Adherence or non-adherence?


The case of Kiwoko Hospital.

Kate D Wooding

Submitted in partial fulfilment of the MA degree in Humanitarian and Development Practice, Oxford Brookes University

January 2007
Abstract

AIDS has devastated communities throughout the world and will continue to do so. Sub-Saharan Africa has 72% of the world’s deaths due to AIDS and the adult prevalence is currently 5.9% (UNAIDS/WHO, 2006). Although it is unlikely a cure can be found for HIV/AIDS, in recent years treatment of HIV/AIDS patients in developing countries has changed due to a global concern to make antiretrovirals (ARVs) available. WHO’s ‘3 by 5’ programme of aiming to reach 3 million people with ARVs by 2005 has accelerated the process, as well as reducing the price of certain generic ARVs.

ARVs must be taken more than 95% of the time in order for them to stop replication of the virus, but ARVs can have serious and potentially lethal side-effects¹ and so the patient needs to be regularly monitored. This research explores what makes an ART (antiretroviral therapy) programme successful for children who have HIV/AIDS in a rural resource-poor setting in regard to adherence. It confirms that in order for there to be good adherence effective counselling needs to be given to the caregiver² prior to receiving ARVs and good relationships between the caregiver, patient and staff should be established. In addition, follow up through regular clinic appointments and home visits are vital. The concerns for the future of ART programmes are whether they are able to receive a constant supply of ARVs and substantial funding.

Primary research was conducted at Kiwoko Hospital, Nakaseke District, Uganda. Observations were made of the programme over a three-week period. Semi-structured interviews with caregivers, programme administrators and HIV counsellors were undertaken. Good adherence was shown and the research confirmed that concentrating resources in a catchment area meant the patients could be monitored effectively.

¹ Side-effects can include allergic reactions, diarrhoea, anaemia, abdominal pain, hepatitis, pancreatitis, lactic acidosis and lipodystrophy.
² Person responsible for giving ARVs to the child.
Preface and Acknowledgements

The MA in Humanitarian and Development Practice has been a fascinating course due to the excellent lecturers and the interaction and friendships formed with the other students.

I would like to acknowledge that without the support and encouragement of my supervisor, Dr Mohamed Hamza and my husband Nick, this dissertation would not have been written. I also want to thank Dr John Barker, Barbara Carlton, Sheila Donaghy, Lisa Parker, Dr Nigel Pearson, Jim Pye, Sophie Rice, Gary Toohey, and Michael Wellby for all their help and advice.

I would particularly like to thank the staff at Kiwoko Hospital. It is a privilege to have worked alongside people who have the level of dedication and commitment to their jobs as they have. I am especially grateful to the following staff:

Juliet Ankunda
Teddy Asaba
Beatrice Asiimah
Dr Raul Depner
Alison Fletcher
Godfrey Kanakulya
William Kiwanuka
Richard Kytereka
Alfred Lejju
Niall Manogue
Monica
Paul Mugisha
Justine Naatumani
Saudah Nakawesa
Mary Nakigudde
Godfrey Sedeeba
Moses Ssekidde
Rev Daniel Wamala
Dr Rory Wilson

I would like to thank all the caregivers and children on the HIV/AIDS programme who were interviewed. The children’s names in the dissertation have been changed for confidential reasons.

Finally, I would like to thank my children, Ben and Anna, for being so patient with me whilst I was writing the dissertation.
## Acronyms and Abbreviations

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>ARV</td>
<td>Antiretroviral</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral therapy</td>
</tr>
<tr>
<td>CATTS</td>
<td>Community Antiretroviral and Tuberculosis Treatment Supporter</td>
</tr>
<tr>
<td>CBHC</td>
<td>Community Based Health Care</td>
</tr>
<tr>
<td>HAART</td>
<td>Highly Active Antiretroviral Therapy</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>IRCU</td>
<td>Inter-Religious Council of Uganda</td>
</tr>
<tr>
<td>MSF</td>
<td>Médecins Sans Frontières</td>
</tr>
<tr>
<td>NMS</td>
<td>National Medical Stores</td>
</tr>
<tr>
<td>PEPFAR</td>
<td>US President’s Emergency Plan for AIDS Relief</td>
</tr>
<tr>
<td>TASO</td>
<td>The AIDS Support Organisation, Uganda</td>
</tr>
<tr>
<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV/AIDS</td>
</tr>
<tr>
<td>UNDP</td>
<td>United Nations Development Programme</td>
</tr>
<tr>
<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
</tbody>
</table>
## Contents

Abstract ......................................................................................................................... 2

Preface and Acknowledgements ................................................................................. 3

Acronyms and Abbreviations ..................................................................................... 4

Contents ........................................................................................................................ 5

### Chapter One: Introduction ......................................................................................... 8

1.1 HIV/AIDS ....................................................................................................... 8
1.2 Antiretrovirals (ARVs) ................................................................................... 8
  1.2.1 Side-effects ........................................................................................ 9
  1.2.2 Availability ........................................................................................ 9
  1.2.3 Cost .................................................................................................... 9
  1.2.4 Adherence ........................................................................................ 10
  1.2.5 Children ............................................................................................ 10
1.3 Research Question ........................................................................................ 10
1.4 Aims and Objectives ..................................................................................... 11
1.5 Research Methodology ................................................................................. 11
1.6 Research Limitations .................................................................................... 11
1.7 Structure of Thesis ........................................................................................ 12

### Chapter Two: Resource-poor Settings ..................................................................... 13

2.1 Introduction ................................................................................................... 13
  Provider/Supplier Issues of an ART programme: .............................................. 14
2.2 Availability ................................................................................................... 14
2.3 Cost ............................................................................................................... 14
2.4 Infrastructure ................................................................................................. 15
2.5 Staff ............................................................................................................... 16
2.6 Donors ........................................................................................................... 16
  Recipient/Patient Issues of an ART programme: .............................................. 17
2.7 Clinics ........................................................................................................... 17
2.8 Food and Nutrition ........................................................................................ 18
2.9 Cultural and Traditional Beliefs ................................................................... 18
2.10 Disclosure ..................................................................................................... 19
2.11 Adherence ..................................................................................................... 19
2.12 Conclusion .................................................................................................... 20
Chapter Three: Case Study Kiwoko Hospital

3.1 Introduction

3.1.1 Kiwoko Hospital

3.1.2 HIV/AIDS Programme

3.1.3 Research Methods

3.2 Ministry of Health

3.3 Hospital Infrastructure

3.3.1 Laboratory and Pharmacy

3.3.2 Transport

3.4 Staff

3.4.1 Calibre of Staff

3.4.2 Staff Training

3.5 Donors

3.6 Support

3.6.1 Clinics

3.6.2 Caregiver

3.6.3 Food and Nutrition

3.6.4 Home Visits

3.6.5 Quarterly Workshops and Youth Club

3.7 Challenges

3.7.1 Cultural and Traditional Beliefs

3.7.2 Psychosocial Issues

3.7.3 Illness

3.7.4 Disclosure

3.7.5 Syrups, capsules or tablets

3.7.6 Transport

3.7.7 ARV Treatment Card and Other Challenges

3.8 Adherence

3.9 Summary

Chapter Four: Discussion

4.1 Introduction

4.2 What were the reasons for the levels of success in the programme?

4.2.1 Uninterrupted supply of ARVs

4.2.2 Medical benefits

4.2.3 Responsible caregivers

4.2.4 Staff commitment

4.2.5 Clinics

4.2.6 Resources

4.2.7 Adherence

4.2.8 Summary
4.3 What could make this ART programme more effective? ............................. 47
  4.3.1 Community Antiretroviral and Tuberculosis Treatment Supporter. 48
  4.3.2 Medical reviews ................................................................. 48
  4.3.3 Computer System ............................................................... 48
  4.3.4 Growth Charts ................................................................. 49
  4.3.5 Cotrimoxazole ................................................................. 49
  4.3.6 Disclosure ........................................................................ 49
  4.3.7 Summary ........................................................................... 50

4.4 What could affect the programme and jeopardise its future? ....................... 50
  4.4.1 Supply ............................................................................... 51
  4.4.2 Expansion ......................................................................... 51
  4.4.3 Funding ............................................................................ 52
  4.4.4 Key Community Leaders ............................................... 53
  4.4.5 Cultural beliefs ................................................................ 54
  4.4.6 Summary ........................................................................... 54

4.5 Conclusion ................................................................................ 55

Chapter Five: Recommendations and Conclusions ........................................... 56
  5.1 Research ................................................................................ 56
  5.2 Recommendations for Further Research ........................................ 56
  5.3 Conclusions ........................................................................... 57

Appendices .............................................................................................. 59
  Appendix 1 – Interview Questions with Caregivers .................................. 60
  Appendix 2 – Interview Questions with Key Informants ........................ 61
  Appendix 3 – Interview Questions with HIV Counsellors ...................... 62
  Appendix 4 – Map of Ugandan Districts .............................................. 63
  Appendix 5 – Map of Kiwoko Hospital, Kikamulo ................................. 64
  Appendix 6 – CATTS Job Description .............................................. 66
  Appendix 7 – Photographs from the Home Visits ................................... 67
  Appendix 8 – Photographs from the Quarterly Workshop ...................... 68
  Appendix 9 – ARV Treatment Card ................................................. 69
  Appendix 10 – CATTS Weekly Report Sheet .................................... 70

Bibliography ........................................................................................... 71
Chapter One: Introduction

1.1 HIV/AIDS

AIDS (Acquired Immune Deficiency Syndrome) has devastated many communities throughout the world. HIV (Human Immunodeficiency Virus) attacks the immune system and replicates itself quickly and can infect all cells in the body. Those living with HIV succumb more easily to illnesses, called opportunistic infections, which the body struggles to fight.

In rural resource-poor settings where HIV/AIDS is common, everyone is affected by the results of HIV/AIDS, through the death of a loved one or the inability to work due to constant illness. The elderly are often the ones caring for their grandchildren as their children have become infected with HIV/AIDS. In communities where HIV/AIDS is a social stigma, many patients have been ostracised and can suffer alone.

1.2 Antiretrovirals (ARVs)

There is no available cure for HIV/AIDS and the expectation that a cure will be found is unlikely, as the virus very quickly replicates itself throughout the body. However, over the last ten years antiretrovirals (ARVs) have become available, and more recently to developing countries, due to a global concern to reach them. The WHO’s 3 by 5 programme of aiming to reach 3 million with ARVs by 2005 helped accelerate this. There has also been a huge reduction of price in some of the generic drugs. If good adherence occurs then a patient can produce an undetectable viral load.\(^1\) This enables the patient to function ‘normally’ and resume work and live a ‘normal’ life. Once a patient is on ARVs they need to remain on them for life. Highly active antiretroviral therapy (HAART) is a combination of three or more drugs, which stop

\(^1\) The HIV cannot be detected in the blood stream.
replication of the virus. As patients are susceptible to other illnesses, cotrimoxazole\(^2\) is generally prescribed alongside ARVs as a preventative treatment, to stop patients developing certain bacterial infections.

### 1.2.1 Side-effects

The multiple medications that patients with HIV/AIDS require have a variety of different side-effects, which need to be effectively monitored. The side-effects of the ARV drugs alone are serious and can be life-threatening. They include allergic reactions, diarrhoea, anaemia, abdominal pain, hepatitis, pancreatitis, lactic acidosis and lipodystrophy.

### 1.2.2 Availability

Availability of ARVs is a critical issue. If the patient is unable to obtain ARVs once treatment has been started, then the body develops viral resistance. In resource-poor settings there is a problem of regularly accessing the drugs. In Nigeria, after one and a half years of providing ARVs the government supply ran out in all centres (Nwoke and Farouk, 2005). Although ARVs have been available for over ten years in Kampala, the capital of Uganda, it is only since 2001 that they have been introduced outside Kampala (Enzama et al., 2004).

### 1.2.3 Cost

The cost of ARVs is prohibitively expensive to the vast majority of people living in developing countries, even though some generic drugs have reduced considerably in price. Therefore, without external funding, ARVs are unaffordable to a patient in a rural developing community. Once a patient develops resistance to the first line of treatment, the second line of treatment drugs may be too costly and so unavailable to most programmes.

---

\(^2\) A broad spectrum antibiotic.
1.2.4 Adherence

Adherence to ARVs is crucial to the success of treatment. WHO guidelines recommend that patients must take the ARVs at least 95% of the time in order for the ARVs to be effective in stopping viral replication. In rural resource-poor settings there are a number of challenges that impact on the taking of ARVs. These include the local culture and belief systems, the lack of understanding of the importance of taking the drugs daily, experience of side-effects, and transportation issues in getting the drugs. In addition, once the patient is feeling better and the CD4 count\(^3\) has improved, then the patient may decide to stop taking the ARV drugs.

WHO guidelines recommend three adherence counselling sessions before a potential patient receives ARVs. These sessions enable the patient to understand the process and the importance of adhering to the regime.

1.2.5 Children

ARVs given to children will involve a caregiver who is the person responsible for giving the ARVs to the child. Children are often malnourished in rural resource-poor settings. A programme of teaching better nutrition is very important for children with HIV/AIDS. This also helps reduce the adverse side-effects of the ARVs. While receiving ARVs the children need to be well monitored due to the possibility of adverse side-effects and body weight fluctuations.

1.3 Research Question

This research focuses on whether or not ARVs are being taken by the patients regularly i.e. is there good adherence or not? It is crucial that the patient takes the treatment to stop viral replication. If the viral load stays high and the CD4 count remains low, the patient can become sick from opportunistic infections. The patient

\(^3\) A measure of how well the immune system is doing.
then needs to change to other drugs, which may not be available and are likely to be extremely expensive. The research looked at the adherence level of the programme.

1.4 Aims and Objectives

The aim of the research was to explore what makes a successful ART (antiretroviral therapy) programme for children with HIV/AIDS. It concentrated on what needs to be in place for there to be good adherence in an ART programme. The primary research was carried out at Kiwoko Hospital in Nakaseke District in Uganda, which is a rural resource-poor setting. It identified the challenges associated with taking ARVs and looked at the wider issues in regard to the supply of ARVs and funding provision.

1.5 Research Methodology

A literature review was undertaken to see what information was available about ART programmes and adherence issues. Three weeks was then spent observing and learning about the ART programme at Kiwoko Hospital. Semi-structured interviews were undertaken with the caregivers, HIV counsellors and other health care staff involved in the programme. Senior management staff were interviewed to discuss the wider issues surrounding ARVs including the accessibility of drugs and funding. Three weeks at Kiwoko Hospital was thought to be a realistic timeframe for looking into their programme, as relationships had already been established with staff, due to the researcher having spent six years living there in 1997-2003.

1.6 Research Limitations

The focus of the research was limited to children with HIV/AIDS. The primary research looked at a programme where there were twenty children on ARVs, and the longest a child had been taking ARVs was just over a year. The research did not focus on children less than eighteen months old, whose pregnant mothers had been

---

4 See Appendices 1–3 for fieldwork interview questions.
given ARVs, as there are different issues involved. Adults on ARVs also pose a number of different issues that need to be addressed in another research paper.

1.7 Structure of Thesis

Having outlined the general issues pertaining to ARVs in the introduction, the next chapter outlines the context of the research focus: resource-poor settings. Chapter Three then presents the Case Study of Kiwoko Hospital where an ART programme for children has been in existence for over a year. Chapter Four discusses the reasons for the success of the programme; the improvements that could be made to the programme and the issues that would affect the programme in the future. It also discusses the wider implications that could benefit other ART programmes. Chapter Five concludes and makes recommendations with regard to adherence in ARV programmes in rural resource-poor settings.
Chapter Two: Resource-poor Settings

2.1 Introduction

Developing countries are also described as resource-poor settings due to the limited resources they have. Problems in resource-poor countries include: a lack of basic infrastructure; frequent power shortages; and major price fluctuations such as in fuel costs. The majority of those living in resource-poor settings live in poverty and the facilities around them are inadequate. Accessing health care facilities is costly and clinics are basic in terms of what they can provide.

Rural areas suffer even more from a lack of resources. President Museveni said a mother in Uganda might have to walk twenty miles to obtain an aspirin for her sick child or five miles to collect water (Green, 2003). Klouda (1995) cited in Holden (2003, p.24), a former director of UNDP’s HIV and Development Programme, said ‘even if a supply of pure drinking water was the cure for AIDS, it would be unavailable to large numbers of people’.

Over recent years there has been a debate as to whether administering ARVs in resource-poor settings is feasible and realistic, due to the constraints of limited resources. ART is complex even in developed countries. Research has shown that it is possible for people to access an ART programme in resource-poor settings (Kasper et al., 2003). However, the majority of research has been carried out with adult patients.

In 2003 WHO/UNAIDS launched their 3 by 5 programme: 3 million people to be put on antiretrovirals in low and middle income countries by 2005. Although the target was not reached, in sub-Saharan Africa the increase was considerable, as it went from 100,000 to 810,000 people (WHO/UNAIDS, 2006).
**Provider/Supplier Issues of an ART programme:**

In order for an ART programme to operate and be effective there are various requirements that need to be in place in a resource-poor setting. This section will look at the main provision issues of an ART programme.

### 2.2 Availability

It is essential that ARVs are constantly available to an ART programme. Nwoke and Farouk (2005) revealed that in the government centres within Nigeria the ARV supply was interrupted for over five months.

Médecins Sans Frontières (MSF) outlines the procurement problems of ARVs reaching Africa, involving costly, vulnerable and complex supply routes. Drug companies are gaining good publicity by announcing that their drugs will be available to developing countries, but are delaying to register the drugs in those countries (Ford and Darder, 2006).

### 2.3 Cost

The cost of ARVs a few years ago was US$10,000 per adult patient per year and, although it has dropped to US$209 (Kasper et al., 2003), it is still unaffordable to the majority of people living in resource-poor settings. Farmer et al. (2001) estimated that 75-80% of the costs of their project were spent on medicines. The cost of treating HIV/AIDS adult patients with ARVs has been shown to be cost effective as fewer patients are admitted to hospital (Kasper et al., 2003).

The studies undertaken as to whether administering ARVs is feasible in developing countries have often been where there is significant external funding (Colebunders et al., 2005). People with limited resources may find enough money to start their treatment but after a while realise they are unable to sustain the cost. ARVs should...
be provided for free to the poor (Lange et al., 2004). The costs of children’s ARVs are more expensive than adults.

The total cost of administering an ART programme, including the infrastructure that is needed, is extensive - it is significantly more than the cost of the ARVs themselves.

### 2.4 Infrastructure

An effective infrastructure needs to be in place if an ART programme is to be successful. There needs to be good quality management and strong financial structures in order for the services and funds to be available. The facilities in rural areas can be basic due to lack of resources and corruption (Lange, 2002).

The WHO has called for a scaling up of access to ARVs. However there must be adequate resources to cope with scaling up ARV programmes. Since the provision of such resources takes time in terms of recruiting and training staff and securing funding, there has to be rationing in the interim as to who will receive ARVs first. Bennett and Chanfreau (2005) discussed the need for policies to include rationing approaches. The Ugandan Government developed a draft policy which used selection criteria and targeted certain groups, one of them being children. The WHO/UNAIDS (2006) figures reveal that nine out of ten children in need of ART are living in sub-Saharan Africa.

Keeping good patient records enables the patients to be monitored more effectively and efficiently (Mukherjee, 2004).

Laboratories play an important role in the delivery of an ART programme but laboratory facilities are few and often inadequate in rural resource-poor settings. One problem is the high costs of viral load tests, which reveal the level of the HIV virus in the body. One suggestion is that it would be cheaper for an ARV programme to employ and train staff as treatment counsellors than invest in the expensive equipment needed for viral load tests (Colebunders et al, 2006). The counsellors would review
the clinical and treatment history of the patient, alongside some basic laboratory tests such as total lymphocyte counts and haemoglobin levels, to predict virus resistance.

### 2.5 Staff

Dedicated staff involved in the ART programme, who build up relationships with the patients and are involved in home visits, are crucial to the success of ART programmes. In sub-Saharan Africa WHO/UNAIDS (2006) estimates there to be a shortage of one million professional health workers, as well as the additional loss of 20,000 trained staff to emigration every year. To attract doctors to leave Kampala and work in rural areas has become very difficult in recent years due to Global Fund money being available for research projects.

Due to the shortage of trained doctors and nurses in resource-poor settings, other staff should be trained to be part of a team in administering ARVs. In resource-poor areas Lange (2002) cites a lack of committed and experienced staff in ART and the need for full time dedicated staff as the biggest challenges faced by large scale ART programmes. Retaining and recruiting staff is a major concern in rural areas.

TASO (The AIDS Support Organisation) in Uganda trained staff to administer ARVs in their home, in a pilot study. The field officers visited on average seven patients per day. However after six months their study revealed that 10% of the field officers had resigned and 19% expressed a desire to change their role. (Nabiryo *et al.*, 2005). Staff committed to delivering an ART programme are an enormous asset, as will be described in the next chapter in the case study of Kiwoko Hospital.

### 2.6 Donors

Donors are essential in the provision of ARVs in many countries. In resource-poor settings the annual budget for healthcare is often less than the total cost of ART provision for a year (Tayler, 2004). Assistance from the World Bank, the Global Fund to Fight AIDS, Tuberculosis, and Malaria, and PEPFAR (US President’s
Emergency Plan for AIDS Relief) has meant ARVs are now more accessible to patients in resource-poor settings.

Donors are fundamental in a rural resource-poor setting, to provide much needed treatment as well as ARVs to people living in poverty.

In order for there to be an effective ART programme there needs to be a regular supply of ARVs available, whether externally funded or not. A functioning infrastructure is necessary alongside dedicated staff administering the programme.

**Recipient/Patient Issues of an ART programme:**

The issues surrounding the provision of an ART programme have been outlined. In the following section the issues for the patients who have access to an ART programme will be addressed.

### 2.7 Clinics

Accessing health care facilities can be a huge challenge, whether one can afford the health care or not. The patient may have to travel a considerable distance.

The WHO gives clear, practical guidelines as to how to administer an ART programme in a resource-poor setting. The WHO (2006) recommends that all children aged three years and above with a CD4 count of less than 15% should be given ARVs. The WHO (2004) guidelines suggest at least three counselling sessions for the preparation of starting a patient on ARVs. Practicalities of administering the drugs should also be included in the counselling topics.

Each child patient should have a caregiver (WHO, 2006) who is appointed to administer the ARVs. At the clinic the patient should be reviewed and CD4 counts taken every three to six months (Mukherjee, 2004).
Colebunders et al. (2005) research showed that many patients overwhelm clinics with the increased availability of ARVs. Clinics are the place where an ART programme can be effectively administered. Reviewing whether a patient has good adherence should be done at each clinic and home visit.

Recording the height and weight of child patients on growth charts helps monitor the effects of ARVs (Mukherjee, 2004). Growth charts enable one to see if the child is growing at the right rate and be alerted to how effective the ART treatment is. Body weights fluctuate and once a child has started on ARVs they can gain weight quickly. The correct dosage of ARVs in relation to the body weight of the patient needs to be regularly monitored and adjustments made to the dose.

2.8 Food and Nutrition

Children in resource-poor settings are often malnourished and, if they are HIV positive, their immune system is weak and they need nutritional support (Mukherjee, 2004). The caregiver may struggle to supply enough nutritional food that the child needs, particularly as the appetites of children on ARVs can increase. The children’s ability to withstand the side-effects of ARV drugs is improved if they have a nutritious diet.

2.9 Cultural and Traditional Beliefs

Cultural and traditional beliefs can severely undermine an ART programme. Dr Tshabalala-Msimang, South Africa’s health minister, promoted garlic, beetroot and African potatoes as an alternative to ARVs (McGreal, 2006). A Ugandan newspaper article disapproved of the increase of pastors who convinced patients to pray instead of taking the ARV drugs (New Vision, 2006).

The stigma attached to being HIV positive was reduced in Haiti, with the remarkable improvements seen from ARVs (Farmer et al., 2001). Hardon (2005) confirms that
there does not appear to be stigma associated with ARVs, but calls for the need for studies observing the benefits of ARVs in normal, everyday situations.

### 2.10 Disclosure

Cultural beliefs can also hinder the process of disclosing to a child that they are HIV positive. There may be a ‘culture of silence’ in regard to discussing HIV/AIDS with children (Healthlink Worldwide, 2004). Child-centred approaches are needed to tackle this issue.

### 2.11 Adherence

The WHO (2004, p.41) definition of adherence is ‘accepting, agreeing and following correctly a prescribed treatment’. A young child is totally dependent on its caregiver to give them the ARVs. In order for ART to be effective there needs to be more than 95% adherence rate to the treatment as otherwise viral resistance builds up. First line treatments are easier to manage and have fewer side-effects than second line treatments. If a patient has very good adherence then they can live for many years on a first line treatment. Second line treatment is more expensive (WHO, 2004).

The WHO (2004, p.72) states ‘understanding the need for complete adherence is the cornerstone of successful ART treatment for every patient’. Colebunder et al. (2006) suggests non-judgemental counsellors are able to ascertain good adherence or not from the patient if good relationships have been formed. He also proposes that treatment failure could be detected when a symptom that was present before taking ARVs, for example itching, reoccurs. Lange et al. (2004) believes that patients in developing countries have been less exposed to other drugs and therefore are less likely to have viral resistance. A positive response to ARVs can be seen through a patient’s weight gain and lack of opportunistic infections (Mukherjee, 2004).

Research suggests that after being on ARVs for a while, the patient can expect an undetectable viral load if they are good adherers. The Ministry of Health (2003) in
Uganda cites one study that showed 78% of patients having an undetectable viral load within six months, with more than 95% adherence. Of those patients who took less than 70% of the required treatment, only 18% had an undetectable viral load. Colebunders et al. (2006) suggests after one year on a first line treatment, at least 80% will have an undetectable viral load if there is good adherence.

Regularly attending a clinic is vital for the patient on ARVs. A child needs to be regularly monitored, even more than adults, and adherence assessed. The influence of the community leaders and the use of traditional medicines can undermine the patient’s adherence in resource-poor settings.

2.12 Conclusion

To conclude, studies have shown that it is possible to run an effective ART programme in a resource-poor setting.

Kasper et al. (2003) suggests the three keys to a successful ART programme are making the drugs affordable, involvement of the community and the patients themselves. The Ministry of Health (2003) in Uganda mentions two important aspects of an ART programme: whether the patient is able to pay for the ARVs, and the proximity of the clinic to the patient, so that they can be monitored effectively. The lack of adherence is seen as being due to the cost of the ARVs rather than the caregivers not giving them.

In a rural resource-poor setting without international donors it would not be possible to run an ART programme. The provider could not afford the staff to run the programme nor the resources to concentrate on monitoring and reviewing the patients. The patients cannot afford the costly ARVs.
The majority of research has been in the area of adult ART programmes but more research is needed in the area of administering ARVs to children. The next chapter looks in greater detail at one such programme and the issues surrounding adherence where the ARVs have been externally funded.
Chapter Three: Case Study Kiwoko Hospital

3.1 Introduction

3.1.1 Kiwoko Hospital

Research into the adherence and practice in administering ARVs to children with HIV/AIDS, was carried out at Kiwoko Hospital in the Nakaseke District of Uganda. Kiwoko Hospital is in a rural resource-poor setting. The hospital serves a population of 474,627 with 243 beds and 299 staff. Last year it treated 46,110 outpatients (Kiwoko Hospital, 2006).

3.1.2 HIV/AIDS Programme

The HIV/AIDS Department has evolved from the hospital’s Community Based Health Care programme (CBHC). The department receives funds specifically for HIV/AIDS patients and runs separate adults’ and children’s programmes.

Kiwoko Hospital has been prescribing ARVs to children since May 2005. There are 70 children on the programme of whom 20 are on ARVs. Within six months of starting to run this ART programme, ARVs became available from the Ugandan Ministry of Health.

The programme follows WHO guidelines. Each child has a caregiver who is the main carer and who attends adherence counselling sessions before ARVs are prescribed. The caregiver is then expected to attend fortnightly clinics with the child. There is a monthly youth club for the older children, and a quarterly workshop designed to educate the caregivers as well as providing entertainment for the children.

The children’s programme is concentrated in the sub-county,¹ Kikamulo, which

¹ A sub-county is an administrative area: village, parish, sub-county, county and then district.
surrounds the hospital and has a population of 22,597.² Kiwoko Hospital’s clinic for children is unique in the area since there are no other children’s clinics in the surrounding districts.³

### 3.1.3 Research Methods

Research was carried out over a three-week period in July 2006. The research involved observation of the programme and the staff who run it by attending clinics, patient consultations, adherence counselling sessions and a quarterly workshop. In addition, interviews were held during the three weeks with the managers and staff who run the programme. Interviews were also held with the caregivers and these were usually held at their homes.

The interviews with the staff were in English, the language used in schools, and the interviews with the caregivers were conducted in Luganda, the local language, with the counsellor as the translator. Although translation was necessary, enough Luganda was known by the researcher to enable the researcher to understand the essence of the conversation and for the researcher to be able to offer the appropriate greetings and cultural formalities in Luganda. Using the counsellor as the translator meant that the caregiver was at ease and was willing to volunteer additional information, which had not been asked for.

### Provider/Supplier Issues of an ART programme:

Good adherence is about the child taking ARVs each day but this is dependent on there being a constant supply of the drugs. Therefore the research examined the different links in the chain in regard to the supply of ARVs, which is discussed below.

---

² 2002 Population Census.
³ See Appendices 4 -5 for maps of Ugandan Districts and of Kiwoko Hospital, Kikamulo sub-county.
3.2 Ministry of Health

The Ugandan Ministry of Health is based in Kampala and is responsible for the supply and delivery of ARVs to Kiwoko Hospital. There are 148 adults and 20 children on ARVs. The Ministry supplies Kiwoko Hospital with first line treatment in the form of Triomune.

**Triomune** is a combination drug of three antiretroviral agents. Generally a young child will have this prescribed as three separate drugs: Stavudine, Lamivudine and Nevirapine. The older child might be prescribed a fraction of the combination drug: Triomune. The Ministry also supplies a small amount of Efavirenz, which can be used as an alternative to Nevirapine, and is necessary if a patient is on TB treatment. This is because Nevirapine interacts negatively with the drugs used for the treatment of TB.

Despite Kiwoko Hospital’s constant requests for second line treatment drugs, in case they have need of it, they have not received any.

The pharmacist at Kiwoko Hospital personally delivers the necessary monthly report on ARVs to the Ministry in Kampala. This enables him to assure National Medical Stores (NMS) in Entebbe that he has delivered it since there is poor communication between the Ministry of Health and NMS who are 34 kilometres apart. The pharmacist spends a considerable amount of time requesting his next delivery of ARVs as he is often worried about running out of stock. Although the ARVs are supposed to be delivered by NMS, on two occasions the hospital has needed to collect the ARVs from Entebbe in order not to run out.

Within the last seven months, Kiwoko Hospital has had a severe shortage of ARVs on four occasions - on one occasion the period lasted for two weeks. Due to the resourcefulness of the pharmacist, as is described in 3.3.1, only a couple of adult patients missed ARVs for a few days.
The pharmacist was concerned that the Ministry would soon run out of ARVs and so not be able to supply Kiwoko Hospital. The month before the researcher arrived, there had been an article in one of the main Ugandan newspapers warning of a shortage of ARVs. In addition the communication from the NMS had changed from saying ‘we will supply’ to ‘we will contact you’. Recently the Ministry had only been supplying Triomune 30, instead of Triomune 30 and 40 for adult patients, which was another reason for there being concern that ARVs might run out.

3.3 Hospital Infrastructure

In order for ARVs to be provided to patients, the infrastructure needs to be in place. At Kiwoko Hospital there are strong financial structures and good quality management, which ensures the services and funds are available. The service offered at Kiwoko Hospital is good. The hospital is well-resourced subject only to its ability to recruit staff.4

Good quality record keeping is needed to know details of clinic appointments, HIV test results and when the CD4 counts need to be taken. Kiwoko Hospital has begun to use a computer system to register some of these details.

3.3.1 Laboratory and Pharmacy

Within the hospital infrastructure there are different departments that enable the ART programme to function. The well-equipped laboratory is able to do a wide variety of tests including HIV testing and taking blood for the CD4 counts. Blood for the CD4 counts is taken to Entebbe by the hospital and the government funds the test itself. The results are emailed back to the hospital after a period of two weeks. Viral load testing costs 180,000/= per test and is available in Kampala.5 This is more than a month’s salary for most staff and so is not offered to any of the patients.

---

4 It has struggled to recruit doctors in recent years.
5 Approximately £54.50.
The patients benefit from the well-run pharmacy at Kiwoko Hospital because the medicines are available when needed. Good stock control is essential to the ART programme since ARVs must be taken at least 95% of the time. The caregivers and patients have been taught never to miss a dose and therefore a lack of ARVs would have a very negative impact on the programme both medically and psychologically. Normally a patient is prescribed a month’s supply of ARVs, and after the appropriate check-ups in the clinic, goes to the pharmacy to collect them.

Due to the pharmacist’s dedication, stock outs\(^6\) have been minimal. When the pharmacist is aware stocks are running low in the hospital and he is facing delays at NMS, he starts to monitor the patients that are requesting their normal monthly supply. If the patient lives nearby, he requests them to take a week’s supply so that those who live further from the hospital are still able to take their month’s supply. There have been a few ARVs remaining from the children’s clinic from the time they were bought on the open market. The pharmacist has therefore been able to supplement the Ministry supplies with that stock where necessary.

If the Ministry was unable to supply ARVs for even a short period the open market would not be able to cope with the demand, as only a few pharmacies stock ARVs in Kampala due to their high cost.\(^7\)

Without the diligence of the pharmacist in regularly contacting the Ministry to ask for ARVs, balancing stocks and being hands on in his approach to the supply of ARVs, Kiwoko Hospital would have faced many stock outs.

### 3.3.2 Transport

The size of Kiwoko Hospital means that it has more resources than smaller organisations. This helps the hospital cope with the demands of the ART programme.

---

\(^6\) This is the term the pharmacist used when the pharmacy ran out of drugs.

\(^7\) 80,000/= (£24) for a monthly supply of ARVs for an adult, the equivalent of two-thirds of the monthly wage of a counsellor.
For example, collecting drugs for all the hospital patients requires three trips a month with a full minibus load and includes collecting cotrimoxazole and the drugs to cure opportunistic infections. In addition, the hospital has funds to meet the transport needs of the ART programme. For example, the blood for the CD4 tests needs to be taken each week to Entebbe, which is 114 kilometres away.

3.4 Staff

3.4.1 Calibre of Staff

The calibre of the staff is crucial to the success of administering ARVs. The child patients and caregivers regularly visit the hospital at clinic appointments and therefore build up relationships with the staff. Good relationships create trust and help the caregivers to continue in their role of giving ARVs to the child. The caregivers are given opportunities to discuss any problems or concerns they have.

The area around Kiwoko was devastated by the civil war in the 1980s and, although only 80 kilometres from the capital Kampala, few were willing to work there. However, Kiwoko Hospital has been fortunate in its ability to recruit and retain high calibre staff. One group of staff are referred to as the ‘historicals’ since they have been working at Kiwoko Hospital since its inception in 1988. The pharmacist is one of the historicals and entered the laboratory school as a student. Later the hospital sent him for further training to become the hospital pharmacist. His commitment is not related to pay but because he serves his community through his job. Many of the other staff in the HIV/AIDS department are also historicals. They are local to the area and serve the community – some were working in the community before salaries were paid for such community work.

Staff at Kiwoko Hospital are not as highly paid as they would be if they worked in government health units. In addition the workloads are higher because of the quality of care that is offered and the limited resources available. However, most of the staff are committed to the work of Kiwoko Hospital.
During the interviews the researcher carried out, the high level of trust and the good relationships between the staff and caregivers were clearly apparent. The caregivers talked openly; they were relaxed; and they were not wary of being interviewed. If the interviews had been carried out by an independent translator it is unlikely there would have been as much openness. The caregiver would have been suspicious about why the interview was taking place.

3.4.2 Staff Training

Many of the staff, who came to Kiwoko Hospital without any qualifications, now have recognised national qualifications, which have been gained through Kiwoko Hospital’s nurse training school and its laboratory school. In addition to internal training, some staff receive external training. The Ministry of Health ran a training course in 2005 on ARVs, before the ARVs were supplied to the hospital, and doctors, nurses and counsellors from Kiwoko Hospital attended it.

TASO (The AIDS Support Organisation) trained all the HIV/AIDS counsellors in the hospital. The chaplain of the hospital was sent for TASO counselling training in 1997-98 whilst he was at the hospital. He is now regularly employed to run training courses - for example for aide counsellors. Some of the counsellors, who have been trained by the Ministry of Health on adherence counselling, have then trained others at Kiwoko Hospital. The hospital is planning to train its own CATTSs (Community Antiretroviral and Tuberculosis Treatment Supporter)\(^8\) - the first were trained externally. Kiwoko Hospital is good at giving further training to the loyal members of staff and this has helped staff retention.

3.5 Donors

The children’s HIV/AIDS programme has benefited from having a major donor. This donor was found by the expatriate paediatrician, who started the clinics for children

\(^8\) See Appendix 6 for CATTS Job Description.
and later the ART programme, whilst working at the hospital. She bought the ARVs on the open market before the Ministry supplied them. The children’s HIV/AIDS programme is comprehensive as it offers to all children free treatment costs, cotrimoxazole, and subsidised transport for travel to and from the hospital. Some needy children have also been given school fees, uniforms and nutritional support. A wide-ranging and high level of care has been given due to the donor’s willingness to fund these areas. Another donor was already paying the HIV/AIDS department’s staff salaries and that has continued.

In September 2005 the Global Fund (2005) stopped their grants to Uganda for two months, but funding for ‘life-preserving’ programmes were not supposed to have been affected. Staff at Kiwoko Hospital were unaware eight months later that the grants had been reinstated. They thought the shortages in the supply of ARVs, or lack of Triomune 40, were related to the grants having been stopped. Although the flow of all essential medical supplies were not supposed to have been interrupted it did have a knock-on effect. However, the grants were halted due to misappropriation of funds and this reveals how vulnerable resource-poor settings are to donor funding and corruption.

**Recipient/Patient Issues of an ART programme:**

### 3.6 Support

#### 3.6.1 Clinics

At Kiwoko Hospital, if a child is found to be HIV positive, they become a client and register with the Thursday clinic. At this stage the child will be given cotrimoxazole, vitamins and will have opportunistic infections treated. Their CD4 counts are done every three months; recently this was changed from being done every six months. If the CD4 count is 15% or below, the child will have ARVs prescribed.

The programme has seen only one death from a child on ARVs. The child was started on ARVs with only a 2% CD4 count and soon died. This reinforces the need for
children to be registered with the clinic before their health deteriorates and their CD4 count drops. The more regularly a patient is seen, the better the care the programme can give, and the stronger the relationship between the medical personnel, and counsellors and the child and caregiver.

Once a child is in need of ARVs, the caregiver is requested to attend three adherence counselling sessions, which are held at the same time as the clinic. These are done by one of the counsellors. A doctor or nurse normally does the third and final adherence counselling session before the child is prescribed the ARVs.

The sessions were done in small groups of about five caregivers in an informal atmosphere and there was good interaction between the caregivers and counsellors. Caregivers were asked questions that reiterated what had been taught earlier, and there were also opportunities for the caregivers to talk about their concerns. Discussions would arise on such issues as to how to remember when to give ARVs.

For those children on ARVs already, caregivers were asked to bring the ARVs every time they attended the clinic. The drugs were counted to cross-check that they were being taken regularly and that enough remained until the next visit to the clinic. The ARV treatment card was also checked to ensure it had been filled in correctly. The caregiver is expected to tick the treatment card once the drugs have been given. They had been taught how to fill in the card in the adherence counselling sessions.

### 3.6.2 Caregiver

Each child has a caregiver who looks after them and is responsible for giving them the ARVs. Kiwoko Hospital counsellors call them caretakers rather than the more recognised term of caregiver. Occasionally it is a parent, but it is more often the grandmother, aunt, or older sister who is bringing up the child. Almost all the caregivers were women, although a couple of men were met during the three weeks.
It is important that the caregivers understand the way ARVs work and the importance of the children taking them regularly so that they will ensure the children keep taking them. The training of the caregivers in ARVs is crucial.

A counsellor talked about a child, who was reluctant to take cotrimoxazole, and was later prescribed ARVs. The caregiver said to the counsellor: “The child is tired, taking drugs every day”. Through counselling the caregiver became aware of the benefits of the ARVs and how essential it was that the child took them each day. The counsellor followed up this meeting with regular home visits and, as a result, the child has continued with ARVs.

The responsibility to ensure the child takes the ARVs every morning and evening, to attend the clinic, to remember to keep appointments and to always have a supply of ARVs, is the caregiver’s. Thus the role of the caregiver is critical to the success of the child’s adherence to taking ARVs.

3.6.3 Food and Nutrition

All patients are advised to take food when taking their ARVs. The preparation and cooking of food on small charcoal stoves takes many hours. One caregiver kept aside some porridge in a flask from the night before so that each morning there was food, which could be taken with the ARVs. Some caregivers said they could not always afford to give a meal to the child when they took ARVs and so sometimes gave them chai (hot milky tea with sugar).

A number of children were receiving nutritional support from the clinic, on a monthly basis, to supplement their diet. They received cooking oil, ten eggs, half a kilogram of meat and a bar of soap. This support was targeted at the poorer families and was meant for the child and not the rest of the family. Culturally this could be a sensitive issue as normally a visitor is given the best food.
3.6.4 Home Visits

The child patients registered at Kiwoko Hospital are primarily living in Kikamulo sub-county. In order to offer an effective service, the decision was made to target the programme in the local area. This means the counsellors are able to do home visits on a regular basis. Of the children that are on ARVs, fifteen live in Kikamulo, two live in Luweero district and three live further away with the furthest living in Nakasongola district which is at least two and a half hours away.

The researcher was able to visit eleven homes. With each visit there was a warm welcome, which confirmed the strong relationships that exist between the counsellor, the caregiver and children. Home visits have many benefits compared with the visits the caregivers and children make to the clinic as is discussed in 3.6.1. On one visit we learnt that the caregiver was the older sister of the child and she had been taught what to do from the grandmother, who had attended the adherence counselling sessions. On this home visit the counsellor encouraged the sibling to come to the adherence sessions herself.

At every visit the counsellor would ask for the ARVs to be brought out and then the different drugs would be counted and cross-checked against the ARV treatment card. A check would be made as to when the next appointment was due. There was more time available on a home visit than on a clinic consultation to do all this. It was also necessary to check the appointment dates because when clinics were busy mistakes had been made such as making an appointment on a day when there was no clinic. The counsellor also checked that the patient had enough ARVs until the next appointment.

There was time for caregivers to ask questions and for the counsellor to reiterate the importance of taking ARVs and to find out what difficulties the caregiver and the

---

9 The research was carried out with fourteen of these children and interviews held with the caregivers, either at their homes or at the hospital.
10 See Appendix 7 for photographs from the home visits.
child faced. The bond between the hospital staff and the people we visited seemed strong.

However, doing home visits does take up a lot of time and for some homes the counsellors had to make their visits at pre-arranged times to ensure the caregivers were not in their shambas (fields) working.

### 3.6.5 Quarterly Workshops and Youth Club

Every quarter all the children on the HIV/AIDS programme come for a day to the hospital. The purpose of the workshops is to bring the children together for social support, spiritual input, building friendships and increasing self esteem. A day trip to Entebbe Zoo was being planned for November.

The researcher's last day was spent observing the quarterly workshop at which about sixty children came accompanied by their caregivers. Having seen many of these children in clinics or on home visits, they seemed transformed in this different setting. The smiles, the laughter and the joy of having fun made the day very special. The caregivers were given health education and watched a video, while the children played outside. The activities for the children included aerobics and team games such as keeping a balloon in the air. Then the children were taught the Bible story of Noah’s Ark and afterwards in age groups did arts and crafts associated with the story. This entailed making masks and collages and, for the older children, drama. The children at the end acted out Noah’s Ark with their homemade props to their caregivers.\(^\text{11}\) The researcher did not recognise one of the older children, who has psychosocial problems, because the child was constantly beaming during the games, although for the previous three weeks, had only been seen with a very drawn face.

\(^{11}\) See Appendix 8 for photographs from the quarterly workshop.
As well as the quarterly workshops there is a youth club that is held on a monthly basis. This is for the children who are at least eight years old and is not attended by the caregivers. The aim is for this club to be a forum where a child can open up and talk to others and the counsellors. The staff are keen that at least one of them is trained as a child counsellor to facilitate this aim. The one-week training course offered at TASO, however, costs twenty times the monthly salary of a counsellor.

3.7 Challenges

3.7.1 Cultural and Traditional Beliefs

One experienced counsellor said that in Uganda there is a cultural barrier to taking western drugs. Traditionally Ugandans consult the traditional healer for all matters, who often lives locally to them and serves the village. The healer mainly gives out herbs, and people fear them due to the mystery surrounding these medicines and the preparation of them. It is customary for the healer to appear to spit, or as some people believe, cast a spell, as they prepare the mumbwa,\(^{12}\) which is mud mingled with herbs.

Research revealed that those patients who are already within the hospital system and regularly consult medical personnel when ill are perceived to be putting their trust in the ‘western’ system. However, those people who do not normally attend a hospital when ill are unlikely to consult doctors but will go to the traditional healer. Those who have no experience of hospitals, and have little education and knowledge outside their village, fear them.

Even if a person is on ARVs they could still be consulting the healer and so the mumbwa could be interacting negatively with the ARVs. Patients are unlikely to admit to visiting the healer and so it may be difficult to learn if this has been the case. If a patient does not visit the healer, then the healer is likely to come and visit them. The healer does not want to lose a profitable income since people give money or gifts in kind to the traditional healers.

\(^{12}\) Local medicine.
There are rumours that ARVs are a ploy to enable the Europeans to kill Ugandans. Another myth is that when you return to the village from hospital having started taking ARVs, they say you will die faster. These rumours may originate from the fact that by the time a person comes to the hospital they are often critically ill. When they are then put on ARVs, they are in such a poor state that they can die.

The mother of a child, who was also a patient on ARVs, had ‘got saved’ and the pastor had told her that she was healed and she no longer needed her ARVs. The counsellor heard of this and advised her that she needed to keep taking the ARVs. She refused to listen, and after six months got very sick, and returned to start taking ARVs again. The discussion arose amongst the staff as to whether the child should be put on ARVs or not due to the mother’s lack of adherence. Having counselled the mother, who expressed a willingness to adhere for herself and the child, they were both put on ARVs.

The stigma associated with AIDS has reduced in Uganda as AIDS is so widespread and people all know of others who have died of AIDS related illnesses. However, there is sometimes stigma within families.

One child was brought along to the clinic by the grandmother, as the mother did not want to be identified as having a child with HIV. She was herself HIV positive and later died.

Culturally Uganda is paternalistic and children are taught in schools by rote learning. Therefore instructing patients to take ARVs, because the medical personnel advise them, is more effective in Uganda than in many other countries.
Staff are aware of the cultural and traditional beliefs within the community, as they have themselves come from communities holding these beliefs. However, they have learnt to put their confidence in ‘western’ medicine.

### 3.7.2 Psychosocial Issues

Although the majority of patients were having no problems and their lives had greatly improved since being on ARVs, there was one significant exception.

Alex had been taking ARVs for a year, but was beginning to regularly attend the hospital with various ailments. The situation came to a head while the researcher was there. Alex, a teenage refugee, had seen both parents die and had been adopted by a man whose wife and children were unhappy with the situation. The counsellors were aware that Alex was not happy at home, but there was no alternative. Alex let them know that the mother and her children were taunting him/her saying “You will give us HIV”. They were picking up the child’s clothes with a stick so that they would not ‘catch it’.

Later in the week it was decided to visit the child at school, but we arrived to find the child not there because of illness. We were able to meet the adopted father who told the counsellors that the child’s behaviour at home was not acceptable and that Alex had even run away for a few days to Luweero, sleeping rough. We then reached the home to find the mother in as well as the child. She spent a considerable time berating the child verbally in front of us.

The counsellor requested the child to bring the ARV drugs to us. Unlike all the other home visits we had made, when people would bring the ARVs in a clear plastic bag with the treatment card, there was a delay until one or two drugs were finally brought out. It transpired that Alex was only taking the ARVs in the form of a syrup or tablet and so was not taking drugs in the form of a capsule. This meant Alex had been only taking two out of the three ARV drugs.
Knowing the home situation was deteriorating and this was not an appropriate moment, the child was invited to come to the clinic the next day, when the counsellors knew they could counsel Alex uninterruptedly. It transpired that the child had been receiving ARVs before registering at Kiwoko Hospital, and the importance of taking all three drugs, twice a day had not been explained. Thus Alex’s lack of understanding that all three ARV drugs needed to be taken was seen to be the problem. A solution to this was to give the child Triomune, which was one tablet rather than three separate drugs.

The child looked subdued and depressed through most of the consultations and the psychosocial problems appeared overwhelming to us. It reiterated the importance of home visits.

### 3.7.3 Illness

Another child started to suffer from various ailments during the three-week period that the researcher was doing the case study.

The child’s caregiver was viewed as one of the best caregivers and was caring for two grandchildren on ARVs and these children had been the first to start ARVs. Paul was suffering from a bad cough and was in pain. After a number of consultations he was finally admitted on the wards and started on TB treatment. His ARV drugs needed to be altered, as he could no longer be on Nevirapine. The hospital staff could not be sure if he was building up a resistance to his ARVs because he was not a good adherer; or whether his body was resisting the ARVs in which case he was in need of second line treatment; or whether he had caught TB, which is common and does not need to be AIDS related. Without viral load testing and with the limited resources Kiwoko Hospital had, they were unable to tell. The counsellors were adamant that he was a good adherer. The grandmother was open in the
researcher’s interview and talked about how there was one stage when Paul queried having to take his ARVs all the time. She had mentioned it to the children’s coordinator, who had counselled him. The grandmother said since that time he had not brought up the subject again.

3.7.4 Disclosure

Most of the children knew they were taking drugs called ARVs but had yet to correlate ARVs with HIV and AIDS, despite attending the clinic. The researcher had assumed that, as the counsellors were talking about ARVs in front of the children, the older children were aware of their own HIV status but this did not turn out to be the case. Alex was aware of his/her status due to the taunts of the children in the house but he/she had not been given any counselling. This illustrates, as in 3.6.5, again the need for a trained child counsellor.

3.7.5 Syrups, capsules or tablets

ARV drugs come in various forms for children depending on the drug: syrups, capsules and tablets. Although the children mainly prefer the syrups, as they are sweeter, the caregivers find them less easy to give. The syrups are already made up and the caregivers are advised to store them in a cool place such as under a bed. However, they are also encouraged to store the ARVs in a place where they can be seen to help remind them to give the children the ARVs. Tablets can be cut in halves or quarters either at the hospital pharmacy or at home.

When the Ministry stopped supplying Triomune 40, for the older children, it meant that they had to have a different fraction of the Triomune 30 dose and this was more complicated to administer.

---

13 One child patient had drunk a bottle of syrup, one of the ARV drugs bought from Kampala, and had been admitted to the hospital because the family were concerned for the child’s kidneys.
14 The average temperature at Kiwoko would be 22°C.
The procedure for taking the capsules appeared, to the researcher, to be complicated although nobody had complained about it. If half a capsule was required then the grandmother, who was the caregiver in this case, had to either empty the contents of the capsule on a plate and then scoop half of the contents back into the capsule and replace the lid or had to tip out half of the contents of the capsule and then put back the lid. The counsellor encouraged the grandmother not to put the half capsule back in the pot with the full capsules, but to store it somewhere else. This was a typical house, which was made of mud, and we were sitting outside, as there was not enough room for three people to sit in the house. When the rain came half an hour later we had to stand indoors in the front room and avoid the places where the corrugated iron sheet roof leaked. Thus the issue of good hygiene and keeping ARV drugs in a clean place is not easy to follow in rural surroundings like Kikamulo. None of the homes we visited had running water and only a few that were near Kiwoko town had electricity.

The families we visited had clean ARV drug pots, which were stored in easily accessible places, with the exception of Alex’s home.

3.7.6 Transport

Within Kikamulo sub-county, transport links can be difficult. A matatu, which is a shared public taxi, may go to Kiwoko in the morning and then return late afternoon. The standardised transport subsidy given at the clinic only covers a single journey, if they live near the boundaries of the sub-county.

A moped or motorbike was used to reach the homes of the children that the researcher visited. The HIV aide counsellor rode the moped, the female counsellor, who was the translator, sat at the back, and in the middle sat the researcher. Hazards on the road, such as potholes and animals, can be a problem when travelling in the area. During one
of the visits a cow ran across our path when we were on the moped. If we had been travelling faster, as we had been the day before when we were on a motorbike, we would have probably hit it.

At the clinic people also came from Nakasongola, which is about two and a half hours away although in the rainy season it would take significantly longer. Many of the patients and caregivers that attend the children’s clinic have to travel considerable distances. This is not only expensive but also time-consuming.

### 3.7.7 ARV Treatment Card and Other Challenges

Each ARV patient is given a treatment card so that the caregiver can tick a small box when they give out the ARVs every morning and evening. It is revealing that when asked what the challenges were in taking ARVs, some said they did not have a pen to tick the box.

One person would tick for a whole week, as they had a child in boarding school who came home at weekends, so they ticked in advance. Another experience a counsellor had was of a person who ticked for a whole month, as they had no pen. In resource-poor settings every aspect of what is needed to help adherence needs to be thought through.

Although caregivers were taught how to fill in the card, for those that were illiterate as many were, even ticking boxes can be difficult.

One of the home visits we made revealed how the elderly grandmother, who was the caregiver, was unable to read and so was not able to understand how to tick the boxes. The child was eleven years old, so the counsellor taught the child how to tick the boxes.

---

15 See Appendix 9 for ARV Treatment Card.
Although the caregiver had a wall clock, she could not afford to replace the batteries. She was reliant on asking a child, who was the timekeeper at the local school, who lived near them for the time.

The home visits had revealed incorrect appointment dates, patients who did not have enough ARVs until their next appointment date and incorrectly completed ARV treatment cards.

### 3.8 Adherence

The researcher arrived at Kiwoko Hospital with the preconception that the side-effects of taking ARVs might be so severe that the patients would struggle with adherence. However, it quickly became apparent in the interviews with the various caregivers, that even if a child did suffer from side-effects it was generally in the first two weeks and only to a minor extent. It was revealing that since the children had been on ARVs the majority had not been admitted to hospital. Previously many of these children had been admitted monthly, or even weekly, with illnesses. Since being on ARVs the caregivers were saying the children were healthier, and were stronger – they could walk to school, collect firewood and run around. This was a significant motivation in terms of adherence since neither the caregivers nor the children would want to go back to a situation where the children were always getting sick. It should also be noted that attending the hospital regularly, as an inpatient, would be very costly to a family, unless there was a donor to cover the costs, as there is in the children’s ART programme.

During the interviews with the caregivers their strong resolve never to miss a dose became apparent. In addition a number of interviews revealed that children as young as four years old were reminding their caregivers and badgering them to give them their ARVs!
A caregiver had gone to visit their neighbour and the four year old had come to fetch her, and said, “I have not taken my drugs, you come and give me my drugs and then you go back to your friends”.

Another situation was when a caregiver had forgotten once or twice in rainy season to give the child his ARVs, as she was busy in the fields. She had run after the child who had already left for school, to give him his dose.

One caregiver told us that she went to meet the child from school, as the child had not yet returned and yet it was near the time to take the ARVs.

The researcher’s findings revealed a high level of determination and creative ways to make sure adherence was met from both caregivers and children.

Radio is used to communicate information, and a number of people in rural areas have radios. Interviews revealed that there is a radio station that on the hour, at around the times when people take ARVs, made announcements such as: ‘Wake up and take your ARVs’.

A clinical officer’s view was that adherence was good because patients are fearful of AIDS as they have all seen people die. They see ARVs positively as it prolongs their life.

3.9 Summary

Research during the three weeks at Kiwoko Hospital revealed many different issues related to administering ARVs within a rural resource-poor setting. The Ministry of Health is the main provider of ARVs to the hospital but there is major concern about the Ministry’s ability to provide a regular supply of ARVs to the hospital. The hospital infrastructure enables the ART programme to function well as it provides
laboratory and pharmacy support as well as transportation. The calibre and retention of staff involved with the ART programme is high and the staff are well trained.

The programme for the children benefits from a major donor who funds a wide range of services, but this dependency on one donor makes the programme vulnerable. If the donor of the children’s programme stopped, or reduced the level of funding, it would have a very negative impact on the level of care that could be offered to the patients.

Overall there is a high level of adherence of ARVs by the children due to the dedication of the caregivers, which is key to this success. The adherence levels have been assessed through counting the ARV drugs on every clinic and home visit, as well as discussing with the caregivers how often the child is taking the drugs. Another sign of assessing the level of adherence is related to the improvement in the children’s health, which has been considerable.

The ARVs are being efficiently administered to the children through the ART programme at Kiwoko Hospital despite being within a rural resource-poor setting. However, there are various issues pertaining to this programme that will be outlined in the next chapter.
Chapter Four: Discussion

4.1 Introduction

This chapter will comment on the ART programme for children at Kiwoko Hospital. The comments are based on the research that was done which identified that the programme was effective in terms of the supply of ARVs and the adherence of the patients. However the research identified some vulnerable areas associated with the programme. The reasons for the success of the programme will be discussed first, followed by exploring what elements of the programme could be improved. Finally the factors which could jeopardise the programme in the future will be examined.

4.2 What were the reasons for the levels of success in the programme?

4.2.1 Uninterrupted supply of ARVs

A key explanation for the good adherence levels seen at Kiwoko Hospital is the uninterrupted supply of ARVs to the programme. The children’s ART programme has been able to access drugs from two sources: the Ugandan Ministry of Health and the donor of the children’s programme. By having two sources of supply, failures of the Ministry to supply ARVs have been overcome. However, in the future the supply will only be from the Ministry. The adult programme has not been so fortunate and a few patients have missed doses for a few days due to a shortfall of ARVs from the Ministry.

4.2.2 Medical benefits

Children and caregivers have seen clear medical benefits from taking ARVs. The caregiver is concerned that if the child stops taking ARVs the medical improvements they have seen will disappear. The caregivers saw progress through the child quickly gaining weight and there no longer being the need for the child to be admitted to
hospital, as had been Kasper et al.’s (2003) experience. The children had regained their strength, were able to walk to school and were gradually carrying out chores in the home. All these factors had encouraged compliance. As ARVs are making a tangible difference in the children’s lives both caregivers and children have a strong incentive to continue with the programme and ensure the children do not miss a dose. Hardon (2005) suggests more studies should be carried out to see the social and cultural benefits arising from taking ARVs.

4.2.3 Responsible caregivers

The caregivers play a central role in the ART programme as they give the ARVs to the children. They are the ones responsible for administering the ARVs and are following the WHO’s (2004) definition of adherence. The caregivers had been given adequate training in the adherence counselling sessions and felt able to consult staff. The research revealed how well they managed their role and took responsibility in giving ARVs to the children, despite the challenges they faced.

4.2.4 Staff commitment

The hospital staff are a crucial asset to this programme and the staff on the programme are dedicated to the community and offer quality care. Patients and caregivers have established good relationships with the staff and this helps with the assessment of adherence (Colebunders et al., 2006). Whereas in other programmes they have struggled to retain staff, as researched by Nabiryo et al. (2005), Kiwoko Hospital has been able to keep their staff. Trust has been built up and so when ARVs were introduced, despite the regime’s rigidity, the caregivers were willing to believe the staff and to follow their instructions. The caregivers were also willing to voice concerns in the adherence counselling sessions.

Without the pharmacist’s determination to ensure ARVs were available for the children there would have been shortfalls.
4.2.5 Clinics

Both the visits to the clinics and the home visits are essential parts of the ART programme. The clinic is at Kiwoko Hospital, a regional centre for those living in Kikamulo sub-county. It is therefore relatively easily accessible to everyone, although the distances many have to travel may still be considerable. Subsidising transport costs helps ensure the caregivers and the children attend. Clinics are where the patient and caregiver can be reviewed and seen by medical personnel. Home visits supplement the clinic appointments by cross-checking information and checking adherence levels. Kiwoko Hospital is able to do home visits, because it concentrates its resources in Kikamulo.

Other programmes have delivered ART in the home (Weidle *et al.*, 2006), which has meant the difficulties with reaching a clinic were reduced. Although patients were accessing some services from a clinic, most services – such as dispensing ARVs and reviewing patients - were carried out at home. If Kiwoko Hospital recruited more staff and bought resources, like motorbikes, this could be achieved.

4.2.6 Resources

The last important factor in order to run a successful ART programme is the resources available. Kiwoko Hospital has the infrastructure to run the programme, as it is a well-functioning hospital coping with a large number of demands. The programme has a major donor who has been covering the costs of running the programme and another donor who pays for the staff salaries. The donors are content with the way the programme is run and continue to fund it. The hospital recognises the ART programme’s importance and is committed to supporting the service and making sure the resources, like collecting ARVs from Entebbe, are available wherever possible.
4.2.7 Adherence

Adherence levels of the ARVs appeared to be good. This view that adherence was good was based on the monitoring by the counsellors, as suggested by Colebunders et al. (2006); as well as carrying out pill counts at clinic and home visits. The patients were taking ARVs and appeared not to be missing a dose. Another determining factor was the measurable improvement in the children’s health. Although some patients had experienced adherence difficulties, they had been recognised and dealt with by the counsellors through counselling - in the case of Alex, the psychosocial issues were going to be looked into. No child has yet needed second line treatment.

4.2.8 Summary

The reasons for the success of the programme at Kiwoko Hospital can be seen in two major areas: an uninterrupted supply of ARVs to the patients and the apparent good adherence levels in the patients. The proximity of the clinic to where patients lived enabled them to access the services offered. Other causes of success were the clear improvement in the health of the children, which encouraged them and their caregivers to ensure adherence. The dedication of the caregivers in fulfilling their role as well as the services run by the hospital in respect of clinics and home visits also helped in the administering of ARVs. The provision of the right level of resources to the ART programme with the assistance of donors had also been key to the success of the programme.

4.3 What could make this ART programme more effective?

There were various aspects of the programme that could be improved. The following section outlines the factors that could make the service more effective.
4.3.1 Community Antiretroviral and Tuberculosis Treatment Supporter

CATTSs could play a more valuable role in the ART programme. More part-time staff could be recruited and trained up to carry out regular home visits and monitor patients on ARVs. The CATTS weekly report sheet\(^1\) should alert senior staff to significant issues. HIV/AIDS will be an on-going issue and more staff will be needed as the programme is expanded. Thus if volunteers and part time members of staff can be used to do monitoring jobs, qualified staff will be released to concentrate on areas that only they can do.

4.3.2 Medical reviews

The hospital needs to be doing more medical reviews for patients on ARVs to monitor the effectiveness of viral resistance. Kiwoko Hospital has the capacity to do more clinical tests, such as testing haemoglobin levels as suggested by Colebunders et al. (2006). These tests are indicative as to how well the immune system is coping, whether the ARVs are having an effect, and monitoring ARV toxicity. His research showed that 80% of patients had an undetectable viral load within a year of starting on ARVs. Further research needs to be carried out as to what one can expect from a CD4 count, if viral load testing is unavailable, as is the case for Kiwoko Hospital. Kiwoko Hospital’s experience was that child patients’ CD4 counts were improving but slowly. Further research needs to be done as to what other projects have experienced in regard to CD4 counts. Medically levels of adherence need to be measured as well as assessing the adherence level through pill counts and talking to the caregivers.

4.3.3 Computer System

Overall the programme needs a more accurate patient record-keeping system, for example it was often hard to compare previous CD4 counts for a patient, as it had not been recorded on the patient’s file. This record keeping was expected to improve, as

---

\(^1\) See Appendix 10 for CATTS weekly report sheet.
the staff were aware of the problem. Their new computer could be used to record when a patient is expected to return for an appointment, CD4 counts and the dosage of the ARVs the child is currently on. A computer system can be a valuable and efficient tool in administering ARVs (Mukherjee, 2004).

4.3.4 Growth Charts

The patients have their weight recorded every time they attend clinic. Introducing growth charts where the height and weight are recorded, and then plotting it on a chart can be useful for demonstrating a response to the ARVs. Although children can gain weight quickly on ARVs, their height may only increase a year or two later as observed by Donaghy (2006). Using growth charts would aid the review of the patient’s adherence to ARVs as well as seeing how effective the first line of treatment is working.

4.3.5 Cotrimoxazole

Clinical evidence shows that cotrimoxazole should be given to all patients as it prevents other illnesses that a patient with HIV is prone to (Chintu et al., 2004). An ART programme must always include this drug. A treatment card, similar to the ARV card, could be made for taking cotrimoxazole, which would prepare the patient for taking ARVs at a later date. This would allow the staff to assess how good the patient would be at taking ARVs.

4.3.6 Disclosure

Disclosing to the children that they are HIV positive is an area in the programme that is lacking. Almost all the children do not know that they are HIV positive. They are aware they are on ARVs but do not realise that this means they have HIV/AIDS. TASO’s experience has shown that when the child is eventually told, they become angry and resent not having been told earlier.
Virtually all the children were reliant on their caregiver giving them ARVs. However as they grow older they need to be taking the lead in this. Disclosure can be a gradual process but needs to be as early as a child can start understanding the concepts - TASO would advise from eight years old. The children’s co-ordinator was reluctant to start teaching disclosure without training in child counselling. My observation would be that he naturally has the ability and insight to counsel children and teach them about their status due to his work experience with children over ten years.

The counsellors need to start talking about the child’s HIV status and the issues surrounding it. The youth club was set up for this purpose. The children also need to learn about their status to prevent transmitting the virus as they become sexually active and, as discussed earlier, they need to start understanding that they are HIV positive in order not to react negatively at a later stage and stop taking their ARVs.

### 4.3.7 Summary

Various areas could be improved in order to make the programme more effective. Medical reviews need to look at the effectiveness of the ARVs in regard to clinical response to viral resistance levels. Other improvements should include training others to do basic monitoring at home; improving the patient record-keeping on a computer system; introducing growth charts to monitor progress; and monitoring the adherence to cotrimoxazole as preparation for taking ARVs in the future. Finally, revealing and discussing with the children their HIV status is important and needs to be started sooner rather than later.

### 4.4 What could affect the programme and jeopardise its future?

HIV/AIDS continues to increase and dominate sub-Saharan Africa and the need to scale up treatment of ARVs is constantly discussed and acknowledged. Major funding, through the Global Fund and PEPFAR, is currently available. The need is to expand the programmes.
4.4.1 Supply

The challenge of providing ARVs in a resource-poor setting is immense. Over the last year the Ugandan Ministry of Health has had periods when it has been unable to supply the hospital despite the immediate need. Although the pharmacist’s resourcefulness meant only a few adult patients went without for a few days, the potential for a more serious scenario was only prevented by his commitment and ingenuity.

Whilst the researcher was in the country there were rumours that ARVs were due to run out following an article in a major Ugandan newspaper. An efficient supply chain is paramount for the supply of ARVs. A constant supply of ARVs is clearly essential to the programme.

4.4.2 Expansion

The children’s ART programme has grown organically within a small catchment area and this is a major strength of the programme. The programme works efficiently due to the calibre of staff and the resources made available as well as the support provided in clinics and home visits. All these elements need to continue when the programme expands to ensure its continuing success.

The children’s programme is to be incorporated into the adults programme in respect of home visits for logistical, practical and financial reasons. Experience has shown in the adult ART programme that suddenly acquiring 700% additional patients to the programme, many of whom were a long way from the hospital, will only be successful if there are the resources to deal with the additional patients. Thus expanding the ART programme, which is essential, needs to be done gradually in order for the programme to continue to be effective.
The hospital would need to recruit and train committed staff that were able to live within the areas they operated in. This could make scaling up the delivery of an ART programme possible. Further investigation into TASO’s model of ART home delivery programme outlined in Nabiryo et al. (2005) and Weidle et al. (2006) could lead to a more innovative approach. For example, running a mobile medical clinic in the area every six weeks would help access areas that are too far from the hospital for the caregivers and patients and ensure the quality of care and support was maintained.

### 4.4.3 Funding

It is a reasonable assumption that an ART programme, in a resource-poor setting, can only operate with a considerable amount of donor funding. Thus donors are a necessity in a rural developing community for such programmes - Colebunders et al. (2005) pointed out that many of the studies that have been done are where there has been major donor funding. However this makes ART programmes very vulnerable as they are so dependent on their donors. Patients would be unable to cover the costs, if donors withdrew, and some caregivers would be unable to access the clinic and collect the ARVs without their transport cost to the clinics being subsidised.

The programme has benefited from one major donor who has been willing to cover the costs of a comprehensive service to the child patients. If the donor decides not to continue with the funding at a future point this would jeopardise the service offered. The more donors are involved in aspects of a project, then the less of a shortfall the hospital will have if a donor stops funding. A possible issue that could lead to such a problem would be if the children’s ART programme was incorporated with the adults’ programme against the donor’s wishes. Having a donor who is sympathetic and understanding regarding the programme can ensure a higher quality of service, as seen in the Kiwoko Hospital programme.

The first instalment of PEPFAR money through Inter-Religious Council of Uganda (IRCU) put an emphasis on voluntary counselling and testing (VCT). It also gave clear guidelines as to what the money could and could not be used for in the adult
programme at Kiwoko Hospital. The expected new grant appears to be more flexible and treatment costs, as well as cotrimoxazole, are covered. Funding does need to be available for all the aspects that are essential to an ART programme. This includes the provision of ARVs, treatment costs, provision of a comprehensive level of care and subsidised transport. A shortfall in any of these areas puts at risk the investment in ART programmes in resource-poor settings.

PEPFAR and Global Fund money is due to end in 2008. With a new US President priorities may change. This could affect the amount of money available and to whom it is dispensed – for example it might be redirected away from faith-based organisations as a backlash to President Bush’s current emphasis on such organisations. This illustrates that the dependence on donors leaves ART programmes in resource-poor settings severely exposed. However, it would be deemed highly irresponsible if financial support was reduced in ART programmes which led to such programmes having to be abandoned.

### 4.4.4 Key Community Leaders

There are various community leaders who can influence adherence to ARVs. There are some pastors who encourage those in their congregation who are on ARVs to stop taking them, once they start getting better, by teaching them that God has healed them. This teaching clearly threatens the impact of the adherence levels of patients and, in the case of child patients, influences the caregivers, who may believe that the children no longer need to take the ARVs.

Traditional healers’ influence on people is very strong. The traditional healer may visit a patient who is taking ARVs and persuade the patient to stop taking the ARVs or take *mumbwa* alongside ARVs, which are likely to make the ARVs less effective. Further research needs to be carried out in this area to ascertain the impact of taking *mumbwa* with ARVs.
CBHC leaders within the hospital need to liaise with the community leaders and educate them on the impact of their teachings. The key community leaders need to be educated in the way ARVs work and what the benefits are. In the case of traditional healers western medicine, such as ARVs, threatens their livelihood and so this has to be borne in mind when tackling the problem. The last traditional healers’ conference Kiwoko Hospital organised, on the subject of how the HIV virus can be transmitted, was well attended.

4.4.5 Cultural beliefs

The field research at Kiwoko Hospital showed good levels of adherence to ARVs in a rural resource-poor setting. However, Wamala (2006) warned that only those believing in western medicine accessed the hospital resources and, if eligible, the ART programme. This would lead one to suggest that there are many, and in Wamala’s view the vast majority, who never access the hospital as they only believe in traditional healers. Often those that come to the hospital have visited the traditional healer first and, only when they have not got better, finally turn to the hospital. Further research is needed in the community itself to do a fact-finding survey on cultural beliefs in this regard. If an ART programme is to reach out to all the local community, and those that are eligible are put on ARVs, the adherence levels could be poor due to this lack of belief in western medicine.

4.4.6 Summary

As outlined above there are several key issues that could jeopardise the future of the ART programme. These include failure of the Ugandan Ministry of Health to provide ARVs, too rapid expansion of the ART programme, and failure of the international donor community to provide the right level of funding for the ART programmes. Locally the community leaders and their beliefs can hinder the adherence levels of patients due to their influence in encouraging them to stop taking ARVs or to take alternative medicines alongside ARVs. Finally if the programme is expanded, a large
majority might refuse to access the ART programme, as they only believe in traditional medicine.

4.5 Conclusion

This chapter has discussed and analysed the reasons for the success of Kiwoko Hospital’s ART programme by looking at the major benefits of the service, namely the uninterrupted supply of ARVs, the clear medical improvements the children experienced and the quality of staff and caregivers associated with the programme. Improvements to the programme were suggested in the areas of more effective use of staff, improving medical reviews and better record keeping. Finally issues, that could jeopardise the future of the programme, were discussed. These included the supply problems relating to ARVs, reduced donor funding and too rapid expansion of the programme. The next chapter will conclude and make recommendations for running a children’s ART programme in a rural resource-poor setting, in regard to adherence.
Chapter Five: Recommendations and Conclusions

5.1 Research

The research looked into the adherence of children on ARVs in a rural resource-poor setting in Uganda. The research is significant because nine out of ten children needing treatment for HIV/AIDS live in sub-Saharan Africa (WHO/UNAIDS, 2006). In addition, most previous studies have concentrated on the treatment of adults rather than children, and on pilot studies where a considerable amount of resources and external advice have been given.

There were two main limitations to the research. Firstly, it was based on a programme which covered only twenty children and, secondly, the longest a child had been taking ARVs was just over a year. However the level of adherence shown was consistent across this small group of children.

5.2 Recommendations for Further Research

There is a need for additional research. An issue is whether adherence in taking ARVs will become more of a problem in the future. One concern is whether the medical improvements seen at the beginning of the treatment may be forgotten and so the incentive for caregivers and patients to continue with ARVs may be reduced. There is a need to look at the children’s CD4 counts, and do other laboratory tests, to find out whether a child’s body is showing signs of improvement or developing viral resistance to the ARVs - Kiwoko Hospital is unable to do such viral load testing due to limited resources.

Another area that needs to be researched is the influence of community leaders, which is particularly strong in rural resource-poor settings. An issue is the need to educate pastors on the impact of their teaching – some pastors, for example, urge patients to stop taking ARVs when the patient converts. Another issue is the effect of traditional
healers’ urgings that a patient take *mumbwa* alongside ARVs – the influence of the *mumbwa* on the efficacy of the ARVs is unknown.

### 5.3 Conclusions

Good adherence was shown, due to the steady supply of ARVs to the programme, and the conscientiousness of the caregivers in giving the ARVs to the child patient. The caregivers’ resolve that the children should never miss a dose meant adherence levels were understood to be more than 95%. The children’s health had improved considerably and so this was a constant reminder of the benefit of taking ARVs to both the child and caregiver. Before starting the ARVs the children had been regularly admitted to the hospital, but they were now experiencing good health.

The provision of a regular supply of ARVs to the child patients is essential. Rural resource-poor areas are totally reliant on a constant supply and do not have back-up to cover supply failures. Research revealed in Uganda and Nigeria how vulnerable resource-poor settings are to failures in this supply chain.

The dedication of the staff at Kiwoko Hospital was a key to the success of the programme in promoting adherence and overcoming problems. An example of this was the efforts of the pharmacist to ensure there was a constant supply of ARVs to the patients despite stock outs.

The programme was only able to function effectively due to the provision of external funds. In a rural resource-poor setting, the issue is not just the cost of the ARVs but also the long-term provision of all the resources needed to run an ART programme. Patients do not have the means to pay for ARVs. The Kiwoko Hospital programme provided cotrimoxazole, treatment costs for opportunistic infections, ARVs, nutritional support and subsidised transport costs. The psychological health of the patients was being addressed through a youth club and quarterly workshops.
The programme needs to expand to reach more children within the district. As the programme expands it may be harder to recruit and supervise staff and offer the same level of service. Since the calibre of staff is crucial to the success of the programme, expansion needs to be done carefully and realistically. The ART programme for children was concentrated in one sub-county, which enabled the programme to offer an effective and well-resourced service that included regular clinics and home visits.

The issue of disclosing to the children their HIV status and the reason for taking the ARVs becomes increasingly important, as they get older.

To sum up, the research concluded that good adherence can be achieved in administering ARVs to children HIV/AIDS in a rural resource-poor setting. This was because the caregivers and patients were good at adhering to the ARVs, as they appeared to be taking them more than 95% of the time. However, the major concerns were the provision of a constant supply of ARVs to the programme and the long-term need for external funding.
Appendices

Appendix 1  Interview Questions with Caregivers
Appendix 2  Interview Questions with Key Informants
Appendix 3  Interview Questions with HIV Counsellors
Appendix 4  Map of Ugandan Districts
Appendix 5  Map of Kiwoko Hospital, Kikamulo
Appendix 6  CATTS Job Description
Appendix 7  Photographs from the Home Visits
Appendix 8  Photographs from the Quarterly Workshop
Appendix 9  ARV Treatment Card
Appendix 10  CATTS Weekly Report Sheet
Appendix 1 – Interview Questions with Caregivers

How long has the child been on ARVs?

Have you seen any improvements since the child started on ARVs?

What improvements have you seen?

Did the child experience any side effects?

What times do you give the child their ARVs?

Do you give the child food when you give them?

How do you remember to give them?

How do you find using the ARV treatment card?

What problems have you experienced giving ARVs to the child?

Have you ever missed giving the child their dose of ARVs?

   *If the answer was no:* - Have you not missed not even once?

   *If the answer was yes:* - Tell me what happened please…

What did you think about the teaching on ARVs in the hospital?

In your experience is it true what you were taught?

Was there anything you were not told?

How has the child found the quarterly workshop/youth club?

Is there anything you would like to tell me that I have not asked about, that would help me understand your situation better?
Appendix 2 – Interview Questions with Key Informants

What is your experience of children on ARVs?

What do you teach about ARV adherence?

What training have you been on?

What is your understanding of how much a patient needs to adhere?

Is that what the patient is told?

Do you think the caregiver realises the importance of taking ARVs?

How much training does the caregiver have?

What about the side effects of ARVs, what is your experience?

What are the most important factors to be in place for a patient to have good adherence?

Have you heard of patients selling their ARVs or sharing them with a partner?

Is there stigma associated with ARVs?

What about traditional beliefs and ARVs - are there issues?

Is there anything you would like to tell me that I have not asked about, that would help me understand your situation better?
Appendix 3 – Interview Questions with HIV Counsellors

What do you teach people in the sessions on adherence counselling?

What do you teach about nutrition?

What has been your experience with patients taking ARVs?

Tell me some of your patients’ stories of when they have not been good adherers…

Do you think in your experience of your patients that if they do not adhere it is because they have problems rather than they actually forget to give ARVs, or is it both?

Do you think the caregivers tick the ARV treatment card even when they forget to give the ARVs?

What is the solution for those that do not adhere?

What happens to those patients who do not attend a clinic appointment?

What has the supply of the ARVs been like from the pharmacy?

Do you think the hospital’s HIV/AIDS programme is good at assessing whether someone is adhering or not?

What affect do the traditional healers have on patients?

Is there stigma associated with ARVs?
Appendix 4 - Map of Ugandan Districts

Adapted from: http://cgap.org/savings/Uganda_LargeMap.pdf
Retrieved on 7 December 2006.
Appendix 5 – Map of Kiwoko Hospital, Kikamulo

Adapted from: http://www.luwero.go.ug/overview/dist_map.htm
Retrieved on 7 December 2006.
Appendix 6 – CATTS Job Description

Your Job Description as a
Community Antiretroviral and Tuberculosis Treatment Supporter:

Visit your 10 clients every week

Check client’s medication and ARV treatment card

Teach the client how to take their medication correctly and how to tick the card after they have taken their pills

Check client’s appointment card

Remind the client of their appointment at the clinic

Remind the client of when you will come next week

Get to know the client’s problems

Be a counsellor

Advise about problems according to your training

Work as a team with central volunteers, the clinic, counselling aids, and all people in the departments

Know your limit and communicate that clearly

Record whatever you have seen when you visit each client

Bring the report for every client to the network meetings

Come to the Weekly Network meeting for your area each week

Discuss any difficult problems and find solutions together

Come to the Monthly Network Meeting every month

Use the network to help solve problems

Report on any abrupt journey a client takes, any bad side effects, or any problems immediately

If some clients need more attention, visit them as many times that week as needed

Source: Kiwoko Hospital adapted from Reach Out, Mbuya
Appendix 7 – Photographs from the Home Visits
Appendix 8 – Photographs from the Quarterly Workshop
Appendix 9 – ARV Treatment Card

<table>
<thead>
<tr>
<th>DATE OF NEXT VISIT</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

REMARKS:

CLIENT NO: ..............................................

NAME: ......................................................

ADDRESS: ..................................................

RX SUPPORTER: ..............................................

<table>
<thead>
<tr>
<th>DATE OF STARTING ARV THERAPY (___________ / __________ / __________)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Month Day 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31</td>
</tr>
</tbody>
</table>
Appendix 10 – CATTS Weekly Report Sheet

<table>
<thead>
<tr>
<th>Client Name</th>
<th>Medications:</th>
<th>Treatment Card:</th>
<th>Social Issues:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>[ ] taken correctly</td>
<td>[ ] marked correctly</td>
<td>[ ] not marked correctly: describe</td>
</tr>
<tr>
<td>Date of visit</td>
<td>[ ] not taken correctly: describe</td>
<td>[ ] not marked correctly: describe</td>
<td></td>
</tr>
<tr>
<td>Remarks:</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Client Name</th>
<th>Medications:</th>
<th>Treatment Card:</th>
<th>Social Issues:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>[ ] taken correctly</td>
<td>[ ] marked correctly</td>
<td>[ ] not marked correctly: describe</td>
</tr>
<tr>
<td>Date of visit</td>
<td>[ ] not taken correctly: describe</td>
<td>[ ] not marked correctly: describe</td>
<td></td>
</tr>
<tr>
<td>Remarks:</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Client Name</th>
<th>Medications:</th>
<th>Treatment Card:</th>
<th>Social Issues:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>[ ] taken correctly</td>
<td>[ ] marked correctly</td>
<td>[ ] not marked correctly: describe</td>
</tr>
<tr>
<td>Date of visit</td>
<td>[ ] not taken correctly: describe</td>
<td>[ ] not marked correctly: describe</td>
<td></td>
</tr>
<tr>
<td>Remarks:</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Client Name</th>
<th>Medications:</th>
<th>Treatment Card:</th>
<th>Social Issues:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>[ ] taken correctly</td>
<td>[ ] marked correctly</td>
<td>[ ] not marked correctly: describe</td>
</tr>
<tr>
<td>Date of visit</td>
<td>[ ] not taken correctly: describe</td>
<td>[ ] not marked correctly: describe</td>
<td></td>
</tr>
<tr>
<td>Remarks:</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Client Name</th>
<th>Medications:</th>
<th>Treatment Card:</th>
<th>Social Issues:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>[ ] taken correctly</td>
<td>[ ] marked correctly</td>
<td>[ ] not marked correctly: describe</td>
</tr>
<tr>
<td>Date of visit</td>
<td>[ ] not taken correctly: describe</td>
<td>[ ] not marked correctly: describe</td>
<td></td>
</tr>
<tr>
<td>Remarks:</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: Kiwoko Hospital adapted from Reach Out, Mbuya


**Bibliography**


