AN INTERDISCIPLINARY STUDY EXPLORING HOW HEALTH COMMUNICATION CAN MOST EFFECTIVELY EXPLAIN ANTIRETROVIRAL MEDICATION (ART) AND MOTIVATE ADHERENCE AMONG YOUNG PEOPLE.

By

Warren Hickson

HCKWAR001

Submitted in fulfilment of the requirement of the degree of Doctor of Philosophy

Faculty of Health Sciences

University of Cape Town

June 2016

Supervisors: Associate Professor Pat Mayers

Dr Helen Newing

Declaration

I, *Warren Hickson*, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

I empower the university to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

Signature: Signed by candidate

Signature removed

Date: 12.July 2016

1.1 Abstract

The aim of this study was to explore factors contributing to the success of health communication strategies and supporting visual communication tool(s) designed to explain antiretroviral medication (ART) adherence, and motivate young people who live with HIV to follow an adherence regime. The study drew from the social sciences, including psychology, health sciences and communication. Currently there are an estimated 6.8 million people living with HIV in South Africa, making it the site of the largest HIV epidemic in the world (UNAIDS, 2014). Antiretroviral Therapy (ART) is the only effective treatment for HIV and is one of the most demanding medicine regimes, requiring a 90% compliance. Various studies have documented worryingly poor levels of adherence to ART, especially amongst adolescents and young adults in South Africa.

The empirical research consisted of a qualitative case study in Khayelitsha, a peri-urban township on the edge of Cape Town. It focused on young people from Khayelitsha and health care professionals - doctors, nurses, HIV counsellors and pharmacists. Using grounded theory data collection was carried out during two phases of fieldwork, interspersed with periods for data processing and analysis. The principal methods used were focus groups, semi-structured interviews and participant observation.

Two key factors emerged from the data that form the basis of a new theoretical understanding: first, concerning how young people become motivated to learn about treatment and adhere to it, and second, concerning how information about treatment can best be communicated to them. In relation to the first of these, findings showed that young people were traumatised by an HIV diagnosis, fearing both that they would get sick and suffer an early death and also that they would be rejected by their belonging groups. This meant that they could not take in the factual information offered, and in addition, had no motivation to do so because the diagnosis resulted in a loss of hope for their present and future lives. According to young people, motivation was an outcome of re-connecting to one or more trusted significant other(s) from within their belonging group, who accepted and supported them. This in turn affirmed their prior belonging identities of son, daughter, cousin or close friend and then reconnected them to their present and future hopes. This renewed motivation to live was the basis for their becoming motivated to learn about treatment and adhere to it.

In relation to the second factor, this study found that current communications about treatment were not effective. Specifically, the use of metaphors, which was seen among clinicians as a method of simplifying the complexity of ART adherence messages, was in fact creating confusion. Also, the use of printed information in isolation was not effective; communication was much more effective when it provided a space for discussion.

These two key factors form the basis of a health communication strategy for young people who live with HIV and need to adhere to ART. Following on from these findings the study included the production of a film and animation that were identified as the visual communication media that would best support young people's understanding and motivation to adherence. The film presents a case study of a young person who overcame their initial diagnosis shock and, through the acceptance and support of his family, learned to live a normal life with HIV. Young people had said that they wanted to be able to view a film of this kind soon after their diagnosis. The animation, which was designed using a participatory process, used ‘iso-type’ as the central visual language. It was piloted, and this showed that the best use of a visual communication tool was in a setting that allowed young people to talk about prior losses to HIV within their families and community and about their confusion about treatment, and to ask questions about the meaning of complex biomedical concepts such as an undetectable viral load.

All young people who visited the clinics, irrespective of test results, said that they wanted to learn about ART so that they could support friends and family members who lived with HIV, change perceptions about HIV among peers and better prepare in the case of becoming HIV positive themselves. Therefore it is recommended that communication strategies should target patients, their belonging groups and the wider community.

This substantive theory contributes knowledge relevant to how ART adherence is communicated to young people. More broadly, this thesis argues that an interdisciplinary approach is required if communication practitioners are to properly understand the meaning that a population attributes to a health challenge; especially in the context of motivation and understanding. It is only when those meanings are fully identified through consolidated social science research that a communication strategy and supporting visual tools can be successfully designed.

Acknowledgements

I would like to thank the following people who have significantly contributed to this research project and who have supported me throughout.

Professor Ken Neil, who encouraged me to explore my initial ideas, that led me to travel to South Africa and spending time on a HIV ward. Thanks Ken for being so open to new ideas!

Professor Stephen Rollnick who supported this PhD as secondary supervisor for the initial two years. I am very grateful to you Steve for your input, insightful conversations and encouragement throughout.

Associate Professor Minette Coetzee who encouraged me to explore the social sciences and especially how to best engage with adolescents and young people. I will always be grateful to you for your openness, creativity and support – thank you for opening a new world of thinking to me.

Associate Professor Pat Mayers who as my principle supervisor has guided me through the territory of academia and academic rigor. I have enjoyed and learnt a great deal from you and especially enjoyed our debates and discussions as we have explored the data and emerging theories. I am deeply grateful for all of your input and support in what has been an exciting and challenging journey. I have learnt a great deal from you – I am extremely grateful Pat!

Professor Graeme Meintjes who as my initial contact in South Africa opened the door that allowed me to explore and discuss research opportunities in the world of HIV care. You have been an advisor, mentor and friend throughout and I look forward to continuing working with you in the future. I certainly owe you some beers!

Dr Gilles van Cutsem (Medi Sans Frontiers) Thank you Gilles for agreeing to our collaboration for this research project. You have always been open to discuss new findings and ideas as well as offering your youth resources throughout. I am very grateful to you Gilles and your team in Khayelitsha. My gratitude also to Brian

Mbanga – (MSF youth worker) who supported me throughout the field trips – so much would have not been achieved without you - thank you!

Dr Daniela Garone – thank you for your constant personal encouragement, especially in the low moments – a true and dear friend!

Professor Lesley Henley...what can I say! Thank you your advice, support and encouragement – let's meet up for a glass or two of the red stuff when I'm back in Cape Town.

Dr Helen Newing who engaged as secondary supervisor during the last year of the PhD. Helen not only are you a dear friend, but you have brought a specialist knowledge of interdisciplinary research, especially in the social sciences and coached me in academic writing methods. Thank you!!

Adri Winkler. Adri, you are one of the loveliest people I have met! I have so appreciated your on-going support and encouragement. I have always looked forward to dropping in for a catch up during my visits to UCT; thanks for everything and to your great team too!

Thank you to Josh Blackledge, Mark Humphrey and Ben Blackledge for your design in-put to the animation proto-type – and for your constant encouragement too!

Alison Townson. Just before I travelled to Cape Town to carry out the first stage of the field work I was diagnosed with PTSD and I remember seriously considering cancelling the trip and even the PhD because of my acute symptoms. As a dear sister and friend it was you who helped me to feel that despite my own trauma that I could and should continue - of which I am deeply grateful. Thank you for travelling out to visit me and encouraging me to keep going. You are a great sister and a wonderful friend – I love you!

Tanya Holland, Betina Benz, Daniel Zimmerli – wonderful friends! Thanks for the encouragement, love and friendship!

This thesis is dedicated to the young people of Khayelitsha – thank you for making me feel welcome, for sharing your lives with me and for contributing to my growth, healing and knowledge – you have taught me a great deal indeed! As South Africa's future I wish you well as you make your country into everything you want it to be!

Table of Contents

Chapter One – Introduction

Chapter Two – The use of visual communication in medicine instructions

Chapter Three – Young People and the challenge of ART adherence

Chapter Four – Theoretical Approaches to Health Communication

Chapter Five – Research Design and Methods

Chapter Six – How ART Adherence is communicated by Clinicians

Chapter Seven – Becoming Motivated to Adhere to ART

Chapter Eight – The development and Initial piloting of an animated visual tool designed to communicate ART adherence

Chapter Nine – A film that communicates hope

Chapter Ten – Communicating ART adherence to young people

Table of Tables

Table of Boxes

Table of Figures

Glossary

AIDS - Acquired Immune Deficiency Syndrome

HIV - Human immunodeficiency virus

ART - Antiretroviral Therapy

ARV's - Antiretroviral Therapy

WHO – World Health Organisation

CD4 cell count - A CD4 count is a lab test that measures the number of CD4 T lymphocytes (CD4 cells) in a sample of your blood. In people with HIV, it is the most important laboratory indicator of how well your immune system is working and the strongest predictor of HIV progression. (https://www.aids.gov)

Young People - The United Nations, for statistical purposes, defines
'youth', as those persons between the ages of 15 and 24 years. Participants included in this study were between 16-24 years. (www.**un**.org/esa/socdev/documents/**youth**/fact-sheets/**youth**-definition.pdf)

Visual Communication - Visual Communication science is the process of exploring and understanding how messages and ideas are communicated through the use of images. This can include signs, typography, drawings or photographs and can be displayed through visual based media, for example, printed materials, video, computer graphics etc.

Prototype - A design prototype is a completed design idea that is their use. There are a many methods of visual analysis including exploring content of visual images, visual anthropology, cultural context, semiotics and iconography. The purpose of the prototype is so that the design can be tested to evaluate how effective it is, usually feedback results in changes being made so that the design is improved for final use.

CHAPTER ONE: INTRODUCTION

1.1 Rationale: HIV/AIDS and ART adherence amongst young people

This dissertation explores how health communication can most effectively explain antiretroviral medication (ART) and motivate adherence among young people. It does so through a qualitative case study in the township of Khayelitsha, South Africa. There are an estimated 6.8 million people living with HIV in South Africa, making it the site of the largest HIV epidemic in the world (UNAIDS, 2014). The UNAIDS Report on the global AIDS epidemic emphasizes that young people are particularly vulnerable to HIV and account for approximately 45% of all new HIV infections worldwide. Currently, 5.6 % of 15- to 19-year-old South African adolescent girls are living with HIV, increasing to 17.4% among 20- to 24-year-old women. HIV prevalence among adolescent boys and young men is significantly lower, with estimates of 1% and 5% respectively (UNAIDS, 2014). Antiretroviral Therapy (ART) is the only effective treatment for HIV and was introduced into the South African health system in 2004 as part of the country's policy for fighting the epidemic. The main factor that compromises the effectiveness of the therapy, however, is the imperative of strict patient adherence to ART (Mills et al., 2006). Research indicates that patients who take less than 90% of their ART doses develop resistance to the medication, which results in therapy failure (Meintjes et al., 2014). A second and third line of treatment is available in the public sector in South Africa, but if sub-optimal adherence behaviour continues a patient's health deteriorates chronically, resulting in death (Meintjes, 2014).

Various studies have documented worryingly poor levels of adherence to ART, especially amongst adolescents and young adults in South Africa. For example, Nachega et al. (2009) documented adherence outcomes among adolescents and adults enrolled on a private-sector employer health programme in South Africa called "Aid for AIDS". They reported that adolescents were 50% less likely than adults to achieve long-term optimal adherence. Similarly, Nglazi et al. (2012) reported lower levels of adherence among adolescents than among young adults in a study at a public sector community-based ART programme in Cape Town. Both studies highlighted the urgent need to develop interventions that support ART adherence among young South Africans.

Effective communication that clearly explains how to take medicines for life-long chronic diseases such as HIV/AIDS is shown to significantly improve adherence among patients (Dowse & Eshers, 2004; Katz, Kripalani & Weiss, 2003; Chan et al., 2013). The importance of effective communication, and the need for youth-centred interventions, have both been acknowledged by the South African government. In their recently published National Strategic Plan (NSP 2012 – 2016), they outline a 20-year vision for fighting the HIV/AIDS epidemic. This includes the goal of reducing new HIV infections by at least 50% and initiating at least 80% of eligible patients on ART, with a goal of 70% maintaining long term adherence. Whilst the report recognizes that there are a number of challenges to adherence, including poverty and food insecurity, it identifies effective communication as a key strategic enabler that will "underpin the entire NSP", stating:

> "Effective communication is critical to the successful implementation of the NSP. Social and behavioural change communication is also critical to changing risk behaviour and social conditions that drive the HIV and TB epidemics, which at the same time support a demand for prevention, care and support, and treatment services" (2012:13).

It is within this context that this study sets out to explore what factors increase the effectiveness of communication in facilitating young people's adherence to ART.

1.2 Education and historical treatment narratives: the context of current ART adherence communications in Khayelitsha

Ensuring that medicine instructions are clearly communicated during patient consultations is essential to the delivery of effective healthcare, and HIV prevention and ART treatment information is readily available throughout the ART clinics located in Khayelitsha. These materials include pamphlets, posters and magazines that are designed for young people to read, and they include large quantities of written explanation and instructions. They attempt not only to describe ART but also to explain why it is necessary, how it works and how it should be taken. However despite the provision of these materials, many clinicians find that young people struggle to grasp the concepts that are used. The literature shows that a person's ability to read, write and process complex bio-medical concepts can all directly impact their ability to understand medicine instructions (Ngoh & Shepherd, 1997; Sojourner & Wogalter, 1997; Houts et al., 1998; Morrow et al., 1998; Morrow et al., 2000; Dowse & Eshers, 2004; Kripalani et al., 2004; Morrow et al., 2005; Houts et al., 2006; Mansoor & Dowse, 2006; Mwingira & Dowse, 2006; Kripalani et al., 2007; Dowse & Browne, 2011; Dowse et al., 2011; Grenier et al., 2011; Finocchario-Kessler et al., 2012; Kheir et al., 2013). Low levels of literacy are a serious structural barrier to ART adherence throughout South Africa (Kagee et al., 2011). Indeed, the WHO Health Literacy report (2013) advocates that functional literacy (the ability to read and understand basic health related information) is a key determinant of health and wellbeing, stating that "literacy is a stronger predictor of an individual's health status than income, employment status, education level and racial or ethnic group" (2013:7). In 2012, the South African government commissioned the National Education Evaluation & Development Unit (2012) to report on the state of schools in South Africa. The report found that most teachers did not teach reading effectively and often resorted to a didactic style of teaching, encouraging pupils to read out loud collectively in a "parrot" style, rather than learning to read independently. After five years of exposure to these methods of teaching, 13% of pupils were illiterate and only 20% were able to pass a comprehension test (2012:74). These findings are reflected in the most recent Cape Town Census (2011), which reported that only 30.2% of the population of Khayelitsha had achieved Grade 12 at secondary school. This suggests that many young people who need to take ART may struggle with properly understanding the printed information provided by the HIV clinics in Khayelitsha.

1.2.1 Historical narratives of HIV and ART

Education and a young person’s ability to comprehend complex biomedical communications are not the only factors affecting their interpretation of ART messages. At a deeper level, patients may “frame” the messages with their own unique interpretation and meaning or reject them altogether (Jacobs & Johnson, 2007). Hall (2007) argues that messages that are intended to be interpreted in a particular way by the authors are often understood through the prism of an individual’s own cultural conventions and history. This is an important point in the context of South Africa, where biomedical ART instructions do not exist in isolation from the influence of other treatment narratives (Bogart et al., 2011; Tun et al., 2012).

Various narratives that have been associated with HIV and ART in the past have been shown to have an impact on the effectiveness of communications about ART adherence. Fassin & Schneider (2003) argue that the effects of the post-apartheid response to the HIV epidemic (in particular that of the Mbeki administration) remain embedded in the memory of the South African people (2003:495). According to Fassin (2002) one of the tragic consequences is a suspicion among the people who have been most affected by the epidemic towards biomedical science and the treatments it advocates for HIV. This, according to a number of South African scholars, is directly traced to a catalogue of controversial decisions about HIV prevention and treatments (Robins, 2004; Bolognesi & Swartz, 2007; Nattrass, 2007). For example, in 1996 large amounts of public funding provided for prevention interventions were spent on a musical show called Sarafina, the script of which was widely criticized as being both confused and irrelevant. The following year (1997) Mbeki officially supported a drug called Virodene that had not undergone the proper regulatory approval processes for human trials and was later identified as an antifreeze solution. In 1998 the Government blocked the use of a new drug called AZT (Zidovudine) that was proven to reduce mother to child transmission, arguing that the medication was too toxic. In 2003, due both to international pressure and to the local activism of an organization called the Treatment Action Campaign (TAC), the government changed its position and announced its commitment to the rollout of

ART treatment. During the same period however, Dr Tshabalala-Msimang, the then Health Minister, announced that the principal public health advice for the treatment of HIV for the people of South Africa was to eat "fruit and vegetables", repeatedly advising that "raw garlic and a skin of the lemon" would not only give one "a beautiful face and skin but would also protect you from disease" (CNN, 2005, cited in Bolognesi & Swartz, 2007:10).

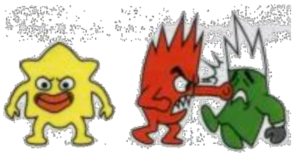
According to Bolognesi & Swartz, this long period of repeated controversy provided a cocktail of sensationalism that generated rich material for the South African media and resulted in public confusion about a "life threatening disease" and its treatment (2007:26). Rubincam (2013) confirmed this position, showing that this period continues to influence how young adults engage with the biomedical messages that are communicated throughout the ART clinics of Khayelitsha. He did so by means of a mixed-method study that included a survey of 2905 19- to 29-year-olds, followed by a series of focus groups (n=47) and 20 in-depth interviews with Treatment Action Campaign peer educators. Findings showed that although respondents mostly trusted the information shared by doctors, nurses and TAC peer educators (90%, 80% and 60% respectively), 50% remained open to the influences of the alternate treatments advocated by Tshabalala-Msimang and 45% to the denialist beliefs endorsed by Mbeki. Rubincam argues that although many young people would not be able to attribute the historical narratives of denialism or alternative treatments to either Tshabalala-Msimang or Mbeki, the complex weave of historical narratives continues to influence current localized understandings of HIV and ART, resulting in some people feeling ambivalent towards current ART health information.

1.3 Adherence: Current communication approaches in Khayelitsha

Several different actors are involved in communicating ART adherence to young people in Khayelitsha. Since the introduction of ART into the South African health system in 2004, the training of lay counsellors has been prioritized, and they are the main channel of communication for adherence promotion (Mabuto et al., 2014). Counsellors play an important role in the delivery of HIV testing and in the process of initiating young people onto ART that includes three counselling sessions that focuses on explaining treatment information. Doctors, nurses and pharmacists who work throughout the ART clinics in Khayelitsha also communicate ART adherence messages to young people. Lastly, there are voluntary treatment support educators, who are members of an NGO, the Treatment Action Campaign (TAC). TAC was formed in 1989 as an organization that campaigned for the introduction of ART and undertook to provide training and provision of voluntary treatment educators throughout the South African health services. The communication approach they use focuses on educating people about HIV/AIDS and its treatments. This usually occurs in a group setting in waiting room areas, but also occurs on a one-to-one basis.

The use of inappropriate cultural metaphors dominates ART adherence communication throughout the South African health services (Ashforth & Natrass, 2005). Figure 1.1 gives some examples of the pictorial representations of these metaphors.

Figure 1.1: Variety of pictorial representations of HIV and AIDS (reproduced from visual aid provided by Medi-Sans-Frontiéres)

			
CD4 soldier of the body	HIV virus: Monsters	Yellow monster: Disease Red monster: HIV Green soldier: CD4	Blue/green soldier: ART

A particularly strong metaphor that is widely used is that of a monster depicting the infection of HIV as something that pollutes the body. This representation is thought to originate from the beliefs of traditional healers who seek to “cleanse” a person from the pollutant force that is seen as the cause of illness, creating a treatment narrative in which HIV is *“another form of dirt in the blood and ART as a cleaning agent”* (Ashforth & Natrass, 2005:286). The second main metaphor, defined as “soldiers of the body” is used to describe the normal function of the immune system. This metaphor is used to describe how CD4 cells in a healthy person combat infection and disease, enabling a successful immune system. In the narrative used to explain how HIV attacks the immune system, the monsters representing the HIV virus attack and destroy the “soldiers” (CD4 cells). This concept originates from the isiZulu term, *amasokha omzimba*, which most probably derives from the Zulu translation of the concept of immunity (Ashforth & Natrass, 2005).

Within the Khayelitsha ART clinics there is a variety of visual communication materials that are designed to communicate both prevention and ART to patients. The majority of these materials use visual metaphors to represent and describe the biomedical concepts of HIV, immunity and how ART combats the HIV virus. Metaphors are central to lay counsellors’ communications and are commonly used by clinicians in addition to more ‘scientific’ explanations. In contrast, TAC uses biomedical language and visual representation in its communication of ART treatment, and avoids the use of metaphors. As a result, three different narratives are currently being communicated to young people within the health services in Khayelitsha to explain HIV and ART. This is likely to create confusion amongst young people, many of whom are also likely to interpret the different messages through the lens of historical treatment narratives, and who have a limited educational background. It is within this context that this study is located.

1.4 Research aims and objectives

The aim of this study was to explore how health communication can most effectively explain antiretroviral therapy (ART) and motivate adherence among young people. The empirical research consisted of a qualitative case study in Khayelitsha, a peri-urban township on the edge of Cape Town. The research objectives were as follows:

1. What are the current adherence messages that are used in Khayelitsha to explain ART and motivate young people to adhere to ART?
2. How are adherence messages in Khayelitsha perceived by young people, and are they effective?

3. What motivates young people in Khayelitsha to adhere to ART or hinders their doing so?
4. What would be the most effective tools for communication in Khayelitsha to facilitate young people's motivation and understanding?
5. Overall, how does the study inform wider understanding of factors contributing to the effectiveness of communication strategies and supporting visual tools to facilitate young people's adherence to ART?

1.5 Structure of the thesis

The proposal for this study originated in relation to an applied problem, and therefore the research followed an inductive process. It started with a broad exploration of the problem in the field and this led to the identification of relevant themes areas of the literature in different disciplines. The research design was interdisciplinary, drawing principally from health and visual communication and from the social sciences, and was developed iteratively as each stage of fieldwork and analysis informed the next. This process, which is described in detail in chapter five, is reflected in the structure of the rest of the thesis. Chapters two and three review the literature on two aspects that were identified as central to the study during early visits to the field site: the use of visual communication in medicine information, and social and psychological barriers to adherence. During the first visit to Khayelitsha clinicians described how difficult they found it to explain the complex bio-medical concepts associated with ART adherence to young people, and young people stated that they found the written materials in the clinics both difficult and uninteresting. Therefore in chapter two I review the literature on the use of visual communication in medicine information and instructions. In further fieldwork it became clear that although understanding of ART instructions was important in helping young people in Khayelitsha to adhere to their medication, a more complex psychosocial process appeared to be central to why and how they became motivated. In chapter three I review the literature on common psychological and social barriers to adherence by young people.

Chapters four and five present the broad theoretical and methodological framework for the study. In chapter four I explore the main theories and models informing health communication interventions that are designed to motivate people to healthy behaviours. Chapter five introduces grounded theory as the overall methodological framework for the research, and then gives a detailed account of the research design and methodology.

Chapters six to nine present the results of the study. In chapter six I focus on how clinicians explain ART adherence to young people in Khayelitsha, and discuss how these messages are based upon behaviour models that are commonly used in health communication. Chapter seven then presents a broader emerging theory of how young people become motivated to adhere to ART regimes. This theory challenges current communication approaches used in Khayelitsha HIV clinics in that it emphasises social and psychological factors that include acceptance and support from significant family members and friends, alongside the need for knowledge and understanding. In chapters eight and nine I discuss the development of two visual tools that were informed by these findings. In chapter eight I discuss the design process, production and pilot testing of a new visual tool that was designed to communicate ART adherence, which took the form of an animation. Chapter nine presents a film that describes one young man’s journey to becoming motivated to adhere to ART. Finally in Chapter ten, I discuss the study findings in the context of existing literature, and conclude with recommendations for practice, policy and further research.

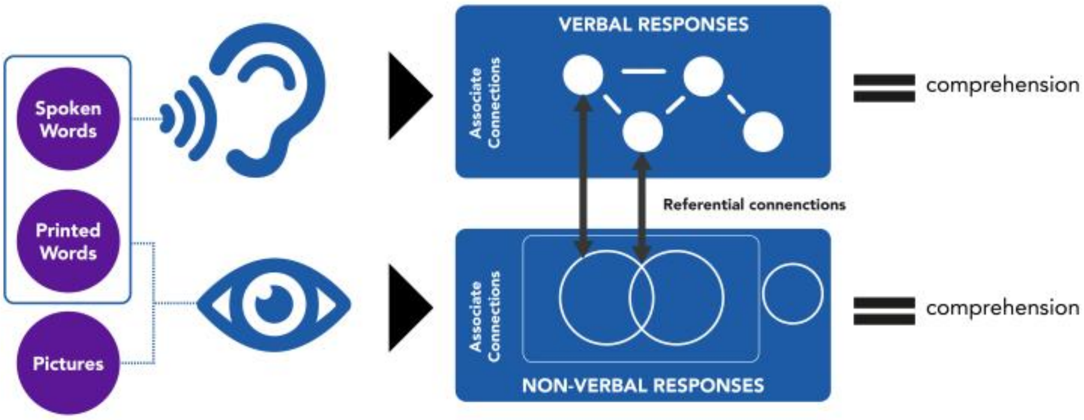
CHAPTER 2: THE USE OF VISUAL COMMUNICATION IN MEDICINE INSTRUCTIONS

2.1 Introduction

In this chapter I discuss how different forms of communication are used in medicine instructions to better explain the tasks that are required for adherence. Typically, medicine instructions include patient information leaflets (PIL) and medicine container labels. Patients who fully understand and remember medicine instructions are more likely to achieve optimal adherence (Weiss, 2003; Dowse & Eshers, 2004; Katz, Kripalani & Weiss, 2006 & Chan et al., 2013). Medicine instructions are often designed and written based on the assumption that patients are sufficiently literate to be able to read, comprehend and adhere to them, and also that they are familiar with the biomedical language / terminology used. Many studies have identified that adherence is seriously compromised among low-literate populations (Ngoh & Shepherd, 1997; Sojourner & Wogalter, 1997; Houts et al.,1998; Morrow et al., 1998; Dowse & Eshers, 2004; Morrow et al., 2005; Houts et al., 2006; Mansoor & Dowse, 2006; Mwingira & Dowse, 2006; Kripalani et al., 2007; Dowse, Ramela & Browne, 2011; Dowse et al., 2011; Grenier et al., 2011; Finocchario-Kessler et al., 2012; Kheir et al., 2014). In addition, clinicians often find explaining biomedical terminology a challenge, especially when they are unable to spend sufficient time with patients (Houts et al., 2006).

The main strategy used to help patients understand written medicine instructions, especially low-literate populations, is to include images, which may take the form of pictures, photos, illustrations or pictograms (Dowse & Eshers., 2004; Dowse et al., 2011; Grenier et al., 2011). Multi-media medicine instructions that combine images with written text and / or spoken explanation are shown to improve comprehension, recall (remembering the information), and the ability to carry out the instructions in contrast to text only or picture only information (Sojourner & Wogalter, 1997; Dowse & Eshers, 2004; Houts et al., 2006; Mansoor & Dowse, 2006; Mwingira & Dowse, 2006; Kripalani et al., 2007; Dowse et al., 2011). Two main learning theories that provide an insight into why the combination of pictures and words improve learning outcomes are Paivio’s Dual Code Theory (1986) and Mayer’s (2009) Cognitive Theory of Multi-Media Learning. Paivio’s Dual Code Theory (1986) describes how spoken, written and pictorially presented information is cognitively processed. Figure 2.1 shows how pictures and words that are spoken or printed are received into the brain through the visual and auditory sensory functions, facilitating a dual cognitive process of sense-making. This process includes two responses that connect the presented information to existing stored data, leading to successful comprehension. First, referential connections connect sounds, written text and images to corresponding stored data, processing words into images and images into words. For example, the word ‘book’ would connect to a stored image of a book. Second, associative connectivity occurs when presented words are joined with other (stored) associations that are used to frame the meaning of the original spoken or written word. An example cited by Paivio is that when a student hears the word “school” it ‘might elicit such verbal associations as “hate”, “boring” or “afraid”’ (Clark & Paivio, 1991:153). Dual Code Theory posits that it is when both of these functions are engaged that an individual is best able to process and comprehend the presented information.

Figure 2.1: Paivio’s Dual Coding Model (Clark & Paivio, 1991:152)

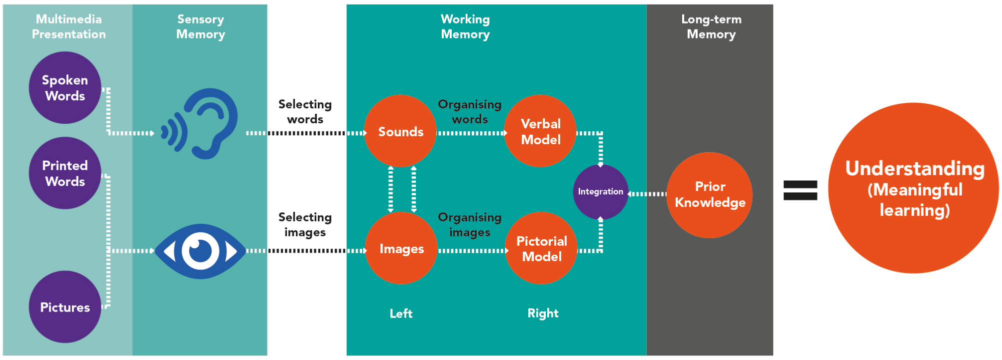


According to Mayer (2009), whilst Paivio’s Dual Code Theory offers a model of how words or pictures are cognitively processed, its relevance is limited to single modes of media delivery (either text only or picture only information). Furthermore, Paivio’s theory prioritises comprehension as the key learning outcome, which according to Mayer is insufficient for instructional communication. He argues that knowledge transfer (transfer of knowledge that enables the learner to perform the task communicated) should be the principal measure of effective or ‘meaningful' learning. For meaningful learning to occur, Mayer argues that words (spoken and / or written) that are presented together with pictures in multi-media messages provide the best learner outcomes (2009:21).

Building on Paivio’s Dual Coding Theory, Mayer (2009) developed the Cognitive Theory of Multi-Media Learning. Similar to Paivio’s model, Mayer's model (Figure 2.2) posits that cognitive processing includes the memory as well as the visual and auditory sensory functions. The memory, according to Mayer (2009:61-62), functions on three levels: the sensory memory, the working memory and the long-term memory. Information received through the visual and auditory senses is momentarily held in the sensory memory, gathered and then transferred into the working memory. The working memory has two sub-functions corresponding to the auditory and visual communication channels. Spoken instructions are converted through the auditory side of the working memory and then translated into visual representations (images). Pictures and written text are similarly converted in the working memory, forming a visual representation (similar to Paivio’s concept of referential and associative connections). These two functions of working memory are then integrated and connected (or placed into context) to prior knowledge that exists in the long-term memory, which then enables both comprehension and knowledge transfer (meaningful-learning) (2009:28-30).

In the rest of this chapter I discuss the evidence for two different aspects of communication in multi-media medicine instructions: first, the different impacts of pictures, text and / or spoken communication on comprehension and adherence, and second, the impacts of different elements in pictorial representation designed for multi-media medicine instructions.

Figure 2.2 Mayer's Cognitive Model of Multimedia Learning (Mayer, 2009:61).

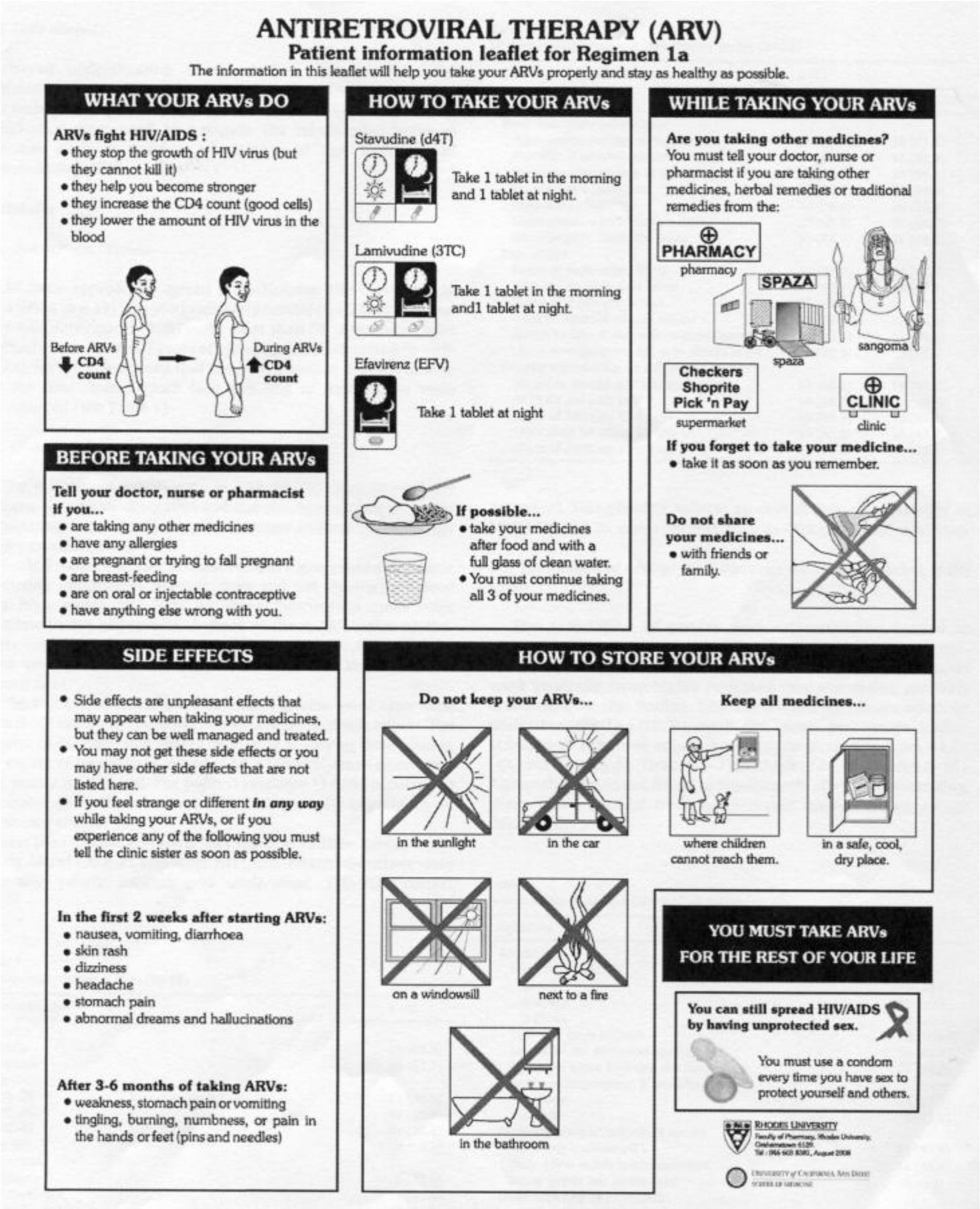


As can be seen from table 2.1, there are only a few studies that examine the impact of multi-media medicine instructions on comprehension, recall and adherence, and they have been conducted in a variety of settings. Any general conclusions must therefore be tentative, but nonetheless there are some common findings. In line with Mayer's Cognitive Theory of Multi-Media Learning, four studies found that an improved level of comprehension was achieved when pictures and written or spoken verbal instructions are combined compared to verbal or picture versions alone (Morrow et al., 1998; Mansoor & Dowse, 2003; Myingira & Dowse, 2006; Dowse, Ramela & Browne, 2011; see Figure 2.3 for an example of the Multi-media patient information leaflet used by Dowes, Ramela & Browne (2011). Three of these studies were based in South Africa. However, despite involving local participants in the design process, relatively low levels of comprehension were reported.

Table 2.1. Studies comparing comprehension of multi-media medicine instructions (pictures and written / spoken instructions) and picture or text only versions.

Reference	**Location**	**Population**	**Visual communication materials tested**	**Method of assessment**	**Findings**
Morrow et al., 1998	USA	36 older adults (64-90 years) and 36 younger adults (20 – 30 years)	1. Pictogram only 2. Pictogram integrated into text	Interviewer-administered questionnaire	Pictogram integrated into text improved comprehension in comparison to pictogram alone
Mansoor & Dowse, 2003	South Africa	60 low – literate Xhosa speaking adults	1. Locally designed (pictures and text) medicine label 2. Text only versions	Interviewer-administered questionnaire	73% displayed a high level of understanding of the picture and text version compared to 53% for the text only version. Inclusion of pictograms increased comprehension of more complex information.
Mwingira & Dowse, 2006	South Africa	60 Xhosa speaking adults with varied literacy skills	Locally designed ART PIL combining pictures and text	Interviewer-administered questionnaire	Average rate of understanding was 80%. All participants believed that pictures would contribute to their understanding.
Thompson et al, 2010	Canada	100 literate adults	1. Picture leaflet only 2. Text leaflet only	Interviewer-administered questionnaire	No differences of comprehension or recall were found between the two leaflets.
Dowse, Ramela & Browne, 2011	South Africa	39 low – literate Xhosa speaking adults	Locally designed ART PIL that combined pictures and text	Interviewer-administered questionnaire	Average comprehension of the leaflet was 60%
King et al., 2012	USA	161 literate adults	1. Text only leaflet 2. Text with pictograms 3. Pictograms only	Interviewer-administered questionnaire	No significant difference regarding participants' ability to recall (remember) pictogram meanings.

Figure 2.3 Multi-media patient information leaflet used by Dowes, Ramela & Browne (2011).



ANTIRETROVIRAL THERAPY (ARV)

Patient information leaflet for Regimen 1a

The information in this leaflet will help you take your ARVs properly and stay as healthy as possible.

WHAT YOUR ARVs DO

ARVs fight HIV/AIDS :

- they stop the growth of HIV virus (but they cannot kill it)
- they help you become stronger
- they increase the CD4 count (good cells)
- they lower the amount of HIV virus in the blood

Before ARVs ⬇ CD4 count → During ARVs ⬆ CD4 count

BEFORE TAKING YOUR ARVs

Tell your doctor, nurse or pharmacist if you...

- are taking any other medicines
- have any allergies
- are pregnant or trying to fall pregnant
- are breast-feeding
- are on oral or injectable contraceptive
- have anything else wrong with you.

HOW TO TAKE YOUR ARVs

Stavudine (d4T)

Take 1 tablet in the morning and 1 tablet at night.

Lamivudine (3TC)

Take 1 tablet in the morning and1 tablet at night.

Efavirenz (EFV)

Take 1 tablet at night

If possible...

- take your medicines after food and with a full glass of clean water.
- You must continue taking all 3 of your medicines.

WHILE TAKING YOUR ARVs

Are you taking other medicines?
You must tell your doctor, nurse or pharmacist if you are taking other medicines, herbal remedies or traditional remedies from the:

PHARMACY
pharmacy

SPAZA
spaza

sangoma

Checkers
Shoprite
Pick 'n Pay
supermarket

CLINIC
clinic

If you forget to take your medicine...

- take it as soon as you remember.

Do not share your medicines...

- with friends or family.

SIDE EFFECTS

- Side effects are unpleasant effects that may appear when taking your medicines, but they can be well managed and treated.
- You may not get these side effects or you may have other side effects that are not listed here.
- If you feel strange or different ***in any way*** while taking your ARVs, or if you experience any of the following you must tell the clinic sister as soon as possible.

In the first 2 weeks after starting ARVs:

- nausea, vomiting, diarrhoea
- skin rash
- dizziness
- headache
- stomach pain
- abnormal dreams and hallucinations

After 3-6 months of taking ARVs:

- weakness, stomach pain or vomiting
- tingling, burning, numbness, or pain in the hands or feet (pins and needles)

HOW TO STORE YOUR ARVs

Do not keep your ARVs...

in the sunlight

in the car

on a windowsill

next to a fire

in the bathroom

Keep all medicines...

where children cannot reach them.

in a safe, cool, dry place.

YOU MUST TAKE ARVs FOR THE REST OF YOUR LIFE

You can still spread HIV/AIDS by having unprotected sex.

You must use a condom every time you have sex to protect yourself and others.

RHODES UNIVERSITY
Faculty of Pharmacy, Rhodes University,
Grahamstown [illegible]
Tel : [illegible], August [illegible]

UNIVERSITY of CALIFORNIA, SAN DIEGO
SCHOOL OF MEDICINE

Two studies that focused on examining the impact of pictograms on recall (memory) found no significant difference between leaflets that incorporated text only, pictures only and both pictograms and text (Thompson et al., 2010; King et al., 2012). However a limitation to both studies was that only short term recall was tested and participants were allowed only minimal exposure to the leaflets. Long term recall was not explored and findings may have been very different if participants had been allowed to take the instructions home to further read and digest.

Only four studies have examined the impact of multi-media instructions on adherence itself (Ngoh & Shepherd, 1997; Dowse & Ehlers, 2004; Mansoor & Dowes, 2006; Briach et al., 2011). These are summarised in table 2.2. All four studies showed that multi-media medicine instructions could contribute to short-term adherence. However it is difficult to generalise these findings, as participants may have been motivated to adhere because they knew their medication were going to be counted during followed-up home visits by researchers.

It is interesting to note that the most successful adherence outcomes were reported by Ngoh and Shepherd (1997) and Braich et al. (2011), where visual tools were used as part of an educational session designed to facilitate learning. These findings support Mayer's theory that better learning outcomes are achieved when pictures are supported by spoken instructions (2009).

Table 2.2: Summary of studies that examined the impact of multi-media medicine instructions on adherence

Reference	**Location**	**Population**	**Visual communication materials tested**	**Method of assessment of adherence**	**Findings**
Ngoh & Shepherd, 1997	Cameroon	78 non-literate women	Locally designed antibiotic medicine instructions: 1. Pictures and text plus spoken explanation 2. As above plus educational session 3. No information (control)	Pill counts during a follow-up home visit.	Mean percentages for adherence for the three groups: 1. 89.56%, 2. 94.64%, 3. 77.54%.
Dowse and Ehlers, 2004	South Africa	87 low–literate Xhosa speaking adults	1. Antibiotic medicine label with pictures and text. 2. Antibiotic medicine label with text only.	Self reporting and pill counts during a follow-up home visit. Comprehension was measured with an interviewer-administered questionnaire	Mean percentages for adherence: 1. 95% 2. 70% Mean percentages for comprehension: 1. 90% 2. 72%
Mansoor & Dowes, 2006	South Africa	120 low–literate Xhosa speaking	1. Antibiotic medicine PILwith pictures and text. 2. Antibiotic medicine PILwith text only 3. No information (control).	Self-reporting and pill counts.	Mean percentages for adherence 1. 88.3%, 2. 73.6% 3. 67.7%
Braich et al., 2011	India	225 low–literate adults	1. Medicine administration leaflet for eye drops that included pictograms only, with educational session. 2. As above; also given pictograms to take home. 3. Spoken instructions only (control).	Remaining liquid (medicine) was measured 28 days after the medicine had been received.	The group taking pictograms home (Group 2) used more medicine than other groups, suggesting higher level of adherence

2.3 Design and use of pictures in multi-media medicine instructions

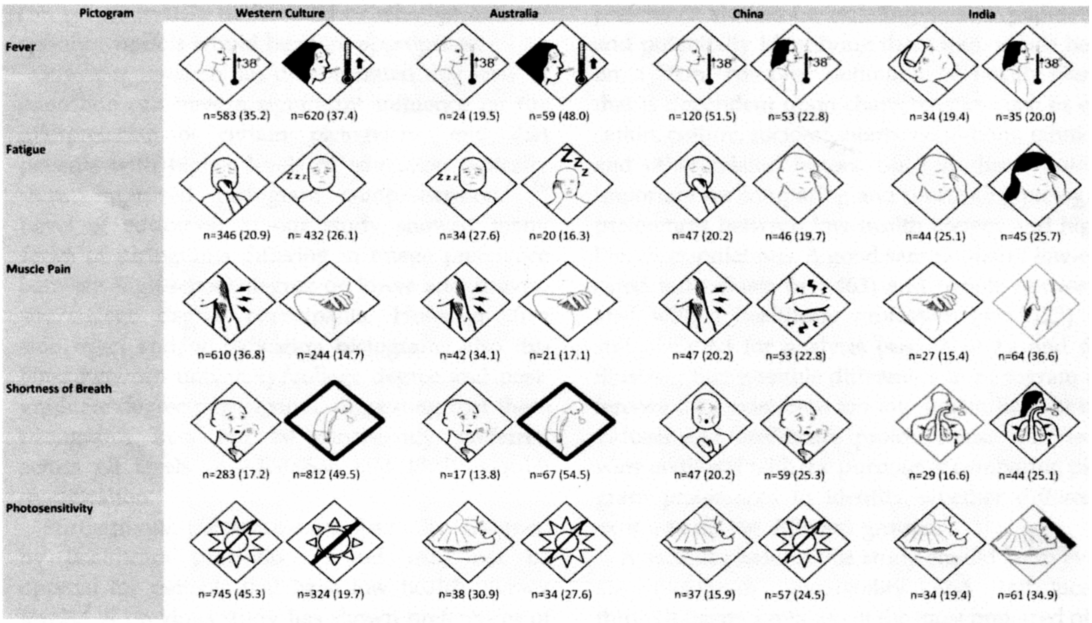
Pictures that are incorporated in multi-media instructions must have the right design qualities to be recognised and understood by the learner. This section examines current understanding of these qualities. According to Carney and Levin (2002), pictures should achieve two principal functions that maximise their impact. The first function, motivation, relates to how pictures increase a person's interest in the presented material. The picture design should be simple, clear and interesting enough to attract the attention of the audience so that they are motivated both to read the text and to take in the image. The second function is reiteration, which relates to how pictures repeat the written message, offering the viewer a 'double exposure' to the information.

The role of the pictures is to transform complex concepts into simple and clear visual language (Levin, 1981:27). Levin (1981) proposes four functions that should be applied to the design of pictures so that they successfully achieve both motivation and reiteration. First, the representational function details how the picture must represent (illustrate) the intended meaning of the written text and clearly describe its intention. Secondly, the organisational function details how the picture should be placed next to the descriptive text, so that the audience can properly link text to images and images to text and in this way, navigate effectively through the presented information. The third function, interpretation, specifies that the design of the picture should represent the text literally, so that "difficult-to-comprehend information is made understandable" (Levin, 1981:27). Finally, the transformational function concerns the design of pictures that illustrate complex conceptual information that may be difficult to remember. Examples cited by Levin include medicinal and other scientific texts that from the reader's perspective contain "unfamiliar technical terminology".

Whilst Levin's functional framework is helpful, studies show that achieving successful levels of comprehension from pictures that are designed to explain complex bio-medical concepts is difficult (Kassam, Vaillancourt & Collins, 2004; Dowes & Ehlers, 2004; Carstens et al., 2006; Dowes et al., 2011; Grenier et al., 2011; Wilson et al., 2012; Richler et al., 2012; Kheir et al., 2013). Many of these studies show that representing complex ideas through visual language is dependent upon how well the designed image is recognised or understood by the intended audience, especially among low-literate populations (Dowes & Ehlers, 2004; Kassam, Vaillancourt & Collins, 2004; Carstens et al., 2006; Dowes et al., 2011; Grenier et al,. 2011; Kheir et al., 2013). Recognition and correct interpretation of pictures is also shown to be dependent upon whether their meaning has been explained verbally to patients (Yin et al., 2008; Joshi & Kothyal, 2011).

The most popular type of pictures used in medicine instructions are pictograms (see figure 2.4). Pictograms are graphic symbols that are designed to represent an object, action, place or concept. They are designed to be self-explanatory and provide a concrete interpretation of the intended meaning (Montagne, 2013). The International Pharmaceutical Federation (FIP)[*] recommends the use of pictograms in medicine instructions, stating that “Pictograms give health professionals a means of communicating medication instructions to people with no common language and/or who may be illiterate” (www.fip.org).

Figure 2.4: Examples of pictograms tested by Richler et al. (2012).



---

[*] FIP is a non-for profit international organization that sets pharmacy standards and guidelines, policy statements for health organizations and practitioners.

The FIP provides an extensive database of pharmaceutical pictograms that are available for international (universal) use. However two studies (described in table 2.3) explored comprehension of a wide range of these pictograms across cultures (Richler et al., 2012; Wilson et al., 2012) and reported that interpretations of pictograms differed significantly for participants from Africa and Latin America in comparison to Asia, Europe, North America and Oceania. The studies offer an important insight into the design and development of pictograms for international audiences. They show that pictograms do not always transfer successfully across populations, particularly where significant cultural differences occur. Both studies (and the FIP) recommend that pictograms should be designed and tested locally, ensuring that localised cultural influences are taken into account, so that they offer the best possibility of being understood among the intended populations.

Table 2.3: General characteristics of studies examined the comprehension of universally designed pictograms

Reference	**Location**	**Population**	**Kinds of visual communication materials tested**	**Method of assessment of comprehension**	**Findings**
Yin et al,, 2008	USA	245 adults	1. Pictogram and teach-back session 2. Control Group: counselling only	Interviewer-administered questionnaire	The pictograms used with teach-back session resulted in decreased medication dosing errors and improved short term adherence compared to the control group.
Joshi & Kothyal, 2011	India	200 non–literate adults	1. Pictograms only 2. Pictograms with explanation	Interviewer-administered questionnaire	Only 1% of participants correctly interpreted the meaning of all 10 pictograms when presented by themselves, in contrast to 9.5% of those who received an explanation for each pictogram.
Wilson et al., 2011	84 countries	850 participants (from 15 years old)	8 sets of pictograms	On-line survey	The study found that while some pictograms were universally understood, interpretations of others differed across national populations.
Richer et al., 2012	Canada, China, India, Australia, the UK, Netherlands, the USA and Spain.	2,719 participants (from 11 years old)	28 sets of pictograms	On-line survey	Only two of the 28 pictograms were properly identified, and none of them achieved the standard 85% criterion for comprehension (set by the American National Standard Institute (ANSI)*.

2.3.1 The impact of locally designed pictograms

Based upon the principle of placing culture at the forefront of the picture design process, a series of studies have examined the impact on comprehension of locally produced, culture-specific pictograms (see table 2.4). These studies show that involving local community members in the design of pictograms can significantly improve their comprehension, although achieving a consistent level of comprehension that meets the ANSI 85% criterion[**] across a range of pictograms was not achieved for the majority of pictograms tested. Only one study (Wilby et al., 2011) achieved comprehension averages above 85%, and this may be because in this study participants were literate and they were given both counselling and spoken explanations of the meanings of the pictograms. These findings further support Mayer's theory that multi-media instructions that combine pictures with spoken explanations provide better learner outcomes, particularly when they are conveying complex information (2009:200).

[**] The American National Standards Institute (ANSI) is an independent body that oversees the development of voluntary consensus standards for products, services, processes, systems, and personal in the U.S. The ANSI Standard for measuring comprehension of pictograms is an internationally recognised standard for evaluating pictograms.

Table 2.4: General characteristics of studies examined the comprehension of locally cultural specific designed pictograms

Reference	Location	Population	Kinds of visual communication materials tested	Method of assessment of comprehension	Findings
Dowes & Ehlers, 2004	South Africa	304 low-literate adults from eight different South African language groups.	Comprehension levels compared between 23 "universal" pictograms designed by the USP Convention* and 23 corresponding locally designed pictograms	Interviewer-administered questionnaire	Only two of the USP pictograms achieved 85% comprehension, compared to 12 of the locally designed pictograms.
Kassam, Vaillancourt & Collins, 2004	Canada	39 adults from China, Somalia and India who could not speak English, French or Spanish	16 locally designed pictograms	Interviewer-administered questionnaire	Locally designed pictograms achieved an average comprehension of 67.15 %.
Wilby et al., 2011	Canada	82 adults	1. Pictogram, counselling and spoken explanation for pictograms 2. Counselling and text only PIL	On-line survey	88% of group 1 correctly identified pictograms at follow-up compared to 2% in group 2
Grenier et al., 2011	Canada	66 low-literate First Nation (aboriginal) adults	1. Text plus spoken instructions 2. Pictograms only 3. Pictogram with spoken instructions	Focus groups and questionnaire	Locally designed pictograms appear to be helpful but no significant findings
Kheir et al,. 2013	Qatar	123 low-literate migrant workers	1. Text plus spoken instructions 2. Pictograms only 3. Pictogram with spoken instructions	Interviewer-administered questionnaire	Pictograms supported by spoken instructions were better understood

* The United States Pharmacopeial (USP) Convention is a scientific nonprofit organization that sets standards for the identity, strength, quality, and purity of medicines, food ingredients, and dietary supplements manufactured, distributed and consumed worldwide. (www.USP.org)

2.3.2 Visual elements that are incorporated in picture design

The studies discussed above show the complexity of how pictograms, even when they are locally designed, can often be misinterpreted by the intended audience. Pictures that are used in medicine instructions often incorporate a series of visual elements that collectively represent the intended meaning of the designed picture. According to the theory of visual semiotics, images provide two possible layers of interpretation (Leeuwen, 2008). The first is the denotation layer, where the viewer is able to identify the intended literal meaning of the image (Leeuwen, 2008:94). The second layer of interpretation is connotation, which relates to the subjective meanings that the viewer may interpret from the image (Hall, 1997: 38). According to Mayer, denotative interpretations are fully dependent upon the prior corresponding visual / word images that are stored in the long-term memory (Mayer, 2009: 61-62).

Visual elements include representations of everyday objects and actions, symbols, and mathematical and alphabetical symbols. A number of studies have evaluated participants' understanding of the separate visual elements in locally designed pictures (Dowes & Ehlers, 2004; Carstens et al., 2006; Dowes et al., 2011), and I now discuss these with reference to these categories.

2.3.3 Representations of everyday objects and actions

Carstens et al. (2006) evaluated the comprehension of 14 pictures that were incorporated in ART instructions by literate and non-literate participants from South Africa, of which some examples are given in Figure 2.5. They found that representations of everyday objects such as a bed, food and cigarettes were easily recognised. This was also true for pictures that included familiar objects or actions from medical settings; for example, the action of ‘place drops in the ear’ was easily understood. In contrast however, representations of analogous elements that were designed to communicate instructional messages were more likely to be misunderstood. For example, a clock showing the time of 2 pm (Figure 2.5 (i)) that was intended to communicate ‘take your pills at the same time everyday' was misunderstood as meaning 'take your pills at precisely 2 p.m. every day' among both the literate and illiterate groups (73.3% and 91.7% respectively).

Similarly, Dowes & Ehlers (2004) tested a locally produced pictogram (Figure 2.5(ii)) that included an arrow designed to instruct women to 'insert (medication) into the vagina'. The pictogram was understood by 63% of low literate and 67% of literate respondents, however interpretation from those who misunderstood its meaning included, 'take your pills when your pregnant', the medicine makes you urinate often' and it represented ' a woman with a painful leg'. Carstens et al. (2006) showed that an illustration of two people designed to represent a patient being counselled by a health practitioner (Figure 2.5(iii)) was interpreted as a husband and wife talking to each other.

These studies show that the individual visual elements that are incorporated into picture designs (including pictograms) are often misinterpreted. Although the studies tested the comprehension of pictures without supporting text, they nevertheless offer an important insight into the complexity of picture development, even when the design process includes the participation of local people (Dowes & Ehlers, 2004; Carstens et al., 2006; Dowes et al., 2011). Findings show that pictures are not viewed as one unified image, but rather as a collection of elements that may result in interpretations that are denotative, connotative or a combination of both.

2.3.4 Metaphorical symbols

Metaphorical symbols are often included within pictures to represent ideas, concepts, objects, persons and places (Leeuwen, 2008:100). However, some symbols are difficult to interpret (Carstens et al., 2006; Dowes et al., 2011). Carstens et al. (2006) showed that the symbol of a monster (Figure 2.5(iv)), used to represent the danger of AIDS, was recognized by only 16% of respondents. The most popular interpretation was that it represented sickness (a germ or bacteria or virus) or danger. In the same study the symbol of a balloon (Figure 2.5(v)), which was intended to represent a person's speech or thoughts, was misinterpreted as meaning a 'closed space' and a sign of 'togetherness', indicating that the people in the balloon were 'contained by it'.

Figure 2.5: Pictures that were incorporated in ART instructions reproduced from Carstens et al. (2006)

Fig. 2.5 (i). Picture showing a clock at 2.pm (Carstens, Maes & Gangla-Biri, 2006).

Fig. 2.5 (ii). Picture representing how to insert medication into the vagina (Dowes and Ehlers, 2004).

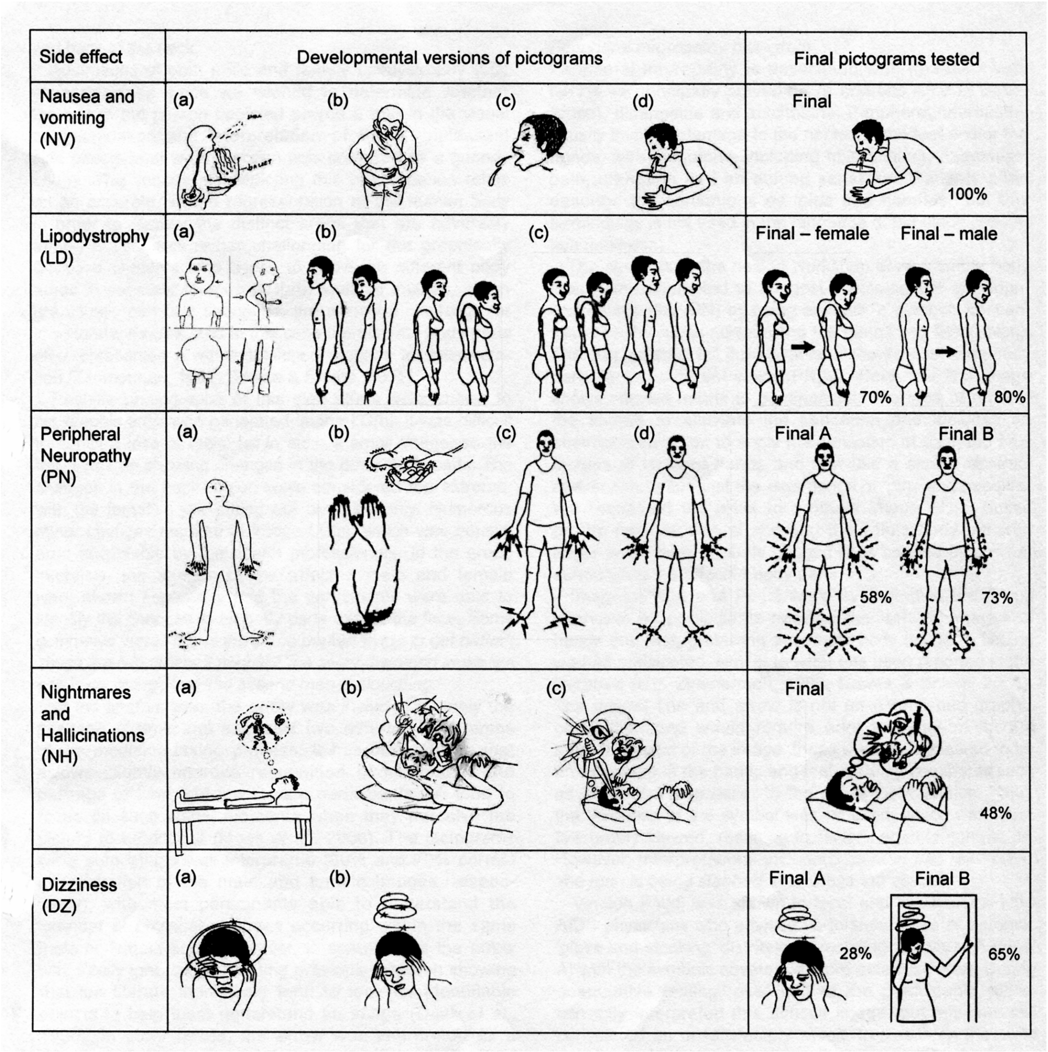
Fig. 2.5 (iii). Picture representing a patient being counselled by a health practitioner (Carstens, Maes & Gangla-Biri, 2006).

Fig. 2.5 (iv). Picture showing a monster designed to represent the danger of AIDS (Carstens, Maes & Gangla-Biri, (2006).

Fig. 2.5(v). Picture showing a speech or thought bubble (Carstens, Maes & Gangla-Biri, (2006).

Dowes et al. (2011) found that symbols used to represent ART side effects were also misinterpreted. They developed and evaluated a series of locally produced pictures with input from students, a pharmacist and illustrator, among 40 low-literate Xhosa speaking adult South Africans (Figure 2.6). Several pictures were presented during focus groups and then modified successively according to the ensuing discussion. The study found that the abstract elements incorporated in the pictures were particularly difficult to understand. For example, an image including metaphorical symbols of an eye, knife, explosion and a menacing-looking animal contained in a bubble placed above a sleeping person’s head, which was intended to represent a person having a bad dream was misunderstood by more than half the participants. Interpretations included ‘this is a dead person’, ‘a person with mental problems’, ‘all of the things happening in the bubble are happening to his eye’ and ‘he has eye problems as his left eye is popping out’ (Dowes et al. 2011:220).

Figure 2.6: Developmental and final versions of pictograms representing side effects in the form of nightmares and hallucinations. Dowes et al. (2010).



2.3.5 Mathematical and alphabetical symbols

Mathematical and alphabetical symbols are often used in medicine instructions, but their meaning is often not understood by low-literate audiences. Dowse and Ehlers (2004) found that the symbol ‘R’, commonly used in the U.S. Pharmacopeial Convention (USP) pictogram conventions to mean ‘medicine’, had no meaning for the study participants. Carstens et al. (2006) also found that mathematical and alphabetical symbols were often misinterpreted by participants. For example only one participant understood that the symbols ‘+’ and ‘=’ were intended to mean ‘unite’ and ‘product of’.

2.4 Conclusions

Multi-media medicine instructions that combine pictures and verbal (written or spoken) explanations have been shown to achieve a higher level of comprehension, especially among non and low-literate populations, compared to instructions using pictures or verbal explanations alone. However designing pictograms and pictures for multi-media instructions is a complex process, and although there are a number of international bodies that provide pre-designed pictograms for general use, they are of limited effectiveness among non-western populations. Engaging local community members in the design process improves comprehension among low-literate audiences but it remains a challenge to achieve the ANSI 85% comprehension criterion across a range of images that are typically included in medicine instructions. Based on these findings, a number of the studies recommend that medicine instructions should be presented using spoken instruction during consultation sessions, ensuring that patients fully understand them (Dowse & Eshers, 2004; Mansoor & Dowse, 2006; Mwingira & Dowse, 2006; Dowse et al., 2011). These recommendations are consistent with Mayer’s theory of Cognitive Multi-Media Learning that recommends that people learn more deeply when complex instructions are presented using spoken words and pictures in comparison to printed words and pictures alone (Mayer, 2009: 201-203).

Only three studies described above have confirmed that multi-media instructions can improve comprehension and short-term adherence to antibiotics. Currently there are no longitudinal studies that have explored the impact of multi-media instructions for long term ART that are published in English language.

CHAPTER 3: YOUNG PEOPLE AND THE CHALLENGE OF ART ADHERENCE

3.1 Introduction

In this chapter I examine the challenges that young people experience when they are faced with the need to adhere to the rigorous and unforgiving demands of ART. I begin by defining adherence, and describe how adherence is measured and what optimal adherence to ART means. I then explore the literature that identified barriers to adherence among young people. Finally I discuss the literature on youth-centred interventions intended to improve ART adherence.

The chapter is informed by a literature search using the UCT search engine “Primo” covering the period of 1999 – 2016, with the key words “adherence”, “ART”, “antiretrovirals”, and “ART” in combination with “youth”, “young people”, “teenagers” and “adolescents”. This period was chosen because it was the period when ART became widely available. The search produced a total of 358 papers, which were distilled down to 98 after reading titles and abstracts and then to a final group of 27 that reported research specifically on ART adherence and young people. Studies were considered eligible for inclusion because they evaluated barriers or facilitators to ART adherence and focused on 14- to 16- year-olds (or younger if they included perinatally infected young people).

3.2 Adherence

In 2003 the World Health Organisation (WHO) published its report on adherence, which to date remains the organisation’s main guidance document. The report defines adherence as “the extent to which a person’s behaviour – taking medication, following a diet and / or executing lifestyle changes - corresponds with agreed recommendations from a health care provider” (2003:3) [*]. The same report estimates

---

[*] To help support patients who are prescribed medicines for long-term chronic conditions clinicians sometimes adopt a collaborative approach to adherence, known as “concordance”. According to Horn et al. (2005), whilst concordance is acknowledged as an alternate term to adherence, the interchangeability has caused confusion.

that only 50% of people who live with a chronic illness in high-income countries adhere properly to their prescribed medicines. Adherence levels in low-income countries are considerably lower; for example reporting that only 26%-43% of patients among these populations who are prescribed antihypertensive medicines achieve long-term adherence. Adherence to antiretroviral medicines for the treatment of HIV also remains a challenge, with compliance rates reported to be between 37% and 83% worldwide (2003:7).

The WHO predicts that by 2020 chronic illnesses, including HIV, will exceed 65% of the worldwide burden of diseases and that poor adherence will become an increasingly serious health concern. A recent UNAIDS report (2013) echoes the same concerns, reporting that although ART offers a “powerful force for saving lives”, only half the current worldwide HIV population have access to ART. For those who are on treatment the report underlines the urgent need to improve adherence outcomes.

3.2.1 Measuring adherence

Measuring adherence involves a variety of approaches that employ both subjective (indirect) and objective (direct) methods. Subjective methods include providers’ and patients’ feedback; the use of questionnaires, patient diaries and “pill counting”, and electronic innovations such as pill bottle lids that record pill use every time they are removed. Objective methods include direct observation of a patient taking their tablets every day (known as Directly Observed Therapy (DOT) and measurement of adherence markers in urine or blood samples (Farmer, 1999; Garber et al., 2004; Osterburg et al., 2005; Gaur et al., 2010).

Both objective and subjective methods, however, have been reported to be problematic. For example, health providers have been shown to exaggerate patients’ adherence when reporting outcomes and questionnaires have been shown to be problematic for the same reason (Osterburg et al., 2005). Counting remaining doses during patients’ visits to the clinic is susceptible to counting inaccuracies, which may result in over-optimistic assessments of adherence (Osterburg et al., 2005). The

---

They recommend that the term “adherence” best describes patients’ medicine-taking behaviour.

WHO report challenges these strategies because they fail to capture both the timings and the patterns of missed doses, which is crucial to any intervention that seeks to measure adherence (2003:4-5). Pharmacy databases are also used to measure adherence, but this method is also problematic, as refill prescription data do not indicate whether the collected medicines are taken by the patient as required.

Objective approaches to measurement of adherence are not without their challenges either (WHO, 2003). Markers in blood or urine samples can be influenced by diet, absorption and rate of excretion. In conclusion, the report notes that no one method is truly effective in measuring adherence, and suggests that “the current state-of-the-art in measurement of adherence behaviour” is a multi-method framework that includes both self-reporting and an objective approach (2003:4).

3.2.2 Optimal Adherence to ART

Achieving optimal adherence to ART is essential for people who live with HIV / AIDS. The treatment minimises the risk of opportunistic diseases, reduces the viral load to “undetectable” levels and improves general well-being (Roberts, 2005). The treatment consists of the daily ingestion of one to three pills, depending on the prescribed therapy (WHO, 2013). Although the medicines are powerful and effective, they do not eradicate the virus completely; low levels remain in small reservoirs within the immune system. Adherence to ART must be nearly perfect (between 90-95%) if a person is to maintain an undetectable viral load, making it one of the most complicated and demanding medicine regimes prescribed (WHO, 2013).

3.3 Young people and the barriers to ART adherence

Adolescents and young adults who live with HIV often struggle with maintaining optimal adherence to their ART (Kim et al., 2014). Based on the literature reviewed, I identified seven groups of factors that constitute the main challenges to ART adherence among young people. They are difficulties in taking the medication itself (Belzer et al., 1999; Murphy et al., 2001; Martinez et al., 2000; Lyon et al., 2003; Comulada, Dallas & Swendeman, 2003; Hosek, Harper & Domanico., 2005; Veinot et al., 2006; Rao et al., 2007; Merzel et al., 2008; MacDonell et al., 2013);

difficulties in managing the ART regime (Belzer et al., 1999; Lyon et al., 2003; Hosek, Harper & Domanico., 2005; Veinot et al., 2006; Williams et al., 2006; Merzel et al., 2008; Vijayan et al., 2009; Calabrese et al., 2012; Chandwani et al., 2012; Dima, 2013); engaging in risk behaviours (Rao et al., 2007; Rudy et al., 2009); psychological distress (Murphy et al., 2001; Lyon et al., 2003; Abadia-Barrero et al., 2006; Williams et al., 2006; Lam, Narr-King & Wright, 2007; Rao et al., 2007; Chandawani et al., 2012; Dima et al., 2013), stigma (Hosek, Harper & Domanico., 2005; Veinot et al., 2006; Rao et al., 2007; Abramowitz et al., 2009; Vivayan et al., 2009); structural barriers (Martinez et al., 2000; Johnson et al., 2003; Rudy et al., 2009), and access to treatment information (Martinez et al., 2000; Lyon et al., 2003; Hosek, Harper & Domanico., 2005; Veinot et al., 2006; Murphy et al., 2010). I will now explore each of them in further detail (see Table 3.1 for a summary of the studies cited).

3.3.1 Difficulties taking medication

Side effects, the taste of pills, their size and quantity all contribute to difficulties that young people experience in taking their medication. A number of studies found that whilst the quantity and/or the taste of pills were reasons for non-adherence in some cases, side effects were by far the most common reason for missing doses among young people (Belzer et al., 1999; Comulada, Dallas & Swendeman, 2003; Lyon et al., 2003; Hosek, Harper & Domanico., 2005). Side effects can result from a person's response to the toxicity of the medication (The South African ART Guidelines, 2014). The majority of ART side effects are temporary and they are usually experienced in the early stages of treatment; they include nausea and vomiting, dizziness, vivid dreams, rashes and headaches. Others are longer lasting, such as lipodystrophy and neuropathy (Veinot et al., 2006).

Table 3.1 Studies that have identified barriers to ART adherence among young people

Reference	Location	Population	Study purpose	Study method	Barriers to ART
Belzer et al., 1999	USA	31 young people aged 13 to 24	To explore the barriers to ART adherence	Survey	• Pill quantity • Side effects Fear of disclosure/stigma • Difficulty managing pill regime • Forgetting • Depression
Martinez et al., 2000	USA	32 young people aged 13 to 21	To investigate ART adherence among young people who were engaged in an adolescent and young adult health care clinic.	Retrospective analysis of adherence using medical records	• Housing instability • Pill quantity • Access to treatment information
Murphy et al., 2001	USA	161 young people aged 13 to 18	To investigate ART adherence among young people who were attending the REACH (Reaching for Excellence in Adolescent Care and Health) across 13 cities in the USA.	Computer and face to face interviews	• Depression • Pill identification • Sleep disturbance
Comulada, Dallas and Swendeman, 2003	USA	253 young people aged 14 to 29	To examine ART adherence	Computer assisted interviews	• Pill quantity • Side effects • Cost of medication
Johnson et al., 2003	USA	107 young people aged 15 to 25	To examine components required for effective care that supports	Questionnaire and interviews	• Unstable housing • Food insecurity • Lack of childcare support

			adherence among young people who live with HIV		- Transport to clinics - Cost of medication
Lyon et al., 2003	USA	23 young people aged 15 to 22	To evaluate a family group intervention aimed at increasing ART adherence among young people	Focus groups	- Size of pills - The taste of pills - Side effects - Pill quantity - Forgetting - Depression - Access to treatment information
Hosek, Harper & Domanico, 2005	USA	42 young people aged 15 to 25	To examine ART adherence among adolescents and young people	One hour interview	- Forgetting - Falling asleep - Didn't have medication with them - Difficulty managing pill regime - Fear of disclosure/stigma - The taste of pills - Side effects - Pill quantity - Access to treatment information
Abadia-Barrero & Castro et al., 2006	Brazil	50 children and adolescents aged 1 to 15	To explore the experiences of stigma and access to ART among young people	Ethnographic interviews	- Stigma
Veinot et al., 2006	Canada	34 young people aged 12 to 24	To explore young people's perceptions of ART	Semi-structured interviews and survey	- Access to treatment information - Feeling that they had no choice to take medicines - Difficulty managing pill regime - Side effects/Fear of side effects - Forgetting - Fear of disclosure/stigma

Williams et al., 2006	USA	2088 perinatally infected children and young people aged 3 to 18	To examine the predictors of ART adherence in children and adolescents	Observation and questionnaire	• Handing over responsibility of managing adherence too early to young adolescents • Treatment fatigue • Depression
Rao et al., 2007	USA	25 young people aged 17 to 25	To identify the barriers to ART adherence	Focus groups	• Fear of disclosure/stigma • Side effects • Pill quantity/size • Forgetting • Deppression
Lam, Narr-King & Wright, 2007	USA	66 young people aged 16 to 25	To examine social support and disclosure as predictors of mental health	Questionnaire	• Low levels of social support were related to higher incidents of depression - although no link to effect on adherence was found
Merzel et al, 2008	USA	31 perinatally infected young people (16 were under 10 years old and 15 were aged between 10 and 16), 15 parents and 9 clinicians	To examine the psychosocial factors associated with adherence among young people	Open-ended interviews	• Regime fatigue • Resistance to taking medication • Missing doses • Difficulties managing pill regime
Abramowitz et al, 2009	USA	166 young people aged 13 to 21	To examine the nature, type, and source of social support and impact on depression	In-depth interviews	• Lack of psychological support, especially from a person's family

Rudy et al, 2009	USA	396 young people aged 12 to 24	To examine the barriers to ART adherence among young people	Observation	• Depression • Substance abuse • Unstable housing • No health insurance
Vivayan et al, 2009	USA	30 caregivers of perinatally infected young people aged 10 to 16	To examine the transitioning of care of perinatally infected young people to adult services and the impact on adherence	In-depth interviews	• Fear of disclosure/stigma • Difficulty managing pill regime
Chandwani et al, 2012	USA	104 young people aged 13 to 17	To examine the predictors of ART adherence among adolescents	Computer and face to face interviews	• Fear of disclosure/stigma • Depression • Difficulty managing pill regime
Calabrese et al, 2012	USA	25 perinatally infected young people aged 11 to 18	To examine non-adherent behaviours among perinatally infected children and adolescents		• Difficulty managing pill regime • Forgetting • Being ill (related to AIDS)
MacDonell et al, 2013	USA	186 young people aged 16 to 24	To examine non-adherent behaviours among young people	Computer-assisted personal interviews	• Side effects/Fear of side effects • Forgetting • Pill times clashing with social schedules
Dima et al, 2013	Romania	184 young people aged 18 to 25	To explore the barriers to ART adherence		• Side effects • Depression • Difficulty managing pill regime

Eight studies showed that young people missed doses because they had *actually* suffered side effects, although they did not indicate if these were only experienced during the early stages of taking ART or on the long term (Belzer et al., 1999; Comulada, Dallas & Swendeman, 2003; Lyon et al., 2003; Hosek, Harper & Domanico., 2005; Veinot et al., 2006; Rao et al., 2007; Dima et al., 2013; MacDonell et al., 2013). Two of these studies also reported that the *fear* of side effects caused young people to worry about taking their medications prior to starting ART (Veinot et al., 2006; MacDonell et al., 2013). A number of these studies indicated that despite experiencing side effects many young people persisted with their medication (Hosek, Harper & Domanico., 2005; Rao et al., 2007; MacDonell et al., 2013). None of the studies, however, looked directly at whether treatment knowledge affected the level of concern about side effects and the likelihood that people would continue to take their medication.

3.3.2 Difficulties with managing regime

According to Blos (1979:412), adolescence is marked by the active pursuit of psychological and functional separation as young people discard prior family dependencies and begin to manage and direct their daily and personal affairs without interference from their parents or carers. This transition toward functional independence can be problematic for those who live with HIV as they begin to integrate the strict demands of ART into their daily routines (Hosek, Harper & Domanico., 2005; Williams et al., 2006; Merzel et al., 2008; Rudy et al., 2009; Vijanen et al., 2009; Calabrese et al., 2012; Chandwani et al., 2012). This was particularly evident in studies that explored the transition of perinatally infected young people, who during the early stages of adolescence want to take responsibility for their adherence from their parents/carers (Williams et al., 2006; Merzel et al., 2008). Findings from these two studies showed that 12- to 16-year-old adolescents who had been given overall responsibility for their ART routine achieved lower levels of adherence than those who remained under close monitoring from a parent or caregiver. Treatment fatigue (becoming tired of having to take medicines regularly every day at similar times) was cited as the main challenge. Both of these studies recommend that careful attention and preparation should be considered during this transitional phase, especially in the context of neuroscience research that shows that cognitive abilities connected to logical reasoning and basic information-processing only begin to reach maturity at the age of 16 (Steinberg, 2008).

Whilst these findings offer important insight into the challenges of transitioning adherence among perinatally infected adolescents, they were conducted in the USA where there is no epidemic. Also, in the USA there is a well-resourced social support system including both adoption and foster parent schemes for children and adolescents who are born with HIV. In contrast, South Africa continues to suffer from one of the world's most severe HIV / AIDS epidemics, with an estimated 390,000 people up to the age of 14 and 867,000 between the ages of 16 and 24 affected, of whom the majority live in low-resourced settings (UNAIDS, 2013). UNICEF (2014) estimates that 150,000 of these young people live in child-headed homes and have lost parents to AIDS. They are often required to take on domestic responsibility, looking after siblings and caring for a sick or dying parent. For some, homelessness, begging on the streets or seeking food is part of daily living (UNICEF, 2014). Although the government is currently engaged in an ambitious national roll-out of ART throughout South Africa, supporting these young adolescents to properly adhere to ART offers its own set of unique challenges.

3.3.3 Risk behaviours

Adolescence is a period of intense physical change and growth when young people become acutely aware of their bodies and their sexual drive, opening the door to new possibilities of exploration, and leading them to seek pleasurable physical sensations (Kohlberg & Gilligan, 1971). During puberty there is a significant increase of gonadal hormones, increasing sexual drive and the desire to seek sexual pleasure. Simultaneously, adolescents experience significant changes in the brain's dopaminergic system, which provides the neuro-pathways that process pleasure and reward (Steinberg, 2008). According to Loevinger (1993, cited in Kroger, 2009) it is during this developmental phase that adolescents become focused solely on the present, leading them to make decisions in which "past or future are not of any immediate value, for what they bring is not happening now" (2009:129).

Most pleasure-seeking behaviour occurs as adolescents meet together in their peer groups, often experimenting with alcohol and recreational drugs. Three studies identified the latter as reasons why young people either forgot to take their pills or slept through their dose time (Hosek, Harper and Domanico, 2005; Veinot et al., 2006; Chandawani et al., 2012). Although the findings from these studies are helpful, they did not explore whether the reason for substance abuse was to seek pleasure only, or whether it was due to addictive behaviour underlain by wider and more complex reasons. According to Steinberg (2008), many adolescents find pleasure from risk behaviours over a relatively short period of time, moderating their behaviour as they begin to recognise the associated potential consequences. For others, pleasure found through substance abuse may become habitual because the induced feelings of pleasure help them to block trauma and depression. Wilde et al. (2004) argue that risk behaviour is strongly associated with low self-esteem among adolescents who have experienced self-rejection from their family and close peer group, increasing the likelihood that they will engage with delinquent peer groups where risk behaviours are central to codes of belonging. Similarly, Richter argues that adolescents who come from unstable homes have often not developed sufficient coping mechanisms, and when confronted with psychological stress are vulnerable to adopting risk behaviours that become an alternative way of coping (2010:28). It is within this context that young people who suffer from a low sense of self-worth as a result of stigmatisation and rejection may become particularly vulnerable to risk-taking behaviours.

3.3.4 Psychological distress

Psychological distress among young people who live with HIV is shown to be one of the most significant barriers to ART adherence (WHO, 2003:99). Depressive symptoms cited in the literature include tiredness, sleep disturbance, lack of hope, decreased motivation, problems with memory and concentration, negative feelings of worthlessness and hopelessness, and isolation, all of which are known to directly impact a young person's motivation and ability to maintain effective adherence (Belzer et al., 1999; Murphy et al., 2001; Lyon et al., 2003; William et al., 2006; Lam, Narr-King & Wright, 2007; Rao et al., 2007; Chandwani et al., 2012: Dima et al., 2013). The three studies cited identified that the main reasons for non-adherence among depressed young people was missing or forgetting to take their pills and not being able to correctly identify them. The above studies did not explore the wider contexts that may have contributed to the depressive symptoms. In contrast, however, several studies in the USA have been able to identify factors contributing to depressive illness amongst participants. Battles and Wiener (2002) showed a significant association between depression and anxiety and the loss of a family member or close friend to AIDS among perinatally infected young people. Lam, Naar-King and Wright (2007) identified social isolation due to non-disclosure as a factor contributing to depression for 50% of 16- to 25-year-old participants. However the authors acknowledge that because participants were gay, lesbian or bisexual, fear of homophobia may have been a contributing factor underlying non-disclosure. Homelessness, limited access to transport for travel to health providers, problems related to school and having to take care of children were also identified by Rudy et al. (2009) as contributing stressors leading to depression among young people.

Whilst these studies identified the broader contexts that contributed to depression among the participants, it is important to recognise that they were conducted in the USA where the socio-economic context and experience of HIV are quite different to that of the majority of people who live with HIV in South Africa. In South Africa there is a high prevalence of depression, post-traumatic stress disorder (PTSD) and suicidal ideation among the population who live with HIV. This is attributed to having been badly injured, raped, having suffered a serious physical attack, been threatened with a weapon or held captive or kidnapped, or having had been involved in a flood or fire (Olley, 2006; Martin & Kagee, 2011). Both of the studies cited offer a significant insight into the localised contexts that contribute to depression and PTSD among those who live with HIV in South Africa, but they did not explore the association between depression and ART adherence. Also, although they included young adults among their cohort, they were not youth-focused. In the context of this study, given that Khayelitsha has one of the highest recorded levels of violent crimes in South Africa, including murder, sexual crimes, assault and robbery (Khayelitsha

Commission of Inquiry, 2014), it is likely that psychological distress may be a significant barrier to ART adherence among young people.

3.3.5 Stigma

Goffman (1963:14) describes "stigma" as "an attribute that is deeply discrediting", that reduces the bearer "from a whole and usual person to a tainted, discounted one". According to Wilkinson, (2001) adolescence is a time of consolidation – "a stabilizing of sexual identity into an irreversible pattern, establishing firm representations of self and others, and developing a greater sense of autonomy" (Kroger, 2009:68). During this process, adolescents often suffer from a heightened level of self-consciousness, together with low self-esteem. They begin to seek positive evaluation from peer group members, and this can become one of the main sources of receiving and feeling self-worth (Simmons, Rosenburg & Rosenburg, 1973). It is within this context that young people who live with HIV feel particularly vulnerable to rejection and discrimination from family members, friends or peers (Belzer et al., 1999; Hosek, Harper & Domanico., 2005; Veinot et al., 2006; Rao et al., 2007; Vivayen et al., 2009; Chandwani et al., 2012).

The literature describes three aspects of stigma that are experienced by people who live with HIV:

- Experienced stigma, where a person is rejected or discriminated against because they are HIV positive (Simbayi et al., 2007).
- Internalised stigma that results in a person feeling shame and self-blame (Gilbert & Walker, 2010).
- Felt stigma where people fear discrimination from others (Scambler, 2004).

Rao et al. (2007) reported that young people had actually experienced either discrimination or rejection from family or friends because of their HIV status, but did not report any direct association between stigma and adherence behaviour. The majority of studies report that young peoples' *fear* of stigma, rather than *experienced* discrimination and rejection, was the main cause of behaviours that prevent optimal adherence to ART. Several studies report that fear of discrimination caused young people to hide their medicines from others and deliberately not take them to sleepovers or parties (Veinot et al., 2006; Lam, Naar-King & Wright 2007; Rao et al., 2007). Non – disclosure due to the fear of stigma causes young people to feel isolated and lonely, leaving them particularly vulnerable to depression (Rao et al., 2007; MacDonell et al., 2010). Studies that focus on perinatally infected young people all report the fear of stigma as a major barrier to disclosure. Abramowitz et al. (2007) discuss how the perceived fear of stigma felt by the parents of perinatally infected young people caused the young people to remain closed about their status because of the risk of disclosing their parents' status – something that they define as "double disclosure" - which leaves them feeling socially isolated and vulnerable to depression. The literature suggests that these younger adolescents are particularly vulnerable to the fear of stigmatisation that becomes internalised at an early age, for example not wanting to take medication because the pills themselves remind them of their status (Belzer et al., 1999; Veinot et al., 2006).

Stigma is a complex phenomenon where persons who live with a stigmatised disease experience discrimination not only from non-infected community members. Abadia-Barrero et al. (2006) examined the impact of stigma on a group of children and young people who were living in two HIV care homes located in a poor community in Sao Paulo, Brazil. They found that new arrivals to the homes suffered stigmatisation from their peers because of their emaciated physical appearance – something that is typical of the late stages of untreated AIDS. As they began treatment and became physically well, they no longer experienced discrimination from their peers. For these young people, taking ART was not only about recovering from illness, but was also motivated by the desire to receive social acceptance from their peer group (Abadia-Barrero et al., 2006).

Studies conducted in South Africa show that people who live with HIV frequently experience discrimination (Kalichman & Simbayi, 2003; Deacon, Stephany, & Prosaledic, 2005; Kalichman et al., 2005; Wingwood et al., 2008). Kalichman et al. (2005) conducted a survey in local townships near Cape Town and found that community members believed that people living with HIV should not be allowed to work with children, and should have restrictions placed on their freedom. Simbayi et al. (2007) found that 40% of 1063 study participants who regularly attended HIV health clinics in the Cape Town district had experienced HIV-related discrimination, and one in five had been made to leave home or had lost a job. Over a third of participants described feeling dirty, ashamed, or guilty because of their HIV status, and overall, 30% reported depressive symptoms that were associated with stigmatisation. None of the studies, however, examined the impact of stigma on ART adherence among young people.

3.3.6 Structural barriers to ART adherence

Structural barriers that make it difficult for people to access health care, especially homelessness, unstable housing and remoteness from clinics, have been shown to influence their ability to comply with their ART regimes (Nachega et al., 2005 Nachega et al., 2006; Kagee et al., 2011; Nel & Kagee, 2013). Unstable housing was shown to disrupt young peoples' attendance at clinics in the USA, because of travelling complications (Martinez et al., 2000; Johnson et al., 2003; Rudy et al., 2009). This was particularly evident when young people had to move into a new area, resulting in them either having to change clinics or travel long distances to their original health care provider. The move disrupted education or work commitments that challenged their ability to attend clinical appointments (Martinez et al., 2000).

Rudy et al. (2009) also reported in a U.S. study that unemployment among young people affected their ability to afford the medical insurance needed for health care and medication, stating that although health care insurance grants were often available, they found it difficult to navigate the bureaucracy required to access them. Young people also reportedly found it difficult to complete prescriptions and manage clinic appointments, especially when the latter clashed with school or work commitments.

In South Africa, three studies that were carried out in the Western Cape (among adults) have identified specific structural barriers to HIV health care (Nachega et al., 2006; Peterson et al., 2010; Coetzee et al., 2011). Barriers identified that affected adherence included food insecurity (patients were reported not to want to take their medication on an empty stomach, and therefore they missed doses when they did not have enough to eat) and lack of money for travelling to clinics to collect medicines

(Nachega et al., 2006; Peterson et al., 2010). These findings were confirmed by Coetzee et al. (2011) who also found that patients reported deliberately not taking their medication in order to maintain a low CD4 count, so that they could re-qualify for a grant that is issued to patients whose CD4 count is below 200. Clinicians noted that many people who live in the townships in the Western Cape travelled regularly to meet family members, especially for funerals, and were unable to access health services whilst away from home because they didn't obtain the letters of transfer that were required by the health authority.

3.3.7 Access to treatment information

Young people who find it difficult to access treatment information, or understand the available information, often develop misconceptions and scepticism about ART (Martinez et al., 2000; Lyon et al, 2003; Veinot et al., 2006). One key factor in accessing and understanding treatment information is health literacy. According to WHO, health literacy is essential to a person's on-going health and wellbeing and is defined as their ability to "gain access to, understand, appraise and apply health information in order to make judgements and take decisions in everyday life concerning health care, disease prevention and health promotion to maintain or improve quality of life during the life course" (WHO, 2013:3). The main tools for measuring health literacy focus on word recognition. The Rapid Estimate of Adult Literacy in Medicine (REALM) tests a person's ability to recognise 66 medical terms, whilst the Test of Functional Health Literacy in Adults (TOFHLA) tests a person's numeracy and their ability to read and comprehend sections of health-related texts. Both tests are reliant upon the participants' education, and they are applied mostly to people that have accessed on-going education. Murphy et al. (2010) used the TOFHLA test to examine the relationship between functional literacy (the ability to read or write simple sentences) and adherence among 186 16- to 24-year-olds who attended HIV / AIDS clinics across five U.S. cities, and found that 85% of participants achieved adequate functional literacy. However, although health literacy was associated with higher levels of access to health care, it did not influence ART adherence. It should be noted, however, that this study's measure of adherence was subjective (the use of a self-administered questionnaire) and was restricted to a relatively short period of time.

Although several studies exploring barriers to ART adherence recognise that low levels of health literacy exist among the research communities, no studies have focused on the relationship between health literacy and ART adherence among adolescents and young people in South Africa. This may be because there is recognition that many young South Africans within the Township populations have low levels of literacy, and that using the REALM and TOFHLA tools would provide relatively predictable data. Although, as discussed in the previous chapter, researchers have explored the use of pictograms in helping low literate audiences in South Africa to understand medicine instructions.

3.4 Youth-centred interventions designed to improve ART adherence

I now turn to the literature on interventions that are designed to improve adherence among young people who live with HIV. Only nine studies describing such interventions were identified during the literature review (see table 3.2 for study summaries). The interventions fell within three categories: Directly Observed Therapy (DOT), cell phone reminders and treatment education.

Table 3.2 Summary of studies that have explored interventions designed to support ART adherence among young people

Reference	**Location**	**Population**	**Study purpose**	**Study method**	**Barriers to ART**
Rogers et al., 2001	USA	65 young people (average age 18)	The evaluation of a family group intervention aimed at increasing ART adherence among young people	Questionnaire / evaluation form	• 18 completed the full programme
Lyon et al., 2003	USA	23 young people aged 15 to 22	The evaluation of a pilot family group educational intervention aimed at increasing ART adherence among young people	Focus Groups	18 completed the pilot intervention, of which 9 reported improved adherence to ART
Puccio et al., 2006	USA	Eight young people aged 16 to 24	To explore the impact of cell phone reminder calls (Pilot Study)	Retrospective analysis of adherence using medical records	• Tapered call reminders over limited period provided insufficient support to adherence
Glikman et al., 2007	USA	Nine perinatally infected young people aged 7 to 17	To examine the efficacy of a hospital based DOT adherence intervention for young people	Adherence measured from medical records	• Short, hospital-based DOT achieved lower viral load among eight of the participants
Garvie et al., 2009	USA	17 young people aged 16 to 25	To design and test the feasibility and acceptability of a DOT intervention	Focus Groups	Recommendations based on young people's responses included that the DOT provider should be familiar and empathetic, and communication should be available between provider and young people – preferably via mobile phone
Gaur et al., 2010	USA	20 young people aged 17 to 22	To evaluate a 6-month DOT intervention	Survey/interview. Adherence measured via viral load from medical records	• Only half the participants sustained adherence after 12 weeks. Only six maintained optimal adherence over 24 weeks.

Dowshen et al., 2012	USA	25 young people aged 14 to 29	To evaluate the feasibility, acceptability and efficacy of short message service (SMS) reminders to improve adherence among young people over a 24-week period	Questionnaire and text response to confirm adherence.	• Participants indicated that the intervention helped them to miss fewer doses, and that they would like to continue receiving reminder SMS's
Shegog et al., 2012	USA	10 young people aged 14 to 22)	To evaluate a pilot of a web-based ART adherence intervention	Computer based questionnaire and observation	• Participants reported that the program was easy to use. Limited findings
Thurston et al., 2014	USA	2 young people	To evaluate the usability of an educational intervention ("Positive Steps") designed to address barriers to ART adherence	Case studies	• Respondents found the programme helpful but no findings related to adherence

Three studies reported that DOT interventions were a successful method that improved adherence among adolescents and young people, although only over short periods of time. Glikman et al. (2007) found DOT to be successful during the study periods, but soon after the intervention ended, patients regressed to previous non-adherent behaviours. These findings were confirmed by Gaur et al. (2010), who reported that only half the participants sustained optimal adherence after the programme had ended. Thus whilst these studies show that adolescents and young people achieve optimal adherence during a DOT intervention, DOT has not yet been proven to equip or motivate young people to maintain ART adherence over the long term. It is important to note that all of these studies were conducted in health facilities in the USA that can offer the resources that DOT requires. The use of DOT during the ART roll-out among the youth population in South Africa is unlikely, due to limited resources for health care provision and the enormous numbers of young people who live with HIV.

Cell phone reminders have been shown to offer a significant contribution to adherence among young people. Two studies (Puccio et al., 2006 and Dowshen et al., 2012) explored whether cell phone reminders would help train young people to maintain long-term adherence. Findings showed that whilst participants found the reminder calls helpful, they continued to struggle with adherence once the programme was completed. Receiving a reminder text message when socialising was reported as a barrier to adherence, because the message might disclose their HIV-positive status to friends (Dowshen et al., 2012). Furthermore, these interventions rely upon the young person’s ability to afford a phone and the airtime contract that is required to receive calls / texts. Even if they have the money, unemployed young people in communities such as Khayelitsha are often unable to obtain a monthly airtime contract because they do not have the required proof of employment. Most often young people use pay as you go airtime options because they are cheaper. These options, however, require ‘top up’ payments that may result in periods of time when the phone is not in use.

Although the most common recommendation in the literature was for the development of youth-specific educational interventions designed to enhance adherence outcomes, only four pilot studies of such interventions were found, all of which were based in the USA. Three of the studies used a variety of visual communication media including video and booklets, although whilst participants expressed that the tools were helpful, findings were inconclusive on the impact that these interventions had on adherence (Rogers et al., 2001; Lyon et al., 2003; Thurnston et al., 2009). A fourth pilot study explored the usability of a web-based training programme (+CLICK) that was designed to enhance ART adherence among young people (Shegog et al., 2012). The programme was effective in helping to increase young people's treatment knowledge; however the impact on adherence was not reported as it was excluded from the research design. In summary, whilst these studies report new innovations designed to improve treatment knowledge among young people, currently they are still in the pilot stages of their design.

3.5 Conclusion

Lifelong adherence to ART among adolescents and young people is influenced by a complex, often interconnected series of psycho-social, economic and structural factors that are dependent on each individual's life experiences and their local contexts. Gaining an understanding of how these factors interface with young people's ability to adhere to their medication in localised settings such as Khayelitsha is crucial in understanding what supports (or prevents) them from taking their ART every day. This confirmed that this study needed to go beyond the dicsiplinary perspectives of visual and health communication alone and incorporate elements from the social sciences.

CHAPTER 4: THEORETICAL APPROACHES TO HEALTH COMMUNICATION

4.1 Introduction

In this chapter I track the main theories, models and approaches used by health communication professionals and researchers to inform health communication strategies. Health communication researchers are generally motivated by the prospect of gaining new insights that can inform the design of health communication intervention, which in turn can help to improve people's health (Glanz et al., 2008:26). An effective communication strategy is crucial to the success of health prevention and education interventions, and should be grounded in sound theory (Airhihenbuwa & Obregon, 2000).

According to Glanz et al. (2008:27), a theory is a set of interrelated concepts, definitions, and propositions that present a systematic view of situations and thus help to explain and predict human behaviour. In the context of health communication research they state:

> "Theories are useful during the various stages of planning, implementing, and evaluating interventions. Programme planners can use theories to shape the pursuit of answers to 'Why?', 'What?', 'How?'. In other words, theories can be used to guide the search for why people are not following public health and medical advice or not caring for themselves in a healthy way."

According to Thompson (2003), the two main social science paradigms used in studies that inform health communication interventions are post-positivism and interpretativism. The majority of early health communication studies were located in the post-positivist tradition, which led to an emphasis on seeking to explain, control and predict variations in health outcomes according to the message content, its application, and measurement of how effective a particular message was to the target audience (Thompson, 2003). Lupton (1994:58) argues that this approach focuses on the ideology of biomedicine, which frames health and sickness within the processes of diagnosis and treatment, objectifying the human body as a “mechanised commodity”. May and Mumby (2005:20) discuss in more detail how the principles of post-positivism have been adopted in communication research. Positivist research, they argue, adheres to the principles of rigorous systematic observation, which focuses on the idea that “phenomena” can only be explained on the basis of natural laws, and therefore any claim to knowledge must be verified through empirical experience. Whilst post-positivism values this rigorous “scientific” approach, there is also an acknowledgement that empirical observation is never entirely “theory free”. May and Mumby (2005: 24) further add that observation is open to interpretations that *“*emerge from the inquirer’s own grounding in a particular time and place*”*. Within the post-positivist paradigm however, these interpretations (or knowledge-claims) are not recognised as valid unless they are rigorously tested and criticized. Typically, this is achieved through a deductive process, using statistical tests that seek to disprove a finding, an existing idea or a theory (Lindlof & Taylor, 2011: 6).

In the main, post-positivist researchers in health communications employ quantitative approaches to explore what kind of specific message content and message delivery help to motivate health-enhancing behaviours. Makoul et al. (1995:1242) comment that this type of research focuses on developing and improving “communication competence”, or good communication practice, and is used to improve clinician-to-patient engagement within health care settings. For example, Inui et al. (1982:536) used a post-positivist approach to examine how successful compliance to prescribed medicine regimes can be influenced by the way in which doctors communicate with their patients. They recorded doctor-patient conversations and then subjected them to interactional analysis (a method used for investigating the interactions between human beings). The results showed that patients were more likely to comply when doctors showed empathy and gave sufficient time to explain the information about the prescribed medicines fully. Other researchers have reported similar findings for physician-patient interactions about prescription medicines (Makoul et al., 1995); between physician and patients in relation to chronic disease (Kaplan et al., 1989), and oncologist/patient interactions during hospital rounds (Blanchard et al., 1983; Waitzkin, 1984; Smith et al., 1991; Street, 1991). Over the past two decades, post-positivist researchers (mostly behavioural scientists) have developed a variety of models based on cognitive theory that are designed to help motivate health change behaviours. I now discuss these in more detail.

4.2 Health behaviour models

Health behaviour models emphasise that human behaviour is influenced by the "beliefs, expectations, motives and perceptions" attributed to a specific behavioural action (Glanz, Rimer & Viswanath, 2008:12). These models focus on the process of "thinking, reasoning, hypothesising and expecting" and seek to shift an individual's thinking so that they value and action behaviours to "actively avoid an illness or prevent (or ameliorate) disease" (Champion & Skinner, 2008:46).

The three types of health behaviour that the models seek to influence are as follows (Karl & Cobb, 1966 cited in Glanz et al., 2008:12):

1. Preventative health behaviour: any activity undertaken by an individual who believes themselves to be healthy, for the purpose of preventing or detecting illnesses in an asymptomatic state.

2. Illness behaviour: any activity undertaken by an individual who perceives themselves to be ill, to define the state of health, and to discover a suitable remedy.

3. Sick-role behaviour: any activity undertaken by an individual who considers themselves to be ill, for the purpose of getting well. It includes receiving treatment from medical providers, involves a whole range of dependent behaviours, and leads to some degree of exemption from one's usual responsibilities.

According to a number of health communication scholars (Airhihenbuwa & Obregon., 2000; Parker, 2004; Zoller and Dutta; 2009) the most popular models within the post- positivist paradigm that are used to inform HIV health communication strategies are the Health Belief Model; the Extended Parallel Process

Model; the Theory of Reasoned Action; the Theory of Planned Behaviour, and Social Cognitive Theory.

4.2.1 The Health Belief Model

The Health Belief Model (HBM) is based on the hypothesis that an individual's health behaviour is determined by (i) the value that they place on a health-related goal, and (ii) their evaluation of whether a particular behavioural action will achieve that goal (Janz & Becker, 1984). Typically, HBM has been used to help identify why individuals take action to prevent, screen or control illness symptomology (Champion & Skinner, 2008:46). Hochman (1958) originally applied the model to the public health concern that very low numbers of people were coming forward for TB screening, which had been made available from mobile X-ray units. He discovered that people's beliefs about their susceptibility to infection and about the perceived benefits of screening directly corresponded with their X-ray uptake.

The HBM has also been applied in a variety of other contexts, including in relation to screening interventions, diabetes, renal failure and hypertension (Becker & Janz, 1985; Bond, Aiken and Somerville, 1992; Roenstock, 1994), as well as HIV prevention interventions (Montgomery et al., 1989; Mattson, 1999).

The Health Belief Model comprises the following main dimensions (Champion & Skinner, 2008:47):

- Perceived susceptibility: how susceptible or vulnerable a person feels to a health condition or illness (their perception of the risk of contracting the condition).
- Perceived severity: how an individual feels about the seriousness of contracting an illness (or not seeking treatment). It includes their evaluation of the potential physical consequences, such as death, disability or pain, and also potentially of the social consequences, such as the impact on their ability to work and on family and social relationships.
- Perceived benefits: the individual's belief in the effectiveness of a health behaviour and whether it will sufficiently reduce the threat of contracting the

disease (or boost the effectiveness of the treatment of the disease). As Janz and Becker (1984:92) state, “a ‘sufficiently threatened’ individual would not be expected to accept the recommended health action unless it was perceived as feasible and efficacious”.

- Perceived barriers: the individual’s evaluation of the potential negative aspects of the health behaviour (for example side effects, pain and inconvenience), which are then weighed against its perceived benefits.

The Health Belief Model argues that perceived susceptibility and perceived severity together motivate a person to enact a health behaviour, framed by the perception of the behaviour’s benefits. Health communication campaigns that are informed by HBM use cues to action designed to engage the intended audience. These usually comprise the symptoms of an illness, messages from media campaigns and / or interpersonal health communications that occur between clinician and patient (Taylor et al., 2007).

4.2.2 The Extended Parallel Process Model

The Extended Parallel Process Model (EPPM) argues that an individual’s perception of a threat (of a specific action or risk) is directly related to their exposure to a threatening message that communicates the associated danger(s). The purpose of generating fear is to concentrate the mind on the extreme negative outcome of a specific action, which then motivates the individual to adhere to a preventative behaviour (Witte, 1992). Fear messages that have been used to motivate behavioural change include the fatal outcomes of not wearing a car seat-belt; cancer that results from smoking; excessive use of alcohol (Witte, 1992; Witte & Allen, 2000); death or injury from drinking and driving (Khon et al., 1982), and dietary messages aimed at lowering cholesterol to avert the risk of cardiac arrest (Maddux & Rogers, 1983).

EPPM employs three key concepts that influence an individual’s appraisal of and response to a health message: perceived threat, perceived efficacy, and fear:

- Perceived threat: If an individual evaluates the communicated threat as real, then the threat elicits enough fear to initiate a behavioural response.

- Perceived efficacy: The efficacy of the behaviour that is required to control the threat is then evaluated.
- Fear: Perceived threat and efficacy cause the fear response, which then becomes the key determinant motivating behaviour to protect or defend the person against the threat.

4.2.3 The Theory of Reasoned Action and the Theory of Planned Behaviour

The Theory of Reasoned Action (TRA) was developed to understand and identify the attitudes and intentions that influence a person's behaviour (Ajzen, 1991). An individual's intention to enact a given behaviour is central to the TRA model. Intention is influenced by an individual's attitude toward the behaviour and subjective norm. Attitude is determined by a person's beliefs about the personal value of the outcome of the performed behaviour. Subjective norm is determined by the level of motivation that is influenced by other people's approval or disapproval of the behaviour, defined as normative beliefs.

Whilst TRA argues that behavioural intention is the central determinant of behaviour, behavioural scientists have recognised that intention is also influenced by factors that facilitate or prevent behavioural performance, such as finance, time and ability/skills (Ajzen, 1991:182). In response "perceived behavioural control" has been added to the model, thus creating the Theory of Planned behaviour (TPB) (Montaño & Kasprzk, 2008:71). Because of the similarities, researchers and health communication practitioners often use an aggregate of components from both of the models. Both models have been used extensively to help understand the determinants of health behaviours and inform health promotion campaigns (Taylor et al., 2007). Some examples include campaigns about HIV prevention and condom use (Albarracin et al., 2001); weight gain prevention and eating behaviour (Baranowski et al., 2003); exercise interventions (Downs et al., 2006), and addiction-related cessation such as adolescent smoking (Hoffman, Sussman & Unger, 2006).

4.2.4 Social Cognitive Theory

Social Cognitive Theory (SCT), initially known as social learning theory, includes both cognitive theory and cognitive functional learning. It posits that information is processed from experience, observation and communication within an individual's social context (McAlister, Perry & Parcel, 2008: 170). Central to SCT is the notion of self-efficacy, which is defined as a person's belief that they have the power to produce the desired changes through their own actions (Bandura, 1998). Self-efficacy is related to both the skills and the motivation required to action a proposed behaviour. Motivation is based upon the goals that an individual attributes to the behaviour together with their determination to reach these goals. Determination must incorporate and help resource the individual's ability to overcome potential obstacles to self-efficacy.

The four main determinants of self-efficacy, according to SCT, are as follows (Bandura 1998):

- Mastery experiences

  Self-efficacy is reinforced by successful outcomes that result from becoming proficient in the performed behaviour. Continued success provides the individual with a confidence in the chosen health behaviour that further strengthens self-efficacy.

- Vicarious experiences

  Seeing others who are facing the same challenges succeed reinforces a person's self-belief that they too can achieve self-efficacy. Bandura (1998) defines this as the modelling influence, where someone who has achieved self-efficacy then teaches others to reach the same outcomes.

- Social persuasion

  Social persuasion can further strengthen a person's belief in the proposed behaviour. Other people (called efficacy builders) can actively support the person through verbal persuasion, encouraging them to master the required actions.

- Stress reduction

  Reducing people's stress reactions helps support self-efficacy. Actively modifying negative emotions and beliefs that could create barriers to success is seen as a crucial factor within the SCT model.

SCT has been used to inform many kinds of health interventions, including interventions to control or lose weight (Perry et al.,1992), promote cancer screening (Ramirez et al.,1999) and promote HIV prevention (Bandura,1990).

4.2.5 Summary of the use of these models

Although the different models have been successful in identifying factors that influence health behaviour, such as cognitive processes, attitudes, fear, and perceptions of vulnerability and benefits, they have come under significant criticism when they have been used to underpin HIV prevention health communication strategies in Africa, Asia, Latin America and the Caribbean (Airhihenbuwa & Obregon, 2000; Campbell, 2003; Parker, 2004; Dutta-Bergman, 2005. Several studies have evaluated the use of these models and have shown that they are ineffective in HIV prevention campaigns in sub-Saharan African communities (Witte, 1998; Agha & Van Rossem, 2004; Gallant & Maticka-Tyndale, 2004; Hounton, Carabin & Henderson, 2005). For example, the HBM model was used to inform an intervention aiming to encourage abstinence and condom use among 416 14- to 23-year-olds in Zambia and was examined by Agha and Van Rossem (2004). Whilst they observed an initial change in the adolescents' normative beliefs about abstinence and condom use, beliefs about condoms were shown to have reversed within six months of the programme's delivery. Another study used the HBM model to identify barriers deterring condom use among 251 participants in rural Benin in Sub Saharan Africa (Hounton, Carabin and Henderson, 2005). Whilst participants were fully aware of both the risk and the severity of HIV infection, condom use remained low. They concluded that the HBM model is limited in its ability to understand the complexity of sexual behaviour and that interventions informed by HBM are unlikely to achieve significant behavioural change among the intended audiences.

These conclusions are echoed by Zac-Place & Stern (2004), who argue that although HBM has been used as a theoretical basis for health communication strategies for over half a century, it is seen by many as over-simplistic. Framing perceived susceptibility and severity as predictors of health behaviour may not necessarily apply to every person's experience of a particular health threat, that results in sections of the intended audience disregarding the communicated health messages.

EPPM was used to evaluate a series of posters, pamphlets and stickers promoting the use of condoms by workers who travel regularly along the Trans-Africa Highway in Kenya (Witte et al., 1998). Campaign materials were discussed in a series of focus groups that included sex workers, truck drivers, their assistants and young men who lived and worked at the truck stops. Although respondents understood the materials that communicated the threat of HIV, they did not communicate how to avoid contracting HIV and therefore were found to be in-effectual. The study concluded that health communication interventions that use fear-based messaging alone, with no advice or hope about how to avert the risk communicated, are likely to cause audiences to actively avoid the messages because they find them too frightening.

Although often used to underpin the design and implementation of HIV prevention campaigns, these models have not been widely adopted for communication interventions designed to inform and motivate adherence to ART. This is probably because of the general criticism that they have attracted over the last decade, due to their failure to deliver substantial or sustainable reductions in HIV transmission between individuals or communities (Coates, Richter & Caceres, 2008). The few studies of cases where they have been used to underpin adherence interventions have arrived at similar conclusions: that they frame adherence as a responsive behaviour that results from understanding instructional messages. For example, Munro et al. (2007) conducted a review that evaluated the impact of health behaviour models used to promote long-term medication adherence for TB and HIV. They concluded that there was very little evidence for the effective use of these models in adherence interventions. They argue that the HBM, EPPM and TRA models are too simplistic, framing adherent behaviour as a series of rational decisions that need to be incorporated into a person's daily schedule. The models also discount the complexity of what it means to live with HIV, which so often includes localised cultural beliefs and stigma that can significantly influence a person's motivation to adherence.

Despite these challenges, the same review identified a model that *has* attempted to incorporate the broader complexities of human behaviour into the context of long-term adherence. Building on the principles of SCT, the Information-Motivation-Behavioural skills (IMB) model proposes that information, motivation and behavioural skills are the main determinants required to achieve self-efficacy. Information should clearly explain the medicine regime, including pill times and potential side effects. Motivation includes attitudes and beliefs about the potential outcomes of optimal and suboptimal adherence, and the patients' perceptions of how significant others could support them to achieve optimal adherence. Finally, training is needed in the behavioural skills necessary for successful ART adherence. These include reminders for pill times, incorporating the ART regime into daily routine, strategies to minimise side effects and understanding of how to acquire social support (Starace et al., 2006).

Although the authors discuss the *potential* of IMB in informing adherence interventions, only one study was found that evaluated its *actual* impact on ART adherence behaviour. Sampaio-Sa et al. (2008) conducted a randomized controlled trial of an ART intervention with 118 perinatally infected 12– to 13-year-olds in Brazil comparing the impact of an IMB educational workshop that focused on treatment information, motivation and skills required for adherence, with that of four sessions showing an educational video that explained ART regimes. They found no differences in reported adherence and viral loads between the groups subjected to the two interventions over a period of two years. This may have been because these young people already had a reasonable level of treatment knowledge and were mainly reliant upon their parents/carers for maintaining adherence.

4.3 The interpretative approach

Unlike the post-positivist, biomedical approach, the interpretative approach is not concerned with testing a variety of defined concepts quantitatively to help shape a "cause and effect" communication intervention; rather, it allows concepts to emerge through a qualitative research process (May & Mumby, 2005: 24). This is achieved by engaging with the people who are challenged by a particular health issue. The researcher, using ethnographic methods, gathers rich descriptions and accounts of the meanings that participants make from their experience of illness and health care. These experiences and meanings offer key insights that can inform the design of health communication strategies (Deetz, 2005). The two interpretative approaches that are most often adopted in health communication research are the social construction approach and the critical health communication approach (Sharf & Vanderford, 2008).

4.3.1 The social construction approach

According to Sharf and Vanderford (2008:11), social construction theory was introduced as a health communication approach because of growing concerns amongst scholars about the dominant post-positivist, "biomedical" model. Social construction theorises that people construct their worldview (meanings) through the social relationships that they encounter in their day-to-day lives (May & Mumby, 2005; Gergen, 2009). Using this approach, researchers place a particular emphasis on listening to people's narratives or descriptions of their clinical journeys in order to understand their health experiences and their related health-based decisions (Zoller & Dutta, 2009:13). According to Charmaz (1999), a person's story about their illness can help them to shape meaning from their suffering, creating an opportunity for them to reflect and then reframe their lives, whether through a specific episode of sickness, or in relation to a life-long chronic condition. Illness narratives that are gathered from the field are integrated with bio-medical messages, with the goal of achieving a consensus across community participants and clinicians. The consensus reached in this way ensures that a health communication intervention is specific and relevant to the experiences of the intended audience (Sharf & Vanderford, 2008:15).

One project that used this approach was a film outreach project called "The Steps". It involved the production of a series of films that were delivered throughout several communities heavily affected by the HIV epidemic in South Africa. The aim of the project was to encourage community members to attend local clinics for an HIV test.

The film series was reported to be particularly successful because it included real-life actors, who told their own stories about how HIV had affected them (Englehart, 2003). For example, one of the films described the stories of how two young women from Alexandra Township near Johannesburg came to terms with the discovery that they were HIV positive during their pregnancy. Both of the women attended the film screenings, encouraging other young pregnant women in the audience to go for an HIV test and receive ART if they were shown to be positive. Sharing their narratives both through the film and directly with the audience was shown to increase attendance for HIV testing among young pregnant women at a maternity clinic (Englehart, 2003).

Deetz (2001, cited in Zoller & Dutta, 2009:13) argues that many researchers, however, remain concerned that by exploring descriptions alone, "researchers find themselves with a focus on understanding "social consensus" rather than critiquing that consensus or seeking transformation". Furthermore, whilst patient narratives are valued as an important contribution to health communication interventions, as exampled by the Steps film series, the biomedical narrative and position of the clinical expert often remains central to the design and implementation of health communication strategies (Dutta & Zoller, 2009:13). Further issues include the sustainability of narrative-focused interventions, especially when narratives are communicated to audiences via expensive media channels such as television and film. Therefore there is general recognition among health communication practitioners that the impact of narrative-focused programmes is often limited to a specific duration, because of their dependence on funding (Dutta & Zoller, 2009:36-37).

4.3.2 The critical health communication approach

The critical health communication approach recognizes that authority and power relations within a social system often influence how people construct meanings about their life world. This is done through the enforcement by those in power on others of their "ideology" (concepts and beliefs), for their own benefit (Geuss, 1981:5). Researchers who adopt this approach recognise that the top-down "expert" biomedical narrative can influence (or prevent) effective communication, and argue that power relations and ideologies must be suspended so that authentic discursive interaction can occur in what Deetz refers to as “communicative contexts” (2005:91). Communicative contexts are deliberately created spaces where the voices of all social actors are heard, encouraging everyone to contribute toward a common goal, and aiming to reach a shared understanding without manipulation (2005:91). These spaces of discursive reflection enable a community to reach a more liberated “life world”; or symbolic space, within which culture, social integration and personality are sustained and reproduced (Sharf & Vanderford, 2008: 15).

In the context of health communication research, the aim of the critical approach is not only to understand the “taken-for-granted” assumptions and dominant health messages and strategies within an organisation or community, but also to identify and challenge them clearly, to ensure that community members are able to represent their interests and “contribute equally to the development and implementation of a new health communication strategy” (Deetz, 2005: 91).

In health communication practice, the critical approach is most evident in community-based programmes that actively engage local community members in both the programme’s design and its delivery. For example, Merzel and D’Afflitti (2003) reviewed the impact of 32 community-based interventions in the USA related to cardiovascular disease, smoking cessation, substance abuse, cancer prevention and HIV prevention. Despite the fact that the programmes were informed by critical theory however, and involved active collaboration with community members and groups, most of the interventions proved ineffective in changing the health behaviours because a series of design and planning limitations. These including the following:

- Length of intervention; programmes did not last long enough to impact community members.
- Insufficient tailoring; Many programmes use behavioural theories to inform the intervention design and messages, which results in a one message fits all approach because the targeted individuals were viewed as one homogenous group in a geographically defined community. Because of this the needs of different subgroups are not taken into account.

- Low level of community engagement. Programmes often have difficulty in engaging the relevant community stakeholders, because of differences in goals and priorities between researchers, healthcare providers and community members or groups. Although outcomes may be agreed at the beginning of an intervention, sustaining the coalition often becomes problematic, resulting in stakeholders disengaging from the programme.

These limitations are exemplified by a three-year community-based programme aimed at sex workers and migrant mine workers in the district of Summertown, near Johannesburg, during the 1990s (Campbell, 2003). The programme was designed to reduce HIV transmission through an education intervention. Similar to the community-based programmes reviewed by Merzel and D'Afflitti (2003), it employed ideas from critical theory, actively engaging the local grassroots community with the aim to generate ownership, identification and trust. It involved three subgroups within the African community: approximately 70,000 mine workers who lived in local hostels, 2,000 sex workers from smaller shack settlements and 100,000 residents of the formal township of Summertown, consisting mostly of young people. According to Campbell (2003:18), despite the project's attempt to secure an equality of power across stakeholders, biomedical experts dominated the discourse and the programme failed to develop a better understanding of the social complexity of the epidemic. Lack of cohesion across stakeholders resulted in insufficient monitoring of key areas of the programme, which contributed to its failure. For example, although education workers had been trained in the use of participatory health communication methods (including drama, singing and one-to-one counselling), they reverted to a didactic method of teaching that proved to be ineffective.

In summary, the Summertown project and those reviewed by Mertzel and D'Afflitti (2003) show that whilst there may be good intentions to develop and implement community-based programmes with an equality of power across multiple partners and stakeholders, the reality of maintaining that equality throughout programme delivery is both unrealistic and complex. As Cheadle (cited in Mertzel & D'Afflitti, 2003:566) argues, "it takes an article of faith that locating programmes in the community and involving community members in planning, implementation, and evaluation can be an effective strategy for improving population health", especially for the long-term.

4.3.3 The culturally sensitive health communication approach

Building on the critical health communication approach, researchers have become increasingly aware of the influence of culture on the impact of health communication interventions (Lupton, 1994). Kreuter and McClure (2004:439) comment that "it is generally believed that by understanding the cultural characteristics of a given group, public health and health communication programmes and services can be customized to better meet the needs of its members". The culturally sensitive approach sees culture as "the values, beliefs and traditions" that contribute to the process of an individual's development of self-identities (Dutta, 2008:3). These identities are formed within the community to which members belong, where localised cultural values and beliefs are lived out, influencing how individuals see themselves and how they relate to one another. According to Airhihenbuwa (2000) it is these cultural identities that frame how people relate to health issues within their social contexts. Therefore health behaviours can only truly be understood by recognizing how localized cultural meanings shape individuals' approaches to both disease and health.

Kreuter and McClure (2004) describe how culture can inform the work of health communication practitioners in terms of segmenting their targeted audience and building campaigns based on the "cultural characteristics of a given audience segment" (2004:441). This approach is described by Romer et al. (2009), who conducted in-depth interviews with a sample of African American young people (the number of participants was not reported in the study) to explore their beliefs about the use of condoms, in order to develop culturally tailored messages encouraging safer sexual practices. The research was used to inform a series of vignette dramas that were transmitted on radio and television channels over a 15-month period throughout four U.S. cities. Data gathered were compared to data from another four cities that were not exposed to the media intervention. It was found that media messages did improve young people's opinions about the use of condoms in comparison to participants who had not received the mass media messaging.

However, it is difficult to establish the impact of the culturally sensitive elements in this study because there was no comparison with a campaign that did not use culturally sensitive messages. More broadly, research that directly examines the effect of considering culture against not doing so is scarce.

4.4 Conclusion

In this chapter I have tracked the main theories and models used by health communication professionals and researchers. It is evident from the literature that health belief models, whilst commonly used to inform the design of communication strategies about appropriate ways of behaving, are generally ineffective when used to challenge sexual behaviours that place young people at risk of HIV infection. They have not been successful when used to facilitate adherence to ART because they are too simplistic (Munro et al., 2007).

In response to these outcomes, increasingly researchers and practitioners employ one or a variety of alternative approaches in order to gain an understanding of how people construct their own meanings of illness and health. These include the critical health communication and culturally sensitive approaches. However to date the main impact of these approaches has been to foster community-based interventions which, although they have delivered some successful outcomes in the short-term, have often failed when funding ceases and programme leadership is handed to community members.

As argued by Glanz et al. (2008:27) and discussed in the introduction to this chapter, health communication research can only find the answers to the ‘Why?’, ‘What?’ and ‘How?’ questions of complex social phenomena when it is underpinned by the use of an appropriate theoretical framework. Therefore it is important to locate the current study within a theoretical approach that is focused on the discovery and sense-making of the meanings that young people who are living with HIV attribute to ART adherence.

As discussed in chapter three, adherence to ART is complex, as young people find themselves having to interact with multiple factors. These include the medicines themselves; engagement with health practitioners, family members and friends; the need to cope with the reality or threat of stigma, and the need to correctly interpret treatment information, as well as the everyday challenges of poverty and other health-related issues such as depression. In the context of this study, these challenges are also framed by the on-going influences of historical treatment narratives and confused explanations about treatment, as discussed in chapter one.

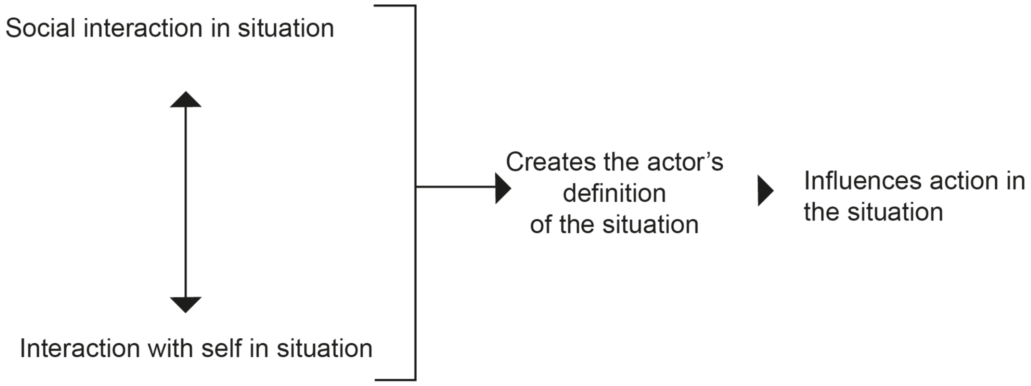
In addition, chapter two showed that multi-media instructions alone, even if they have been developed locally, are insufficient as a means of communicating adherence. It is clear from the literature that ART adherence is not simply about understanding a set of medicine instructions, but is determined by multiple psychosocial factors that together influence how a young person develops their meaning of adherence and chooses to act upon that meaning within their social environment. In view of this, symbolic interactionism was identified as an appropriate theoretical approach for this study.

Symbolic interactionism views people as active participants within their life-world: how they interact, engage with and respond to life events and the world around them is central to how they attribute meanings to a given social phenomenon, activity or behaviour(s). This includes the meanings that they attribute to their social interactions – interactions not only with other individuals and groups of people but also with objects, institutions, government, cultural values, histories and language (Blumer, 1969). According to Blumer (1969:2) the three core principles of symbolic interactionism are:

1. "... that human beings act toward things on the basis of the meanings that the things have for them
2. … the meanings of such things is derived from, or arises out of, the social interaction that one has with one's fellows
3. …these meanings are handled in, and modified through, an interpretative process used by the person dealing with the things he encounters…"

Blumer (1969) argues that an essential part of the process of meaning-making occurs through the process of self-interaction. It is through this self-communication that the “actor” attributes meanings to and from the interactions that occur within social situations, which then directs their behaviour. According to Charon (2011:115-116), in social situations "humans act according to their definition of the situation". Goffman refers to these situations as "social occasions", in which a person comes into the immediate presence of another as participant (1963:180). During these social occasions an inner conversation begins and "emotional structures" become attributed to the meaning/definition of the situation, causing the participant to become "caught up in the occasion" (Goffman, 1963:19). As a result, a person's definition of the situation is influenced both by their interaction with others and by their interaction with self. Their actions, in turn, are influenced by the resulting definition (see Figure 4.1).

Figure 4.1: Model of symbolic interaction showing how a person defines a situation (Charon, 2011:114)



These core principles of symbolic interactionism map across the main findings from the literature reviewed. Young people do not see adherence as simply responding to a set of medicine instructions; adherence is dependent upon the meaning that they attribute to it. The meaning of adherence is derived from their self and social interactions, which include those with clinicians, family, friends and with treatment information itself. According to Blumer, the central focus for the researcher is to ”view the given sphere of life under study as a moving process in which the participants are defining and interpreting each other’s acts” (1969:53). This type of study, as Blumer continues, cannot be undertaken if the researcher approaches it with a predisposed understanding that social phenomena are an outcome of people’s response to a series of pre-determined factors, such as a set of treatment instructions or a specific health belief model. The meanings that people attribute to ART adherence can only be understood by discovering participants’ own definitions and interpretations of what adhering to a life-long medication means to them.

CHAPTER 5: RESEARCH DESIGN AND METHODS

5.1 Introduction, research aims and objectives

This chapter presents the research design and methodology for the study, and also describes the study site. The research took the form of a qualitative case study of ART adherence in the peri-urban township of Khayelitsha in South Africa. The initial proposal for the research was developed during 2009 following an informal scoping visit to a District Hospital that provided HIV healthcare to the Khayelitsha community. My background was in corporate and visual communication and I was interested in how both of these could enhance current HIV health communication strategies. During the visit, several doctors asked if I could help to develop a communication strategy and supporting visual media to better communicate the complexities of ART adherence to young people. The conversations that emerged during this time focused on the difficulties clinicians were having when explaining the complex concepts of HIV infection and ART adherence; they believed that current communication strategies, message content and visual communication materials were not working. It was within this context that the overall research question for the PhD was defined as:

> "How can health communication most effectively explain antiretroviral medication (ART) and motivate adherence among young people?"

The objectives were to address the following more specific questions:

1. What are the current adherence messages that are used in Khayelitsha to explain and promote ART?

2. How are adherence messages in Khayelitsha perceived by young people, and are they effective?

3. What motivates young people in Khayelitsha to adhere to ART or hinders their doing so?

4. What would be the most effective tools for communication in Khayelitsha to facilitate young people's motivation and understanding?

5. Overall, how does the study inform wider understanding of factors contributing to the effectiveness of communication strategies and supporting visual tools to facilitate young people's adherence to ART?

In the following sections of this chapter I describe the study setting (section 5.2); present the methodological approach and overall choice of methods used (5.3). I then present the overall study design, together with the detailed methodology (5.4). I present the data analysis methods (5.5), and then discuss ethical considerations (5.6) and issues of quality and credibility (5.7). The chapter finishes with a brief discussion of possible limitations of the study, including issues related to sampling, and potential response biases (5.8).

5.2 The study setting: Khayelitsha

Khayelitsha is a township of over 500,000 inhabitants located on the outskirts of Cape Town and has one of the highest prevalence rates of HIV in South Africa (Garone et al., 2013). The township was developed by the apartheid government during the 1980s, separated from the white population of Cape Town by poor transport and distance. Over 95% of the population is black African, of whom 96.8% speak Xhosa as their primary language; approximately 62% originate from the Eastern Cape. The majority of residents live in relative poverty; nearly 60% live in informal dwellings and 40% of the labour force (those between the ages of 15 and 64) remain unemployed. Only 46.4% were able to complete secondary school, of whom only 30.8% achieved Grade 12, and only 4.9% went on to higher education (City of Cape Town Census, 2012).

In relation to HIV, in 2001 a small pilot programme was launched in Khayelitsha by Médi Sans Frontiéres (MSF) and an organization called Treatment Action Campaign (TAC), making ART available to 180 adults. This was then followed by further treatment programmes at three public sector primary care clinics in the township (Fox & Goemaere., 2006; Boulle et al., 2010). By 2007 over 7000 adults were receiving treatment, and in 2011 it was reported that over 25,000 people in Khayelitsha were receiving ART (Garone et al., 2013). Youth services have been developed and continue to be part of the ART service delivery, with the aim of engaging young people in order to test them for HIV and initiate them on treatment when required. These services include youth specific ART adherence programmes based at two of the main public sector clinics in Khayelitsha, of which one is overseen by MSF and the other by the local health authority. Although the South African National Department of Health ensures that ART is readably available through the clinics in Khayelitsha, 61% of 14- to 25-year-olds who have been diagnosed as HIV positive and are eligible for ART disengage from the health services before even starting treatment, and nearly 30% have treatment failure after five years on ART (Khayelitsha Annual Activity Report 2008-2009).

This study focused on young people from Khayelitsha and the various professionals who were involved in their care - doctors, nurses, HIV counsellors and pharmacists. Five institutions were identified that were concerned with HIV adherence and treatment: A district hospital (which serviced HIV patients from Khayelitsha), three HIV clinics in central Khayelitsha (for the purpose of this study identified as clinics 1, 2 and 3), and the Khayelitsha office of Médi Sans Frontiéres (MSF), (See Figure 5.1 for field site locations).

Figure 5.1: Field site locations

5.3 Methodological approach: grounded theory and the overall choice of methods

The methodology followed the principles of grounded theory, which are compatible with a symbolic interactionist perspective (see chapter four). Grounded theory is an inductive approach to research that was developed in the 1960s by Glaser and Strauss, who argued that systematic qualitative data analysis could legitimately generate new theory to explain complex social processes (Charmaz, 2006). The aim of grounded theory is to develop a theory that emerges from the data that *"gives understanding about how persons, organizations or communities experience and respond to events that occur"* (Somekh & Lewin, 2005:49). The researcher compares and "codes" (classifies) data throughout the study in order to identify concepts, relationships and themed categories, and then builds on the emerging picture through further, more directed data gathering.

Since the publication of Glaser and Strauss's book in 1969, grounded theory has diverged into two versions (Charmaz, 2006). Glaser maintained a positivist, objectivist perspective, according to which there is "one reality" or "one truth" embedded in the data; the research should aim at a representation of this objective truth independent of the researcher (Annells, 1996). In contrast, Strauss developed a relativist perspective, according to which there are "multiple realities" or ways of interpreting specific data (Somekh & Lewin, 2005:50). Strauss, together with his colleague Juliet Corbin, went on to develop their own version of grounded theory, which stresses that a researcher must actively obtain theory from the data, and that the theory (formal theory) must be relevant to the participants' "stories of the world" in which they live, and must be based on their realities (Mills, Bonner & Francis, 2006). In contrast, Charmaz adopts a "constructivist" approach which aims to develop a substantive theory that "serves as a way to learn about the worlds we study and a method for developing theories to understand them" (2006:10). Unlike the Glaser and Strauss approaches, Charmaz advocates that the researcher plays an intrinsic role in the research process as they interpret data whilst they interact with participants; through this process the researcher and participants co-construct an interpretation of reality that generates a "substantive" theory (Charmaz, 2006:64).

Given that the purpose of this study was to develop a better way of communicating ART adherence to young people, it was important to use an approach where findings were "relevant" to participants' "realities" of what it is to live with HIV and depend on life-long medication. Using the constructivist approach of grounded theory enabled me to interact with the young people who live with HIV as they engaged with their health care providers. This in turn helped me to develop insights into their narratives of illness and health and to discover what being motivated to adhere to ART means for them and how that can be best communicated.

I now turn to the choice of methods used for the study, which were focus groups, semi-structured interviews and participant observation.

5.3.1 Focus groups and semi-structured interviews

Focus groups and interviews were used to complement one another throughout the study, and were the main tools used to generate discussion of HIV and ART. Focus groups are used for creating, collecting, identifying, discovering, explaining and generating thoughts and creating new ideas (Morgan, 1996). They also allow the researcher to gain an understanding of individuals' language, knowledge, and experience, including drawing out shared life experiences (Fern, 2001). According to Jankie, Garegae and Tsheko (2011) focus groups are particularly useful in helping the researcher to understand adolescents' perspectives on sexual behaviours and HIV. The authors argue that it is within their social context that young people develop certain beliefs, values, assumptions, insights and ways of knowing about what adherence to ART means for them. Focus groups allow adolescents and young people to "speak for themselves and be listened to with regard to what these issues mean in their lives" (Jankie, Garegae and Tsheko, 2011:133).

A number of factors should be considered to ensure the best possible outcomes of a focus group. These include making sure that the environment is as comfortable as possible, as the setting ambience can impact how participants behave (Fern, 2001). The focus group moderator also plays an important role in guiding the participants through the agenda, whilst facilitating group discussion. According to Morgan (1996) the moderator can exercise either a structured approach by guiding the group with a pre-prepared set of questions, or a less structured approach that allows the group to pursue its own interests (1996:145). In this study I chose the less structured approach in order to allow the participants to discuss openly what communicating ART adherence sounded and looked like to them.

Semi-structured interviews were used both to gather primary empirical data where focus groups were not necessary or possible (for example one to one interviews with young people in clinic waiting areas), and also to expand on and clarify focus group discussions. Semi-structured interviews are interviews that are pre-organised, with a set of pre-determined questions (Corbin et al., 2008:200). Within the framework provided by these questions, the purpose is to allow participants the opportunity to explore and discuss issues that are important to them (Holloway & Wheeler, 2010: 89). The interviewer's aim is to gain in-depth perspectives from participants while guiding the discussion, so that rich, descriptive data are captured that are specific to the study purpose (Holloway & Wheeler, 2010).

Focus groups and interviews were conducted in English and were audio-recorded and then transcribed. For groups with young people, English was used as the "thread" language, and when Xhosa was spoken the MSF youth worker/research assistant (a Xhosa-speaking local) translated. Copies of audio tapes and transcriptions were stored securely.

5.3.2 Participant observation

Participant observation was also used throughout the fieldwork. Participant observation is a method that enables the researcher to take part in the "daily activities, rituals, interactions, and events of the people being studied" (Dewalt, Dewalt & Wayland, 1998: 260). According to Van Maanen (1995:2 cited in Cohen, 2000:316), participant observation is the act of "being there" that results in gaining an understanding of the shared values, behaviours, beliefs and language of a specific group. Somekh and Lewin (2005) describe how participant observation allows the researcher to walk alongside a participant in order to share his or her experience, and in this way to access their social contexts and the ways in which they interact. As Jorgenson (1989:15 cited in Holloway & Wheeler, 2010:108) states, "participant observation provides direct experiential and observational access to the insiders' world of meaning". It is important for the researcher to become a part of the study setting and of the group to be observed, so that they are sseen as familiar among participants, allowing minimum disturbance and potential bias that can occur when a stranger is present (Tedlock, 1991). In the context of health care settings, participant observation offers the researcher an essential insight into clinical practice and interaction between patient and clinician (Savage, 2000).

Dewalt, Dewalt and Wayland (1998:261) outline three main objectives of participant observation:

1. Learning from observation (keeping in mind that the observer becomes a part of what is being observed).

2. Being actively engaged in the lives of people brings the ethnographer closer to understanding the participants' point of view, and

3. Achieving understanding of people and their behaviours.

There are four categories of participant observation that are widely recognised within the field of ethnographic research (Gold, 1958):

i. *Complete participant*: where the role of the observer is unknown by the community being studied. Whilst the intention of the researcher is to embed themselves into a specific social setting as "neutral", the reality is that they need to "perform" in order to maintain their covert approach and identity.

ii. *"Participant as observer"*: adopting this role the researcher is able to observe formally, because their role is known among members of the social setting. An important factor for this approach is that the researcher builds trust among community members so that informants do not feel uneasy in their presence.

iii. "*Observer as participant"*: this involves organising simple interviews that explore a specific aspect within the social setting being examined. According to Gold, the difficulty with this approach is that the researcher can be misunderstood as there has been no attempt to build relationships with community members.

iv. “*Complete observer”,* where the researcher intentionally makes no attempt to engage with informants, who are unaware that they are being observed; this approach however runs the risk of the researcher being seen as someone who is “eavesdropping” if their activity and identity is discovered.

For the purpose of this research I adopted the category that was most appropriate to the setting. I used the “participant observer” approach during my visits to the youth clinics where I sat in the waiting rooms whilst participating in the process of waiting for an HIV test. In contrast I adopted the third category, “observer as participant”, when I organised specific times to observe how ART adherence is communicated and discussed between clinician and patient. These events are described in more detail in section 5.4.

5.3.3 Visual Thinking

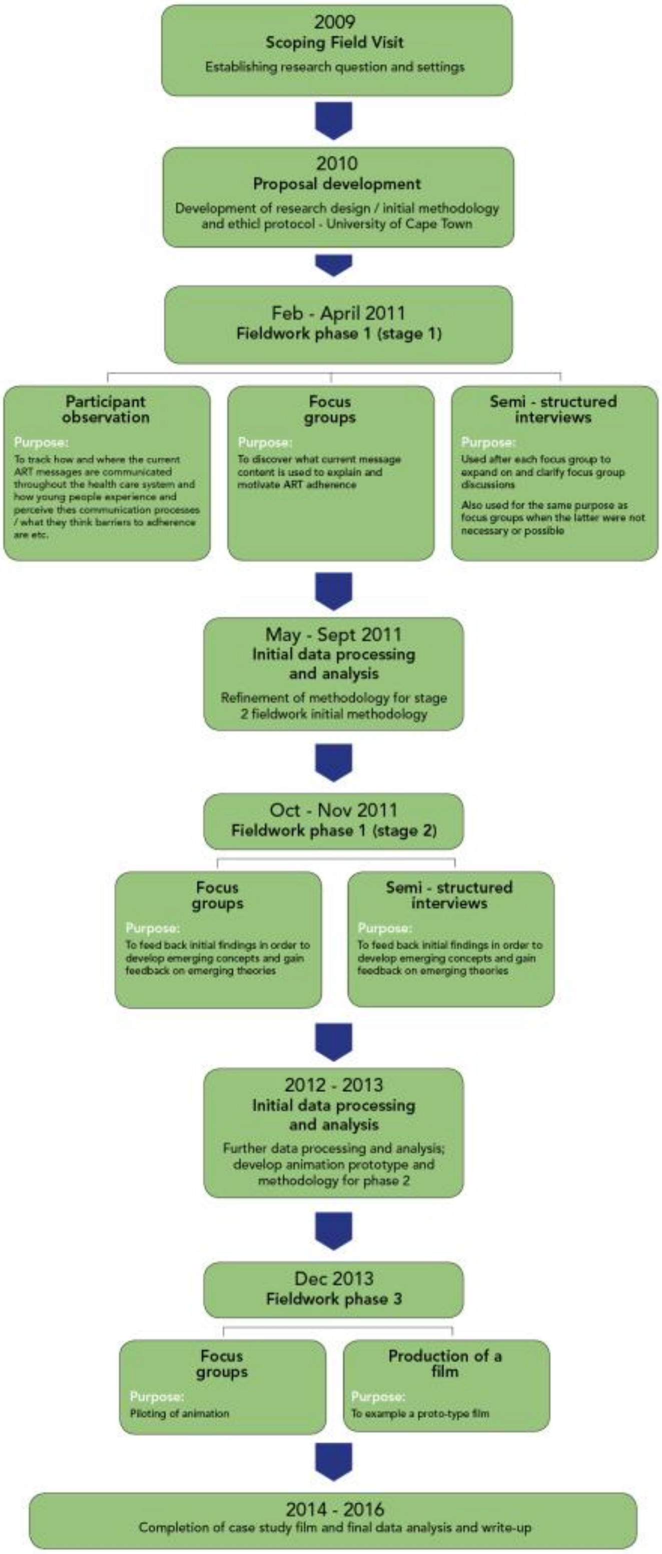
One exercise used in some of the focus groups was “visual thinking” - a method of problem solving that uses the practice of drawing to describe and make sense of complex concepts, ideas and human experiences (Reilly, Ring & Duke, 2005). It involves asking participants to make a drawing to represent their ideas and experiences about a specific topic. The drawings themselves are not analysed; rather, their purpose is to facilitate discussion, encouraging participants to “think out loud”, putting “their observations and ideas into words”, and helping them to find new meanings about the subject of their drawing (Reilly, Ring & Duke, 2005). Rudolf Arnheim (1969:257) comments that visual thinking “helps people to ‘unravel’ the multiple relations that are connected to problems, bringing a new clarity and understanding to the subject in question.”

5.4 Study design

Data collection was carried out during two phases of fieldwork, interspersed with periods for data processing and analysis. In line with a grounded theory approach, the details of the methodological design for each phase were informed by the results up to that point. Thus the process was an iterative cycle of induction and deduction, in which each stage of data collection, processing and analysis further guided the next (as recommended by Charmaz, 2006). Throughout the research, data gathering and analysis “become more precise, analytic, and incisive” (2006 :110). The iterative cycle continues until new data no longer provide significant new insights – a point defined as “saturation”.

Figure 5.3 summarises the different phases and stages of the study. Phase one of the fieldwork was carried out in 2011 and was split into two stages, the first from February to April and the second from September to December. The second phase was carried out in December 2013.

Figure 5.3 Phases and stages of the study design



5.4.1 Phase 1, Stage 1 (Feb – April 2011)

The first fieldwork period began with a series of meetings with senior health officials from the different institutions with whom I would be working. The purpose of the meetings was to discuss the study's aim and objectives and to establish the role and contribution of each institution towards the successful implementation of the research. The following contributions were agreed:

MSF:

1. A meeting room at the Khayelitsha office for focus groups
2. The support of the MSF youth worker based at the MSF Khayelitsha offices
3. The support of the MSF youth doctor based at Clinic 2

District Hospital and Clinics:

1. The use of a room for a focus group
2. Permission to observe clinicians' consultations with young people. A permission form each site was signed by the appropriate person (Appendix 1).

I also gained permission to conduct research at the clinic 3 from the NGO who were responsible for it.

Following these meetings, purposeful sampling was used to recruit participants for the initial focus groups and semi-structured interviews and to plan participant observation. As Patton states:

> *"The logic and power of purposeful sampling lie in selecting information-rich cases for study in-depth. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the study of the inquiry, thus the term purposeful sampling".*
>
> (Patton, 2002:230).

Accordingly I recruited experienced clinicians at each of the study sites and young people who were fully engaged with their healthcare providers, in order to collect a first layer of rich descriptive data that would offer initial insight and understanding of how ART adherence is communicated and understood.

In the first phase of the fieldwork I conducted separate focus groups with young people and the different types of clinicians to explore their perspectives on how ART adherence is currently communicated. Each focus group began with the following opening question:

> *What are the message elements that are used to explain and motivate young people to adhere to their ART?*

After 20 minutes I summarized the key themes that had emerged and then introduced a "visual thinking" exercise. I asked participants to draw something about each emerging theme that was particularly meaningful to them. After ten minutes of drawing, I then asked participants to describe their drawing to the group. The descriptive data that were captured through group discussion were used in subsequent analysis. The exercise was carried out successfully with all groups except those with doctors and pharmacists, who would not engage because they were concerned with time constraints.

At the end of each focus group I asked one of the participants for a 20 - 40 minute follow-up semi-structured interview to further explore what had been discussed[1]. Participants were chosen for the post-focus group interviews who had demonstrated a clear articulation of the issues discussed in the group.

The opening question for the interviews was:

These are the message elements that have emerged during the focus group, do you think there is anything to add and further discuss that is particularly important to you?

Table 5.1 gives details of participants included in the phase 1 focus groups and the follow-up interviews. The recruitment of participants for focus groups was necessarily different for the different actors. Because I spent considerable time based at the MSF offices in Khayelitsha, I was able to recruit doctors for a focus group

---

[1] I was unable to conduct an interview after the nurses' group because the participants were eager to travel home immediately.

myself. For each of the other three groups of clinicians, I met with a senior staff member and gained their support for the organisation of focus groups and recruitment from their staff. Collaboration of this kind was given by a senior pharmacist at the District Hospital, one of the counsellors' managers at the hospital, and the sister at Clinic 1. The pharmacists' focus group took place early one morning at the hospital before they began their shift. The counsellors' and nurses' groups at the end of the day after they had completed their shifts, at the hospital and clinic 1 retrospectively.

The young people's focus group took place at the MSF offices. Recruitment of young people was more complex than that of other groups. According to Watson (1999), during fieldwork the researcher can be seen as a stranger who has come from the outside as an unknown quantity. As a British, non-Xhosa speaking white male, I was conscious that one of my main challenges was to gain the trust of young people who are HIV positive, enabling them to feel confident to participate and discuss their experiences. This was overcome partly with the help of the research assistant. It was through his network and longstanding friendships that he encouraged young people to participate. As a local Xhosa speaking man, he helped me recruit the young people for the focus groups and semi-structured interviews and acted as the translator during the main fieldwork period.

Table 5.1: Participants in focus groups (FGs) and follow-up interviews (I) during stage 1 of Phase 1

Type of Participants (and number for FGs)	**Focus group (FG) or interview (I)**	**Characteristics of participants**	**Location of focus groups**
Young men (n=5)	FG	16 to 22-year-olds who were living with HIV in Khayelitsha township. All were prescribed ART and were regular attendees of the MSF support group at clinic 2. The cohort included both prenatally and behaviourally infected young people.	MSF Offices
Young women (n=8)	FG		MSF offices
Young adults	I	1. 22-year-old man, perinatally infected with HIV, had been taking ART for several years. 2. 21-year-old woman, behaviourally infected with HIV, recently prescribed ART.	MSF offices

Counsellors (n=8)	FG	HIV counsellors working for two local NGOs at the District hospital or at clinics 1 and 2.	District Hospital
Counsellor	I	Counsellor who had been working in the field for five years	District Hospital
Nurses (n=5)	FG	Female nurses who worked at clinic 1	Clinic 1
Pharmacists (n=5)	FG	Pharmacists based at District Hospital (2 male and 3 female).	District hospital
Pharmacists	I	Pharmacist who had shown considerable interest in how visual communication supports their engagement with young people	District hospital
Doctors (n=4)	FG	Doctors who worked for MSF (2 male and 2 female)	MSF offices
Doctors	I	The MSF youth doctor based at Clinic 2	MSF offices

The aim of participant observation in Phase one was to track the communication about ART between clinicians and young people throughout each stage of healthcare engagement: attending a clinic for an HIV test, being tested, receiving a diagnosis, post-test counselling, and attending the CD 4 test and three ART initiation counselling sessions (C1, C2 & C3). During these visits I sat in the waiting rooms, joining young people as they waited for their HIV test or consultation, which helped develop a sense of familiarity and trust among both HIV counsellors and young people. On three occasions I also followed the HIV test procedure, which proved particularly helpful in generating open conversation among young participants.

Table 5.2 gives details of the different observation events. Observation included clinical consultations where young people discussed adherence with a pharmacist, a nurse, a counsellor and a doctor. For each of the observation sessions I discussed the research outline and its aims with clinicians in order to gain ethical clearance for me to observe a consultation. Access for further participant observation with young people was arranged at clinic 3 with the counsellors based at the clinic. Participants were all 18- to 24-year-old men and were attending the clinic for an HIV test. The recruitment permission form (Appendix 2) was used to gain consent.

Table 5.2: Participant observation of the different stages of healthcare engagement related to HIV / ART

Stage of health care engagement	**Clinician**	**Description of event(s)**
Testing, receiving a diagnosis and post-test counselling	HIV counsellor who was based at clinic 3	I attended clinic 3 for an HIV test. I waited in the clinic's reception with other men and followed the process of being tested, waiting for the result, receiving the test result and then being de-briefed by the clinic's nurse.
Communication of ART adherence post HIV test	Nurse at clinic 1	I sat in the consultation room during a one-to-one consultation with a young person who has just received their diagnosis
ART initiation sessions (C1, C2, C3)	HIV counsellor who was based at clinic 1	I attended three counselling sessions with young people designed to initiate them onto ART.
Pharmacist communication about medication issues	Pharmacist who had attended a focus group and had volunteered to be involved in the observation session at the district Hospital.	I sat in the pharmacy listening to conservations with patients about ART adherence through a small window between the pharmacy and the waiting room.
Doctor communication about medication issues	Doctor who worked for the provincial health authority and was based at the district hospital.	I sat in on a consultation with a 23-year-old woman who was struggling with ART adherence
HIV clinic waiting room	Clinic 3	I sat in the clinic waiting room listening and involved in conversations about being tested and waiting for test results

After analysis of the data a final, large focus group was organised in order to feed back some initial results to the participants and facilitate further discussion. Access and recruitment for this focus group was managed by the MSF youth worker, who invited 12 young people to attend at clinic 2. However due to high interest generated in the subject by previous youth engagement, a total of 39 young people attended. All but one were 18- to 24-year-old women. The young man who attended was 16 years old. All were living with HIV, were prescribed ART, lived in Khayelitsha and attended the MSF support groups based at clinic 2. The opening question in the focus group was:

> *These are the message elements that have emerged so far that are used to explain and motivate ART adherence to young people: do you recognise them and do they work for you?*

During May to September 2011 I returned to the UK to transcribe and analyse the data. By cross-comparison of the data it became evident that another trip to the field was required to further explore the emerging themes.

5.4.2 Phase 1 – Stage 2 (Sept – Dec 2011)

Using theoretical sampling I conducted a further focus group during the second phase of fieldwork to present more detailed results to the participants and ask for further feedback. Access and recruitment were organised by the MSF youth worker as described above. This focus group was based in a room in Khayelitsha library. As above, the focus group was followed up with a semi-structured interview with one of the participants. In addition, two further interviews were conducted at clinic 3. Access and recruitment for these two interviews were organised through the HIV counsellors who worked at the clinic. Table 5.3 give details of the participants for the focus group and interviews.

Table 5.3: Participants in focus group and follow-up interviews during Phase 2 stage 2 fieldwork

Type of participants (and number for FGs)	**Focus group or interview**	**Characteristics of participants**	**Location**
Young people (n=20)	FG	16- to 24-year-olds of mixed status. 14 men, six women.	Khayelitsha library
Young man	Interview		Khayelitsha library
Young men (n=3)	Group interview	18- to 21-year-old men resident in Khayelitsha. Mixed status.	Clinic 3
Young men (n=5)	Group interview	18- to 21-year-old men resident in Khayelitsha. Mixed status.	Clinic 3

The opening questions used in the focus group were:

> *Many young people during this study have mentioned the importance of support when they have just been told that they are HIV positive, can you help me understand what support looks like for you?*
>
> *Based on the message elements that have emerged so far that are used to explain and motivate ART adherence to young people I have developed some ideas of how they can be visually represented through an animation – I would like to ask you to help me further develop them...*

The opening question used for the interviews was:

> *This study has revealed that an animation would be useful in helping to explain ART adherence to young people and a film to take home that tells the story of a young person's journey from HIV diagnosis to making it through to living a normal life – would you find these both helpful?*

Following this field trip I returned to the UK to transcribe and analyse the additional data collected. Based on the data gathered so far I also developed a prototype animation designed to explain HIV infection, disease impact on immunity (CD4 count) and the importance of taking ART every day. The animation concluded with a supportive message stating that young people are not alone and that ART treatment can help them live normal lives.

5.4.3 Phase 2 (Dec 2013)

Phase 2 of the fieldwork was concerned with piloting the animation and making a short film. I obtained ethics permissions from UCT Faculty of Health Science Human Research Ethics Committee (HREC) for these activities prior to returning to the field. The animation was piloted at clinic 2 where it was presented to groups of young people a local young man who I had recruited as a paid research assistant for this purpose. He played an important role in helping to recruit young people from the clinic's waiting room and acted as translator during the subsequent focus groups. Additionally, I recruited clinicians and showed them the animation individually. Permission forms (see appendix 4) were used during this study phase.

After the viewing of the animation, there was a discussion based on the following open questions:

Was the animation useful?

How could it best be used among young people?

What messages did you find helpful or confusing?

Further development and pilot involved eleven young people, a nurse, a doctor and HIV counsellor (see table 5.4).

Table 5.4: Participants during phase 2 (Piloting the animation)

Participants	**Location**	**Number**
16- to 22-year-old young men living in Khayelitsha and attending Clinic 2	Clinic 2	5
16- to 22-year-old women living in Khayelitsha and attending Clinic 2	Clinic 2	6
Nurse (clinic manager) at Clinic 2	Clinic 2	1
Young man – research assistant	Clinic 2	1
Young woman – NGO treatment educator	Clinic 2	1
HIV counsellor based at Clinic 3	Clinic 3	1
HIV specialist based at UCT	UCT	1

In addition to the animation I made a film, together with a Masters student based at UCT, telling the story of a young person who had survived the HIV diagnosis and was successfully adhering to ART. This was in response to a direct request from the young people who participated in the study. The production of the film will be described in more detail in chapter 9.

5.5 Data processing and analysis

All focus groups and interviews were transcribed verbatim, omitting all names and other identifiable information, and each transcription was checked against the original recordings to ensure textual accuracy. Notes made during observation sessions were also included in the data analysis. The analysis itself followed the principles of grounded theory (see section 5.3).

A grounded theory study begins with the process of "gathering rich data" from research participants (Charmaz, 2006:13). Once the first layer of data has been gathered and analysed, the researcher begins a process of cross-comparison across the data using a coding system. In this way concepts and categories begin to emerge and the researcher begins to learn how participants make sense of their experiences.

Codes are labels that assign units of meaning to the data. The purpose of initial coding is to gain a "close look" at what participants have said and what is most important to them (Charmaz, 2006:50). Line-by-line coding is used to name words, lines or segments of data, and is followed by focused coding, which allows the researcher to select the most frequent and significant initial codes, comparing participants' experiences and stories across data sources, in order to separate, sort, synthesize and compare large amounts of data. This process helps the researcher to identify and organise codes that have similar properties into categories (Charmaz, 2006:59).

As categories emerge, the researcher clarifies meanings and actions by continual cross-comparison of data, facilitated by writing extended reflective notes or "memos". The researcher then identifies what new data need to be collected in order to further develop their ideas and categories. This is defined as theoretical sampling (Charmaz, 2006). In their turn, memos also direct further data gathering – another instance of "theoretical sampling" - whereby participants, activities and topics are selected iteratively as areas are identified that need further exploration. Throughout this process the researcher repeatedly reviews the emerging categories, looking for new patterns of experience within the narrative. When these cease to occur, the researcher can assume that a saturation point has been reached and no more data are required (Coyne, 1997). Box 5.1 below gives an example of how one category – diagnosis trauma – was developed.

Box 5.1: An example of developing a core category: Diagnosis trauma

During initial analysis (reading through the transcripts and using line-by-line coding), I assigned the code LOH (Loss of hope) to the following field note:

> Whilst we were waiting for our HIV test results in the small waiting room at the men's clinic, I asked the young man sitting next to me "How are you doing?" "Ummm, OK." He replied. I went on to ask; "how will you feel if you find out that you are HIV positive?" He replied; "I would lose all hope, my life would be over."

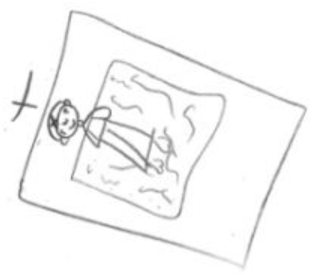
(Interview, Men's clinic, February 2011)

The code LOH belonged to a series of codes that emerged describing young people's experiences immediately before and at the point of receiving an HIV diagnosis. Another such code (FODS) was "Fear of death and sickness", which came from the following quote and which I then applied systematically to relevant passages throughout the dataset:

> "…… there was a fear of death, fear of death, fear of getting sick and feelings of loneliness"

(Young people's focus group: 18 March 2011)

In both the above cases the code mirrors the words used by participants so that the coding system prioritises their voices and meanings.



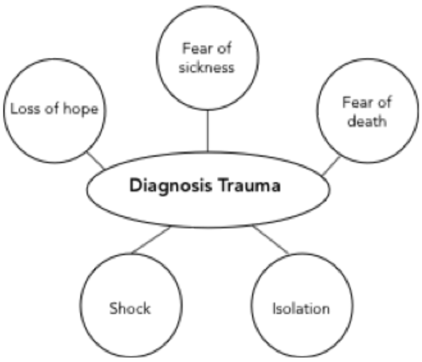
The code was also applied to some of the participants' descriptions of the drawings they made during the visual thinking exercise. For example the adjacent drawing was made by one of the participants who attended the women's focus group (held on 18 March 2011). She drew herself in a coffin, which described how she felt when she was first diagnosed as HIV positive: she said that she was afraid of being sick and dying.

As I continued analysis it became clear that these codes were frequent and were pointing to a significant experience related to receiving an HIV positive diagnosis. “Diagnosis experience” then became one of the “focused codes” that were applied across the data to compare participants’ “experiences, actions and interpretations” (Charmaz, 2006:59).

At this stage I introduced the practice of memo writing to allow further new ideas and insights to emerge (Corbin & Strauss, 2008). Memos could take the form of either text or diagrams. The following example of a diagram shows a memo that enabled me to develop the emerging category of “Diagnosis Trauma” based directly on the data.

Memo: Diagnosis Trauma

The diagram represents the following narrative. When young people are first told that they are HIV positive they feel a loss of hope for their futures. They see an HIV diagnosis as a death sentence and fear that they will become sick and die, and become overwhelmed with feelings of loneliness and isolation. Young people who experience these feelings when they are diagnosed as HIV positive use the term “traumatised”.



Using cross-comparison I then examined the relationship between these emerging properties that enabled me to clarify property clusters (shown adjacent). Once clusters had been identified I applied theoretical coding to either challenge or confirm current participants’ narratives by applying guiding questions to the data (Charmaz 2006: 67). I continued this process until gathered data reached a saturation point resulting in the category Diagnosis Trauma that comprised 5 properties.

5.6 Ethical considerations

The ethical framework for the study took into account the relational and ecological aspects discussed by Flinders (1992). Relational ethics suggest that research be informed primarily by respect and consideration for those the researcher seeks to understand, and privileges the ideas of “attachment, caring and respect” of participants over and above the consent agreements that are issued at the beginning of people’s participation (Flinders, 1992). This means that the researcher must seek to avoid any pressure on participants. Ecological ethics place an emphasis on the interdependent nature of relationships, striving to situate moral decisions within their broadest possible context. They encourage the researcher to be sensitive to the meanings and language of the local community, especially during the recruitment process (Flinders, 1992). Relational and ecological ethics together ensure that researchers do not become detached from participants or their environment, and to this end, these approaches must be maintained throughout the data gathering process, analysis and report writing (Miles & Huberman, 1994:289).

Within this framework, the specific ethical protocol for the study was based upon the key principles of both the Declaration of Helsinki (2008) and the UCT Faculty of Health Sciences Human Research Ethics policy, which are as follows:

- All research will maintain a high level of integrity and excellence
- All research will maintain a sensitivity and responsibility to social issues
- All research will respect the dignity and self-esteem of all individuals involved, as required by Human Rights conventions.

Based on these principles this study employed the following ethical protocols:

Respect for persons

Respect for each person remained a major priority based on the concern for safety, wellbeing, beliefs and customs of both the individual and the community involved. No coercion of any nature was applied during the recruitment process. It was always made clear that participants could change their mind and leave before or during a focus group, semi-structured interview, or observation session.

Respect for vulnerable persons

The autonomy of participants was maintained throughout the study. If there were any concern that a person might be misunderstanding the consent process I would offer greater clarity about what it meant to participate or withdraw from the recruitment process with that person.

Privacy and confidentiality

All participants were anonymised in the field notes through the use of identification numbers. Data gathered and transcribed excluded any names or any other method of personal identification.

Miles and Huberman (1994) discuss the importance of ensuring the confidentiality and anonymity of participants by safeguarding the data. Protecting data is crucial in controlling the risk of diffusion where it could be misused and cause harm to respondents (1994:294). For this study all data (recordings, field-notes and drawings) were kept secure at my residence during the fieldwork. On return from the field recordings were held on a separate hard drive. Transcribed papers and drawings were held in a file that remained confidential to the researcher and supervisor. Data will be destroyed after five years of the date it was captured.

Respect for Justice and Inclusiveness

Care was taken to adhere to non-discriminatory protocol and ensure that no unfair burden was placed on any individual or element of the community. The participating young people were 16- to 24-year-old men and women who had been diagnosed recently as HIV positive and lived in the township community. Outside these criteria there were no other reasons for exclusion.

Balancing harms and benefits

Balance between the benefits and burdens of this study were carefully considered and monitored. Potential burdens were time given for participation, loss of earnings and disclosure by other participants. The researcher provided travel support to participants who had to adjust their usual travel arrangements.

Unassisted consent for 16- to 18-year-old participants

It was important for this study that young people below the normal age of unassisted consent were included. The published MSF Khayelitsha Annual Activity Report (2009-2010) showed that 61% of 14- to 25-year-olds from the clinics across Khayelitsha who are eligible for ART, drop out before even starting treatment, and nearly 30% of young people have treatment failure after 5 years on ART. However, due to the sensitivity of disclosure of both sexual activity and HIV status it was highly unlikely that young people in this age range would have wanted their parents or guardians to know that they were taking part in the study. In view of this, it was decided to exclude 14-15 year olds, and it was agreed by the UCT Faculty of Health Sciences Human research Ethics Committee that I proceed with unassisted consent for 16 – 18 year olds. (Ref: HREC 061/2011 – issued on 18 Feb, 2011).

Access and ethical approval, including permission to observe clinicians' consultations with young people, were also gained from the different institutions in charge of the field sites, which included clinics run by Cape Town City Health (IN Number 10254). For phase two of the fieldwork I gained permission from the UCT Faculty of Health Sciences Human research Ethics Committee for producing the film, ethics was issued on 13. 9. 2012, (Ref: HREC 061/2011). Ethics approval to pilot the animation at Clinic 2 from the Sub District Manager was issued on 8. 10. 2013 (Ref: HREC 061/2011).

In all phases of the study, the recruitment process included the presentation to each potential participant of an outline of the study, either in written form or through verbal explanation, including an explanation of its potential benefits and risks. They were then asked to sign a consent form (see Appendix 2 - 4). They were informed that they could withdraw from the study at any time and that their names would not be included in the data, ensuring their anonymity. When required, a travel allowance of up to $5 was made available for young people who participated.

5.7 Quality and Credibility

According to Charmaz (2006), “the quality and credibility” of a study begins by ensuring that the researcher gathers “rich and descriptive data”. Immersing myself at the study site engaging with clinicians and young people I was able to meet this criterion. One aim of using three different qualitative methods was to gain corroboration and ensure quality and validity of data through triangulation (Silverman, 2008:121). Cross-method triangulation helps the researcher to “take bearings” within the data that have been captured across multiple methods. This enables the researcher to compare data, “checking for consistencies and inconsistencies between different sources” (Newing, 2011:116). This process of checking across data also helps the researcher to identify “gaps” that require further follow up in the field. Using this process of triangulation the researcher eventually finds a “consonance” in the findings, confirming that enough data has been collected (Farmer et al., 2006).

In addition, the use of recording and full transcription of all interviews and focus groups minimised errors in data processing, ensuring on-going quality. Credibility was further enhanced through the use of coding, constant comparison and regular presentation of findings back to participants as described above. Reflective marks were used throughout the study, which helped to add substantial meaning during the write-up phase. Conclusions based on the reflective process were discussed with both my supervisor and advisors, who challenged, confirmed or co-constructed appropriate interpretation of findings.

5.8 Limitations

The study used a trans-disciplinary approach that presents unique challenges because the researcher is not necessarily an expert in the disciplines explored. Whilst I have expertise in communication strategy and informational design, I make no claim of expertise in HIV/AIDS medical science. I have however, drawn from the expertise of leading researchers and practitioners in the latter field.

There are also limitations related to both sampling and potential response bias. In terms to sampling, this study was carried out in the peri-urban township of Khayelitsha, which has its own unique physical, social, cultural and health characteristics. The study focused on 16- to 24-year-olds, and therefore limits its findings to this demographic. However, typical of qualitative studies, findings can offer insights that may be informative for research in similar locations and populations.

Although not necessarily achieving optimal adherence, many of the young people who participated in the study were actively engaged with treatment programmes that were provided by their local healthcare systems. A further limitation of sampling is that the study did not engage with young people who tested positive and then stayed away from the clinic.

This thesis must be viewed in the context of the obvious potential for response biases when asking people to talk about a highly sensitive issue. In addition it should be noted that as a qualitative study, its aim was not to measure behaviour or offer a generalized theory based on a relatively small sample of people, but rather to explore the underlying issues in depth. I cannot claim that all contributions were truthful or represented participants' genuine feelings or experiences. On a number of cases when young people gave me the impression that they were adhering to their ART, I later discovered that they were experiencing problems. This may have been because young people felt that they needed to tell me what they thought I wanted to hear, possibly because they were hoping for benefits from participating in the study. Nevertheless, overall young people appeared to be enthusiastic in discussing ART adherence openly as was demonstrated by the level and quality of participation, particularly in focus groups.

CHAPTER 6. HOW ART ADHERENCE IS COMMUNICATED BY CLINICIANS

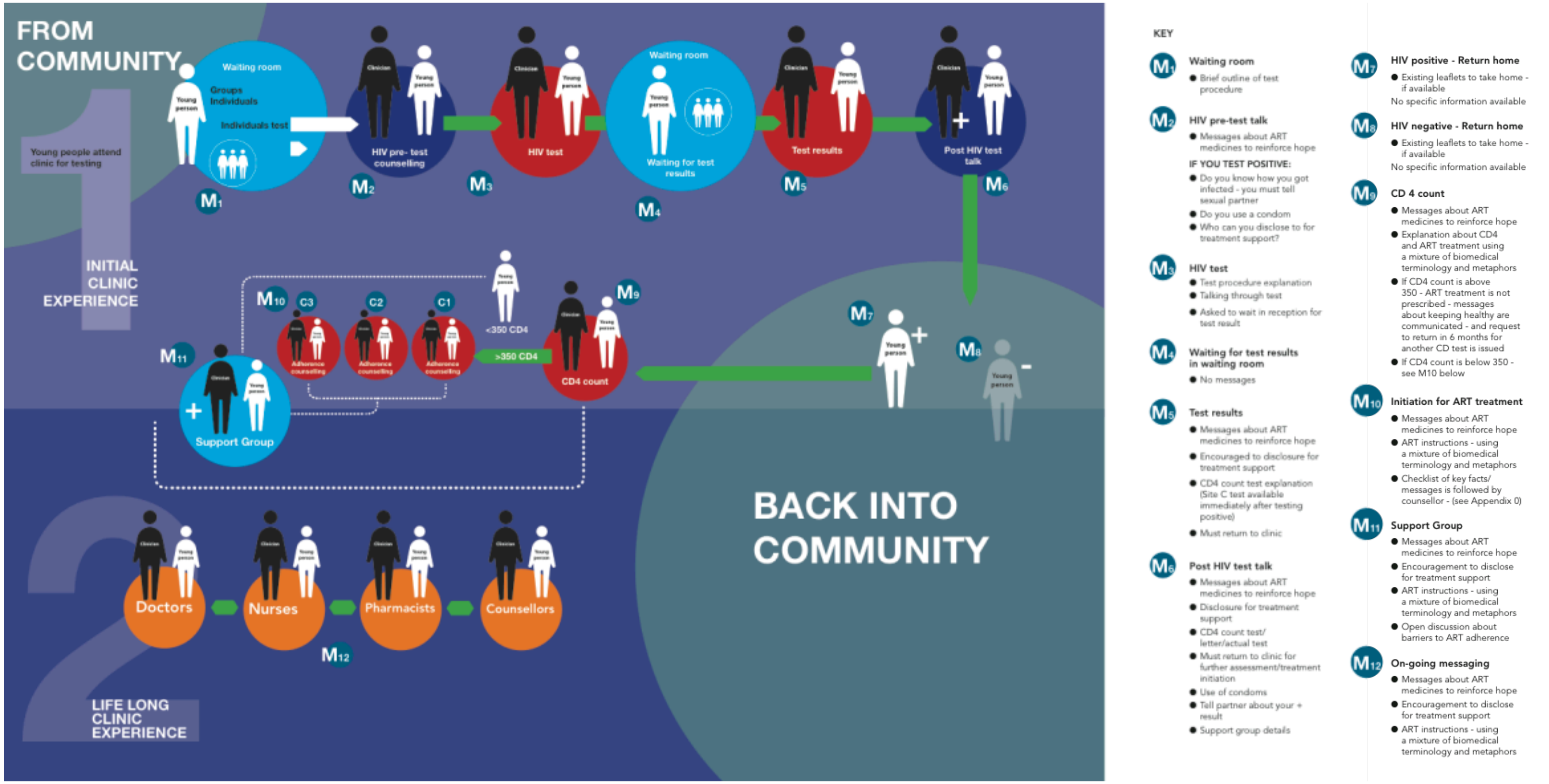
> "…gone are the days whereby you were tested and told that you must go home and wait for the day you are going to die. Now that there is something that is done, there are medicines that can suppress the virus and boost back your immune system, it's important to do the test so that if you are positive, then you can take the treatment that is going to suppress it."
>
> (Awonke, HIV counsellor, 28 February 2011)

6.1 Introduction

In chapter one I discussed how clinicians and health workers use a hybrid of ART messages which draw upon a mixture of metaphors and bio-medical terminology, and are framed by local historical treatment narratives. It was within this context, through the use of participant observation, that I explored the messages communicated by clinicians at the different stages of HIV health care in Khayelitsha (see Figure 6.1).

The stages included the initial wait for the HIV test in the clinic, the HIV test itself, communicating the test results, arranging a CD4 count test, doing the CD4 count test, three ART initiation counselling sessions, dispensing the pills, and on-going conversations between the person diagnosed as HIV positive and the pharmacist, nurses and doctors throughout the healthcare journey. Emerging concepts and categories were identified through grounded theory analysis and triangulated on an ongoing basis with further data that were gathered from focus groups and semi-structured interviews, as described in chapter five.

Figure 6.1: The healthcare journey that shows the clinical spaces where ART adherence messages were communicated to young people who had tested HIV positive by clinicians



KEY

M1 Waiting room
- Brief outline of test procedure

M2 HIV pre-test talk
- Messages about ART medicines to reinforce hope

IF YOU TEST POSITIVE:
- Do you know how you got infected - you must tell sexual partner
- Do you use a condom
- Who can you disclose to for treatment support?

M3 HIV test
- Test procedure explanation
- Talking through test
- Asked to wait in reception for test result

M4 Waiting for test results in waiting room
- No messages

M5 Test results
- Messages about ART medicines to reinforce hope
- Encouraged to disclosure for treatment support
- CD4 count test explanation (Site C test available immediately after testing positive)
- Must return to clinic

M6 Post HIV test talk
- Messages about ART medicines to reinforce hope
- Disclosure for treatment support
- CD4 count test/ letter/actual test
- Must return to clinic for further assessment/treatment initiation
- Use of condoms
- Tell partner about your + result
- Support group details

M7 HIV positive - Return home
- Existing leaflets to take home - if available

No specific information available

M8 HIV negative - Return home
- Existing leaflets to take home - if available

No specific information available

M9 CD 4 count
- Messages about ART medicines to reinforce hope
- Explanation about CD4 and ART treatment using a mixture of biomedical terminology and metaphors
- If CD4 count is above 350 - ART treatment is not prescribed - messages about keeping healthy are communicated - and request to return in 6 months for another CD test is issued
- If CD4 count is below 350 - see M10 below

M10 Initiation for ART treatment
- Messages about ART medicines to reinforce hope
- ART instructions - using a mixture of biomedical terminology and metaphors
- Checklist of key facts/ messages is followed by counsellor - (see Appendix 0)

M11 Support Group
- Messages about ART medicines to reinforce hope
- Encouragement to disclose for treatment support
- ART instructions - using a mixture of biomedical terminology and metaphors
- Open discussion about barriers to ART adherence

M12 On-going messaging
- Messages about ART medicines to reinforce hope
- Encouragement to disclose for treatment support
- ART instructions - using a mixture of biomedical terminology and metaphors

The analysis identified six key message elements that were used by clinicians to communicate ART adherence. The messages were (i) encouraging hope; (ii) explaining HIV, CD4 and treatment; (iii) talking about pill timings; (iv) identifying your pills; (v) talking about side effects, and (vi) encouraging healthy living. In this chapter I examine each of these in depth, describing the message itself, the challenges that clinicians faced in communicating it, and ways in which they attempted to overcome these challenges.

6.2 Encouraging hope

During observation it became evident that the message of hope was communicated immediately after diagnosis, especially when a young person became distressed after learning that they were HIV positive. This message was shared principally by HIV counsellors, who are the main providers of HIV testing throughout the clinics, although nurses and doctors also spoke of how they communicated hope during their consultations with young people.

The quote at the start of this chapter illustrates how the introduction of ART in 2004 has radically transformed the message that is communicated to people newly diagnosed with HIV. Prior to 2004, Awonke, the counsellor quoted above, repeatedly faced the need to tell people who had become infected "to go home and wait for the day you are going to die". However, since the national roll-out of ART throughout South Africa, she can tell her patients that HIV is a manageable chronic illness that is treatable by taking ART. In this way a key part of her message has become the element of hope. This was also reported by other clinicians and health workers
The message of hope, however, is conditional. One local HIV counsellor expressed it as follows:

> "I explain like this: there is hope if you are taking your medication the right way..."
>
> (Cardel, HIV counsellor, 28 February 2011)

Discussion stimulated by drawings made during the visual thinking exercise (see section 5.3.3) provided further evidence for a focus on conditional hope in communications immediately following diagnosis. For example, Figure 6.2 shows a drawing of a young person standing with their partner and child, outside their place of work, which represents them as a normal happy family who are able to work to support their children. However the writing above the figures - "BUT IF U take ARVs" - represents the fact that this is only possible if the young person who has been diagnosed as HIV positive attends the clinic for a CD4 count, successfully engages in a treatment programme and fully adheres to their antiretroviral (ARV) medicine.

Figure 6.2: HIV counsellor's drawing showing the relationship between ART and the message of hope. Source: Visual thinking exercise, clinicians' focus group (28 February 2011).

Several nurses and doctors confirmed that they also communicated hope as conditional. Not becoming sick and suffering an early death could only be guaranteed if a young person was willing to return to the clinic and fully engage with an ART treatment programme. One doctor explained it like this:

> "The key message I want them to know, to remember, even if they forget everything else, is to know that there is hope; that they are not going to die today or tomorrow or in a week. There is treatment, they can live a normal life, they just have to come back and follow the correct programme."
>
> (Mandy, Doctor, 11 April 2011)

It was clear that young people were often extremely distressed when they were told that their test result was positive, and this was a major challenge to communication at this time. In chapter seven I will explore this in more depth, and describe young people's responses to these messages of hope.

6.3 Explaining CD4, HIV and treatment

Once a young person has been told that their test result is positive, they are asked to sit in reception and wait for the nurse to see them. The nurse then explains to them that they need to come back to the clinic for a CD 4 blood test. When they do so, the nurse explains that if the CD4 count is above 350* and they are without further health complications (for example suffering from tuberculosis), there is no need for them to begin ART at that time. They are then encouraged to live a healthy lifestyle and return to the clinic at four- to six-month intervals for ongoing monitoring. If, however their CD4 count is below 350, they would need to start ART immediately.

Clinicians spoke of how difficult it was to explain the biomedical concept of CD4, especially in the context of HIV infection and treatment. The majority of clinicians attempted to address this difficulty by using a series of metaphors (as described in section 1.3), including the description of CD4 cells as "soldiers of the body" (*amasokha omzimba*), which form a person's immunity. HIV was described as a monster who attacks the immune system, destroying the "soldiers" (CD4 cells), who are unable to combat the infection. Clinicians believed that using these metaphors helped young people to understand these complex concepts, especially if they had difficulty to read and write:

> "Our patients, most of them, they didn't go to school, they are HIV positive, and we don't usually talk about CD4 count, we are usually saying '*amajolo omsimba*', and then... '*soldiers of the body*'... they understand clear."

(Isebel, HIV counsellor, 28 February 2011)

---

* WHO guidelines have revised the criteria for ART initiation, now recommending that all people who test positive are eligible for treatment - moving away from CD4 criteria. Since this study was carried out the South African Department of Health's criteria for treatment is currently CD4<500, with the intention to adopt the WHO recommendations in the near future.

The use of metaphors to explain ART adherence was particularly evident in a drawing by one of the nurses (Figure 6.3). The drawing shows two parallel narratives. The first, across the top half of paper, is titled “NO ARVs”, and describes the story of a young person who fails to adhere to their ART. It shows a young person crying because HIV (symbolised by monster bugs) are attacking the body, resulting in the destruction of the CD4 cells. In contrast the second narrative, shown across the bottom half of the paper and titled “TAKING ARVS,” shows a young person who is happy because they are taking their medicines properly, resulting in the virus going away.

Figure 6.3: Drawing by Odele (nurse), showing the use of metaphors in explaining the consequences of taking ARVs or failing to take them. Source: Visual thinking exercise, nurses’ focus group, 9 March 2011.

Similar metaphors were included in doctors' explanations of CD4, HIV infection and ART. For example, Figure 6.4 reproduces a series of pictures drawn by a doctor, showing how she explained to young people why they must come back to the clinic for a CD4 count, and why they must take ART. The first drawing shows a human figure with a lot of circles on the outside edge. These represent a healthy CD4 count of 500 to 1000 cells / mm^3. The doctor then drew two monster faces on the right hand side of the paper, designed to represent the HIV virus. These, she said, attack the CD4 cells, making a person very ill. She illustrated this by drawing a thin person with only a few circles around their body.

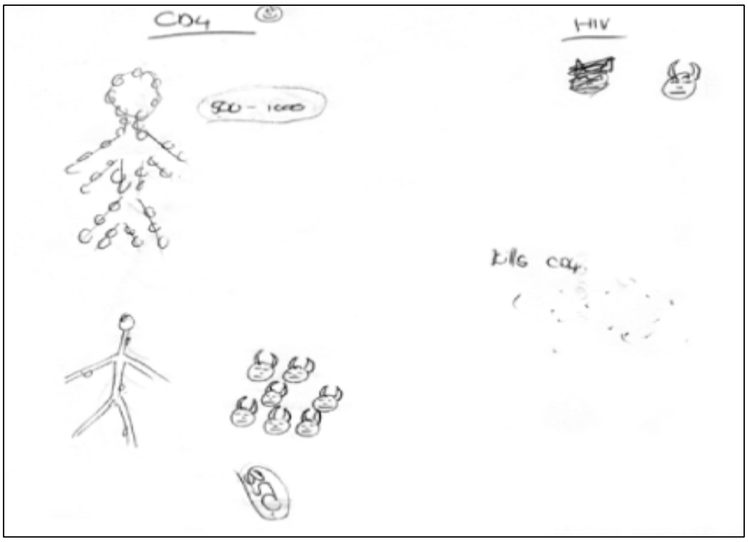


Figure 6.4: Drawing by Mandy (doctor), showing how she explains why young people must come back to the clinic for a CD4 count and take ART. Source: Visual thinking exercise, doctors' focus group, 11 March 2011.

She then explained how ART reduces the HIV virus to an undetectable level, a message that she reinforced by rendering over the face of one of the monsters, saying "the ARVs make the virus go away, but not totally".

The doctor, Mandy, believed that using metaphors helped her to communicate these medical concepts simply:

> "What I find is to keep it as simple as possible, so to explain it in very simple terms and not to use very high medical words or a concept that they are not going to understand."

(Mandy, Doctor, 11 April 2011)

Although young people often used medical terminology such as viral load and CD4 during consultations, she was still not confident that they fully understood:

> "... they will come and they will say what's my viral load or what's my CD4 and then I'll ask them to explain them to me; what it is a viral load; and then they won't know. So they just throwing around these words that they hear, but they have no idea what it means."

(Mandy, Doctor, 11 April 2011)

Mandy's concern that young people found these messages difficult to understand was echoed by other clinicians and also by young people themselves. Specifically, a misunderstanding of viral loads could cause people to stop treatment altogether:

> "… I have a friend, he came and was told he has an undetectable viral load, then he said he was OK now, so he stopped taking his ARVs. They do that, they stop because they think that they are OK."

(Ziyanda, young woman with HIV, 11 December 2013)

Two clinicians also spoke of how young people can misinterpret 'undetectable viral load' to mean that they no longer need treatment:

> "…now they have an undetectable viral load and that they feel and look well, they think they are fine so they stop, they fail then."

(Sandra, Nursing Sister, 11 December 2013)

> "They hear their results and think they are OK, they leave and we don't see them then."

(Simon, Clinic manager, 11 December 2013)

Overall, although clinicians used metaphors to simplify the complexity of this message, most of them remained sceptical about the effectiveness of doing so. The above comments show that young people’s understanding of the bio-medical concepts of CD4, HIV infection and ART remains limited, and that this can have serious consequences, including their abandonment of taking medication.

6.4 Talking about pill times

Another key message element was to do with pill times. This is a particularly important aspect of ART adherence as a minimum compliance of 90 – 95% is required (WHO, 2013). In other words, a person can only miss an average of three doses per month. Getting young people to understand the importance of taking their medication every day was therefore seen as a priority, and was communicated repeatedly by all clinicians throughout the clinical pathway. There was an overwhelming consensus among clinicians that this was one of the most difficult aspects of adherence for young people, who would often forget to take their medicine. Therefore clinicians would encourage young people to use a series of available tools and aids to assist them. These included pillboxes, which were supplied by pharmacists at the clinics, or a tick sheet provided by HIV counsellors.

It was widely recognised by clinicians that when young people had support from a treatment assistant or family members they were more likely to take their pills on time. Some clinicians strongly encouraged young people to ask a trusted friend or family member to become a treatment assistant or “buddy” who was committed to helping them to remember to take their pills. Others recommended that the treatment assistant should be another young person on ART:

> “… if somebody is a treatment assistant and they are also on their own medication, it works wonders. Because then they know, they’ve been through it and they’ve overcome it, so that they can reassure the one that is about to start.”
>
> (Linda, Nurse, 9 March 2011)

Both nurses and counsellors encouraged young people to disclose their status so that they did not feel that they had to hide their tablets from their family or friends. Otherwise this could cause them to miss or forget to take their medication for that day:

> "… we normally encourage the patient to disclosure, because it affects them when they take the tablets. Imagine I'm now the only one at home that takes treatment and everybody doesn't know that I'm HIV positive or am on treatment. I must now always hide the treatment; that can also affect the time of taking the medication..."
>
> (Sally, Nurse, 9 March 2011)

This message was particularly difficult for young people who, due to their perceived fear of stigma, were anxious about the potential consequences of disclosure. This will be explored in more detail in chapter eight.

Clinicians attempted to explain to young people that the reason that they should take their pills every day was so that they could achieve an undetectable viral load. This concept was difficult to explain, and one nurse attempted to simplify the message by using the example of painkillers:

> "I sometimes make an example to them that you see when you take a pill when you've got a pain, and then you take Panadol or a painkiller, four to six hours that pain will be better or goes away. After that six hours you'll feel like the pain comes back. Then you need to take another painkiller, but with these tablets, you don't feel a pain, but there is a time that you need to take a tablet; you must take tablets within that time, so that's why we tell you that use a time that suits you, if you take it seven in the morning, take it seven in the evening, because at seven p.m. the power of the tablets is now becoming weaker in your blood, thats when the virus kicks in."
>
> (Hentie, Nurse, 9 March 2011)

Explanations of pill timings as described above included encouragement to keep to precise times. Precise times were often aligned to cues that could help them to remember, for example a favourite television program or the daily news. Pharmacists expressed concern that the use of precise pill timings was being misunderstood by young people, who interpreted them as being the *only* times that they could take their medicines:

> "It's like the counsellor said you must take your tablets at eight when it is Generations [A television show that is broadcast at 8pm most evenings]. So, sometimes you're not at home, you are at a prayer meeting or you went somewhere. When you get home oh my word it's half past eight. They don't know you can still take the medicine. So some of them are failing because of issues like that."

(Samantha, Pharmacist, 9 March 2011)

According to both pharmacists and doctors, this was one of the reasons why young people failed their treatment. Therefore they argued that it would be better to explain that there is a "window of time" for taking medication.

6.5 Knowing the name(s) of your pills

Once a young person has completed their ART initiation counselling, they are prescribed medication by a doctor. Once they have the prescription they are able to attend the pharmacy either at clinic 1 and 2 or at the hospital to get their pills. When young people come back for their repeat prescriptions (every three months at the clinics), Pharmacists encourage young people to learn the names of the pills that they have been prescribed, so that they can ask for a new prescription when travelling to another part of South Africa.

However, young people often struggled to remember the names of the pills and preferred to identify them by their shape and colour. This strategy was often compromised because the appearance of the tablets changed regularly as the suppliers' contracts were updated, due to the government-purchasing scheme. According to the pharmacists who attended the focus group this was the main reason to why young people found it so difficult to identify their pills properly:

> "And the colours of the tablets, the colours of the tablets, that's also confusing. One time it was one colour and the next month it was another colour... Which is very bad…So if it's going to change so often, that's obviously going to confuse them even more."

(Jenny, Pharmacist, 9 March 2011)

Another pharmacist described how young people further complicate pill identification by transferring pills from their original packaging into clear plastic bags or vitamin tablet containers. This, she said, was common practice, because people were anxious that their family members might recognise the pills as HIV medication and therefore find out about their HIV status:

> "You see, they hide the containers and they put everything in one bag, and that's where the confusion lies. I mean they will sit on the chairs and they will get rid of the boxes and they will squeeze them out and then put them in a plastic bag or vitamin thing; that's where the confusion lies. Because now they don't know what is what."

(Samantha, Pharmacist, 9 March 2011)

In spite of these problems, pharmacists emphasised how important it was to teach young people the names of their pills:

> "I think if you teach the patient, educate the patients about the medication given, it doesn't matter... if they know which regime they're on….That is very important. Patient education."

(Jane, Pharmacist, 9 March 2011)

One solution that was suggested was as follows:

> "…Have a piece of paper that you write what regimen you're on, you know, have it on a piece of paper. Hide it somewhere in your wallet or whatever, because you could by lying in hospital and the doctors don't know what regimen…"

(Samantha, Pharmacist, 9 March 2011)

6.6 Explaining side effects

Explaining side effects emerged as an important message element during the three ART initiation sessions, the consultations with nurses and doctors and at the time of pill collections from pharmacists. Clinicians discussed the serious risk of young people stopping their ART medicines because of side effects. One nurse spoke of how important it was to explain the potential side effects clearly during the early stages of taking ART, and to make it clear how important it was for patients to continue to take the tablets:

> "You explain that there could be side effects, especially when you start your ARVs. And you explain which side effects people normally experience, so that when you give tablets they don't stop their medication when they feel that the medication makes them sick."

(Jadine, Nurse, 9 March 2011)

Nurses recommended that during the early phase of ART, a young person would benefit from having a treatment assistant to support them whilst they were suffering side effects. They believed that the treatment assistant should be a young person who had also experienced side effects in the early stages of taking ART, and who now lives a normal life. The testimony of this person, according to nurses and counsellors, could encourage the person who is suffering side effects to continue their treatment.

Although nurses encouraged young people to continue ART despite experiencing difficult side effects, they also explained how important it was to ensure that young people understood that some side effects were very dangerous and should be reported immediately to them or to a doctor. According to counsellors this was difficult to explain, as they did not want young people to become frightened of taking their medication. To help communicate this message they used a tick sheet (Appendix 5) to separate normal side effects from those that were dangerous and should be reported:

> "We even give them papers where they tick, say for instance the patient starts ARVs today, so they must notice or must be vigilant what happen. Did I feel dizzy? Did I feel nausea, or whatever, any symptoms on the first day that you start? That's why I said they must watch anything, especially from the first day that they start; they must be vigilant and see what happened and if they see something; or they experience something, you must come and report it."

(Jerimia, counsellor, 28 February 2011)

Similarly pharmacists used a chart to help them communicate about the different ART tablets and the related potential side effects.

6.7 Encouraging a healthy lifestyle

Young people whose CD4 count was 350 or above, and who were therefore told that they did not yet need treatment, were encouraged by clinicians to maintain a healthy lifestyle in order to strengthen their immune system. This message was communicated on receipt of their CD4 count test result, and also during the three ART initiation sessions. People were advised to eat fresh fruit and vegetables, drink lots of water, exercise regularly and always use a condom during sexual intercourse. Nurses encouraged young people to eat a mixture of five fruits and vegetables per day in their diet, so that they gained the right balance of nutrients to support their immune system. However, occasionally young people would tell them that they could not afford to purchase fresh foods:

> "It's not easy to a lot of people, they will tell you that they are unemployed, '*I'm not working…'* Some of them will come to the clinic and tell you '*I didn't take my tablets, because I didn't have food to eat*'…"

(Julie, Nurse, 9 March 2011)

There was also some evidence of cultural barriers that made it difficult for young people to respond to this message. For example, during an ART initiation counselling session one patient seemed to struggle with the idea of including fresh food into her diet because "my mother does not use these foods and we don't know how to cook them".

Safe sex was also included in the "healthy living" message, with nurses and counsellors encouraging young people to wear a condom even if their partner was also HIV positive. This was because each person could become re-infected with another strain or sub-type of the virus. According to doctors this was particularly difficult to communicate to young people and often created considerable confusion. One of the doctors expanded on the idea of re-infection, describing the risk in terms of drug resistance rather than co-infection of virus sub-types. A doctor explained how a person ART can pass levels of ART through insemination, which can cause them to become resistant to that particular treatment regime:

> "Well, if they are both on ARVs, and say the one is not taking her ARVs as well as the other one, then he builds up a resistant HIV, so then they tell you have maybe a resistance ARVs... now you're giving this resistant HIV to that other person, so when she's taking her drugs, she also becomes resistant...it's very tricky to explain…"

(Ellie, Doctor, 11 April 2011)

A number of clinicians spoke of a further challenge related to the message to maintain a healthy lifestyle, which is that this is sometimes misinterpreted to mean that as long as someone "looks healthy", they do not need to return to the clinic for further monitoring and / or treatment.

6.8 Conclusions

This chapter has shown that ART adherence communication in Khayelitsha is comprised of a series of message elements which are more complex than they at first appear. Because of this, their communication to young people presents some substantial challenges. In this section I discuss each message element in the context of the literature, and show how the findings informed the development of the visual communication tool that is the subject of chapter eight.

6.8.1 ART, hope

It has been shown that clinicians recognise the initial despair that young people feel when they are told that they are HIV positive (this will be explored further in chapter eight), and respond by offering reassurance and hope that young people can continue to enjoy their present and future lives, because HIV is a treatable condition. This approach is typical of the Health Belief Model (HBM) discussed in section 4.2.1, which centralises the benefits of a health intervention or treatment as the key determinant to becoming motivated to the proposed behaviour (Champion & Skinner, 2008). According to Janz and Becker (1984), the HBM posits that a patient is only able to engage with messages that outline the benefits of a health intervention or treatment once they have become "sufficiently threatened" by the disease or non-healthy behaviour. Witte (1992) argues that the fear of illness and death can "concentrate the mind" and this then motivates an individual to adhere to a "preventative" behaviour. Whilst in this case young people's traumatic response to their diagnosis was not a result of any health communication intervention, it nevertheless prompted clinicians to communicate hope as a benefit of ART adherence. Therefore, hope was only attainable if a young person was willing to return to the clinic for further health care and take their medication every day. In line with HBM this message is communicated in the belief that a young person will become motivated to adhere to ART because they have understood its benefits. However, as discussed in chapter eight, this was not seen as the key determinant that motivated young people to adhere to ART.

6.8.2 CD4, HIV and treatment

Clinicians working in Khayelitsha found it particularly difficult to explain to young people the relationship between CD4, Viral load, HIV infection and ART. The main narrative used by clinicians to explain these complex concepts included a mixture of both metaphors and medical terminology, which were the same as those discussed by Ashforth and Natrass (2005) (see section 1.3). According to Periyakoil, (2008) the concept of metaphor originates from the Greek root *metapheiren*, defined as the process of "willing to transfer" a narrative that is used to clarify the meaning of a complex concept by translating it into familiar terms. However, as Rubincam (2013) argues, metaphors run the risk of being misunderstood. This study showed that metaphors used in treatment narratives were vulnerable to misinterpretation, especially when used to explain the concept of achieving an undetectable viral load. Clinicians reported that in some cases young people understood the term to mean that they no longer needed to continue with their treatment[2]. This confusion may arise because both "CD4" and "viral load" are used as biomedical measures during a young person's healthcare. The CD4 count is used as the metric to determine when treatment should begin, whilst treatment success is determined by a person's "viral

---

[2] Once a young person has been initiated onto ART, they are periodically tested (from a blood sample) to measure their HIV viral load (amount of HIV virus that remains detectable in their blood). If they have maintained optimal adherence the viral load becomes so minimal that it is 'undetectable' using conventional laboratory assays; hence the term 'undetectable viral load'.

load" (how many copies of the HIV genome remain detectable in the blood). The viral load becomes "undetectable" when a person is successfully adhering to ART. However, young people may adopt their CD4 count as the main marker of treatment success, because treatment enables the CD4 count to rise. This would seem a logical position, since their initiation onto treatment was determined by a low CD4 count.
According to Meintjes (2012) and Battegay et al. (2006), using CD4 as the main marker for treatment success can be misleading in some patients for measuring adherence and treatment success, because even when there is an undetectable viral load, the CD4 count may not return to the pre-infection range. Meintjes (2012) discusses other ways in which a CD4 count can be misleading for measuring treatment success. For example, a patient who recently became poorly adherent may show a stable CD4 count alongside an increasing viral load. This, as Meintjes (2012) describes, is because as non-adherence develops, a person's viral load will increase before their CD4 count begins to fall. If in these cases the individual focuses only on their CD4 count, they are in danger of developing a false sense of security that their medication is still working in spite of their non-adherence. Meintjes (2012) argues that it is because of these issues that clinicians and young people alike should shift their primary attention onto achieving and sustaining an undetectable viral load rather than a restored/stable CD4 count. It is essential therefore that adherence communication separates the CD4 count message from viral load message, emphasising that achieving and maintaining an undetectable viral load should be the main aim for young people .

6.8.3 Talking about Pill timings

Clinicians and health workers emphasised to young people that ART adherence meant taking their pills every day at the same time. To help young people remember their pill times health workers would suggest that they used a favourite television program as a cue to remind them to take their medication. However in line with the literature discussed in section 2.3.3, young people were susceptible to interpreting these messages too literally, believing that the pill times communicated were the *only* times that they could take their medication. This literal interpretation was cited as one of the main reasons why young people fail treatment. As described above in the previous section ART messages are vulnerable to mis-interpretations that should be carefully considered during the design of health messages and during the production of health communication materials aimed at low-literate populations.

Young people were also encouraged to disclose their HIV status to a trusted family member or friend, who could then act as a “treatment buddy” offering them regular adherence support (including reminding them to take their pills). This strategy is supported by several of the behavioural models described in chapter four. The Theory of Reasoned Action (TRA) and Theory of Planned Behaviour (TPB) models (section 4.2.3) argue that self-efficacy is more likely to occur when a supportive individual or social group encourages a new proposed health behaviour (Taylor et al., 2007; Montaño & Kasrzk, 2008:76). Social Cognitive Theory (section 4.2.4) also argues that mastering specific health behaviours, such as taking medication regularly, is dependent on “efficacy builders” who provide support (McAlister, Perry & Parcel, 2008:170). However this message was particularly challenging to young people who found the idea of disclosure very difficult because of their perceived fear of stigmatisation. This is in line with studies that were discussed in section 3.4, which found that social isolation due to non-disclosure was a significant barrier to adherence among young people who live with HIV (Hosek, Harper & Domanico., 2005; Veinot et al., 2006; Rao et al., 2007; Abramowitz et al., 2009; Vivayan et al., 2009).

6.8.5 Identifying pills

Clinicians encouraged young people to learn the names of their medication so that they could tell other medical professionals what ART regime they had been prescribed if they were away from home or became hospitalised. A common practice that made this very difficult was that young people would re-package their pills into clear plastic bags or vitamin containers in order to hide their identity. This was due to the fear that the medication, if identified by a family member or friend, would automatically disclose their status. This finding confirms the significance of felt stigma (the fear of experiencing stigma) as a barrier to adherence, as reported by Veinot et al. (2006); Lam, Naar-King and Wright (2007), and Rao et al. (2007) (see section 3.3.5).

It is clear that at the time of this study, felt stigma was a significant concern among young people in Khayelitsha, causing them to remain isolated from support and to hide their medication from family members and friends. This has some important implications for the design of an ART adherence communication strategy, in that unless perceptions of HIV and AIDS are addressed in the wider community, it is likely that stigma will continue to undermine a young person's potential to successfully adhere to ART. I discuss this further in chapter ten.

6.8.6 Talking about side effects

As clinicians explain pill timings to young people with HIV, they also address the issue of the side effects that may be experienced in the early stages of ART. Young people spoke of their "fear of the pills" because they had heard rumours of how ART can make them very sick. However according to Veinot et al. (2006) the fear of potential side effects is more likely to be a barrier to adherence than the actual experience of side effects. Clinicians addressed these fears by reassuring young people that most side effects were normal and would eventually subside. However, they also had to explain that some side effects were serious, and that if people experienced symptoms related to these, they should report them. They therefore faced a potential contradiction between encouraging people to work through harmless side effects and warning them to report the more serious side effects.

Health Belief Models (discussed in section 4.2) recognize that an individual may weigh up the "pros and cons" of enacting a health behaviour based on the information available to them, and that this may result in a decision to disengage completely from treatment (Taylor et al., 2007). In order prevent disengagement, Taylor et al. (2007) used a visual communication tool to address young people's fear of side effects, and this could be a useful element in a communication strategy. However, this study did not examine how effective this was in helping young people recognise the difference between normal and dangerous side effects.

6.8.7 Encouraging Healthy Living

Clinicians encouraged young people to live a 'healthy lifestyle', including eating healthily, not drinking alcohol or smoking drugs and wearing a condom during sexual intercourse. Findings showed, however, that these behaviours (other than the prohibition of alcohol and smoking drugs) were seen as difficult to perform and integrate into daily living. For example eating healthily was dependent upon affordability as well as having the knowledge and ability to prepare and cook healthy food. These factors are related to a person's "perceived behavioural control" (in the TRA / TPB behavioural models), recognising that a given health behaviour may well depend upon the wider contexts of an individual's life-world that include their financial circumstances, time and ability and skills (Ajzen.1991; Montaño & Kasprzk, 2008). Dutta (2008) argues that health communication messages of these types, which focus on behavioural change but do not consider the structural barriers that often exist within marginalised communities, are likely to fail, because the proposed health behaviour cannot be enacted due to poverty and lack of resources. It is clear from this study that these messages need to be linked support for young people to access available financial resources as well as places / information where they and family members can learn how to cook fresh foods.

Wearing a condom was also emphasised by health workers as part of the healthy living message. Clinicians found this message particularly complex to communicate as it related to risk of HIV co-infection and passing ART across to a partner through insemination. This is an area that will benefit from further research in the future.

6.8.8. Summary

In summary, it was clear that clinicians found it very difficult to explain the complexity of ART adherence, and despite their attempts to simplify the messages through the use of metaphors, young people found them difficult to understand, or at worst misinterpreted them altogether. Based on these findings, in the final phase of fieldwork a prototype animation was developed and piloted which focused on the two messages that were related to misinterpretation of the treatment regime: (i) explaining CD4, HIV and treatment, especially the concept of 'undetectable viral load'; and (ii) "talking about pill timings". The animation is the subject of chapter eight.

CHAPTER 7: BECOMING MOTIVATED TO ADHERE TO ART

Warren: “What are the message elements that would work best in a new communication that would help motivate the young people to adhere to ART medicines?”

Unahti (young man living with HIV): “Well Warren, this is not where we begin, we don’t start here, we start at the beginning!”

(7 April 2011)

7.1 Introduction

The previous chapter explored the current messages that are used to explain ART adherence and described how clinicians use a hybrid of metaphors and bio-medical terminology for this purpose. Their approach is informed by a variety of health behaviour models that frame motivation to adherence as an outcome of people’s understanding of the benefits of treatment in relationship to the associated risks of living with HIV. Therefore their communications focus on the transmission of factual knowledge and the facilitation of understanding about how to adhere to ART. As shown in the quote at the head of this chapter, however, young people did not prioritise the communication of information post-diagnosis. Therefore, in order to develop a communication strategy and define the role of visual communication tools, it was important to move away from looking at communication message content in isolation and begin to look more broadly at people’s experiences of living with HIV, from diagnosis onwards, and to explore what had either motivated them to adhere to ART or hindered them from doing so. I therefore asked them to tell their stories from the beginning during focus groups, semi-structured interviews and participant observation.

The analysis of their stories identified three stages of young people’s journeys to become motivated to adhere to ART: how they respond to a positive HIV test result (Diagnosis Trauma); coming to terms with being HIV-positive (Acceptance and support), and learning about ART (Learning to live with HIV). In this chapter I explore each of these in turn, describing the communication process that can facilitate young people's motivation to ART adherence.

7.2 Diagnosis trauma

In the previous chapter I reported how clinicians communicated hope to young people post-diagnosis, which included telling young people that they could continue to live normal lives because HIV is a treatable condition. Whilst clinicians believed that young people were listening to these messages, the initial response most commonly reported by participants was that they were unable to hear them because they are so shocked by their HIV test result. For example during one of the focus groups a young woman stated:

> "When you first receive the HIV- positive results, first of all you don't listen – whatever comes out after you were told that you're HIV-positive, you don't listen…"

(Charne, young woman living with HIV, 7 April 2011)

There was only one exception to the many accounts where young people described the shock of receiving an HIV diagnosis. One young woman who had been born HIV-positive and had suffered the loss of her mother to AIDS when she was very young described how she was happy to have received an HIV-positive diagnosis: "Ja... I was happy, because my mother died when I was young and I grew up with my grandmother. I've always been sick, so when I know that I was HIV-positive, I was happy, because everyone didn't find the reason why I got sick every time I didn't go to school, because I was sick. So I was happy, because I could find the reason why I'm always sick."

Young woman living with HIV, 7 April 2011)

Analysis identified four components of diagnosis trauma that young people commonly experienced. I will now examine these in detail.

7.2.1 The fear of rejection and loss of identity

It became evident that the trauma that young people suffered upon receiving their diagnosis was connected to a fear that they would be rejected by significant others, which left them feeling completely hopeless. For example whilst waiting for his test result at the clinic, one young man described what an HIV-positive diagnosis would mean for him:

> "I'd lose my girlfriend, and then no woman would ever want to be with me ever again, then I could not have children and no one would ever give me a job and I will never be able to buy a house… my life would be over!"

(Akhona, young man, 25 February 2011)

Throughout the study young people expressed similar views and several HIV counsellors confirmed that this was a common reaction amongst them. During a semi-structured interview another young man who was waiting for his test results at the clinic described how his life would end if he was diagnosed as HIV-positive because he would lose his family and friends

Receiving an HIV-positive diagnosis triggered a fear that young people would be rejected by significant others within their belonging groups, where their relational self-identities were defined and affirmed. For young people it was these relationships that provided the contexts of where and how they lived their present lives and with whom they invested their future hopes. Being told that they had tested positive caused them to fear that these relationships and associated identities would be destroyed, all of which left them with an overwhelming sense of hopelessness and isolation.

7.2.2 The fear of becoming sick and dying

Figure 7.1 A drawing that represents the fear of becoming sick and dying made during a focus group

In addition to this, receiving a diagnosis caused young people to feel frightened that they will become sick and suffer an early death. This was particularly evident during the young women's focus group, where a number of participants drew themselves in coffins (Fig.7.1) that represented that they were "*afraid of being sick and dying"*. Although clinicians reassured them that HIV was now a treatable disease, the suddenness of hearing that they were HIV-positive re-activated their memories of people they had lost to AIDS, including parents, brothers, sisters, friends and community members. This compounded their fear that they too would become sick and die.

7.2.3 The shock of being infected by someone

When young people heard that they were HIV-positive they felt shocked, not only because thay had become infected but also because they had been infected by someone. Coming to terms with the fact that a trusted sexual partner, or someone they had shared an intimate moment with, had infected them created feelings of betrayal. Sometimes they became suspicious as to why their partner had kept their status from them whilst continuing to engage in unprotected sex, which constantly placed them at risk of becoming infected. Therefore receiving an HIV-positive diagnosis presented two realities that young people struggled with, neither of which could be reversed or changed: the reality of the infection itself and the reality that someone they were close to had infected them.

7.2.4 Responding with disbelief and faith

Despite being told post-diagnosis about the benefits of ART, some young people chose not to believe their HIV test results. As a result they either sought a second test to disprove the initial result, or as one doctor explained, "they are so distraught that they go home never to be seen again”. Obviously this study did not reach these people because they were absent from the clinics, but it did engage with many of those who had initially experienced denial and returned to the clinics for treatment.

Some young people also responded to their diagnosis by attending churches where it was believed that HIV was a result of sin, and therefore could be healed through prayer. One counsellor said that how young people often came back to tell him that they were no longer HIV-positive because their pastor had prayed for them and had told them that they had been healed.

7.4.3 Acceptance and support

As described above, immediately after their diagnosis young people were unable to hear the messages that clinicians communicated to them. In response to this finding I began to ask young people what they had wanted to hear at that time. In response they described two forms of communication that would have met their needs. The first would have been to hear stories of other young people who had survived the ordeal that they were now experiencing. This could offer them hope and reassure them that they would not become sick and die. As one young woman explained:

> … you need to show them that there is hope, that there is a light at the end of the tunnel; that they won't be sick, that they won't be wheelchair bound; that they won't die if they take very good care of… they must someone who is also HIV-positive, who has walked that road before, can come and hold their hands through that process.

(Lakhela, young woman living with HIV, 7 April 2011)

Young people wanted these stories to be provided in the form of a DVD that they could take home with them, so that they could view it in the privacy of their own homes. They believed that this would help them to process the reality of their HIV-positive diagnosis. In chapter nine I describe how I produced a small film in response to this, which showcases how one local young man learned to live with HIV.

The second form of communication that young people wanted to experience at this juncture was to receive reassurance that their families would continue to love, accept and support them, irrespective of their diagnosis. This was particularly evident during a focus group with young people who were living with HIV. As we explored what was the most important thing that they needed to hear and experience immediately after they had received their diagnosis, a young man in the group, a 16-year-old who was sitting next to me, suddenly looked up and with tears in his eyes and said "it's simple, it's simple, the answer is 'love'". His contribution was followed by an overwhelming consensus from the group that the most important thing young people felt that they needed to know post-diagnosis was that they would be accepted and supported by their family member(s).

Young people felt particularly vulnerable immediately after they had been diagnosed as HIV-positive. They identified the need to feel loved and reassured by a family member(s) as one of the most important factors in coming to terms with the diagnosis. Many young people actively sought affirmation and support from their parents or carers immediately or soon after diagnosis. Acceptance and love from family members meant that although they had become infected with HIV, fundamentally nothing had changed for them.

7.4.3.1 Moving towards acceptance and support

Gaining acceptance and support from a family member(s) was seen as a challenge among young people because in order to do this, they first had to communicate their recent diagnosis. For some, this communicative act of "telling" was not difficult and family members told them that they remained loved and accepted. For example Anika, a young woman living with HIV, described how immediately after her diagnosis she longed for the support of her mother, who had died previously of AIDS, but phoned her cousin, who then came to console her, and reassured her that she would be fine. The support that Anika received from her cousin helped her to accept her diagnosis and to find the courage to tell her uncle about her test result. Although she said he was a very strict man, he responded by hugging her and crying with her, reassuring her that she would be fine.

Whilst this account offers a positive outcome from the act of telling, in many cases young people were not confident about their parents' or wider families' responses. Many of them feared that they would be rejected. In some cases rejection was seen as a punishment, because it was seen as a result of doing something wrong:

> “Ya, it’s sort of when, it’s when you are growing and sometimes you are naughty and you are stealing some people’s stuff. That I have done something wrong, they be angry at home for me. They say no, go out, we don’t want you here, you’re just a cruel person who is just a criminal.
>
> (Isake, Young man living with HIV, 15 October 2011)

In response to the possibility of being rejected by family members some young people had decided to come to the clinics in groups, so they could support one another if one or more became infected, as explained by a group of young men:

> Jaco: "I go with my friends, like go to the same room with them, they must know. I go with my friends and then like they must know my status. We always open to each other. That's what we normally tell to support each other. We talk about this every day."
>
> Jeremia: "Like, if they are my friends, there's no need to leave them behind. You see I must wait for them…"
>
> Kgaba: "Ya, my friend, I can't leave them behind."
>
> Mava: "Ya, like when you come to the clinic, I don't care about the results…"
>
> Louw: "You see the thing is, we came as a group, all five, you and me, and me positive and him and I negative. In the support that you came as friends and you go as friends."

(Group Interview, 12. November 2011)

Similarly, during a focus group, one young man spoke of how important it was for him to attend the clinic with a close friend, because he knew that they would support him if he were to be diagnosed as HIV-positive:

> "... you know... if you're going the first time. When you go home, you're going to.. you're going to feel lonely and then if there are a friend of yours beside you, someone to lean on, so you got to know that there's life after this..."

(Mbuyiseli, young man, (24 September 2011)

7.5 Learning to live with HIV

As young people began to experience acceptance and support from significant others and/or friends they began to feel motivated to learn about ART. They then began to learn that HIV was a treatable condition and that, providing they take their treatment, they would not get sick or suffer an early death. This knowledge gave young people a sense of control and power over their condition, which over time becomes a normal part of their lives. As they grew in confidence, they began to joke with one another about their infection, because they were no longer frightened or traumatised. This new realisation liberated them and allowed them to go on and live their lives as before. One young woman described the realisation that HIV was a treatable condition as a significant turning point in her life:

> " I just accept it, then you take it as a living thing that you are living within you. Then everything, I mean to say, everything that appears in your body that just take easy and just live your normal life. I think the last time I was here, I even said that it's not a death sentence just like everyone just said now. No, no it's not the end of the world. It's just the beginning of the positive world for you. It's just a step back for a come-back….Ya, a step back is, is step back a set up to a come-back."

(Gatsha, young woman living with HIV, 24 September 2011)

A second young woman described how, as a result of gaining the knowledge that HIV was a manageable chronic condition, she was no longer afraid of her infection:

> "We even tease about it. I'm have AIDS - so what. I'm like all the symptoms are coming now, if you have small rash, you know. If you normally take your pills right and then like you, you take your pills like your blood pressure... you're fine. It's not a monster that controls you, and you take that away, you take the power of it away."

(Icici, Young woman living with HIV, 24 September 2011)

7.5.1 Learning about ART in the family

As family members accepted a young person's diagnosis they would seek out treatment information from the clinics so that they were able to understand how to properly support their loved one. One young woman spoke of how her mother went to the clinic to learn about ART:

> "My mother accepted my status, and while I was sick she went to the clinic to ask about the pills so she could support me. From then she made sure I took the pills every day, my mother saved my life."

Iminathi, young woman living with HIV, (24 September 2011)

Similarly a young man spoke of how his family became proactive in making sure he took his medication:

> "... they know that I must take my medication at night. I take my medication at 9 at night; they know if we're out like we're out somewhere, I must be at home before 9 to get my medication. So it's not that hard for me… I'm living happy."

Minenhle, young woman living with HIV, (24 September 2011)

Gaining treatment knowledge empowered family members to support young people to adhere to ART. However, a proper understanding of ART adherence was crucial for effective support. An example of the consequence of inaccurate understanding by the family was given by a young woman during a clinic obervation, where she described how her father stopped her from continuing with her medication because he thought she had fully recovered from AIDS:

> "When I was first told I have AIDS I was sick at the hospital and they gave me the pills. I got better and told my father who supported me. At home I took the medicine every day and my father always asked, have you eaten the pills? Then when I was very well, better and looked fat again. He said, why do you still take the pills? You are better now, you don't need to keep taking the pills. So I stopped."

Landi, young woman living with HIV, (23 March 2011)

7.5.2 Learning to live with HIV as a community

Young people who tested negative for HIV often left the clinic and had no further contact until they returned for another HIV test. Many of them saw HIV-positive support groups as a form of segregation; they wanted to attend these groups too so that they too could learn about HIV and ART treatment. Gaining this new knowledge would help them to support their peers who were diagnosed as HIV-positive, and would also help them to challenge the discrimination against those who were HIV-positive. This is illustrated by the following conversation:

> Motheo: "I was going to say its better if you bring all the people together, not the positive alone, because when they are alone, they are like separated, it's like they're not a part of the community any more, you know."
>
> Vuyo: "I think it [would] take out the stigma."
>
> Zakhi: "Ya, to give them knowledge you know, because they behave in certain ways because they don't have the knowledge of HIV. Some people commit suicide."
>
> Focus group, mixed status, (24 September 2011)

7.6 Conclusion

This chapter has shown that when young people received the news that they were HIV-positive, they became deeply shocked and traumatized. There were several components to their trauma. First, the diagnosis left them feeling frightened that they would become sick and suffer an early death. Shock and death anxiety have also been identified as a response to receiving an HIV diagnosis in other studies (Stevens & Doer, 1997; Safren et al., 2003; Flowers et al., 2006; Baumgartner & David, 2009). Baumgartner and David (2009) described this response as "catastrophising", whereby individuals automatically believe that the worst will happen to them. According to Ehlers and Clarke (2000:321) catastrophic thinking is a common response to trauma that can generate both "situational and over-generalized fear", which may be imagined or may be based on real life experiences. In relation to the context of the current study, the real-life experience of many young South Africans would have included the suffering and death of a close relative, partner or friend to HIV (Peterson et al., 2010). In addition, as discussed in chapter one, it is also important to recognize that the young people who participated in this study (aged between 16 and 26[3]) would have been exposed to media reports of countless lost lives prior to 2004, when ART was still unavailable through the public health system. As both Fassin (2002) and Safren et al. (2003) argue, these historical narratives and experiences of personal loss have become embedded in the memories of the South African people, and are very likely to generate "collective memories" that fuel an on-going fear among young people of HIV (Fassin. 2002:65).

A second component of diagnosis trauma was related to an overwhelming fear that they had suddenly become somebody that nobody would ever want; someone who would always be rejected, unloved and permanently isolated.

The fear of being rejected by significant others was a form of "felt" stigma. As outlined in Chapter three (3.3.5), Scambler (2004) calls the fear of discrimination "felt" stigma, whereas "enacted stigma" is discrimination that has been actually experienced. It is important to acknowledge that only a small number of cases of enacted stigma were encountered during this study, but this may have been because engagement with young people occurred mostly in the clinics. Other studies carried out in the same region have reported high levels of enacted stigma[*].

Gilbert and Walker (2010:140) describe "felt" stigma as a process of internalizing a sense of shame and blame, as well as experiencing an "overwhelming fear of being discriminated against". Shame is a self-conscious emotional response to the perceived evaluation or rejection of the "social self" by others, who see an individual as "unworthy of acceptance or group membership". This can become internalized into a "negative self-evaluation" (Dickerson, Gruenewald & Kemeny, 2004: 1195). It was this fear of no longer being worthy of belonging as a family and close peer group member that became young people's overwhelming concern; the thought of

---

[3] The older participants (24-26) would have been 16-18 years old whilst the youngest members (16) would have been eight years old when the National roll-out of ART began in 2004.

suffering rejection from family and friends made them feel frightened of being abandoned and left them in a state of despair and hopelessness[*].

Some young people found the thought of rejection so difficult that they chose to disbelieve their test results and attended another clinic to re-test, in the hope of disproving their initial diagnosis. Others went to their pastors for prayer in the hope of being healed, or chose to deny their diagnosis completely and never returned for further health care. Almeleh (2006) argues that denial is often manifest in the process of distancing oneself from the threat of discrimination and rejection, which is associated with a profound sense of shame of being HIV-positive. If individuals feel that there is a serious likelihood of being rejected from their family and peer group they are likely to "control diagnosis information", which, as Almeleh states, can result in "non-engagement with healthcare and social support" (2006:138).

It is important to understand these findings in the context of the developmental journey of adolescents and young people, as they seek to develop an autonomous self-identity (Erikson 1980:134). This development of individuation is not an isolated process; the emerging autonomous self requires affirmation and acceptance from both their original carers and their close friends, enabling them to validate their emerging self-identity as an "I" (authentic me) in the context of their social world. This can result in an acceptance of the self and a meaningful experience of belonging to others (Erikson 1980:120).

To be faced suddenly with the possibility of being rejected by family members and friends during this process is particularly catastrophic for a young person:

---

[*] Both societal and internalized stigma has been shown to be evident in the Cape Town region, in particular in the surrounding townships. For example Kalichman et al. (2005) conducted a study that included 2306 adults from Cape Town and found that 38% felt ashamed about being HIV-positive and 41% felt guilty about having become infected with HIV. Similar findings were reported in a later study (Kalichman et al., 2009), also based in Cape Town that reported that one in three of the 1063 participants who live with HIV endorsed AIDS related self-discriminative views. Similar to the earlier study self-abasing views included feeling dirty, guilty, ashamed and worthless because of being HIV infected. Both of these studies also reported that participants said that they experienced being treated differently by family members to whom they had disclosed. Whilst these studies did not concentrate on young people they do indicate the prevalence of stigma that exists within the surrounding areas of Cape Town.

> “To be rejected from these groups for the adolescent is the equivalent to being cast out from life.”
>
> Hoffer (1953, in Kroger 2009:130)

In response to the fear of rejection and isolation, some young people decided to support one another by attending the HIV clinics together. This phenomenon can perhaps best be understood in the light of adolescent and development theory, which describes how a young person becomes emotionally more reliant upon peer friendships as he or she moves away from reliance on the primary carer (Kroger, 2009:68). Blos (1979:143) describes this as a “pendulum” effect. As Howe (2011) argues, the primary carer’s influence continues to play a crucial role during this developmental phase, and in moments of vulnerability remains the core support for a young person:

> “…even though friends, including boyfriends and girlfriends, increasingly provide relationships in which issues of care and attachment are managed, at times of need and stress parents still feature high up in the adolescent’s attachment hierarchy.”
>
> Howe (2011:80)

A further possible explanation as to why young people came to the clinics in groups is that during adolescence young people often develop positive social behaviours in response to conflict experiences (Carlo et al., 1999). It could be that the young people of Khayelitsha who attend clinics had co-constructed a prosocial moral code of acceptance and support as part of their response to the threat discrimination and rejection, if they too were to become infected.

Overall, it has been shown that the process of becoming motivated to adhere to ART was complex and often challenging, and included a series of communicative acts between clinicians, family members, friends and other young people who live with HIV. It begins with receiving the diagnosis itself. Young people said that at this point they were unable to listen to important instructions on what they should do next to engage in on-going health care and treatment because of the trauma of diagnosis. This confirms Baumgartner and David’s observation (2009) that feeling stunned by an HIV-positive diagnosis can impair hearing of important treatment information that is communicated post-diagnosis.

According to young people in this study, factual messages were not a priority at this juncture. Instead they wanted to hear and experience two kinds of communication. The first comprised messages of hope in the form of narratives of other young people who had experienced the same trauma and were now living normal lives; they suggested that these could be made available to view on a DVD at home in their own time, as they began to process the shock of their diagnosis. The second form of communication that they wanted to experience was interpersonal, that emphasised the social value/experience of hearing messages that leaves them feeling loved, accepted, affirmed and supported - especially during and immediately post-diagnosis from family member(s).

These findings are particularly important as they challenge the notion that health communication that is designed to promote adherence should focus only on a patient's comprehension of medicine instructions. Instead, at least initially, health communication needs to give greater priority to emotional support as an outcome of interpersonal communication. As young people experience acceptance and support from significant others they become motivated to learn that HIV is a treatable chronic illness, and begin to shift from their overwhelming experience of trauma to feeling like a "*normal*" young person again, who happens to living with a treatable chronic illness. This sense of re-connection and affirmation from significant others, along with gaining an understanding about HIV and ART, empowers young people to regain a sense of control over their lives as they re-connect to their present and future hopes and lives. This in turn becomes the underlying motivation to adhere to ART. I discuss the implications of these findings further in chapter ten.

The wish for greater understanding of HIV and its treatment was not limited to people who had become infected; it also included young people's families and friends. However, during this study period there was no provision for supporting family members and friends to fully understand ART treatment information. An unfortunate example of the consequences of this is the case described above of the young women whose father told her that she no longer needed to take ART because she was now well. These findings are unlikely to be unique to Khayelitsha or to HIV/

AIDS and have important broader implications for the future development of health communication strategies.

In addition to family members, young people who tested negative also wanted to learn about ART treatment so that they could better support friends who lived with HIV. They also wanted to increase their knowledge about HIV and ART so that they would be better equipped in the event of testing positive themselves at a later date. Learning about treatment was also associated with the reduction of stigma, as gaining knowledge was seen as a way of reducing the fear of HIV and of those who lived with HIV. Mall et al. (2013) also found that increased knowledge of HIV and ART can decrease stigma among peri-urban populations in South Africa who have access to treatment information. The process of reducing stigma in Khayelitsha could begin by providing opportunities for young people to learn and talk about HIV and ART treatment in groups where HIV status is not prioritised or made a pre-condition of attendance. I also discuss the implication of these findings further in chapter ten.

In the next two chapters I report the findings that describe the visual tools that clinicians and young people said would best support them in their process of diagnosis acceptance and learning to live with HIV. In chapter eight I describe the development and initial pilot of an animation that was designed to communicate how an undetectable viral load is achieved and maintained, and how to choose a flexible time period for taking ART. Chapter nine describes how a film was produced that tells the story of how one young man came to terms with his HIV positive diagnosis, told his family and how the chose to accept and support him.

CHAPTER 8: THE DEVELOPMENT AND INITIAL PILOTING OF AN ANIMATED VISUAL TOOL DESIGNED TO COMMUNICATE ART ADHERENCE

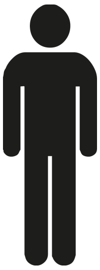
8.1 Introduction

The previous two chapters have shown that explaining ART adherence to young people in Khayelitsha was complex, and that communications by clinicians were not always effective. Clinicians reported that the two message elements that were most susceptible to misinterpretation or misunderstanding were (i) how to achieve and maintain an undetectable viral load and (ii) that there was some flexibility in the timing of taking pills, contrary to the emphasis on exact pill times that was being communicated. Tragically, this sometimes caused young people to fail treatment. Clinicians often used metaphors to explain the bio-clinical aspects of HIV and ART, both in verbal explanations and also in visual tools and magazines available in the clinics. However the use of metaphors was contributing to misinterpretations and confusion, and therefore an alternative form of visual representation was needed. Participants favoured animation as a potential alternative, and therefore an animation was developed in the later stages of this study. The two messages outlined above were selected as the subject of the animation.

Rather than using metaphors, the animation was based on the use of pictograms in the form of isotypes. As described in Chapter two (table 2.1), several studies have shown that pictograms offer an effective visual language that can support written and / or verbal medicine instructions (Morrow et al., 1998; Mansoor & Dowse, 2003; Mwingira & Dowse, 2006; Dowse, Ramela & Browne., 2011). The isotype system for pictogram design (Figure 8.1), which is used in conventions such as FPI and ANSI (discussed in section 2.3), was developed during the 1920s by Otto Neurath and was intended as a universally readable visual language based on a convention of graphic pictures to convey social information independently of verbal language (Lupton, 1986). Isotype pictures should represent a “neutral mode of expression” offering a visual language that is independent of any particular culture or language (Lupton, 1986:47). By choosing isotypes, therefore, I was able to minimise the representation of gender, age or race.

Unlike conventional approaches to the development of visual tools, the design, development and piloting of the animation were heavily informed by prior research findings and analysis, and in turn fed back into the research itself. Therefore in this chapter I report on the development and initial piloting of the animation in detail.

Figure 8.1: An example of a typical isotype symbol of a human figure



8.2 Development of the animation

Once the visual language had been decided, the next step was to develop the storyboard for the animation.[4] The process began with a consultation with a senior HIV clinician, who advised on the biomedical science aspects of the message content. The design concepts that emerged from this consultation were modified in a subsequent focus group with mixed status young people (see section 5.4.3 for sampling and logistical details), and were modified again in a second consultation session with the clinician. Subsequently two workshops were held with three designers in the UK to further develop the emerging design concepts. Once the concepts had been finalised an illustrator was commissioned to produce the final storyboard, which was then passed to an animator, who produced the proto-type animation.

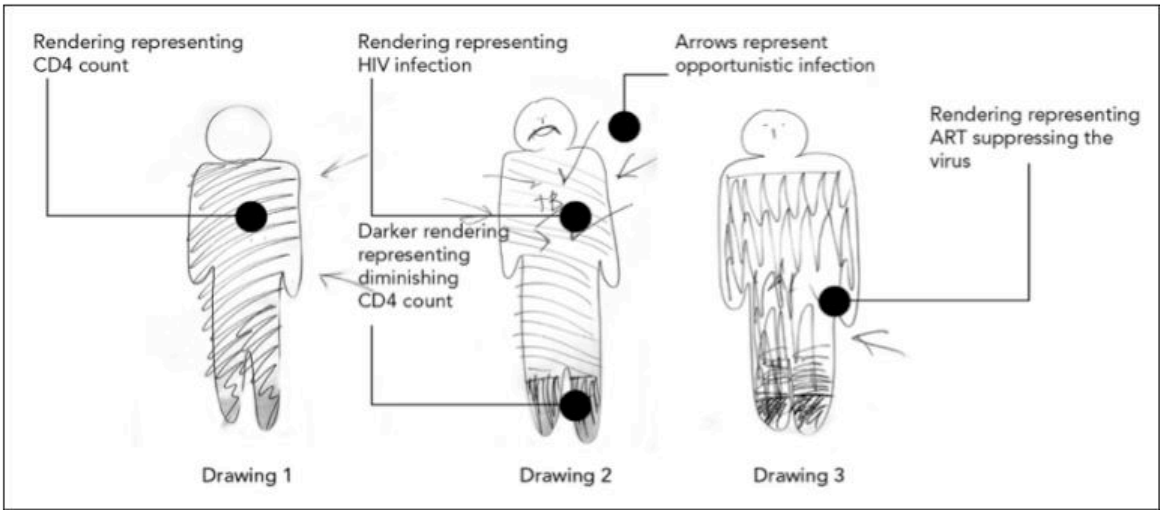
Figure 8.2 shows the outcome of the focus group with young people. During the focus group I placed a large piece of paper on the floor and began to make a drawing, based on the consultation with a clinician. Drawing One in the figure shows how rendering was used to represent a healthy person's immunity (showing a normal CD4

---

[4] A storyboard is a detailed representation and description of the visual elements such as illustrations, graphics, pictures and text, which instructs the production team for the making of animations/films (Orr, Golas & Yao, 1994).

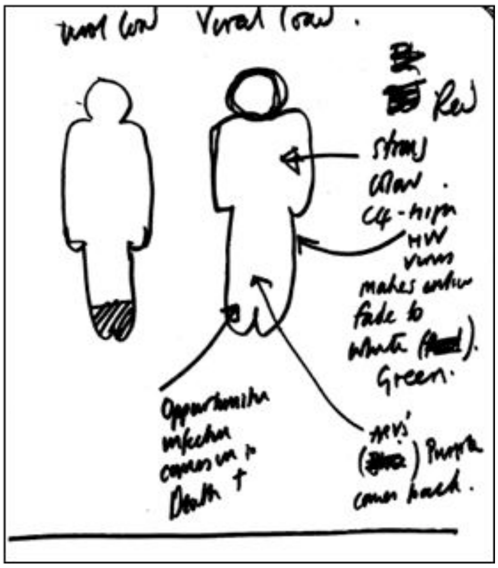
count). I then asked the group to help develop the drawing and a number of the young people moved from their chairs, sat on the floor beside me, and began to direct the drawing process. Following some discussion, arrows were added to represent the threat of disease and opportunistic infection, with TB being suggested as one of the main risks for people living with HIV in Khayelitsha. Drawing Two was then made using a different rendering (from left to right) to represent the body being infected by the HIV virus. The dark shading in the lower legs and feet represented the diminished CD4 count. Drawing Three shows a different rendering style again (vertical up and down) representing how ART destroys the virus, restoring the CD4 count and reducing the viral load to an undetectable state (shown by the dark shading in the lower legs and feet). It was also agreed during the focus group that colour should replace the black and white rendering.

Figure 8.2: Drawings produced during focus group with young people



During a second consultation with the clinician I re-drew the storyboard (Figure 8.3) as I explained each of the emerging design concepts. It was at this juncture that we agreed that using the body pictogram as a 'container' to represent a low CD4 count and viral load in the lower legs and feet could be misinterpreted. There was a risk that it would be understood as an explanation of why some patients suffer the side effect of peripheral neuropathy, which can cause pins and needles in the feet and hands.

Figure 8.3: Drawing made during the second consultation with the clinician



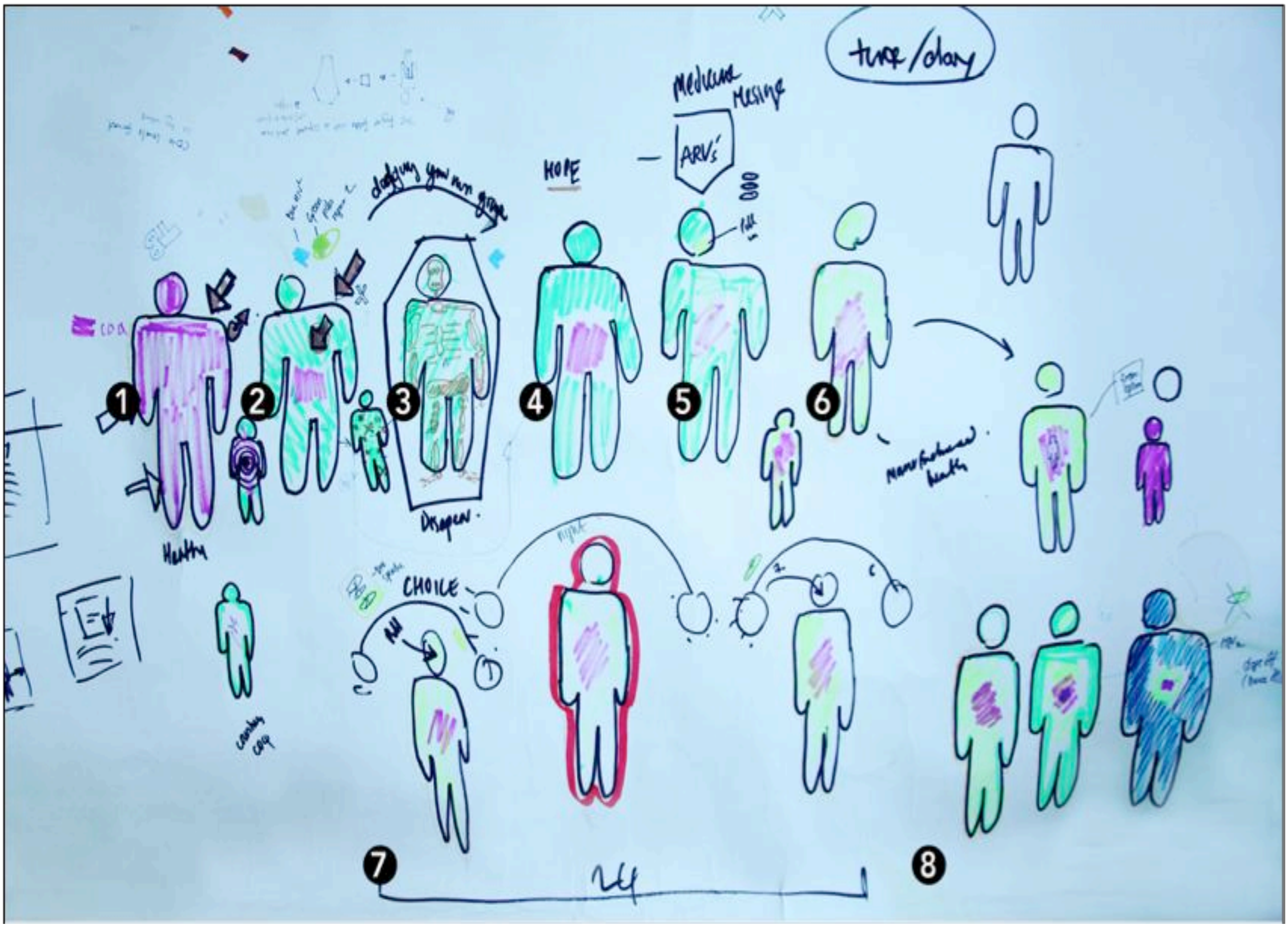
Instead, it was agreed that fading colours should be used to represent diminishing CD4, infection and ART.

The next stage of development was a workshop with three designers in the UK who were familiar with storyboard production. The aim of the workshop was to develop the emerging concepts into a coherent narrative in which each of the stages that describe how an undetectable viral load is achieved and maintained was visualised. At the beginning of the workshop I presented the findings on adherence communication (see chapter six), which focused particularly on the difficulties clinicians had described when communicating the concept of an undetectable viral load. These findings informed the conceptual development of the storyboard, focusing on the use of colour to describe infection, CD4 count and viral load.

Figure 8.4 shows the modified storyboard that was produced during the workshop. There was a consensus that the following design requirements should be adopted:

- Colour areas and circles should be used to represent the biomedical concepts of CD4 count, its reduction by HIV infection, and the reduction of HIV by ART.
- The same visual language should be used to show how the viral load increases when ART is not taken properly. This should include the use of colour changes to represent viral resistance, which requires a second ART regime.

Figure 8.4: Modified storyboard developed during the first workshop with designers



Key:

Purple: Immune system (CD4 count)

Green: HIV virus

Yellow: ART medicine

Red: 'Power' of ART to suppress HIV virus (see text)

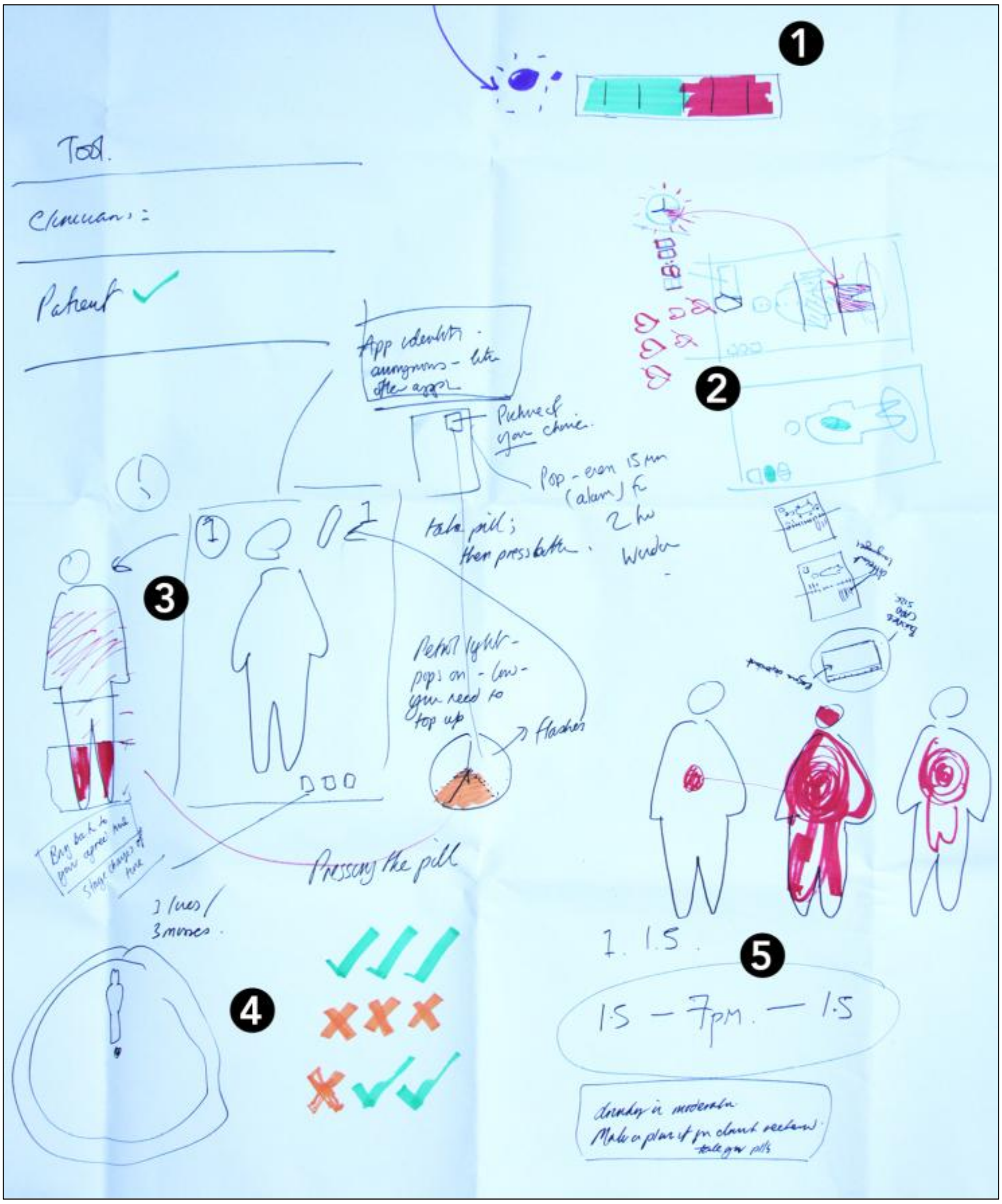
Blue: HIV resistant to first line of ART

The figure shows the following numbered steps:

1. The purple figure represents a person with a healthy immune system (CD4 count) that is able to defend the body successfully from disease and infection (represented by the arrows).
2. The figure is now green, representing the HIV infection that fills the body as it destroys the CD4 cells. The body can no longer defend itself from disease and infections.
3. This illustration shows how, without treatment, HIV will develop into AIDS, leading to death.
4. This pictogram repeats image two, beginning a new narrative of hope that HIV is a treatable disease through ART.
5. This illustration shows an HIV-infected person taking the ART pills, which are represented by the yellow lozenge shapes drawn at the top right of the head.
6. The ART (shown as yellow) destroys the HIV virus (green).
7. These three pictograms illustrate the importance of taking ART every day. The circles on the left represent a sun denoting morning, with the circles on the right denoting evening. The red outline on the middle larger figure represents how the ART maintains its ‘power’ to suppress the HIV virus, provided that it is taken regularly.
8. These three figures attempt to show the impact of non-adherence. HIV becomes resistant to the first line of ART, represented by a change from yellow to green. The green to blue sequence shows how the HIV continues to become resistant to ART second line regime if optimal adherence is not achieved.

Despite an attempt to illustrate pill times within this narrative (shown in drawing seven), this part of the storyboard was not resolved effectively due to time constraints. Therefore a further workshop was organised with the same group of designers. Figure 8.5 shows the drawings from this second workshop.

Figure 8.5: Modified storyboard developed in second session with designers



Key:

Green: HIV virus

Red: ART

Drawings one to four represent several concepts showing the link between pill timings and an undetectable viral load, as follows:

1 This visual was exploring a sliding scale linked to a sun and moon icon drawn on the left side. Red would represent ART and green the HIV virus.

Taking ART would maximize the red bar, which would represent the fact that an undetectable viral load has been achieved. If pill doses are missed the green bar would then increase, moving to the left, indicating an increasing viral load.

2. The sliding scale concept was then transposed into a pictogram of a human figure. This was linked to a clock used to communicate pill timings and a series of hearts designed to represent being alive each day. If a pill dose is missed a line or cross would appear on the heart, as a visual representation that a person's life is at risk.
3. Continuing the theme of a sliding scale we tried to combine a clock face, a person and a pill that could be introduced in sequence to describe the relationship between adherence and viral suppression.
4. In this drawing we continued to explore how to visualise the impact of missing doses. The circle that contains a human pictogram would be used as a sliding scale, representing how ART offers protection. The ticks and crosses would represent good adherence and non-adherence.

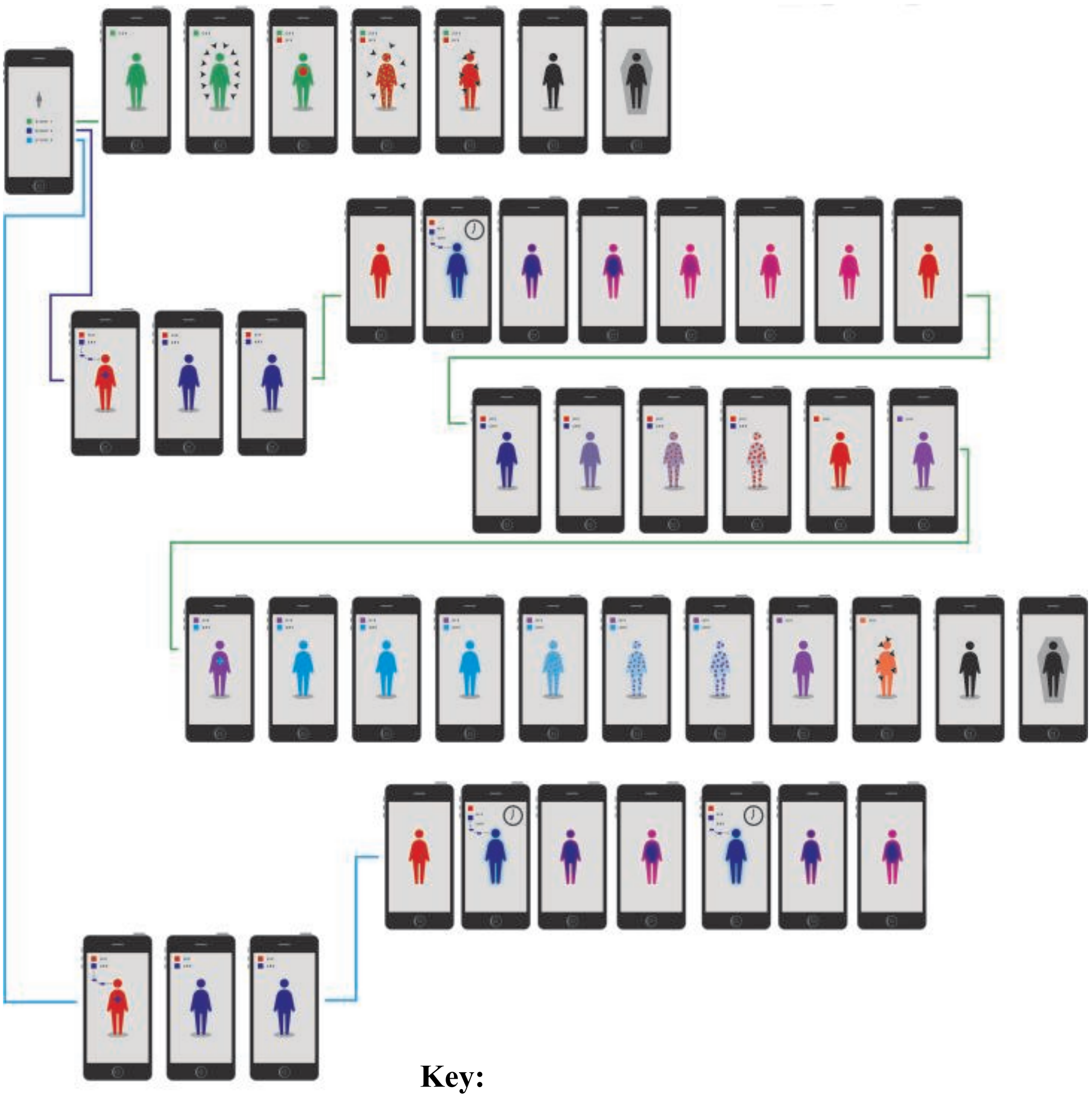
The final group of drawings (5) was an attempt to represent all of the concepts explored up to that point (1 - 4) by using colour within the pictogram figure. It shows how ART (represented by red) expands into the body from a red dot, and reduces the HIV (viral) load to an undetectable level. The red then reduces back to a circle as levels of ART fall, allowing the virus to strengthen and re-fill the figure. This represents the outcome of non-adherence.[*]

It was also agreed that the red colour would glow in the animation to represent each time a dose of ART was ingested; this would represent the medicine's ability to suppress the virus. As the day progressed the red would begin to fade, moving back towards a circle, showing that the medication was required daily in order for it to maintain its ability to suppress the virus. Overall consensus was reached that this design concept should be adopted and further developed, and this was done by the illustrator. The final storyboard that was produced is shown in Figure 8.6.

---

[*] After further discussions with the HIV specialist this element needs to be modified for implementation as increased viral load would only occur after a longer period of non-adherence.

Figure 8.6: The final storyboard illustration

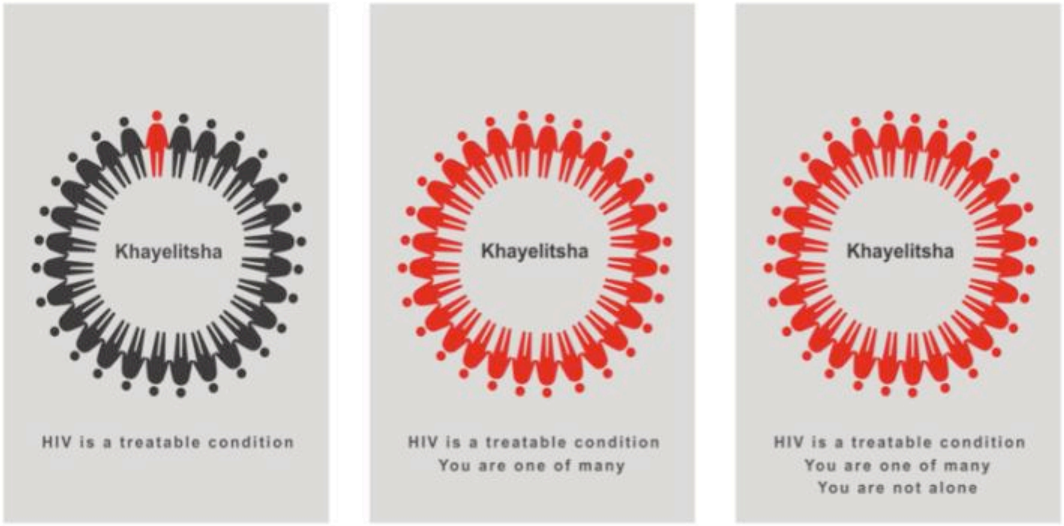


Key:

Green:	CD4
Red:	HIV infection
Blue:	First line of ART therapy
Purple:	HIV resistance to first line of therapy
Cyan:	Second line of therapy
Orange:	HIV resistance to second line of therapy

The storyboard was then passed to a professional animator. The platform chosen for the animation development was an ipad. In a consultation, the animator was informed about the different aspects of diagnosis trauma that have been presented in section 7.2, particularly the fear of becoming sick and suffering an early death, and also feeling isolated post-diagnosis. In response, the animator developed an additional sequence of images, to reinforce the message that HIV was treatable and that many other young people were also infected in Khayelitsha and lived normal lives. This sequence is shown in Figure 8.7.

Figure 8.7: Additional sequence for the animation designed to address diagnosis trauma.



It was also decided to include written text alongside the pictures for each section of the animation. This was partly because the text could provide cues to the presenter for delivery of each section of information. However in addition, the literature reports that increased comprehension is achieved when pictograms incorporate supporting text explanations (see tables 2.1 and 2.2 in this thesis; Mayer, 2009). Supporting text could increase comprehension, especially if the animation were viewed as a standalone multi-media presentation.

Pill timings were also explored during the meeting with the animator, particularly in relation to explaining that pills can be taken within a period of time rather than having to keep to exact times. In response the animator suggested an interactive tool that a person could use to choose a suitable time frame[*] (see Figure 8.8).

---

[*] According to the HIV specialist this element needs to be modified to show a time window of one hour either side of the chosen time, not two hours as shown in the graphic and animation.

Figure 8.8: Potential interactive tool for choosing the time frame for taking pills

8.3 Piloting the animation

The animation was piloted through three group presentations to young people of mixed HIV status (involving a total of six women and five young men), and also through separate individual presentations to a nurse, a treatment educator, a doctor and an HIV counsellor (see section 5.4.3). The presentations to young people were facilitated by a local young man living with HIV who had been recruited as a paid research assistant for this purpose. He recruited groups of young people from the clinic's waiting room, showed them the animation, and acted as translator during the subsequent discussions. Each group comprised two to three friends who were attending the clinic together. They were encouraged to stop the animation whenever they wanted to ask questions or comment and discuss content, which allowed for interactive discussion throughout each session.

After each viewing of the animation, there was a discussion based on the following open questions:

- Was the animation useful?
- How could it best be used among young people?
- What messages did you find helpful or confusing?

Although the time frame animation was shown during the pilot, there were no significant responses to report. This was partly due to shortage of time, because the main animation generated very enthusiastic responses from participants. The communication of this message element, however, is important and should be further researched.

Young people's initial responses to the presentation were that it would be useful in raising awareness about the ongoing risks of HIV within their community, and would help them to better understand both HIV infection and treatment. For example, one young man said:

> "It can make people pay attention to it, coz the thing is we don't understand how this thing [ART] all works you see"
>
> (Lungelo, young man, HIV negative, 11.12 2013)

Participants said that the animation offered a quick and simple visual explanation about HIV infection, ART and pill timings, and helped them to understand the adherence messages. They enjoyed the animation medium, finding it more engaging than the booklets or magazines provided at the clinics. As one participant said, "you get to learn some stuff without reading a book or something [magazine]".

Through grounded theory analysis of the transcriptions, the following two categories were identified and are discussed in turn below:

i. Hearing their stories

ii. The desire to own ART information

8.3.1 Hearing their stories

During the sequence that showed the picture of a person in a coffin representing the outcome of non-treatment or non-adherence, participants displayed their shock, responding by looking for reassurance from one another and in one case holding each others' hands, affirming their support for one another. As the presenter responded empathetically to their shock, saying "but you don't have to die", and moved to the sequence that shows that HIV is treatable and that they are not alone, the young people would express their relief with a verbal "phew", a smile or a laugh. It was at this juncture that some participants would share their fears about HIV infection and tell their stories about family members or friends who had been lost to AIDS. In this way the animation, when presented in a supportive and empathetic style, allowed participants to share their fears about HIV infection and their stories of loss and grief about loved ones who have died of HIV. Dadds (2008:280) describes empathy as 'the human capacity to identify oneself with the feelings, experiences and perspectives of others". The ability to show empathy during the presentation of multi-media information, which includes human narratives of suffering, validates the stories shared by audience members (Whitehead, 2010).

8.3.2 Owning ART information

> "It would be nice to have a this on my [mobile smart] phone because I know I don't have to come to the clinic to get the information. I already have it on a phone, so I can just look at it any time I want."

(Addington, young man living with HIV, 11 December 2013)

As illustrated by the above quote, some participants expressed the desire to have the animation in an APP format on their mobile phones so that they could access the health information for themselves, independently from the clinics. They saw the animation as an effective method for increasing their understanding of the risk of HIV, both for themselves and for their friends in the wider youth community. It was suggested in the discussions that they could use it to help friends who live with HIV to take better care of themselves. Participants said that they imagined an APP would create a curiosity among their peers, which would engage them with treatment information. In this way it could help young people to acknowledge the risk of HIV rather than continue to ignore it:

> "Being on the phone, people can get curious you know. They will want to see what is this all about. And eventually when you are all alone and you will start thinking. You know the thing is with us people when we with friends you ignore things."

(Alizea, young man living with HIV, 11 December 2013)

Clinicians saw the APP as a tool that young people could use repeatedly, which could help them to learn about the risk of HIV infection of those who were un-infected. It could also support those who had recently been diagnosed, helping them to understand how to adhere to their treatment. As the clinic manager confirmed:

> "… If you could end up like an APP, it would be very good if it was installed in a phone. It would be very good because young people are ignoring, they tend to turn a blind eye on HIV and if now it starts on their phone - it could change their perspective…"

(Samuel, clinic manager, 11 December 2013)

8.4 Conclusions

In this chapter I have described how a prototype animation was designed through a step-by-step consultative process and was tested among young people and clinicians at one of the HIV clinics based in Khayelitsha. As mentioned at the beginning of the chapter the main objective in developing the animation was to explore an alternative visual language and medium for communicating the complex concept of ‘undetectable viral load’ and pill timings. This was in response to data (described in chapter seven) that showed that the use of metaphors by clinicians and health workers is causing confusion among young people. The use of the isotype figure (figure 8.1) was successful in that it provided an easily recognised symbol of a person that could ‘frame’ the narrative of infection and of how ART, when taken properly, suppresses the viral load to an undetectable amount. Using the isotype figure meant that the use of other symbols was kept to a minimum, limited to symbols for pills (a lozenge shape), medication (a cross) and infection (a dot). This enabled the design to remain as simple as possible, reducing the possibility of visual misinterpretation due to multiple use of visual elements, which other studies have identified as problematic (Carstens et al., 2006; Dowes et al., 2011).

In contrast to the didactic individualistic approach used by clinicians that seeks to transfere treatment information as a one way communication, this study found that young people wanted to learn about HIV infection and treatment within a social context, where they were able to discuss their anxieties about infection, treatment and trauma narratives that were related to personal losses to AIDS. In particular, young people found the opportunity to interact with the animation and the presenter helpful as it enabled them to ask questions about the sequences that they didn’t understand and talk about their confusion, which was related to treatment rumours that they had heard within their community. According to Mayer (2009:176), “segmenting” multimedia messages in repeatable sections allows the learner to move through the information according to their cognitive capacity, which prevents an overload to the working memory that is essential to their learning experience. These findings show that segmenting also allows young people to work through treatment information according to their emotional capacity that is linked to trauma memories stored in their long-term memory. I discuss this finding in the context of a communication strategy in more detail in chapter ten.

Both young people and clinicians felt excited and enthusiastic about the possibility of including the animations as part of an APP technology that would be made available for their personal use. The use of mobile phone solutions for health purposes is increasing, and includes the use of texting to inform diagnosis, reminders for clinical appointments and adherence. APP technologies are also becoming readily available, for example to support blood pressure monitoring or diabetes management (Kaplan, 2006; Patrick et al., 2008). However, according to Kaplan (2006) whilst placing treatment knowledge onto mobile phone technologies offers exciting opportunities in terms of increasing dissemination of important health messages to wider populations, there are limitations within low-income countries. Kaplan (2006) states that because of no or limited income people often share phones, and this could compromise patient confidentiality and lead to the disclosure of a young person’s HIV status. Smart mobile phone ownership in Khayelitsha is increasing and this phenomenon of sharing phones and sometimes swapping handsets was popular among the young people who participated in this study. Further research would need to be undertaken to ensure that an APP aimed at supporting ART adherence among young people would not trigger unintended disclosure, thus causing considerable harm among this population.

Colt and Quadrelli (2006) also add a note of caution to the use of mobile technologies to provide health information, due to the possibility of misinformation and misinterpretation. In this context, Colt and Quadrelli (2006) discuss the importance of proper advocacy for these technologies, arguing that these platforms should be accompanied with measures to ensure social and professional responsibility when used to disseminate medical knowledge into the public domain. Their point is an important one because as discussed in Chapter two, stand-alone visual communications that are not supported by verbal explanations run the risk of misinterpretation. As a result many researchers in this field recommend that multi-media treatment instructions (pictures supported by text) should be presented in the context of counselling or educational spaces.

In Chapter ten I consider these challenges and discuss how an interactive multi-media presentation delivered via mobile phone technologies could contribute to the dissemination of treatment knowledge among young people, their families and their wider community, in order to support a communication strategy designed to increase their understanding and their motivation to take their ART.

CHAPTER 9: A FILM THAT COMMUNICATES HOPE

> “You cannot really process any information at the clinic, it could have helped to take some more information home once you’ve calmed down.”
>
> (Young woman living with HIV, April 12, 2011)

9.1 Introduction

In chapter seven I described how young people felt so shocked by their diagnosis that they were unable to hear the messages communicated by clinicians. Young people spoke of how useful it would be if they could take a DVD film home to watch, which included stories of other young people who had survived the same experience and were now successfully living normal lives. They said that this could give them the hope that they too could survive their shock and go on to live a normal life. Film was seen as a suitable medium because it didn’t require them to read (which some young people found difficult), and unlike the printed leaflets and magazines that were available at the clinics, was not seen as boring or difficult to understand.

Based on these data, a small film was produced that presents a case study of a young person who had recovered from the trauma of receiving an HIV diagnosis and how they had negotiated acceptance and support from their family members. Eisenhardt (1989) describes a case study as a research design that aims to ‘elucidate social phenomena’ within a specific social setting, and can be used to provide rich descriptive data to test an emerging theory (Eisenhardt, 1989: 535).

This chapter describes how the film was produced. Grounded theory analysis of the original data helped to identify actor profiles and generate a set of interview questions for use in the film. In the film itself, the pre-set questions were put to the participants and they then answered in their own words; thus the film was not fully scripted in advance. The resulting dialogue was then analysed using grounded theory, which provided four themes as a framework for the final script. The chapter concludes by discussing how this story offers one example of the three stages that young people experience post-diagnosis which help them find the acceptance and support that they need to become motivated to take ART.

9.2 Methodology

Using grounded theory analysis of the young people's transcripts (discussed in chapter seven), I identified the groups of people from whom young people either had experienced, or would have liked to have experienced, love, acceptance and support. The three groups identified were trusted family members, trusted friends and clinicians.

9.2.1. Identifying actors

The next stage was to build a series of detailed profiles (personas) (see Appendix 6) for each actor group. Personas are accurate descriptions of hypothetical individuals, and are constructed from data usually gathered from ethnographic research. Personas inform a design/film production team of the requirements and needs of the intended audience, ensuring that the intervention offers maximum impact (Blomquist & Arvola, 2002).

9.2.2. Recruiting actors

Using the personas, I discussed the film with my research assistant Lee (recruited during phase three of this study), with the objective of scoping possible actors that could be recruited from among the young people that had participated in this study. As we discussed the film production, Lee began to share how his own experience and that of his family was similar to the proposed personas. He offered to participate in the film and to ask his family if they too would like to participate. They agreed and we proceeded on this basis. Because of this, the film that was made featured only the actor profiles that were important in Lee's story; no clinicians or friends were included, but only his family. Permission forms (see Appendix 3) were used during this study phase.

Using the personas, I developed the following set of interview questions for Lee and his family, which mapped across the three stages as follows:

Diagnosis trauma:

For Lee: *How did you feel when you were first diagnosed as HIV positive?*

For family member: *How did you feel when you first heard that Lee was HIV positive?*

Diagnosis acceptance:

For Lee: *How did you accept your diagnosis?*

For family member: *How did you accept Lee's diagnosis?*

Learning to live with HIV/AIDS:

For Lee: *What is it now like to live with HIV/AIDS?*

For Lee: *How did learning about ART help you?*

For family member: *Have you ever thought about learning more about ART so that you can support Lee?*

9.2.3. Filming

Ethics approval was obtained for the film production and its public use from UCT Faculty of Health Sciences Human Research Ethics policy committee. Filming and production were carried out with the assistance of Jackie Murphy, a film student at UCT. A series of filming sessions was organised with Lee and his family between December 2013 and March 2014. Filming occurred both at Lee's home and at his parents' house. Filming occurred with individual family members and with the family as a group. Sound recording occurred separately to the film in the quietest rooms in the homes so as to ensure sound quality (Sound was then aligned to film sequences during the editing process). This decision was also made due to the restrictions of a low budget, as the rental fee for microphone technologies that are used alongside filming above available budget. Each participant was recorded individually, with the film-maker conducting the interview using the questions listed above in order to facilitate open-ended answers and narratives.

Recordings from the film were then transcribed and analysed according to the principles of grounded theory. In the next section I discuss the analysis and show how it informed the final script edit.

9.3. Analysis of initial film script

The following four themes emerged from the analysis:

9.3.1 Diagnosis shock

The film begins with both Lee and his sister describing their feelings of shock and disbelief immediately after Lee had received his HIV positive diagnosis. His sister explained that although she knew HIV was ‘all around’ she believed that it would never affect her family.

> Sister: “It was 2011 on April we find out that Lee was positive. We knew that there was HIV but I didn’t know that someone in my family can get it also. So I was very shocked, crying; but I told myself no man, I have to take it; I have to accept it because it is there. And now I know that HIV is existing.”

Mbonu et al. (2009) describe this response as a form of "defensive” denial, which seeks to avoid the realities of the threat of a disease that exists within a community. Van der Velde (1992) argues that defensive denial generates a form of unrealistic optimism that can influence people’s perceptions of risk or vulnerability to a health risk. Lee’s infection dislodged this myth and left his sister suddenly having to face the reality that a member of her family was now HIV positive.

9.3.2. Telling the family

The film then focuses on Lee’s narrative, as he describes his anxiety over whether to tell his family members about his recent diagnosis or not.

> Lee: “I was thinking of the people around me, the family, the friends; what are they gonna say. I felt as if I had disappointed them in a way, my parents. So I needed to actually come clean and tell them.”

Petronio (2002:177) describes this as "boundary turbulence” where the initial "defensive boundaries” that protect diagnosis information are negotiated, as an individual considers revealing their status to significant others. For Lee, the process of negotiating the act of telling his family was not easy, as he was worried that they might be disappointed in him. Lee described his motivation to tell his family as connected to the need to "come clean” with them, suggesting that he felt a moral duty not to hide his diagnosis from his belonging group. According to Kohlberg (1984), moral reasoning is an intrinsic part of the developmental phase of adolescents, where belonging group values are evaluated against the group's ethical codes of belonging. Young adults often conform to their belonging group's values out of a "sense of duty" whilst developing and maintaining their "sense of self-ownership and authorship" (Kroger, 2009:193). This study did not examine Lee's family value system, but it is possible that his family's expectation to conform may have been behind Lee's motivation to tell them about his recent diagnosis.

9.3.3 Acceptance and the affirmation that nothing has changed

The film shows how Lee's family was initially shocked when he told them that he had been diagnosed as HIV positive.

> Brother 1: "By the time he's telling us I was shocked and I didn't say even a one word - but at the bottom I know that he's my brother."
>
> Mother: "Even me I was very shocked on that time when he tell us "

Bury (1982) describes how chronic illness often brings families "face to face with the character of their relationships in stark form, disrupting normal rules of reciprocity and mutual support" (1982:169). Lee's parents' and brothers' initial reactions exemplify this kind of sudden disruption to relational norms, as they were faced with the need to respond to Lee and his diagnosis. It was Lee who in this moment of vulnerability turned to his mother and asked her what is going to happen now. Despite her shock, Lee's mother affirmed his primary self-identity as son by saying, "My son, I love you so much, there is nothing can change you – you [are] still my son". Similarly, as with his brothers, Lee's father affirmed Lee compassionately as his son, who had not been changed by becoming HIV positive, saying "he is still the Lee we knew, nothing has changed him". The re-affirmation of Lee's place as a valued member of the family enabled Lee to re-affirm his own prior self-identities as son and brother, and this became his "turning point", empowering him to declare confidently that "This is nothing, HIV is nothing, it doesn't describe Lee, no, not by a long shot ya".

9.3.4. Learning about ART

The film also shows how Lee's prior learning about HIV and ART from attending an HIV counselling course helped him to cope with his diagnosis. This prior knowledge increased his confidence to tell his family about his infection, because he knew that HIV was a treatable chronic illness and could reassure them that he would be OK.

> Lee: "Actually I did counselling course, so I knew I have a certificate on that… so, I know everything I have to know…"

These data suggest that prior treatment knowledge may equip young people to better cope with an HIV positive diagnosis. In terms of an overall communications strategy, then, these findings suggest that treatment knowledge should be made available to all young people within the community who are at risk of infection, rather than only to those who are already infected. This point will be revisited in chapter ten.

The film continues with Lee's description of how his sister decided to go back to the clinic to learn about ART, so that she too could better support her brother.

> Sister: "So the time I went to the clinic I learn that how do the pills help in the body. So how many time must he take it, what time whatever? So I'm always encouraging him."

These stories echo those of members of other young people's families in this study who chose to learn about ART so that they could understand how to support a young family member to adhere. As exampled in the film, Lee's mother had gained sufficient treatment knowledge to understand the importance of reminding Lee regularly to take his medication. Although family members felt confident that they had a good understanding about ART adherence, this is not always evident in practice. Lee's sister when shown the animation (discussed in chapter eight), admitted that her knowledge was limited, and at the end of the presentation she said "I didn't realise that you must take the tablets every day". Furthermore, Lee's brothers, who used Clinic C to test for infection, described how little information about ART is available and how few opportunities there are to learn about ART. In chapter ten I discuss these findings further.

9.4 The final film

Based on the analysis described above, the following content outline was used to inform the final film script and the film production:

1. Diagnosis shock
2. Telling the family
3. Acceptance and the affirmation that nothing has changed
4. Learning about ART

The full transcript is presentedbelow. The editing was carried out by a freelance editor based in Cape Town. It was during this stage that it was decided to add sub-titles to help viewers follow the script, especially if they speak limited English as is the case among populations in the townships. Due to time constraints and limited funding the film has not been shown to participants for their feedback which is a limitation to the participatory nature of its production.

9.4.1 Final film script: 'LEE'

Diagnosis shock

> Lee: "My name is Lee, I went with my sister to the clinic – she wanted to go test so I was accompanying her, and when I got there the results came back I was positive and she was not. It was a big shocking even though um, I know I am strong. Ah, it was shocking."

> Sister: "It was 2011 on April we find out that Lee was positive. We knew that there was HIV but I didn't know that someone in my family can get it also. So I was very shocked, crying; but I told myself no man, I have to take it; I have to accept it because it is there. And now I know that HIV is existing."

Telling the family

> Lee: "I was thinking of the people around me, the family, the friends; what are they gonna say. I felt as if I had disappointed them in a way, my parents. So I needed to actually come clean and tell them."

Sister: “So I called our parents and our brothers. We explained to them we told them about the virus, ya our brothers didn’t take it well, but my mother was brave enough to comfort us all.”

Acceptance and the affirmation that nothing has changed

Mother: “Even me I was very shocked on that time when he tell us. And he come to me: ‘and mum, my daddy told you about my status?’ I said ‘Yes, he told me’. ‘And mom what is gonna happen now?’ I said, ‘my son, I love you so much, there is nothing can change you still my son.’ I support him so much.”

Father: “Lee is still the Lee we know there is nothing changed to him and we are keeping on supporting him and we also not affected too much”

Brother 1: “It was not easy for us to accept it, but when the time goes we realise that we can’t change it, he’s HIV and he’s our brother so we just, we did accept it, there is nothing we can change - take your pills before you go to your friends.”

Brother 2: “By the time he’s telling us I was shocked and I didn’t say even a one word - but at the bottom I know that he’s my brother.”

Learning about ART

Sister: “So the time I went to the clinic I learn that how do the pills help in the body. So how many time must he take it, what time whatever? So I’m always encouraging him. There’s nothing’s changed Lee is still my brother, I love him so much. He’s like a friend to me more than a brother.”

Mother: “Ya the first time he take the medication he told me ‘Mommy, I use the medication now’ and I’m very happy must use this and you are be strong if you use this. Every time when you go... when you come here, you must bring it here. When you go to your friend if you gonna sleep there you must take your medication there where you sleep...”

> Father: “But all we are doing is to keep on loving him and that’s it. He’s our son, and will be our son, so we gonna keep on supporting him till the end because he is our son, we cannot let him go away from us...”
>
> Lee: “But ya I am surviving am still surviving am still a fighter I know. This is nothing, HIV is nothing it doesn’t describe Lee, no, not by long shot ya. I want to live, longer than anyone who’s ever had HIV in their life. I want to live. I want to be the one man standing.”

9.5 Conclusions

To conclude, the film provided one example of how a young man received acceptance and support from his family members. This process comprises a series of communicative acts on the part of the young person who is HIV positive, which include telling a significant other about their diagnosis. The response that they desire from their significant other(s) does not focus primarily on the content of their reply, but rather on a feeling of acceptance and affirmation of their identity as son, daughter, brother or sister. Affirmation includes the feeling of being accepted irrespective of having become HIV positive, which reinforces the fact that they are the same person and have not been changed by their infection. An intrinsic part of acceptance is the offer of support, which includes the desire by the significant other to learn together with the young person about ART so that they can encourage them and sometimes check that they are properly adhering to their ART medicines.

Latour (2005) describes this form of communication as transformational, where communication generates an experience of being interpersonal connection; where one person feels alive to the presence of the other that results in a changed person;

> “In love’s injunction, attention is redirected from the content of the message, but to the container itself, the person making. One does not attempt to decrypt the sentence as if it transported a message, but as if it transformed the messengers themselves.”

(2005:29).

Craig (1999) categorizes this communication approach as within the phenomenological paradigm, which defines communication as a series of meaningful “communicative experiences’. According to this paradigm communication is defined as the felt experience that occurs between two persons, rather than a communication that is defined by message content only (1999:138).

The film shows the process of how a young person found the courage to tell his family about his diagnosis and how they were able to re-affirm their acceptance of him, which reinforced his self-identity as something that had not changed. It was these experiences that enabled Lee to believe that he could continue to live his life in the same way as he had prior to his diagnosis – reconnecting him to his motivation to live a normal life, that in turn motivated him to take his medication.

It was evident when Lee spoke of how prior treatment knowledge that he had gained (before his infection) through attending an HIV counsellors’ course had helped him to cope with his diagnosis, and increased his confidence to tell his family. In chapter ten I discuss how teaching young people about treatment, irrespective of status, can increase both the resilience to cope with a potential HIV positive diagnosis and build confidence to tell family members and trusted friends.

In summary, the film provides a useful case study that contributed to the emerging theory of how young people become motivated to adherence, as described in chapter seven. However, whilst this film shows the narrative of acceptance and support from a very accepting family unit, other young people's stories of reconnection may be very different, and in some cases are negative. In the context of its use as part of an intervention it would need to be included with a number of other narratives that show different routes of reconnection, including those who experienced discrimination and how they found new relationships that offered support and acceptance.

CHAPTER 10: COMMUNICATING ART ADHERENCE TO YOUNG PEOPLE

“He who has a *why* to live for can bear with almost any *how.”*

Nietzsche

10.1 Introduction

The purpose of this study was to explore how health communication can most effectively explain antiretroviral medication (ART) and motivate ART adherence among young people. During fieldwork I explored the adherence messages that were used by clinicians in Khayelitsha in South Africa to explain ART adherence and motivate young people, and how the messages were perceived. As discussed in chapter six, clinicians used a mixture of metaphors and biomedical terminology to explain adherence, but they said that young people often struggled to understand them fully. Complex concepts such as the relationship between infection and a person’s CD4 count, the meaning of an undetectable viral load and why it is so important to take ART every day within a similar period of time were particularly difficult for young people to understand, and in some cases this led to misinterpretation and non-adherence. Clinicians spoke of how animation could offer the best potential tool in helping them to explain these complex concepts of adherence to young people. In response to these findings I developed a proto-type animation designed to support clinicians’ ART communications (see chapter eight), which was tested in one of the youth clinics and found to be effective in helping young people to better understand the complexity of adherence.

The study also explored how young people become motivated to take their medicines. A distinct difference was revealed between clinicians’ and young people’s understanding of what motivates them to adhere successfully to their medication (see chapter seven). According to young people, motivation was an outcome of their re-connecting to one or more trusted significant other(s) who accepted, affirmed and supported them. In this way they felt that they were still accepted, irrespective of their recent diagnosis. Support from family members involved their finding out more about ART, so that they could encourage the young person to take their medicines regularly. Following on from this finding the study included the production of a case study film, which supported and further informed the emerging theory of what motivates young people to adhere to ART. The film presents a story of a young person who overcame his initial diagnosis shock and, through the acceptance and support of his family, learned to live a normal life with HIV. Young people had said that they wanted to be able to view a film of this kind soon after their diagnosis. In this chapter I discuss the implications of these different elements of the study – the empirical data on current ART messages and on factors affecting young people's motivation for adherence, together with the development of an animation and a film – for the design of an effective health communication strategy, both in Khayelitsha and more generally.

In addition to these findings, this thesis offers a number of novel insights that point to promising new lines of enquiry for research and practice. The most significant of these is the importance of the use of interdisciplinary approaches, drawing from the social sciences, psychology, health sciences and communication. Marzano (2006, cited in Newing 2012:12) describes interdisciplinary research as a "means of solving problems and answering questions that cannot be addressed satisfactorily using single methods and approaches". Parrott and Kreuter (2011) describe how health communication research has traditionally been guided by two separate disciplines, namely "health" and "communication". The health element has been linked to disciplines such as public health, health promotion, health education, and patient education, whilst the communication element is guided by the disciplines of public relations and advertising/media. The design of communication strategies based on these two disciplines typically follows two key stages. The first stage is to define and understand the health problem that is specific to a particular community; the second is to frame the communication strategy/programme by a health behavioural model or theory, which then determines message content. These stages together form the basis of a brief (project instructions) that is used when commissioning designers to produce visual communication materials/tools.

The goal of visual communication is to persuade an audience, by means of a two-dimensional communicative object, to adopt a certain behaviour (Tyler, 2006). Using this mode of production the designer interrogates the subject by exploring related concepts or themes, and combining linguistic (text) and pictorial (pictures) content into a coherent pattern of information. Typically, visual materials/tools are then provided to the intended audience. In this model, the audience is seen as a "passive reader" in the communicative process and individuals are left to decode and interpret the visual message for themselves. Whilst this methodology offers a rigorous process for the design and production (from concept to completed product), its effectiveness is reliant upon the precise message content and a complex set of determinants of motivation, which are factored in according to existing theories of human behaviour, provided by health promotion/education specialists. Parrott and Kreuter (2011) state that this approach results in communication being treated as "a tool to address a problem rather than a discipline guided by theory and practice", and argue that complex health-related issues require a more interdisciplinary approach. In response to these challenges, this study drew from a number of disciplines that provided important insights for the design of a health communication strategy that could best support young people's understanding and motivation to ART adherence. Drawing from the social sciences, grounded theory was employed as an open-ended qualitative methodology that enabled me to approach participants without any prior influence from different disciplines concerning the determinants of motivation and understanding. Instead, grounded theory allowed me to build an understanding from the data. An essential part of this process was the tracking of adherence messages throughout the HIV-related health care journey. The journey begins at diagnosis, and continues with a CD4 test, a series of counselling sessions and youth support groups, and eventually the receiving of the prescribed medication from the pharmacist. Tracking this journey through the use of qualitative social science methods enabled me to gain an in-depth understanding of the message content of ART instructions and how they are communicated to young people, and also of how young people interpreted them and reacted.

Tracking the adherence messages helped identify that clinicians communicated about adherence only to young people who were diagnosed as HIV positive, and only within the clinical spaces (see Figure 6.1). Mapping of the communication acts that young people saw as important suggested that treatment information should be made available to all young people who come to the clinic for testing irrespective of their test results, and also to their families, friends and the wider communities that are located outside the clinic. Grounded theory also revealed how young people became motivated to adherence, offering critical insights into how a health communication strategy could be designed and what kind of visual communication tools would support and facilitate motivation

10.2 Factors affecting motivation

The essential central element to designing an effective health communication strategy is to understand the key determinants of the communication outcome (Kreuter and Wray, 2003). As discussed in chapter four, many health communication strategies are informed by health belief theories/models that offer a framework for how health messages are constructed and designed. These messages are invariably aimed at individuals' cognition only and seek to inform and shift their understanding of two factors: perceived risk of disease versus health benefit. This understanding is presumed to be a central determinant of a person's motivation to enact the communicated health behaviour (Weinstein, 2003; Dutta, 2004; Airhihenbuwa et al., 2009).

However for the young people who participated in this study, motivation to adhere to ART was not only an outcome of understanding these factors. Instead, in the majority of cases, perceived risk (post diagnosis) was also associated with the possibility of rejection by members of their family rather than just with the threat of disease, and this caused young people to lose hope and meaning for their lives. For them, motivation to adherence was an outcome of re-connecting to one or more significant other(s) who through acceptance and support affirmed their belonging identity, which enabled them to reclaim hope for their present and future lives.

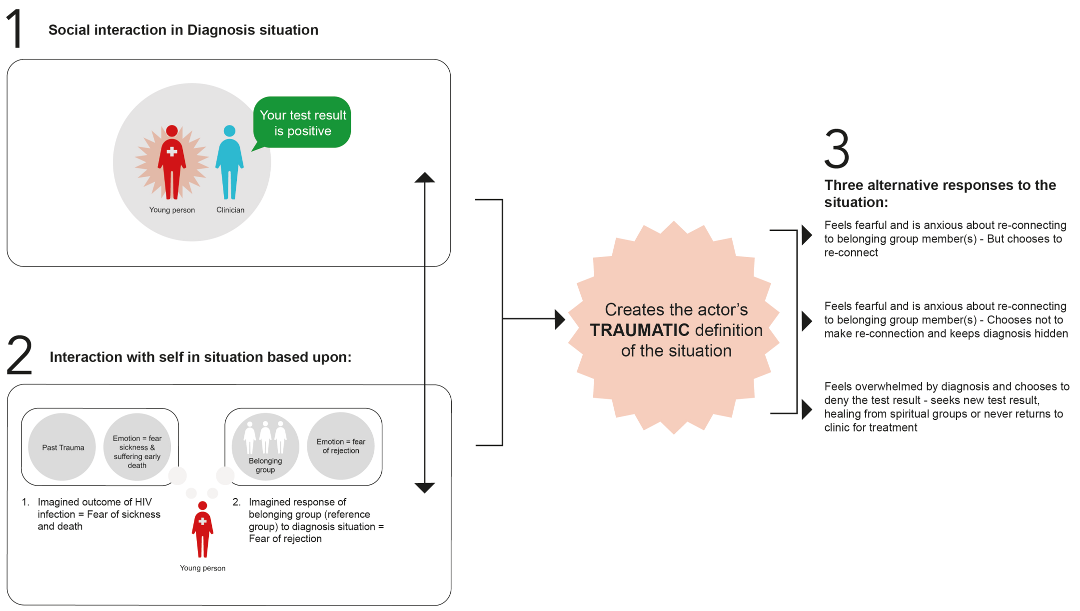
This study showed that immediately after young people received a diagnosis they wanted to feel accepted and supported by a significant other. Support was described as loving and empathetic, reassuring them that they would not get sick or die or be rejected. Solomon and Siegel describe empathy as the emotion that connects one with another and "allows two minds to join each other as they share in the flow of energy and information between them" (2003:7). Empathetic relationships, especially those that exist within the family unit, are essential to the experience of belonging. It is from these places of belonging that self-identities are formed and where their meaning is lived out relationally, both in the present and in the imagined futures (ibid.). Lambert et al. (2013) define belonging as essential to the "human drive". Baumeister and Leary (1995:497) argue that isolation, or "a lack of belongingness" is the cause of "severe deprivation". Twenge, Cantanese, and Baumeister (2003:410) found that social rejection can cause people to develop a state of "cognitive deconstruction" and decreased meaningfulness. Belonging is the context in which our identities are defined, through recognition and validation from those with whom we most often interact within our social worlds (Charon, 2011:84). From a symbolic interactionist perspective, self-identity is a self-perception that is "socially bestowed" through the act of interaction with others. Similarly Scott locates self-identity within the social, defining it as the "social self", arguing that selfhood is relational; it occurs through social interaction at "micro level" (2015:5). As Charon (2011) describes, "the names given to us within these intimate contexts become our names, our social addresses, our definitions of who we are in relation to those with whom we interact" (2011:84). Burke (1980:18) argues that identities are meanings that a person assigns to them self (and others assign to them) within the social context of belonging, and are the source of human motivation.

As discussed in chapter three (section 3.3.5), the *fear* of stigma, defined by Scrambler (2004) as "felt stigma", is reported in the literature as a main barrier to adherence among young people. For the young people who participated in this study, receiving a positive diagnosis caused them to perceive that their sense of belonging and meaningful identities were suddenly under threat. There was no identifiable outward sign that made them recognisably different and could have generated immediate discrimination from others. In contrast the young people appeared well and healthy, but through the sudden knowledge of being HIV-positive, they had in their own imaginations become different. Goffman (1963) refers to this as a "discreditable stigma", where a person regards them self, if discovered, as deviant, and can therefore choose to hide the perceived deviancy. Hiddenness takes the form of concealing the attribute through "information control", as the young person develops new strategies of carefully revealing "different versions of themselves" to those around them (Scott, 2013:157). This, according to Goffman (1963:47), can cause a "radical reorganisation of their lives" that comprises reframing self-identification, and involves feelings of "self-estrangement" as a person is forced to re-explore who they are and who they can become. During this reorganisation of self-identity, young people who had recently been diagnosed felt overwhelmed by the prospect of being cast out from their belonging group because they would be judged as deviant and therefore no longer wanted. This challenged their identities. In summary, experiencing an HIV diagnosis into the context of adolescence, which as Erikson (1980) states is in itself the most vulnerable period of human experience, propelled young people into an existential crisis that challenged both who they were and to whom and where they belonged.

For the young people who participated in this study, the definition of diagnosis included the overwhelming fear of being rejected by those to whom they belonged, which would result in the terrifying possibility being socially isolated. Charon (2011) describes how emotions are an intrinsic part of our self-interaction within a social situation, and play a significant role in how we define the situation. They "become objects" that are open to interpretation that may be based upon the imagined emotional response of others, such as disappointment and or anger, which young people described as potential responses from their parents on finding out about their diagnosis. The fear of being rejected post-diagnosis, however, was "perceived" rather than actual for most participants: most of those who spoke of their experiences in reconnecting to family members experienced successful affirmation and support from them. However the *fear* of rejection was very real for young people and was an outcome of self-interaction with imagined negative responses from belonging group member(s). Symbolic interactionism refers to this as "taking the role of other" where an individual imagines how their communication will be understood by the other. Others are seen as the main influence during self-interaction, whose perspective is most valued because of their significance to the individual. This group of significant others becomes the main "reference group" or "generalised other" that informs how a person defines a situation (Charon, 2011:104). Figure 10.2 illustrates this process within the framework of symbolic interactionism.

In line with their fear of rejection, for the majority of young people their main concern was to re-connect with one or more significant other(s) in order to receive their acceptance and support. It was at this juncture that young people struggled the most to determine the way forward and felt the most fear as they anticipated the response of others. For some, reconnection occurred soon after their diagnosis, but for others they withdrew and hid their status from those to whom they belonged. These findings show how crucial it is for a communication strategy to facilitate and support the interpersonal communication between a young person and trusted members of their belonging group in order to generate acceptance and support. This offers a significant challenge, as the act of telling a family member poses the potential risk of being rejected.

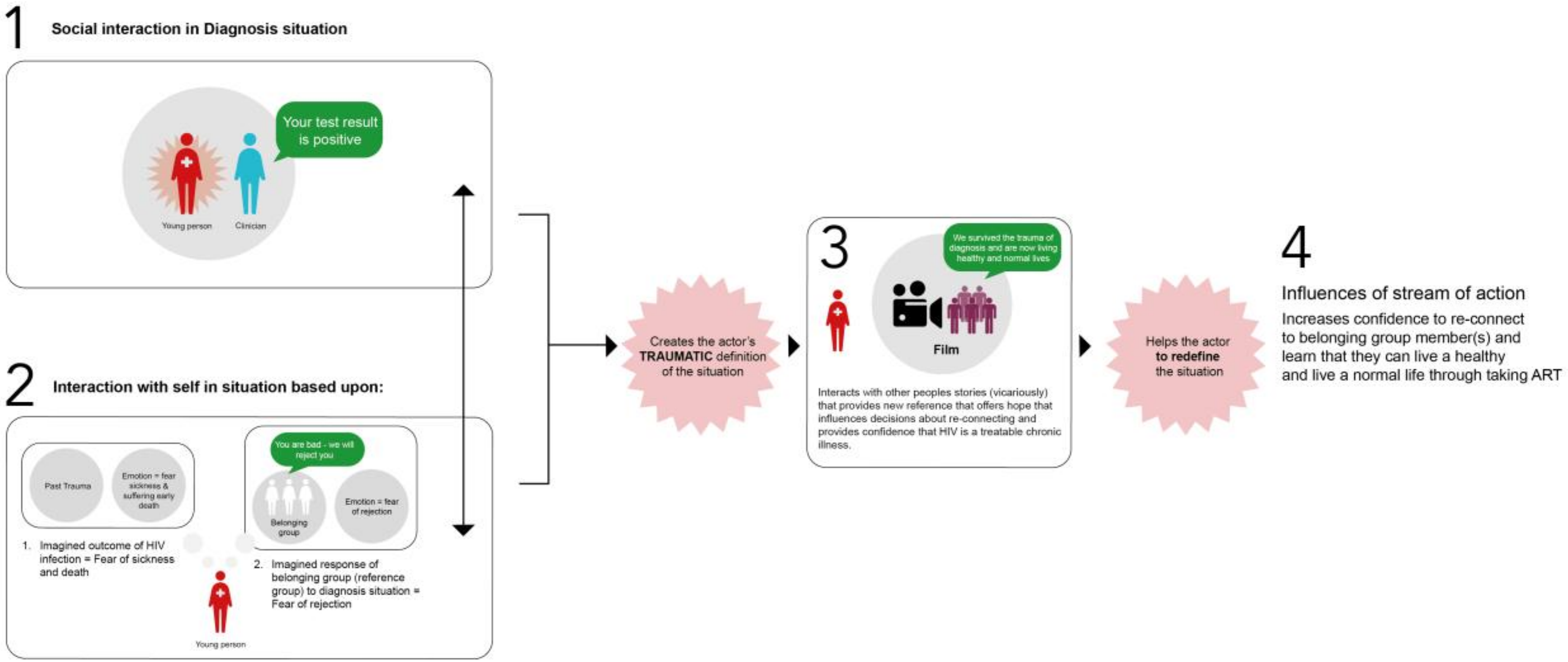
Figure 10.1: Symbolic interactionist model of how a person defines an HIV positive diagnosis situation



10.2.1 A film as a visual communication tool that supports young people's desire to re-connect

The process of reconnection described by young people in this study, and exemplified in the film that was made, involves a series of interactions between self and others, known in symbolic interactionism as the "stream of action". The stream of action is complex and continuous, and involves a series of decisions that determine a person's goals and objects. These are constantly being influenced by interactions with others and with self along the way (Charon 2011:117). As discussed above, for many young people in this study the main goal was to re-connect with significant others, but because they feared rejection they often hesitated to pursue reconnection. To help support them at this difficult moment, participants said that they wanted to listen to other young people's stories of how they had re-connected and had moved beyond the trauma of diagnosis to living normal full lives. A film of this type, made available immediately post diagnosis, would offer the possibility of providing another "reference group" with whom the newly diagnosed young person could interact, albeit vicariously (the people in the film) (see Figure 10.3).

Figure 10.2: Illustration of how a film could provide an additional reference group with whom a newly diagnosed young person could interact, facilitating hope that they too can re-connect to a trusted member(s) of their belonging group.



The use of narratives to describe the journey of how people experience and survive illness, its symptoms, diagnosis and treatment is recognised as a powerful tool that facilitates acceptance and integration of disease into self-identity (Ezzy, 2000). According to Charon (2006:52) illness narratives can "join one human being with another" and help them to decode and reframe a traumatic event such as a serious diagnosis. The process of listening to the story of someone else's suffering that mirrors their own can generate the experience of empathy, both validating their experience as real and authentic and beginning to break their sense of isolation (Mattingly & Garro, 2000:6). According to Seigal, empathy is experienced mainly through the visual senses as a person watches the communicator's non-verbal cues:

> "We are hard wired to have meaning and emotions shaped by the perception of eye contact and facial expressions. We are also hard wired to express emotional states through the face. Complex neural/bodily aspects of emotional processes are not easily translated into words. Non-verbal expressions, including those of the face, tone of voice, and gestures, can transfer information about internal states more fully to the outside world than words."

(Seigal, 1999:95)

Cohen (2001) argues that when the viewer strongly identifies with real life stories that are shown on film, they become connected through a "shared experience" that evokes "empathetic identification". Similarly, Håkansson (2006) describes how important it is for the viewer to see the "other" as representing, describing and experiencing their "situation in a similar manner" (2006:400). Cohen (citing Oatley, 1994), argues that when empathetic identification occurs, the viewer "adopts" the character's goals and life-world, and this can become a new reference point in the process of building self-identity.

Initial responses from clinicians to the film that was made during this study were very positive, however further research that tests the film directly with young people would be required. It is possible that the film could generate the "empathetic identification" that young people were keen to experience from viewing a DVD post-diagnosis. These findings show how the use of film that shows the narratives of both young people and their families, describing how they overcame their initial shock of diagnosis through accepting and supporting their child/sibling, could make an important contribution to a communication strategy*.

10.3 Factors affecting understanding

This study found that there are three key factors that affect understanding of communications related to ART adherence. The first factor is to do with the actual form and content of the communication message. The second is the context in which the message is shared, which proved crucial in encouraging people to engage with the information and learn. The third factor is the tragetting of the message and the fact that it needs to reach significant others within a young person's belonging group so that they can properly support them to adhere.

10.3.1 The message form and content

One of the key challenges for this study was to develop a visual tool that would best facilitate young people's understanding of ART adherence. As discussed above and in chapter six (section 6.8.2), the biomedical concept of undetectable viral load was a central element to the adherence message, but was an element that young people found particularly difficult to comprehend. The main challenge in designing a visual tool was to minimize misinterpretation and misunderstanding of this point, which, as discussed in chapter two, could easily occur when they looked at the existing standalone health communication materials.

As discussed in chapter two, the most popular visual approach in the design and development of treatment instructions is pictograms that include supportive text. In addition, as described in chapter six (section 6.6.3), at the time of this study metaphors were commonly used in Khayelitsha to explain ART. Whilst the use of metaphors was seen among clinicians as a method of simplifying the complexity of ART adherence messages, in fact their use created confusion. This is in keeping with the literature, which shows that the cognitive functional processing required to make sense of metaphors in language is specific to the social and cultural setting, and is more complex than picture/word combinations (Gentner & Bowdle., 2001; Steen,

---

* The film included in this study shows one story of how a young man successfully reconnected to his family - other narratives should be included that allow for cases where families were not so accepting and show that life can go on for them too, with support from alternative belonging groups

2008). According to Steen (2008), understanding metaphors requires a process of categorization in order to make the necessary connections. For example, when clinicians and health workers use the metaphor of a monster to describe the HIV virus, a person needs to refer to a "superordinate category" that includes both monster and virus as entities of war and invasion.

Recognising the level of confusion among young people in Khayelitsha, to which metaphors were a contributing factor was an important starting-point in this study during the consideration to how a visual tool should be used. It informed the design of the animation, which focused on explaining the relationship between HIV, CD4 count and undetectable viral load.

10.3.2 The context in which the message is shared: spaces to learn about adherence

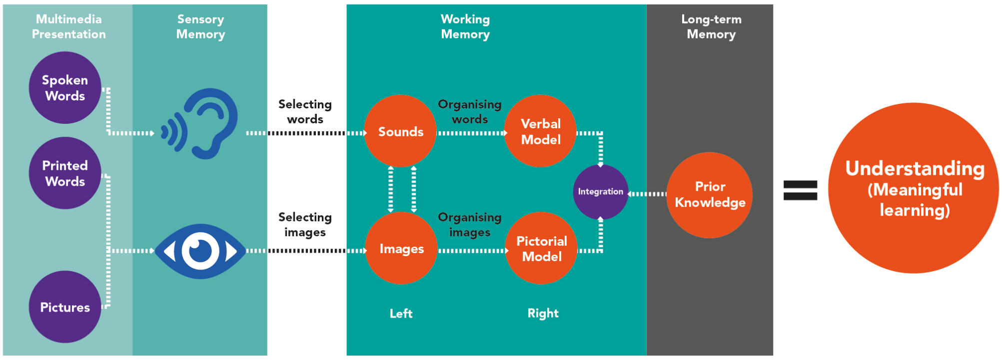
It was during the testing of the proto-type animation that it became evident that the best way to minimize misinterpretation and misunderstanding was to use the animation as a teaching aid that offered young people the opportunity to learn about ART adherence during an interactive session, rather than as a standalone visual communication designed for independent use only.

This study found that a didactic approach to communicating treatment knowledge, which was being used within the clinics, was ineffective. Clinicians recognized that many young people left the clinics having not understood, or in some cases having misinterpreted, their explanations about treatment. As discussed in chapter one, it is not surprising that clinicians (especially HIV lay-counsellors, treatment educators and nurses, many of whom lived in the townships themselves) had adopted this style of communication. Many of them would have experienced this method of learning within the local township school system themselves. However, as Bleakley, Bligh and Browne argue (2011:15), many medical doctors also adopt a didactic style of information delivery because medicine education is modelled largely on “vertical hierarchies, based on technical expertise” that still dominate medical practice. Technical expertise is taught within a culture of “autonomy” and “individualized” learning, where learning outcomes are measured by observable behaviours when students begin to practice medicine (2011:15). Within the context of this study, this may explain why not only the clinical staff living within the townships, but also other doctors who were influenced by the learning styles that they had experienced during their education, communicated treatment knowledge in this way.

According to Solomon and Seigal (2003) this approach “bombards” individuals with information that they are unable to process effectively. Bombardment of this kind can result simply in “chaos and uncertainty” (op cit:5). Solomon and Seigal describe that when working with traumatized individuals, collaborative and contingent communication must include the opportunity for people to process emotional sensations that are associated to their prior lived experiences. These emotions are stored in their long term memory and may be triggered by content in presented information (2003:13). Allowing spaces for traumatic autobiographical narrative enables the individual to free the mind of “restrictive and chaotic” memories, which then allows information to flow more spontaneously, facilitating a renewed “sense of discovery and connection” (2003:7).

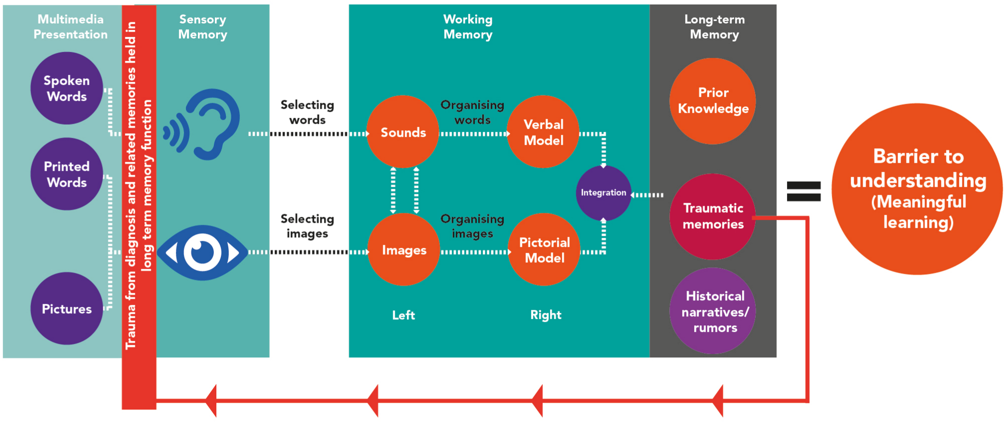
As discussed in chapter two (section 2.1) the process of understanding multi-media instructions involves five steps: selecting relevant words from the presentation (or narration), selecting relevant images, organizing selected words into coherent verbal representations, organizing selected images into coherent visual representation and then integrating both visual and verbal representations with prior knowledge. (2009:57). Essential to this learning process is prior-knowledge that provides the connecting function, allowing the integration of image and words that forms understanding. Once understanding is achieved, Mayers argues that new knowledge can be “transferred” into practice – a process he defines as “meaningful learning” (2003:7) (See Figure 10.3 and 2.2).

Figure 10.3: Mayer's model of cognitive learning theory



However, as Solomon & Seigal (2003) argue, if long-term memory also stores prior traumatic knowledge (memories) that are triggered by presented new knowledge, learning is likely to be severely hindered. It is not until the memories of the past are applied to the situations in our present that we are able to guide the decisions that face us in the present: it is only when we interact with those memories that we can choose how they inform our present actions (Charon, 2011). When treatment knowledge was presented to young people who were living with HIV it often triggered memories of historical treatment narratives and rumours and traumatic memories of loss that presented a potential barrier to learning continuation (see Figure 10.4). This may also have been a contributory factor to why young people went "blank" when they were presented with treatment knowledge immediately after their diagnosis: the diagnosis may have triggered memories of related traumatic events held in the long-term memory which further exacerbated their trauma response (see Chapter eight, section 8.3.1).

Figure 10.4 shows how traumatic memories and historical treatment narratives / rumours that are contained within long-term memory create a barrier to meaningful learning.



These findings are important in the context of a communication strategy. They suggest that spaces of learning about infection and treatment should be made available that allow young people to discuss their experiences of HIV and AIDS openly. These may include the loss of a significant other(s), and their understandings/confusion about treatment knowledge.

10.3.3 Learning for the family and peer friendships

As described above, as young people experience acceptance, affirmation and support they begin to re-connect to a renewed hope for living. This can result in them becoming motivated to learn about ART in order to ensure that they stay healthy and well, enabling them to enjoy their lives as normal young people. During this process of re-connection, family member(s) can also become motivated to learn about ART.

For many family members in this study, it was important to gain treatment knowledge so that they could better support their recently diagnosed relative. This finding shows that treatment knowledge was relevant not only for an infected person, but also for their belonging group. This was particularly evident for Lee's family, who described how they often reminded him to take his medicines with him when he went out for the night to party, or to stay at another family member's house. For Lee's father, gaining treatment knowledge was a way of "keeping him alive". Treatment knowledge enables family members to provide a "solidarity", which Molm, Collett and Shaefer (2007) describe as "the integrative bonds that develop between persons and social units to which they belong" (2007:207). They argue that social solidarity is dependent upon the quality of social exchange, and forms a mutual dependence based upon trust (defined as “the belief that the exchange partner will not exploit the actor”) and effective regard (defined as “positive feelings for, and evaluations of the partner”) (ibid.).

As discussed above, it is clear from the narratives of young people that the interaction of telling one or more significant other(s) of their diagnosis was based on a sufficient level of trust that the main response would not be exploitative, because of the person's positive feelings for them and their value of them. Molm, Collett and Shaefer (2007) argue that these types of acts of trust are often reciprocated by an act of solidarity, which although it initially benefits the recipient, also benefits the giver. In the context of the young people who testified that they had disclosed their diagnosis to a trusted significant other, one of the main reciprocating acts of acceptance and support was to offer them support with their adherence in order to participate actively in helping loved ones to stay alive, all of which reinforces the notion in the recipient that they belong.

10.4 Measures to increase acceptance and support from others

In this study, many young people who visited the clinics to be tested, especially those who came in groups, wanted to learn about treatment irrespective of their test result. They said that learning about ART would better equip them to support a family member or trusted friend who became infected, and would help them to cope if they ever tested positive themselves. According to Kolk (1996:448), gaining knowledge about a potentially traumatic event prior to its potential occurrence can limit the shock of exposure and decrease the surprise of the unexpected, which together can facilitate a sense of control and hope. Young people also wanted to learn about treatment because they wanted to change their communities' perspective about HIV. For them, having a better understanding about HIV and ART empowered them to challenge stigmatisation and misunderstanding among their friends and family. Symbolic interactionism defines this phenomenon of "shared perspective" in the context of localised culture, through which people in society view reality (Charon, 2011:158). According to Shibutani (1955) shared perspectives occur through social interaction, where people negotiate and relate to one another through shared values and norms. Charon (2011) describes these negotiated perspectives in terms of the "generalised other", defined as the "socially created conscience" that guides the group's behaviour according to its rules. Blumer (1969) argues that groups are held together not because they are dictated to by the rules of a society, but because they have chosen to follow them.

It was evident that young people’s interpretation of their community's perspective, in which the "generalised other" held a negative view towards people who live with HIV, was something that they wanted to challenge. The ability to challenge this perspective was related to learning about treatment, and sharing treatment knowledge with others within their community. Charon (2011:154) describes this as “cooperative action”, where individuals engage in cooperative problem-solving through interaction.

This finding points to the value of a communication strategy that explores how clinics can harness the enthusiasm and desire of young people who want to learn about treatment, irrespective of status. The development of an APP technology could contribute to this, by providing a mobile communication platform for young people to use to educate friends and family members about ART and encourage acceptance and support. Hoadley and Kilner (2005) describe this kind of process as socio-cultural learning, where communities build and share knowledge that is focused around a particular type of shared interest and related practice. Engeström (cited in Bleakley, Bligh and Browne, 2011) states that social learning occurs within “dynamic social” contexts, where:

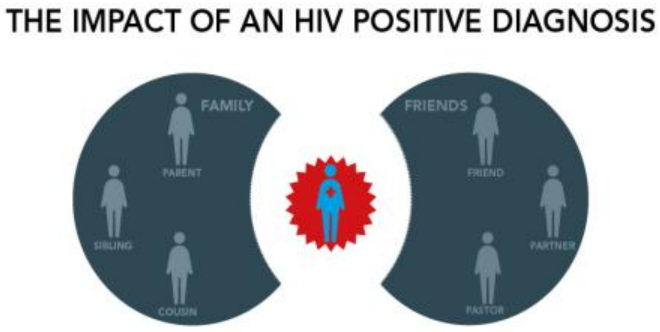
> “… the learner is not simply socialized into the knowledge held by a community, but rather participates in the production of knowledge and its application within their psycho-social contexts.” (2011:53).

However, despite the possibilities that an APP technology could provide, as discussed in chapter eight (section 8.4) further research would need to be undertaken to determine the potential role of a standalone APP in an overall communications strategy. Careful consideration would have to given to ensure that treatment information made available on the APP would be connected to shared spaces that allow for open discussion and questions/learning as described above. It would also be essential to ensure that an APP aimed at supporting ART adherence among young people would not trigger unintended disclosure, which could cause considerable harm among the population.

10.5 Conclusion

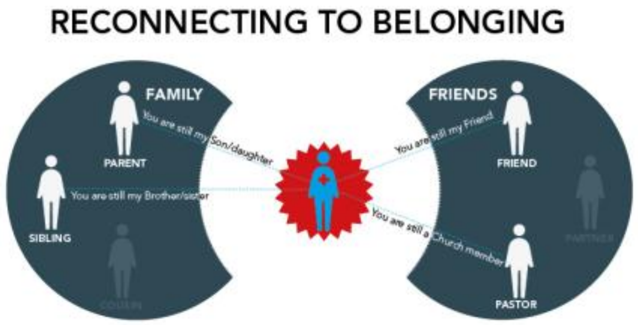
In conclusion, this study has identified a new model of motivation to adherence to adolescents and young people. For young people the impact of receiving an HIV positive diagnosis is overwhelming, causing them to feel traumatised because they feel terrified of becoming sick and suffering an early death, and that they will be rejected by their families and trusted friends. For young people, to be separated from their core belonging group was to be cast out, to become someone without identity, purpose and hope. In essence, for a young person, receiving an HIV positive diagnosis triggers an existential crisis that feels traumatic and catastrophic (see figure 10.5).

Figure 10.5 shows how a young person feels disconnected and isolated immediately after they have been told that they are HIV positive



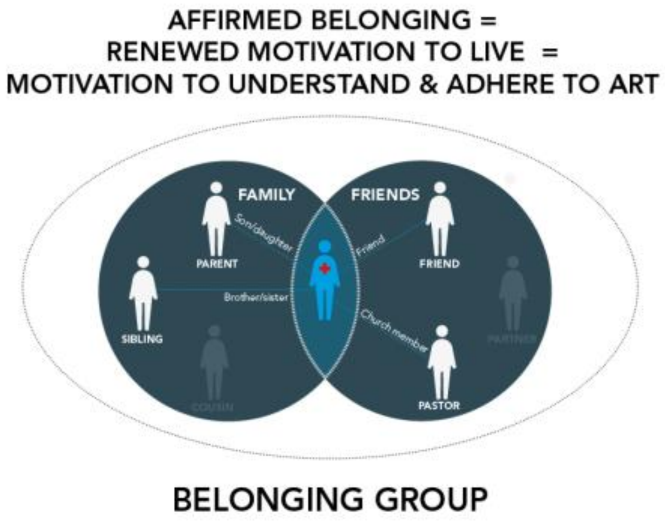
Soon after diagnosis young people needed to reconnect with trusted members of their belonging group, who through acceptance and support affirm them as someone who has not fundamentally changed; they were still a son, daughter, brother, cousin and friend (see Figure 10.6).

Figure 10.6 shows the messages that they want to hear from belonging group members post diagnosis



When a young person recieves acceptance and support they become reconnected to their belonging identity that in-turn reconnects them to their motivation for living their present and future lives. It is *this* motivation to live that becomes the central driver for becoming motivated to learn about treatment and to adhere to it. (see figure 10.7).

Figure 10.7 shows how affirming message help reconnect a young person to their sense of belonging that is the central driver to their motivation to learn about treatment and adhere to it.



This model shows that ART adherence is a social construction and that a communication strategy needs to facilitate and support young people to reconnect to trusted members of their belonging groups, and support belonging group members to accept, affirm and learn how to support their loved ones to adhere.

This study recommends an interdisciplinary approach to health communication that includes the use of social sciences to enable the researcher to gain an in-depth insight into the social phenomena of illness, health care and treatment. It should focus especially on identifying (i) the factors affecting motivation, (ii) the factors affecting understanding, and (iii) measures to increase acceptance and support from others. These three factors then provide a framework for the design of a health communication strategy and supporting visual materials, which can then be designed through a participatory process with community members. The latter process should include proto-type development of visual tools, allowing for initial pilot testing in order to inform how the visual tool is best used in the specific community for which it is intended.

Whilst it could be argued that participatory design methods do commonly actively engage and include audiences in defining the design problem and the solution, conventional methods do not interrogate the psychosocial aspects of motivation or investigate the cognitive processes of how people understand treatment instructions, and how these may be influenced by culturally specific aspects in a particular community. This thesis argues that in the context of developing effective communication strategies and supporting visual communication tools that motivate young people and facilitate their understanding of the importance of adherence to ART, it is imperative that these factors are fully understood. To achieve this, an inter-disciplinary approach is required.

Grounded theory provides a methodology that locates the health communication practitioner and designer as participant. He or she engages with people and privileges their voice, describing what communicative interactions need to occur from their perspectives and within their communities in order to facilitate health behaviours such as optimal adherence. Gaining these insights informs the design both of a communication strategy and of supporting visual tools to facilitate their motivation and understanding of ART adherence.

10.6 Recommendations

The South African National Strategic Plan (NSP) states that “effective communication is critical to the successful implementation of the NSP” (SANAC 2011). The findings of this study have a number of implications for policy, practice and education that are aligned to the NSP core objectives. The following recommendations are specific to Khayelitsha and other peri-urban locations within South Africa, although aspects may be transferable to other contexts:

Policy

Multiple messages are currently communicated within the healthcare system across Khayelitsha, creating mixed messaging that causes confusion and misinterpretations among young people. To address and overcome this structural barrier, clear guidelines on messaging should be developed and issued as a matter of urgency. At the South African Department of Health, a clear policy could be considered that provides a framework to support all agencies working in the field to align ART adherence communication strategies and message content throughout the health care pathway.

Practice

A health communication training programme could be considered that provides clinicians with sufficient training to enable them to communicate the complexity of both HIV and ART effectively.

Training could include sessions on communication skills that facilitate discussion and active learning, and move away from the didactic information transfer model. In addition, the focus should shift from seeing each patient as an isolated individual who is the sole recipient of communication to a viewpoint that sees a young person as part of a belonging group who collectively need to receive key health messages. Encouraging, supporting and resourcing young people who are in the process of telling a trusted member(s) of their belonging group should be prioritised within a health communication strategy.

This study however, also showed that for some young people, telling their parents about their diagnosis posed a significant risk of rejection. It is essential that the process of resourcing – “telling” - is sensitive to these cases. It should include working with young people to risk assess their circumstances properly, ensuring that telling is the appropriate action for them, if they are comfortable to do so. For the young people who are at most risk, the process of integration may take a different journey, where new attachments are developed that affirm them as normal young people. This is an area that should be informed by further research.

Message alignment – maintaining a sustainable message

Maintaining sustainable consistency in message delivery across HIV positive support groups and throughout the health services within each region is a challenge. Using a visual tool that navigates the communicator through each key message component would help support both message consistency and quality.

The same visual tool could also be made readily available for young people to engage with, by accessing transportable media platforms such as mobile phones, laptop computers and tablet technologies. For those who do not yet have access to these technologies, access should be made available from a localised web platform for viewing at local internet cafes. DVDs could be supplied for home TV viewing. This would create a consistent communication network that delivers the same message content and visual language, to will reinforce learning and create better knowledge recall among young people. Furthermore, using mobile technology provides the possibility for these key messages to go viral among young people, their families and their wider community.

Community workers

Community workers should also be trained to deliver the same messages, so that they are properly resourced to communicate about both HIV and ART if and when it is appropriate to do so during their home visits.

Education: Health & Wellness - spaces to learn

Many young people who attend clinics for testing leave with no or very little information that makes sense to them about HIV infection and ART. Youth clinics could offer these young people the option of attending workshops where they learn about disease, treatment and the social impact of HIV.

This would offer the opportunity to instil better knowledge about both disease and treatment, which could better prepare young people to manage their shock and trauma if they ever receive an HIV positive diagnosis, and to increase their confidence to tell trusted members of their belonging group. Other benefits would be to equip young people to support family and friends who are or become infected, and to reduce the impact of stigma. This should, however, be the subject to further research.

Belonging groups

Communication resources should be made available for belonging group members so that they can also engage with support and learning opportunities. This would help them both to process the news that a family member/friend has become infected and also to learn how to support them effectively. Workshops could be a key part of this communication strategy.

National communication campaign to build acceptance and support

South Africa Health Department could consider a long term sustained public health campaign that communicates the importance of families and friends through the support and acceptance they give to young people who tell them that they have become HIV positive. The campaign should offer guidance on:

- How to respond and support – the importance of acceptance and affirmation
- Where people can access further support and learning that equips them to support effectively.

10.7 Final reflections

At the beginning of this study I had very little knowledge about HIV/AIDS and ART medicines. I also knew very little about how these complex biomedical concepts were currently being communicated to the young people of Khayelitsha. My experience had been located in the corporate sector as both a communications strategist and information design consultant; it did not include health communication. During the period of this study I have engaged with over 100 young people and 37 clinicians and have learned about how young people cope with receiving and then living with an HIV positive diagnosis. I have also learnt that the free supply of medication for a chronic disease such as HIV is by no means a guarantee that it will be taken effectively by young people. The most important thing I have learnt is that listening to young people is the essential communicative act for both researcher and health communication practitioner if we are ever to truly understand the communication strategies that young people follow, which then result in their becoming motivated to understand and adhere to ART medicines.

References

Abadía-Barrero, C.E. & Castro, A. 2006. Experiences of stigma and access to HAART in children and adolescents living with HIV/AIDS in Brazil. *Social Science & Medicine*. 62(5):1219-1228.

Abramowitz, S., Koenig, L.J., Chandwani, S., Orban, L., Stein, R., LaGrange, R. & Barnes, W. (2009) Characterizing Social Support: Global and Specific Social Support Experiences of HIV-Infected Youth. *AIDS Patient Care and STDs*. 23(5):323-330

Agha, S. & Van Rossem, R. 2004. Impact of a school-based peer sexual health intervention on normative beliefs, risk perceptions, and sexual behavior of Zambian adolescents. *Journal of Adolescent Health*. 34(5):441-452.

Airhihenbuwa, C.O. & Obregon, R. 2000. A critical assessment of theories/models used in health communication for HIV/AIDS. *Journal of Health Communication*. 5(S1):5-15.

Airhihenbuwa, C.O. 1990. A conceptual model for culturally appropriate health education programs in developing countries. *International Quarterly of Community Health Education*. 11(1):53-62.

Airhihenbuwa, C., Okoror, T., Shefer, T., Brown, D., Iwelunmor, J., Smith, E., Adam, M., Simbayi, L. et al. 2009. Stigma, culture, and HIV and AIDS in the Western Cape, South Africa: An application of the PEN-3 cultural model for community-based research. *Journal of Black Psychology*. 35(4):407-432.

Ajzen, I. 1991. The theory of planned behavior. *Organizational Behavior and Human Decision Processes*. 50(2):179-211.

Albarracin, D., Johnson, B.T., Fishbein, M. & Muellerleile, P.A. 2001. Theories of reasoned action and planned behavior as models of condom use: a meta-analysis. *Psychological Bulletin*. 127(1):142.

Almeleh, C. 2006. Why do people disclose their HIV status? Qualitative evidence from a group of activist women in Khayelitsha. *Social Dynamics*. 32(2):136-169.

Annells, M. 1996. Grounded theory method: Philosophical perspectives, paradigm of inquiry, and postmodernism. *Qualitative Health Research*. 6(3):379-393.

Arnheim, R. 1969. *Visual thinking*. Univ of California Press.

Ashforth, A. & Nattrass, N. 2005. Ambiguities of 'culture'and the antiretroviral rollout in South Africa. *Social Dynamics*. 31(2):285-303.

Babrow, S.A. & Mattson, M. 2008. Theorizing about Health Communication. *Handbook of Health Communication*. L.T. Routledge Publishing Inc. 35-61.

Bandura, A., 1998. Health promotion from the perspective of social cognitive theory. *Psychology & Health*. 13(4):623-649.

Bandura, A. 1990. Perceived self-efficacy in the exercise of control over AIDS infection. *Evaluation and Program Planning*. 13(1): 9-17.

Baranowski, T., Cullen, K.W., Nicklas, T., Thompson, D. & Baranowski, J. 2003. Are current health behavioral change models helpful in guiding prevention of weight gain efforts? *Obesity Research*. 11(S10):23S-43S.

Battegay, M., Nüesch, R., Hirschel, B. & Kaufmann, G.R. 2006. Immunological recovery and antiretroviral therapy in HIV-1 infection. *The Lancet Infectious Diseases*. 6(5):280-287.

Battles, H.B. & Wiener, L.S. 2002. From adolescence through young adulthood: psychosocial adjustment associated with long-term survival of HIV. *Journal of Adolescent Health*. 30(3):161-168.

Baumeister, R.F. & Leary, M.R. 1995. The need to belong: desire for interpersonal attachments as a fundamental human motivation. *Psychological Bulletin*. 117(3):497.

Baumgartner, L.M. & David, K.N. 2009. Accepting being poz: the incorporation of the HIV identity into the self. *Qualitative Health Research*. 19(12):1730-1743.

Becker, M.H. & Janz, N.K. 1985. The health belief model applied to understanding diabetes regimen compliance. *The Diabetes Educator*. 11(1):41-47.

Belzer, M.E., Fuchs, D.N., Luftman, G.S. & Tucker, D.J. (1999). Antiretroviral adherence issues among HIV-positive adolescents and young adults. *The Journal of Adolescent Health*. 25(5):316-319.

Blanchard, C.G., Ruckdeschel, J.C., Blanchard, E.B., Arena, J.G., Saunders, N.L. & Malloy, E.D. 1983. Interactions between oncologists and patients during rounds. *Annals of Internal Medicine*. 99(5):694-699.

Bleakley, A., Bligh, J. & Browne, J. 2011. *Medical Education for the Furtue. Identity, Power and Location*. First ed. London: Springer.

Blomquist, Å. & Arvola, M. 2002, October. Personas in action: ethnography in an interaction design team. In *Proceedings of the Second Nordic Conference on Human-Computer Interaction. 197-200*. ACM

Blos, P. 1979. *The Adolescent Passage, Developmental Issues*. New York: International Universities Press, Inc.

Blumer, H. 1969. *Symbolic Interactionism, Perspective and Method*. London, England: University California Press.

Bogart, L.M., Skinner, D., Weinhardt, L.S., Glasman, L., Sitzler, C., Toefy, Y. & Kalichman, S.C. 2011. HIV/AIDS misconceptions may be associated with condom use among black South Africans: an exploratory analysis. *African Journal of AIDS Research*. 10(2):181-187.

Bolognesi, N. & Swartz, L. 2008. The Media Management of HIV/AIDS in Sub-Saharan Africa with Particular Reference to South Africa: A Window to Developing Communication Strategies. In *on the Occasion of the International Association of Media and Communication Research (IAMCR) 50th Anniversary Conference 2007*. 6.

Bond, G.G., Aiken, L.S. & Somerville, S.C. 1992. The health belief model and adolescents with insulin-dependent diabetes mellitus. *Health Psychology*. 11(3):190.

Boulle, A., Van Cutsem, G., Hilderbrand, K., Cragg, C., Abrahams, M., Mathee, S., Ford, N., Knight, L. et al. 2010. Seven-year experience of a primary care antiretroviral treatment programme in Khayelitsha, South Africa. *AIDS (London, England)*. 24(4):563-572.

Braich, P.S., Almeida, D.R., Hollands, S. & Coleman, M.T. 2011. Effects of pictograms in educating 3 distinct low-literacy populations on the use of postoperative cataract medication. *Canadian Journal of Ophthalmology/Journal Canadien d'Ophtalmologie*. 46(3):276-281.

Brashers, D.E. & Babrow, A.S. 1996. Theorizing communication and health 1.

Burke, P.J. 1980. The self: Measurement requirements from an interactionist perspective. *Social Psychology Quarterly*. :18-29.

Bury, M. 1982. Chronic illness as biographical disruption. *Sociology of Health & Illness*. 4(2):167-182.

Calabrese, S.K., Martin, S., Wolters, P.L., Toledo-Tamula, M.A., Brennan, T.L. & Wood, L.V. 2012. Diagnosis disclosure, medication hiding, and medical functioning among perinatally infected, HIV-positive children and adolescents. *AIDS Care*. 24(9):1092-1096.

Campbell, C. 2003. *'Letting them die' Why HIV/AIDS prevention programmes fail*. Bloomington & Indianapolis: Indiana University Press in association with the International African Institute.

Campbell, C. & MacPhail, C. 2002. Peer education, gender and the development of critical consciousness: participatory HIV prevention by South African youth. *Social Science & Medicine*. 55(2):331-345.

Carney, R.N. & Levin, J.R. 2002. Pictorial illustrations still improve students' learning from text. *Educational Psychology Review*. 14(1):5-26.

Carstens, A., Maes, A. & Gangla-Birir, L. 2006. Understanding visuals in HIV/AIDS education in South Africa: differences between literate and low-literate audiences. *African Journal of AIDS Research*. 5(3):221-232.

Champion, L.V. & Skinner, S., Celette. 2008. The Health Belief Model. In *Health Behaviour and Health Education. Theory, Research, and Practice*. Jossey-Bass. 46.

Chan, A.H. & Chan, K.W. 2013. Effects of prospective-user factors and sign design features on guessability of pharmaceutical pictograms. *Patient Education and Counseling*. 90(2):268-275.

Chandwani, S., Koenig, L.J., Sill, A.M., Abramowitz, S., Conner, L.C. & D'Angelo, L. 2012. Predictors of antiretroviral medication adherence among a diverse cohort of adolescents with HIV. *Journal of Adolescent Health*. 51(3):242-251.

Charmaz, K. 1999. Stories of suffering: Subjective tales and research narratives. *Qualitative Health Research*. 9(3):362-382.

Charmaz, K. 2006. *Constructing Grounded Theory. A Practical Guide Through Qualitative Analysis*. London: Sage Publications.

Charon, R. 2011. *Narrative Medicine. Honoring the Stories of Illness*. New York: Oxford University Press.

Charon, M. J. 2006. *Symbolic Interactionism. An Introduction, An Interpretation, An Integration*. New Delhi: PHI Learning Private Limited.

City of Cape Town Census. 2012.
Clark, J.M. & Paivio, A. 1991. Dual coding theory and education. *Educational Psychology Review*. 3(3):149-210.

Clark, R.E. & Craig, T.G. 1992. Research and theory on multi-media learning effects. In *Interactive multimedia learning environments*. 19-30. Springer Berlin Heidelberg

Coates, T.J., Richter, L. & Caceres, C. 2008. Behavioural strategies to reduce HIV transmission: how to make them work better. *The Lancet*. 372(9639):669-684.

Coetzee, B., Kagee, A. & Vermeulen, N. 2011. Structural barriers to adherence to antiretroviral therapy in a resource-constrained setting: the perspectives of health care providers. *AIDS Care*. 23(2):146-151.

Cohen, J.H. 2000. Problems in the field: Participant observation and the assumption of neutrality. *Field Methods*. 12(4):316-333.

Cohen, J. 2001. Defining identification: A theoretical look at the identification of audiences with media characters. *Mass Communication & Society*. 4(3):245-264.

Colt, H. & Quadrelli, S. 2006. Democratization of medical knowledge and technology: brief commentary on implications for medical education. *Simulation in Healthcare*. 1(4):238-239.

Comulada, W.S., Swendeman, D.T., Rotheram-Borus, M.J., Mattes, K.M. & Weiss, R.E. 2003. Use of HAART among young people living with HIV. *American Journal of Health Behavior*. 27(4):389-400.

Corbin, J. & Strauss, A. 2008. *Basics of Qualititave Research*. Sage Publications.

Coyne, I.T. 1997. Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? *Journal of Advanced Nursing*. 26(3):623-630.

Craig, R.T. 1999. Communication theory as a field. *Communication Theory*. 9(2):119-161.

Dadds, M. 2008. Empathetic validity in practitioner research. *Educational Action Research*. 16(2):279-290.

Stephney, I. & Prosalendis, S. 2005. *Understanding HIV/AIDS stigma: A theoretical and methodological analysis*. HSRC Press.

Deetz, S. 2005. Critical Theory. In *Engaging Organizational Communication, Theory & Reserach. Multiple Perspectives*. S. May & K.D. Mumby, Eds. London. UK: Sage Publications. 85-111.

Dewalt, K.M., DeWalt, B., Wayland, C. & Bernard, H. 1998. Handbook of methods in cultural anthropology.

Dickerson, S.S., Gruenewald, T.L. & Kemeny, M.E. 2004. When the social self is threatened: Shame, physiology, and health. *Journal of Personality*. 72(6):1191-1216.

Dima, A.L., Schweitzer, A., Diaconiţă, R., Remor, E. & Wanless, R.S. 2013. Adherence to ARV medication in Romanian young adults: Self-reported behaviour and psychological barriers. *Psychology, Health & Medicine*. 18(3):343-354.

Downs, D.S., Graham, G.M., Yang, S., Bargainnier, S. & Vasil, J. 2006. Youth exercise intention and past exercise behavior: Examining the moderating influences of sex and meeting exercise recommendations. *Research Quarterly for Exercise and Sport*. 77(1):91-99.

Dowse, R. & Ehlers, M. 2004. Pictograms for conveying medicine instructions: comprehension in various South African language groups. *South African Journal of Science*. 100(11 & 12):687-693.

Dowse, R. & Ehlers, M. 2005. Medicine labels incorporating pictograms: do they influence understanding and adherence? *Patient Education and Counseling*. 58(1):63-70.

Dowse, R., Ramela, T., Barford, K.L. & Browne, S. 2011. Developing visual images for communicating information aboutantiretroviral side effects to a low-literate population. *African Journal of AIDS Research*. 9(3):213-224.

Dowse, R., Ramela, T. & Browne, S.H. 2011. An illustrated leaflet containing antiretroviral information targeted for low-literate readers: Development and evaluation. *Patient Education and Counseling*. 85(3):508-515.

Dutta, M.J. 2008. Communicating About Culture and Health: Theorizing Culture-Centered and Cultural Sensitivity Approaches. *Communication Theory*. 17(3):304-328.

Dutta-Bergman, M.J. 2005. Theory and practice in health communication campaigns: A critical interrogation. *Health Communication*. 18(2):103-122.

Dutta-Bergman, M.J. 2004. The unheard voices of Santalis: Communicating about health from the margins of India. *Communication Theory*. 14(3):237-263.

Ehlers, A. & Clark, D.M. 2000. A cognitive model of posttraumatic stress disorder. *Behaviour Research and Therapy*. 38(4):319-345.

Eisenhardt, M. K. 1989. Building Theories from Case Study Reserach. *Academy of Management*. 14(4):532-550.

May, S. & Mumby, K. D. 2005. *Engaging Organizational Communication, Theory & Research*. California, USA: Sage Publications.

Englehart, L. 2003. Media Activism in the screening room: The significance of viewing locations, facilitation and audience dynamics in the reception of HIV/AIDS films IN South Africa. *Visual Anthropology Review*. 19(1-2):73-85.

Erikson, H.E. 1980. *Identity and the Life Cycle*. London: W.W Norton & Company Ltd.

Ezzy, D. 2000. Illness narratives: time, hope and HIV. *Social Science & Medicine*. 50(5):605-617.

Farmer, K.C. 1999. Methods for measuring and monitoring medication regimen adherence in clinical trials and clinical practice. *Clinical Therapeutics*. 21(6):1074-1090.

Farmer, T., Robinson, K., Elliott, S.J. & Eyles, J. 2006. Developing and implementing a triangulation protocol for qualitative health research. *Qualitative Health Research*. 16(3):377-394.

Fassin, D. 2002. Embodied history. Uniqueness and exemplarity of South African AIDS. *African Journal of AIDS Research*. 1(1):63-68.

Fassin, D. & Schneider, H. 2003. The politics of AIDS in South Africa: beyond the controversies. *BMJ (Clinical Research Ed.)*. 326(7387):495-497.

Fern, E.F., 2001. *Advanced focus group research*. Sage publications.

Finocchario-Kessler, S., Catley, D., Thomson, D., Bradley-Ewing, A., Berkley-Patton, J. & Goggin, K. 2012. Patient communication tools to enhance ART adherence counseling in low and high resource settings. *Patient Education and Counseling*. 89(1):163-170.

Flinders, D.J. 1992. In search of ethical guidance: constructing a basis for dialogue 1. *Qualitative Studies in Education*. 5(2):101-115.

Flowers, P., Davis, M., Hart, G., Rosengarten, M., Frankis, J. & Imrie, J. 2006. Diagnosis and stigma and identity amongst HIV positive Black Africans living in the UK. *Psychology and Health*. 21(1):109-122.

Fox, R.C. & Goemaere, E. 2006. They call it "patient selection" in Khayelitsha: The experience of Médecins Sans Frontières–South Africa in enrolling patients to receive antiretroviral treatment for HIV/AIDS. *Cambridge Quarterly of Healthcare Ethics*. 15(03):302-312.

Gallant, M. & Maticka-Tyndale, E. 2004. School-based HIV prevention programmes for African youth. *Social Science & Medicine*. 58(7):1337-1351.

Garber, M.C., Nau, D.P., Erickson, S.R., Aikens, J.E. & Lawrence, J.B. 2004. The concordance of self-report with other measures of medication adherence: a summary of the literature. *Medical Care*. 42(7):649.

Garone, D., Conradie, K., Patten, G., Cornell, M., Goemaere, E., Kunene, J., Kerschberger, B., Ford, N. et al. 2013. High rate of virological re-suppression among patients failing second-line antiretroviral therapy following enhanced adherence support: a model of care in Khayelitsha, South Africa. *Southern African Journal of HIV Medicine*. 14(4):170-175.

Gaur, A.H., Belzer, M., Britto, P., Garvie, P.A., Hu, C., Graham, B., Neely, M., McSherry, G. et al. (2010) Directly observed therapy (DOT) for nonadherent HIV-infected youth: lessons learned, challenges ahead.(CLINICAL TRIALS/CLINICAL STUDIES)(human immunodeficiency virus)(Report). *AIDS Research and Human Retroviruses*. 26(9):947.

Gentner, D. & Bowdle, B.F. 2001. Convention, form, and figurative language processing. *Metaphor and Symbol*. 16(3-4):223-247.

Gergen, J.K., 2009. *An Invitation to Social Construction*. Sage.

Geuss, R., 1981. *The idea of a critical theory: Habermas and the Frankfurt School.* Cambridge University Press.

Gilbert, L. & Walker, L. 2010. 'My biggest fear was that people would reject me once they knew my status…': stigma as experienced by patients in an HIV/AIDS clinic in Johannesburg, South Africa. *Health & Social Care in the Community*. 18(2):139-146.

Glanz, K., Rimer, K., Barbara & Viswanath, K. Eds. 2008. *Health Behaviour and Health Education, Theory, Research, and Practice*: Jossey-Bass.

Glikman, D., Walsh, L., Valkenburg, J., Mangat, P.D. & Marcinak, J.F. 2007. Hospital-based directly observed therapy for HIV-infected children and adolescents to assess adherence to antiretroviral medications. *Pediatrics*. 119(5):e1142-8.

Global AIDS Response Progress 2012. South Africa: SANAC.

Global Report, UNAIDS report on the global AIDS epidemic 2014. 2015.

Goffman, E. 1963. *Stigma, Notes on the management of spoiled indentity*. Penguin Books.

Gold, R.L. 1958. Roles in sociological field observations. *Social Forces*. 217-223.

Grenier, S., Vaillancourt, R., Pynn, D., Cloutier, M.C., Wade, J., Turpin, P.M., Pascuet, E. & Preston, C. 2011. Design and development of culture-specific pictograms for the labelling of medication for first nation communities. *Journal of Communication in Healthcare*. 4(4):238-245.

Håkansson Eklund, J. 2006. Empathy and viewing the other as a subject. *Scandinavian Journal of Psychology*. 47(5):399-409.

Hall, S. Ed. 1997. *Representation, Cultural Presentations and Signifying Practices*. London: SAGE Publications.

Hoadley, C.M. & Kilner, P.G. 2005. Using technology to transform communities of practice into knowledge-building communities. *ACM SIGGROUP Bulletin*. 25(1):31-40.

Hoffman, B.R., Sussman, S., Unger, J.B. & Valente, T.W. 2006. Peer influences on adolescent cigarette smoking: A theoretical review of the literature. *Substance use & Misuse*. 41(1):103-155.

Holloway, I. & Wheeler, S. 2010. *Qualitative Research in Nursing and Healthcare*. John Wiley-Blackwell.

Hosek, S.G., Harper, G.W. & Domanico, R. 2005. Predictors of medication adherence among HIV-infected youth. *Psychology, Health & Medicine*. 10(2):166-179.

Hounton, S.H., Carabin, H. & Henderson, N.J. 2005. Towards an understanding of barriers to condom use in rural Benin using the Health Belief Model: a cross sectional survey. *BMC Public Health*. 5(1): 1

Houts, P.S., Bachrach, R., Witmer, J.T., Tringali, C.A., Bucher, J.A. & Localio, R.A. 1998. Using pictographs to enhance recall of spoken medical instructions. *Patient Education and Counseling*. 35(2):83-88.

Houts, P.S., Doak, C.C., Doak, L.G. & Loscalzo, M.J. 2006. The role of pictures in improving health communication: a review of research on attention, comprehension, recall, and adherence. *Patient Education and Counseling*. 61(2):173-190.

Houts, P.S., Witmer, J.T., Egeth, H.E., Loscalzo, M.J. & Zabora, J.R. 2001. Using pictographs to enhance recall of spoken medical instructions II. *Patient Education and Counseling*. 43(3):231-242.

Howe, D. 2011. *Attachment across the Lifecourse. A breif introduction*. New York: Palgrave Macmillan.

Jacobs, S. & Johnson, K. 2007. Media, social movements and the state: competing images of HIV/AIDS in South Africa. *African Studies Quarterly*. 9(4):10.

Jankie, D., Garegae, K.G. & Tsheko, G. 2011. Using focus group interviews to research adolescents' beliefs and perceptions of sex, sexuality, HIV and AIDS in educational settings: methodological successes and challenges.

Janz, N.K. & Becker, M.H. 1984. The health belief model: A decade later. *Health Education & Behavior*. 11(1):1-47.

Johnson, M.O., Catz, S.L., Remien, R.H., Rotheram-Borus, M.J., Morin, S.F., Charlebois, E., Gore-Felton, C., Goldsten, R.B. et al. 2003. Theory-guided, empirically supported avenues for intervention on HIV medication nonadherence: findings from the Healthy Living Project. *AIDS Patient Care and STDs*. 17(12):645-656.

Joshi, Y. & Kothiyal, P. 2011. A pilot study to evaluate pharmaceutical pictograms in a multispecialty hospital at Dehradun. *Journal of Young Pharmacists*. 3(2):163-166.

Kagee, A., Remien, R., Berkman, A., Hoffman, S., Campos, L. & Swartz, L. 2011. Structural barriers to ART adherence in Southern Africa: challenges and potential ways forward. *Global Public Health*. 6(1):83-97.

Kagee, A., Le Roux, M. and Dick, J., 2007. Treatment adherence among primary care patients in a historically disadvantaged community in South Africa: a qualititative study. *Journal of Health Psychology*. 12(3):444-460.

Kalichman, S.C. & Rompa, D. 2000. Functional health literacy is associated with health status and health-related knowledge in people living with HIV-AIDS. *Journal of Acquired Immune Deficiency Syndromes*. 25(4):337.

Kalichman, S.C., Simbayi, L.C., Jooste, S., Toefy, Y., Cain, D., Cherry, C. & Kagee, A. 2005. Development of a brief scale to measure AIDS-related stigma in South Africa. *AIDS and Behavior*. 9(2):135-143.

Kalichman, S.C. & Simbayi, L.C. 2003. HIV testing attitudes, AIDS stigma, and voluntary HIV counselling and testing in a black township in Cape Town, South Africa. *Sexually Transmitted Infections*. 79(6):442-447.

Kaplan, S.H., Greenfield, S. & Ware Jr, J.E. 1989. Assessing the effects of physician-patient interactions on the outcomes of chronic disease. *Medical Care*. 27(3) 110-127.

Kaplan, W.A. Can the ubiquitous power of mobile phones be used to improve health outcomes in developing countries? *Globalization and Health*. 2:9-9.

Kassam, R., Vaillancourt, L.R. & Collins, J.B. 2004. Pictographic instructions for medications: do different cultures interpret them accurately? *International Journal of Pharmacy Practice*. 12(4):199-209.

Katz, M.G., Kripalani, S. & Weiss, B.D. 2006. Use of pictorial aids in medication instructions: a review of the literature. *American Journal of Health-System Pharmacy*. 63(23):2391-2398.

Kheir, N., Awaisu, A., Radoui, A., El Badawi, A., Jean, L. & Dowse, R. 2014. Development and evaluation of pictograms on medication labels for patients with limited literacy skills in a culturally diverse multiethnic population. *Research in Social and Administrative Pharmacy*. 10(5):720-730.

Kim, S., Gerver, S.M., Fidler, S. & Ward, H. 2014. Adherence to antiretroviral therapy in adolescents living with HIV: systematic review and meta-analysis. *AIDS*. 28 (13):1945-1956.

Kohlberg, L. & Gilligan, C. 1971. The adolescent as a philosopher: The discovery of the self in a postconventional world. *Daedalus*. 1051-1086.

Kohn, P.M., Goodstadt, M.S., Cook, G.M., Sheppard, M. & Chan, G. 1982. Ineffectiveness of threat appeals about drinking and driving. *Accident Analysis & Prevention*. 14(6):457-464.

Van der Kolk, B.A. and McFarlane, A.C. eds 1996. *Traumatic Stress. The Effects of Overwhelming Experience on Mind, Body, and Society*. The Guildford Press.

Kreuter, M.W. & McClure, S.M. 2004. The role of culture in health communication. *Annu. Rev. Public Health*. 25:439-455.

Kreuter, M.W. & Wray, R.J. 2003. Tailored and targeted health communication: strategies for enhancing information relevance. *American Journal of Health Behavior*. 27(Supplement 3):S227-S232.

Kripalani, S., Robertson, R., Love-Ghaffari, M.H., Henderson, L.E., Praska, J., Strawder, A., Katz, M.G. & Jacobson, T.A. 2007. Development of an illustrated medication schedule as a low-literacy patient education tool. *Patient Education and Counseling*. 66(3):368-377.

Kroger, J. 2009. *Identity in Adolescence, The balance between self and other*. London and New York: Routledge, Taylor & Francis Group.

Lam, P.K., Naar-King, S. & Wright, K. 2007. Social support and disclosure as predictors of mental health in HIV-positive youth. *AIDS Patient Care and STDs*. 21(1):20-29.

Lambert, N.M., Stillman, T.F., Hicks, J.A., Kamble, S., Baumeister, R.F. & Fincham, F.D. 2013. To belong is to matter: sense of belonging enhances meaning in life. *Personality & Social Psychology Bulletin*. 39(11):1418-1427.

Latour, B. 2005. 'Thou Shall Not Freeze-Frame' or How Not to Misunderstand the Science and Religion Debate.". *Science, religion, and the human experience*. 27-48.

Leeuwen, Theo, Van. Hewitt, Carey. Ed. 2008. *Handbook of Visual Analysis*. London: Sage.

Levin, J.R. 1981. On functions of Pictures in Prose. *Neuropsychological and Cognitive Processes in Reading*. 203.

Lindlof, R.T. & Taylor, C.B. (2012). *Qualitative Communication Research Methods*. Third ed. London, UK: Sage Publications Inc.

Lupton, D. 1994. Toward the development of critical health communication praxis. *Health Communication*. 6(1):55-67.

Lupton, E. 1986. Reading isotype. *Design Issues*. :47-58.

Lyon, M.E., Trexler, C., Akpan-Townsend, C., Pao, M., Selden, K., Fletcher, J., Addlestone, I.C. & D'Angelo, L. (2003). A family group approach to increasing adherence to therapy in HIV-infected youths: Results of a pilot project. *AIDS Patient Care and STDs*. 17(6):299-308.

Mabuto, T., Latka, M.H., Kuwane, B., Churchyard, G.J., Charalambous, S. & Hoffmann, C.J. 2014. Four Models of HIV Counseling and Testing: Utilization and Test Results in South Africa. *PloS One*. 9(7):e102267.

MacDonell, K., Naar-King, S., Huszti, H. & Belzer, M. 2013. Barriers to medication adherence in behaviorally and perinatally infected youth living with HIV. *AIDS and Behavior*. 17(1):86-93.

Maddux, J.E. & Rogers, R.W. 1983. Protection motivation and self-efficacy: A revised theory of fear appeals and attitude change. *Journal of Experimental Social Psychology*. 19(5):469-479.

Makoul, G., Arntson, P. & Schofield, T. 1995. Health promotion in primary care: physician-patient communication and decision making about prescription medications. *Social Science & Medicine*. 41(9):1241-1254.

Mall, S., Middelkoop, K., Mark, D., Wood, R. & Bekker, L. 2013. Changing patterns in HIV/AIDS stigma and uptake of voluntary counselling and testing services: The results of two consecutive community surveys conducted in the Western Cape, South Africa. *AIDS Care*. 25(2):194-201.

Mansoor, L. & Dowse, R. 2006. Medicines information and adherence in HIV/AIDS patients. *Journal of Clinical Pharmacy and Therapeutics*. 31(1):7-15.

Mansoor, L.E. & Dowse, R. 2003. Effect of pictograms on readability of patient information materials. *The Annals of Pharmacotherapy*. 37(7/8):1003-1009.

Martin, L. & Kagee, A. 2011. Lifetime and HIV-related PTSD among persons recently diagnosed with HIV. *AIDS and Behavior*. 15(1):125-131.

Martinez, J., Bell, D., Camacho, R., Henry-Reid, L., Bell, M., Watson, C. & Rodriguez, F. (2002). Adherence to antiviral drug regimens in HIV-infected adolescent patients engaged in care in a comprehensive adolescent and young adult clinic. *Journal of the National Medical Association*. 92(2):55.

Mattingly, C. & Garro, C.L. Eds. 2000. *Narrative and the Cultural Construction of Illness and Healing*. Berkely: University of California Press.

Mattson, M. 1999. Toward a reconceptualization of communication cues to action in the health belief model: HIV test counseling. *Communications Monographs*. 66(3):240-265.

May, S. & Mumby, K.D. Eds. 2005. *Engaging Organizational Communication Theory & Research. Multiple Perspectives*. London: SAGE.

Mayer, R.E. 2003. The promise of multimedia learning: using the same instructional design methods across different media. *Learning and Instruction*. 13(2):125-139.

Mayer, R.E. 2009. *Multimedia learning*. Cambridge university press.

Mayer, R.E. & Sims, V.K. 1994. For whom is a picture worth a thousand words? Extensions of a dual-coding theory of multimedia learning. *Journal of educational psychology*. 86(3):389.

Mbonu, N.C., van den Borne, B. & De Vries, N.K. 2009. Stigma of People with HIV/AIDS in Sub-Saharan Africa: a literature review. *Journal of Tropical Medicine*.

McAlister, A, Perry, C.L, Parcel, G. 2008. How Individuals, Environments, and Health Behaviours Interact. *Health Behaviour*. 169

Molm, D.L., Collett, L.J & Shaefer. 2007. Building Solidarity through Generalised Exchange: A Theory of Reciprocity. American *Journal of Sociology*. 2007:113(1)205-242.

Frontieres, M.S. 2010. Providing HIV/TB care at the primary care level. *Khayelitsha Annual Activity Report 2008-2009*.

Meintjes, G., Conradie, J., Cox, V., Dlamini, S., Fabian, J., Maartens, G., Manzini, T., Mathe, M. et al. 2014. Adult antiretroviral therapy guidelines 2014. *Southern African Journal of HIV Medicine*. 15(4):121-143.

Meintjes, G. & Maartens, G. 2012. Guidelines for antiretroviral therapy in adults. *Southern African Journal of HIV Medicine*. 13(3):114-133.

Merzel, C. & D'Afflitti, J. 2003. Reconsidering community-based health promotion: promise, performance, and potential. *Journal Information*. 93(4): 557-574.

Merzel, C., Vandevanter, N. & Irvine, M. 2008. Adherence to antiretroviral therapy among older children and adolescents with HIV: a qualitative study of psychosocial contexts. *AIDS Patient Care and STDs*. 22(12):977.

Mfecane, S. 2010. *ARV USE: A Study of Men Living with HIV in a South African Village*. (Doctorial dissertation, Faculty of Humanities, University of Witwatersrand, Johannesburg).

Miles, B.M. & Huberman, M. 1994. *Qualitative Data Analysis*. second ed. Sage Publications.

Mills, E.J., Nachega, J.B., Bangsberg, D.R., Singh, S., Rachlis, B., Wu, P., Wilson, K., Buchan, I. et al. 2006. Adherence to HAART: a systematic review of developed and developing nation patient-reported barriers and facilitators. *PLoS Med*. 3(11):e438.

Mills, J., Bonner, A. & Francis, K. 2006. Adopting a constructivist approach to grounded theory: Implications for research design. *International Journal of Nursing Practice*. 12(1):8-13.

Montagne, M. 2013. Pharmaceutical pictograms: a model for development and testing for comprehension and utility. *Research in Social and Administrative Pharmacy*. 9(5):609-620.

Montaño, E.D. & Kasprzyk, D. 2008. Theory of Reasoned Action, Theory of Planned Behavior, and Integrated Behavioural Model. In *Health Behaviour and Health Education. Theory, Research, and Practice*. K. Glanz, K. Rimer Barbara & K. Viswanath, Eds. Fourth Edition ed. Jossey - Bass. 76.

Montgomery, S.B., Joseph, J.G., Becker, M.H. & Ostrow, D.G., Kessler, R.C. and Kirscht, J.P., 1989. The Health Belief Model in understanding compliance with preventive recommendations for AIDS: How useful? *AIDS Education and Prevention*.

Morgan, D.L., 1996. Focus groups. *Annual Review of Sociology*. :129-152.

Morrow, D.G., Hier, C.M., Menard, W.E. & Leirer, V.O. 1998. Icons improve older and younger adults' comprehension of medication information. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*. 53(4):P240-P254.

Morrow, D.G., Weiner, M., Young, J., Steinley, D., Deer, M. & Murray, M.D. 2005. Improving medication knowledge among older adults with heart failure: a patient-centered approach to instruction design. *The Gerontologist*. 45(4):545-552.

Munro, S., Lewin, S., Swart, T. & Volmink, J. 2007. A review of health behaviour theories: how useful are these for developing interventions to promote long-term medication adherence for TB and HIV/AIDS? *BMC Public Health*. 7(1):104.

Murphy, D.A., Wilson, C., Durako, S., Muenz, L. & Belzer, M. 2001. Antiretroviral medication adherence among the REACH HIV-infected adolescent cohort in the USA. *AIDS Care*. 13(1):27-40.

Murphy, D.A., Lam, P., Naar-King, S., Robert Harris, D., Parsons, J.T. & Muenz, L.R. 2010. Health literacy and antiretroviral adherence among HIV-infected adolescents. *Patient Education and Counseling*. 79(1):25-29.

Mwingira, B. & Dowse, R. 2006. Comprehension and acceptability of a patient information leaflet (PIL) for antiretroviral therapy: research. *Health SA Gesondheid*. 11(3): 49-61.

Nachega, J.B., Lehman, D.A., Hlatshwayo, D., Mothopeng, R., Chaisson, R.E. & Karstaedt, A.S. 2005. HIV/AIDS and antiretroviral treatment knowledge, attitudes, beliefs, and practices in HIV-infected adults in Soweto, South Africa. *Journal of Acquired Immune Deficiency Syndromes*. 38(2):196-201.

Nachega, J.B., Hislop, M., Dowdy, D.W., Lo, M., Omer, S.B., Regensberg, L., Chaisson, R.E. & Maartens, G. 2006. Adherence to highly active antiretroviral therapy assessed by pharmacy claims predicts survival in HIV-infected South African adults. *Journal of Acquired Immune Deficiency Syndromes*. 43(1):78-84.

Nachega, J.B., Hislop, M., Nguyen, H., Dowdy, D.W., Chaisson, R.E., Regensberg, L., Cotton, M. & Maartens, G. 2009. Antiretroviral therapy adherence, virologic and immunologic outcomes in adolescents compared with adults in southern Africa. *Journal of Acquired Immune Deficiency Syndromes*. 51(1):65-71.

National Education Evaluation & Development Unit (NEEDU), 2013. National Report. 2012: The state of literacy teaching and learning in the foundation phase.

Nel, A. & Kagee, A. 2013. The relationship between depression, anxiety and medication adherence among patients receiving antiretroviral treatment in South Africa. *AIDS Care*. 25(8):948-955.

Newing, H. 2011. *Conducting research in Conservation. A social science perspective*. Routledge.

Nglazi, M.D., Kranzer, K., Holele, P., Kaplan, R., Mark, D., Jaspan, H., Lawn, S.D., Wood, R. et al. 2012. Treatment outcomes in HIV-infected adolescents attending a community-based antiretroviral therapy clinic in South Africa. *BMC Infectious Diseases*. 12(21):2334-12-21.

Ngoh, L.N. & Shepherd, M.D. 1997. Design, development, and evaluation of visual aids for communicating prescription drug instructions to nonliterate patients in rural Cameroon. *Patient Education and Counseling*. 30(3):257-270.

Olley, B.O. 2006. Psychological distress in the first year after diagnosis of HIV infection among women in South Africa. *African Journal of AIDS Research*. 5(3):207-215.

Olley, B.O. 2006. Psychological distress in the first year after diagnosis of HIV infection among women in South Africa. *African Journal of AIDS Research*. 5(3):207-215.

Orphans and vulnerable children. 2014. Available: unicef.org [12.4.2015].

Osterberg, L. & Blaschke, T. 2005. Adherence to medication. *New England Journal of Medicine*. 353(5):487-497.

Paivio, A. 1986. *Mental Representation: A dual-coded approach*. Oxford, England: Oxford University Press.

Parker, W. 2004. Rethinking conceptual approaches to behaviour change: The importance of context. *Centre for AIDS Development, Research and Evaluation (CADRE)* 3-11.

Patton, Q., M. 2002. Qualitative Research & Evaluation Methods. Sage Publications.

Patrick, K., Griswold, W.G., Raab, F. & Intille, S.S. 2008. Health and the mobile phone. *American Journal of Preventive Medicine*. 35(2):177-181.

Periyakoil, V.S. 2008. Using metaphors in medicine. *Journal of Palliative Medicine*. 11(6):842-844.

Perry, C.L., Kelder, S.H., Murray, D.M. & Klepp, K.I., 1992. Communitywide smoking prevention: long-term outcomes of the Minnesota Heart Health Program and the Class of 1989 Study. *American Journal of Public Health*. 82(9):1210-1216.

Petersen, I., Bhana, A., Myeza, N., Alicea, S., John, S., Holst, H., McKay, M. & Mellins, C. 2010. Psychosocial challenges and protective influences for socio-emotional coping of HIV adolescents in South Africa: a qualitative investigation. *AIDS Care*. 22(8):970-978.

Petronio, S. 2002. *Boundaries of Privacy. Dialectics of Disclosure*. New York: State University of New York Press.

Puccio, J.A., Belzer, M., Olson, J., Martinez, M., Salata, C., Tucker, D. & Tanaka, D. 2006. The use of cell phone reminder calls for assisting HIV-infected adolescents and young adults to adhere to highly active antiretroviral therapy: a pilot study. *AIDS Patient Care & STDs*. 20(6):438-444.

Ramirez, A.G., Villarreal, R., Mcalister, A., Gallion, K.J., Suarez, L. & Gomez, P. 1999. Advancing the role of participatory communication in the diffusion of cancer screening among Hispanics. *Journal of Health Communication*. 4(1):31-36.

Rao, D., Kekwaletswe, T., Hosek, S., Martinez, J. & Rodriguez, F. 2007. Stigma and social barriers to medication adherence with urban youth living with HIV. *AIDS Care*. 19(1):28-33.

Reilly, J.M., Ring, J. & Duke, L. 2005. Visual thinking strategies: a new role for art in medical education. *Fam Med*. 37(4):250-252.

Richler, M., Vaillancourt, R., Celetti, S.J., Besançon, L., Arun, K. & Sebastien, F. 2012. The use of pictograms to convey health information regarding side effects and/or indications of medications. *Journal of Communication in Healthcare*. 5(4):220-226.

Richter, M. 2010. *Risk Behaviour is Adolescence*. Springer Fachmedien

Richter, L.M., van Rooyen, H., Solomon, V., Griesel, D. & Durrheim, K. 2001. Putting HIV/AIDS counselling in South Africa in its place. *Society in Transition*. 32(1):148-154.

Roberts, K.J. Barriers to antiretroviral medication adherence in young HIV-infected children. *Youth & Society*. 37(2):230-245.

Rogers, A.S., Miller, S., Murphy, D.A., Tanney, M. & Fortune, T. 2001. The TREAT (therapeutic regimens enhancing adherence in teens) program: theory and preliminary results. *Journal of Adolescent Health*. 29(3, Supplement 1):30-38.

Romer, D., Sznitman, S., DiClemente, R., Salazar, L.F., Vanable, P.A., Carey, M.P., Hennessy, M., Brown, L.K. et al. 2009. Mass media as an HIV-prevention strategy: using culturally sensitive messages to reduce HIV-associated sexual behavior of at-risk African American youth. *American Journal of Public Health*. 99(12):2150-2159.

Rosenstock, I.M., Strecher, V.J. & Becker, M.H. 1994. The health belief model and HIV risk behavior change. *Preventing AIDS: Theories and Methods of Behavioral Interventions*. 5-24.

Rubincam, C. 2013. Alternative beliefs about HIV/AIDS: re-examining distrust among young adults in Cape Town, South Africa (Doctorial dissertation, The London School os Economics and Political Science (LSE).

Rudy, B.J., Murphy, D.A., Harris, D.R., Muenz, L. & Ellen, J. 2009. Patient-Related Risks for Nonadherence to Antiretroviral Therapy among HIV-Infected Youth in the United States: A Study of Prevalence and Interactions. *AIDS Patient Care and STDs*. 23(3):185-194.

Sabaté, E., 2003. *Adherence to long-term Therapies - evidence for action*. World Health Organisation

Safren, S.A., Gershuny, B.S. & Hendriksen, E. 2003. Symptoms of posttraumatic stress and death anxiety in persons with HIV and medication adherence difficulties. *AIDS Patient Care and STDs*. 17(12):657-664.

Sampaio-Sa, M., Page-Shafer, K., Bangsberg, D.R., Evans, J., de Lourdes Dourado, M., Teixeira, C., Netto, E.M. & Brites, C. 2008. 100% Adherence study: educational workshops vs. video sessions to improve adherence among ART-naïve patients in Salvador, Brazil. *AIDS and Behavior*. 12(1):54-62.

SANAC South Africa National AIDS Committee, 2011. National Strategic Plan on HIV, STIs and TB. 2012-2016. Johannesburg, South Africa: Ed. Department of Health (DoH).

Scambler, G. 2004. Re-framing stigma: felt and enacted stigma and challenges to the sociology of chronic and disabling conditions. *Social Theory & Health*. 2(1):29-46.
Scott, S. 2015. *Negotiating Identity. Symbolic Interactionist Approaches to Social Identity*. First ed. Polity Press.

Sharf, F.B. & Vanderford, L.M. 2008. Illness Narratives and the Social Construction of Health. In *Handbook of Health Communication*. L.T. Thompson, and others, Eds. London UK: Routledge Publishing Inc. 9-34.

Shegog, R., Markham, C.M., Leonard, A.D., Bui, T.C. & Paul, M.E. 2012. " CLICK": pilot of a web-based training program to enhance ART adherence among HIV-positive youth. *AIDS Care*. 24(3):310-318.

Shibutani, T. 1955. Reference groups as perspectives. *American Journal of Sociology*. 60(6):562-569.

Siegel, J.D. 1999. *The Developing Mind. How relationaships and the brain interact to shape who we are*. New York: The Guildford Press.

Silverman, D. 2008. *Doing Qualitative Research*. London, UK: Sage Publications Ltd.

Simbayi, L.C., Kalichman, S., Strebel, A., Cloete, A., Henda, N. & Mqeketo, A. 2007. Internalized stigma, discrimination, and depression among men and women living with HIV/AIDS in Cape Town, South Africa. *Social Science & Medicine*. 64(9):1823-1831.

Smith, R.C. & Hoppe, R.B. 1991. The patient's story: integrating the patient-and physician-centered approaches to interviewing. *Annals of Internal Medicine*. 115(6):470-477.

Sojourner, R.J. & Wogalter, M.S. 1997. The influence of pictorials on evaluations of prescription medication instructions. *Drug Information Journal*. 31(3):963-972.

Solomon, F.M. & Siegel, J.D. 2003. *Healing Trauma. Attachment, mind, body, and brain*. New York: W. W. Norton & Company.

Somekh, B. & Lewin, C. 2005. *Research Methods in the Social Sciences*. London: Sage Publications.

Starace, F., Massa, A., Amico, K.R. & Fisher, J.D. 2006. Adherence to antiretroviral therapy: an empirical test of the information-motivation-behavioral skills model. *Health Psychology*. 25(2):153.

Steen, G. 2008. The paradox of metaphor: Why we need a three-dimensional model of metaphor. *Metaphor and Symbol*. 23(4):213-241.

Steinberg, L. 2008. A social neuroscience perspective on adolescent risk-taking. *Developmental Review*. 28(1):78-106.

Stevens, P. & Tighe Doerr, B. 1997. Trauma of discovery: Women's narratives of being informed they are HIV-infected. *AIDS Care*. 9(5):523-538.

Street, R.L. 1991. Physicians' communication and parents' evaluations of pediatric consultations. *Medical Care*. 29(11):1146-1152.

Tarrant, M., N, A.C., Edridge, M.D., Kirk, L.E., Smith, E.A. & Turner, R.E. 2001. Social identity in adolescence. *Journal of Adolescence*. 24(5):597-609.

Taylor, D., Bury,M., Campling, N., Carter, S., Garfield, S., Newbould, J and Rennie, T., 2006. A Review of the use of the Health Belief Model (HBM), the Theory of Reasoned Action (TRA), the Theory of Planned Behaviour (TPB) and the Trans-Theoretical Model (TTM) to Study and Predict Health Related Behaviour Change. *National Institute for Health and Clinical Excellence*. 1-215.

Tedlock, B. 1991. From participant observation to the observation of participation: The emergence of narrative ethnography. *Journal of Anthropological Research*. :69-94.

JUNPoHA, U.N.A.I.D.S., 2013, Global report: UNAIDS report on the global AIDS epidemic 2013. Contract No: ISBN. 978-92

Thompson, A.E., Goldszmidt, M.A., Schwartz, A.J. & Bashook, P.G. 2010. A randomized trial of pictorial versus prose-based medication information pamphlets. *Patient Education and Counseling*. 78(3):389-393.

Thompson, L.T., Dorsey, A., Miller, I.K. & Parrott, R. Eds. 2003. *Handbook of Health Communication*. New York: Routledge.

Thompson, T.L., Parrott, R. and Nussbaum, J.F. eds., 2011. *The Routledge handbook of health communication*. Routledge.

O’Regan, K and Pikoli, V., 2014. Towards a Safer Khayelitsha. Report of the Commission of Inquiry into Allegations of Police In efficiency and a Breakdown in Relations between SAPS and the Community of Khayelitsha. *Summary August*.

Tun, W., Kellerman, S., Maimane, S., Fipaza, Z., Sheehy, M., Vu, L. & Nel, D. 2012. HIV-related conspiracy beliefs and its relationships with HIV testing and unprotected sex among men who have sex with men in Tshwane (Pretoria), South Africa. *AIDS Care*. 24(4):459-467

Van der Velde, Frank W, Hooykaas, C. & van der Joop, P. 1992. Risk perception and behavior: Pessimism, realism, and optimism about AIDS-related health behavior. *Psychology and Health*. 6(1-2):23-38.

Van Rossem, R. & Meekers, D. 2007 *The reach and impact of social marketing and reproductive health communication campaigns in Zambia. BMC Public Health*. 7(1):1

Van Winghem, J., Telfer, B., Reid, T., Ouko, J., Mutunga, A., Jama, Z. & Vakil, S. Implementation of a comprehensive program including psycho-social and treatment literacy activities to improve adherence to HIV care and treatment for a pediatric population in Kenya. *BMC pediatrics*. 8(1):1

Veinot, T.C., Flicker, S.E., Skinner, H.A., McClelland, A., Saulnier, P., Read, S.E. & Goldberg, E. 2006. "Supposed to make you better but it doesn't really": HIV-positive youths' perceptions of HIV treatment. *The Journal of Adolescent Health*. 38(3):261.

Vijayan, T., Benin, A.L., Wagner, K., Romano, S. & Andiman, W.A. 2009. We never thought this would happen: transitioning care of adolescents with perinatally acquired HIV infection from pediatrics to internal medicine. *AIDS Care*. 21(10):1222-1229.

Waitzkin, H. 1984. Doctor-patient communication. *JAMA: The Journal of the American Medical Association*. 252(17):2441-2446.

Watson, C.W. 1999. *Being There, Fieldwork in Anthropology*. London: Pluto Press.

Weiss, L., French, T., Finkelstein, R., Waters, M., Mukherjee, R. & Agins, B. 2003. HIV-related knowledge and adherence to HAART. *AIDS Care*. 15(5):673-679.

Wilby, K., Marra, C.A., da Silva, J.H., Grubisic, M., Harvard, S. & Lynd, L.D. 2011. Randomized controlled trial evaluating pictogram augmentation of HIV medication information. *The Annals of Pharmacotherapy*. 45(11):1378-1383.

Wild, L.G., Flisher, A.J., Bhana, A. & Lombard, C. 2004. Associations among adolescent risk behaviours and self‐esteem in six domains. *Journal of Child Psychology and Psychiatry*. 45(8):1454-1467.

Williams, P.L., Storm, D., Montepiedra, G., Nichols, S., Kammerer, B., Sirois, P.A., Farley, J. & Malee, K. 2006. Predictors of adherence to antiretroviral medications in children and adolescents with HIV infection. *Pediatrics*. 118(6):E1745-E1757.

Wilson, E.A., Vaillancourt, R., Pascuet, E., Besançon, L. J & Wolf, M.S. 2012. Seeking international consensus in the use of icons for medication instructions. *Journal of Communication in Healthcare*. 5(1):67-72.

Wilson, E.A.H. & Wolf, M.S. 2009. Working memory and the design of health materials: A cognitive factors perspective. *Patient Education and Counseling*. 74(3):318-322.

Witte, K. 1992. Putting the fear back into fear appeals: The extended parallel process model. *Communications Monographs*. 59(4):329-349.

Witte, K. & Allen, M. 2000. A meta-analysis of fear appeals: Implications for effective public health campaigns. *Health Education & Behavior*. 27(5):591-615.

Witte, K. 1998. A theoretically based evaluation of HIV/AIDS prevention campaigns along the trans-Africa highway in Kenya. *Journal of Health Communication*. 3(4):345-363.

Yin, H.S., Dreyer, B.P., van Schaick, L., Foltin, G.L., Dinglas, C. & Mendelsohn, A.L. 2008. Randomized controlled trial of a pictogram-based intervention to reduce liquid medication dosing errors and improve adherence among caregivers of young children. *Archives of Pediatrics & Adolescent Medicine*. 162(9):814-822.

Zak-Place, J. & Stern, M. 2004. Health belief factors and dispositional optimism as predictors of STD and HIV preventive behavior. *Journal of American College Health*. 52(5):229-236.

Zoller, M.H. & Dutta, J.M. Eds. 2009. *Emerging Perspectives in Health Communication. Meaning, Culture, and Power*. New York: Routledge.

APPENDICES

HREC REF: 061/2011
Health Sciences Faculty

LOCATION FACILITY CONSENT FORM

Working with Young People to Choose Life – a participative study to create a visual communication tool to promote and motivate adherence to Antiretroviral Therapy in Khayelitsha.

RESEARCHERS:

Kholekile Menziwa : HIV Counsellor and co-researcher.

Warren Hickson MA. PhD researcher based at UCT .

Principle supervisor: Professor Minette Coetzee (UCT).

AIM: To search for a visual solution that effectively communicates the importance of Drug adherence to young people who live with HIV/AIDS.

STUDY BENEFITS: *'Additional research is needed to identify the optimal strategies to promote long-term adherence and particularly to respond to those patients who do not adhere to therapy'* (Coetzee et al, 2004)

Young people find adherence to imposed regimens a particular challenge. A recent report from Khayelitsha states that 'youth proved to be at especially high risk of defaulting ART' and that specific interventions to support adherence amongst youth are urgently needed (G, Van Cutsem, 2009). This sense of urgency is supported in the South African Department of Health's National Strategic Plan outlining key HIV/AIDS strategies. The National Strategic Plan also recognises that young people represent the main focus for altering the course of the epidemic and should be the focus of all interventions (Department of Health, 2009).

High prevalence in adolescents, good evidence that they do not manage to sustain contact with health services and adherence to ART once started poses a great challenge. If this does not improve the morbidity and mortality in this age group is likely to rise. Many clinicians working in the field confirm the urge for a coherent strategy to effectively communicate around ART and adherence.

The purpose of this study is to work with young people and health professionals to design a communication tool and strategy that would facilitate understanding and support adherence to ART in clinical settings.

Interview

At the end of the group meeting we may ask one of you to stay behind for another 45 minutes to help us understand some of the main points that people have shared in the focus group. As mentioned above if staying behind to help us further has affected your travel arrangements we will we will help you with the cost of a bus or taxi so you can get home safely.

Observation

To help us find out what messages are already being used that explain how important it is to take ART medicine everyday we would like to join you during one of your meetings. Warren and Kholekile will quietly sit with you during one of your consultations and simply take notes when the issue of medicine is discussed.

If you join a focus group, stay behind for a structured interview or allow us to sit with you in one of your consultations we want you to know that we fully respect your privacy and will not use your name or any other way of identifying you. You will be given a number that will be used to identify you and your contribution in the group, interview or observation. However, if you are joining a focus group today it is important to let you know that we cannot guarantee that other members of the group will not talk about what happened in the group to other friends and family. But, because we are talking about positive stories about taking ART medicine, we don't see any reason for you to be concerned. However, as a result of being a member of a focus group there is a possibility that somebody that you know could discover that you are HIV positive. We canot guarantee that this may not happen and it is important for you to consider this possibility before you agree to join us in this study. We will all talk about these issues together at the end of the meeting to make sure we all are happy with what has been shared.

Thank you for thinking about sharing your valuable story, for taking the time to listen to us and for reading this form. If you feel you do not want to contribute that's fine, we wish you well! If you do want to share your story with us, then please feel free to talk more with us, ask as many questions as you like and then once you are really sure, kindly sign this form to tell us that your happy to join us in our journey to find what message could work best to help young people take their medicine everyday.

Thank you!

Name:

Signature:

Date:

Please tick the box of the event you are happy to contribute to.

Focus Group ☐ Structured Interview ☐

Participatory Observation ☐

HREC REF: 061/2011
Health Sciences Faculty

PARTICIPATION INFORMATION /CONSENT FORM

Thank you for considering being involved in this project.

Many young people who live with HIV find taking their medicine everyday a real challenge. A recent report by doctors from Khayelitsha recognises this difficulty and says that new ways of helping young people to take their medicine are urgently needed. This sense of urgency is also supported by the South African Health Department, who has published a special report called the ‘National Strategic Plan. This plan fully recognises that young people should be the focus of all new interventions. It is for this reason, that we believe it is important to ask you for your help so that together we can find the best messages that will help young people to take their medicine everyday.

There are many different people who are helping us to find this new message. Young men and women from Khayelitsha who live with HIV, Nurses, HIV Counsellors, Pharmacists and Doctors - all who work with young people who live with HIV in Khayelitsha. This study recognises the equal importance of everyone in these groups, and that whatever story you choose to share will be a valuable contribution that will help us all build a new picture of what and how this new message should look like.

Your participation is deeply valued because we value you and your story. We now would like you to understand a few important points to help you think about whether you would like to share your story with us.

Your involvement is voluntary and will be based on the following understanding:

1. Your name and identity will always remain confidential and anonymous.
2. Your involvement will not effect your ongoing treatment or the care receive.
3. Your contribution is very valuable and all information you offer will be respected and appreciated and will be useful to this research project.

There are three ways we are using to help gather your stories together. We have already explained which of these we are asking you to help with today, but please read them all for your own interest and information.

Focus Group/interview

The focus group or interview will last for up to 45 minutes. The discussion we have will be based around a set of open questions key to this stage of our research. During our time together a drink and sandwiches will be provided and if you have missed your normal transport home, we will help you with the cost of a bus or taxi so you can get home safely.

Interview

At the end of the group meeting we may ask one of you to stay behind for another 45 minutes to help us understand some of the main points that people have shared in the focus group. As mentioned above if staying behind to help us further has affected your travel arrangements we will we will help you with the cost of a bus or taxi so you can get home safely.

Observation

To help us find out what messages are already being used that explain how important it is to take ART medicine everyday we would like to join you during one of your meetings. Warren and Kholekile will quietly sit with you during one of your consultations and simply take notes when the issue of medicine is discussed.

If you join a focus group, stay behind for a structured interview or allow us to sit with you in one of your consultations we want you to know that we fully respect your privacy and will not use your name or any other way of identifying you. You will be given a number that will be used to identify you and your contribution in the group, interview or observation. However, if you are joining a focus group today it is important to let you know that we cannot guarantee that other members of the group will not talk about what happened in the group to other friends and family. But, because we are talking about positive stories about taking ART medicine, we don't see any reason for you to be concerned. However, as a result of being a member of a focus group there is a possibility that somebody that you know could discover that you are HIV positive. We canot guarantee that this may not happen and it is important for you to consider this possibility before you agree to join us in this study. We will all talk about these issues together at the end of the meeting to make sure we all are happy with what has been shared.

Thank you for thinking about sharing your valuable story, for taking the time to listen to us and for reading this form. If you feel you do not want to contribute that's fine, we wish you well! If you do want to share your story with us, then please feel free to talk more with us, ask as many questions as you like and then once you are really sure, kindly sign this form to tell us that your happy to join us in our journey to find what message could work best to help young people take their medicine everyday.

Thank you!

Name:

Signature:

Date:

Please tick the box of the event you are happy to contribute to.

Focus Group ☐ Structured Interview ☐

Participatory Observation ☐

HREC REF: 061/2011
Health Sciences Faculty

Working with Young People to Choose Life –
a participative study to create a visual communication tool to promote and motivate adherence to Antiretroviral Therapy in Khayelitsha.

A film of hope!

PARTICIPATION INFORMATION/CONSENT FORM

Thank you for considering being involved in this film project

Many young people who live with HIV find taking their medicine everyday a real challenge. A recent report by doctors from Khayelitsha recognises this difficulty and that new ways of helping young people to take their medicine are urgently needed. This sense of urgency is also supported by the South African Health Department, who has published a special report called the 'National Strategic Plan'. This plan fully recognises that young people should be the focus of all new interventions. It is for this reason that we believe it is important to ask you for your involvement so that together we can, through making this film, help young people to take their medicine everyday.

As you know we have been talking to young people, like yourselves who find it very challenging when they first hear that they are HIV positive at the clinic. They have described their experience as traumatic, shocking and frightening. But, many who shared their stories with us also spoke of how, through support, friends, family and taking the ARV medicines, they moved beyond this point and now continue to live full and normal lives. During our research many young people said that they wanted to help make a film where they could share their stories of how they felt when they were first diagnosed and how they now live with HIV - often saying we are 'normal young people just like everybody else'. These stories, your story, could offer real hope and courage to the many other young people who today, tomorrow and in the weeks ahead will also hear that they are now HIV positive. Making this film is about helping them to hear the stories, (your stories) of other young people in Khayelitsha, stories that will tell them that life will not end, that they are not alone and that there are many others just like them who are well and enjoying life.

Your participation is deeply valued because we value you and your story. We would now like you to understand a few important points to help you think about whether you would like to share your story as part of this film.

HREC REF: 061/2011
Health Sciences Faculty

Working with Young People to Choose Life –
a participative study to create a visual communication
tool to promote and motivate adherence to
Antiretroviral Therapy in Khayelitsha.

A film of hope!

Your involvement is voluntary and will be based on the following understanding:

1 After the film editing process you may appear on the film which is intended to be shown in clinics throughout Khayelitsha and could be seen on television and You Tube.

2 Your contribution is very valuable, but if you are HIV positive, appearing on a film will mean that everyone who watches the film will know your status. That could include people who know you, and that could mean that they tell other people you know, including friends and family and people at your work place.

3 Your involvement will not effect your ongoing treatment or the care you receive. If you are interested please talk to Lee and he will explain the film project in more detail and answer any questions you may have. Please think very carefully about being involved and the possible consequences related to disclosure. It is important to let you know that you can withdraw from this film project at any time during the film making stages, we will all fully understand and will wish you well and thank you for your help. All film footage that includes you will then be destroyed. However, it is important to fully understand that we cannot remove you from the film once it has been made and released.
There is no payment available for taking part in this film, but you will receive a final copy of the film in DVD format. Refreshments will be available during film sessions.

Thank you for thinking about sharing your valuable story, for taking the time to listen to us and for reading this form. If you feel you do not want to contribute that's fine, we wish you well! If you do want to share your story with us, then please feel free to talk with Lee. Ask as many questions as you like and then once you are really sure, kindly complete and sign this form to tell us that your happy to join us in making this exciting film. Thank you!

To tell us you are happy to join in this film project then please write your name, date and the sign the sections shown below. This will mean that you are giving your permission for the film be shown in clinics, peoples homes, on television and on the internet, and that you fully understand that will mean people who view the film will know that you are HIV positive.

Name: ☐ **Date:** ☐

Signature: ☐

APPENDIX 4

HREC REF: 061/2011
Health Sciences Faculty

A new way of explaining ARV medication

Working with Young People to Choose Life –
a participative study to create a visual communication tool to promote and motivate adherence to Antiretroviral Therapy in Khayelitsha.

PARTICIPATION INFORMATION/CONSENT FORM

Thank you for considering being involved in this project

Many young people who live with HIV find taking their medicine everyday a real challenge. A recent report by doctors from Khayelitsha recognises this difficulty and that new ways of helping young people to take their medicine are urgently needed. This sense of urgency is also supported by the South African Health Department, who has published a special report called the 'National Strategic Plan'. This plan fully recognises that young people should be the focus of all new interventions. It is for this reason that we believe it is important to ask you for your involvement so that together we can further develop an interactive tool that is currently being designed to help clinicians explain ARV medicine instructions to young people.

Helping us to find out what works best:

1. Research has shown that explaining how ARV medicines work and how they should be taken is quite a difficult thing to do. As part of this research project a proto-type interactive aid has been developed as a potential solution, designed to be used by clinicians as the explain ARVs to young people.

2. This interview is to simply go through how this tool would be used allowing you to feedback your thoughts and what you think works and what doesn't. Your contribution is valuable in helping us to continue with the design and development of this visual aid.

If you are happy to participate in this interview then please write your name, date and the sign the sections shown below. This will mean that you are giving your permission to use your contribution as part of our research. Your name and details will remain confidential and will not be used in the research report or any subsequent publication.

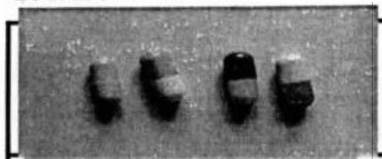
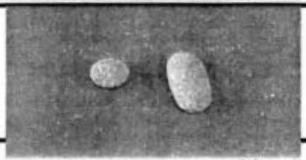
Name: ☐ **Date:** ☐

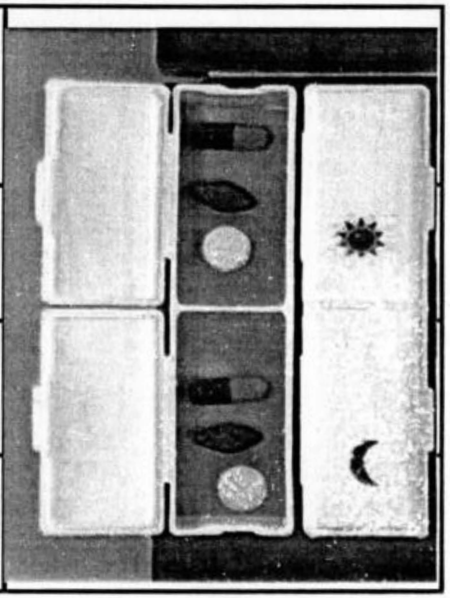
Signature: ☐

APPENDIX 5

NAME :

DATE :

		MORNING ☼	EVENING ☾
	**Stavudine D4T** Side effects : pain or cramps in hands or feet	○	○
	**Lamivudine 3TC 150** Side effects : no side effects	○	○
	**Niverapine NVP 200mg** Side effects : rash, liver problem	○	○



		Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
morning	☼							
evening	☾							
morning	☼							
evening	☾							
morning	☼							
evening	☾							
morning	☼							
evening	☾							
morning	☼							
evening	☾							

Next appointment :

Date	**Any Problem**

FILM ACTOR PERSONA’S

Persona: Young person - Unahti

Demographics

Home: Khayelitsha

Age: 21

Employment:
Cape Town Office

Current state

Unahti now lives a full life, enjoying his present and future hopes and dreams.

Impact of HIV diagnosis: how did a positive diagnosis impact Unahti?

Immediate life:	Medical intervention:	Family/friends:
Felt trauma and shock. Left the clinic alone and was not sure what to do next or who to speak too.	Was told to return to the clinic for a CD4 test.	Did not tell anyone for a few weeks - felt very unsure how they will respond.

Message framework for Unahti to hear:

Diagnosis trauma:

You are not alone - HIV diagnosis is not a death sentence. Present hopes and dreams do not have to change.

Diagnosis acceptance:

Through support and learning about HIV and treatment you can begin to accept your diagnosis. Acceptance from family members and trusted friends will help you to feel hopeful about your present hopes and dreams.

Gaining acceptance and support from significant others:
Other young people also feel anxious about telling trusted family members about their diagnosis, but gaining acceptance and support from trusted family member(s) is an important step towards learning to live with HIV.

Learning more about HV/AIDS and ART treatment:
It’s important to engage with the clinic to properly learn about his HIV and treatment.

Living with HIV/AIDS:

Unahti was encouraged by the stories of other young people who also experienced shock when they were first told that they were HIV positive. He eventually told his family and experinced acceptance and support from them. He now realises that it is possible to live a normal life.

Persona: HIV counsellor - Awonke-

Demographics

Home: Khayelitsha

Age: 42

Employment:
Clinic

Current state

Awonke is currently working in the youth clinic based in Khayelitsha

Impact of HIV diagnosis: how did she feel when she told Unahti that he was HIV positive

Immediate:	Medical intervention:	Family/friends:
Was concerned that Unahti was so shocked and was not listening to her encouraging messages	Was told to return to the clinic for a CD4 test. But was not sure if Unahti understood her instructions	

Message framework Awonke to communicate:

Diagnosis trauma:

You are not alone - HIV diagnosis is not a death sentence. Present hopes and dreams do not have to change. Medication is available and the clinic will support you.

Diagnosis acceptance:

Through support and learning about HIV and treatment you can begin to accept your diagnosis. Acceptance from family and trusted friends will help you to feel hopeful about your present hopes and dreams.

Gaining acceptance and support from significant others:

Other young people also feel anxious about telling trusted family members about their diagnosis, but gaining acceptance and support from trusted family member(s) is an important step towards learning to live with HIV.

Learning more about HV/AIDS and ART treatment:

It’s important to engage with the clinic to properly learn about his HIV and treatment.

Living with HIV:

You can learn to live with HIV. Present hopes and dreams do not have to change.

Persona: Family member(s)

Current state

Unahti tell his family that he is HIV positive. They accept his diagnosis and fully accept him because he is their son/brother. They tell him that they love, accept and support him.

Impact of HIV diagnosis: how did they feel when they heard that Unahti was HIV positive

Immediate life:	Medical intervention:	People:
They were worried and concerned for Unahti and were unsure what to do.	They knew that there was treatment, but had very little knowledge about it.	Would like to ask for help and advice, but don't know where to go.

Demographics

Home: Khayelitsha

Age: Various

Employment: Various

Message framework family member to communicate:

Diagnosis trauma:

Unahti was shocked by his diagnosis but they helped him to cope through their love, acceptance and support

Diagnosis acceptance:

Unahti struggled to accept that he is HIV positive, but they helped him to accept it by accepting and supporting him.

Gaining acceptance and support from significant others

By showing their acceptance of Unahti they reaffirm him as their son/sibling that helped him to realise that nothing had changed - he was still their son/brother.

Learning more about HIV and ART treatment:

Learning about HIV and ART helped them to support Unahti; they remind him to take his medication everyday.

Living with HIV/AIDS:

Through their acceptance and support Unahti began to realise that it was possible to feel and live a normal life as a young man who lives with HIV.

Persona: Trusted friend - Akhona

Current state

When Unahti told Akhona that he was recently diagnosed HIV positive. Akhona was upset for his friend, but wanted to support him.

Impact of HIV diagnosis: how did Akhona feel when he heard that Unahti was HIV positive

Immediate life:	Medical intervention:	People:
Shocked and worried for Unahti.	Akhona knows ART is available, but has heard various rumers and has limited undersatnding about how they work.	Would like to ask for help and advice, but don't know where to go.

Demographics

Home: Khayelitsha

Age: Various

Employment: Various

Message framework family member to communicate:

Diagnosis trauma:

Unahti was shocked by his diagnosis but Akhona helped him to cope.

Diagnosis acceptance:

Unahti struggled to accept his diagnosis, but Akhona helped him to accept it.

Gaining acceptance and support from significant others:

By receiving Akhona's acceptance, Unahti was able to realise that nothing had changed - he was still Akhona's good friend.

Learning more about HIV and ART:

Learning about HIV and ART helped Akhona to support Unahti; Akhona reminds him to take his medication everyday, especially when they go out to socialise.

Living with HIV:

Through Akhona's acceptance, Unahti began to realise that it was possible to feel and live a normal life as a young man who lives with HIV.

APPENDIX 7

UNIVERSITY OF CAPE TOWN

Health Sciences Faculty
Faculty of Health Sciences Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • **Facsimile** [021] 406 6411
e-mail: sumayah.ariefdien@uct.ac.za

18 February 2011

HREC REF: 061/2011

Mr W Hickson
c/o A/Prof M Coetzee
Paediatrics
School of Child & Adolescent Health

Dear Mr Hickson

PROJECT TITLE: WORKING WITH YOUNG PEOPLE TO CHOOSE LIFE-A PARTICIPATIVE STUDY TO CREATE A VISUAL COMMUNICATION TOOL TO PROMOTE AND MOTIVATE ADHERENCE TO ANTIRETROVIRAL THERAPY IN KHAYELITSHA

Thank you for addressing the concerns raised by the committee.

It is a pleasure to inform you that the Ethics Committee has **formally approved** the above-mentioned study.

Approval is granted for one year till the 28 February 2012.

Please submit a progress form, using the standardised Annual Report Form (FHS016), if the study continues beyond the approval period. Please submit a Standard Closure form (FHS010)if the study is completed within the approval period.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the REC. REF in all your correspondence.

Yours sincerely

Signed

PROFESSOR M BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
sAriefdien

UNIVERSITY OF CAPE TOWN
IYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD

FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee

Form FHS006: Protocol Amendment

Note: All amendments should include a Synopsis for the amendment (please see notice dated 23 April 2012)

HREC office use only (FWA00001637; IRB00001938)			
Approved ✓	X Type of review: Expedited	☐ Full committee	
This serves as notification that all changes and documentation described below are approved.			
Signature Chairperson of the HREC	Signed	Date	13/09/2012

Principal Investigator to complete the following:

1. Protocol information

Date	10 September 2012
HREC REF Number	061/2011
Protocol title	Working with young people to choose life – A participative study to create a visual communication tool to promote and motivate adherence to antiretroviral therapy in Khayelitsha
Protocol number (if applicable)	
Principal Investigator	Warren Hickson Email: warren@hdca.co
Department / Office Internal Mail Address	Department of Paediatrics and the School of Child and Adolescent Health. Red Cross Children's Hospital, Klipfontein Road Rondebosch 7701

1.1 Does this protocol receive US Federal funding?	☐ Yes	☐ No - no
1.2 Is this a major or a minor amendment (see FHS006hlp)?	X Major	Minor

2. List of Proposed Amendments with Revised Version Numbers and Dates

Please itemise on the page below, all amendments with revised version numbers and dates, which need approval. This page will be detached, signed and returned to the PI as notification of approval. Please add extra pages if necessary.

Young people will be recruited in the same way as stated in the original study outline with the exception to one amendment. This amendment outlines the risk to participants who are shown in the final film in regard of the automatic disclosure of their HIV status. Participants of this study who have expressed enthusiasm to be involved have already been made aware of these issues, and showed a full understanding of these risks. Their desire to be included in the film and its making remains.

Additions to the consideration of participants are:

- Film locations will be carefully organised prior to the actual filming. Locations will be discussed with participants ensuring that they are comfortable and in full agreement.
- Children will not be included in this film. All participants will be between the ages of 18 - 28.
- The principal researcher will supply refreshments.
- Participants can withdraw at any stage from the film making process and footage that includes them will be deleted and destroyed. All participants will be able to view the final film cut and will have a final opportunity to withdraw from the project. Further editing will then include the removal of their footage.