit verduidelik waaroor hierdie projek gaan. Vra gerus die navorser oor enige deel van die projek wat jy nie heeltemal verstaan nie. Dit is baie belangrik dat jy heeltemal tevrede is dat jy goed verstaan waaroor die navorsing gaan en hoe jy daarby betrokke kan wees. Onthou ook, jou deelname is **heeltemal vrywillig**, en jy mag nee sê. As jy besluit om nié deel te neem nie, sal dit hoegenaamd geen slegte gevolge vir jou inhou nie. Jy kan ook in enige stadium aan die studie onttrek, selfs al het jy aan die begin ingestem om deel te neem. Hierdie studie is deur die **Universiteit Stellenbosch se Gesondheidsnavorsingsetiekkomitee** goedgekeur **(S17/09/182)**.

WAAROOR GAAN HIERDIE NAVORSING?

Met hierdie studie wil ons graag weet hoe jy ’n visuele demonstrasie ervaar wat jou kind se antiretrovirale behandeling (ARV’s) aan jou sal verduidelik. Die studie word by twee hospitale gedoen, en ons sal 20 tot 30 mense nooi om deel te neem. As jy instem om aan die studie deel te neem, sal ons jou vra om drie vraelyste in te vul. Dit sal ongeveer 30 minute duur om te voltooi. Daarna sal jy na ’n demonstrasie van ongeveer 15 minute kyk, waarna ons jou sal vra om een laaste vraelys te voltooi en in ’n onderhoud met ons te gesels, wat sowat 45 minute sal duur. Met jou toestemming sal ons graag hierdie onderhoud op band wil opneem. Die hele sessie sal dus altesaam sowat ’n uur en ’n half van jou tyd in beslag neem.

Jou deelname aan hierdie studie sal nie verhinder dat jy jou gewone mediese dienste ontvang nie. Die inligting wat ons uit jou deelname kry, sal anoniem wees (nie jou óf jou kind se name sal gebruik word nie) en jou persoonlike besonderhede sal vertroulik gehou word. Deelname is nie verpligtend nie. Jy kan in enige stadium aan die studie onttrek.

HOEKOM WORD EK GENOOI OM DEEL TE NEEM?

Jy word genooi om aan hierdie studie deel te neem, want jy is die versorger van die kind wat jy kliniek toe gebring het. Dít beteken jy bring die kind vir gereelde sessies kliniek toe en/of gee die kind se medisyne. Die kind is tussen die ouderdom van 0 en 5 jaar, en ontvang tans chroniese medisyne, spesifiek antiretrovirale middels (ARV’s).

WATTER VOORDEEL IS DAAR VIR MY AS EK AAN HIERDIE NAVORSING DEELNEEM?

Daar is geen direkte voordele verbonde aan deelname aan hierdie studie nie. Tog sal jou deelname aan hierdie navorsing waarskynlik kennis skep wat in die toekoms ander versorgers en hulle kinders wat chroniese medisyne ontvang, kan help.

IS DAAR ENIGE RISIKO'S VERBONDE AAN DEELNAME AAN HIERDIE NAVORSING?

Deelname aan hierdie studie hou geen risiko's in waarvan ons weet nie. As enigiets jou bekommer, moenie huiwer om die navorser te kontak nie. As jy ontsteld voel terwyl jy die vraelyste invul of in die onderhoud met ons gesels, sê dit asseblief vir die navorser, wat jou dan na die geregistreerde berader of sielkundige by jou gesondheidsorgsentrum sal verwys. As jy ná die sessie ontsteld voel, skakel asseblief die navorser wat jou dan na die geregistreerde berader of sielkundige by jou gesondheidsorgsentrum sal verwys, of skakel die Gesondheidsnavorsingsetiekkomitee.

WIE SAL NA MY OR MY KIND SE MEDIESE INLIGTING KAN KYK?

Ons sal nie na jou of jou kind se mediese inligting kyk nie.

SAL EK BETAAL WORD OM AAN HIERDIE STUDIE DEEL TE NEEM, EN SAL DIT MY ENIGIETS KOS?

Nee, jy sal nie betaal word om aan die studie deel te neem nie. Deelname sal jou ook niks kos nie.

IS DAAR ENIGIETS ANDERS WAT EK MOET WEET OF DOEN?

- As jy ontsteld voel, bel asseblief die navorser (Melissa Bradshaw) by 021 808 2857, wat jou dan na die geregistreerde berader of sielkundige by jou gesondheidsorgsentrum sal verwys.
- As jy meer inligting oor hierdie studie wil hê, bel asseblief die navorser (Melissa Bradshaw) by 021 808 2857, of die navorsingstudieleier (Dr Coetzee) by 021 808 3979.
- As jy voel dat die navorser nie jou probleme of klagtes behoorlik hanteer het nie, kan jy die Gesondheidsnavorsingsetiekkomitee by 021 938 9207 bel.
- Jy sal 'n afskrif van hierdie inligtingsblad en toestemmingsvorm kry vir jou eie gebruik.

Verklaring deur deelnemer

Deur hieronder te teken, stem ek, ……, in om deel te neem aan ’n navorsingstudie getiteld *Exploring the acceptability of a visual intervention to improve paediatric adherence to antiretroviral therapy.*

Ek verklaar soos volg:

- Ek het hierdie inligtingsblad en toestemmingsvorm gelees of dit is aan my voorgelees, en dit is geskryf in ’n taal waarmee ek gemaklik is en wat ek goed praat.
- Ek het kans gekry om vrae te stel en ál my vrae is goed genoeg beantwoord.
- Ek verstaan dat deelname aan hierdie studie **vrywillig** is, en niemand het my gedwing om deel te neem nie.
- Ek weet ek kan besluit om die studie in enige stadium te verlaat sonder dat ek op enige manier gestraf of benadeel sal word.
- Ek besef ek kan gevra word om die studie te verlaat voordat dit klaar is indien die navorser voel dit is in my belang, of as ek nie die studieplan volg waaroor daar ooreengekom is nie.

Ek stem in [*merk asseblief die nodige blokkies*]:

- ... om vandag deel te neem.
- ... dat ’n stemopname van die onderhoudsessie gemaak word.

Geteken by *(plek)* ..... op *(datum)* …….. 201…..

……
Handtekening van deelnemer

Verklaring deur navorser

Ek, *(naam)* ……, verklaar soos volg:

- Ek het die inligting in hierdie dokument aan ..... verduidelik.
- Ek het hom/haar aangemoedig om vrae te vra, en het genoeg tyd daaraan afgestaan om dit te beantwoord.
- Ek is tevrede dat hy/sy alle aspekte van die navorsing, soos dit hierbo uiteengesit is, voldoende begryp.

Geteken by *(plek)* ..... op *(datum)* …….. 201…..

……
Handtekening van navorser

Appendix E: Biographical Questionnaire

Caregiver and Child Background Information

Instructions: Please answer each question as accurately as possible by circling the correct answer or filling in your response in the space provided.

Caregiver

What is your age? _____

What ethnic group do you belong to? _____

What is your gender?

1-Female 2-Male 3-Other

What is your home language? _____

Where do you currently live? _____

Please choose one of the following that best describes your social class.

1-Lower 2-Working 3-Middle 4-Upper middle 5-Upper

What is the highest level of education you have completed? _____

What is your current employment status? _____

What is your relationship to the child you have brought to the clinic?

1-Biological mother 5-Foster mother

2-Biological father 6-Foster father

3-Grandmother 7-Stepmother

4-Grandfather 8-Stepfather

9-Other (please specify): _____

Do you regularly attend clinic visits with the child?

1-YES

2-NO (if no, please specify who regularly attends clinic visits with the child):

_____

Do you administer the child's medication on a regular basis?

1-YES

2-NO (if no, please specify who (or all involved) administers the child's medication):

_____

Are you on any medications?

1-YES 2-NO

If yes, which? And for how long?

_____

Child

What is the age of the child? _____

What is the child's gender?

1-Female 2-Male 3-Other

Where does the child currently live? _____

When was the child diagnosed? _____

How long has the child been receiving ART? _____

Who else in your household knows about the child's virus?

_____

Does the child know why they take medication?

1-YES 2-NO 3-Other: _____

Why does the child think that they take medication?

_____

_____

Does the child have a name for their virus? / What does the child call their virus?

_____

Agtergrondinligting oor Versorger en Kind

Instruksies: Beantwoord asseblief elke vraag so akkuraat soos moontlik deur die korrekte antwoord te omkring of jou antwoord in die beskikbare ruimte in te vul.

Versorger

Hoe oud is jy? _____

Tot watter etniese groep behoort jy? _____

Wat is jou geslag?

1-Vrou 2-Man 3-Ander

Wat is jou huistaal? _____

Waar woon jy tans? _____

Kies asseblief een van die volgende wat jou sosiale klas die beste beskryf.

1-Laer 2-Werkers 3-Middel 4-Hoër middel 5-Hoër

Wat is die hoogste vlak van opvoeding wat jy voltooi het? _____

Wat is jou huidige werkstatus? _____

Wat is jou verwantskap met die kind wat jy kliniek toe gebring het?

1-Biologiese ma
2-Biologiese pa
3-Ouma
4-Oupa
5-Pleegma
6-Pleegpa
7-Stiefouma
8-Stiefoupa
9-Ander (spesifiseer asseblief): _____

Kom jy gewoonlik saam met die kind vir sy/haar kliniekbesoeke?

1-JA

2-NEE (indien nie, sê asseblief wie gewoonlik saam met die kind vir kliniekbesoeke kom):

_____

Gee jy gewoonlik die kind se medisyne?

1-JA

2-NEE (indien nie, sê asseblief wie (almal) die kind se medisyne gee):

_____

Gebruik jy self enige medisyne?

1-JA 2-NEE

Indien wel, watter medisyne? En vir hoe lank?

_____

Kind

Hoe oud is die kind? _____

Wat is die kind se geslag?

1-Vrou 2-Man 3-Ander

Waar woon die kind tans? _____

Wanneer is die kind gediagnoseer? _____

Hoe lank is die kind al op ARV's? _____

Wie anders in die huishouding weet van die kind se virus?

_____

Weet die kind waarom hy/sy die medisyne drink?

1-JA 2-NEE 3-Ander: _____

Waarom dink die kind drink hy/sy die medisyne?

_____

_____

Het die kind 'n naam vir sy/haar virus? / Wat noem die kind sy/haar virus?

_____

Appendix F: Beliefs and Understanding Questionnaire

Child's Diagnosis and Treatment Questionnaire

This questionnaire asks you some questions about your child's diagnosis and treatment.
There are no right or wrong answers for these questions – a correct answer is one that is true for you.
All of the information you provide to us is in confidence, and will only be used for the purposes of this study.

Please answer the following by circling a number for each question.

How much do you think your child's virus affects their life?										
0	1	2	3	4	5	6	7	8	9	10
No effect at all										Severely affects their life
How long do you think your child's virus infection will continue?										
0	1	2	3	4	5	6	7	8	9	10
A very short time										Forever
How much control do you feel that there is over your child's virus?										
0	1	2	3	4	5	6	7	8	9	10
Absolutely no control										Extreme amount of control
How much do you think medication can help your child's virus?										
0	1	2	3	4	5	6	7	8	9	10
Not at all helpful										Extremely helpful
How much do you think your child experiences symptoms from their virus?										
0	1	2	3	4	5	6	7	8	9	10
No symptoms at all										Many severe symptoms

How much do you think does your child experiences symptoms from their medication? 0 1 2 3 4 5 6 7 8 9 10 No symptoms at all — Many severe symptoms
How concerned are you about your child's virus? 0 1 2 3 4 5 6 7 8 9 10 Not at all concerned — Extremely concerned
How well do you feel you understand your child's virus? 0 1 2 3 4 5 6 7 8 9 10 Don't understand at all — Understand very clearly
How much does your child's virus affect you emotionally? (E.g. would it make you scared, angry, or upset?) 0 1 2 3 4 5 6 7 8 9 10 Not at all affected emotionally — Extremely affected emotionally
How much do you think your child's virus affects them emotionally? 0 1 2 3 4 5 6 7 8 9 10 Not at all affected emotionally — Extremely affected emotionally

How much do you feel your child needs their medication prescribed for their virus?										
0	1	2	3	4	5	6	7	8	9	10
They don't need it at all										It is absolutely essential for them
How motivated are you for your child to take the medication prescribed for their virus?										
0	1	2	3	4	5	6	7	8	9	10
Not at all motivated										Extremely motivated
How concerned are you about the long-term use of medications prescribed for your child's virus?										
0	1	2	3	4	5	6	7	8	9	10
Not at all concerned										Extremely concerned
How serious do you think your child's virus is?										
0	1	2	3	4	5	6	7	8	9	10
Not serious at all										Extremely serious
Overall, how difficult do you feel it is for your child to take their current treatment as recommended by your doctor?										
0	1	2	3	4	5	6	7	8	9	10
Extremely difficult										Not difficult at all

Vraelys oor MIV-Diagnose en -Behandeling

Hierdie vraelys gaan oor jou kind se diagnose en behandeling.
Daar is geen regte of verkeerde antwoorde op hierdie vrae nie. Die 'regte' antwoord is die een wat jou omstandighede die beste beskryf.
Alle inligting wat jy ons gee, sal vertroulik gehou en vir geen ander doel as vir hierdie studie gebruik word nie.

Beantwoord asseblief die volgende vrae deur by elke vraag 'n nommer te omkring.

Hoe 'n groot invloed dink jy het jou kind se virus op sy/haar lewe?										
0	1	2	3	4	5	6	7	8	9	10
Geen invloed nie										Ernstige invloed
Hoe lank dink jy sal jou kind se virusinfeksie duur?										
0	1	2	3	4	5	6	7	8	9	10
'n Baie kort rukkie										Vir altyd
Hoeveel beheer voel jy is daar oor jou kind se virus?										
0	1	2	3	4	5	6	7	8	9	10
Hoegenaamd geen beheer nie										Geweldig baie beheer
Hoeveel dink jy kan medisyne vir jou kind se virus help?										
0	1	2	3	4	5	6	7	8	9	10
Help glad nie										Help geweldig baie
Hoeveel simptome dink jy ervaar jou kind van sy/haar virus?										
0	1	2	3	4	5	6	7	8	9	10
Hoegenaamd geen simptome nie										'n Klomp ernstige simptome

Hoeveel simptome dink jy ervaar jou kind van sy/haar medisyne?										
0	1	2	3	4	5	6	7	8	9	10
Hoegenaamd geen simptome nie										’n Klomp ernstige simptome
Hoe bekommerd is jy oor jou kind se virus?										
0	1	2	3	4	5	6	7	8	9	10
Glad nie bekommerd nie										Geweldig bekommerd
Hoe goed dink jy verstaan jy jou kind se virus?										
0	1	2	3	4	5	6	7	8	9	10
Verstaan dit glad nie										Verstaan dit baie goed
Hoe ’n groot uitwerking het jou kind se virus op jou emosies (gevoelens)? (Maak dit jou byvoorbeeld bang, kwaad of ontsteld?)										
0	1	2	3	4	5	6	7	8	9	10
Hoegenaamd geen uitwerking op emosies nie										Geweldige uitwerking op emosies
Hoe ’n groot uitwerking dink jy het jou kind se virus op sy/haar eie emosies?										
0	1	2	3	4	5	6	7	8	9	10
Hoegenaamd geen uitwerking op emosies nie										Geweldige uitwerking op emosies

Hoe nodig dink jy is die medisyne wat vir jou kind se virus voorgeskryf word?										
0	1	2	3	4	5	6	7	8	9	10
Glad nie nodig nie										Absoluut noodsaaklik
Hoe gemotiveerd is jy dat jou kind elke dag die medisyne neem wat vir sy/haar virus voorgeskryf word?										
0	1	2	3	4	5	6	7	8	9	10
Glad nie gemotiveerd nie										Geweldig gemotiveerd
Hoe bekommerd is jy oor die langtermyngebruik van die medisyne wat vir jou kind se virus voorgeskryf word?										
0	1	2	3	4	5	6	7	8	9	10
Glad nie bekommerd nie										Geweldig bekommerd
Hoe ernstig dink jy is jou kind se virus?										
0	1	2	3	4	5	6	7	8	9	10
Glad nie ernstig nie										Geweldig ernstig
Hoe moeilik dink jy is dit oor die algemeen vir jou kind om die huidige medisyne te neem soos wat julle dokter aanbeveel het?										
0	1	2	3	4	5	6	7	8	9	10
Geweldig moeilik										Glad nie moeilik nie

Appendix G: CAMP – Caregiver Evaluation

Comprehensive ART Adherence Measurement for Paediatrics (CAMP) – Caregiver Evaluation

This questionnaire will be administered in the form of an interview.

I am going to ask you some questions about your child [child's name] and his/her medicines. This questionnaire is designed to help us understand how it is for you both to do what you have been asked to do with the medicines. Please answer these questions as best you can.

Medication Description Questions

1. What are the medicines [child's NAME] is supposed to be taking for HIV infection *[their virus]*? *Have the caregiver explain how much is given and when. If they do not know names, record whatever the caregiver says to describe the medicine.*

Medication Name	Amount of Medication to be Given	Times Given
_____	□ Could not name	_____
_____	□ Could not name	_____
_____	□ Could not name	_____
_____	□ Could not name	_____
_____	□ Could not name	_____
_____	□ Could not name	_____
_____	□ Could not name	_____

2. Any other medicines given to [child's NAME]? If yes, which ones?

Medication Name	Amount of Medication to be Given	Times Given
_____	□ Could not name	_____
_____	□ Could not name	_____
_____	□ Could not name	_____
_____	□ Could not name	_____

3. What herbals, teas, or traditional medicines is [child's NAME] using?

4. Is [child's NAME] using any other medications from other doctors, clinics or hospitals? If yes, which ones?

Medication Name	Amount of Medication to be Given	Times Given
_____	□ Could not name	_____
_____	□ Could not name	_____

5. What else have you been doing or using to help the child become strong or healthy?

_____

_____

6. Who gives [name] his/her medicines? *(tick all that apply)*
□ Mother □ Father □ Guardian □ Relative who lives in home □ Relative who lives outside of home □ Neighbor □ Sibling □ House help □ Child takes meds themselves □ Other (specify) _____

7. Does anyone besides you know that [name] takes these medicines? □ Yes □ No
If yes, how many people know?_____
Who knows? (specify)_____
If no, why not? (specify)_____
_____

8. In an average week, how many days of the week are you the one who gives the child medicines?
□**Morning doses** □ 0 □ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □7
□**Evening doses** □ 0 □ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7

9. Does the child know that he/she is taking the medicines for HIV? ***[Alternative: Does your child know why he/she is taking medicines?]*** □ Yes □ No

Many parents and caregivers tell us that they sometimes have problems with giving the child medicines every day or at the right time. There are many reasons for families to struggle with the medicines. Many parents just forget when they are too busy or they do not give the medicines when they do not have food.

10. Do you ever just forget to give the medicines when you are busy?
□ Yes □ No
If yes, how often?
□ Many times □ Some times
□ Occasionally ____times in a week

11. Do you ever forget to keep time in giving the medicines?
□ Yes □ No
If yes, how often?
□ Many times □ Some times
□ Occasionally ____times in a week
When? □ Mornings □ Evenings □Weekends □ Weekdays □ Other: _____

12. Do you ever have problems keeping time with the medicines?
□ Yes □ No
If yes, how often?
□ Many times □ Some times
□ Occasionally ____times in a week
When? □ Mornings □ Evenings □Weekends □ Weekdays □ Other:_____

13. Do you ever not give the medicines because you do not want to give them in front of other people?
□ Yes □ No
If yes, how often?
□ Many times □ Some times
□ Occasionally
___times in a week

14. Do you ever delay giving the medicines because you do not want to give them in front of other people?
□ Yes □ No
If yes, how often?
□ Many times □ Some times
□ Occasionally
____times in a week

15. Are there times when you do not have enough food for your family?
□ Yes □ No

How many meals in a week do you miss food?
____meals in a week

How many meals in a week does your child miss food?
____meals in a week

16. Do you ever not give the child the medicines because you do not have food to give with the medicines?
□ Yes □ No
If yes, how often?
□ Many times □ Some times
□ Occasionally ____times in a week

17. Do you ever have problems with getting your child to take the medicines?
□ Yes □ No
If yes, how often?
□ Many times □ Some times
□ Occasionally ____times in a week

What problems does child raise?
_____
_____

18. Do you ever have problems with giving the medicines because the child does not know why they are taking them?
□ Yes □ No
If yes, how often?
□ Many times □ Some times
□ Occasionally
___times in a week

19. Have the medicines ever made the child sick or ill? □Yes □No
If yes: □ Vomiting □ Rash □ Anemia □ Sleep problem □ Liver problem □ Other:_____
If yes, why do you think the child became ill? □ Medicines too strong
□ Side effect of medicines
□ Did not take with food
□ Child not used to medicine
□ Other reason (specify)_____
_____

20. Did your child miss any doses yesterday?
□Yes □No
□ Don't know

21. How many doses of medicine has your child missed in the last 3 days?
(write number) _____
□ Don't know

22. How many doses of medicine has your child missed in the last month? _____
□ Don't know

23. Some families tell us that their child worries them or makes it difficult to give them the medicines. Has your child [name] not taken medicines for any of these reasons:

□ He/she does not know why taking the medicines or keeps asking questions about the medicines
□ He/she did not understand the medication instructions □ He/she forgot to take medicine
□ He/she was playing or at school or work □ He/she refused to take medicine
□ He/she felt ill or was vomiting □ He/she felt better
□ He/she does not want others to see the medicines □ He/she believes medicine does not help
□ He/she had harm or side effects caused by the drugs □ Has problems with 1 formulation (tablets, liquids)
□ Finds medicines too bitter □ He/she is tired of taking the medicines
□ Can't take without food □ None of the above
□ Other (specify:_____

24. Sometimes, a child does not take their medicines every day or at the same time every day because of difficulties for the caregiver. I am going to read a list of issues that may be problems for you as a caregiver in having the child take the medicines. Stop me when you hear a problem mentioned that applies to you or the child's caregiver. I [or the caregiver]:

□ I had difficulty with reading instructions □ I was afraid of side effects on child
□ I did not understand the medication instructions □ I thought other matters were more urgent
□ I thought treatment was completed □ I was away from home (work, field, etc.)
□ I was not always around with the child □ I was discouraged or losing hope
□ I was taking alcohol or other drugs □ There were frequent changes in caregivers
□ I did not want others to see □ Caregiver being too busy and forgetting
□ I had trouble with timing or giving the doses on time □ I was not aware of child's status
□ I did not think the drugs were helping □ I wanted to try another treatment or prayers
□ I thought child needed a break from the medicines □ None of the above
□ Other (specify) _____

25. Sometimes, children do not take their medicines because of difficulties within the community. Have any difficulties in the community caused your child to miss taking their medicines? Stop me when you hear a problem mentioned that applies to you:

□ I was unable to explain why the child taking medicines □ I did not want the child to be seen taking medicines
□ I was being discouraged by neighbors/friends/family □ I feared discrimination and isolation
□ Child in school and I did not want to remove from school □ Others did not believe medicines are needed
□ I did not receive help from neighbors/friends/family □ Other: (specify)_____
□ Could not get to clinic without others wondering □ None of the above

26. Sometimes, problems at the clinic make it difficult for families to give these medicines every day. Have any of these things been a problem for you:

□ The clinic staff didn't explain well enough how to give or take the medicine or did not write instructions
□ The clinic staff seemed to have a negative/judgmental attitude about the medicines
□ The clinic staff made you feel harassed
□ There was no money to purchase medicine
□ The medicine was not available in the pharmacy. ***Which medicine?*** □ ARVs □ Septrin □ Other (include abx)
□ Other (specify) _____□ None of the above

27. When children are sick, families often try other forms of treatment in addition to or in place of the ARVs. Is your child currently going for any of these other types of treatment: (Specify *tick all that apply*)

□ Herbal (including leaves, stems, roots) □ Teas □ Chinese □ Prayers for healing □ South African supplements
□ Witchcraft □ Cutting □ Other: (specify) _____

28. At times, families have difficulties with other matters related to the medicines. Have any of these things made it difficult for your child to take the medicines everyday or at the right time?

□ Too little/no food to give with medicine □ Ran out of medicine before clinic appointment
□ Pouring of medicines □ Family refused medication
□ Nobody to administer medication □ No clean water to use with medicines
□ Needing to hide medicines □ Delaying doses of medicines
□ No money for transport to clinic □ No transport to clinic available
□ Other (specify) _____ □ None of the above

29. In general how do you feel about taking medicine? □ I am willing to take medicine □ I dislike taking medicine, but I take it when I need it □ I use herbs instead of taking pills □ I never take medicine for any reason

30. Everyone misses taking their medication sometimes for various reasons. Do you have any trouble giving the child their medicines? □ Yes □ No **If yes, how often?** □ Many times □ Some times □ Occasionally

31. In the past week,

a. How many days were you with the child? □0 □1 □2 □3 □4 □5 □6 □7

b. On how many days did the child miss at least one dose? □0 □1 □2 □3 □4 □5 □6 □7

c. On how many days did the child take a dose more than an hour late? □0 □1 □2 □3 □4 □5 □6 □7

d. On how many days did the child miss **all** of his/her doses? □0 □1 □2 □3 □4 □5 □6 □7

e. How many doses did the child miss altogether? _____

f. How many extra doses or syringes of medicine did the child take? _____

32. How many people usually live in your household or are staying with you now? _____

33. How many children under 5 years of age live in your household?_____

34. How many people in your household take medicines for HIV? _____

35. Who else in the household takes medicines for HIV?

_____

_____

36. Who do you and this child stay with? *(Tick all that apply)*

□ No one (stay alone) □ Child's Parents
□ Caregiver's Spouse □ Child's Grandparents
□ Caregiver's Partner □ Child's Uncle/ Auntie/cousins
□ Other children □ Friends

37. Which of these people know the child takes medicines?*(Tick all that apply)*

□ No one (stay alone) □ Child's Parents
□ Caregiver's Spouse □ Child's Grandparents
□ Caregiver's Partner □ Child's Uncle/Auntie/Cousins
□ Other children □ Friends

38. Are you employed outside the home?

□ Yes □ No

If yes:

□ Full-time
□ Part-time
□ Casual

39. How long does it take you to travel to clinic?

□ ≤ 30 minutes
□ 30min-1hr
□ >1hr but <2hr
□ >2hr but <3hr
□ >3 hrs

40. How much do you pay for transport to come to clinic (one way)?

R_____

41. Do you have any difficulties with transport to clinic?

□ Yes □ No **If yes, how often?** □ Many times □ Some times □ Occasionally

What problem? □ lack of money □ lack of means □ lack of time □ Other _____

Many families try to take their pills around the same time or with the same activity every day so that they won't forget to take the medicines…..

42. Is there something that you are currently doing that helps to remind you to give the child his or her medicines at the same time every day? □ Yes □ No

If yes, what helps to remind you? □ Phone □ Watch □ Radio □ Taking medicines at meal times □ Sun □ Others in house take medicines together □ Other: _____

Omvattende ARV-getrouheidsmeting vir pediatrie ("CAMP") – Evaluering van Versorger

Hierdie vraelys sal deur middel van 'n onderhoud voltooi word.

Ek gaan jou 'n paar vrae oor jou kind [kind se naam] en sy/haar medisyne vra. Hierdie vraelys is saamgestel om ons te help verstaan hoe maklik of moeilik dit vir julle albei is om met die medisyne te doen soos julle gevra is. Beantwoord die vrae asseblief so goed jy kan.

Beskrywende vrae oor medisyne

1. Watter medisyne is [kind se NAAM] veronderstel om vir sy/haar MIV-infeksie *[sy/haar virus]* te drink? *Laat die versorger verduidelik hoeveel van die medisyne wanneer gegee word. As die versorger nie die name ken nie, teken aan wat ook al die versorger sê om die medisyne te beskryf.*

Naam van medisyne	Hoeveelheid medisyne wat gegee moet word	Medisynetye
_____	□ Kon nie sê nie	_____
_____	□ Kon nie sê nie	_____
_____	□ Kon nie sê nie	_____
_____	□ Kon nie sê nie	_____
_____	□ Kon nie sê nie	_____
_____	□ Kon nie sê nie	_____
_____	□ Kon nie sê nie	_____

2. Kry [kind se NAAM] enige ander medisyne? Indien wel, watter medisyne?

Naam van medisyne	Hoeveelheid medisyne wat gegee moet word	Medisynetye
_____	□ Kon nie sê nie	_____
_____	□ Kon nie sê nie	_____
_____	□ Kon nie sê nie	_____
_____	□ Kon nie sê nie	_____

3. Watter kruiemiddels, tees of tradisionele medisyne gebruik [kind se NAAM]?

4. Drink [kind se NAAM] enige ander medisyne van ander dokters, klinieke of hospitale? Indien wel, watter medisyne?

Naam van medisyne	Hoeveelheid medisyne wat gegee moet word	Medisynetye
_____	□ Kon nie sê nie	_____
_____	□ Kon nie sê nie	_____

5. Wat anders doen of gebruik jy om die kind te probeer sterk of gesond maak?

_____

_____

6. Wie gee vir [naam] sy/haar medisyne? *(Merk almal wat van toepassing is)* □ Ma □ Pa □ Voog □ Familielid wat in dieselfde huis woon □ Familielid wat elders woon □ Bure □ Broer of suster □ Huishulp □ Kind neem self medisyne □ Ander (spesifiseer) _____

7. Weet enigiemand buiten jy dat [naam] hierdie medisyne drink? □Ja □Nee
Indien wel, hoeveel mense weet?_____
Wie weet? (Spesifiseer)_____
Indien nie, hoekom nie?
(Spesifiseer)_____
_____

8. In 'n gemiddelde week, hoeveel dae van die week is jy die een wat vir die kind sy/haar medisyne gee?
□ **Oggenddosis** □ 0 □ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □7
□ **Aanddosis** □ 0 □ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □7

9. Weet die kind dat hy/sy die medisyne vir MIV drink? ***[Ander moontlikheid: Weet jou kind waarom hy/sy die medisyne drink?]*** □Ja □Nee

Baie ouers en versorgers sê hulle sukkel soms om die kind sy/haar medisyne elke dag of op die regte tyd te laat neem. Daar is 'n klomp verskillende redes waarom gesinne met die medisyne sukkel. Baie ouers vergeet om die medisyne te gee as hulle besig is, of hulle gee nie die medisyne as hulle nie kos het om te eet nie.

10. Vergeet jy ooit om die medisyne te gee as jy besig is?
□Ja □Nee
Indien wel, hoe gereeld?
□ Dikwels □ Soms
□ Gewoonlik ____keer per week

11. Vergeet jy ooit om die medisyne op die regte tyd te gee?
□Ja □Nee
Indien wel, hoe gereeld?
□ Dikwels □ Soms
□ Gewoonlik ____keer per week
Wanneer? □ Soggens □ Saans □ Naweke
□ Weeksdae □ Ander: _____

12. Sukkel jy ooit om die medisyne op die regte tyd te gee?
□Ja □Nee
Indien wel, hoe gereeld?
□ Dikwels □ Soms
□ Gewoonlik ____keer per week
Wanneer? □ Soggens □ Saans □ Naweke
□ Weeksdae □ Ander:

13. Gee jy ooit nié die medisyne nie, want jy wil dit nie voor ander mense doen nie?
□Ja □Nee
Indien wel, hoe gereeld?
□ Dikwels □ Soms
□ Net af en toe
___keer per week

14. Stel jy ooit uit om die medisyne te gee, want jy wil dit nie voor ander mense doen nie?
□Ja □Nee
Indien wel, hoe gereeld?
□ Dikwels □ Soms
□ Net af en toe
____keer per week

15. Is daar tye wanneer jy nie genoeg kos vir jou gesin het nie?
□Ja □Nee

Hoeveel maaltye per week het jy nie kos om te eet nie?
____maaltye per week

Hoeveel maaltye per week het jou kind nie kos om te eet nie?
____maaltye per week

16. Gee jy ooit nié die kind se medisyne nie, want jy het nie kos om saam met die medisyne te gee nie?
□Ja □Nee
Indien wel, hoe gereeld?
□ Dikwels □ Soms
□ Gewoonlik ____keer per week

17. Sukkel jy ooit om die kind die medisyne te laat neem?
□Ja □Nee
Indien wel, hoe gereeld?
□ Dikwels □ Soms
□ Gewoonlik ____keer per week

Waarom sê die kind sukkel hy/sy om dit te drink?
_____
_____

18. Sukkel jy ooit om die medisyne te gee, want die kind weet nie hoekom hy/sy dit drink nie?
□Ja □Nee
Indien wel, hoe gereeld?
□ Dikwels □ Soms
□ Net af en toe
____keer per week

19. Het die medisyne al ooit die kind siek of olik gemaak?
□Ja □Nee
Indien wel: □ Braking □ Veluitslag
□ Anemie □ Slaapprobleme
□ Lewerprobleme
□ Ander:_____
Indien wel, hoekom dink jy het die kind siek geword? □ Medisyne te sterk □ Newe-effekte van medisyne
□ Het dit sonder kos gedrink
□ Kind is nie gewoond aan medisyne nie
□ Ander rede (spesifiseer)_____
_____

20. Het jou kind gister enige dosisse oorgeslaan? □Ja □Nee
□ Weet nie

21. Hoeveel dosisse medisyne het jou kind die afgelope drie dae oorgeslaan?
(Skryf getal neer) _____
□ Weet nie

22. Hoeveel dosisse medisyne het jou kind die afgelope maand oorgeslaan? _____
□ Weet nie

23. Party gesinne sê die kind bekommer hulle of maak dit vir hulle moeilik om sy/haar medisyne te gee. Het jou kind [naam] al ooit om enige van die volgende redes nié die medisyne gedrink nie?

□ Die kind weet nie waarom hy/sy die medisyne drink nie, of hou aan vrae vra oor die medisyne
□ Die kind het nie die medisyne-instruksies verstaan nie
□ Die kind het vergeet om die medisyne te drink
□ Die kind het gespeel of was by die skool of werk
□ Die kind het geweier om die medisyne te drink
□ Die kind het siek gevoel of gebraak
□ Die kind het beter gevoel
□ Die kind wil nie hê ander moet sien hy/sy drink dit nie
□ Die kind glo nie medisyne help nie
□ Die kind het skade of newe-effekte van die medisyne opgedoen
□ Sukkel met een medisynevorm (pille, vloeistof)
□ Sê medisyne is te bitter
□ Die kind is moeg daarvoor om die medisyne te drink
□ Kan dit nie sonder kos drink nie
□ Nie een van bogenoemde nie
□ Ander (spesifiseer):_____

24. Soms drink kinders nie hulle medisyne elke dag of op dieselfde tyd elke dag nie omdat die versorger sekere probleme ervaar. Ek gaan nou 'n lys lees van moontlike probleme wat jy [of die kind se versorger] dalk ondervind om vir die kind sy/haar medisyne te gee. Stop my asseblief as jy 'n probleem hoor wat op jou [of op die kind se versorger] betrekking het.

□ Ek het gesukkel om die instruksies te lees
□ Ek was bang die kind ontwikkel newe-effekte
□ Ek het nie die medisyne-instruksies verstaan nie
□ Ek het gedink ander goed was dringender
□ Ek het gedink die behandeling is klaar
□ Ek was nie tuis nie (werk, veld, ens.)
□ Ek was nie altyd by die kind nie
□ Ek was mismoedig of het moed verloor
□ Ek het alkohol of ander middels gebruik
□ Versorgers het gereeld verander
□ Ek wou nie hê ander mense moes sien nie
□ Versorger was te besig en het vergeet
□ Ek het gesukkel met tydbepaling of om die dosisse betyds te gee
□ Ek was nie bewus van die kind se status nie
□ Ek het nie gedink die medisyne help nie
□ Ek wou 'n ander behandeling/gebed probeer
□ Ek het gedink die kind het 'n blaaskans van die medisyne nodig
□ Nie een van bogenoemde nie
□ Ander (spesifiseer) _____

25. Soms drink kinders nie hulle medisyne nie as gevolg van probleme in die gemeenskap. Het enige probleme in die gemeenskap al veroorsaak dat jou kind sy/haar medisyne oorslaan? Stop my as jy 'n probleem hoor wat op jou van toepassing is:

□ Ek kon nie verduidelik waarom die kind medisyne drink nie
□ Wou nie hê ander moet sien die kind drink medisyne nie
□ My bure/vriende/familie het my afgeraai
□ Was bang vir diskriminasie en isolasie
□ Kind in skool, en ek wou hom/haar nie uit skool haal nie
□ Ander het nie geglo medisyne is nodig nie
□ Ek het nie hulp van bure/vriende/familie ontvang nie
□ Ander: (spesifiseer)_____
□ Kon nie kliniek toe gaan sonder dat ander wonder nie
□ Nie een van bogenoemde nie

26. Soms maak probleme by die kliniek dit moeilik vir gesinne om die medisyne elke dag te gee. Was enige van die volgende al vir jou 'n probleem?

□ Die kliniekpersoneel het nie goed genoeg verduidelik hoe om die medisyne te gee of te drink nie, of het nie die instruksies neergeskryf nie
□ Die kliniekpersoneel het negatief/veroordelend oor die medisyne gelyk
□ Die kliniekpersoneel jaag 'n mens op hol en maak jou gespanne
□ Daar was nie geld om medisyne te koop nie
□ Die apteek het nie die medisyne gehad nie ***Watter medisyne?*** □ ARV's □ Septrin □ Ander (sluit antibiotika in)
□ Ander (spesifiseer) _____ □ Nie een van bogenoemde nie

27. Wanneer kinders siek is, probeer gesinne dikwels ander soorte behandeling benewens of in die plek van die ARV's. Ontvang jou kind tans enige van hierdie ander soorte behandeling? (*Merk alle toepaslike antwoorde.*)

□ Kruie (soos blare, stingels, wortels) □ Tees □ Chinees □ Gebede vir genesing □ Suid-Afrikaanse aanvullings
□ Toordokter □ Sny □ Ander: (spesifiseer) _____

28. Partykeer ondervind gesinne ander probleme met betrekking tot medisyne. Het enige van die volgende dit al vir jou kind moeilik gemaak om die medisyne elke dag of op die regte tyd te drink?

□ Te min/geen kos om saam met medisyne te gee
□ Medisyne het opgeraak voor kliniekafspraak
□ Skink van medisyne
□ Gesin het medisyne geweier
□ Niemand om medisyne te gee nie
□ Geen skoon water om saam met medisyne te drink nie
□ Moet medisyne wegsteek
□ Vertraging in medisynedosisse
□ Geen geld vir vervoer kliniek toe nie
□ Geen vervoer beskikbaar kliniek toe nie
□ Ander (spesifiseer) _____
□ Nie een van bogenoemde nie

29. Hoe voel jy oor die algemeen daaroor om medisyne te neem? □ Ek sal medisyne drink □ Ek hou nie daarvan om medisyne te drink nie, maar sal as ek moet □ Ek gebruik kruie in plaas van pille □ Ek drink nooit om enige rede medisyne nie

30. Almal slaan soms hulle medisyne om verskillende redes oor. Sukkel jy ooit om vir die kind sy/haar medisyne te gee? □ Ja □ Nee **Indien wel, hoe dikwels?** □ Dikwels □ Soms □ Net af en toe

31. In die afgelope week:

a. Hoeveel dae was jy by die kind? □0 □1 □2 □3 □4 □5 □6 □7
b. Op hoeveel dae het die kind ten minste een dosis oorgeslaan? □0 □1 □2 □3 □4 □5 □6 □7
c. Op hoeveel dae het die kind 'n dosis meer as 'n uur laat gedrink? □0 □1 □2 □3 □4 □5 □6 □7
d. Op hoeveel dae het die kind **al** sy/haar dosisse oorgeslaan? □0 □1 □2 □3 □4 □5 □6 □7
e. Hoeveel dosisse het die kind altesaam oorgeslaan? _____
f. Hoeveel ekstra dosisse of spuite medisyne het die kind gedrink? _____

32. Hoeveel mense bly gewoonlik in jou huishouding, of bly op die oomblik by jou? _____

33. Hoeveel kinders onder vyfjarige ouderdom bly in jou huishouding?_____

34. Hoeveel mense in jou huishouding drink MIV-medisyne? _____

35. Wie anders in die huishouding drink MIV-medisyne?
_____
_____

36. By wie bly jy en hierdie kind? *(Merk alle toepaslike antwoorde.)*
□ Niemand (bly alleen) □ Kind se ouers
□ Versorger se man/vrou □ Kind se grootouers
□ Versorger se maat □ Kind se oom/tannie/nig/neef
□ Ander kinders □ Vriende

37. Watter ander mense weet die kind drink medisyne?*(Merk alle toepaslike antwoorde.)*
□ Niemand (bly alleen) □ Kind se ouers
□ Versorger se man/vrou □ Kind se grootouers
□ Versorger se maat □ Kind se oom/tannie/nig/neef
□ Ander kinders □ Vriende

38. Werk jy weg van die huis?
□Ja □Nee
Indien wel:
□ Voltyds
□ Deeltyds
□ Los werk

39. Hoe lank duur dit om by die kliniek te kom?
□ ≤ 30 minute
□ 30 min-1 uur
□ >1 uur, maar <2 uur
□ >2 uur, maar <3 uur
□ ≤ 3 uur

40. Hoeveel betaal jy vir vervoer kliniek toe (eenrigting)?
R_____

41. Het jy enige probleme met vervoer kliniek toe?
□ Ja □ Nee **Indien wel, hoe gereeld?** □ Dikwels □ Soms □ Net af en toe
Watter probleem? □ Het nie geld nie □ Het nie vervoermiddel nie □ Het nie tyd nie □ Ander _____

Baie gesinne probeer kinders se pille elke dag min of meer dieselfde tyd of saam met dieselfde aktiwiteit gee sodat hulle nie van die medisyne vergeet nie …

42. Is daar iets wat jy tans doen wat jou help onthou om die kind se medisyne op dieselfde tyd elke dag te gee?
□Ja □Nee

Indien wel, wat help jou onthou? □ Foon □ Horlosie □ Radio □ Drink medisyne saam met maaltye □ Son □ Ander in die huis drink saam medisyne □ Ander: _____

Appendix H: Demonstration Script

DAY	Verbal Script	Demonstration Instructions
	• I'm going to show you how your child's medicine works to control their virus and keep them healthy.	*Body with pink solution is ready to start.*
	• As you will know, living with this virus means that your child needs to take their medicine every day. • If your child doesn't take his/her medicine , the condition becomes worse and worse over time. • Eventually without medicine, their body would have no immunity. This means that their body wouldn't be able to fight off illnesses. • The good news is that by giving your child their medicine every day you can stop this from happening. • Although the virus is always present inside their body, it will not make them sick as long as they take their medicine each day. • Let me show you how taking medicine each day works to control the virus.	
DAY 1	• As you know, the virus is always trying to grow inside of your child's body. • This pink colour represents the virus.	*Bring model out. Starting solution is present inside (pink colour).*
	• Watch what happens when your child takes their medicine.	*Add medicine solution into pink solution.*
	• As you can see, when the medicine is inside of the body, the water slowly starts to become less pink, and eventually it turns to clear. • This clear colour shows that by taking their medication, your child's virus is under control.	*Water will begin to change colour until it has made solution clear.*
DAY 2	• Now let's see what happens the next day. • On day 2, although you took your medicine yesterday on day 1, the virus is still in your child's body and trying to grow. • Remember that the virus is always there.	*Drop day 2 solution into mixture and turn back to pink.*
	• So again, on day 2 you give your child their medicine. • You can see that the same thing happens - when the medicine enters the body the liquid starts to change from pink to clear, meaning the virus is controlled and cannot grow.	*Drop medicine solution into pink solution. Solution becomes clear.*

	• So, from this demonstration, you can see that your child needs to take their medicine every single day. • The virus is inside of their body all of the time. • So, by taking their medicine each day, the virus is controlled, and this helps them stay healthy.	
	• What happens if you do forget to give your child their medicine for a day or two?	
DAY 3	• Here is the body on day 3, after taking medicine for the last two days. • You can see again that the virus is still in your child's body, because it is always there.	*Drop day 3 solution to change to pink.*
	• Perhaps today you forget to give your child their medicine. • So on this particular day, no medicine is going into their body. • Remember, this means that the virus will not be controlled.	*No medicine solution added.*
DAY 4	• The next day, day 4, again you can see that the virus is in your child's body.	*Drop day 4 solution to change to pink.*
	• And again on day 4, you forget to give your child their medicine.	*No aspirin solution added.*
DAY 5	• Now it's day 5, and again the virus is still in your child's body. • You can see that the body has become more pink, which shows that the virus has been slowly growing without any medicine to control it.	*Drop day 5 solution to change to pink.*
	• Perhaps on this day, you do remember to give your child their medicine, and realize that they missed taking it for the past two days. • Some people do miss a dose of their medicine from time to time. • The body can recover from this, as long as you remember to give your child the next dose of medicine, and then continue giving it each day again without forgetting. • If this does happen to you, it is important to remember NOT to give your child all of the doses they missed. • You should only give them the doses needed for that day. • Your child's body can only handle a certain amount of the medicine, so taking more than the needed doses per day will not help, even if they missed more than one dose.	
	• So let's see how the body recovers from a couple of missed doses. • So remember it's day 5, and today you remember that you need to give your child their medicine after forgetting to for the past couple of days.	*Drop medicine solution into pink solution.*

	• You can see that today when we add the medicine, it makes the water become a bit lighter but it does not change back to clear. • Because your child didn't take their medicine for two days, the amount of virus in their body was able to grow a small amount.	*Water becomes lighter but not clear.*
DAY 6	• On day 6, the virus is still in your child's body.	*Drop day 6 solution in.*
	• Today, again you remember about your child's medicine and you give them the dose.	*Drop medicine solution into pink solution.*
	• You can see that as happened yesterday, the medicine makes the liquid become lighter but still not completely clear.	*This time solution even lighter pink but still not clear.*
DAY 7	• The next day is day 7, and again the virus is there in your child's body as always.	*Drop day 7 solution in.*
	• Again today you remember to give your child their daily dose of medication. • You can see that eventually, after remembering to give your child their medicine each day, the body does change back to clear. • This shows that you can get the virus can back under control, if you remember to keep giving your child their medicine after missing only one or two doses. • If they do miss a dose, it is important to remember to keep giving your child their medicine every day after, to get the virus controlled and stop them from becoming sick.	*Drop medicine solution into pink solution.*
	• It will make your child sick if they do not take their medicine all of the time. • Now let's see what happens inside your child's body if you do not give them their medication for a long time.	
DAY 8	• So, day 8 - the virus is there. • And no medicine is taken.	*Pour solution for Day 8 in.* *NO MEDICINE SOLUTION.*
DAY 9	• Day 9 - the virus again is inside your child's body. • And again, they do not take their medicine.	*Pour solution for Day 9* *NO MEDICINE SOLUTION.*
DAY 10/11/12	• The same thing happens again and again and you do not give your child their medicine for all of these days. • You can see that after no medication has been taken for so long, the water has become very pink. This is because the virus has been able to grow inside of the body.	*Pour in solution for day 10/day 11/day 12 straight after one another.*

DAY 13	• Perhaps you eventually remember to give your child their medicine after missing their doses for all of this time. • See what happens now.	*Medicine solution added to pink solution.*
DAY 13	• This time, even though your child takes their medicine, the liquid does not change at all and it stays a deep pink colour. • So this time the medicine was not able to control the virus. • When medication is not taken each day the virus grows inside your child's body. • If this happens, the medicine cannot reverse this. • The medicine will stop working and won't be able to keep your child healthy. • This isn't good because there are not many medicines that can treat this virus.	
END	• So you can understand how important it is that your child takes their medicine every single day, all of the time. • If they do miss one dose, remember to continue giving their medicine again each day so that their body can recover and they don't become sicker. • But, If your child does not take their medicine all of the time, the virus can grow inside their body. • This means that the medicine will stop working and they will become sick. • Remember that they are still able to lead a healthy, normal life with this infection. • Just remember to give your child the prescribed dose of their medicine each day, to stop the virus from growing and keep your child healthy.	

DAG	Teks vir Voorlesing	Demonstrasie Instruksies
	• Ek gaan jou wys hoe jou kind se medisyne werk sodat dit die virus in hulle lyf kan beheer en hy/sy kan gesond hou.	*Body with pink solution is ready to start.*
	• Soos jy weet, moet jou kind elke dag hulle medisyne neem as hulle met hierdie virus leef. • As jou kind nie hulle medisyne vat nie, raak die siekte erger en erger soos die tyd verbygaan. • Sonder die medisyne sal hulle lyf uiteindelik geen weerstand teen siekte oorhou nie. Dit beteken dat hulle lyf teen geen siekte sal kan terugbaklei nie. • Die goeie nuus is: Jy kan keer dat dit gebeur deur elke dag vir jou kind hulle medisyne te gee. • Die virus bly nog steeds in hul lyf, maar solank hulle elke dag hulle medisyne neem, sal die virus hulle nie laat siek raak nie. • Kom ek wys jou hoe die virus beheer word deur om medisyne elke dag te vat.	
DAG 1	• Soos jy weet, probeer die virus heeltyd groei daar in jou kind se lyf. • Die kleur pienk wys waar die virus is.	*Bring model out. Starting solution is present inside (pink colour).*
	• Kyk nou wat gebeur as jou kind hulle medisyne neem.	*Add medicine solution into pink solution.*
	• Soos jy kan sien, wanneer die medisyne binne-in die lyf is, begin raak die water stadig aan minder pienk, en uiteindelik raak dit heeltemal deurskynend. • Hierdie deurskynende water wys vir ons dat om deur hulle medikasie te vat, is jou kind se virus onder beheer.	*Water will begin to change colour until it has made solution clear.*
DAG 2	• Kom ons kyk nou wat die volgende dag gebeur. • Gister was dag 1, en toe het jou kind sy medisyne geneem. Nou is dit dag 2. Maar die virus is nog steeds in jou kind se ligaam en probeer steeds groei. • Onthou, die virus is altyd daar.	*Drop day 2 solution into mixture and turn back to pink.*
	• So, op dag twee, gee jy vir jou kind hul medisyne. • Jy kan sien dieselfde gebeur as gister - wanneer die medisyne binne-in die lyf is, begin die pienk kleur weer deurskynend raak. Dit beteken die virus is onder beheer en dit kan nie groei nie.	*Drop medicine solution into pink solution. Solution becomes clear.*
	• So, van hierdie demonstrasie, kan jy nou sien dat jou kind hulle medisyne elke liewe dag móét neem. • Die virus is heeltyd daar in hul lyf.	

	So, om deur hulle medisyne elke dag te neem, hou dit die virus onder beheer, en op dié manier help dit jou kind om gesond bly.	
	• Wat gebeur as jy wel ’n dag of twee vergeet om vir jou kind hulle medisyne te gee?	
DAG 3	• Hier is die lyf op dag 3, nadat medisyne geneem is vir die laaste twee dae. • Hier kan jy weer sien dat die virus nog steeds in jou kind se liggaam is, want dit is altyd daar.	*Drop day 3 solution to change to pink.*
	• Sê nou jy vergeet vandag om vir jou kind hul medisyne te gee. • Op hierdie spesifieke dag, gaan geen medisyne in hulle lyf nie. • Onthou, dit beteken dat die virus nie onder beheer gehou word nie.	*No medicine solution added.*
DAG 4	• Die volgende dag, dag 4, kan jy steeds sien die virus is in jou kind se lyf.	*Drop day 4 solution to change to pink.*
	• En alweer op dag 4, vergeet jy om vir jou kind hulle medisyne te gee.	*No medicine solution added.*
DAG 5	• Nou is dit dag 5, en alweer is die virus nog steeds in jou kind se liggaam. • Jy kan sien dat die lyf het nog pienker geraak, wat wys dat die virus stadig weer begin groei het sonder medisyne om dit te beheer.	*Drop day 5 solution to change to pink.*
	• Sê nou vandag onthou jy om jou kind se medisyne vir hulle te gee, en jy besef hulle het dit die vorige twee dae nie gedrink nie. • Party mense mis ‘n dosis van julle medisyne nou en dan. • Die lyf kan weer regkom, maar dan moet jy onthou om vir jou kind die volgende dosis van hulle medisyne te gee, en dan aanhou om elke dag na dit vir hulle gee, sonder om te vergeet. • As dit gebeur met jou, is dit belangrik om te onthou om nie al die vergete dosisse vir jou kind te gee nie. • Jy moet net vir hulle die dosisse gee wat vir daai dag bedoel is. • Jou kind se lyf kan net ’n sekere hoeveelheid van die medisyne op ’n slag hanteer, so om meer as daai dag se dosisse te neem, sal dit dus niks help nie, nie eens as hulle meer as een dosis gemis het.	
	• Kom ons kyk nou hoe die lyf weer regkom na ‘n paar orgeslaan dosisse. • Onthou, dit is dag 5, en vandag onthou jy dat jy vir jou kind hulle medisyne moet gee, nadat jy dit ’n paar dae lank vergeet het.	*Drop medicine solution into pink solution.*

	• Soos jy kan sien, as ons die medisyne insit, maak dit die water 'n bietjie ligter, maar dit raak nie heeltemal deurskynend nie. • Omdat jou kind nie hul medisyne vir twee dae geneem het nie, het die virus kans gekry om 'n stuk in hul lyf te groei.	*Water becomes lighter but not clear.*
DAG 6	• Op dag 6, is die virus nog steeds in jou kind se liggaam.	*Drop day 6 solution in.*
	• Vandag onthou jy weer van jou kind se medisyne en gee vir hulle die dosis.	*Drop medicine solution into pink solution.*
	• Jy kan sien dat dieselfde gebeur as gister, die medisyne maak die water ligter, maar dis nog steeds nie heeltemal deurskynend nie.	*This time solution even lighter pink but still not clear.*
DAG 7	• Die volgende dag is dag 7, en alweer is die virus in jou kind se lyf soos nog altyd.	*Drop day 7 solution in.*
	• Vandag onthou jy alweer om vir jou kind hulle medisyne te gee. • Soos jy kan sien, raak die water uiteindelik weer deurskynend nadat jy begin het om weer elke dag vir jou kind hulle medisyne te gee. • Dit wys hoe jy die virus weer onder beheer kan kry, as jy onthou om vir jou kind elke dag hulle medisyne te gee, nadat hulle net een of twee dosisse gemis het. • As hulle 'n dosis mis, is dit dus baie belangrik dat jy onthou om vir jou kind elke dag na dit hulle medisyne te gee, want dit is hoe die virus onder beheer hou is en om te keer dat hulle siek raak.	*Drop medicine solution into pink solution.*
	• Dit sal jou kind siek maak as hulle nie hulle medisyne altyd neem nie. • Nou, kom ons kyk wat in jou kind se lyf gebeur as jy nie hulle medisyne vir hulle gee nie vir 'n lang tyd.	
DAG 8	• So, dag 8 – die virus is daar. • En geen medisyne is geneem nie.	*Pour solution for Day 8 in.* *NO MEDICINE SOLUTION.*
DAG 9	• Dag 9 – die virus is alweer in jou kind se lyf. • En alweer, neem hulle nie hulle medisyne nie.	*Pour solution for Day 9* *NO MEDICINE SOLUTION.*
DAG 10.11/12	• Dieselfde gebeur weer en weer en jy gee nie vir jou kind hulle medisyne nie vir al hierdie dae. • Soos jy kan sien, raak die water baie pienk as die medisyne vir so 'n lang tyd nie bygesit is nie. Dit is omdat die virus heeltyd kans gekry het om binne in die lyf te groei.	*Pour in solution for day 10/day 11/day 12 straight after one another.*
DAG 13	• Kom ons sê jy onthou na 'n ruk om vir jou kind hulle medisyne te gee, nadat jy vir al hierdie tyd hulle dosisse gemis het. • Kyk wat nou gebeur.	*Medicine solution added to pink solution.*

DAG 13	• Hierdie keer teen spyte van die feit dat jou kind hulle medisyne neem, verander die kleur van die water glad nie, en dit bly donker pienk. • So, die medisyne kon dit regkry om die virus te beheer nie. • As medisyne nie elke dag geneem is nie, groei die virus in jou kind se lyf. • As dit gebeur, kan die medisyne die virus nie meer gekeer kry nie. • Die medisyne sal dus ophou werk, en dan kan dit jou kind nie meer gesond hou nie. • Dit is sleg, want daar is nie baie soorte medisyne wat hierdie virus kan behandel nie.	
EINDE	• Jy kan dus verstaan hoekom dit so belangrik is dat jou kind elke liewe dag hulle medisyne moet neem. • As hulle een dosis mis, onthou net om weer van die volgende dag af elke dag vir hulle hulle medisyne te gee sodat hulle lyf kan herstel en hulle word nie sieker nie. • Maar, as jou kind nie hulle medisyne neem nie altyd, kan die virus binne hulle lyf groei. • Dit beteken dat die medisyne sal ophou werk, en dan gaan hulle siek raak. • Onthou, al het hulle hierdie virus, kan hulle nog steeds gesond bly en ’n normale lewe hê. • Onthou net om vir jou kind elke dag die voorgeskrewe dosis te gee om die groei van die virus te beheer en om jou kind gesond te hou.	

Appendix I: Petrie Device Demonstration Questionnaire

Questionnaire Caregiver Experience of the Petrie Device demonstration

We are interested in how effective you found the demonstration which explained your child's medication.

Please answer the following questions by circling a number for each question.

How helpful was the demonstration in helping you understand your child's virus?										
0	1	2	3	4	5	6	7	8	9	10
Not at all helpful										Extremely helpful
How helpful was the demonstration in helping you understand your child's medication?										
0	1	2	3	4	5	6	7	8	9	10
Not at all helpful										Extremely helpful
Did seeing the demonstration make you anxious about your child's virus?										
0	1	2	3	4	5	6	7	8	9	10
Not at all anxious										Extremely anxious
Did seeing the demonstration make you anxious about your child's medication?										
0	1	2	3	4	5	6	7	8	9	10
Not at all anxious										Extremely anxious
How interesting did you find the demonstration?										
0	1	2	3	4	5	6	7	8	9	10
Not interesting at all										Extremely interesting
How much did seeing the demonstration motivate you to give your child their medication?										
0	1	2	3	4	5	6	7	8	9	10
Not at all motivated										Extremely motivated

Vraelys oor Versorger Ervaring van die Petrie Apparaat Demonstrasie

Ons wil graag weet hoe doeltreffend jy dink die demonstrasie is wat jou kind se medisyne verduidelik het.

Beantwoord asseblief die volgende vrae deur by elke vraag 'n nommer te omkring.

Hoe nuttig was die demonstrasie om jou die kind se virus te help verstaan? 0 1 2 3 4 5 6 7 8 9 10 Glad nie nuttig nie Geweldig nuttig
Hoe nuttig was die demonstrasie om jou die kind se medisyne te help verstaan? 0 1 2 3 4 5 6 7 8 9 10 Glad nie nuttig nie Geweldig nuttig
Het dit jou angstig gemaak oor jou kind se virus toe jy die demonstrasie sien? 0 1 2 3 4 5 6 7 8 9 10 Glad nie angstig nie Geweldig angstig
Het dit jou angstig gemaak oor jou kind se medisyne toe jy die demonstrasie sien? 0 1 2 3 4 5 6 7 8 9 10 Glad nie angstig nie Geweldig angstig
Hoe interessant was die demonstrasie vir jou? 0 1 2 3 4 5 6 7 8 9 10 Glad nie interessant nie Geweldig interessant
Hoe gemotiveerd het die demonstrasie jou laat voel om vir jou kind sy/haar medisyne te gee? 0 1 2 3 4 5 6 7 8 9 10 Glad nie gemotiveerd nie Geweldig gemotiveerd

Appendix J: Semi-Structured Interview Schedule

Interview Schedule: Thoughts and Experiences of the Visual Model

[Read the following introductory script to the participant, and then use the questions that follow to stimulate a discussion concerning the participant's thoughts and experiences of the Petrie device demonstration]

This study wants to see if a visual model is an acceptable thing to use to try to enhance adherence to antiretroviral medication amongst children. I would like to ask you some questions about the demonstration that you saw just now. Would you mind if I record your answers using a voice recorder? [Allow the participant to respond]

- What thoughts ran through your mind when you saw the demonstration?
- Did you learn anything from seeing the demonstration? Please tell me about specific things you learnt.
    - What did you learn about your child's virus? What did you learn about your child's medication?
- What information did the demonstration give you [or not give you] about your child's virus?
- What information did the demonstration give you [or not give you] about your child's medication?
- How did the demonstration make you feel about your child's virus and the medication that they need to take?
- Has the demonstration changed the way that your feel/think about your child's virus and the medication that they need to take? If so, in what ways?
- Think about giving your child their medication. How does this make you feel?
- Do you think it is important or not for your child to take their medication? Why? Why not?
- Was there anything that you didn't understand about the demonstration?
- Was anything in the demonstration unclear?
- Was there anything about the demonstration which made you worried? Please tell me why.
- Do you think, after seeing the demonstration, that you will do anything differently when you give your child their medication? What would you change or not change?
- Do you have any suggestions for how you think we can make the device and the demonstration better? Were there any explanations that we could have improved? How could we improve this for other caregivers?

- Do you think the demonstration is an effective (useful, helpful, valuable) way to teach people about how their medication helps them to stay healthy? Why? Why not?
- Do you think the demonstration is a feasible (practical, realistic) way to teach people about how their medication helps them to stay healthy? Why? Why not?
- Who do you think should present the demonstration? What type of person should present the demonstration? Why?
- Where should the intervention be delivered? Could this demonstration be used in clinics? Why? Why not?
- What would you have thought if this was used in your child's clinic sessions? Is this something you would have liked or not liked to have had in your child's clinic sessions?
- Do you have any other comments, or something else that you would like to say/ask?

Onderhoudskedule: Gedagtes en Ervaring van die Visuele Model

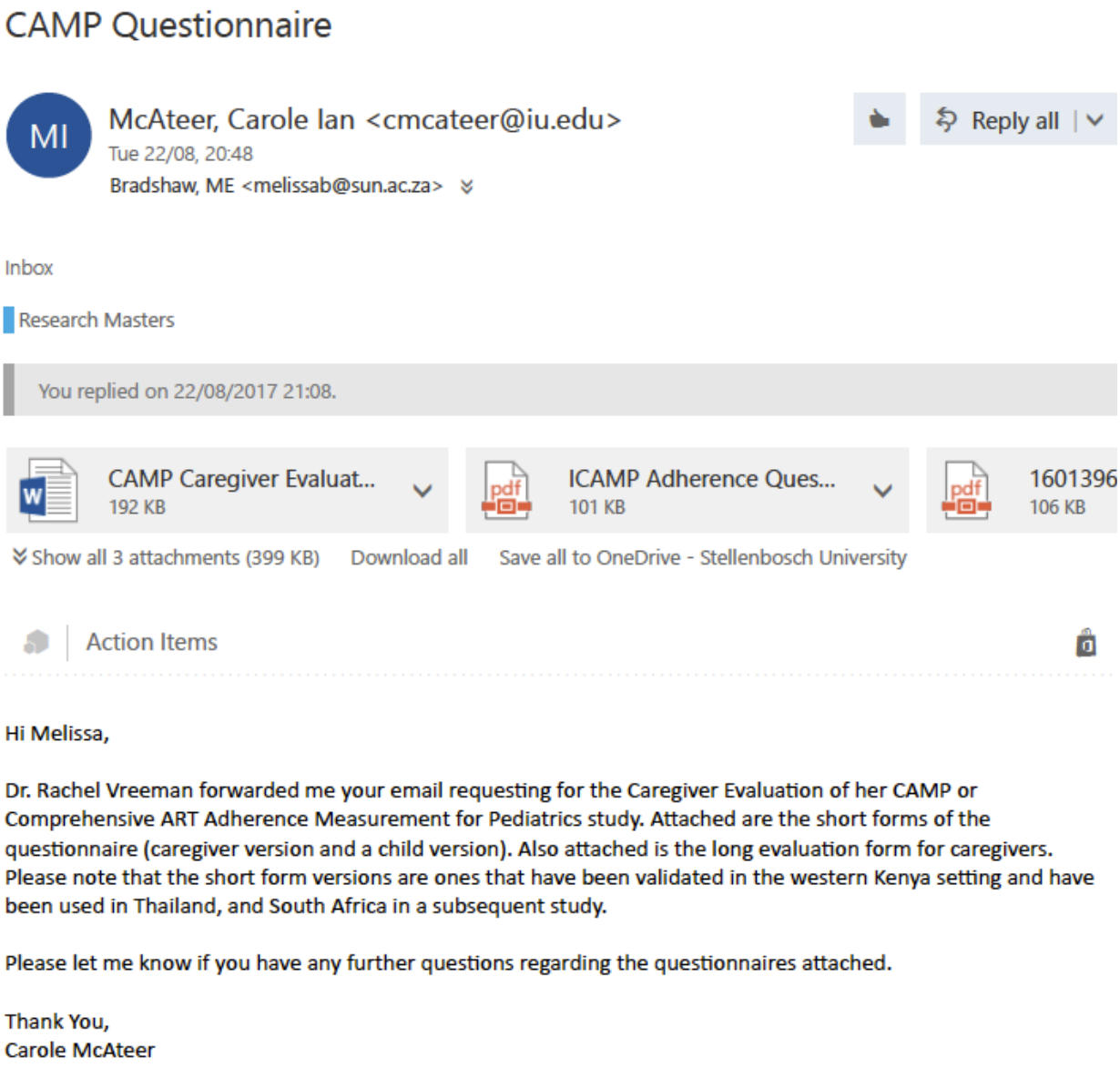
[Read the following introductory script to the participant, and then use the questions that follow to stimulate a discussion concerning the participant's thoughts and experiences of the Petrie device demonstration]

Met hierdie studie wil ons uitvind of 'n visuele model 'n aanvaarbare manier is om kinders hulle antiretrovirale medisyne meer getrou te help drink. Ek wil jou graag 'n paar vrae vra oor die demonstrasie waarna jy nou net gekyk het. Sal jy omgee as ek 'n stemopname van jou antwoorde maak? [Wag dat die deelnemer antwoord.]

- Watter gedagtes het by jou opgekom toe jy die apparaat sien?
- Het jy enigiets daaruit geleer om die demonstrasie te sien? Vertel my asseblief van spesifieke goed wat jy geleer het.
    - Wat het jy van jou kind se virus ge leer? Wat het jy van jou kind se medikasie geleer?
- Watter informasie het die die demonstrasie vir jou gegee [of nie gegee nie] van jou kind se virus?
- Watter informasie het die die demonstrasie vir jou gegee [of nie gegee nie] van jou kind se medikasie?
- Hoe het die demonstrasie jou laat voel oor jou kind se virus en die medisyne wat hy/sy moet drink?
- Het die demonstrasie jou anders laat voel/dink oor jou kind se virus en die medisyne wat hy/sy moet drink? Indien wel, op watter maniere?
- Dink aan om vir jou kind hul medisyne te gee. Hoe laat dit jou voel?
- Dink jy dit is belangrik of nie om vir jou kind hul medikasie te gee? Hoekom? Hoekom nie?
- Was daar enigiets oor die demonstrasie wat jy nie verstaan het nie?
- Was enigiets in die demonstrasie onduidelik?
- Was daar enigiets aan die demonstrasie wat jou bekommer het? Hoekom? Hoekom nie?
- Dink jy, nadat jy die demonstrasie gesien het, dat jy enigeiets anders gaan doen as jy vir jou kind hulle medisyne gee? Wat sou jy verander of nie verander nie?
- Het jy enige voorstelle oor hoe jy dink ons die apparaat en die demonstrasie kan verbeter? Was daar enige verduidelikings wat ons dalk kan verbeter? Hoe kan ons dit vir ander versorgers en kinders verbeter?
- Dink jy hierdie demonstrasie is 'n doeltreffende (nuttige, waardevolle) manier om mense te leer hoe hulle medisyne hulle help gesond hou? Hoekom? Hoekom nie?

- Dink jy hierdie demonstrasie is ’n uitvoerbare (praktiese, realistiese) manier om mense te leer hoe hulle medisyne hulle help gesond hou? Hoekom? Hoekom nie?
- Wie dink jy moet die demonstrasie lewer? Watter tipe person moet die demonstrasie lewer? Hoekom? Hoekom nie?
- Waar moet hierdie demontrasie gelewer word? Kon hierdie demonstrasie gebruik word in klinieke? Hoekom? Hoekom nie?
- Kan hierdie demonstrasie in klinieke gebruik word? Hoekom? Hoekom nie?
- Wat sou jy daarvan dink as dit in jou kind se klinieksessies gebruik word? Is dit iets wat jy in jou kind se klinieksessies sou wou hê of nie?
- Het jy enige ander komentaar, of iets anders wat jy wil sê/vra?

Appendix K: Permission to Use CAMP – Caregiver Evaluation



CAMP Questionnaire

MI

McAteer, Carole Ian <cmcateer@iu.edu>

Tue 22/08, 20:48

Bradshaw, ME <melissab@sun.ac.za>

Reply all

Inbox

Research Masters

You replied on 22/08/2017 21:08.

CAMP Caregiver Evaluat... 192 KB

ICAMP Adherence Ques... 101 KB

1601396 106 KB

Show all 3 attachments (399 KB) Download all Save all to OneDrive - Stellenbosch University

Action Items

Hi Melissa,

Dr. Rachel Vreeman forwarded me your email requesting for the Caregiver Evaluation of her CAMP or Comprehensive ART Adherence Measurement for Pediatrics study. Attached are the short forms of the questionnaire (caregiver version and a child version). Also attached is the long evaluation form for caregivers. Please note that the short form versions are ones that have been validated in the western Kenya setting and have been used in Thailand, and South Africa in a subsequent study.

Please let me know if you have any further questions regarding the questionnaires attached.

Thank You,
Carole McAteer

Appendix L: Chemistry Used in Study with Adults

HIV model chemistry with Aspirin 300mg

Three different solutions included in demonstration

- *Phenolphthalein indicator solution (100mls):*
  - ONLY NEEDED WHEN RUN OUT
  - Combine 50mls methanol with 50ml water.
  - Weigh out 0.5g phenolphthalein powder
  - Mix into liquid solution.
- *Starting 'body' solution (0.01 mole NaOH solution):*
  - Measure 300mls water
  - Weigh out 0.125g sodium hydroxide
  - Combine into liquid solution
  - Mix until all is dissolved
- *'HIV virus' solution (1 mole NaOH solution):*
  - ONLY NEEDED WHEN RUN OUT – 500mls SHOULD BE ENOUGH FOR 7 PARTICIPANTS
  - Measure out 500mls water
  - Weigh out 30g sodium hydroxide
  - Combine into liquid solution
  - Mix until all is dissolved

Steps for each new demonstration:

1. Prepare starting 'body' solution of 300mls
2. Add 20-30 drops of the phenolphthalein indiciator solution to the solution and mix in glassware BEFORE pouring it into the model.
3. Pour pink solution into the model using a funnel.

	DAY	'Virus' amount in each vial	Aspirin used
Adherence	Day 1/START	Starting solution	Yes
	Day 2	5mls	Yes
Non-adherence + adherence	DAY	'Virus' amount in each vial	Medication
	Day 3	6mls	No
	Day 4	6mls	No
	Day 5	4mls	Yes
	Day 6	2mls	Yes
	Day 7	1ml	Yes
Non-adherence	DAY	'Virus' amount in each vial	Medication
	Day 8	5mls	No
	Day 9	5mls	No
	Day 10	5mls	No
	Day 11	5mls	No
	Day 12	5mls	Yes

Appendix M: Chemistry Used in Present Study

Body solution	0,25	L
Body sol NaOH conc	0,01	M NaOH
Body sol pH	12	pH
Mol NaOH in BS	0,0025	mol
g NaOH in BS	0,1000	g
g NaOH needed (sol)	0,200	g NaOH sol in BS
g NaOH needed (salt)	0,103	g NaOH salt in BS

After Medicine target pH	3	pH
$[H^+]$ @traget pH	0,001	mol/L
mol H^+ in BS @ target pH	0,00025	mol in BS
mol Acid req to reach target pH	0,00275	mol
Acid dosage volume	5	mL
Acid concentration	0,55	M Acid
Acid needed (dosages)	10	dosages
Acid needed (vol)	50	mL
Total acid needed (mol)	0,0275	mol
Toal acid needed (g)	1,6514	g Acid
Total acid sol needed (g)	1,6851	g Acid sol

After virus target pH	12	pH
$[OH^-]$ @traget pH	0,01	mol/L
mol OH^- in BS @ target pH	0,0025	mol in BS
mol NaOH req to reach target pH	0,00275	mol
NaOH dosage volume	6	mL
NaOH concentration	0,46	M NaOH
Virus needed (dosages)	10	dosages
Virus needed (vol)	50	mL
Total NaOH needed (mol)	0,0229	mol
Toal NaOH needed (g)	0,9166	g NaOH
Total NaOH sol needed (g)	1,8332	g NaOH sol
Total NaOH salt needed (g)	0,9450	g NaOH salt

Schedule	Dosages		Volume after		mol after		Concentration after		pH after		Outcome	
	Virus (mL)	Medic (mL)	Virus (mL)	Medic (mL)	Virus (mol)	Medic (mol)	Virus (M)	Medic (M)	Virus (M)	Medic (M)		
DAY 1/START	250	5	250	255	0,002500	0,00025	0,010	0,001	12,00	3,88	1	1
DAY 2	5	5	260	265	0,002042	0,00071	0,008	0,003	11,90	3,66	1	1
DAY 3	6	0	271	271	0,002042	-0,00204	0,008	-0,008	11,88	11,88	0	
DAY 4	6	0	277	277	0,004792	-0,00479	0,017	-0,017	12,24	12,24	1	
DAY 5	4	5	281	286	0,006625	-0,00388	0,024	-0,014	12,37	12,13	1	1
DAY 6	2	5	288	293	0,004792	-0,00204	0,017	-0,007	12,22	11,84	1	1
DAY 7	1	5	294	299	0,002500	0,00025	0,009	0,001	11,93	3,91	1	1
DAY 8	5	0	304	304	0,002042	-0,00204	0,007	-0,007	11,83	11,83	1	
DAY 9	5	0	309	309	0,004333	-0,00433	0,014	-0,014	12,15	12,15		
DAY 10	5	0	314	314	0,006625	-0,00663	0,021	-0,021	12,32	12,32		
DAY 11	5	0	319	319	0,008917	-0,00892	0,028	-0,028	12,45	12,45		
DAY 12	5	5	324	329	0,011208	-0,00846	0,035	-0,026	12,54	12,41		