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**Reasons for non-adherence, treatment  
interruption and loss to follow-up in a  
decentralised antiretroviral treatment programme  
in rural Zimbabwe**

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Thesis submitted in fulfilment of the requirement for the award of the  
degree of Doctor of Public Health (DrPH)

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Funding contribution through a research fellowship by the Swiss  
National Science Foundation, Bern, Switzerland

6<sup>th</sup> October 2014

I, Thomas Gass, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.



/

## Abstract

By the end of 2012, Zimbabwe had enrolled more than half a million patients on free antiretroviral treatment (ART). Reviews of ART programmes in sub-Saharan Africa revealed that one third of the patients drop out of the programme during the first three years of treatment. I explored reasons for programme attrition in an NGO-supported ART programme in rural Zimbabwe.

In a mixed-methods design, I combined a retrospective cohort study among 8425 adult patients who initiated ART from 2005 to 2012, with a qualitative inquiry including 44 interviews, 8 focus group discussions with 78 participants, and participant observation during two months of field work.

Programme retention at three years was 75%. Tracing of patients lost to follow-up revealed that mortality at 12 months was 1.8 times higher than reported before tracing: corrected mortality was 11.5%, 18.8% and 21.3% after 12, 36 and 60 months. 574/1055 (54.4%) deaths occurred before the next ART appointment, 481/1055 (45.6%) after missing the appointment. Programme retention did not imply consistent adherence to ART: 1780/6291 (28.3%) retained patients temporarily interrupted ART at least once for more than seven days.

Qualitative data showed that patients temporarily interrupted ART for different reasons rooted in social, cultural and gender conflicts and related to mobility. ART restart was facilitated by social capital in family and kinship networks, decentralised access to ART and trusting patient-health worker relationships. Social isolation and discrimination of HIV-positive women by partner and in-laws, health workers blaming patients for missing an ART appointment and distance to the initiation site were the main reasons for prolonged and potentially fatal ART discontinuation.

Our findings suggest that ART re-engagement after interruption is key for long-term retention. Programmes can prevent attrition from ART by decentralising their services, supportive management by health workers, and early tracing of medically- and socially-vulnerable treatment interrupters.

# Table of contents

Abstract .....	3
Table of contents .....	4
List of figures .....	8
List of tables .....	9
Abbreviations.....	10
Acknowledgments.....	11
DrPH integrating statement.....	12
<b>1 Introduction.....</b>	<b>16</b>
<b>2 The study setting.....</b>	<b>19</b>
2.1 Zimbabwe, recovering from a series of crises.....	19
2.2 HIV/AIDS in Zimbabwe.....	20
2.3 Zaka and Bikita.....	21
<b>3 Literature review.....</b>	<b>25</b>
3.1 Review method and search strategy.....	25
3.2 Review of quantitative research.....	26
3.2.1 Retention, death and loss to follow-up on ART.....	27
3.2.2 Factors associated with retention and attrition.....	30
3.2.3 True outcomes of losses to follow-up after tracing.....	32
3.2.4 Treatment interruption.....	35
3.3 Review of qualitative research.....	37
3.3.1 Personal characteristics.....	42
3.3.2 Psychological factors.....	42
3.3.3 Clinical factors.....	43
3.3.4 Socio-economic factors.....	44
3.3.5 Health care system.....	45
3.3.6 Social capital.....	47
3.3.7 Cultural models of health, illness and treatment.....	48

<b>4</b>	<b>Aim, objectives and study design .....</b>	<b>51</b>
<b>5</b>	<b>The SMART programme .....</b>	<b>53</b>
5.1	Description of the programme interventions.....	53
5.1.1	The Zimbabwean ART programme.....	53
5.1.2	History and scope of the SMART programme.....	54
5.2	Patient tracing: A SMART pilot intervention .....	56
5.2.1	Design and aim of the tracing intervention .....	56
5.2.2	Operational procedures .....	57
5.2.3	Health worker cadres used for tracing .....	57
<b>6</b>	<b>Retention, loss to follow-up and mortality: quantitative findings .....</b>	<b>59</b>
6.1	Methodology.....	59
6.1.1	Design.....	59
6.1.2	Study population.....	59
6.1.3	Procedures .....	60
6.1.4	Statistical analysis .....	61
6.1.5	Definitions.....	61
6.1.6	Roles .....	63
6.1.7	Confidentiality.....	63
6.2	Results .....	64
6.2.1	Characteristics at ART initiation.....	64
6.2.2	Outcomes at last visit before tracing .....	65
6.2.3	Tracing results.....	65
6.2.4	Programme outcomes before and after tracing.....	67
6.2.5	Cohort analysis.....	70
6.2.6	Treatment interruption .....	71
6.2.7	Retention and deaths at different time points corrected after tracing.....	72
6.2.8	Characteristics of deaths .....	74
6.2.9	Characteristics of unreported deaths .....	77
6.2.10	Time between the missed appointment and death.....	78
6.3	Discussion of the quantitative findings .....	79

6.3.1	High retention on ART in spite of a socio-economic crisis.....	79
6.3.2	Tracing reveals high mortality on ART .....	81
6.3.3	Decentralised tracing .....	82
6.3.4	Treatment interruption a neglected threat to long-term retention.....	83
6.3.5	Risk factors for death.....	83
6.3.6	Death a consequence of ART discontinuation .....	84
6.3.7	Strengths and weaknesses.....	85
<b>7</b>	<b>Understanding ART interruption and restart: qualitative findings.....</b>	<b>88</b>
7.1	Conceptual framework.....	88
7.2	Methodology.....	91
7.2.1	Cluster sampling strategy .....	91
7.2.2	Data collection methods .....	93
7.2.3	Data analysis.....	96
7.2.4	Roles .....	97
7.3	Interrupting ART: Case characteristics and narratives .....	97
7.4	Analytical framework.....	105
7.5	Reasons for treatment interruption.....	109
7.5.1	Failed initiation .....	109
7.5.2	Stigma in marriage .....	111
7.5.3	Mobility .....	112
7.5.4	Religious authorities .....	115
7.6	Facilitators and barriers for ART restart after interruption .....	116
7.6.1	Health status .....	117
7.6.2	Social capital .....	118
7.6.3	Health system.....	122
7.7	Discussion: medical and social vulnerability after treatment interruption.....	130
7.7.1	ART interruption despite strong motivation to remain in care.....	134
7.7.2	Safety nets after interruption key for long-term retention.....	135
7.7.3	Kinship networks: a key source of social capital .....	137
7.7.4	The need for a supportive health system .....	138

7.7.5	Strengths and weaknesses.....	140
<b>8</b>	<b>Discussion and conclusions.....</b>	<b>143</b>
8.1	Discussion of main findings .....	143
8.1.1	Return after interruption key for improved retention .....	146
8.1.2	Mortality on ART: the need for early tracing .....	147
8.1.3	Improving retention over time .....	149
8.2	Strengths and limitations .....	150
8.2.1	Strengths .....	150
8.2.2	Limitations .....	152
8.3	Reflective commentary .....	153
8.4	Recommendations for programming and research .....	155
	<b>References .....</b>	<b>157</b>
	Appendix 1: Criteria to assess study quality.....	166
	Appendix 2: Ethical approval letters.....	167
	Appendix 3: SMART patient data base (screenshot).....	169
	Appendix 4: SMART patient tracing form .....	170
	Appendix 5: Participant Information Sheets & Informed Consent Forms.....	171
	Appendix 6: Topic Guides.....	179
	Appendix 7: Narratives of patients who interrupted ART .....	197

## List of figures

Figure 1-1: History of the national ART programme, SMART and my role.....	18
Figure 2-1: HIV prevalence on the African continent 2009.....	21
Figure 2-2: The provinces of Zimbabwe .....	22
Figure 2-3: Health facilities in Zaka district .....	23
Figure 2-4: Health facilities in Bikita district.....	24
Figure 3-1: Results of the literature search.....	26
Figure 3-2: Death and loss to follow-up according to duration of ART .....	30
Figure 3-3: Estimated survival from a regression model based on data from 34 cohorts in sub-Saharan Africa, corrected for mortality among patients lost to follow-up compared to proportions of 0% and 100% mortality among patients lost to follow-up.....	33
Figure 3-4: Rates of disengagement from care, stratified by calendar year of ART initiation.....	36
Figure 4-1: The mixed-methods research process.....	52
Figure 5-1: Number of enrolled ART patients 2005-2011 in the programme SMART in Zaka and Bikita district (cumulative).....	56
Figure 6-1: Flow chart on the study population.....	60
Figure 6-2: Definitions of retention, interruption and loss to follow-up on the timeline.....	63
Figure 6-3: Flowchart of tracing outcomes.....	67
Figure 6-4: Reasons for attrition before and after tracing.....	69
Figure 6-5: Retention rates of seven annual cohorts in Zaka and Bikita over time....	71
Figure 6-6: Retention and reasons for attrition by time after ART start .....	73
Figure 6-7: Kaplan-Meier survival estimates before and after tracing .....	74
Figure 6-8: Number of patients by time between missed appointment and death .....	79
Figure 7-1: Conceptual framework of the study .....	90
Figure 7-2: Mapping of health facilities and study participants.....	92
Figure 7-3: Frequency of codes linked to interruption of ART and restart of ART, measured as number of concurrent coding references.....	108
Figure 7-4: Reasons for ART interruption .....	109
Figure 7-5: Reasons for therapy interruption and facilitators and barriers to restart on the continuum of ART.....	117
Figure 7-6: Flow chart on facilitators of and barriers to ART restart after interruption .....	136

## List of tables

Table 3-1:	Studies on the magnitude of retention, death and loss to follow-up in ART programs in sub-Saharan Africa .....	27
Table 3-2:	Characteristics of the 29 reviewed qualitative studies.....	38
Table 6-1:	Socio-demographic and clinical characteristics of study participants at ART initiation.....	64
Table 6-2:	Health worker cadres used for tracing by site .....	66
Table 6-3:	Programme outcomes before and after tracing.....	69
Table 6-4:	Selected baseline characteristics of patients by year of first visit.....	70
Table 6-5:	Retention rates by annual cohorts at different time points .....	70
Table 6-6:	Retained ART patients who had at least one treatment interruption of more than 7 days.....	72
Table 6-7:	Programme outcomes at different time points, corrected after tracing ....	72
Table 6-8:	Characteristics of patients lost to follow-up and deaths and risk ratios for death at 24 months, corrected after tracing.....	75
Table 6-9:	Risk ratios for loss to follow-up at 24 months among those not known to have died, .....	76
Table 6-10:	Comparison between reported deaths and unreported deaths .....	78
Table 7-1:	Participants of the focus group discussions.....	95
Table 7-2:	Characteristics of the sixteen study participants who discontinued ART .....	100
Table 7-3:	The analytic framework .....	105
Table 7-4:	Framework matrix on reasons for ART interruption and facilitators and barriers to ART restart in sixteen cases .....	131
Table 8-1:	Mixed-methods integration matrix.....	144

## Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Treatment
BHASO	Batanai HIV/AIDS Support Organisation
CASP	Critical Appraisal Skills Programme
CD4	Cluster of Differentiation 4
CHASA	Community HIV/AIDS Support Agent
CI	Confidence interval
DrPH	Doctor of Public Health
EWI	Early warning indicator
GoZ	Government of Zimbabwe
HIV	Human Immunodeficiency Virus
leDEA	International epidemiologic Databases to Evaluate AIDS
IQR	Interquartile Range
IRIS	Immune Reconstitution Inflammatory Syndrome
LFU	Loss to follow-up
LSHTM	London School of Hygiene and Tropical Medicine
MOHCW	Ministry of Health and Child Welfare
MRCZ	Medical Research Council Zimbabwe
NGO	Non-Governmental Organisation
RR	Risk Ratio
SMART	SolidarMed Antiretroviral Treatment Programme
UK	United Kingdom
UNAIDS	United Nations Programme on HIV/AIDS
USA	United States of America
US\$	US Dollar
WHO	World Health Organization

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## DrPH integrating statement

In September 2008, I attended the symposium “The Future of Primary Health Care: Alma Ata 30 Years On” of the London School of Hygiene and Tropical Medicine (LSHTM). This conference was a key moment in my professional career in two ways. Firstly, in my job as project manager for the Swiss organisation for international health, SolidarMed, I had experienced the pros and cons of donor-funded, vertical HIV/AIDS programmes in Tanzania, where I worked for two years. The LSHTM symposium, accompanied by a series of articles on Primary Health Care in *The Lancet*, was an eye-opener to me because it advocated for renewed efforts to strengthen primary health care services through a more horizontal than vertical approach – a statement that made a lot of sense to me from what I have seen in rural Tanzania. The symposium was a key moment to me in a second way: between two sessions, I picked up a flyer on the Doctor of Public Health (DrPH) programme at the LSHTM. As I wanted to stay a practitioner in international development, a PhD had not been an option. A professional doctorate, however, was different. On my way home from the symposium, I felt reassured that I wanted to develop my public health career, and that the DrPH programme would be my choice.

### DrPH programme core modules

During my first two years at the LSHTM, I attended the two core modules Leadership, Management and Personal Development (LMPD) and Evidence-Based Public Health Policy (EBPHP). As I was about to re-orient my professional career, the LMPD core module was an excellent opportunity to reflect on my professional strengths and weaknesses, to acquire concepts and skills on management and leadership, and to develop a career plan. I was lucky to be part of an enthusiastic and inspiring bunch of class mates. I used our three-day retreat to reflect my personal development and to relate my psychometric profile to the potential tasks in my future career. In the LMPD module, I submitted three assignments: in an essay “Change in SolidarMed 2007-2010: from authoritative leadership to recipe management”, I used change management concepts to analyse a process my organisation had recently gone through under a new leadership. The second assignment was a reflective commentary on my profile as “introverted thinker” (Myers-Briggs type indicator INTJ). The third assignment was an enjoyable exercise to establish a personal development plan. After ten years of job experience in health projects at micro level, I had developed a critical view on the rationale and effectiveness of development interventions. I became more and more

interested in the evidence-base of health policy and programming, and linked to it, in the domain of implementation research.

EBPHP, the second core module, equipped me with some essential concepts and methods I would need in any future position as public health programme manager or policy maker. Our first assignment was a systematic literature review to find the best available evidence on the effectiveness of health warnings on tobacco products. The assignment was a learning experience in two respects: firstly, it was an opportunity to familiarise myself and critically reflect the theoretical assumptions of health promotion campaigns. I find tobacco control an excellent example to illustrate how ideational paradigms rather than scientific evidence can influence health policy. Even though I found no evidence on the impact of graphic warnings on successful smoke cessation, this measure has in the meantime been introduced in many countries – I guess mainly due to the common-sense assumption that people’s behaviour is determined by their knowledge, beliefs and attitudes. In a second assignment related to the systematic review, I applied the tool of a policy brief to translate the evidence into recommendations to the Ministry of Health in India. I learnt that scientific evidence does not “automatically” inform health policy and programming. Putting research into action requires an understanding of the policy process and a clear strategy on how to influence the process. Designing such an influential strategy for a fictional health organisation in Tanzania was our third EBPHP assignment. I chose the case of community case management of pneumonia in children under five years. The aim was to design a strategy how to bring this intervention on the public health agenda in Tanzania, given the scientific evidence that it could save the lives of 45’000 children every year. I conducted a stakeholder analysis, a tool we studied during the EBPHP module and which I think is inevitable for any strategy development.

### **Organisational and policy analysis at the Lighthouse, Malawi**

Through the core modules during the first two years of the DrPH programme, I had agreed with my supervisor Professor Alison Grant to conduct the research project on loss to follow-up in an antiretroviral treatment (ART) programme in Zimbabwe. With my previous employer, I had been involved in developing and managing an ART support programme in Mozambique, Lesotho, Tanzania and Zimbabwe. Growing numbers of patient drop-outs by national ART programmes and NGOs made SolidarMed suggest I could explore the underlying reasons why patients discontinue ART. The Ministry of Health and Child Welfare in Zimbabwe was interested to host the study. In the role of a consultant, I advised SolidarMed and the Ministry on the design of the patient tracing scheme which the parties implemented as from 2011. The data collected through

tracing were later analysed by our study. Yet, before launching the research project, I undertook the organisational and policy analysis (OPA) project of the DrPH programme. Given my interest in operational research under “real world” conditions, my supervisor suggested I conduct my OPA project at the Lighthouse Trust in Lilongwe, Malawi, a proposal which the organisation accepted. The Lighthouse is a NGO running a public HIV/AIDS clinic with a large patient cohort on ART. I spent three months in the monitoring and evaluation department of the Lighthouse clinic to study how the organisation develops innovative services and interventions, conducts operational research, and informs HIV/AIDS policy and programming. I found that a motivating organisational culture and a unique electronic patient data management system – based on real-time data entry at touch-screen terminals throughout the entire clinic pathway – were key success factors for innovation and operational research at the Lighthouse. I identified 25 operational studies Lighthouse conducted between 2005 and 2010, amongst them studies on integrated treatment of HIV/AIDS and tuberculosis and on prevention of vertical HIV-transmission that both influenced policy and programming in Malawi and beyond. Inspired by the work of my OPA co-supervisor, Professor Nigel Crisp, on the spread of healthcare improvements, I reflected the Lighthouse experience in my OPA report.

### **Implementation research in Zimbabwe**

A key lesson of my OPA project was that scaling-up of successful health care innovations not only requires sound scientific evidence, but, even more importantly, collaboration between programme managers, policy makers and researchers working together throughout the entire process of developing, researching and scaling-up innovative health services. My experience in the study project presented in this thesis demonstrated potential gains of implementation research through the research *process*. The stakeholders confirmed that the research process impacted the quality of the ART programme in Zaka and Bikita, and facilitated the dialogue on how to improve the programme between health workers, public health officials at district and provincial level, policy makers at national level, and NGO project managers. Our quantitative research relied entirely on programme data. Data quality was a central aspect of the collaboration between the mentioned stakeholders. In the course of the research project, the study team raised questions with regard to medical recording practices and data management procedures that were discussed and addressed between the partners. The tracing intervention led to a major cleaning exercise of the entire cohort data, and to a re-organisation of paper-based and electronic recording procedures. The study also facilitated utilisation of the data by the health facilities and the district

authorities for monitoring purposes. The study team trained the hospital and district data managers in how to run queries and how to prepare reports, and the health officials used the data for monthly and quarterly feedback discussions with the ART nurses throughout the district. We also facilitated online courses in Good Clinical Practice with programme staff and selected personnel of the ART clinics to develop their scientific skills and qualifications for future operational research projects.

After completion of the DrPH programme, I will be working as Head of Policy Department for the Swiss Red Cross (SRC). I am confident that thanks to the DrPH programme, I will be in a good position to advocate for evidence-based programming and implementation research throughout the international health programme of the SRC.

# 1 Introduction

I first visited Zimbabwe in 2005. In my role as coordinator of the multi-country antiretroviral treatment (ART) support programme of the Swiss non-governmental organisation (NGO) SolidarMed – the SMART programme – I spent two weeks at Musiso Mission Hospital in Zaka district. The hospital wards were crowded with patients in an advanced stage of the HIV disease. Pain management was the only thing the hospital staff could do for these patients, but morphine was regularly out of stock. Nurses said it had been utterly frustrating to see people dying in their hands having nothing to offer but prayers. Why test for HIV if no treatment was available? The announcement that an ART clinic would be established soon was a motivational boost to Musiso's health workers, and everybody participated in the preparation of the programme. During my visit, I helped establish SMART's first yearly action plan and budget. The support package included physical expansion of the hospital facility to accommodate an outpatient HIV/AIDS clinic, provision of laboratory equipment and reagents, training of hospital personnel in HIV medicine, and establishing an electronic database for programme monitoring. Fixed-dose combination ART drugs were provided free of charge by the Ministry of Health and Child Welfare (MOHCW) if the doctor drove to Harare to collect them at the national pharmacy. In April 2005, the first patients were initiated on ART at Musiso hospital. Consultations were conducted by the Swiss doctors. By the end of the year, around hundred patients had been enrolled. However, out there in the district, thousands of people were still dying of AIDS with no access to lifesaving ART. This was the picture not only in Zimbabwe, but across sub-Saharan Africa.

Since 2005, the response to the HIV/AIDS pandemic has been dramatic. Thanks to an unprecedented effort of national ART programmes and global funding initiatives, out of 25.2 million people living with HIV/AIDS in the sub-Saharan region, 7.5 million were receiving free ART by 2012 (UNAIDS, 2013). Yet, the burden of HIV/AIDS to communities and health systems remains enormous: in 2012, 13.7 million people living with HIV in sub-Saharan Africa – representing 65% of those in need – did not have access to ART, and 1.2 million died of AIDS related causes (*ibid.*).

As more and more people were enrolled on life-long ART, retention became a growing concern of policy makers and programme managers. Failed retention on ART can lead to treatment failure and can cause resistance to ART drugs (Aghokeng, 2014). In 2011, the United Nations declared retention at 12 months on ART a core indicator for the

effectiveness of national ART programmes (UNAIDS, 2011b) and an early warning indicator for HIV drug resistance (WHO, 2012).

Seven years after the launch of SMART in Zimbabwe, I returned to Zaka and Bikita in April 2012 to conduct this study. Since 2005, the SMART programme in Zimbabwe had enrolled more than 9,000 patients. In 2010 – I had left SolidarMed and was in my second year of the DrPH programme – I agreed with SolidarMed to conduct my DrPH research project as an operational study in the SMART programme in Zimbabwe. SolidarMed was just about to embark on a major exercise to trace patients who had been recorded as lost to follow-up. It was arranged that I would analyse the tracing data, train the programme personnel in research methods and Good Clinical Practice, and help local data managers run queries and establish reports for the purpose of patient and programme monitoring. In turn, I benefitted from the SolidarMed infrastructure, logistics and partnerships in Zaka and Bikita. After an extended period of preparatory work and obtaining ethical clearance, I formed a study team and commenced the field research in April 2012. The study team comprised the SMART programme manager (a Canadian expatriate with an MSc in international health) as co-investigator and her data managers, three Zimbabwean scientific collaborators, and two community facilitators of the local NGO Batanai HIV/AIDS Support Organisation (BHASO). The research protocol defined the division of roles between SMART and the study, as described in detail in the chapters 5 to 7: patient and tracing data were collected by SMART and analysed by the study, whilst the qualitative study component was conducted exclusively by the study team. Overall, field work lasted four months, including stakeholder workshops towards the end in both districts where preliminary study findings were disseminated.

Figure 1-1 summarizes the evolution of the Zimbabwean ART programme, the SMART programme and my changing role as SMART programme coordinator and DrPH research degree student between 2005 and 2012.

**Figure 1-1: History of the national ART programme, SMART and my role**

	Milestones	2004	2005	2006	2007	2008	2009	2010	2011	2012
<b>National ART programme</b>	Launch of the national ART programme	★								
	Decentralisation of ART follow-up to rural health centres					★				
	519,000 patients on ART at 141 initiation and 449 follow-up sites									★
<b>SMART</b>	Launch of SMART at the hospitals Musiso and Silveira		★							
	Decentralisation of SMART in Zaka and Bikita district					★				
	Launch of Community HIV/AIDS Support Agents (CHASA programme)						★			
	Launch of the Patient Tracing Scheme								★	
	9,500 patient enrolled at 2 initiation and 20 follow-up sites									★
<b>My role</b>	SMART programme coordinator (based in Switzerland)		★							
	DrPH programme at LSHTM						★			
	Research project in collaboration with SolidarMed and the Ministry of Health									★

The thesis is structured as follows: chapter 2 gives general information on Zimbabwe and the study setting Zaka and Bikita. A review of literature on quantitative and qualitative research is presented in chapter 3, including the most relevant and latest studies on retention, loss to follow-up and treatment interruption. After defining the aim and objectives and explaining the mixed-methods design in chapter 4, the SMART programme is described in chapter 5, including the patient-tracing scheme. Chapters 6 and 7 present the findings of the quantitative and qualitative study components, each including sections on methodology, results, and discussion. In the final chapter 8, the quantitative and qualitative findings are integrated and discussed.

## 2 The study setting

This chapter gives an outline on the geographical and demographic setting where the study was conducted. 2.1 presents general facts and figures on Zimbabwe, section 2.2 gives an introduction on HIV/AIDS in the country, and section 2.3 provides information and maps on the study area.

### 2.1 Zimbabwe, recovering from a series of crises

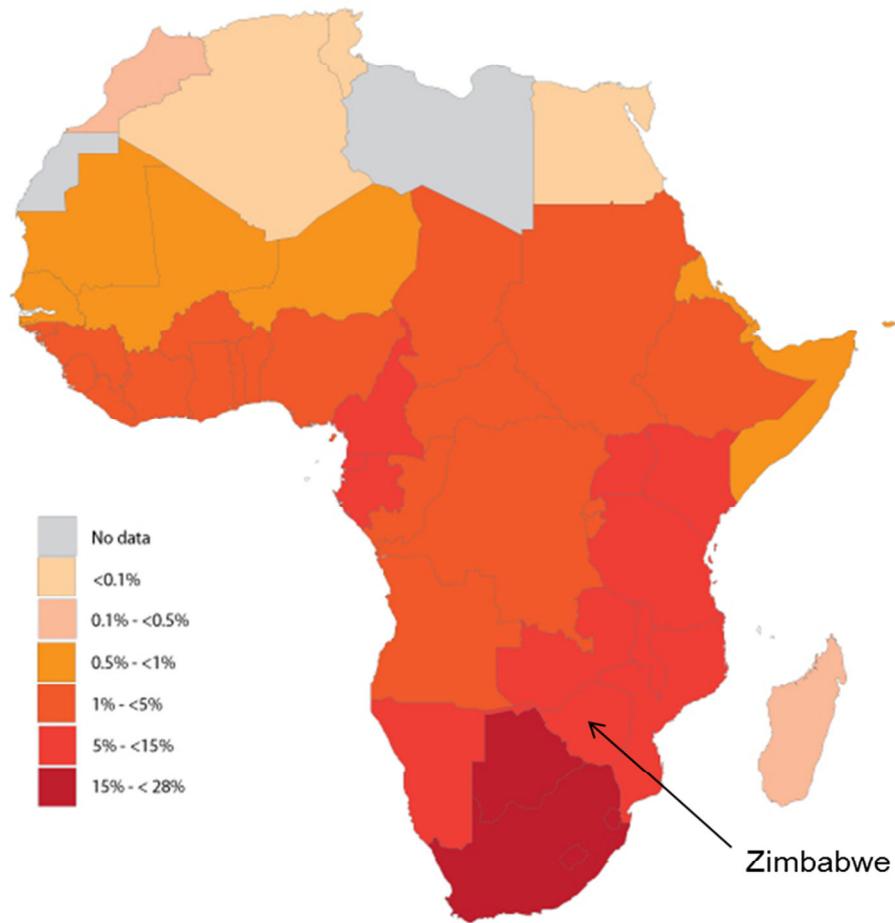
Zimbabwe is a land-locked country in Southern Africa with a population of 13 million, of whom 61% live in rural areas (GoZ, 2012a). The population of Zimbabwe has gone through a series of economic, political and social crises since the beginning of the new millennium. The country's economy has declined dramatically, with a fall of the *per capita* gross domestic product from US\$574 in 1998 to US\$284 in 2008 (GoZ, 2012c). In 2008, the country drifted into a humanitarian calamity characterised by violence, hyperinflation, a major cholera outbreak, and a temporary breakdown of public services, including health care (Barclay, 2010). During the years of crisis, to work outside the country became an important livelihood strategy and source of income for many Zimbabweans. Between 2000 and the peak of the crisis in 2008, it was estimated that one to five million Zimbabweans migrated to South Africa, and that Zimbabwean households received annual median remittances of US\$165 in cash and goods (Polzer, 2008). In spite of a moderate socio-economic and political recovery since the formation of the Government of National Unity in 2009, Zimbabwe remains one of the poorest countries in the world, ranking 172<sup>nd</sup> out of 187 countries on the scale of the Human Development Index (UNDP, 2013). In 2012, 72% of the population lived below the total consumption poverty line, 23% below the food poverty line, and 19% of the households were considered food-insecure (GoZ, 2012c). The socio-economic crisis counteracted the government's development efforts. Zimbabwe is off-track with respect to the health related Millennium Development Goals (ibid.): In 2011, the mortality rate in children under the age of five was 84 per 1000 live births, the 2015 target being 34/1000. Most frequent causes of death were HIV/AIDS, neonatal complications, pneumonia, and diarrhoea. Maternal mortality has increased from 612 in 2006 to 960 deaths per 100,000 live births in 2011, which is one of the highest worldwide.

## 2.2 HIV/AIDS in Zimbabwe

The socio-economic decline Zimbabwe has undergone since the late 1990s has been aggravated by one of the harshest HIV/AIDS epidemics worldwide. There are reports of a devastating adult HIV prevalence of 29% in 1997 and 24% in 2001 (Halperin, 2011). Besides the natural dynamic of the epidemic, behavioural changes such as a reduction in multiple sexual partners have contributed to a slight decrease in HIV incidence and prevalence subsequently (ibid.). In 2012, UNAIDS reported an adult prevalence of 14.7% in Zimbabwe (UNAIDS, 2013b). Yet, with 1.4 million people living with HIV/AIDS, Zimbabwe remains one of the countries most affected by the epidemic on the African continent, as shown in figure 2-1. Given the fact that transmission is ongoing and AIDS related deaths have diminished thanks to ART, HIV prevalence is on the rise again. In 2012, 189 Zimbabweans became infected with HIV and 107 died with advanced HIV disease every day (ibid.). Closely linked with the HIV epidemic is Zimbabwe's high burden of tuberculosis, representing the country's leading cause of mortality and morbidity (GoZ, 2012c). Although HIV prevalence among people with tuberculosis was 70%, only 18% were on ART in 2012 (WHO, 2013b).

Given these challenging circumstances, the roll-out of ART for people living with HIV/AIDS through the national programme has been a true success story. In 2012, 519,000 HIV-positive adults and children received ART (GoZ, 2012c), representing 47% of the projected number of people eligible (ibid.).

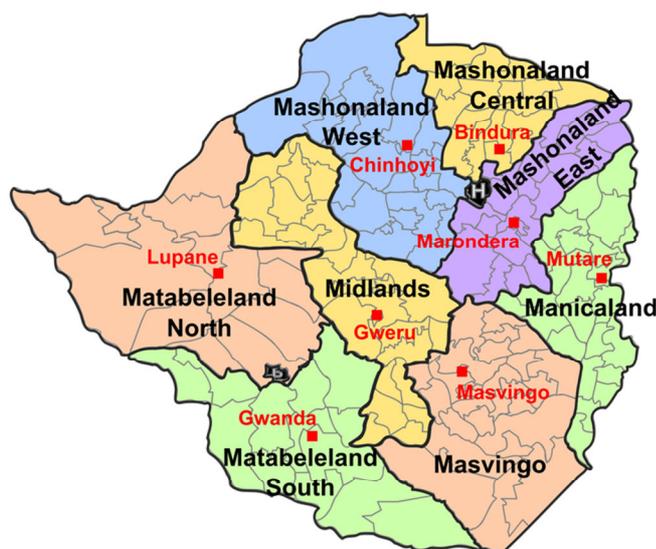
**Figure 2-1:** HIV prevalence on the African continent 2009 (WHO, 2011)



### **2.3 Zaka and Bikita**

The study was conducted in the two rural districts of Zaka and Bikita in the province of Masvingo in the Southeast of Zimbabwe, shown in figure 2-2. The 2012 population was 181,000 in Zaka and 162,000 in Bikita (GoZ, 2012a).

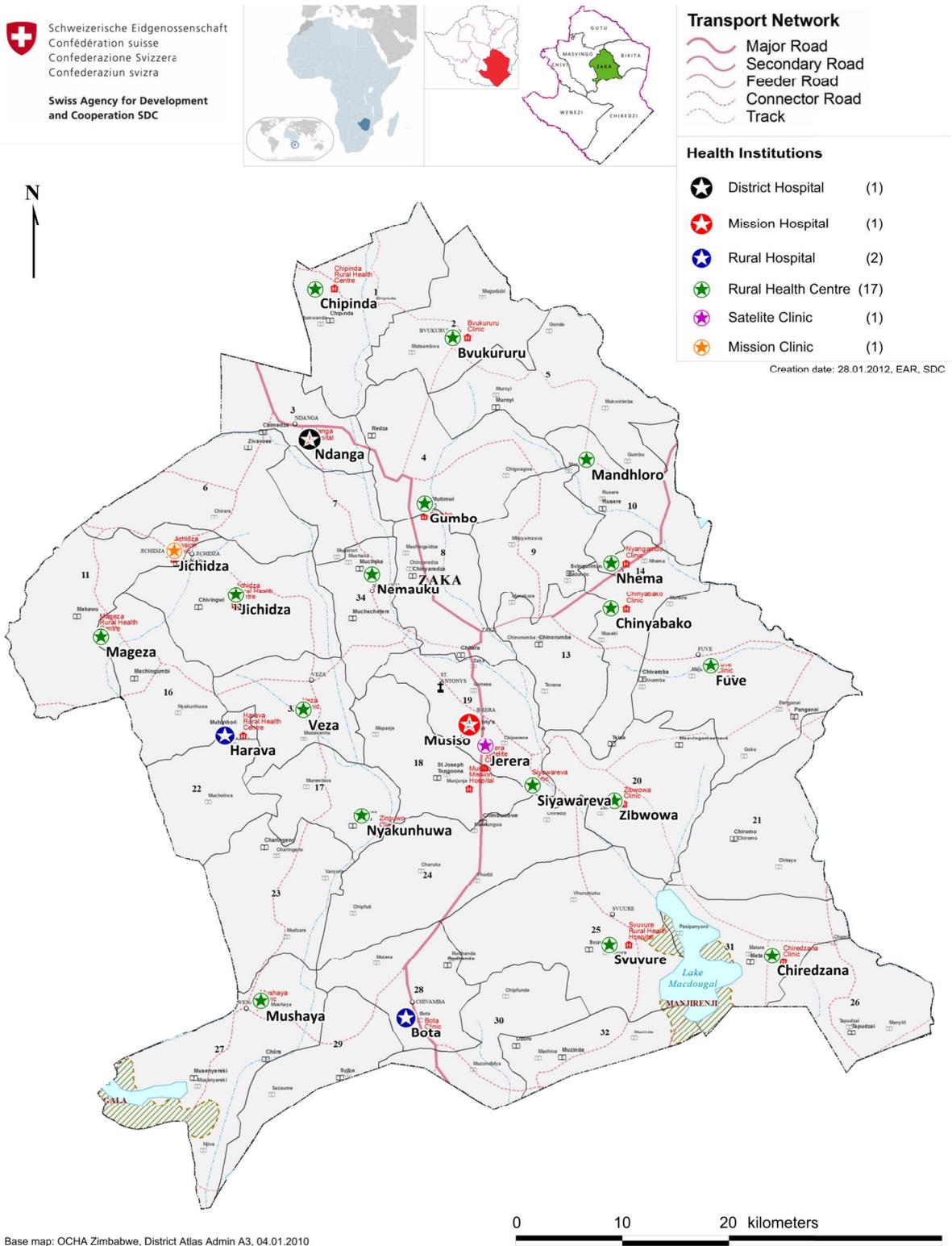
**Figure 2-2:** The provinces of Zimbabwe (source: Wikimedia Commons)



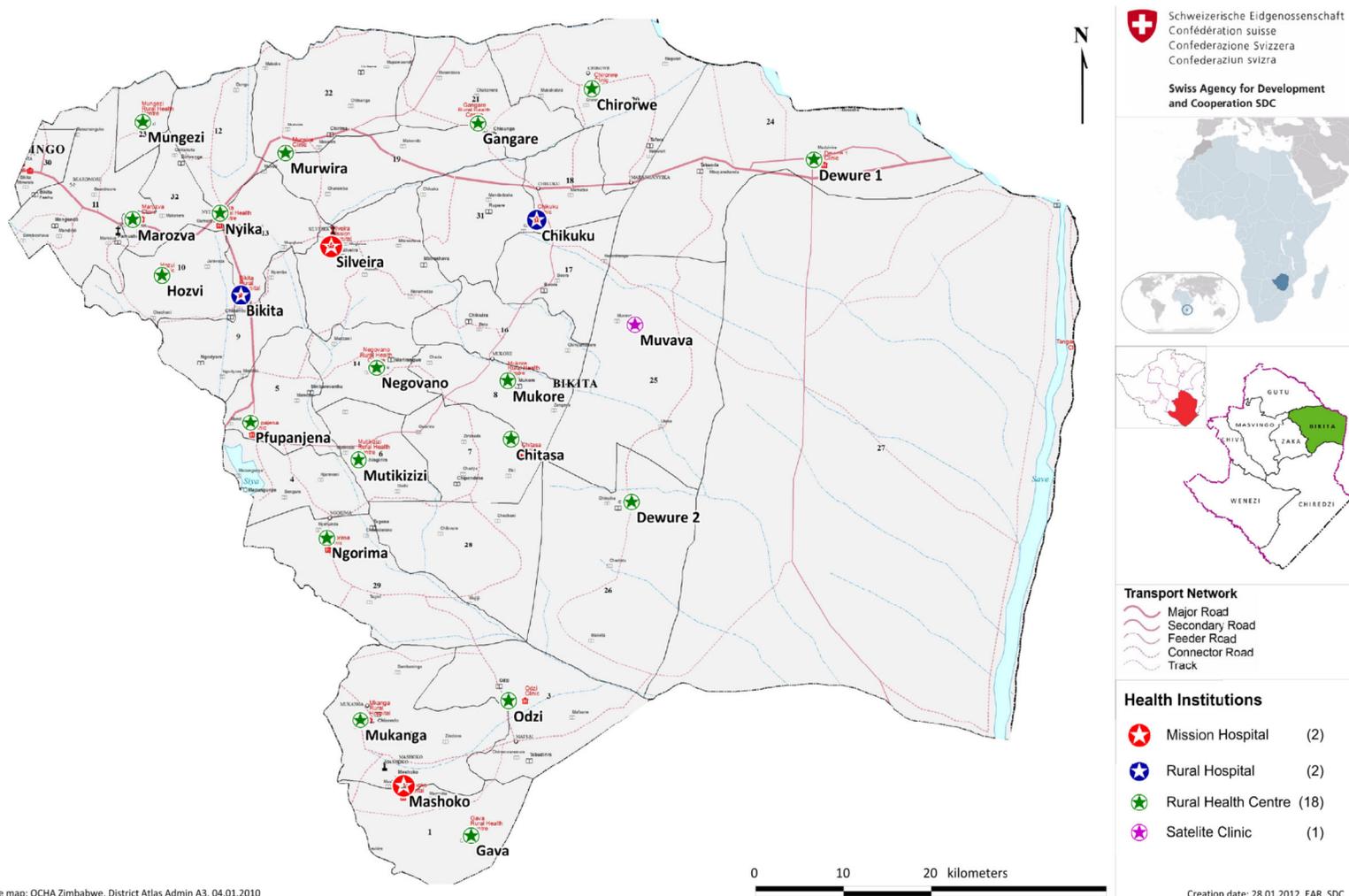
The area is semi-arid and mountainous with poor soils and seasonal rainfall. The large majority of people are subsistence farmers. Outside of the two semi-urban centres Jerera and Nyika, people live as extended families in so-called homesteads, scattered across the districts. Many households in Zaka and Bikita rely on the support by family members working in the big towns and in South Africa. Christianity is the predominant religion in the area, mostly of the Catholic Church. However, a growing number of Zimbabweans are members of an Apostolic Church.

As everywhere in Zimbabwe, health care services in Zaka and Bikita are organised in a district referral system, comprising health facilities at three levels: rural health centres, rural hospitals, and district referral hospitals. In Zaka, there are two referral hospitals, two rural hospitals and nineteen rural health centres, as shown in figure 2-3. Musiso Mission Hospital is the biggest hospital in Zaka, run by the Masvingo Catholic Diocese. In Bikita, there are two referral hospitals, two rural hospitals and 21 rural health centres, as shown in figure 2-4. The referral hospital in Silveira also belongs to the Catholic Diocese. Health services are supervised by the authorities of the MOHCW. Under the Provincial Medical Director, there are District Health Executives, comprising the District Medical Officer and his team. The role of the health facilities and other stakeholders in the provision of ART is described in detail in chapter 5 on the SMART programme.

**Figure 2-3: Health facilities in Zaka district (source: Swiss Agency for Development and Cooperation)**



**Figure 2-4: Health facilities in Bikita district (source: Swiss Agency for Development and Cooperation)**



Base map: OCHA Zimbabwe, District Atlas Admin A3, 04.01.2010

### **3 Literature review**

This chapter gives an overview of the current literature on ART retention from quantitative epidemiological and qualitative social science research. Section 3.1 describes the methodology of the literature review; quantitative findings are presented in section 3.2, qualitative literature in section 3.3.

#### **3.1 Review method and search strategy**

I conducted the literature search in the databases CINAHL Plus, Global Health, MEDLINE, Africa-Wide Information, and Web of Science, last updated on 15 August 2013. Search terms were antiretroviral treatment, retention, loss to follow-up, adherence, patient tracing, qualitative research, anthropology, interview, focus group discussion, sub-Saharan Africa (and synonyms).

The World Health Organization (WHO) defined adherence as “the extent to which a person’s behaviour – taking medication, following a diet, and/or executing lifestyle changes – corresponds with agreed recommendations from a health care provider” (WHO, 2003). There is a vast body of literature on medication adherence in ART, looking at the behavioural, cognitive, affective, biological and structural dimensions of patients’ pill-taking behaviour (Baernighausen, 2011). Since the present study investigated adherence to follow-up appointments with a focus on long-term programme retention, literature on medication adherence was excluded from the review.

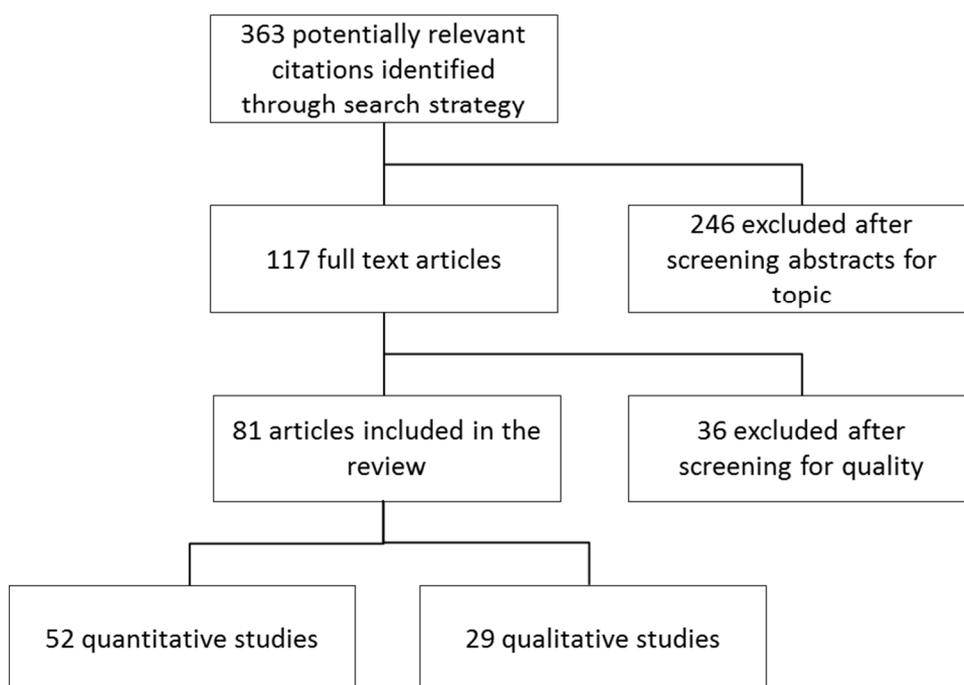
Whilst adherence to ART describes therapy practice at individual level, ART retention is a programme level concept, defined as “proportion of ART patients who are still alive and on ART at a given time after initiating treatment” (UNAIDS, 2011b).

Figure 3-1 shows the results of the literature search. Based on the above stated inclusion criteria, 363 potentially relevant citations were identified. I excluded articles if they focused on the following topics:

- medication adherence (as opposed to appointment adherence),
- the pre-ART phase,
- antiretroviral prevention of mother-to-child transmission,
- paediatric ART, and
- ART in conflict zones.

After excluding for topic, I undertook full-text screening of 117 articles and excluded 36 studies due to poor quality (see quality criteria in appendix 1). After excluding for quality, I reviewed 52 quantitative studies (including 7 reviews) and 29 qualitative studies (including 2 reviews).

**Figure 3-1:** Results of the literature search



### 3.2 Review of quantitative research

Responding to the concerns about programme losses and the risk of drug resistance development, a large number of retention studies have been conducted in recent years. I reviewed the quantitative literature relevant to the following questions:

- what is the magnitude of retention, death and loss to follow-up in sub-Saharan Africa at different ART time points?
- Which factors are associated with retention, loss to follow-up and death?
- What is known about the real outcomes of patients classified as lost to follow-up?
- What is the magnitude and length of temporary ART treatment interruptions, and which factors are associated with interruption and restart?

### 3.2.1 Retention, death and loss to follow-up on ART

There are five large studies available on ART retention in sub-Saharan Africa, shown in table 3-1: two cohort studies from South Africa, Cornell (2010) and Fatti (2010); a meta-analysis of 39 cohorts in sub-Saharan Africa (Fox and Rosen, 2010); a review of national ART data reported to WHO (Tassie, 2010); and a cohort study of the national ART programme of Malawi (Weigel, 2012). Retention at 12, 24, and 36 months, defined as proportion of enrolled ART patients who were neither classified as dead nor lost to follow-up after excluding transfers to another clinic, ranged between 75-80%, 67-76%, and 64-72% respectively. The cited studies defined loss to follow-up as a category of patients who missed their scheduled ART consultation for a defined period of time, but were neither reported dead nor transferred out to another ART clinic. Across the five studies, the threshold for loss to follow-up ranged from 60 days to six months. The WHO and most national ART programs define patients lost to follow-up if they are not seen for more than 90 days after a scheduled appointment (WHO, 2010).

**Table 3-1:** Studies on the magnitude of retention, death and loss to follow-up in ART programs in sub-Saharan Africa

Study	Context (year of study)	Design	Population	Retention	Attrition causes
Cornell 2010	8 public sector ART programs in South Africa (2008)	Retrospective cohort analysis of routine data LFU definition: 6 months after last contact	44,177 ART patients	12 months: 80% 24 months: 71% 36 months: 64%	At 12 months: Death: 6.6% LFU: 14.4%
Fox & Rosen 2010	39 cohorts of government (53%) and NGO (41%) facilities in SSA (2009)	Systematic review and meta-analysis; pooled estimates LFU definition: ranging from 30 days to 6 months after missed appointment	226,307 ART patients	6 months: 86% 12 months: 80% 24 months: 76% 36 months: 72%	Total: Death: 9.1% LFU: 13.0%
Tassie 2010	national programmes in 13 countries in sub-Saharan Africa (2008)	Aggregation of national cohort data reported to the WHO LFU definition: 90 days after missed appointment	ART patients: at 12 mts: 144,038 at 24 mts: 39,017 at 36 mts: 12,523 at 48 mts: 2,973	12 months: 75% 24 months: 67% 36 months: 66% 48 months: 67%	-
Fatti 2010	59 NGO supported, public facilities in 4 Provinces of South Africa (2008)	Retrospective cohort analysis LFU definition: 90 days after missed appointment	29,203 ART patients	24 months: 76%	At 24 months: Death: 7.4% LFU: 12%

Weigel 2012	148 public sector clinics in Malawi (2008)	Cohort study on routine data LFU definition: 60 days after missed appointment	117,945	12 months: 78%	At 12 months: Death: 12.2% LFU: 10%
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ART=Antiretroviral treatment; SSA=Sub Saharan Africa; LFU=lost to follow-up

The cohort studies of Cornell (2010) and Tassie (2010) reported the lowest retention proportions at 24 months, namely 71% in South Africa and 67% in 13 countries of sub-Saharan Africa. The cohort study by Fatti (2010) and the meta-analysis by Fox and Rosen (2010) found 76% retained at the same time point. A comparison of the ART programme settings shows that the first two studies used routine data from government programmes that were compiled in standardized data management systems using consistent definitions of treatment endpoints, such as loss to follow-up. In contrast, ART provision in the latter two studies was supported by research projects or NGOs, and the meta-analysis included mainly urban cohorts and relied on published data only, both factors limiting generalizability. The data analysed by Tassie (2010) are as inconsistent as the national cohort analysis schemes across the reviewed countries. Moreover, this study did not include data from South Africa, the largest ART programme worldwide. A major limitation of the cited large-scale studies is that ART programme outcomes have grown and outcomes changed over time. As the reviewed studies were conducted in 2008 and 2009, their findings do not reflect the most recent trends. Cornell (2010) reported a continuously deteriorating 12-months retention between 2003 (90%) and 2007 (72%), mainly due to increasing losses to follow-up. According to the authors, two reasons contributed to the decline: Firstly, ART programmes expanded and patient numbers increased hugely during the study period, overwhelming scarce health personnel and affecting the quality of ART follow-up and clinical care. Secondly, the authors attribute a proportion of the losses to care to erroneous recording systems. Findings from more recent studies are inconsistent: in their cohort study on 1794 ART patients in South Africa, Fox (2012) reported an increase in retention at 12 months from 58% in 2007 to 71% in 2010. In contrast, in their study among 4674 ART patients in South Africa, Mutevedzi (2013) found that risk of losses to follow-up adjusted for mortality was more than twice as high in patients enrolled 2010-2011 as those enrolled 2004-2006. There are no large-scale studies available on temporal changes of retention since the WHO revised the ART guidelines in 2010, recommending earlier ART initiation for people living with HIV with a CD4 cell count above 350. Given that a low CD4 cell count and an advanced clinical stage of the disease at baseline are key risks factors for mortality on ART (Lawn, 2008), one would expect improved ART retention since 2010.

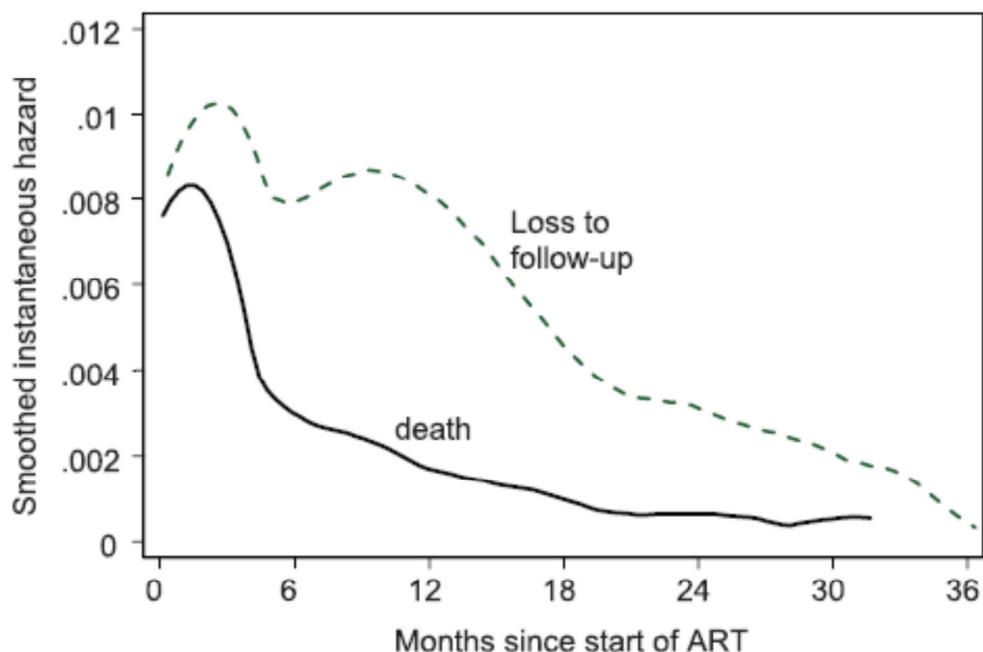
In summary, there is robust evidence that attrition is highest during the first year of treatment, and that more than a third of all enrolled ART patients are no longer in care after three years. There is, however, no clear evidence available on the trend in ART retention since 2010.

Only two retention studies were found from Zimbabwe, both from multi-country programmes, comparing outcomes of the Zimbabwe sites with other countries. The Zimbabwean sites reported excellent retention rates. Rasschaert (2012) compared retention rates of two ART programmes supported by the NGO Médecins sans Frontières: in the Zimbabwean site, retention at 24 months was 80.1%, compared with 75.8% in the Malawian site. Similar findings were reported by a comparative study of ART programmes supported by the Swiss NGO SolidarMed (Wandeler, 2012): retention at 3 years was 75.1% at the Zimbabwean site, whilst similarly supported sites in Lesotho and Mozambique reported retention rates of 55.4% and 51.6% respectively.

The proportion of deaths contributing to attrition was 31% (measured at 12 months) in Cornell (2010), 38% (measured at 24 months) in Fatti (2010), 41% (of the total) in Fox and Rosen (2010), and 55% (at 12 months) in Weigel (2012). The reasons for the relatively wide range of deaths contributing to programme attrition are much more related to the phenomena of unreported deaths across the ART programmes than to truly varying mortalities, as will be discussed in section 3.2.4.

The studies of Cornell (2010) and Fatti (2010) highlighted how the proportion of deaths versus loss to follow-up changed over time on ART. Cornell (2010) reported that 6 months after initiation of ART, 34% of attrition was attributable to deaths and 66% to loss to follow-up, whilst at 36 months, mortality declined to 25% and the loss to follow-up proportion climbed to 75%. The findings of Fatti (2010) confirmed this pattern: figure 3-2 shows hazard estimates of death and loss to follow-up by time of ART (*ibid.*). After an initially identical shape, the death curve falls dramatically during the first six months of treatment, whilst the loss to follow-up curve decreases steadily during the first 36 months of ART. Again, it is important to add that the curves are strongly biased by a supposedly high proportion of unreported deaths among the patients classified lost.

**Figure 3-2:** Death and loss to follow-up according to duration of ART (Fatti 2010)



ART=antiretroviral treatment

### 3.2.2 Factors associated with retention and attrition

The large-scale retention studies presented above showed that programme attrition is a growing concern of ART programmes. A vast body of studies have since explored the factors associated with retention and attrition. This review identified factors associated with retention and attrition in the following five domains:

**Personal characteristics:** Boyles (2011), Charurat (2010), Ekouevi (2010) and Weigel (2012) showed that young age, male sex and a low educational level were associated with attrition, whilst living with a partner facilitated retention. A large multivariate analysis of ART outcomes among 46,201 adult ART patients in South Africa showed that attrition was more frequent in men because they were more likely to initiate ART at an advanced stage of HIV than women, and because of different mortality between men and women in the general population, caused by reasons other than the HIV/AIDS epidemic (Cornell, 2012).

**Clinical characteristics at initiation:** Unfavourable clinical factors, such as a low CD4 cell count (<50), ART initiation as an in-patient, and low haemoglobin were key factors associated with attrition in various studies, such as Boyles (2011), Ekouevi (2010), Cornell (2009), and Charurat (2010). Less expectedly, and linked to losses to follow-up

more than to death, high CD4 cell counts (>350) were also associated with attrition, as shown by Boyles (2011) and Charurat (2010). Boyles (2011) found that patients who were in HIV care before initiating ART were twice more likely to be retained than patients with no pre-ART care.

**Medication:** Charurat (2010) showed that the type of drug regimen can influence retention. In a cohort of 5760 patients in Nigeria, the study found a lower risk (adjusted hazard ratio 0.76) of loss to follow-up in patients using zidovudine compared to patients using stavudine.

**Social and economic background:** Several studies found that patients facing social and economic problems were at higher risk of attrition from ART. Boyer (2011) found that financial difficulties (adjusted odds ratio 11.73) and binge drinking (adjusted odds ratio 4.19) were strongly associated with ART interruption. Cornell (2009) found that the risk of being lost to follow-up was twice as high in patients earning no income compared with patients earning any income (adjusted hazard ratio 0.56).

**Health care system:** A variety of recent studies assessed how retention was influenced by different ART intervention models, ranging from hospital- and doctor-based ART provision to nurse-, primary care facility- and community-based service delivery. A retrospective study across 59 health facilities in South Africa showed that retention at 24 months was 80.1% at primary care facilities compared to 71.5% at district hospitals and 68.7% at regional hospitals, despite primary care facilities receiving more advanced disease stages at ART initiation (Fatti, 2010). Similarly, another study from urban South Africa revealed a four times lower risk of attrition in stable down-referred patients compared to stable patients attending ART consultations at the initiation site (Long, 2011). Research has increasingly been conducted lately on various models of community-based ART interventions complementing facility-based service provision. The largest available research on community-based adherence support was the observational study by Fatti (2012), assessing the effect of adherence and psychosocial support through home visits by community health workers in South Africa. Among 66,953 ART patients, 29% received the intervention, 71% did not. Community-based adherence support reduced mortality by 35% and loss to follow-up by 37%. Patients receiving the intervention also had better viral suppression, with an increasing effect over therapy time, reaching an adjusted odds ratio of 2.66 after 5 years compared to patients not receiving the intervention. An ecological study found similar results: the secondary analysis of aggregated routine data from 349 clinics and 232,389 patients in sub-Saharan Africa by Lamb (2012) demonstrated that clinics with community-based interventions, such as support groups and peer educators, had lower

programme attrition than clinics without community interventions. Similarly, a comparative retrospective study among 13,400 ART patients across 27 NGO supported cohorts in sub-Saharan Africa and the Caribbean (Etienne, 2010) showed two to three times lower loss to follow-up proportions in programmes with community-based adherence support through home visits as compared to programmes which apply facility-based counselling only. The findings of the three cited studies must, however, be interpreted with caution mainly due to information bias and unmeasured confounding. In all three studies, the allocation of the patients to the intervention arms was not randomized so that other factors than community-based adherence counselling could have influenced the outcomes, such as geographic distance or the socio-economic status of the patients. Likewise importantly, the studies by Lamb (2012) and Etienne (2010) were of ecologic design and could therefore not factor in patient characteristics at ART initiation. Moreover, generalizability might be limited since the three studies investigated NGO supported ART programmes. There is, however, a cluster-randomized trial from Uganda among 1336 patients that found a 50% decrease of virological failures among patients receiving adherence support by community-based peer health workers compared to patients not receiving this intervention (Chang, 2010).

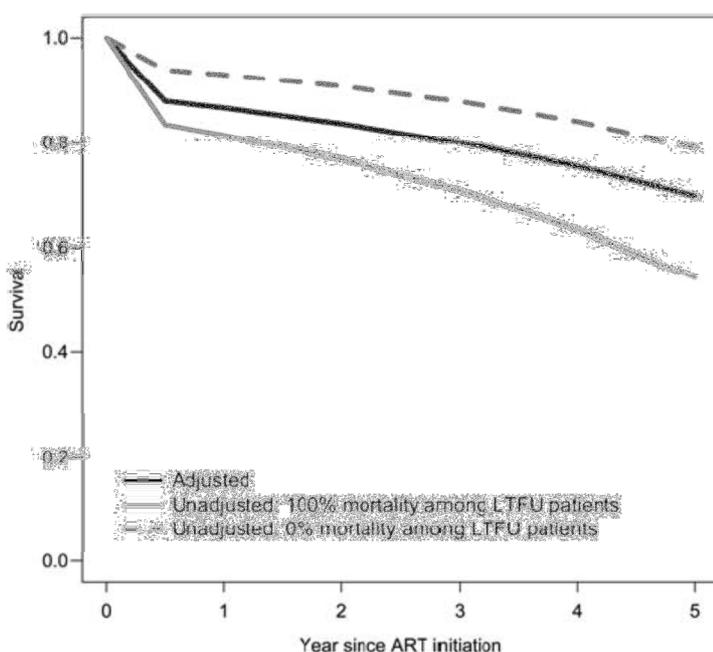
As health systems are struggling to cope with ever-growing ART patient numbers, decentralized ART follow-up at primary health care facilities have become good practice. Two recent studies explored ART outcomes in settings where stable ART patients were further down-referred to community-based models of non-clinical, “self-managed” ART provision. Decroo (2012) reported excellent retention rates from a cluster-randomized trial in Kenya where ART was provided by community care coordinators to 8-20 ART patients and a cohort study in Mozambique where patients obtained their drugs through community ART groups of 6 members each. Similarly, a study from South Africa among 2829 ART patients introduced ART provision in “adherence clubs” and found better retention among the 502 self-selected club members (Luque-Fernandez, 2013).

### **3.2.3 True outcomes of losses to follow-up after tracing**

As shown in 3.2.1, routine ART information systems usually report loss to follow-up as the major reason for programme attrition. Based on routine data, retention studies such as Cornell (2010) and Fox and Rosen (2010) attributed 69% and 59% of programme attrition to losses to follow-up. This section shows that tracing of lost ART patients and linking ART medical records with vital registration data reveals that significant proportions of patients classified as “lost” are unreported deaths. Correcting ART

programme mortality for loss to follow-up considerably changes the shape of the survival curve, as Verguet (2013) illustrated in figure 3-3. Their meta-analysis of 34 cohort studies from sub-Saharan Africa including 102,306 ART patients found that if only reported deaths were considered, life-years gained through ART were overestimated by 14% (ibid.).

**Figure 3-3:** Estimated survival from a regression model based on data from 34 cohorts in sub-Saharan Africa, corrected for mortality among patients lost to follow-up compared to proportions of 0% and 100% mortality among patients lost to follow-up (source: Verguet et al, 2013).



LTFU=lost to follow-up

To determine the ART outcomes of patients recorded as lost to follow-up, Brinkhof (2009) undertook a systematic review of studies which ascertained the vital status of lost patients through tracing. The meta-analysis of 17 studies revealed a combined mortality of 46% among all patients classified as lost to follow-up (ibid.). The study by Van Cutsem (2011) discovered that the mortality of patients lost to follow-up is closely associated with the duration of time after the last ART follow-up consultation: 23% died 1 month after the last visit, 31% 12 months after the last visit, and 44% 24 months after the last visit (ibid.). On the basis of a meta-regression analysis of available tracing data in similar settings, Brinkhof (2010) estimated hazard mortality ratios comparing patients lost to follow-up with those not lost to follow-up for five cohorts in sub-Saharan cohorts. The likelihood of death was estimated between 6 and 23 times in patients lost to follow-

up compared to patients not lost to follow-up. Based on these ratios, corrected programme mortality estimates increased between 27% and 73%.

Unreported transfer to another ART programme was the second most common reason for loss to follow-up, ranging from 12% to 54% of all lost cases, as reported by Brinkhof (2009), Thomson (2011) and Geng (2011).

Patient tracing does not only allow programme managers to ascertain unknown treatment outcomes. From a large cohort in urban Malawi, Tweya (2010) reported that 74% of the patients found alive actually returned back to care after being traced soon after missing the appointment. From the same site, Weigel (2011) reported that having a phone contact doubled tracing success and the odds of identifying deaths. The study by Thomson (2011) on an ART programme supported by Médecins sans Frontières in Kenya found that three months after missing the appointment, 60% patients traced and found returned to the ART programme. The systematic literature review by McMahon (2013) found that tracing contributes to improved retention. The authors compared treatment outcomes between 25 cohorts with tracing (62,791 participants) and 29 cohorts without tracing (124,875 participants). Median retention proportions were 80% (IQR 76-84%) with tracing and 73% (IQR 69-80%) without tracing. Tracing contributed to an increased ART re-engagement of patients who interrupted ART, thus preventing losses to follow-up and deaths. Interpretation of these findings must, however, take into consideration the fact that there are no randomized controlled trials available on ART patient tracing, and that tracing schemes are often performed in NGO or research supported ART programmes disposing of extra resources for enhanced adherence and retention. Also, there are no common standards on when, how, by whom and how often to trace ART patients.

Tracing of lost patients and linking vital registration data with ART records revealed that mortality on ART in sub-Saharan Africa is prominently higher than officially reported by national ART programmes and WHO. A better understanding of loss to follow-up therefore requires first and foremost a shift of focus from loss to follow-up to death on ART. Although this subject was beyond the scope of the present literature review, the findings from recent studies are worth mentioning. As Lawn (2008) and Fatti (2010) have shown (see figure 3-2), death on ART occurs for the most part during the first six months after treatment initiation, mortality rates being more than five times higher during this period than between 6 and 24 months (*ibid*). In their systematic review on early mortality on ART, Gupta (2011) found the highest pooled early (12-months) mortality probability in sub-Saharan Africa (0.17), as compared to Asia (0.11) and the Americas (0.07). The factors associated with early mortality were low baseline CD4 cell

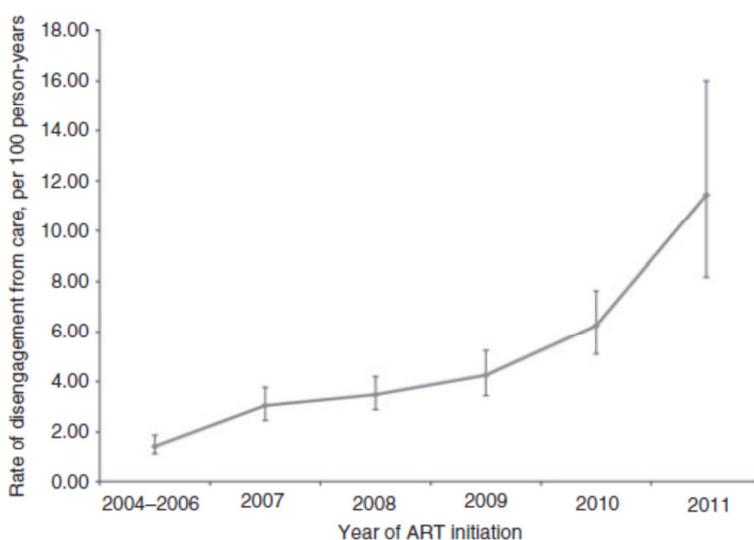
count, male sex, advanced WHO clinical stage, low body mass index, anaemia, and age greater than 40 years (ibid.). On the basis of verbal autopsy, tuberculosis, advanced HIV, and chronic diarrhoea were found to be the most commonly reported causes of death. Wong (2012) conducted the first post-mortem study on mortality during ART in sub-Saharan Africa, using needle autopsy. Tuberculosis was the leading cause of death, with 19/25 (76%) of the deaths on ART being associated with a mycobacterial infection. Immune Reconstitution Inflammatory Syndrome was implicated in 73% of the early ART-deaths, a finding that contradicts earlier studies based on verbal autopsy, reporting an association of Immune Reconstitution Inflammatory Syndrome with only 7% of early deaths (ibid.).

### **3.2.4 Treatment interruption**

Retention studies from sub-Saharan Africa have often neglected unstructured treatment interruption, meaning a therapy stop not agreed with the ART provider. The reason for this research gap has probably been a lack of patient-based electronic data in resource-poor settings that would allow accounting for missed visits and number of days a patient remains without drugs. A systematic review of ART treatment interruptions worldwide revealed that interruptions are a frequent phenomenon, resulting in opportunistic infections, increased risk of virological failure, poor immunological recovery, and ultimately, increased mortality (Kranzer and Ford, 2011). Only 16 out of 70 reviewed studies were from sub-Saharan Africa, and only four of them reported reasons for treatment interruptions, namely treatment costs and pharmacy stock-outs. The review determined a median proportion of 23% patients interrupting treatment and a median duration of 150 days between therapy stop and restart. Brennan (2010) found that 35% patients of a South African ART cohort missed one or more visits by more than 7 days in the first six months of treatment, and that treatment interruption was associated with an increased risk of death and loss to follow-up. In their research on treatment failure in a South African cohort, Kranzer (2010) found that men and patients with high CD4 cell count were more likely to interrupt ART, interruption defined as being without drugs for more than 30 days. The study calculated a 42% probability of restart after discontinuation, factors associated with restart were female sex, older age, and less than 6 months of treatment discontinuation. In their recent study from Uganda, Mills (2013) found that 11.2% of 6970 ART patients had a treatment interruption of more than 12 months, before returning back to care. Factors associated with treatment interruption were high CD4 cell count at initiation and low level of education. Having a partner was associated with ART restart, whilst adolescents were more likely to stay away from care and getting

lost to follow-up. Mutevedzi (2013) reported worryingly increasing rates of ART disengagement over calendar time in South Africa (see figure 3-4), disengagement defined as missing a clinic visit for 180 days and still being alive at this time point. 68% of the treatment interrupters remained resident within their local community.

**Figure 3-4:** Rates of disengagement from care, stratified by calendar year of ART initiation (Mutevedzi 2013)



ART=antiretroviral treatment

This section started with an overview on the current literature on quantitative research of retention in ART programmes, defined as patients being alive and on ART after a certain time period. It was found that in the Southern African region, more than one third of ART patients drop out of therapy within the first three years. Data corrected for mortality among patients lost to follow-up revealed that the majority of programme attrition is due to death, a phenomenon which is being underreported by national and global routine programme data. There is robust evidence from quantitative research about factors associated with good retention. Female sex, adult age, education, income, treatment literacy, living with the partner and certain ARV regimens are associated with retention. Evidence is growing that community-based interventions, such as community-based adherence supporters, support groups and patient tracing, can improve retention and other ART outcomes. Factors associated with attrition – comprising death and loss to follow-up – were young age, male sex, low CD4 cell count and advanced WHO stage at initiation, food shortages, discrimination in the family, financial difficulties, hospital-centred ART provision, long distance to the ART clinic, and drug stock-outs. Eventually, there is new evidence suggesting that unreported

deaths classified as lost to follow-up might be due to undiagnosed tuberculosis to a much greater extent than previously known.

### 3.3 Review of qualitative research

In this section, the state of qualitative social science research on retention will be presented with the aim to understand in more depth the barriers to and facilitators of retention. Qualitative research looks at retention as a social *process* rather than a therapy *outcome*, and attempts to understand why patients interrupt ART.

Castro's bio-social approach on factors influencing adherence to ART care (Castro, 2005) provides a useful framework to organize the review of qualitative research around topics related to the individual as well as the structural spheres of retention. At the individual level, qualitative studies investigated

1. personal characteristics, such as gender and age;
2. psychological factors, such as self-esteem, motivation, and identity;
3. clinical factors, such as opportunistic infections and side effects.

At the structural level, qualitative research explored

4. socio-economic factors, such as poverty and all sorts of costs including transportation;
5. health system related factors, such as the health worker-patient interaction or health financing;
6. social capital factors, such as family and community networks;
7. cultural factors related to religion and models of health and illness other than the biomedical.

Table 3-2 shows the reviewed studies, indicating

- study aim (which aspect related to retention);
- country;
- methodology (data collection method and study population);
- the focus on retention outcomes (to what extent the study findings relate to ART outcomes, such as retention, interruption, loss, death or transfer);
- thematic scope by the categories personal, psychological, clinical, socio-economic, health system, social capital, cultural models; and
- quality, defined as high, medium or low as per CASP criteria (CASP 2013) stated in appendix 1.

**Table 3-2: Characteristics of the 29 reviewed qualitative studies**

Study / Year	Study aim	Country	Methodology	Focus <sup>1</sup>	Scope <sup>2</sup>	Quality <sup>3</sup>
Agnarson 2010	to explore attitudes, perceptions and practices among health care workers, ART patients and community members regarding ART care and the social consequences of ART roll-out	Tanzania	15 FGDs (93 participants) and 25 IDIs with health care workers, community members, ART patients, religious leaders, and social workers; field observations and ethnographic assessments	none	5,7	++
Aspeling 2008	to identify factors that could influence adherence to ART	South Africa	4-8 SSIs during a follow-up period of 8 months with 11 female ART patients who had interrupted ART	strong	1,4,5,6	++
Campbell 2011a	to understand patient and healthcare staff perceptions of good clinical ART care	Zimbabwe	58 IDIs and 8 FGDs (60 participants) with health workers, ART users, and carers of children on ART. 100 hours ethnographic observation at healthcare sites	none	5	+++
Campbell 2011c	to study the impact of antiretroviral treatment availability on HIV/AIDS stigma	Zimbabwe	58 IDIs and 8 FGDs (60 participants) with health workers, ART users, and carers of children on ART. 100 hours ethnographic observation at healthcare sites.	none	2,7	+++
Dahab 2011	to investigate reasons for clinical follow-up and treatment discontinuation among HIV-infected individuals receiving ART	South Africa	27 SSIs with ART patients who had discontinued treatment	strong	2,3,4,5,7	++
Fitzgerald 2010	to examine the way gender shapes the health behaviours, health care experiences and narratives of HIV-positive men initiating ART	South Africa	IDIs with 30 patients initiating ART, of which SSI with 26 patients four months after initiation, 9 IDIs with family members, 5 IDIs with health workers; participant observation	weak	1,2,6	++
Goudge 2011	to explore the reasons for poor adherence among poor urban ART users	South Africa	4 IDIs during 4 months follow-up with 22 adherent and non-adherent ART patients	strong	1,2,4	++
Grant 2008	to gain patient perceptions on factors that facilitate and challenge access and adherence to ART	Zambia	2 SSIs 12 months apart with 40 ART patients; 1 FGD with 12 ART patients	strong	4,6	++
Gusdal 2009	to explore HIV patients' adherence to ART in resource-limited contexts	Ethiopia, Uganda	SSIs with 79 ART patients, 17 peer counsellors, and 22 ART providers	strong	4,5	+++

Study / Year	Study aim	Country	Methodology	Focus <sup>1</sup>	Scope <sup>2</sup>	Quality <sup>3</sup>
Gusdal 2011	to explore peer counsellors' work and their role in supporting patients' adherence to ART in resource-limited settings in Ethiopia and Uganda	Ethiopia, Uganda	SSIs with 79 ART patients, 17 peer counsellors, and 22 ART providers	weak	5	+++
Kagee 2012	to identify the structural barriers that influenced adherence among ART patients	South Africa	SSIs with 10 ART patients	strong	4,5	+
Mattes 2011	to investigate the implementation of ART	Tanzania	ethnographic case studies from IDIs with 26 non-compliant ART patients, SSIs with family members and 27 health workers; extensive participant observation	strong	5,6	+
Merten 2010	to provide a synthesis and an interpretation of the findings of recent qualitative social science research on the questions of retention in ART programmes in sub-Saharan Africa	various	systematic literature review and meta-ethnography of 31 qualitative studies on barriers to adherence in sub-Saharan Africa	strong	1,2,4,5, 6,7	+++
Miller 2010	to better understand the reasons why patients default from ART to help design interventions that improve treatment retention and ultimately, patient outcomes	South Africa	SSIs with 14 patients who interrupted ART and 16 patients who transferred out (in a mixed-methods design)	strong	5	++
Murray 2009	to gain local insight into potentially important factors affecting HIV-infected women's decision to accept or continue with ART	Zambia	47 interviews with ART patients (free listing technique) and 33 SSIs with key informants	strong	1,2	++
Nam 2008	to identify the psycho-social factors related to adherence behaviour	Botswana	32 IDIs with ART patients	strong	2,6,7	+++
Nguyen 2007	to examine adherence in the historical and ethnographic context of access to ART	Burkina Faso, Ivory Coast, Mali	ethnographic methods, not specified	strong	5	+
O'Laughlin 2012	to describe the additional social functions that ART treatment partners serve and shows how these functions contribute to health and survival for patients	Tanzania	3 IDIs with 20 ART patients and their treatment partners	weak	1,2,6	++

Study / Year	Study aim	Country	Methodology	Focus <sup>1</sup>	Scope <sup>2</sup>	Quality <sup>3</sup>
Rachlis 2013	to explore why patients on ART are lost to follow-up (LTFU) by identifying: (1) factors that influence patient losses to follow-up and (2) barriers to effective and efficient tracing	Malawi	group discussions with 90 ART patients and ART providers, using the Concept Mapping technique	strong	2,5	++
Roura 2009	to identify factors affecting sustained attendance at treatment clinics	Tanzania	SSIs with 42 ART patients and 11 providers, and 4 participatory group activities with ART patients	strong	1,2,6	++
Sanjobo 2008	to explore patients' and health care professionals' perceived barriers and facilitators to patients' adherence to ART	Zambia	IDIs with 10 ART patients and 12 health workers; 5 FGDs with 50 ART patients	strong	2,4,5,6	+
Sankar 2006	to understand how qualitative methods have been used in ART adherence research and the contributions they have made	various	systematic literature review of 66 qualitative studies from 1995 to 2006 on adherence to ART	strong	1,2,3,4,5,6,7	+++
Scott 2013	to determine how indigenous resources were enabling people to achieve optimal ART access and adherence	Zimbabwe	58 IDIs and 8 FGDs (60 participants) with health workers, ART users, and carers of children on ART. 100 hours ethnographic observation at healthcare sites	weak	6	+++
Skovdal 2011a	to explore how male denial of HIV/AIDS impacts on their female partners' ability to access and adhere to ART.	Zimbabwe	58 IDIs and 8 FGDs (60 participants) with health workers, ART users, and carers of children on ART. 100 hours ethnographic observation at healthcare sites	strong	1,2,6	+++
Skovdal 2011b	to systematically categorise the spectrum of factors that influence ART.	Zimbabwe	58 IDIs and 8 FGDs (60 participants) with health workers, ART users, and carers of children on ART. 100 hours ethnographic observation at healthcare sites	weak	2,4,5,6	+++
Tuller 2009	to understand structural barriers to ARV adherence and clinical care	Uganda	41 IDIs with ART patients	strong	4	++
Ware 2009	to examine determinants of ART adherence for HIV infected persons in sub-Saharan Africa	Nigeria, Tanzania, Uganda	IDIs with 252 persons taking ART, their treatment partners, and health care professionals; 136 field observations of clinic activities were also conducted	strong	4,6	+++
Ware 2013	to identify reasons for missed visits and to assemble them into a broader explanation of how missed visits may develop into disengagement	Nigeria, Tanzania, Uganda	IDIs with 91 ART patients who had extended treatment interruptions	strong	1,4,5	+++

Study / Year	Study aim	Country	Methodology	Focus <sup>1</sup>	Scope <sup>2</sup>	Quality <sup>3</sup>
Weiser 2010	to understand and contextualize food insecurity in the lives of PLH; to investigate pathways and mechanisms through which food insecurity leads to missed doses and treatment interruptions	Uganda	47 IDIs with ART users	strong	4	++

ART = antiretroviral treatment, FGD = focus group discussion, IDI = in-depth interview, PLH = people living with HIV, SSI = semi-structured interview

<sup>1</sup> Focus of the study on retention / adherence outcomes

<sup>2</sup> Thematic scope of the study on the following biosocial dimensions (Castro 2005): 1 = personal; 2 = psychological; 3 = clinical; 4 = socio-economic; 5 = health system; 6 = social capital; 7 = cultural models

<sup>3</sup> Quality appraisal according to the Qualitative Research criteria of the Critical Appraisal Skills Programme (CASP): aim, methodology, design, recruitment of participants, data collection methods, researcher-participant relation, ethical issues, data analysis, statement of findings, value; + = low quality, ++ = medium quality, +++ = high quality

### **3.3.1 Personal characteristics**

Studies exploring personal characteristics of ART patients revealed that gender and the marital status of patients strongly influence retention on ART. Fitzgerald (2010), Murray (2009) and Skovdal (2011a) uncovered gender specific retention barriers that were deeply rooted in autochthonous conceptions of “hegemonic masculinity” (ibid.) and marriage, shaped by inequalities and dependencies between men and women. For men, HIV/AIDS bore the threat that the disease could undermine their status and dignity as bread-winners and heads of families, households and kin. Fear of embarrassment for not meeting the expectations of their families prevented many men from testing and disclosing their status to their kin, leading to delayed ART uptake and consequently to high attrition. Men needed pressure to start treatment, either from friends or through the experience of suffering from an opportunistic infection. Alcohol often played a role, either as a strategy to cope with denial, or as an excuse to delay ART. On a promising note, though, some men realised that ART provided an opportunity to reconstruct their masculinity (ibid.). After disclosing and initiating ART, men considered themselves as role models for other men, developing a strong sense of responsibility towards their families by adhering to drugs and consultations. Fitzgerald (2010) reported on men’s great fear of gossip and their strong opinion about confidentiality issues in respect to the health workers. In contrast to older men who were more confident in their social role, young men were vulnerable to denial of their HIV status even after initiating ART. Young men often abruptly stopped ART due to a perceived breach of confidentiality or other behaviour of health workers perceived as hostile. Men’s fears and inability to accept HIV did not only influence their own pathway of care, but they also strongly impacted their spouses’ health and adherence to ART. Murray (2009), Goudge and Ngoma (2011) and Skovdal (2011a) underlined women’s distress to disclose their HIV status to their boy-friends or partners and reported that many women took ART secretly or even stopped ART to hide their status. Whilst HIV and ART can potentially destroy partnership and marriage, several studies showed that spouses played a key role in keeping their partners on ART, such as Aspeling and van Wyk (2008), O’Laughlin (2012), Roura (2009), and Ware (2013).

### **3.3.2 Psychological factors**

Adherence and retention have often been studied from a behaviourist perspective. From this perspective, individual attitudes, beliefs, and motivations are the key determinants for retention (see section 7.1 on the conceptual framework). Many studies therefore focussed on the psychological factors of adherence and retention. Campbell

(2011c) and Murray (2009) described the process how people living with HIV escape hopelessness and depression by constructing a new social identity as ART patients. The ART programme allowed patients to regain social value through participation in self-help groups and through economic activities. The availability of ART massively reduced stigma attached to HIV/AIDS due to its link with perceived sexual promiscuity, social embarrassment, and the fear of the terrifying course of the untreated disease. Stigma that is linked to fear and denial nonetheless remained a major obstacle to adherence and retention, as Rachlis (2013) observed in Malawi.

Nam (2008) described adherence as psychological process requiring the individual's acceptance of the positive HIV status. Disclosure led to the patient's new perception and image of "self", including the desire not to be thin and thus visibly identifiable as HIV-positive. Treatment partners as "encouraging confidantes" (ibid.) facilitated adherence by transmitting messages of hope and reversing social isolation (O'Laughlin, 2012). In turn, denial caused self-stigmatisation and depression, identified as major obstacles to adherence and retention.

Personal motivation was identified as key factor for retention by Dahab (2011) who compared ART provision at a workplace setting in comparison with a community setting. At the workplace setting, ART coverage was higher but patients discontinued ART more frequently than in the community setting. The authors explained high attrition from ART at the workplace by a lack of adherence motivation caused by fear of discrimination by the employer and co-workers, and doubts about the HIV status and the effects of ART. In contrast, attrition in the community setting was not a motivational problem, but due to death, migration or high transport costs (ibid.). The study concluded that the "first generation" of ART patients was a selection of self-motivated people living with HIV, many of whom having gone through an illness episode before initiating ART. The workplace setting showed that the "second generation" of healthier people living with HIV who are expected to start in an earlier stage of the disease might be less self-motivated and thus more prone to attrition.

### **3.3.3 Clinical factors**

In line with epidemiological research, there is robust evidence from qualitative studies that the patient's clinical stage at treatment initiation influences adherence and retention. The studies of Nam (2008) and Dahab (2011) found that patients with a low CD4 cell count who started ART only after getting very sick were more motivated to adhere to the drugs and consultations than patients who were still relatively healthy at the time of starting ART. The authors reported that going through an AIDS-related

illness episode facilitated the patients' ability and willingness to accept their HIV status, which was shown to be a mental prerequisite of adherence and retention in the section above. Roura (2009) identified that it was rather the perceived disease severity and the experienced health gain of ART than the medical condition itself that influenced the patient's capacity to continue ART. Nam (2008) found that it is not only the medical recovery, but also the weight gain and changing physical appearance that motivated ART patients to stay on long-term treatment.

Whilst ill-health at treatment start and the dramatic effects of ART on the patient's health and wellbeing were recognized as a motivational factor for retention, the occurrence of adverse effects, opportunistic infections, mental illness or other medical conditions caused therapy interruptions. The qualitative research of Goudge and Ngoma (2011), Kagee (2012), Grant (2008) and Weiser (2010) confirmed findings of clinical studies about patients reporting growing appetite and hunger requiring more food after the initiation of ART. The studies found that nausea, vomiting and dizziness caused by insufficient nutrition made patients stop ART. These findings underlined that ill-health during ART made patients vulnerable for treatment discontinuation, if the episode coincided with other adherence threatening influences, such as money shortage to seek treatment, food insecurity, or gender-based discrimination.

#### **3.3.4 Socio-economic factors**

The roll out of free ART through public health programmes in sub-Saharan Africa has changed the scientific perception on adherence and retention on ART. Out of 66 adherence studies between 1995 and 2005 reviewed by Sankar (2006), only 4 were from sub-Saharan Africa, and 56 were from the USA. The review of Sankar (ibid.) identified mostly individual-level adherence factors, as have been presented above. Prior to the era of free ART in sub-Saharan Africa, adherence was mainly perceived from a health behaviour point of view. Structural barriers and facilitators to adherence were rarely explored nor reported. This picture has changed in recent years since an increasing number of studies on adherence and retention have been carried out in sub-Saharan Africa. Based on their large study in Nigeria, Tanzania and Uganda, Ware (2009) found that in sub-Saharan Africa, most adherence and retention obstacles were related to resource constraints rather than to personal motivation. Merten (2010) reviewed 31 qualitative adherence studies from sub-Saharan Africa between 2000 and 2008. The authors of this review argued that in the context of sub-Saharan Africa, the ability and willingness to continue ART in the long term was largely determined by the patient's structural context, such as the social, economic, institutional and cultural environment.

There is strong evidence from numerous studies that high opportunity cost of attending recurrent ART consultations is the single most important structural barrier to retention. Merten (2010) described adherence largely as the patient's act to balance and negotiate between his individual health needs and the collective livelihood and material needs in his immediate environment. Especially in poor households and in the absence of social security schemes, there were often immediate competing livelihood needs, not allowing a family member to spend money for transport to reach the ART clinic (Aspeling and van Wyk, 2008). Besides housing and schooling, food was identified the major competing family need, aggravated by the fact that reasonable nutrition was an imperative for ART patients, as the studies by Weiser (2010) and Kagee (2012) showed. Households also considered travel for an ART consultation a burden because it not only created costs, but it also prevented the family member from undertaking income-generating activities. In the context of free ART, there were numerous indirect costs creating a financial burden to the ART patient's household. Gusdal (2009) identified transportation as a key cost driver. Depending on the distance from home to the nearest ART clinic, ART patients had to pay substantial amounts for transportation. Referral to another health facility caused additional costs for further transport and for accommodation (Tuller, 2010). Ware (2009) found that ART patients took loans, sold assets, or cut on household expenses to make money available to cover these indirect costs of ART. They took this decision not just for the sake of their individual wellbeing, but to sustain their workforce, to avoid becoming a burden to their family, and to fulfil the duties vis-à-vis their household and community. Nguyen (2007), Mattes (2011) and Merten (2010) suggested that ART programmes offered access not only to treatment, but also to other benefits, such as food aid and income generating projects. These studies found that poor households with several HIV-positive members took a strategic choice as to who should be kept on ART. In such cases of social triage, family members were supported in their efforts to adhere often not on the basis of their vulnerability, but on the basis of the economic needs of the family.

### **3.3.5 Health care system**

The reviewed studies show that the structure, services, and performance quality of the health care system can influence ART retention. The above-mentioned comparative study of Dahab (2011) of ART at workplace and community settings reported 95% ART coverage at the workplace. Whilst access to ART was not reported a problem in this setting, attrition from ART was very high. Patients had immediate and free access to care, but poor patient-health worker relationship undermined the gains of free access. Gusdal (2009) investigated the association of the patient-provider relationship with the

patient's capacity to adhere. The study found that the patients' trust in the ART drugs and in the ART provider were an important factor influencing the degree of the patient's personal responsibility to adhere to ART. Two studies from Tanzania reported widely spread negative attitudes, perceptions and practices of both ART patients as well as providers. Agnarson (2010) observed mistrust towards the ART programme among the community as well as lacking commitment by health workers for the ART programme. In his fundamental critique of the Tanzanian ART programme, the ethnography by Mattes (2011) described ART as a rigid, authoritarian system that promoted adherence on the basis of obedience, stimulus and punishment. The author found that patients experienced adherence as a disciplinary behaviour protocol they often could not comply with due to constraints or conflicting norms in their social and cultural environment. During individual and group adherence sessions, ART nurses educated future ART patients on adherence behaviour, how to "live positively" and the "lifelong contract" on therapy (ibid.). ART patients found it difficult to comply with some of the "contract" conditions. For example, nurses taught that concealment of the HIV status was the result of "self-stigma" and disclosure thus a pre-requisite for ART. Yet, some HIV-positive women decided not to disclose their status to their husband and in-laws because they felt guilty or feared rejection. Other potentially conflicting imperatives were reduced sexual intercourse and refusal of herbal medicine, both behavioural instructions that interfered with culturally shaped expectations and practices of the patients (ibid.). The author's rich insights into the "disempowering" Tanzanian ART programme were limited by insufficient information on methods of data collection and analysis.

A similar analysis was presented under the notion of "therapeutic citizenship" by Nguyen (2007) and in a monograph by the same author (Nguyen, 2010). The concept of therapeutic citizenship implies that ART provided people living with HIV not just with medical treatment, but with a far reaching social security system that is usually offered by governments to its citizens. In the absence of government social security, the author argued that ART represented a set of rights and benefits that are linked with the obligation to adhere (ibid.). In settings where government social security is absent and not even kinship systems can provide social protection, ART programmes, often supported by international organisations, can offer an alternative. ART programmes did not only provide access to material goods to its "therapeutic citizens", ART programmes also mobilised patients for national and even transnational advocacy purposes, for example to claim equitable access to free drugs and CD4 cell counts. As "therapeutic citizens", ART patients were exposed to conflicting "moral economies", as they were at the same time members and subordinates of a kinship system which did

not necessarily consider adherence to ART by one of its members a priority. The cited author has been widely recognized for establishing the concept of “therapeutic citizenship” and launching a critical debate on the political economy of large-scale HIV/AIDS programmes. His publications are based on his personal experience as medical doctor and anthropologist in West African ART programme, but do not declare the methodology of his qualitative research.

The impact of the patient-health worker relationship on ART retention appears to be a critical, yet poorly studied aspect. Negative experiences of patients with the ART programme were also reported from South Africa and Zambia, where Kagee (2012) and Sanjobo (2008) found poor patient-health worker relationships, related to health workers breaching confidentiality. These two studies, though, were of low quality. The study of Campbell (2011a) drew a much more positive picture from rural Zimbabwe, reporting great adherence commitment of patients and nurses dedicated to provide patient-oriented ART services. The authors, however, also found mismatching expectations and priorities in the patient-provider relationship that affected the quality of care. Patients claimed a lack of confidentiality, kindness and acceptance by some ART nurses, who allegedly misconceived adherence to ART as the patients’ obedience to their authority. Long waiting times, high visit frequencies, and unpredictable clinical pathways were further noted as issues affecting client satisfaction.

### **3.3.6 Social capital**

In their ethnography on adherence in Nigeria, Tanzania and Uganda, Ware (2009) explored why and how ART patients in sub-Saharan Africa adhered to ART in spite of the massive structural obstacles and resource constraints, such as poverty, weak health systems, large distances to ART clinics, and considerable indirect costs related to attending regular and life-long ART consultations. The study found that ART patients made huge sacrifices to attend ART consultations, often to the extent of selling assets or borrowing money to pay for transport. The authors suggested that adherent ART patients did not aim at their individual wellbeing, they rather responded to obligations to preserve their social capital, a concept that is described in more detail in section 7.1. The systematic review of Merten (2010) and a large social capital study from Zimbabwe conducted by the London School of Economics and Political Science for the World Bank (Campbell, 2011b) suggested that adherence in sub-Saharan Africa cannot be understood without reference to extended families and community networks serving as social security systems. Whilst the cited studies underlined that ART patients ultimately adhered to fulfil their social obligations, Aspeling and van Wyk (2008), Foster (2010), Grant (2008), and O’Laughlin (2012) described social capital not

as a collective imperative, but as a resource for emotional and functional adherence support. These studies presented “treatment partners”, “medical companions”, spouses and family members as key facilitators for retention. Especially during the initial stage of ART and during crisis, these encouraging “confidantes” (Nam, 2008) reminded ART patients to take pills, provide nutritional support, and accompanied them on ART follow-up consultations.

In resource-poor health systems, community health workers have become increasingly involved in the promotion of adherence and retention. A growing number of qualitative studies describe the significance of community-based lay health workers in bridging the gap between the ART patient and the health system, such as “peer counsellors” (Gusdal, 2011), “expert patients” in Malawi (Tenthani, 2012), and various other types (Hermann, 2009). Complementing the findings of quantitative studies which found considerably better retention in ART programs with community-based adherence support (Fatti, 2012), qualitative studies provided valuable insight into the relationship between such lay counsellors and ART patients. Especially in the early stage after initiation, ART patients considered these lay workers as “living testimonies”, “roles models”, and “models of hope”. “Expert patients”, lay counsellors who are on ART themselves, were particularly well accepted by ART patients, trusted for respecting confidentiality, and for having a positive influence on the patient’s relationship with the professional health worker (Tenthani, 2012). Rachlis (2013) reported that community-health workers were increasingly engaged in tracing of patients who missed their ART follow-up appointments.

### **3.3.7 Cultural models of health, illness and treatment**

Several of the reviewed studies investigated how adherence and retention on ART is influenced by the patients’ cultural explanatory models of health, HIV/AIDS, and treatment. Traditional African medicine and faith provide powerful and potentially complementary or alternative explanatory models to Western biomedicine, as Aspelung and van Wyk (2008), Nam (2008), Dahab (2011), Sanjobo (2008), and Roura (2009) pointed out. Dahab (2011) found that sick patients in South Africa who tested HIV-positive often rejected the diagnosis, arguing they were “bewitched”. In contrast, study participants who were tested HIV-positive in an early stage of the disease who felt perfectly healthy often also rejected their status arguing HIV/AIDS was a visible disease of “thinness” which they neither felt nor saw in their own case. Roura (2009) reported widespread beliefs in Tanzania that spiritual healing and traditional medicine can cure HIV/AIDS, thus fuelling rumours and insecurity in the communities and potentially affecting the ART patients willingness to stay on treatment. The study also

reported misconceptions on ART that are not necessarily rooted in cultural models, such as the incompatibility of alcohol or smoking with ART (ibid.). Nevertheless, cultural and religious models were not only identified as potential barriers, but also as powerful facilitators of adherence. Sanjobo (2008) and Scott (2013) revealed that prayers and church communities had a positive influence on the patients' retention on ART. Nam (2008) found that patients who had dramatically recovered on ART often referred to their faith in God who healed them through ART, whilst ART patients who were experiencing health problems on treatment often blamed biomedicine and turned away from ART, seeking treatment by traditional healers.

Merten (2010) offered an insightful reasoning why patients on ART, in spite of the visible and striking evidence on the efficacy of ART, sometimes rejected the biomedical medicine and got attracted by traditional healing. Contrary to ART which entirely centres at the individual's health and treatment, traditional African medicine understands health and illness in social and spiritual terms. From this perspective, the illness of an individual was perceived as a potential social or spiritual conflict or threat to the community (ibid.). Traditional healing in this view represented social healing, meaning that it aims at collective reconciliation rather than just at individual healing. Taylor (2010) explored the traditional system of health in Zimbabwe, and how the traditional healers, *n'anga*, provided a complementary rather than opposing model for the diagnosis and healing of HIV-related illness. The study found that ART patients had pluralistic treatment seeking strategies, pursuing "multiple avenues of therapeutic relief" by changing back and forth between Christian faith healers, *n'anga*, and biomedicine (ibid.). Most Zimbabweans knew and accepted that HIV/AIDS was a sexually transmitted disease and that ART was effective. However, the *n'anga* were considered particularly competent to identify the underlying cause of the disease, responding to the question "why me?". Also, traditional healers were respected to be confidential, non-judgemental, and discrete, which made them particularly attractive for ART patients who experienced discriminatory conduct and treatment by health workers in hospitals and clinics (ibid.).

In summary, the recent qualitative social science research emphasises that in the context of sub-Saharan Africa, ART patients are highly motivated to adhere to ART drugs and consultations. Programme attrition is not primarily caused by a lack of motivation but rather by barriers in the social, economic, institutional and cultural environment of the ART patient. High opportunity costs, particularly related to transportation, strongly influence decision making in households as to whether or not a family member can be retained on ART. Barriers in the health care system, such as

long distance to the nearest ART site, waiting times, and conflicting patient-health worker relationships, are contributing factors for attrition. The review of qualitative studies also showed that gendered perceptions and power relationships create dominant barriers to retention.

Qualitative studies found a number of facilitators to ART retention that are rooted in the concept of agency (see section 7.1). The evidence shows that patients develop coping strategies that allow them to retain on ART under extremely demanding circumstances. Social networks, starting with the partner and extending to relatives and community organisations are vital facilitators for retention on ART. ART programmes themselves can help patients overcome social isolation and stigma through material benefits, regained self-esteem and identity, and new social relationships in support groups or with caring health workers.

The majority of the reviewed studies were conducted on the basis of data collected among retained ART patients. Only very few studies explored perceptions and lived experience of patients who actually interrupted ART. Whilst facilitators for and barriers to adherence and retention are well documented, temporal dimensions of retention were often undervalued, including the question why some patients who interrupt ART return to care, and others do not. Most of the qualitative research has focused on reasons related to the patient and his or her immediate environment. A smaller number of studies, some of them however of limited quality, suggest that barriers and facilitators related to the health system and the ART programmes itself might critically influence retention on ART.

## 4 Aim, objectives and study design

The aim of this study was to explore ART programme retention and reasons for loss to follow-up and treatment interruption of ART patients in the SMART programme in Zaka and Bikita district, Zimbabwe. The study pursued the following two primary objectives:

1. to describe and quantify retention, loss to follow-up and death in the SMART programme 2006-2012 before and after tracing of patients lost to follow-up;
2. to understand facilitators for and barriers to retention and treatment interruption from the perspective of ART patients who interrupted therapy.

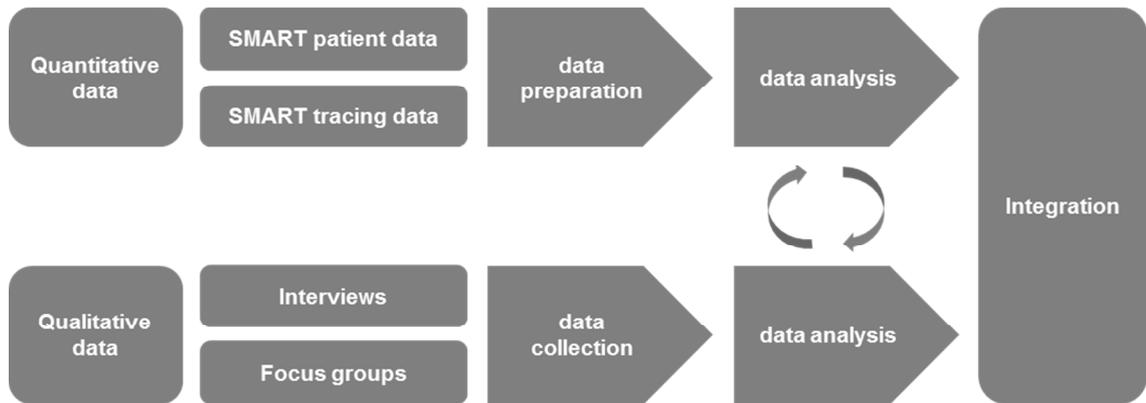
A secondary objective of the study was to describe how the patients and health workers perceived and experienced the SMART tracing intervention.

I chose a mixed-methods approach – combining quantitative and qualitative research – for two reasons: firstly, the involved parties of the ART programme in Zaka and Bikita – the Ministry of Health, the two hospitals, and SolidarMed – had established a tracing scheme to find out the status of the lost patients. The tracing scheme allowed updating and correcting ART patient outcomes in the electronic programme database. Good quality routine data had been stored electronically since the ART programme start, and yet, the data had not been exploited for monitoring and operational research purposes. The quantitative study component would fill this gap. Secondly, understanding the underlying causes of attrition from the patients' perspectives in view of future programme interventions required a qualitative approach. The added value of the mixed-methods is based on combining different data collection methods and techniques, collecting different kind of data on the same subjects, and increasing the depths and credibility of the findings through integration of qualitative and quantitative results (Green and Thorogood, 2009). Mixed-methods did not only refer to the combination of a qualitative and quantitative research, it also included a mix of qualitative approaches, namely in-depth interviews, focus group discussions and participatory observation.

In contrast to mixed-methods studies that follow a principally quantitative or qualitative approach (Ulin, 2005), this study considered both components to be equally important. Also, the two methods were not applied sequentially, but simultaneously, as shown in figure 4-1 and as discussed in chapter 8. Whilst the two research processes evolved independently during data collection, they were connected during analysis. Some quantitative findings raised additional research questions to be addressed during the qualitative content analysis. Equally, some of the qualitative in-sights suggested an

additional statistical query of the available data. To integrate the results of the two individual study components, the findings were synthesised and interpreted in the final stage of the research process.

**Figure 4-1:** The mixed-methods research process



The research methods and techniques are described in more detail in chapter 6 on the quantitative and in chapter 7 on the qualitative study component.

The study was approved by the Medical Research Council of Zimbabwe (MRCZ) on the 19<sup>th</sup> of January 2012 (reference number MRCZ/A/1650) and by the Ethics Committee of the London School of Hygiene and Tropical Medicine on 28<sup>th</sup> of March 2012 (reference number 6140), see appendix 2.

## **5 The SMART programme**

As described in the introduction (chapter 1), this research project was conducted as an operational study, embedded in the ART support programme SMART. This chapter describes the framework of the national ART programme and the intervention package of SMART. Section 5.1 gives a brief history of the SMART programme and explains how it complemented the national ART programme. Section 5.2 presents the tracing scheme implemented between September 2011 and July 2012, an intervention of particular interest for the present study.

### **5.1 Description of the programme interventions**

#### **5.1.1 The Zimbabwean ART programme**

In 2004, the MOHCW launched free ART for eligible patients throughout the country. During the first four years, the programme accredited ART clinics at the referral hospitals of the 59 districts, such as Musiso and Silveira. With the aim to bring ART services closer to the patients, the MOHCW started in 2008 accrediting rural hospitals and health centres as ART follow-up sites. By the end of 2011, the national ART programme covered 141 ART initiation sites and 449 ART follow-up sites (GoZ, 2012b).

The Zimbabwean ART treatment protocol was standardized and regularly updated. When the present study was conducted, ART was provided under the 2010 guidelines, adapted from the revised 2010 ART guidelines of the WHO (GoZ, 2010). ART was initiated in patients with WHO clinical stage 3 or 4, or if they had a CD4 cell count of less than 350. First-line regimens were fixed-dose combinations of tenofovir, lamivudine and nevirapine or zidovudine, lamivudine and nevirapine (*ibid.*). Although the MOHCW planned to phase out stavudine containing regimens, according to monitoring reports provided by the SMART database, more than 50% of SMART patients were still on stavudine at the time of the study.

Whilst ART consultations and drugs were provided free against a very small annual fee throughout the country, health facilities were allowed to charge for laboratory tests (CD4 cell count, haematology and blood chemistry), X-rays, and drugs for opportunistic infections and other conditions.

### 5.1.2 History and scope of the SMART programme

SMART originated at the two hospitals of the Catholic Diocese, Musiso and Silveira. In Zimbabwe, like in many other African countries, faith-based hospitals provide public health services, receiving government grants for salaries and essential drugs. Unlike government health facilities, faith-based hospitals often have access to donor funding thanks to their historic links to foreign missionary institutions. SolidarMed had been supporting these mission hospitals and sending foreign doctors for many decades. The SMART programme interventions targeted three intervention levels:

**District health authorities:** The programme supported the HIV/AIDS prevention and treatment activities of the district health authorities. SMART provided funding and transport for supervisory visits by the district authorities; it also financed district ART coordination and stakeholder meetings.

**Health facilities:** SMART strengthened hospitals and health centres in the areas of infrastructure, equipment, training, logistics and technical expertise. All personnel were employed by the MOHCW or by the Diocese of Masvingo. The programme also contributed salary components (overtime payments, top-ups, locums and allowances for outreaches to rural health centres) to key ART personnel such as the ART nurses, primary care counsellors, and laboratory technicians. SMART funded reagents for the hospital CD4, haematology and biochemistry machines and a limited number of drugs to treat opportunistic infections.

**Community:** Through the Zimbabwean partner NGO “Batanai HIV/AIDS Support Organisation” (BHASO), the programme strengthened support groups of people living with HIV and a network of “Community HIV/AIDS Support Agents” (CHASA). The CHASA were people living with HIV, who were on ART themselves and actively involved in local HIV/AIDS support groups. Under the SMART programme, BHASO recruited, trained and supervised two CHASA per each health facility. CHASA assisted health facility staff in pre-ART group counselling and individual adherence counselling of ART patients. CHASAs were also used as tracers of patients lost to follow-up. The CHASA received a monthly remuneration of US\$15, a robust bicycle and spare parts, T-shirts and a bag through the SMART programme.

In summary, in 2012, people living with HIV/AIDS in Zaka and Bikita were provided with the following services on the HIV/AIDS care and treatment pathway:

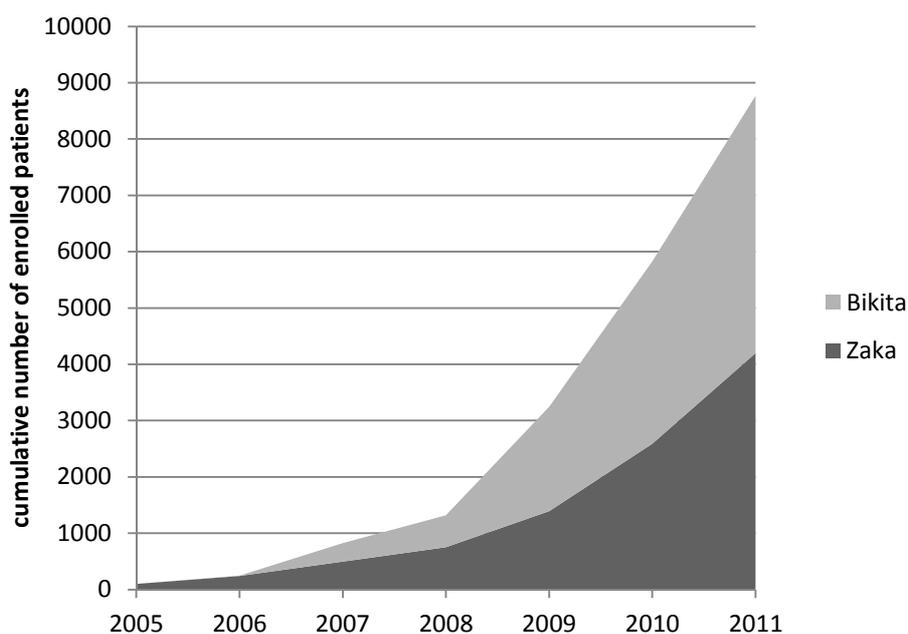
- Free HIV testing and counselling at all health facilities in the district;
- Free prevention of mother-to-child transmission services at all health facilities in the district;

- Free initiation of first-line and second-line ART at hospitals according to MOHCW protocol, outreach initiation at selected local health centres in Zaka district;
- After 6-12 months stable and adherent ART at hospital level, down-referral to local health centre for ART follow-up if the local health centre was an accredited ART site;
- Free treatment of tuberculosis at all health facilities;
- Treatment of other opportunistic infections at patient's expense at hospitals;
- Treatment of other conditions as well as ART side effects at patient's expense;
- Free CD4 cell counts after testing HIV-positive and every 12 months thereafter at hospital and health centres (blood samples sent to hospital laboratory);
- Free laboratory tests during ART treatment according to MOHCW protocol;
- Other diagnostic investigations (for example X-ray) at patient's expense;
- Free co-trimoxazole prophylaxis at all health facilities.

In its first phase (2005-2007), SMART established an ART clinic at Musiso and Silveira hospitals, and introduced an electronic ART patient database. In the second phase (2008-2010), the programme expanded from hospital- and doctor-centred ART provision to health centre and nurse-delivered ART provision. In 2009, the hospitals started referring ART patients to their nearest rural health centre. Eligible for such down-referral were patients who the hospital nurse considered adherent and stable for at least 6 months. The decentralization process was slowed down by the crisis in 2008 and 2009. As the country recovered from the turmoil from 2010 onwards, more and more rural health centres in both districts became accredited ART follow-up sites. By June 2012, seven rural health facilities in Zaka and 13 rural health facilities in Bikita provided decentralised ART follow-up consultations under SMART. In Zaka, Musiso hospital conducted outreach ART initiations at selected health facilities. Otherwise, therapy initiation was restricted to the hospitals.

Between 1 January 2005 and 30 June 2012, 9455 patients were enrolled on ART in the SMART programme. Figure 5-1 shows the rapid growth of patient numbers since 2009. The rapid increase of ART enrolment numbers since 2009 coincided with the acceleration of decentralized ART provision.

**Figure 5-1:** Number of enrolled ART patients 2005-2011 in the programme SMART in Zaka and Bikita district (cumulative)



## 5.2 Patient tracing: A SMART pilot intervention

Concerned by the increasing numbers of patients lost to follow-up and the little knowledge about the reasons behind the losses, SMART launched a patient tracing scheme in 2011.

### 5.2.1 Design and aim of the tracing intervention

There are largely two types of ART patient tracing schemes: tracing through outreach and decentralised tracing. Outreach schemes send professional tracers on motorbikes from the ART initiation site, usually a hospital, to the patient's homes. The tracers usually travel long distances and do not know the patient personally. In decentralised schemes, peripheral health centre send community health workers to trace the patients at their homes, usually on bicycle or on foot. Tracers in this scheme often know the patient or at least his treatment partner or relatives. SMART decided to conduct a decentralized tracing scheme with an outreach component to trace those patients who have been lost for many years or whose address was in long distance from the nearest rural health centre.

With regard to the time point of tracing after a missed ART appointment, again, two approaches can be distinguished: interrupter tracing (after 7-14 days) and loss to follow-up tracing (after 90 days). When to trace depends primarily on the aim of the

tracing scheme. If the scheme primarily aims at ascertaining the patients' vital status for monitoring, evaluation and research reasons, tracing of losses after 90 days is appropriate. If the scheme aims to bring patients back to care, tracing is initiated early after a missed appointment. Given a primary interest in monitoring and research, and owed to doubts on the logistical and organisational feasibility of interrupter tracing, SolidarMed decided to pilot a loss to follow-up tracing scheme.

Loss to follow-up tracing started in September 2011 and included tracing of all patients since 2005 who had missed their last ART follow-up appointment for more than 90 days without being recorded dead or transferred out.

### **5.2.2 Operational procedures**

It is a key challenge of tracing schemes how patients qualified for tracing can be identified in the record system and located geographically. To identify patients lost to follow-up, SMART used the electronic programme database, as shown in appendix 3. Starting from September 2011, the SMART data managers once a month established a list of patients lost to follow-up. The rural health facility nurses were responsible for tracing the listed patient through any health worker cadre locally available. The health centre nurse filled in a tracing form according to the information provided, as shown in appendix 4. The forms were returned to the ART clinics at the referral hospitals Musiso and Silveira, where the tracing outcomes were recorded in the ART follow-up forms, the SMART patient database, and the tracing database.

### **5.2.3 Health worker cadres used for tracing**

The Provincial Medical Director decided that for this pilot, any of the following health worker cadres would be allowed to perform tracing, depending on their availability at the respective rural health centre:

- **Environmental health technicians:** In the Zimbabwean health system, environmental health technicians provide preventative health care such as disease control and hygiene inspections. They are linked to health facilities and use motorbikes. Environmental health technicians are used by several health programmes, for example by the HIV/AIDS programme as "riders" for transport of blood samples and by the tuberculosis programme for patient tracing.
- **Village Health Workers:** In 2000, the MOHCW re-launched the Village Health Worker scheme to contribute community-based health workforce to achieve the health related MDGs. Village health workers are volunteers accredited by the MOHCW and trained in HIV/AIDS, tuberculosis, maternal and neonatal care,

community and home-based care, malaria, and disaster risk reduction. They are supervised by the health authorities and receive a small remuneration.

- **Community HIV/AIDS Support Agents:** The CHASA, as described in section 5.1.2, were a SMART programme intervention in collaboration with BHASO. As from 2011, patient tracing was included in the training curriculum for new CHASAs.
- **Other community health workers:** The Provincial Medical Director agreed that any other types of formally recognized and trained community health workers could be used as tracers as well, provided the nurse instructed them. In Zaka, for example, the NGO CARE International had trained care facilitators for home-based care before the era of ART. They were now used for tracing.

It was agreed that during the initial stage of the tracing pilot, motorized environmental health technicians would be prioritized to trace the large backlog of patients lost to follow-up since 2005. To compensate the involved tracers for their extra work during the initial phase of the tracing scheme (September 2011 – March 2012), SMART paid US\$2 for each correctly filled and returned tracing form to the ART nurse, and US\$1 was paid to the tracer. From April 2012, when the backlog of lost patients had been traced, these payments were ceased.

## **6 Retention, loss to follow-up and mortality: quantitative findings**

The objective of the quantitative research component was to describe and quantify retention, loss to follow-up and death in the SMART programme 2006-2012 before and after tracing of patients lost to follow-up. Section 6.1 describes the methodology of this study component, section 6.2 presents the results, and 6.3 includes a discussion of the findings in the light of the existing literature.

### **6.1 Methodology**

#### **6.1.1 Design**

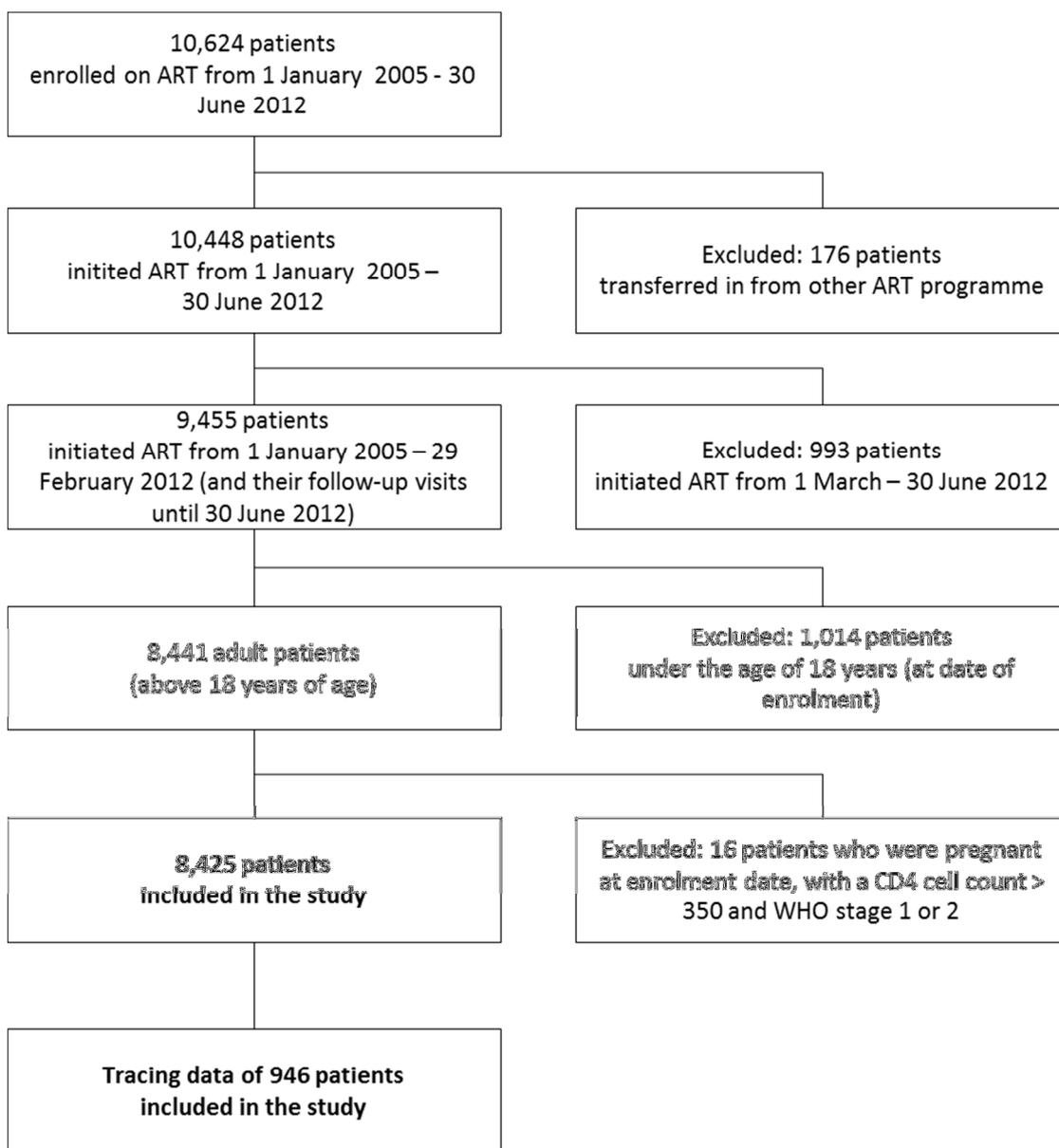
I conducted a retrospective cohort study using electronically available patient level data that was supplemented with data collected through the SMART tracing intervention. Patient level routine data and tracing data were linked to update and correct patient outcomes.

#### **6.1.2 Study population**

The study included adults in the age of 18 years and older in Zaka and Bikita who were enrolled on ART for their own health between 1 January 2005 and 28 February 2012. ART follow-up data was included until 30 June 2012. ART patients who were transferred in from outside the districts of Zaka and Bikita were excluded.

Figure 6-1 shows that after exclusions, 8425 ART patients were included in the study. From the included population, a sub-group of 946 patients was traced by the SMART programme. Their tracing data were included in the study.

**Figure 6-1:** Flow chart on the study population



ART=antiretroviral treatment; WHO=World Health Organization

### 6.1.3 Procedures

The SMART programme collected and recorded patient and tracing data electronically as described in chapter 5. I obtained the electronic patient and tracing data from SolidarMed as per 31<sup>st</sup> July 2012. Prior to handing out the data sets as Microsoft Access 2003 files, the SMART data managers had replaced the national ART number variable with a non-identifying study number. We cleaned and linked the data sets and prepared them for analysis in Stata 12.

#### 6.1.4 Statistical analysis

I used descriptive statistics to analyse frequency distributions of selected characteristics of the study population at the first ART visit, which was the defined cohort entry date. After excluding ART patients who were transferred in, the first ART visit was for all patients the date when they started ART, meaning that the patient obtained the first ART drug supply. The cohort exit date was defined as last visit date in retained patients, and date of death or date of loss to follow-up (90 days after the missed appointment) in non-retained patients. Treatment outcomes were measured using programme data before and after updating with tracing data. To analyse retention outcomes over calendar time, I conducted a cohort analysis. Cohort analysis is a simplified ART patient monitoring tool suggested by WHO (WHO, 2006). A cohort is defined as a group of ART patients starting treatment in the same time period, e.g. month, quarter or year. Cohort analysis compares treatment outcomes at specified time points after enrolment between ART enrolment groups, thus showing trends in programme progress. Retention proportions were determined at different time points between 12 and 72 months after initiation, as defined in section 6.1.5 below. Treatment interruptions were calculated as number of days between the date of a missed appointment and the date of the subsequent ART visit, if the gap was more than seven days. The frequency of treatment interruptions was described irrespective of the patients' duration on ART. I explored associations between baseline characteristics and the ART outcomes death and loss to follow-up using risk ratios. The relative risk for death was calculated among all patients who initiated ART, the relative risk for loss to follow-up among all patients who did not die. Exposures of interest were sex, age, WHO stage, CD4 baseline, tuberculosis diagnosis at ART initiation, health facility type at last visit, site, and haemoglobin. I conducted and plotted a survival analysis using Kaplan-Meier estimates with the survival time measured from the first ART visit, the event date being the date of death, and the censors being the date of loss to follow-up, calculated as 90 days after the missed appointment, or the date of transfer to another health facility. All statistical analysis was performed in Stata 12.

#### 6.1.5 Definitions

The following definitions were used:

**Retention and attrition:** These two terms are mutually exclusive categories related to a patient's status in the ART programme. Retention refers to all ART patients who are alive and on treatment due to the fact that they adhere to follow-up appointments. Attrition, as the opposite term, includes all patients who are registered dead or lost to

follow-up. Gross enrolment included patients transferred out, net enrolment excludes them. To calculate retention and attrition proportions, transfers out of the programme are excluded. Retention proportions were calculated on the basis of the following formula suggested by Fox and Rosen (2010):  $\%RT_t = (I_0 - T_t - D_t - LFU_t) / (I_0 - T_t)$ .  $I_0$  is all patients enrolled on ART;  $T_t$  is all patients transferred out by time point  $t$ ;  $D_t$  is all patients who died by time point  $t$ ;  $LFU_t$  is all patients lost to follow-up by time point  $t$ . UNAIDS (2011a) considers retention at 12 months an ART core indicator. This study calculated retention proportions at 12, 24, 36, 48, 60 and 72 months.

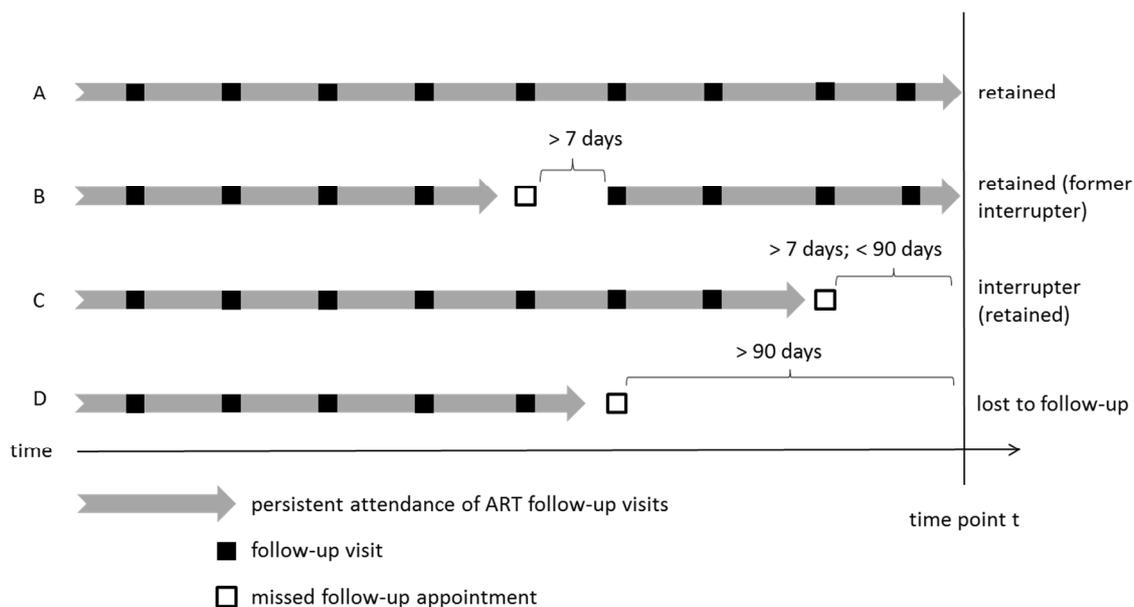
**Loss to follow-up:** In accordance with the WHO definition, patients were classified lost to follow-up if they initiated ART at the site and neither attended a clinical consultation nor picked up ARV drugs within 90 days after the date of their last missed appointment (WHO, 2010). The loss to follow-up definition includes patients who were initiated on ART and never came back for their first follow-up consultation. The definition excludes patients who were reported dead or transferred out.

**Death:** Patients were classified dead if their death was reported (before or after tracing) and recorded in the medical records.

**Treatment interruption:** WHO considers an ART visit “on time” if the patient came within seven days after the scheduled appointment (WHO, 2010). Given that patients in the ART programme in Zaka and Bikita are provided a supply of ART drugs for five extra days, it can be assumed that they run out of drugs from day six after missing an appointment. I therefore considered missing an appointment for more than seven days an appropriate definition for treatment interruption.

Figure 6-2 gives an overview of the definitions for hypothetical patients at time point  $t$ . Patients A, B and C are classified as retained since they were considered alive and on ART at time point  $t$ . Patient A has continuously been classified retained, since he never missed a visit. Patient B missed a visit, was temporarily an interrupter or classified lost to follow-up, if the interruption lasted for more than 90 days. Since he restarted after interruption or loss, he is classified retained at time point  $t$ . Patient C missed his last visit more than 7 and less than 90 days ago, and is therefore considered an interrupter, but still classified as retained. Patient D is classified lost to follow-up, since his missed appointment is more than 90 days ago at time point  $t$ .

**Figure 6-2:** Definitions of retention, interruption and loss to follow-up on the timeline



### 6.1.6 Roles

Two study team members assisted me in cleaning and preparing data sets for analysis: a study statistician (Zvikomborero Madari, ZM) and a research assistant (Jabulani Toringa, JT). After obtaining the two anonymised data sets from SMART, I gave ZM and JT the task to clean the data for missing and erroneous values and inconsistencies. ZM and JT reviewed and verified the data sets in quality feedback sessions together with the SMART data clerks. After obtaining the cleaned data sets from ZM, I imported them into Stata 12 where I linked the patient data with the tracing data and prepared the entire data for analysis. I analysed the quantitative data on my own after completion of the field work.

### 6.1.7 Confidentiality

The data sets I obtained from SolidarMed on 31<sup>st</sup> of July 2012 did not include unique identifiers. Prior to handing over the data files to the study team, the national patient ID was replaced by a study number, and the date of birth was replaced by age. The electronic data has been kept password protected and safely in my computer.

## 6.2 Results

### 6.2.1 Characteristics at ART initiation

Data of 8425 adult patients initiated on ART were analysed. Table 6-1 shows the characteristics of the study population at the first ART visit. The median (IQR) age was 40 (34-49) years, 68.6% were female. Patients had a median (IQR) CD4 cell count of 149 (76-230). 67.4% were in WHO stage III, 5.7% in WHO stage IV. 19.5% patients were on tuberculosis treatment at ART initiation. 64.8% of the patients were initiated after 2009. The comparison between the two site cohorts show that Zaka and Bikita had largely similar socio-demographic characteristics, but they slightly differed with regard to clinical characteristics: the median CD4 cell count was lower in Zaka (137 versus 157 in Bikita), and the proportion of patients in WHO stage IV was higher in Zaka (8.9% versus 2.8% in Bikita).

**Table 6-1:** Socio-demographic and clinical characteristics of study participants at ART initiation

		Zaka		Bikita		Total	
Total patients		4073		4352		8425	
Females (%)		2782	(68.3)	2999	(68.9)	5781	(68.6)
Age	median (IQR)	40	(34-49)	40	(34-49)	40	(34-49)
in years (%)	18-24 years	147	(3.6)	200	(4.6)	347	(4.1)
	25-34 years	1209	(29.7)	1242	(28.5)	2451	(29.1)
	35-44 years	1513	(37.1)	1618	(37.2)	3131	(37.2)
	>45 years	1204	(29.6)	1292	(29.7)	2496	(29.6)
WHO stage (%)	I	238	(5.8)	383	(8.8)	621	(7.4)
	II	729	(17.9)	909	(20.9)	1638	(19.4)
	III	2743	(67.3)	2939	(67.5)	5682	(67.4)
	IV	363	(8.9)	121	(2.8)	484	(5.7)
CD4 cell count at	N	3013		3598		6611	
1st visit	median (IQR)	137	(70-212)	157	(80-240)	149	(76-230)
per mm <sup>3</sup> (%)	1-49	497	(16.5)	523	(14.5)	1020	(15.4)
	50-99	553	(18.4)	584	(16.2)	1137	(17.2)
	100-199	1113	(36.9)	1188	(33.0)	2301	(34.8)
	200-349	783	(26.0)	1175	(32.7)	1958	(29.6)
	>350	67	(2.2)	128	(3.6)	195	(2.9)
On TB treatment		683	(16.8)	961	(22.1)	1644	(19.5)
at first visit (%)							
Year of first	2005	105	(2.6)	3	(0.1)	108	(1.3)
visit (%)	2006	178	(4.4)	4	(0.1)	182	(2.2)
	2007	182	(4.5)	303	(7.0)	485	(5.8)
	2008	263	(6.5)	569	(13.1)	832	(9.9)
	2009	523	(12.8)	836	(19.2)	1359	(16.1)
	2010	1034	(25.4)	1160	(26.7)	2194	(26.0)
	2011	1528	(37.5)	1278	(29.4)	2806	(33.3)
	2012	260	(6.4)	199	(4.6)	459	(5.4)

ART=antiretroviral treatment; IQR=interquartile range; WHO= World Health Organisation; TB=tuberculosis

### **6.2.2 Outcomes at last visit before tracing**

The median (IQR) follow-up time from the first to the last ART visit was 15 (6-28) months. 431 (5%) patients attended the first visit only and did not come back for a follow-up visit. By 30 June 2012, 6291 patients (3105 in Zaka and 3186 in Bikita) were alive and on ART and 442 (163 and 273) were transferred out. The retention proportion was 78.8%. Before SMART started tracing patients lost to follow-up, attrition comprised 590 (7.4%) deaths and 1102 (13.8%) patients lost to follow-up. In Zaka, the proportion of reported deaths was 6.1%, in Bikita 8.6%.

By 30 June 2012, 2457/8004 (31%) patients had at least one follow-up visit at a decentralized health facility. The proportion of decentralized patients was higher in Zaka (35%) than in Bikita (27%).

### **6.2.3 Tracing results**

Between January 2005 and 30 June 2012, a total of 1102 patients were classified lost to follow-up in both districts. Correct tracing data were available from the SMART programme for 946/1102 (86%) patients.

Table 6-2 shows that 42% of the cases were traced by environmental health technicians, 37% by different types of community health workers (mostly CHASAs and village health workers), and 20% by nurses. Between February and June 2012, the period when community health workers were allowed to trace, the proportion was inverted: community health workers traced 52% of the cases, environmental health technicians 25%. 38% of the patients were traced in the framework of a community-based HIV/AIDS intervention, using Community HIV/AIDS Support Agents on bicycles and other community health workers as tracers. The data shows that after SMART had ceased payment of US\$3 per traced patient, the motorized environmental health technicians were rarely involved in tracing: in the first two months of tracing, 87% and 84% of the patients were traced by environmental health technicians. Thereafter, the environmental health technicians' contribution to tracing ranged between 0% and 45%, whilst more patients were traced by community health workers.

**Table 6-2:** Health worker cadres used for tracing by site

Type of health worker cadre	Zaka	%	Bikita	%	Total	%
Environmental health technicians	197	40	199	46	396	42
Nurse	66	13	123	28	189	20
Village Health Worker	104	21	60	14	164	18
Community HIV/AIDS Support Agents	43	9	48	11	91	10
Care facilitator	84	17	0	0	84	9
Primary Care Counsellor	4	1	7	2	11	1
Total	498		437		935	

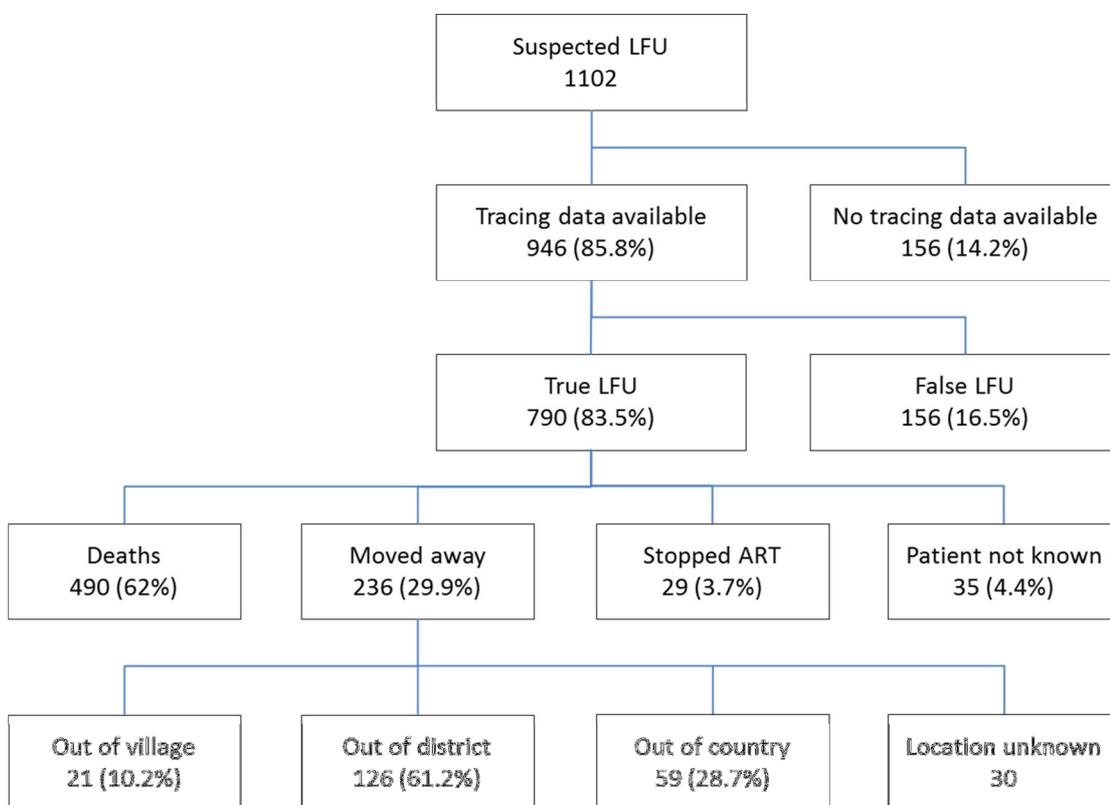
Figure 6-3 shows the tracing outcomes. Out of 946 traced ART patients, 156 (16.5%) turned out to be misclassified losses to follow-up on the grounds of incorrect documentation: according to the medical records kept in the health facility, these 156 patients had missed their scheduled ART visit for more than 90 days, were therefore recorded lost to follow-up, and traced. Yet, the tracers found them alive and on ART. It turned out that the ART records had not been filled in properly at the patients' last visit. Eventually, tracing data of 790 patients who were genuinely "lost to follow-up" were included in the study. The median time between the missed appointment and the date of tracing was 461 days (IQR 256-793), ranging from 98 days to more than six years.

In 490 (62.1%) cases, the patient was found to have died. The proportion of deaths was higher in Zaka (64.7%) than in Bikita (59.3%). For 463 deceased patients, the informant – a close relative – gave a credible account of the date of death. 236 (29.9%) patients moved away (in Zaka 27.4% and in Bikita 30.7%), 29% out of the country, 61% out of the district, and 10% out of the village. Before tracing, 442 patients had been officially transferred out of the SMART programme, meaning that they were given a referral document to continue ART at another health facility out of the district. It was found through tracing that additional 26 patients had obtained such a transfer document, but were not recorded accordingly as transferred. After tracing, a total of 5.6% (468) patients were officially transferred out. Tracing revealed that 235 patients lost to follow-up had moved away. Adding the "silent" transfers to the official transfers resulted in a proportion of 8.3% (703) patients who left the programme due to migration.

At the time of tracing, only 29 (3.7%) lost patients (22 in Bikita and 7 in Zaka) were still alive. The following reasons for stopping ART were reported (n=29, multiple answers possible): transport costs (16), lack of family support (7), good health (7), disclosure issues (5), illness (4), religion (4), travel / migration (4), treatment costs (3), and lack of support by the employer (1). At study closure, 14/29 (48%) had restarted ART. In 35

(4.4%) cases, the traced patient was not known by the community, in most cases due to a wrong address given to the health facility.

**Figure 6-3:** Flowchart of tracing outcomes



ART=antiretroviral treatment; LFU=lost to follow-up

#### 6.2.4 Programme outcomes before and after tracing

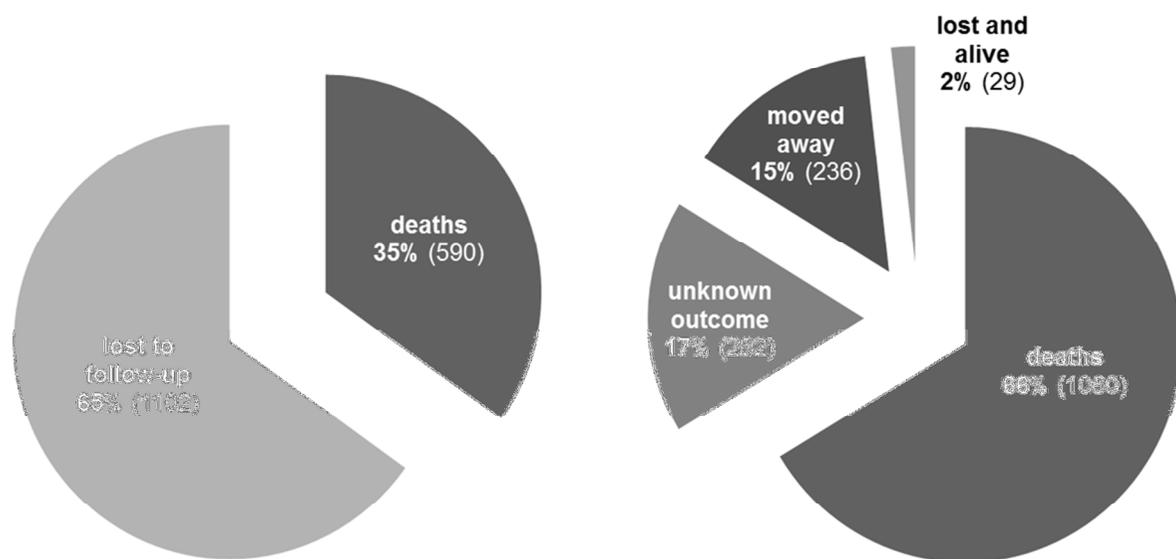
Table 6-3 and figure 6-4 compare the programme outcomes before and after tracing. Tracing revealed that due to documentation errors, the proportion of retained patients was slightly higher in reality than according to the medical records: total retention was 78.8% before and 79.6% after tracing. Retention at 12 months was 83.4% before and 84.7% after tracing. After ascertaining the true status of the lost patients, death became the major reason for attrition from ART: before tracing, 590 (7.4%) patients were reported dead, 1102 (13.8%) were classified lost to follow-up. Tracing revealed that 1080 (13.6%) patients had died and 547 (6.9%) remained lost to follow-up, partly because they moved away without reporting. Tracing increased the proportion of deaths at 12 months by 80% from 6.4% to 11.5%, and at 36 months by 111% from 9% to 19%. Before tracing, programme attrition was attributed to 38% and 51% deaths at

12 and 36 months. After tracing, the proportion of deaths was 75% and 76% at the same time points.

**Table 6-3:** Programme outcomes before and after tracing (January 2005 – June 2012)

	Before tracing			After tracing		
	total	12 months	36 months	total	12 months	36 months
Enrolled gross	8425	6431	2203	8425	6431	2203
Transferred out	442	201	119	468	215	122
Enrolled net	7983 (100)	6230 (100)	2084 (100)	7957 (100)	6216 (100)	2081 (100)
Dead (%)	590 (7.4)	396 (6.4)	270 (13.0)	1080 (13.6)	716 (11.5)	392 (18.8)
Lost to follow-up (%)	1102 (13.8)	639 (10.3)	263 (12.6)	547 (6.9)	237 (3.8)	124 (6.0)
Retained (%)	6291 (78.8)	5195 (83.4)	1551 (74.4)	6330 (79.6)	5263 (84.7)	1565 (75.2)

**Figure 6-4:** Reasons for attrition before and after tracing



## 6.2.5 Cohort analysis

I conducted a cohort analysis between annual ART enrolment groups to explore retention trends over calendar time. Table 6-4 shows selected characteristics of the seven annual cohorts. The analysis shows that the patient volume grew exponentially. In 2005 and 2006 low patient numbers were enrolled, most of them in Zaka. Between 2007 and 2011, the size of the cohorts increased six-fold. 59% of all patients were enrolled in 2010 and 2011. Besides the massive growth of the annual cohorts in numbers, the table shows that over time, the cohorts became younger and the programme managed to initiate patients at an earlier stage of the disease; the median CD4 cell count at baseline increased steadily from 55 in 2006 to 178 in 2011.

**Table 6-4:** Selected baseline characteristics of patients by year of first visit (annual cohort)

Year of ART start	Patients enrolled (%)	% Zaka	% Female sex	Median age in years	CD4 baseline	
					n	median
2005	108 (1.3)	97	72	41	5	116
2006	182 (2.2)	98	64	39	31	55
2007	485 (5.8)	38	69	39	292	78
2008	832 (9.9)	32	68	40	340	107
2009	1359 (16.1)	38	67	39	1119	121
2010	2194 (26.0)	47	70	38	1986	151
2011	2806 (33.3)	54	69	38	2433	178

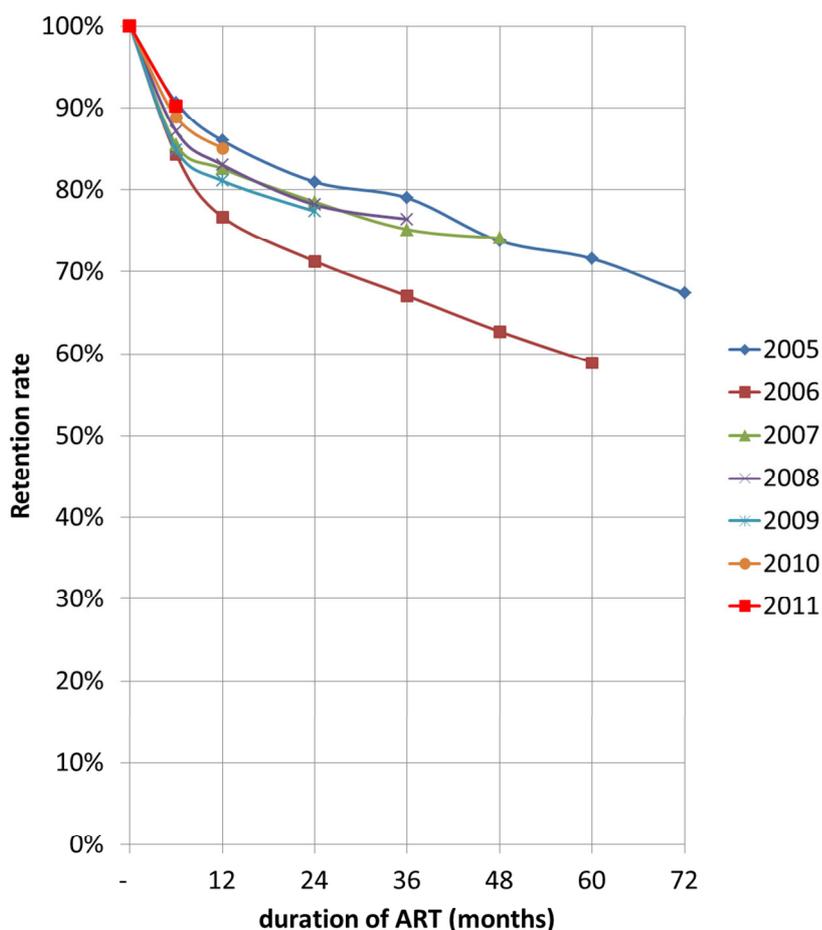
Table 6-5 and figure 6-5 show that retention generally improved over calendar time; with the 2005 and 2009 cohorts being outliers. Retention at 6 months suggests that the positive trend since 2009 is continuing.

**Table 6-5:** Retention rates by annual cohorts at different time points

Annual cohort	Patients enrolled	Retention rate at time points after enrolment						
		6 m	12 m	24 m	36 m	48 m	60 m	72 m
2005	108	90.7%	86.0%	81.0%	79.0%	73.7%	71.6%	67.4%
2006	182	84.3%	76.7%	71.3%	67.1%	62.7%	58.9%	
2007	485	85.4%	82.6%	78.5%	75.2%	74.1%		
2008	832	87.1%	83.0%	78.2%	76.4%			
2009	1359	84.9%	81.1%	77.4%				
2010	2194	88.8%	85.0%					
2011	2806	90.1%						

m=months

**Figure 6-5:** Retention rates of seven annual cohorts in Zaka and Bikita over time



ART=antiretroviral treatment

### 6.2.6 Treatment interruption

As noted in section 6.1.5, a patient was defined as retained if he or she was alive and on ART at the time of database closure (30 June 2012). Yet, retained at a certain point in time does not imply that the patient was consistently adherent to ART appointments. Table 6-6 shows that irrespective of their ART duration, 28.3% of the retained ART patients missed their ART visit appointment at least once for more than 7 days, suggesting that they may have had a treatment interruption. The median (IQR) duration of each patient's longest treatment interruption was 32 (20-60) days. 89.4% of the interrupters returned to care within 90 days after the missed appointment, thus before they were recognized as losses. 10.6% returned to the ART programme after being classified lost to follow-up.

**Table 6-6:** Retained ART patients who had at least one treatment interruption of more than 7 days

	Zaka		Bikita		Total	
Median (IQR) days	42	(22-64)	30	(19-58)	32	(20-60)
8-29 days (%)	259	(36.7)	506	(47.1)	765	(43.0)
30-59 days (%)	215	(30.5)	334	(31.1)	549	(30.8)
60-89 days (%)	136	(19.3)	141	(13.1)	277	(15.6)
>90 days (%)	95	(13.5)	94	(8.7)	189	(10.6)
Total	705	(100)	1075	(100)	1780	(100)
Total interrupters/retained (%)	705/3105	(22.7)	1075/3186	(33.7)	1780/6291	(28.3)

IQR=interquartile range

In summary, a total of 3407/7983 (42.7%) enrolled patients discontinued ART. Of those who discontinued, 1627/3407 (47.8%) died or became lost to follow-up and never came back, whilst 1780/3407 (52.2%) patients restarted after interruption.

### 6.2.7 Retention and deaths at different time points corrected after tracing

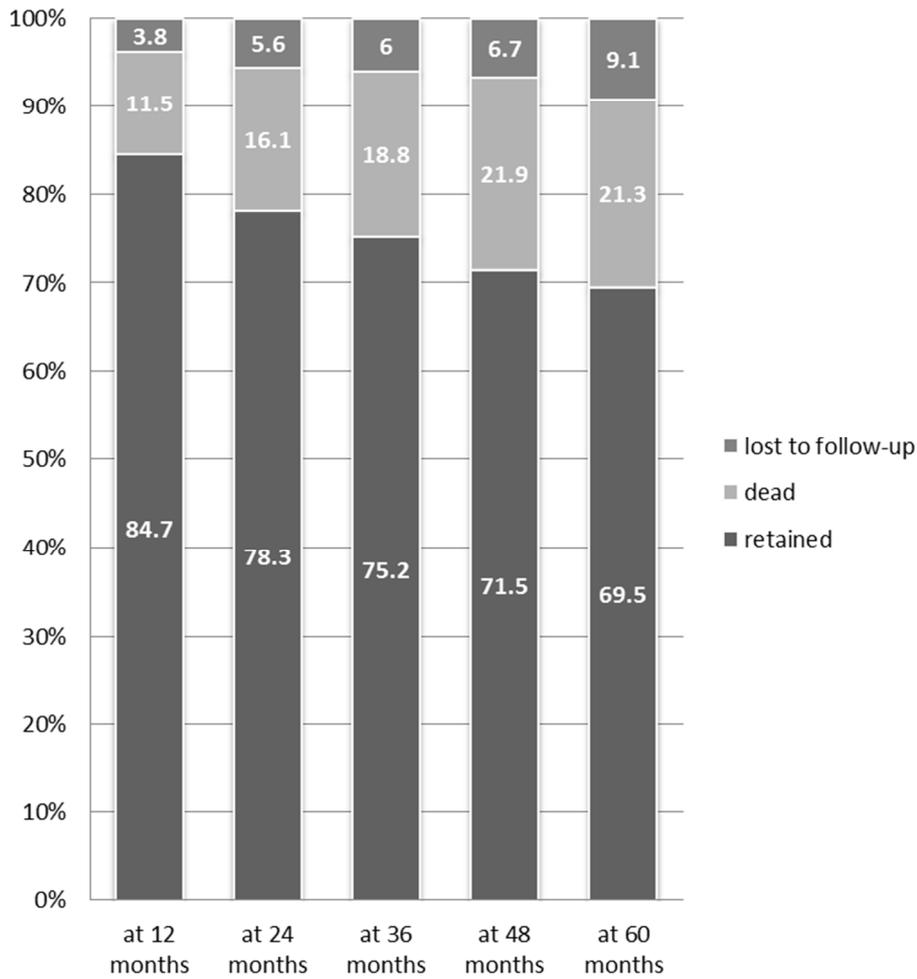
Corrected after tracing, programme attrition was characterised by a high proportion of deaths and losses within the first 12 months of treatment: table 6-7 and figure 6-6 show the proportions of retained, dead and lost patients at different points in time. 12 months after treatment start, 84.7% of the enrolled patients were alive and on ART. The retention proportion decreased over time: at 24, 36, 48 and 60 months, 78.3%, 75.2%, 71.5% and 69.5% were alive and on ART. The proportion of deaths was 11.5% at 12 months, climbing to 16.1%, 18.8% and 21.9% at 24, 36 and 48 months. The analysis also shows that the proportion of programme attrition caused by death versus losses did not change much between 12 months (75%) and 60 months (70%). This result indicates that even though early mortality prevailed, death remained a problem throughout follow-up time.

**Table 6-7: Programme outcomes at different time points, corrected after tracing**

	Enrolled	Transferred out	Retained (%RT <sub>t</sub> )	Dead (%D <sub>t</sub> )	LFU (%LFU <sub>t</sub> )
Total	8425	468	6330 (79.6)	1080 (13.6)	547 (6.9)
at 12 months	6431	215	5263 (84.7)	716 (11.5)	237 (3.8)
at 24 months	3987	206	2960 (78.3)	608 (16.1)	213 (5.6)
at 36 months	2203	122	1565 (75.2)	392 (18.8)	124 (6.0)
at 48 months	1102	82	729 (71.5)	223 (21.9)	68 (6.7)
at 60 months	539	47	342 (69.5)	105 (21.3)	45 (9.1)

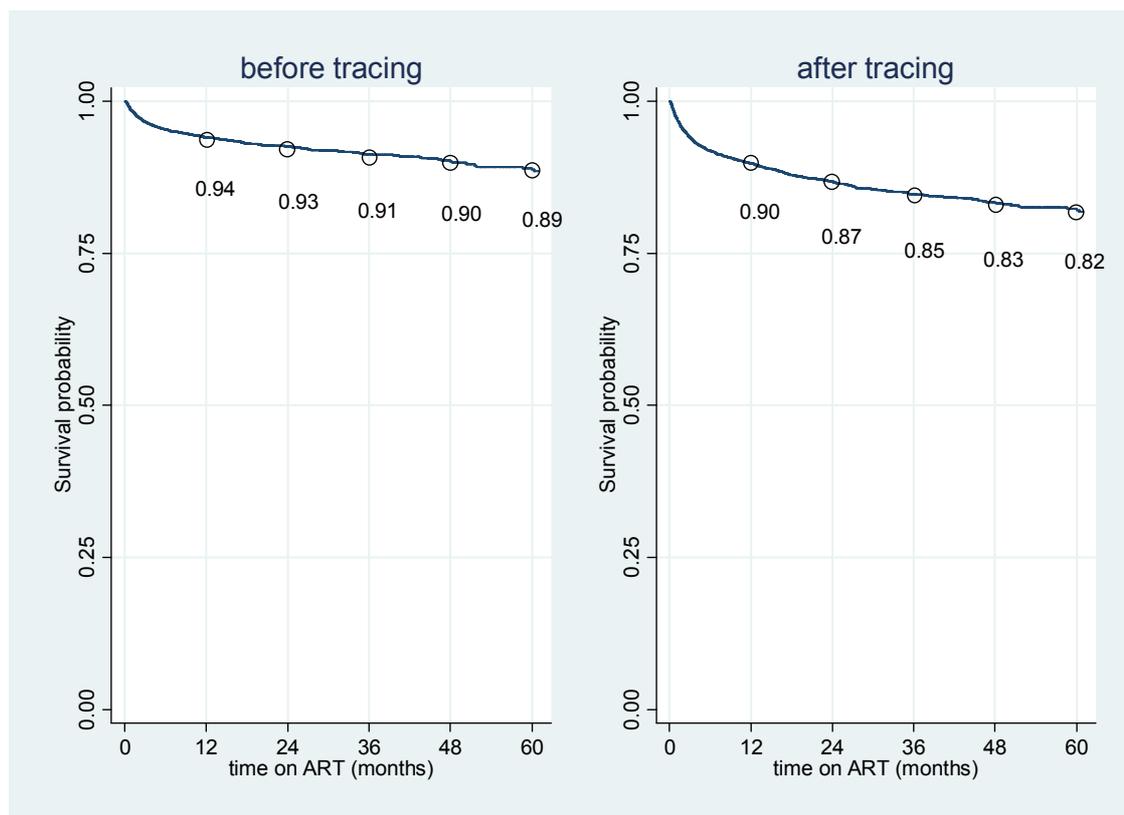
D=dead; LFU=lost to follow-up; RT=retained

**Figure 6-6: Retention and reasons for attrition by time after ART start**



The shape of the Kaplan-Meier curves in figure 6-7 express the sharp decline of the survival probability during the first 12 months. Based on uncorrected data, the probability of survival was 0.94 at 1 year, declining to 0.89 at 5 years. Data corrected for loss to follow-up show a sharper decline during the first few months of treatment, describing a survival probability of 0.90 at 1 year, declining to 0.82 at 5 years.

**Figure 6-7:** Kaplan-Meier survival estimates before and after tracing



### 6.2.8 Characteristics of deaths

Based on corrected data after tracing, I determined associations between patient characteristics at baseline and the outcomes death and loss to follow-up, using unadjusted risk ratios at 24 months, as shown in the tables 6-8 and 6-9. The risk for death at 24 months was considerably higher for men than women (RR 1.71), whilst there was no relevant association between male sex and loss to follow-up (RR 1.17). In contrast, age was associated stronger with loss to follow-up than with death: the risk for loss to follow-up was four times higher in the age group 18-24 than in the age group >45 (RR 0.24). Young age was also associated with death, but to a much weaker extent (RR 0.82 for the age group >45). Unsurprisingly, patients starting ART in WHO stage IV (RR 5.65) were much more likely to die than patients starting in WHO stage I (referent group), II (RR 1.33) and III (RR 2.75). Similarly, the risk of death was almost three times higher in patients with a CD4 below 50 than in patients with a CD4 cell count between 100 and 200 (RR 0.39). Interestingly, the death risk in patients who were on tuberculosis treatment at ART start was largely the same (RR 1.06) as in patients who were not on tuberculosis treatment. Unsurprisingly, death was 25 times more likely to occur when the patient had his last visit at the hospital, as compared to a health centre (RR 0.04).

**Table 6-8:** Characteristics of patients lost to follow-up and deaths and risk ratios for death at 24 months, corrected after tracing

		Retained		Lost to follow-up		Deaths		RR	95% CI
Sex	n (row %)	2960	78.3%	213	5.6%	608	16.1%		
	Female	2081	81.4%	142	5.6%	334	13.1%	1.00	
	Male	879	71.8%	71	5.8%	274	22.4%	1.71	1.48-1.98
Age group	n	2960	78.3%	213	5.6%	608	16.1%		
	18-24	87	69.6%	16	12.8%	22	17.6%	1.00	
	25-34	748	74.3%	76	7.5%	183	18.2%	1.03	0.69-1.54
	35-44	1150	78.4%	83	5.7%	233	15.9%	0.90	0.61-1.34
	>45	975	82.4%	38	3.2%	170	14.4%	0.82	0.55-1.22
WHO stage	n	2960	78.3%	213	5.6%	608	16.1%		
	1	152	88.9%	9	5.3%	10	5.8%	1.00	
	2	459	87.1%	27	5.1%	41	7.8%	1.33	0.68-2.60
	3	2125	78.1%	158	5.8%	437	16.1%	2.75	1.50-5.04
	4	224	61.7%	19	5.2%	120	33.1%	5.65	3.04-10.50
CD4 baseline	n	2033	80.2%	131	5.2%	372	14.7%		
	1-49	354	70.2%	30	6.0%	120	23.8%	1.00	
	50-99	434	78.3%	25	4.5%	95	17.1%	0.72	0.57-0.92
	100-200	836	85.9%	47	4.8%	90	9.2%	0.39	0.30-0.50
	>200	409	81.0%	29	5.7%	67	13.3%	0.56	0.42-0.73
Tuberculosis diagnosis at ART start	n	2960	78.3%	213	5.6%	608	16.1%		
	no	2123	78.5%	154	5.7%	427	15.8%	1.00	
	yes	837	77.7%	59	5.5%	181	16.8%	1.06	0.91-1.25
Health facility type	n	2953	82.4%	181	5.1%	450	12.6%		
	Hospital	1832	74.7%	177	7.2%	443	18.1%	1.00	
	RHC	1121	99.0%	4	0.4%	7	0.6%	0.03	0.02-0.07
Site	n	2960	78.3%	213	5.6%	608	16.1%		
	Zaka	1309	78.3%	98	5.9%	264	15.8%	1.00	
	Bikita	1651	78.2%	115	5.5%	344	16.3%	1.03	0.89-1.20
Haemoglobin	n	1943	79.1%	122	5.0%	390	15.9%		
	<12 g/dl	1352	76.5%	96	5.4%	319	18.1%	1.00	
	>12 g/dl	591	85.9%	26	3.8%	71	10.3%	0.57	0.45-0.73

ART=antiretroviral treatment; CI=confidence interval; RR=risk ratio; WHO=World Health Organization

**Table 6-9:** Risk ratios for loss to follow-up at 24 months among those not known to have died, corrected after tracing

		retained		lost to follow-up		RR	95% CI
sex	n (row %)	2960	93.3%	213	6.7%		
	Female	2081	93.6%	142	6.4%	1.00	
	Male	879	92.5%	71	7.5%	1.17	0.89-1.54
age group	n	2960	93.3%	213	6.7%		
	18-24	87	84.5%	16	15.5%	1.00	
	25-34	748	90.8%	76	9.2%	0.59	0.36-0.98
	35-44	1150	93.3%	83	6.7%	0.43	0.26-0.71
	>45	975	96.2%	38	3.8%	0.24	0.14-0.42
WHO stage	n	2960	93.3%	213	6.7%		
	1	152	94.4%	9	5.6%	1.00	
	2	459	94.4%	27	5.6%	0.99	0.48-2.01
	3	2125	93.1%	158	6.9%	1.24	0.64-2.38
	4	224	92.2%	19	7.8%	1.40	0.65-3.01
CD4 baseline	n	2033	93.9%	131	6.1%		
	1-49	354	92.2%	30	7.8%	1.00	
	50-99	434	94.6%	25	5.4%	0.70	0.42-1.16
	100-200	836	94.7%	47	5.3%	0.68	0.44-1.06
	>200	409	93.4%	29	6.6%	0.85	0.52-1.38
tuberculosis diagnosis at ART start	n	2960	93.3%	213	6.7%		
	no	2123	93.2%	154	6.8%	1.00	
	yes	837	93.4%	59	6.6%	0.97	0.73-1.30
health facility type	n	2953	94.2%	181	5.8%		
	Hospital	1832	91.2%	177	8.8%	1.00	
	RHC	1121	99.6%	4	0.4%	0.04	0.02-0.11
site	n	2960	93.3%	213	6.7%		
	Zaka	1309	93.0%	98	7.0%	1.00	
	Bikita	1651	93.5%	115	6.5%	0.93	0.72-1.21
haemoglobin	n	1943	94.1%	122	5.9%		
	<12 g/dl	1352	93.4%	96	6.6%	1.00	
	>12 g/dl	591	95.8%	26	4.2%	0.64	0.42-0.97

ART=antiretroviral treatment; CI=confidence interval; RR=risk ratio; WHO=World Health Organisation

As indicated in section 6.2.6., programme attrition was most severe during the first 12 months of ART. In effect, the analysis of corrected data revealed a median time between ART start and death of 104 (IQR 36-244) days for the entire study population. 676/1054 (64.1%) deaths occurred during the first 6 months after treatment start. There was a notable difference between the sites: in Zaka, the median duration from initiation to death was 135 days, in Bikita 83 days.

### **6.2.9 Characteristics of unreported deaths**

The proportion of deaths among patients classified lost to follow-up was 44.5% (490/1102), as compared to 7.9% (590/7471) among patients who were not lost to follow-up, resulting in a relative risk of death in losses to follow-up of 5.6 (95% CI: 5.1-6.2). As unreported deaths appeared as an important determinant of programme attrition in Zaka and Bikita, the question is raised: who were these lost patients whose death was not reported? Table 6-10 compares the characteristics of the patients whose death was reported (n=590) with the patients whose death was not reported (n=490). Patients whose death was not reported were on ART for a shorter period of time (28 days) than patients whose death was reported (43 days). Female deaths versus male (RR 1.26), deaths in Zaka district versus Bikita (RR 1.32), and deaths after the first ART visit (RR 1.13) were more likely to be unreported than deaths after more than one ART visit. Deaths were also more likely to remain unreported in patients who died after a treatment interruption (RR 1.61) than without having interrupted ART, interruption again defined as having missed an appointment for more than 7 days.

**Table 6-10:** Comparison between reported deaths and unreported deaths

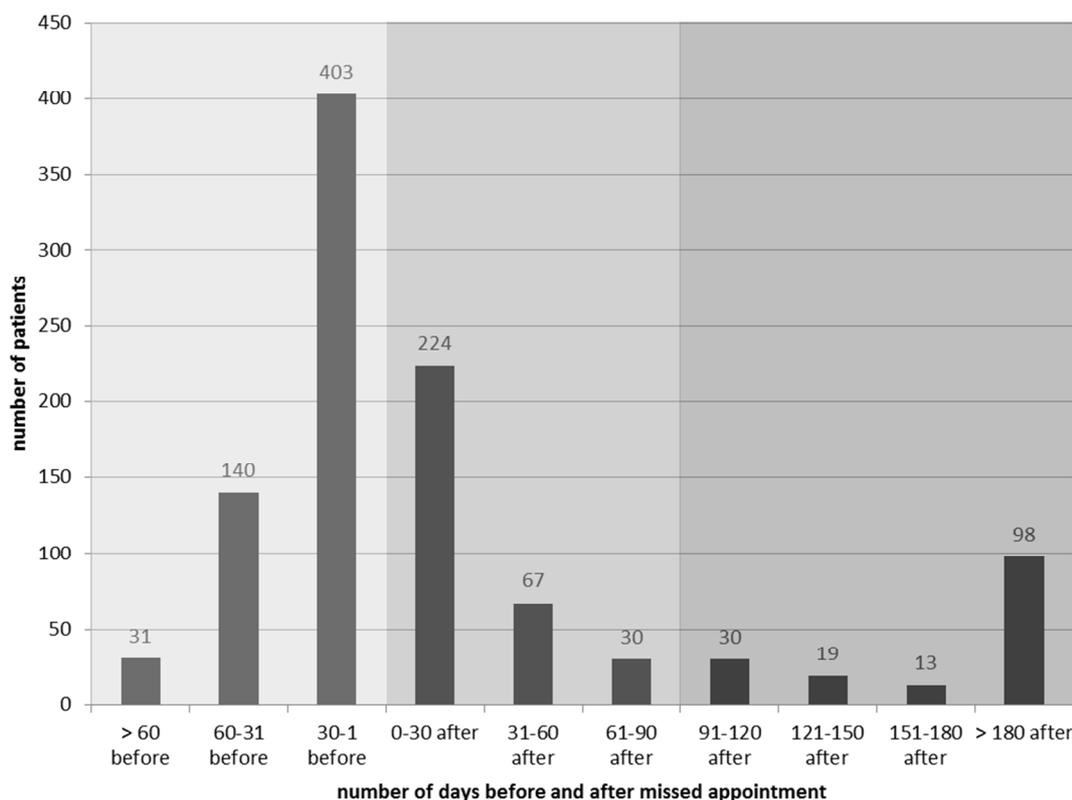
	total deaths	reported deaths (before tracing)	%	unreported deaths (after LFU tracing)	%	risk ratio (95% CI)
total	1080	590	54.6	490	45.4	
median age (IQR)	38 (33-47)	39 (34-47)		37 (32-46)		
median bsl CD4 (IQR)	82 (36-171)	87 (37-174)		76 (34-171)		
duration on ART (IQR)	39 (0-155)	43 (0-205)		28 (0-101)		
males	460	278	60.4	182	39.6	1
females	620	312	50.3	308	49.7	1.26 (1.09-1.44)
no TB diagn at 1 <sup>st</sup> visit	807	435	53.9	372	46.1	1
TB diagn at 1 <sup>st</sup> visit	273	155	56.8	118	43.2	0.94 (0.80-1.10)
Bikita district	582	352	60.5	230	39.5	1
Zaka district	498	238	47.8	260	52.2	1.32 (1.16-1.51)
death after >1 ART visit	780	438	56.2	342	43.8	1
death after first ART visit	300	152	50.7	148	49.3	1.13 (0.98-1.29)
death without interrupt.	572	370	64.7	202	35.3	1
death after interruption	508	220	43.3	288	56.7	1.61 (1.40-1.84)

ART=antiretroviral treatment; CI=confidence interval; LFU=lost to follow-up; RR=risk ratio; TB diagn=tuberculosis diagnosis; bsl=baseline

### 6.2.10 Time between the missed appointment and death

From the ART programme point of view, the time between the missed appointment date and the date of death matters. Figure 6-8 shows that 574/1055 (54.4%) deaths occurred before the next appointment, whereas 481/1055 (45.6%) deaths occurred after the patients had missed an appointment. The analysis shows that there was a time window that would have allowed the health system to trace the missed patient. However, as figure 6-8 shows, it is a narrow time window; 321/481 (67%) died as interrupters (90 days after missing the appointment), 224/481 (47%) within 30 days. Besides death on ART and death after interruption, a third category of deaths, the remaining 160/1055 (15.2%), occurred more than 90 days after the missed appointment, which is equal to the loss to follow-up threshold.

**Figure 6-8:** Number of patients by time between missed appointment and death



ART= antiretroviral treatment

## 6.3 Discussion of the quantitative findings

### 6.3.1 High retention on ART in spite of a socio-economic crisis

The national ART programme of Zimbabwe achieved excellent retention outcomes in the districts of Zaka and Bikita. The retention rate of 75% at 36 months indicates that these two districts were performing in the upper range of ART programmes in sub-Saharan Africa. In comparison, large retention studies reported between 64% (Cornell, 2010) in a South African government programme and 72% (Fox, 2010). in a systematic review of research supported ART programmes across 39 African countries. The achievements of the Zimbabwean ART programme are remarkable not only in the context of a general economic crisis and a poorly resourced health system. It is more than noteworthy that people were retained on ART even during the humanitarian hardship in 2008 and 2009, when the economy suffered hyperinflation, large parts of the health, water and transport infrastructure temporarily broke down, and when Zaka and Bikita were hit by a severe cholera outbreak.

According to the WHO Early Warning Indicator (EWI) for HIV drug resistance “retention in care” (WHO, 2012), the cohorts 2006, 2007, 2008 and 2009 were on “amber” (below the 85% retention threshold at 12 months). The EWI for the cohorts 2010 and 2011 indicated “green” (for above 85%). Whilst retention improved in general over calendar time since the ART programme was launched, there are two exceptions: The 2005 cohort had outstandingly high retention proportions at any time point, starting with 86% at one year to 67.4% at six years. Most probably, this was due to the fact that there were many health workers amongst the first 108 patients who were enrolled in 2005. Health workers represent a patient group that has immediate access to drugs, diagnostics, information and other services that enhance adherence and retention. The second outlier was the 2009 cohort: the 12-months retention dropped temporarily from 83% in the 2008 cohort to 81% in the 2009 cohort, before climbing to 85% in the 2010 cohort. As discussed above, this effect – at a small size though – might have been due to the humanitarian crisis in 2009.

I argue that three factors have contributed to improved retention over calendar time:

**Early initiation:** It is most likely that earlier ART initiation contributed to improved retention: the median CD4 cell count at enrolment increased steadily from 55 in the 2006 cohort to 178 in the 2011 cohort. As low CD4 cell counts clearly increased the death risk in this study, earlier ART initiation obviously led to improved retention.

**Socio-economic recovery:** After the crisis in 2008 and 2009, the socio-economic and humanitarian recovery might have contributed to improved ART outcomes. Since 2010, people had money in their pockets; fuel, water and electricity were available; and the cholera outbreak was under control. Consequently, the annual number of ART initiations has steeply increased since 2009 (from 1359 to 2806 in 2011), and the 6-month retention proportion has improved (from 85% in 2009 to 90% in 2011).

**Decentralisation of ART follow-up:** Even though it was not a specific research question, this study confirms evidence from other studies, such as Fatti (2010) and Long (2011), suggesting that decentralisation of ART provision contributes to improved retention. By 30 June 2012, 31% of all patients in the SMART programme had their last consultation at health centre level. The risk for death was 25 times higher in patients who had their last visit at a hospital, if compared to patients who had their last visit at a health centre. Obviously, this result is strongly influenced by the fact that clinical stability was a criterion for decentralization.

### 6.3.2 Tracing reveals high mortality on ART

A previous study conducted by the leDEA collaboration Southern Africa reported approximately the same proportions of retention, loss to follow-up and deaths for Zaka and Bikita as our study did *before* tracing: at three years, Wandeler (2012) found 75% patients retained (this study 74%), 16% lost to follow-up (this study 13%) and 9% dead (this study 13%) without correcting data for mortality among patients lost to follow-up.

Based on corrected data after tracing, our study revealed that 62% of the patients who were initially classified lost to follow-up had died, and 30% had moved away without reporting it to the health facility. After tracing, the proportion of deaths contributing to attrition doubled. Underestimated mortality on ART is well-known. It has been mainly attributed to early deaths. Based on mortality data after active tracing, Brinkhof (2009) and Egger (2011) developed a mathematical model to calculate mortality estimates adjusted for loss to follow-up. Wandeler (2012) applied these models to the mortality data they found in Zaka and Bikita. The modelling resulted in an estimated mortality increase at 12-months from 6% to 11%, which matches very well with the corrected data ascertained through tracing by this study (6.4% mortality increasing to 11.5% at 12 months). Whilst the model provided accurate estimates of corrected 12 months mortality, our study added long-term retention observations. With a median time of 461 days between the missed appointment and the day of tracing, SMART ascertained the status of patients long after the patients were lost to follow-up. This study showed that late deaths (after 6 months) on ART are even more underestimated than early deaths.

Our findings showed that the status “lost to follow-up” is an administrative category, comprising unreported deaths and unreported transfers. As the risk of death is 5.6 times higher in patients classified as lost than in the rest of the ART cohort, to enhance retention on ART, programmes should investigate and address their unreported deaths. Risk factors for unreported deaths have implications for ART programmes since sustainable patient tracing interventions should target the most vulnerable patients.

After death, unreported “silent” transfers of patients to another health facility were the second reason for losses to follow-up. The SMART tracing pilot showed that a considerable proportion of mobile patients did not obtain a transfer letter when moving away, and might therefore face obstacles to stay on ART without interruption. Ensuring proper transfers of patients to another ART programme would not only assist the patient, but reduce programme attrition. In Zaka and Bikita, transfer letters could only be issued by the two hospitals, but not by ART follow-up sites. It appears that decentralized patients were reluctant to travel to the hospital to obtain a transfer letter.

An electronic patient data system, containing the national patient identification numbers, would contribute to a reduction of losses to follow-up, allowing patients to access ART at any point in the system whilst travelling. ART sites should also provide patients with an extra supply of ART drugs to cover for missed appointments.

### **6.3.3 Decentralised tracing**

Tracing in the SMART programme was conducted at health centre level by professional health workers (nursing personnel and environmental health technicians) and by community health workers. The study results suggest that tracing by professional health workers works well if there are monetary incentives, such as the US\$3 per traced patient in the early stage of the SMART tracing programme. Adding the costs for utilising motorbikes, tracing by professional health workers might not be affordable in the long run. Moreover, considering the severe shortage of professional health workforce in Zimbabwe, home tracing by professionals does not appear an effective allocation of scarce human resources. Phone tracing, which was not performed by the SMART programme, might be a cost-effective alternative worth considering. When payments for tracing were dropped, the professional health workers' tracing efforts decreased remarkably, and the workload was taken over to a large extent by voluntary community health workers, in particular by the CHASA, thus adding valuable extra lower-skilled workforce to the SMART programme.

The programme managed to trace 86% of the suspected losses. The high tracing coverage was due to the fact that tracing was conducted in a decentralized system. Centrally-organised tracing programmes have found it difficult to locate lost patients. Weigel (2011) reported tracing coverage of only 40% from a large ART programme in Malawi, explaining the low response largely by the fact that patient contact information was not available to the tracers. Besides the fact that centrally organised tracing is costly because it requires designated personnel and motorbikes, this study shows that decentralized tracing is feasible and can achieve a high coverage.

12% of the suspected losses were actually patients who were alive and on ART. Inaccurate medical record keeping by the ART nurses contributed to these false losses to follow-up simply caused by health workers failing to keep records on ART consultations. The study team observed that the reason for erroneous documentation in SMART hospitals was attributable to the system. Nurses routinely documented an ART visit after the consultation to safe time. Because long queues of patients were waiting to be seen, ART nurses often only filled in the medical records in the evening, often omitting key data. We perceived a generally careless attitude of health workers

on data management. Good quality electronic data was available only thanks to extensive quality control and data cleaning efforts by the SMART's data managers.

#### **6.3.4 Treatment interruption a neglected threat to long-term retention**

Retention studies tend to overlook the fact that many ART patients temporarily interrupt therapy. This study found that treatment interruption was a frequent event in Zaka and Bikita. 28% of the ART patients who were considered “retained” by SMART actually missed an ART appointment for a median duration of 32 days. This finding compares well with other studies. A cohort study in urban South Africa found that 35% ART patients missed at least one ART visit for more than 7 days (Brennan, 2010). In their systematic review of 70 cohorts worldwide, Kranzer and Ford (2011) found 23% interrupters with a median duration of 150 days. However, only 16 studies were from sub-Saharan Africa, and the review found heterogeneous definitions of ART interruption, ranging from 24 hours to one year. The review revealed a broad range of frequency proportions, from 5.8% therapy interruption in a large Swiss cohort to 83.1% in a prison cohort in the USA (ibid.). Most recently, a study from urban Uganda showed that 11% patients had a treatment interruption of more than 12 months before resuming ART (Mills, 2013b).

As described in section 6.1.5, I defined “treatment interruption” as missing an ART appointment for more than seven days under the assumption that the patient has a reserve supply for five days only and runs out of drugs from day six after missing an appointment. In reality, a treatment gap can occur before the next appointment if the patient loses or sells his or her drugs. On the other hand, patients might borrow pills to cover for more than five days. Using a threshold of 30 instead of seven days still resulted in 16% interrupters among the retained patients. Our findings show that unstructured treatment interruption is a problem in SMART, particularly with regard to drug resistance development.

These findings call into question the validity of the WHO early warning indicator “retention in care” on ART drug resistance (WHO, 2012) which does not take treatment interruption into account. In the light of the findings of this study, the retention indicator does not appear as an appropriate measurement for the risk of resistance development.

#### **6.3.5 Risk factors for death**

Contrary to studies correcting mortality based on mathematic modelling, this study allowed linking tracing data with patient data, and thus describing the group of all

deaths in more detail on the basis of corrected data. This study confirmed available evidence that early mortality is highly relevant, since two thirds of the deaths occurred within 6 months after therapy initiation – a result which according to recent literature on death during ART is most likely to be caused by tuberculosis (Wong, 2012).

Concerning risk factors for death, this study showed consistent results with previous research: male sex, low CD4 cell count, advanced WHO clinical stage and anaemia were strongly associated with death, as reported in the systematic review by Gupta (2011). However, retention studies, including many of those reviewed by Gupta (*ibid.*) use uncorrected data and therefore tend to report risk factors strongly biased for unreported deaths among losses. Compared with the well-known significant associations between low CD4 cell count and mortality, loss to follow-up in our study was *not* associated with the patients' clinical stage at treatment initiation. Other studies, such as Boyles (2011) and Charurat (2010), showed that non-death losses were associated with a high CD4 cell count. In our study, young age was much more strongly associated with loss than with death. These findings underline that loss to follow-up largely comprises two entirely different groups of patients: young and healthy patients classified lost because they moved out of the programme area and unreported death of very sick patients.

### **6.3.6 Death a consequence of ART discontinuation**

We showed that only very few patients did directly benefit from patient tracing. Because tracing was only initiated 90 days after a missed appointment, only very few interrupters were found alive. 62% had already died. Our study revealed that a large proportion (45%) of the deaths was hidden and that deaths were more likely to remain unreported if they occurred after missing a scheduled appointment than before. Interventions to reduce mortality on ART might need to consider the time of death in relation to the missed appointment. Deaths in the SMART programme can be distinguished into three groups; death on ART, death after interruption, and death after loss to follow-up, as shown in figure 6-8.

#### *Death on ART*

More than half of the deaths (54%) occurred *before* the next scheduled appointment, whilst the patients theoretically still had ART drugs. Most likely, these patients were very sick, which might have been the reason why they stopped ART. Treatment might have been initiated in spite of a severe opportunistic infection, or the health worker might have missed life-threatening signs and symptoms. Previous studies have clearly shown that delayed ART initiation is the major reason for these deaths (Lawn, 2008). In

spite of the recommendation by the WHO and the MOHCW to initiate patients earlier, the median CD4 cell count at baseline in the SMART programme was still as low as 180 in 2012. Besides earlier initiation, the literature suggests that preventing this group of deaths requires timely diagnosis and treatment of tuberculosis and a careful, decentralised clinical monitoring of ART patients during the first six months of treatment.

#### *Death after interruption*

The second group, accounting for almost one third of all deaths (30%) died within the first 90 days after missing an appointment and – most likely – running out of ART drugs. Taking into consideration that patients who discontinue ART can die for reasons not related to HIV/AIDS, it appears plausible that many deaths could have been prevented through an ART restart. Due to the fact that patients were traced only 90 days after missing the appointment, there was no chance that SMART could have prevented these deaths through tracing. The analysis shows that there was a time window that would have allowed the health system to trace the missed patients, particularly those with a low CD4 cell count, and to bring them back to care before their condition further deteriorated. However, for half of this group, the time window for tracing would have been extremely narrow, since half of this group died within 30 days.

#### *Death after loss to follow-up*

The third and smallest group (15%) of deaths were patients who died after being lost to follow-up, meaning that they missed their appointment – and were without drugs – for more than 90 days. It can be assumed that many patients in this group died as a consequence of stopping ART. Other than HIV related causes might have contribute to the deterioration of these patients' condition that finally led to their death. In addition to their critical health condition, reasons rooted in the social, economic and cultural environment of these patients could have made them miss their scheduled ART appointment and prevented them from returning back to care.

### **6.3.7 Strengths and weaknesses**

The aim of the quantitative study component was to set the scene for the qualitative research, and to raise questions to be addressed through interviews and focus group discussions. The available good quality electronic data sets allowed a broader analysis than initially planned. A particular strength was the availability of tracing data that was merged with patient and visit level data. Many retention studies are strongly biased by unreported deaths classified as lost. Mathematical modelling can correct mortality

rates, but it does not provide a better understanding of death on ART. A strength of our study was the temporal analysis of corrected data, marked by the time points last visit, missed appointment, tracing date, date of loss to follow-up, and date of death. Our study can be considered fairly generalizable in the context of rural Zimbabwe, since the NGO support was moderate. The electronic database was probably the most sophisticated intervention of SMART, and it is the good quality data generated by this system which is not available in many other rural districts of the country.

There were limitations in this study component. As the priority of the study was initially given to the qualitative component, I was not trained in advanced statistical analysis. This led to a certain lack of depth in the analysis of the data. This methodological constraint limited the validity of the quantitative results, as non-adjusted risk ratios did not allow testing the degree to which confounding was affecting the observed associations. For example, it remains unresolved to which extent factors that were related to the differences between Zaka and Bikita influenced the associations found between patient characteristics and retention outcomes. The settings in terms of the health care system, the ART programme, and the distances were very similar in both districts. The study results suggest that there were slight differences with regard to the SMART interventions and the cohorts: Bikita launched ART services two years after Zaka, and decentralisation of ART follow-up also progressed slower in Bikita (35% in Zaka versus 27% in Bikita attended their last visit at a decentralised site). Zaka (19.3%) enrolled fewer patients during the years of crisis (2008-09) than Bikita (32.3%). Furthermore, patients from Zaka initiated ART at a later stage of the disease than patients from Bikita, as indicated by a median CD4 cell count at baseline of 137 in Zaka versus 157 in Bikita. As for the tracing intervention, formal health care workers were more frequently involved in tracing in Bikita (74%) than in Zaka (53%). The findings also revealed that treatment interruptions among retained ART patients were more frequent in Bikita (33.7%) than in Zaka (22.7%), whilst the median treatment gap was shorter in Bikita (30 days) than in Zaka (42 days). In spite of some minor differences between Zaka and Bikita, the retention outcomes were almost identical between the two sites. To what extent the site differences influenced retention outcomes could have determined by means of multivariate statistics. With regard to the main quantitative and qualitative findings of the present study, however, I consider the site differences of minor relevance.

Our quantitative data suggested that treatment interruption was a relatively frequent event, occurring in every fourth retained patient. It appeared that ART restart after

interruption critically impacted long-term retention. Hence, the key issue to be explored in the qualitative study component was to better understand why patient did or did not return to the ART programme after temporarily stopping therapy.

## 7 Understanding ART interruption and restart: qualitative findings

### 7.1 Conceptual framework

The present study is based on the theoretical assumption that everything that humans do – such as perceiving, feeling, thinking, interpreting and acting – is social practice in a sense that it is both influenced by *structure*, the context where individual action is embedded, and *agency*, the capacity of human subjects to act, take choices, and to change their environment (Ortner, 2006). This theoretical approach, Practice Theory, rejects any deterministic theory that explains social action either as a consequence of entirely individual attitudes and beliefs or as determined by economic, cultural or ecologic structures and power relations.

Influenced by health psychology, theories of individual health behaviour focus on cognitive factors, such as information, knowledge, attitudes, motivations and beliefs. In this theory tradition, health behaviour is the outcome of an individual's perceptions and expectations, as suggested by the Health Belief Model (Nutbeam, 2013). The Social Ecological Model, also focusing on individual behaviour, argues that health behaviour is shaped by "health-enabling social environments" rather than a function of individual beliefs (Skovdal, 2011b). The two models imply different approaches to health promotion. Whilst cognitive theories promote changes of the individual's knowledge and attitudes – for example through information, education and communication methods – the sociological models suggest community-based interventions to increase social cohesion and collective self-determination (ibid.).

Whereas behaviourist and sociological models suggest that people can improve their health primarily through behaviour change, Marxist and feminist theories emphasise that social life is determined by unequal power relationships in the wider society (Ulin, 2005). In these theory traditions, changes in the lives of people require transformation of the social, cultural and economic environment. These theories suggest that societies are fundamentally shaped by power relationships, for example between men and women, rural and urban, or labour workers and property owners. Rather than promoting changes in individual behaviour, health interventions informed by Marxist and feminist approaches attempt to change broader policies and systems affecting the health of disadvantaged groups. This theory tradition was critiqued as "constraint-

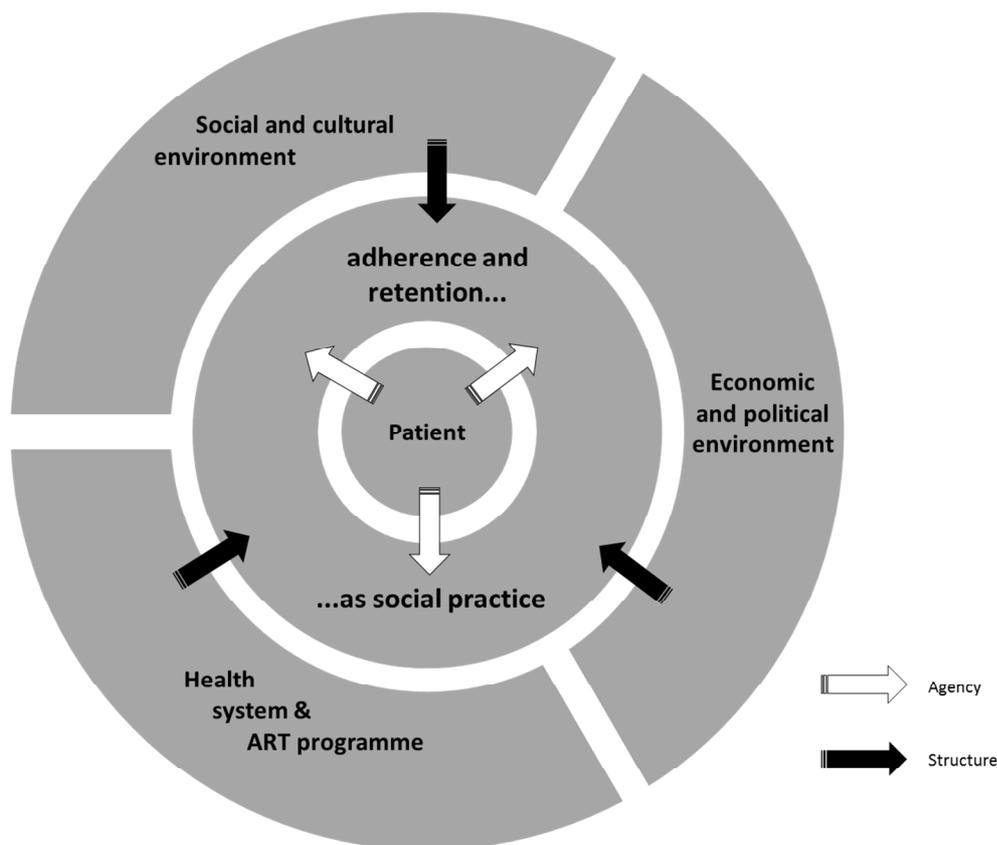
based” (Ortner, 2006), tending to neglect the ability of individuals and communities to improve their health by transforming their immediate environment.

Studies on medication adherence often use a behaviourist approach to explore factors that influence the patient’s “motivation” for pill taking. To gain a better understanding why patients interrupt and restart life-long ART in the setting of rural Zimbabwe, this study required a broader conceptual framework than behaviourist or structuralist models offer.

In the conceptual framework of Practice Theory, social practice is influenced by the individual through “human agency” and by the larger environment through “social structure” (Ortner, 2006). The approach suggests that agency and structure are related to each other by the fact that individuals shape the world in which they live and are at the same time guided in their action by their cultural, social and economic environment (ibid.). Agency is a key concept of Practice Theory. It refers to the individual’s capacity to act, to take decisions and to make choices (ibid.). Closely linked with social practice is the concept of social capital, defined as the individual’s “resources embedded in a social structure which are accessed and/or mobilized in purposive actions” (Lin, 1999). This concept suggests that the quality and quantity of an individual’s social relationships and networks influence the outcomes of his or her actions. Social ties facilitate access to information, exert influence, represent the individual’s social credentials, and reinforce his or her social identity (ibid.). The notion “capital” underlines the individual’s aim to invest in social relationships with expected returns. Individuals engage in social networking through investments as diverse as care, loans, marriage, or participation in community activities. The concept suggests that individuals engage in social networks because they expect future gains.

Translated into the field of ART retention, people living with HIV are “practicing” ART retention, as illustrated in figure 7-1. Through agency that is driven by the patient’s individual needs and desires (white arrows), and constrained by their environment and the health system (black arrows), the patient may or may not be motivated and able to adhere to life-long ART.

**Figure 7-1:** Conceptual framework of the study



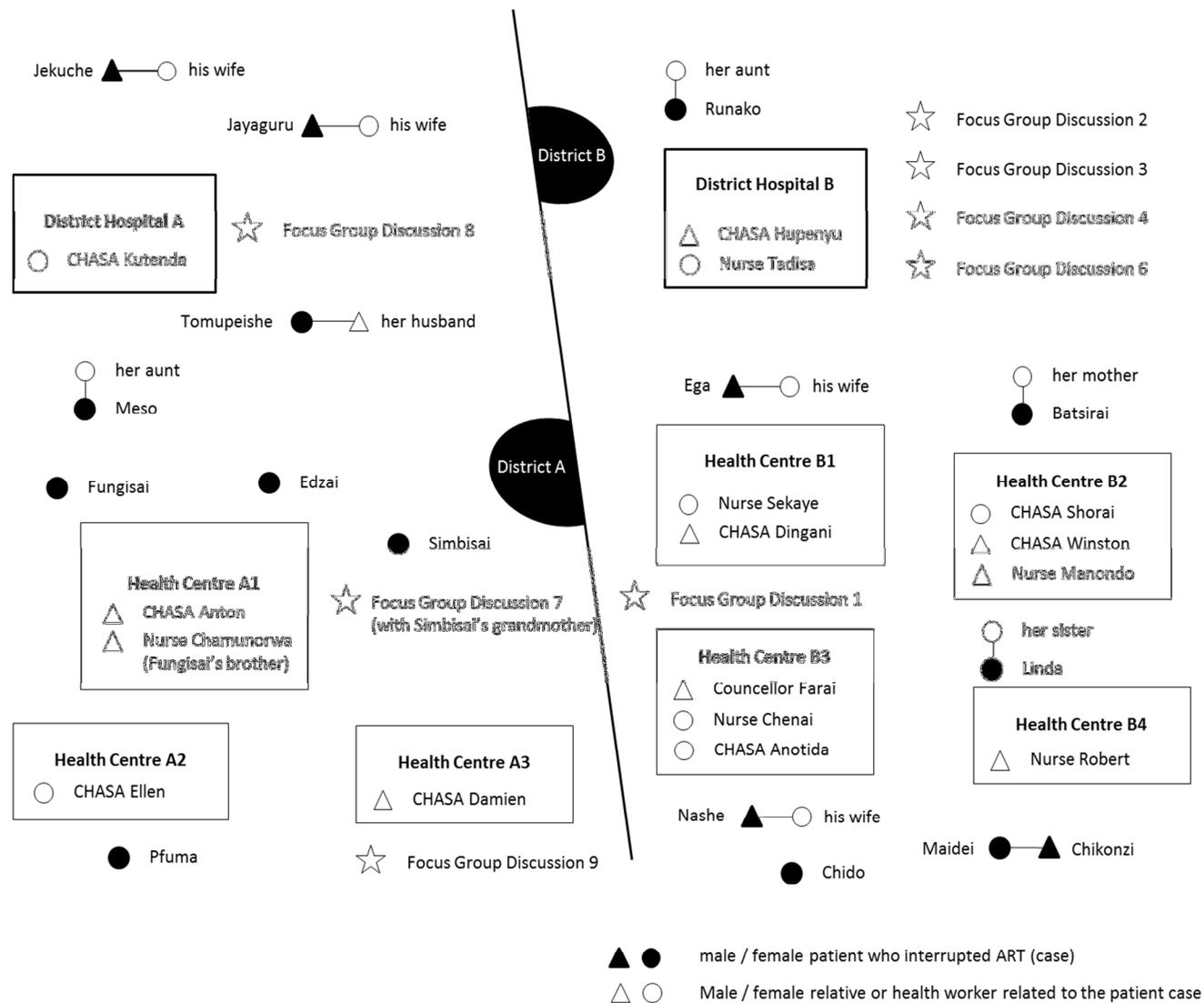
The chosen conceptual framework had a number of implications for the design and the methodology of our study. Firstly, it encouraged a mixed-methods approach including qualitative methods to explore and understand retention as social *practice*. Secondly, since the framework suggested that retention is “practiced” between agency and structure, the study explored the social microcosm of people on ART. Rather than aiming at interviewing a broad variety of individual cases throughout the two districts, data were collected in limited geographical clusters, with a particular focus on the local health care system and the patients’ social networks. Thirdly, the interviews and focus group discussions were held not only with patients lost or retained on ART, but also with members of their family, household and community as well as with their health workers. Fourthly, the conceptual framework informed the topic guides for interviews and focus group discussions in such a way that it covered a broad range of issues related with retention at the level of the individual, the health system and the patient’s immediate social, economic and cultural environment.

## **7.2 Methodology**

### **7.2.1 Cluster sampling strategy**

With the aim to explore patient retention in the context of selected local health facilities and social networks, I limited the study area geographically to four clusters: the surroundings of the two district hospitals and a cluster of health centres in each district. Figure 7-2 maps out the selected health facilities and study participants. The cluster in district A (population 35,000) included three health centres 30-50 kilometres from the district hospital; district B (population 50,000) included four health centres, 20-60 kilometres from the hospital. The selection criteria for the health centre clusters were purposive and logistic: the clusters had to be at least 20 kilometres from the hospital so that transportation and decentralisation were potentially relevant themes; enough ART patients to allow identification of the required number of ART interrupters; and accessible by vehicle within a three-hour drive to allow the interviewers getting there and back within a day.

**Figure 7-2: Mapping of health facilities and study participants**



### 7.2.2 Data collection methods

To better understand the reasons why ART patients discontinue their therapy and under what circumstances they return to the programme, I applied a triangulation approach, choosing three methods of qualitative social science, namely in-depth interviews, focus group discussions, and participant observation (Green and Thorogood, 2009). In my understanding of triangulation, this approach does not aim at validating the “truth” of the patient’s story in the sense of a positivist perspective of health research (Ulin et al., 2005). Distinct from geographical navigation, triangulation in qualitative social science aims at a deeper and more holistic understanding of the research subject. In this study, different data collection techniques provided data – namely perceptions and interpretations – from different angles on the very same research question; ART treatment interruption. To reconstruct and understand the individual stories of the therapy interrupters, I interviewed not only the patient himself, but also his or her relatives and health worker on how they perceived and interpreted the patient’s decisions to stop and restart ART. Sometimes, the accounts were contradictory, and sometimes the stories remained inconsistent. It was striking to recognize that different actors suggested different interpretations of the situation. Besides triangulation of *data*, even more importantly, triangulation of the three *methods* enriched the overall picture on how ART interruption and restart is perceived at different levels, such as the individual, the community, and the health system. In-depth interviews were conducted to capture detailed first-hand information and explanations from a personal point of view. I conducted focus group discussions to complement the interviewees’ personal perspectives. Data from focus group discussions provided – sometimes conflicting, sometimes commonly accepted – insights into community opinions and attitudes on why patients interrupt ART. Participant observation, finally, was conducted to “read between the lines”, and to better understand the meaning of the respondents’ information in the local context and in the setting of the health facility.

#### a) In-depth interviews:

In-depth, open-ended interviews with patients were the principal data collection method with the aim of reconstructing case stories of patients who interrupted ART. In addition, we held one or more interviews with partners and relatives in the social and health care environment of the patients to contextualise the case.

Inclusion criteria for the patient cases were

- an interruption of ART for at least 90 days, either at the time of the interview or in the past;

- age over 18;
- residing in the catchment area of one of the selected health facilities;
- inclusion of both sexes, different age groups and residents of both districts.

We interviewed 44 participants in the following four groups:

- 16 ART patients who interrupted therapy – the “cases”;
- relatives of the cases;
- health workers (9 nurses and 1 professional counsellor) of the cases;
- CHASA who knew the cases.

We recruited the patient cases through purposive and snowballing sampling, pursuing two main strategies. Firstly, we identified patients purposively among those found alive by a tracer through the on-going SMART patient tracing intervention. Secondly, ART nurses and other ART staff at the included hospitals and health centres, including community health workers, were asked through snowballing if they knew retained patients who once interrupted ART. Out of the sixteen cases included in the study, five were found through tracing, eleven through health worker contacts.

We also used purposive sampling to recruit health workers. With the aim to collect data from professional as well as lay health workers, we asked ART nurses and CHASA at every health facility to participate in the study. We included the participants on the basis of their availability during our field visits. To recruit partners or relatives, we used opportunistic sampling. At the end of the interview, we asked the patients whether they would allow us to interview a close relative or their ART treatment partner. In nine out of sixteen cases, we successfully recruited partners or relatives.

We explained the purpose of the study to all candidates, gave them a participant information sheet, and asked them for written consent (see the forms in appendix 5). All candidates agreed to take part in the study. We held and audio-recorded all interviews in Shona language. In interviews I conducted myself, I was assisted by a translator (see section 7.2.5 on roles). We used different interview topic guides for patients, relatives and health workers (see appendix 6). The 10 topics in the guide for patients and relatives were: the patient’s health now; experience and perception of ART and ART interruption; retention and adherence; being HIV-positive; role of the health facility; role of family and kin; role of support groups; partnership and gender relations; knowledge and cultural concepts; and patient tracing. The topic guide for health workers included 8 topics: personal background; ART programme in general; ART patients (including the known cases); retention and adherence; support groups; CHASA; cultural concepts; and tracing.

## b) Focus group discussions

We held eight focus group discussions with 78 participants (48 female), of whom 71 were on ART and 8 were health workers (table 7-1). Three focus group discussions were held in district A and five in district B, as shown in figure 7-2.

**Table 7-1:** Participants of the focus group discussions

	type of participants	number of participants			number on ART	median age
		total	female	male		
FGD 1	support group members	11	8	3	8	52
FGD 2	women age < 25 years	5	5	0	5	23
FGD 3	men > 24 years	13	0	13	13	54
FGD 4	women > 24 years	11	11	0	11	43
FGD 5	health workers (tracers)	8	4	4	5	41
FGD 6	support group members	9	7	2	9	47
FGD 7	women mixed age	9	9	0	9	37
FGD 8	support group members	12	4	8	11	45
	<b>Total</b>	<b>78</b>	<b>48</b>	<b>30</b>	<b>71</b>	<b>43</b>

FGD=focus group discussion; ART= antiretroviral treatment

There were three types of focus groups: ART patients (4 groups), support group members (3), and health workers (1). We formed the groups and recruited the participants through snowballing during field-work in the selected study areas. We chose members of support groups of people living with HIV due to their strong representation in the two districts, and based on the fact that health workers considered the groups as an important link and platform between the health care system and the community. Candidates for group discussions were also informed about the study and asked for written consent. One candidate opted out after receiving the information. Focus group discussions were held in the Shona language and audio-recorded, moderated by one or two trained Zimbabwean facilitators. Topic guides are shown in appendix 6.

## c) Participant observation

During two months of field-work at the included health facilities we engaged in informal interactions and documented our observations in field notes and memos. The study team and I engaged in numerous informal conversations with health workers and patients, particularly at the ART clinics of the two district hospitals, where the researchers were based during field-work. The ART clinics were suitable settings for observing health worker-patient interactions and everyday life in the clinic. Informal chats were held with patients and their relatives in the waiting area, and with health workers and supportive personnel in the administration units. Health centres served as

meeting points for community health workers and support groups, where we benefitted from informal encounters.

### **7.2.3 Data analysis**

We transcribed and translated all interviews and focus group discussions into English. To assure good quality of the transcriptions, we gave the audio files and transcription documents to a third person for checking of the translation. Her comments were discussed with the transcribers. The study team undertook preliminary content analysis of selected interviews in the course of field-work. We discussed the emerging themes as well as the individual cases. Towards the end of the field-work, the interviewers gave a presentation to the health workers of the included health facilities on the tentative study findings.

After completion of the field-work, I imported the transcripts of the interviews and group discussions and the field notes from participant observation into NVivo 9 for data analysis. I found Framework Analysis to be the most appropriate method for analysing the qualitative data, because it was developed explicitly to generate findings for public health practice and to inform policy makers on developing and steering health interventions (Green and Thorogood, 2009). The framework matrix provided a useful grid to display and summarize the patient case stories as well as the key themes.

To familiarize myself with the data, I listened to the audio-files and read the transcripts and other written data sources. During familiarisation, I investigated the qualitative data for themes and coded the text accordingly. I used the emerging coding scheme to index all qualitative data. After discussing the coding scheme with my academic supervisor, I established the analytic framework. The analytic framework included eight thematic categories with a number of related codes each. Moving from description to analysis, I reconstructed the sixteen case stories using the available sources from different interview participants (see section 7.3 for selected case narratives and appendix 7 for the rest of the case narratives). From the analytic framework, I identified key themes and compared them across the sixteen cases and the focus group discussions. I then cross-tabulated the key themes with all utilised codes in NVivo 9 to identify frequent links made by the participants between themes. The results of this descriptive analysis are presented in section 7.4. I mapped out the key themes related to ART interruption and restart and the strength of the links so that patterns could become visible. I established the framework matrix using the sixteen cases as rows and the identified themes as columns (table 7-4). I filled each cell of the matrix with a

summary of the respective data. Finally, I interpreted the entire qualitative data on the basis of the maps and the matrix.

#### **7.2.4 Roles**

Five study team members were involved in the qualitative study component as interviewers (Sibonginkosi Dunjana, SD, and Stephen Buzuzi, SB), translators (Sibonginkosi Dunjana and Lillian Chemhere, LC), community mobilisers (Lillian Chemhere and Mugove Gonese, MG). LC and MG, who work for the local NGO Batanai HIV/AIDS Support Organisation (BHASO), assisted me in recruiting the study participants and communicating with community members for participant observation. I conducted 25 interviews myself, assisted by either SD or LC as translator. SD, who is a trained interviewer with a Master of Social Science, conducted 19 interviews on her own in Shona. I facilitated the focus group discussion with the patient tracers, assisted and translated by SD. The other seven focus group discussions were facilitated in Shona by SB, SD and LC. All transcripts were checked for translation quality by an external translator. At the end of the field work, a workshop was held with the study team, where cases and emerging themes were discussed. I analysed the qualitative data after completing field work on my own in NVivo 9.

### **7.3 Interrupting ART: Case characteristics and narratives**

The qualitative component of our study is built around the stories of sixteen patients who discontinued ART. Three narratives are presented in this section, the rest of the stories can be found in appendix 7. The following is a brief introduction of the 16 cases (all names are pseudonyms), their detailed characteristics are shown in table 7-2.

**Batsirai, the abandoned young mother:** interrupted ART to hide her HIV status from her new husband, was later abandoned by her in-laws, became severely ill, and never restarted treatment until her death a few months after the interview.

**Chido, the primary school teacher:** interrupted ART whilst on travel, was denied down-referral upon return to care, felt maltreated by the hospital nurse for being a “defaulter”, and restarted after 5 months thanks to a close relationship with a health centre nurse.

**Chikonzi, the former prisoner:** was on ART in prison, interrupted treatment after being released, felt blamed as a “defaulter” by hospital staff and claimed long distance to the hospital the main reason for staying away from ART.

**Edzai, the brave widow:** mother of two children whom she had to leave with her parents' when she married again, stopped ART to hide her HIV status to her new husband, but was determined to restart even at the cost of a divorce.

**Ega, the old man with the beautiful garden:** stopped ART after being encouraged to do so by the Apostolic Church leader, felt ashamed for having “defaulted”, and restarted ART after falling ill thanks to the support of his wife and the nurse in-charge.

**Fungisai, the woman who saw flames:** initiated ART during an episode of mental disorder, was never fully adherent and was successfully restarted thanks to her brother who is the nurse in-charge at the local health centre.

**Jayaguru, the wealthy farmer:** famous in the district for his tomato plantation, discontinued ART during extended travel, felt ashamed for having “defaulted” and therefore stayed away from the hospital until a CHASA encouraged him to return to care.

**Jekuche, the religious teacher:** well-known and highly educated Headmaster of a secondary school, stopped ART after an announcement of the Apostolic Church leader to abstain from medication, fell ill and was compelled to restart treatment by his wife.

**Linda, the widow with the stick:** was left by her husband after testing HIV-positive, stopped ART after getting involved with a religious community, became disabled after suffering a stroke, and was then taken home by her sister who helped her restart ART.

**Maidei, the mother who stopped drinking beer:** illiterate widow and mother of five children, considered herself a former alcoholic, stopped ART drugs after completing tuberculosis treatment, married Chikonzi, stopped drinking and restarted ART during pregnancy with her latest child.

**Meso, the maltreated orphan:** probably vertically infected with HIV, lost both parents in early childhood, married early to escape from abusive custody at brother's family, stopped ART to hide HIV status in marriage, lost husband and baby whilst still a teenager, fell ill and died a few months after the interview without having ever found a caring environment.

**Nashe, the labour migrant:** was on ART whilst working in South Africa, discontinued treatment when returning home to wife and baby, stayed away from ART due to lack of income, distance to care, and feelings of shame for having “defaulted”.

**Pfuma, the illiterate mother:** living in extreme poverty in a remote homestead, husband working in South Africa without supporting his family, discontinued ART after

having missed a follow-up consultation and been sent back to hospital for re-start, stayed away from treatment due to long travel distances causing high transport and lodging costs.

**Runako, the teenage orphan:** probably vertically infected with HIV, kept asking herself “why me?” during adolescence, stopped ART secretly, restarted after falling ill, thanks to caring aunt who worked and lived at hospital.

**Simbisai, the rebel orphan:** probably vertically infected with HIV, insisted on moving from grandmother’s rural home to Harare at the age of seventeen, discontinued ART in town where she lived with her sister who influenced her to abandon biomedicine and accept spiritual healing instead; returned to her grandmother’s after falling ill, but stayed away from ART until traced by a CHASA.

**Tomupeishe, the wealthy housewife:** wife of a wealthy teacher who is also on ART, both discontinued ART after missing their follow-up consultation due to prolonged travel; a one-week delay turned into seven-month treatment interruption because the couple felt ashamed and guilty for having “defaulted”.

Interrupting a life-saving medical treatment is an expression of social practice with far-reaching and potentially fatal consequences. Emerging as an irrational choice at a first glance, interrupting ART might become a meaningful act in the light of the whole narrative. Exploring case stories allows a deeper understanding of the interplay between the individual illness and treatment history with the structural determinants in a given context. The following are the narratives of Chido, Edzai and Jekuche.

**Table 7-2:** Characteristics of the sixteen study participants who discontinued ART

name	sex, age	socio-economic status	marital status	Time on ART before interruption	Time between interruption and restart
Batsirai	f, 22	low	divorced	A few months	stopped a year ago, no restart
Chido	f, 36	medium	widow	2 years	5 months
Chikonzi	m, 35	low	married (to Maidei)	one year	stopped > 1 year ago, no restart
Edzai	f, 32	low	married	> 2 years	stopped 6 months ago, no restart
Ega	m, 74	medium	married	four years	3 months
Fungisai	f, 35	medium	divorced	2-3 months	6 months
Jayaguru	m, 57	medium	married	2 years	6 months
Jekuche	m, 57	high	married	4 years	6 months
Linda	f, 48	medium	divorced	a few months	more than 1 year
Maidei	f, 36	low	married (to Chikonzi)	six months	2 years
Meso	f, 20	low	widow	2 years	12 months
Nashe	m, 38	low	married	1 year	stopped 2 years ago, no restart
Pfuma	f, 26	low	married	2 weeks	stopped 7 months ago, no restart
Runako	f, 18	low	unmarried	< 1 year	1 year
Simbisai	f, 18	low	unmarried	> 2 years	12 months
Tomupeishe	f, 36	high	married	2 years	7 months

**Chido: “They don’t deny your drugs, but they just give you small supplies”**

Chido was a mother of three children. Her husband died, and the 9-year-old boy was HIV-positive and on ART. It worried Chido that she had not yet managed to tell him that he was HIV-positive. As a primary school teacher, she had a regular income, yet she was using most of her salary to support relatives, and there was not much money remaining at the end of the month. It was nurse Chenai at the local health centre who diagnosed Chido’s HIV status. Since then, the two women had kept a warm relationship, as the nurse expressed in the following quote:

*She knew I was never going to tell anyone so that is why we clicked. (...) I know her history, I understand her. [interview with Chenai, nurse]*

Chido had been on ART for two years when she travelled to Harare. At that time, life was rough in Zimbabwe; hyperinflation devalued the cash in Chido’s pocket, fuel became short, and public transport collapsed. Chido was not able to return to her home as planned. Without a referral letter from the hospital, Chido was not able to access HIV care at the public ART clinic in Harare. Stuck in the country’s capital city for a couple of weeks, she ran out of drugs, and an interruption of a few weeks turned into a serious crisis for Chido. She finally returned home to her ART clinic at the hospital with a treatment gap of a month. As a “defaulter”, she was given a two-week drug supply only instead of the routine two- or three-months. Yet, the economic crisis did not allow Chido to spend US\$24 for transport there and back every two weeks, so she stayed away from ART for another 4 months. When her stomach started troubling her she felt desperate because of her son who also needed ART. She felt guilty and, eventually, went to nurse Chenai to ask for help. At that time, nurse Chenai’s health centre had become a decentralized ART site. Many ART patients comfortably collected their drugs locally. Yet, as a “defaulter” who had not been on ART for long enough, Chido did not qualify to be decentralized. She felt bitter about what she perceived a punishment by the nurse at the hospital, and about how she was treated:

*They don’t want people to default, so when you do that they punish you by giving you small supplies like two weeks or one month while others are getting supplies for three months. They don’t deny your drugs but they just give you small supplies so that you have to come again and again. (...) If only they could use polite words even if one defaults, because there are certain words that you cannot use when talking to people. Even other staff members know that he is rough. When patients are not behaving they say we will call him to come and deal with you or close down this place. He sometimes send people out of the consultation room and says I will serve you later if you just have*

*a small misunderstanding in answering his questions. I was once offended when I had my child and they said those with children come this side. I went there but was not given the food package others were being given because they said I am a teacher. I have heard some saying there is a bus fare fund for children but I am afraid to ask the nurse because he is scary. [interview with Chido, ART patient]*

Chido was re-initiated on ART only after an intervention of nurse Chenai through the hospital's sister in-charge. Chido has fully recovered since and never missed a pill or an appointment again.

### **Edzai: “This is my way, even if it means divorce”**

We interviewed Edzai in a counselling room at the local health centre. It would have been impossible to visit her at home because her husband did not know that she was HIV-positive. Edzai was 34 years old and had a very poor socio-economic background; she dropped out of school early, not used to write nor read and not able to recall the year when she started ART. She had no income and stayed many walking hours away from the main road in her husband's homestead where they lived from subsistence farming. At the interview, she looked wasted and her voice sounded feeble. Edzai had two boys aged 13 and 6 years from her previous marriage. After her first husband's death, Edzai and her children returned to her parental home where they lived until Edzai remarried. After re-marrying, she moved to her new husband's home and left her children behind. The older son was taken by the family of her first husband. The younger remained with her parents. Edzai was on ART, she used to collect the drugs for herself and for her son. She said she had always taken her drugs when she lived with her parents. But she feared that her new husband would want a divorce if she told him that she was HIV-positive. She hid the drugs outside the house for a while, but soon stopped taking them. She thought that her husband was HIV-positive too, because his former wife died and four children all died. Before they married, she suggested they could test for HIV together. But he refused saying he would only get tested when he fell ill. Edzai did not have anybody to whom she could talk about her desperate and burdening situation. She could not even turn to her parents, who have been supportive to her, as she explained in the following interview section:

*Interviewer: So how do you plan to deal with your husband and your ARVs?*

*Edzai: I wish he could agree that we get tested together. I had planned to just come and take drugs and show him that this is what I have done.*

*Interviewer: Why are you having such thoughts?*

*Edzai: I fear that if I continue not taking ARVs sooner or later I will fall sick and I won't know where to start from if that happens. (...)*

*Interviewer: Does your family know that you stopped ART and what do they say about that?*

*Edzai: To be frank they don't know that I am no longer taking my ARVs and they wouldn't be happy that I stopped taking drugs. (...) It is difficult because I should have told my parents that I stopped but it's not an easy thing to do. Sometimes I would come here at the clinic prepared to restart ART, prepared to take whatever comes, this is my way, even if it means divorce.*

A couple of months before the interview, health centre nurse Chamunorwa realized that Edzai was overdue and sent a village health worker to trace her at her home. She was found ill and the tracer encouraged her to resume treatment. She came to the health centre and was diagnosed with herpes zoster and pneumonia. The nurse said he treated her and advised her to urgently re-initiate ART. Edzai kept refusing. At the time of the interview, six months had elapsed since Edzai stopped ART. Her health had deteriorated and the fact that she was hiding her HIV status both to her husband and to her family members disconnected her from any social and psychological support. Edzai's refusal to restart ART in spite of her ill-health and in spite of feeling guilty in front of her family underscores the power of HIV stigma in marriage, representing both a cause and a consequence of the colossal gender inequality in Zimbabwe's society.

**Jekuche: "They restarted me and I explained to them I had learnt my lesson."**

Jekuche was a 57 years old and a secondary school headmaster. He had been married for nine years and had six children from two marriages. Jekuche's first wife left him when he married his current wife because she did not want to live in a polygamous marriage. In 2007 Jekuche became seriously ill, with diarrhoea and stomach pain. He "tried everything to get healed" [quoting Jekuche] but it did not help. Eventually, his wife encouraged him to test for HIV. He tested positive and initiated ART. His wife tested negative. Three years later, during one of her pregnancies, Jekuche's wife tested again, but she was now HIV-positive.

Jekuche was deeply religious. He and his wife were members of different Christian churches before they joined the African Apostolic Church in 2009. At a public ceremony of the church in June 2011, an Apostolic leader encouraged HIV-positive church

members to stay away from hospitals and to stop ART, as he explains in the following interview section:

*It was at a church function when we were misinformed. We were told that we have all been healed. And I accepted that and I went home, including my wife. After some time (...) I started feeling ill. Shaking and what and what. Then in January, it got worse, I started experiencing real shake-ups and a mild stroke. And I had wounds in the back which were serious and deep. So I had to come to the hospital. Then when I came to the hospital, they restarted me and I explained to them I had learnt my lesson, I will never ever drop these things again, for whatever reason. Now even our church leader explained that no, hospital was made by God, so people are healed by God (...).*

Jekuche was a wealthy and well educated Zimbabwean. As headmaster of the secondary school, he was a locally well-known and respected personality. He had been on ART for four years and he knew that ART saved his life. And yet, the announcement of the religious leader made him stop ART. Jekuche said he restarted ART after changing his mind. However, his wife underlined that he did not want to return to care as long as the church did not withdraw the announcement. It was her who ultimately convinced him that “he would die and leave me alone yet we have a lot of children” [interview with Jekuche’s wife] and took him to the hospital. Jekuche explained that after he restarted, the church reconciled spiritual healing with biomedicine by stating that hospitals were made by God. Jekuche enthusiastically defended his church, underlining that it was a misinformed leader who made the announcement without consulting his superiors:

*A lot of people died. And a lot of people are ill right now because of this problem. Now after this announcement was made, the church leader, he made the public announcement that people should go back to the hospital. Because this is wrong. Hospitals were made by God to assist people. This announcement was wrong. It was misplaced. It meant to kill people. And to make people stay away from the church.*  
[interview with Jekuche, ART patient]

At the time of the interview, the SMART programme considered Chido and Jekuche as retained patients, whilst Edzai was classified lost to follow-up. The cases of Chido and Jekuche show that retention does not indicate persistent adherence to ART drugs and appointments. They both had treatment interruptions of several months before restarting ART. The same was the case with eight other cases. Edzai, like four other cases, has been away from ART for many months without returning to care. Whilst Edzai and two others (Nashe and Chikonzi) restarted ART after the interview, Batsirai

and Meso did not manage to return to care, and died a few months after our encounter. The narrative analysis of the cases suggests that understanding the determinants of long-term retention requires an investigation of two critical passages in the treatment career of an ART patient: firstly, the reasons why patients interrupt treatment, and secondly, under what circumstances patients return to care or turn a temporary ART interruption into a prolonged and potentially fatal therapy discontinuation.

## 7.4 Analytical framework

This section describes the analytical framework I generated from the qualitative data. The content analysis of the qualitative data resulted in 51 thematic codes which I organised in 8 categories as shown in table 7-3.

**Table 7-3:** The analytic framework

Thematic category	Code (number of coding references)
Extended family	marriage & partnership (69) / family and kinship (68) / children (26) / in-laws (11) / adolescents (9) / care-giver (8)
Health and ill-health	illness (48) / feeling healthy (26) / tuberculosis (21) / mental illness (7)
Health care system	health workers (43) / distance (28) / hospital admission (5) / treatment costs (2) / referral (1)
ART programme	ART interruption (91) / tracing (54) / CHASA (49) / drug adherence (44) / HIV test (34) / ART restart (30) / ART initiation (27) / decentralization (24) / appointment keeping (12) / counselling (8)
Biomedicine	CD4 cell count (23) / vertical HIV transmission (15) / CTX prophylaxis (12) / HIV transmission (3) / drug regimen (2)
Livelihood	income (12) / migration and travel (18) / employer (3) / food and nutrition (8)
Community resources	support group (51) / churches (35) / community (21) / traditional healing (10) / witchcraft (6)
Processes	reasons (73) / disclosure (53) / treatment support (52) / perceptions (33) / death (17) / stigma (14) / behaviour (12) / conflict (8) / fear (7) / confidentiality (6) / violence (2)

I analysed in which thematic context the participants of the interviews and focus group discussions talked about the coded themes. The weight of the relationships between the thematic codes, measured as number of text references coded at both themes, is indicated in brackets in table 7-3.

The following is a brief description of the eight thematic categories.

**Extended family:** ART patients, as people living with HIV, consider the extended family the social domain with the strongest influence on their lives. The extended family

includes the marriage at the core, linking the partners' descent groups, and thus forming the larger kinship network of the ART patient. The data showed that the relationships between the patient and his or her extended family strongly determined key aspects of the patient's therapy career, such as disclosure of the HIV status, treatment support, and therapy interruption.

**Health and ill-health:** Patients talked about health and ill-health both as a cause and consequence of failed retention. The data showed that interruption and restart of ART often occurred in the context of an illness episode, often tuberculosis, and that churches appear to have an influence on illness experience.

**Health care system:** The health care system was frequently raised as an influential domain for retention by study participants. The data suggest that health workers had a strong influence on treatment careers, particularly their behaviour and the perceptions of both the patients and the health workers on their relationship.

**ART programme:** Figure 7-3 shows the themes and their weight that emerged in relation with treatment interruption and restart, the two critical stages in the participants' ART careers. The data shows that the patient – health worker relationship, illness, the influence of churches, and family and kinship networks were the most dominant themes related to ART interruption and restart.

**Biomedicine:** CD4 cell count and pre-ART co-trimoxazole prophylaxis were two biomedical themes frequently mentioned by the study participants.

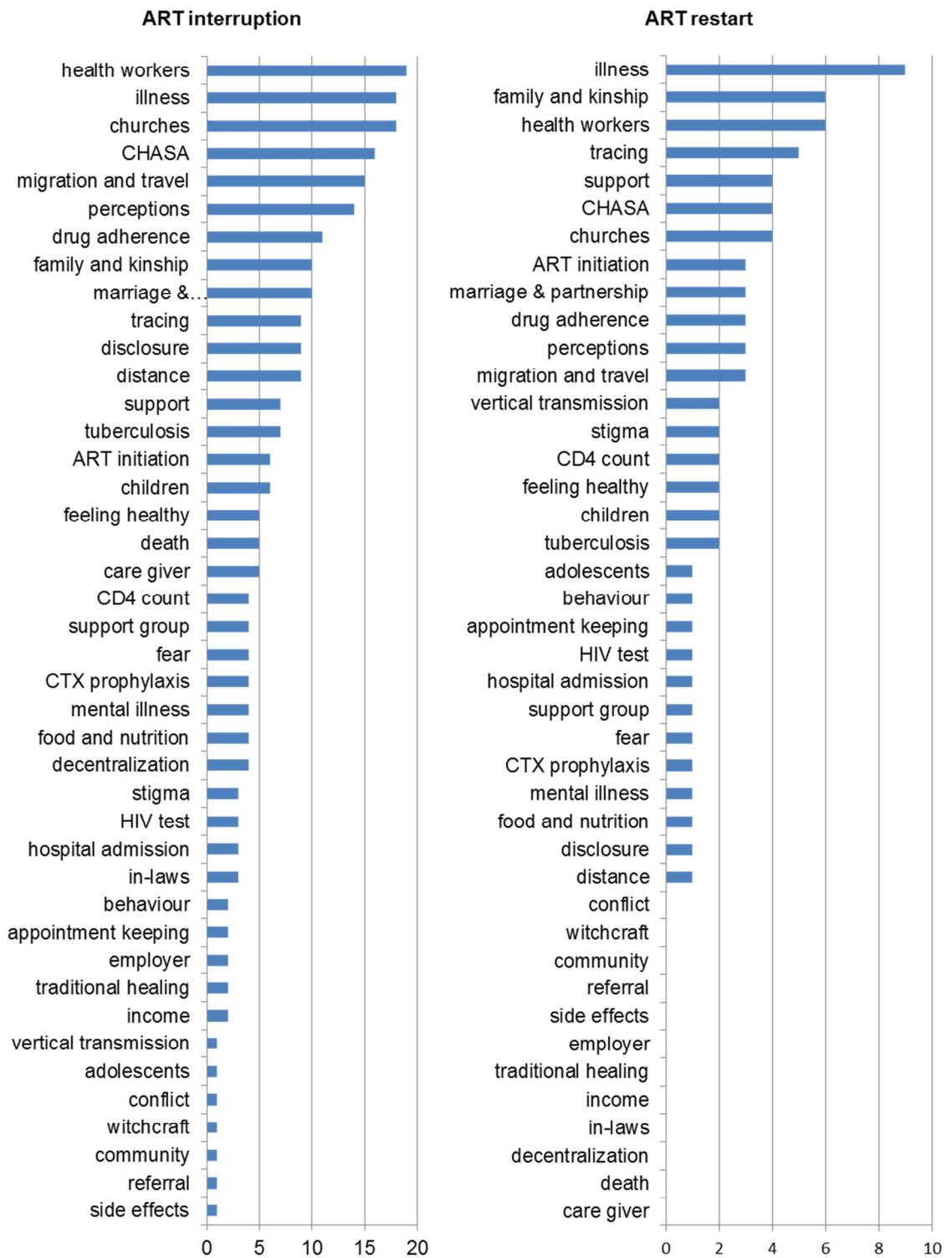
**Livelihood:** The data suggest that socio-economic factors had an influence on the course of ART, particularly related to labour mobility and migration.

**Community resources:** Looking at the community as potential facilitator or barrier to ART retention, churches and HIV/AIDS support groups and CHASA came up as frequently linked themes.

**Processes:** This set of codes included frequently emerging themes explaining social or psychological processes in relation with the participants' treatment experiences. These themes added insightful qualitative characteristics to the above raised themes.

As shown in figure 7-3, the five thematic codes that were most frequently linked with ART interruption were health workers, illness, churches, CHASA, and migration and travel. Thematic codes most commonly linked to ART restart were illness, family and kinship, health workers, tracing, and support.

**Figure 7-3:** Frequency of codes linked to interruption of ART and restart of ART, measured as number of concurrent coding references.



## 7.5 Reasons for treatment interruption

The narrative analysis of the sixteen cases (see appendix 7) and the thematic analysis of the entire qualitative dataset resulted in four main reasons why patients interrupted ART, as shown in figure 7-4:

**Failed initiation:** Patients were enrolled in the ART programme and received the initial ART drug supply, but were not able to adhere to the drug regimen from the start. The dominant causes for failed initiation were mental confusion, adolescence and illiteracy, as was the case with Fungisai, Maidei, Pfuma and Runako.

**Stigma in marriage:** Female patients discontinued ART to hide their HIV status from their new partner and his family, as it was the case with Batsirai, Edzai and Meso.

**Mobility:** Patients interrupted ART because they ran out of drugs during prolonged travel or due to migration and a failed transfer from one ART clinic to another, such as Chido, Jayaguru, Simbisai, Pfuma and Tomupeishe.

**Religious authorities:** Confronted with two conflicting healing paradigms, patients chose to follow religious in preference to biomedical authorities, as Ega, Jekuche and Linda did.

**Figure 7-4:** Reasons for ART interruption



### 7.5.1 Failed initiation

The SMART programme considered a patient as initiated on therapy if he or she attended his or her first ART consultation. At this first ART visit, the patient received his or her first ART drug supply which usually lasted for two weeks. Whilst these patients on the grounds of their formal programme enrolment contributed to programme attrition, in reality, their therapy initiation failed. The cases of Fungisai, Maidei, Pfuma and Runako suggest that the main causes of failed initiation were a lack of treatment

literacy and adherence support in combination with psychological and mental challenges at the point in their lives when they were eligible for ART. Fungisai was mentally confused when she was initiated treatment, as she expresses in this quote:

*I came back from South Africa very ill. I came to the clinic and I couldn't even eat so I survived through drips. I went to the hospital and was initiated on ART. (...) But I confused the drugs and when I went to the ART clinic and explained everything to the nurse (...), then she gave me my second supply. I took it home and suddenly I started seeing the flames of fire turning blue. I went mad and from that time I interrupted ART.* [interview with Fungisai, ART patient]

Maidei could hardly write and read, and she lacked adherence support and knowledge of the different drug regimens for CTX prophylaxis, prevention of mother-to-child transmission, ART, and tuberculosis treatment. She initiated ART during a course of tuberculosis treatment, but stopped the ART drugs after completing the tuberculosis treatment, as she felt healthy and started drinking:

*It was the devil. I wasn't thinking clearly, I used to drink beer by then and taking ARVs together with beer would make me feel a burning sensation in my chest so I decided to stop the ARVs. I was later taught at the clinic that ARVs and beer don't get along so when on ARVs one should stop drinking beer.* [interview with Maidei, ART patient]

Runako was a teenager when she was prescribed ART. As a teenage HIV orphan living with her aunt, Runako did not accept her HIV status. She could not accept that among her siblings she was the only one who was HIV-positive. In denial about her status and pained by the question "why me?" Runako's initial ART initiation failed. Like Meso and Simbisai, the other orphans who participated in the study, Runako was most probably vertically infected. In an environment where people living with HIV were still blamed for their sexual behaviour, HIV-positive adolescents in their fragile life stage were particularly vulnerable and exposed to the stigma of HIV. Encounters with HIV-positive peers helped Runako to understand that becoming HIV-positive was not her fault, and it helped her to return and adhere to ART, as the following quote suggests:

*I would tell them that we are not the one who looked for the virus, it just came to us and it was not our fault. So we just have to keep taking drugs because that is how we keep alive.* [interview with Runako, 19, ART patient]

Pfuma's ART initiation failed because she arrived a day too late at the ART clinic for her first follow-up consultation, and was therefore sent to the district hospital for review where she never went. In contrast to Fungisai, Maidei and Runako, Pfuma was well

aware of the importance of ART and willing to initiate therapy. But Pfuma, with a CD4 cell count of 150, was not aware of the procedures of the ART programme and about her patient rights. Being illiterate, living alone as second woman with her small children in a polygamous marriage, Pfuma lived in extreme poverty and in long distance from health facilities. Initiating ART was the end of a prolonged referral odyssey she undertook between her local health centre where she was tested HIV-positive, the nearest ART site where she attended pre-ART sessions and initiated treatment, and the hospital where she was referred to for re-initiation. Pfuma, who had already travelled far and frequently to access HIV care, was not able to raise money for another transfer, and she gave up.

### **7.5.2 Stigma in marriage**

The fear of being rejected by the husband and the in-laws was a dominant reason why women concealed their HIV status, hid their drugs, delayed initiation or abandoned ART. The stigma of HIV in partnerships and marriage and its impact on ART retention was a frequently debated subject in the focus group discussions, as the following quotes show:

*I know of a girl who stopped ART because she had found a boyfriend who wanted to marry her. She went to live in Harare with the boyfriend and later developed some cancer on her face. She came back and went to the hospital but it was too late and she died shortly after.* [participant of focus group discussion with support group members]

*I didn't tell my husband that I had been tested, and I kept my ARVs in the granary and would sneak to the granary when it was time to take them. I had to lie to my husband that there is a sick relative at my maiden home so I could find an excuse to go home and tell my mother. My mother was supportive and she comforted me. Each time I get an ART appointment I had to lie to my husband that I am visiting relatives.* [participant of focus group discussion with support group members]

Hiding their HIV status from their fiancé or new husband was an overwhelming reason for ART interruption in almost all female ART patient cases. Batsirai stopped ART because she feared her husband's and his family's reaction. When she became ill, she started feeling rejected by her in-laws, as she explains in the following quote:

*He was perverted by his parents, they interfered. They said to him you are keeping a sick person what for? And he left me.* [interview with Batsirai, ART patient interrupting treatment]

Meso found herself in the same dilemma as Edzai who was portrayed in section 7.3 ; concealing her HIV status to the fiancé and at the same time hiding from her own family the fact that she stopped ART:

*Meso: I feared that I they (my brothers and aunts) would ask me why I stopped. I was afraid they would be mad at me.*

*Interviewer: why do so many women stop ART because of marriage?*

*Meso: In fear that if he discovers he will dump you if he knows about your status. In my case, my brothers were discouraging me from getting married, saying you are HIV-positive and no one will ever marry you. [interview with Meso, ART patient]*

Maidei, Linda and Pfuma had also been hiding their HIV status from their husbands, but had not yet started ART. Maidei's husband died before she started treatment. After his death and the death of one of their children, her former in-laws publicly accused her at the child's funeral of being responsible for their deaths. Linda's husband left her after she tested HIV-positive. And Pfuma felt discouraged by her husband to test for HIV when he was still with her.

The perspective of the cited female cases though was challenged by some male FGD participants and by nurses. They claim that men have the right to know their future wives' HIV status, as the following quote shows:

*For instance marrying someone from outside the district means that people marry with little knowledge about each other. As such, people marry HIV-positive people who did not disclose their status to their partners and who would have defaulted ART. It happened recently that someone married someone thinking that she was a young girl yet she was even a widow. Only later when she went to the hospital and she was asked to bring her husband for counselling the man found out. [interview with an ART nurse]*

### **7.5.3 Mobility**

"Searching for greener pastures" is a common saying in Zimbabwe if someone moves away from home to look for a job. For people on ART, to stay away from home can become a threat. Mobility was a reason vigorously debated in interviews and focus group discussions why people interrupted ART, either due to unexpectedly extended travel or as a result of relocation due to employment or family reasons. In the following quote, CHASA Damien was asked what he thought was the major reason for ART interruption:

*The greatest reason is that people go away to look for greener pastures (...). There is a person who, after being initiated on ART and recovering, migrated to South Africa and phoned me saying that he was sick again. I also have a passport and I go out to Botswana but before travelling, I talk to my nurse and ask for more supply than the usual amount and return before it is finished. So some people don't do that prior to travelling. [interview with Damien, CHASA]*

In contrast to the reasons of failed initiation and stigma in marriage, patients who interrupted ART due to mobility would have been willing to continue ART. They dropped out of HIV care simply because they physically left the programme area.

Mobility was a notable pattern in the SMART programme and probably the most common reason why patients interrupted ART. Seven out of the sixteen cases interrupted ART due to mobility. Jayaguru, Chido and Tomupeishe missed their scheduled ART visit to due to an unexpectedly prolonged travel; Nashe, Chikonzi and Simbisai interrupted ART because they moved away from their ART programme.

Jayaguru left his farm for a temporary job in town and ran out of drugs before returning home for his next ART follow-up consultation:

*When I went to Bulawayo I had supply enough for a month and I thought I would be back before it ran out, unfortunately it didn't turn out that way. (...) I didn't talk to anybody about it but I kept pondering about this, fearing that anything could happen to me because of stopping ART. [interview with Jayaguru, ART patient]*

Chido went to Harare where she failed to obtain her drugs from another ART clinic, as shown in her narrative in section 7.3.

Tomupeishe and her husband attended a funeral in town and stayed longer than planned:

*It so happened that we were due for ARVs supply while we were still there and so we missed our appointments. [interview with Tomupeishe, ART patient]*

Simbisai stopped ART when she left her grandmother's home and moved to her sister in town.

*I left my drugs behind and I was not taking anything when I was there. I then fell sick again and came back already sick. [interview with Simbisai, ART patient]*

After being released from prison, Chikonzi moved to his wife's place. Even though he was formally referred to the ART clinic, obtaining his medical records and a transfer

letter from the prison, he did not manage to continue ART. In the following quote, Chikonzi gives a number of reasons for having interrupted:

*When I came out of the prison they gave me a letter that I took to this hospital together with my cards. I was taking my drugs properly and I was staying at my wife's place at that time. I defaulted because these drugs require that someone gets enough food, yet I did not have enough. I also didn't manage to go for my supply appointments because of transport money to go there and lack of adequate food to eat and be strong enough to walk. So I defaulted. [interview with Chikonzi, ART patient interrupting treatment]*

Nashe started treatment when he was employed on a farm in South Africa. The employer supported Nashe to get treatment and ART was easily accessible. Life became difficult for Nashe when he returned to Zimbabwe:

*What happened is that I used to work so I could collect my tablets but when I stopped working and came back home I couldn't afford the bus fare to go and collect drugs in the hospital. I only had it for one month and for the next appointment I walked and it made my leg to swell such that it was extending to the upper part (pointing to the lap). The swelling was serious for 2 to 3 weeks and I told my wife that with this kind of swelling I will no longer be able to continue walking to the hospital to collect drugs. So when those drugs finished I stopped. My wife is fit so she walks to the hospital to collect hers. [interview with Nashe, ART patient interrupting treatment]*

Lack of money for transport or having no access to an ART clinic were the two dominant reasons given by patients who discontinued ART due to mobility. Some health workers and CHASA expressed their doubts about these explanations. The underlying reason, they argue, was the patients' failure to disclose their status in their new environment, as CHASA Shorai said in the following quote:

*There is nothing bad about looking for a job, but if one gets the job then they should disclose their status to the employer. Some default because they go out of the district to look for jobs and when they find the job, they don't disclose their status (...). Some fail to come because when they arrive there they get new lovers and don't disclose their status so they fail to constantly come back for their drugs. I think it's not about challenges in sourcing bus fare to come back for supply but it's about lack of disclosure such that it becomes difficult to keep requesting for off-days to come for ART appointments. [interview with Shorai, CHASA]*

In the case of Chikonzi and Nashe, shame about being HIV-positive and not being able to earn their family's livelihood after returning home made them feel aggressive (Chikonzi) or depressed (Nashe).

#### **7.5.4 Religious authorities**

In Bikita and Zaka, like in other areas of Zimbabwe, certain church communities promoted spiritual healing and discouraged church members to abstain from biomedical health services, such as giving birth in health facilities or ART. Religious authorities temporarily prevailed over biomedical authorities in the treatment careers of Jekuche (see his story in 7.3), Ega, Simbisai and Linda. Similarly to Jekuche, Ega followed the announcement of an Apostolic Church leader and abandoned ART. In Simbisai's case, it was her sister with whom she lived as care-giver, who paid for a church leader who came to sprinkle water at their home to spiritually heal Simbisai. Similarly, when Linda was taken care of by a religious community after suffering a stroke, she was discouraged to stay away from ART by her mentor. Other patients also observed the strong influence by some church communities on the health-seeking behaviour of people living with HIV. There was a time when Jayaguru and his wife were also confronted with discriminatory announcements of their religious leaders. The threats of the religious leader made Jayaguru's wife hid her status and collected her drugs at a different health centre away from the local area:

*Sometimes they discourage us from taking drugs (...). At one time they said those who take drugs will be ordered to take off the garment. At that time I used to visit a clinic that's down that side so that I wouldn't be seen by those who know me. But it's now allowed to take drugs (...), they fear bad publicity, that they will be treated like the other apostolic sect (...) that prohibits people from going to hospitals. [interview with Jayaguru's wife, patient on CTX prophylaxis]*

Tomupeishe and her husband are also deeply religious and members of an Apostolic Church. Yet, stopping ART for religious reasons has never been an option for them, as Tomupeishe's husband said:

*Yes I also heard about those churches and some don't allow people to drink Coca Cola because it is black, but our pastor says people should take ARVs because God gave those who made ART drugs the knowledge (...) so that they save his people. The prophet tells us that the same God is the God whom you are following, and one day he may remove the disease but meanwhile he gave them knowledge. [interview with Tomupeishe's husband, teacher, on ART]*

CHASA Shorai gave a plausible explanation why some church leaders managed to change the attitudes and practices of some ART patients:

*When people become fit they think they are completely healed and at that stage their attitudes are easily changed by religious people who preach about divine healing and discourage the use of ART. People from those churches tell people that they are healed completely and if they continue taking ARVs they will saturate their bodies with the drug and it will eventually kill them. (interview with Shorai, CHASA)*

The same pattern was reported by nurse Sekaye. She said that churches are the main reason why patients stop ART in her region:

*Their church discourages them from taking drugs and they believe that their leader is the prophet sent by the Lord. Some church leaders want to test their powers to see if they actually heal people and they tell people that they are healed and so the patients stop taking their medication. [interview with nurse Sekaye, nurse]*

CHASA Hupenyu reported that patients who are not members of support groups were particularly susceptible to misleading notions promoted by some religious authorities, as the popular claim that “Christian water” cures HIV:

*Those who are not in support groups are the ones who tell us stories like I was given water by a prophet so I am not taking pills anymore, so we just leave them like that as there is nothing else you can say to them. [interview with Hupenyu, CHASA, on ART]*

I showed in this section that failed initiation, stigma in marriage, mobility and influence by religious authorities were major reasons why patients interrupted ART. At the time of our interviews, eleven out of sixteen patients who had interrupted ART had already restarted. The fundamental question to better understand long-term retention that remains to be explored is why some patients restart ART after interruption, and others do not.

## **7.6 Facilitators and barriers for ART restart after interruption**

The narrative and thematic analysis of the qualitative data revealed that after missing a follow-up appointment, patients found themselves in a critical passage of their treatment career – a time window of medical and social vulnerability.

Facilitators and barriers for ART restart were identified in three domains:

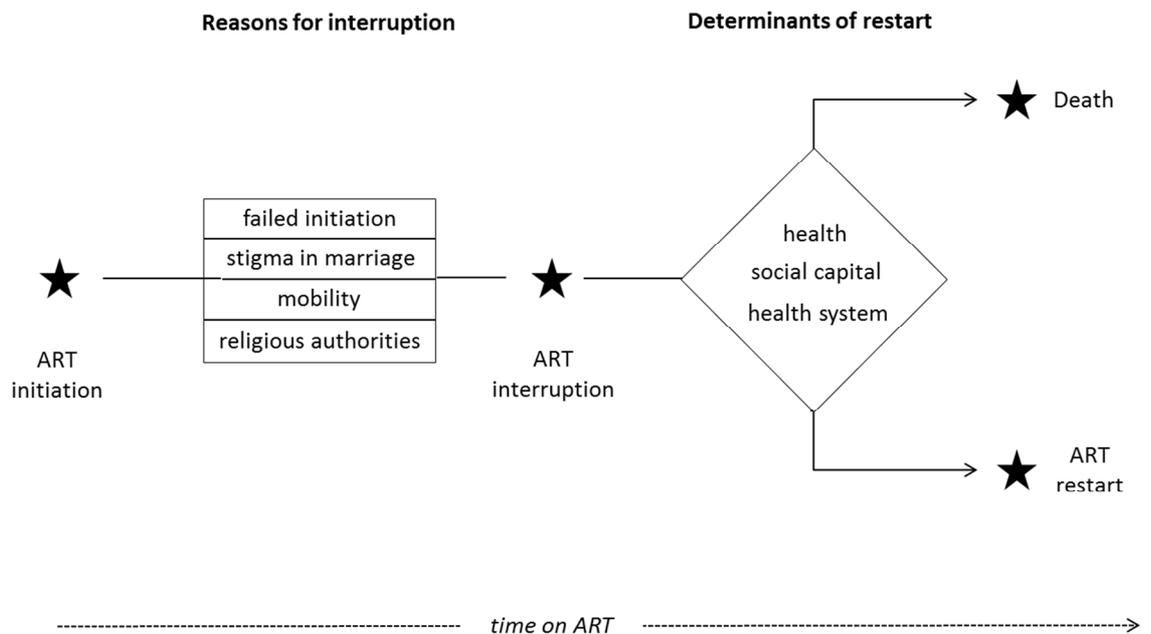
**Health status:** Good health at the time of ART interruption was a resource patients mobilized to return to care after interrupting ART, illness was a major barrier.

**Social capital:** Patients with family and kinship networks supporting disclosure and treatment found it easier to restart ART than socially-excluded patients.

**Health system:** The relationship with health workers and the geographical and social proximity of the nearest ART clinic were key facilitators for ART restart. Distance and the stigma of defaulting were major barriers.

A combination of facilitators and barriers in the three mentioned domains determine the outcome of the interruption episode, which is either a therapy restart or, ultimately, death, as shown in figure 7-5.

**Figure 7-5:** Reasons for therapy interruption and facilitators and barriers to restart on the continuum of ART



### 7.6.1 Health status

The patient's health status after treatment interruption influenced their subsequent re-entry into care in either a positive or a negative way. On the one hand, some healthy patients did not see an urgent reason to restart ART whilst a deteriorating condition of the patient alerted the partner or family members to encourage and assist him or her to return to care. Illness, on the other hand, was often a reason why patients lost the

strength to restart ART, especially if they lacked partner and family support, as I will show in section 7.6.2.

The quantitative results showed that there was a narrow time window for restart after ART interruption. Though, the time window was wide enough for the study participants; most of them had returned to ART. Of the cases in this study, six patients were severely ill at the time of restarting ART, and five were deteriorating. Severe illness after ART interruption was a contributing factor why Fungisai, Jekuche, Linda, Meso, Runako and Simbisai returned to ART after 6 to 18 months. After ART restart, five of them recovered, including Linda who has lived with a disability since. These cases demonstrate that the patients found their way back to care only when it was urgently needed. For one of them, though, it was too late: Meso restarted ART and recovered from tuberculosis, but her health remained fragile, and she died a few months after the interview. Chido, Ega, Jayaguru, Maidei and Tomupeishe also returned to ART more than three months after therapy interruption, but, in contrast to the group mentioned above, they considered themselves only moderately ill. Among the patients who had not restarted ART at the time of the interview, Batsirai was severely ill, Edzai, Nashe and Pfuma moderately, and Chikonzi was feeling healthy.

Interrupting ART hugely increased the patients' medical vulnerability, defined as susceptibility to illness. With very few exceptions, the patients' health status gradually deteriorated. Some patients restarted ART before getting seriously ill, but most returned to care only when they started suffering severe illness. The described cases show that there is usually a time window of several months between ART interruption and potential restart. There were other factors than health and illness facilitating or hindering ART restart – factors to be explored in the next sections.

### **7.6.2 Social capital**

ART interruption did not only increase the medical, but also the social vulnerability of people living with HIV. The study participants described ART overwhelmingly as an escape from social exclusion, provided they were able and willing to disclose their HIV status to their immediate social environment. Thanks to regaining physical and psychological strength, they were able to resume responsibility for the livelihood of their families and to participate in economic and social activities. In the described patient cases, disengagement from ART often contributed to a gradual social disengagement. As their health started deteriorating, the gains of ART were inverted not only medically, but also socially. In the absence of economic resources and social security schemes, social capital, defined as investment in social relations with expected returns (Lin,

1999), emerged as a critical facilitator for ART restart. After treatment interruption and with gradually deteriorating health, marriage as well as family and kinship networks became the patients' essential source of social capital.

### **Marriage: facilitator for men, barrier for women**

The cases of Edzai, Batsirai, Meso and Pfuma demonstrated not only the stigma of HIV in marriage (see section 7.5.2), but showed also the potentially harmful impact of the in-laws on a married women's course of ART. The following quote of CHASA Anotida who is an ART patient herself shows the influence of in-laws, even if the partner is willing to accept his wife's HIV status:

*My husband was supportive but the family members were not. They seemed understanding and accommodating to me but behind my back they said things such as 'how can we live with someone who is sick' and by then they didn't even know my status. So when they got to know about my status they confronted my husband and told him that it was impossible to continue living with me, what if I infected him too? But because I had given my husband enough information about the disease, he was not swayed by what they said. But I was troubled thinking about my fate especially losing him and finding a new partner again. (...). [interview with CHASA Anotida, ART patient]*

Fear of losing the new partner was identified as a reason why women hide their HIV status and stop ART. Whilst failed disclosure in marriage remained a restart barrier for women, marriage was identified as a facilitator for ART restart in concordant partnerships, especially for men: Ega, Jayaguru, and Jekuche were supported by their HIV-positive partners who played a key role, urging them to return to treatment.

### **Rural family and kinship networks as safety net**

Family and kinship networks were the paramount safety net and facilitator for ART retention and restart. Family members were key facilitators for ART restart in the cases of Ega (wife and son), Jayaguru (brothers), Fungisai (brother), Linda (sister) and Simbisai (grandmother). Linda's case demonstrated the importance of the family back home in the rural village as a safety net for female patients who left their homes for marriage. Linda and her sister had always been very close to each other. They grew up in a family of 16 children in the countryside. Whilst her sister married in the village, Linda married in Harare. Her husband left her when she tested HIV-positive, and Linda's life changed abruptly. She was first taken care of by a church community, where things became even worse. Her sister saved her life when she took her to her

rural home after Linda had stopped ART and suffered from a stroke, as her sister explains in the following interview section:

*I thought she was taking pills when she went for some prayers but the church had told her to stop taking pills (...). When she had the stroke they called me because it was difficult; she couldn't go to the toilet or bath alone, she messed herself, I had to go and wash and she messed herself again. She then resumed ART and she got better but she still has stroke. (...) Today, I am always on the look-out, to check if she takes her pills at 8 am, if she leaves her sadza, I heat it and give her. If there is no sadza we make porridge and she eats then takes her pills. If I am there everything is ok.*

[interview with Linda's sister]

### **Support groups: access to social and economic capital for privileged patients**

Family and kinship networks were clearly the most powerful source of social capital for ART patients, especially for women whose partners and in-laws condemned and excluded them for their HIV status. Outside family and kinship networks, ART patients reported few supportive social relationships. Church communities, for example, appeared as important platform for spiritual support. ART patients, however, did not consider religious communities supportive to adherence.

For many people living with HIV in Zaka and Bikita, support and self-help groups were a principal source of social capital beyond family and kinship networks. Support groups provided access to a variety of benefits, such as NGO-funded income-generating activities, loans and HIV counselling and testing campaigns. In the rural setting of the SMART programme, support groups had become a new structure of non-kinship, non-governmental and non-religious self-organisation. Nurses and CHASAs were often the driving forces when new support groups were created. In nurse Tadisá's experience, the public perception of HIV/AIDS had changed dramatically. Before the roll out of ART, people were "*stigmatizing themselves*" [interview with nurse Tadisá], feeling embarrassed, and hiding their HIV status. Support groups changed this:

*We have supported our patients to form support groups. They understand each other in the villages that each one is responsible for himself, and that nobody has to die from AIDS anymore. So they are coming in large numbers, they understand much better. Previously, it was confidential, and people did not want to disclose. They just disclosed for the purpose of treatment. (...) The nurses at the clinics they know the support groups, they report to these people, to the executives of the support groups. So these people they know each other, they report back to the clinic.* [interview with nurse Tadisá]

ART patients reported that support groups offered them an escape from social isolation and self-stigmatisation. At the same time, joining a support group offered them an exceptional opportunity to disclose their status to community members. The following quotes demonstrate the importance of support groups in the view of their members:

*We sponsor bus fares to those without money to go for drug collection. We also run savings clubs and we loan that money to those who need it and they pay it back with interest.* [participant of a focus group discussion with support group members]

*I like support groups because there is a lot of knowledge. There are a lot of things that I didn't know. Sometimes I wish I had known certain things before my husband died I could have done good things for him. Maybe I was the one who caused him to be promiscuous. I learnt a lot of things, including how to be self-sustainable with my family not just waiting to be given things by other people.* [participant of a focus group discussion with support group members]

*We have a slogan in our support group, which we say everyday, "have you juiced", as if it is loading credits on a phone, so that we remind each other on whether people have taken medication? Because if you skip your medication when it is supposed to work for 12 hours, the virus will increase.* [interview with CHASA Hupenyu, ART patient]

Some ART patients were critical about support groups though. They complained about community leaders using the support groups to raise money, and then mismanaging the finances of the support group.

For those who were members, support groups were generally highly valuable source of social capital and economic benefits. However, medically and socially vulnerable patients were rarely members of such support groups. From the ART patient cases, Ega and Fungisai were the only patients who were member of a support group. Ega felt ashamed vis-à-vis his peers for "having defaulted" therapy, and said he pretended he missed ART appointments due to a journey to Mozambique. Fungisai claimed she paid a US\$2 contribution to an income generating activity but was disappointed by the poor results of the project. Other patients knew about support groups but did not trust their leadership, such as Jayaguru and Chikonzi, who considered support groups as exclusive and closed platforms for credit and savings. Women who would have urgently needed adherence support after interrupting ART, claimed they had never heard of support groups, such Batsirai, Edzai Linda, Maidei, Pfuma, Runako and Meso.

Our findings suggest that in the event of a therapy interruption, social capital is a critical resource for ART patients to return to HIV care. Medically vulnerable ART interrupters

who were embedded in a caring safety net of family and kinship had good chances to restart ART. Vulnerable interrupters were largely excluded from community-based networks, such as churches or support groups.

### **7.6.3 Health system**

The way ART patients were connected to the ART programme crucially influenced their chances to restart therapy after interruption. This was particularly the case for patients in a deteriorating health state who lacked caring support in their social environment.

#### **Access to ART follow-up: link to care versus delayed decentralisation**

The "bus fare" was a frequently cited burden for ART patients and their treatment partners who lived far away from the ART follow-up site. In Bikita and Zaka, where ART was free, transport costs were critical indirect costs of treatment. Households were prepared to allocate money for the bus fare to bring a family member to the hospital in an emergency. Since ART required regular travel for check-ups and drug collection, distance became a threat to retention. To bring the services closer to the patients, the SMART programme was in the process of decentralising ART follow-up to health centres. ART patients were eligible for decentralised care if they had been stable for at least six months. Distance was not a problem for Jayaguru, Jekuche, Meso, Runako and Tomupeishe who lived near the district hospital. Physical proximity to the ART clinic neither prevented ART interruption nor facilitated prompt ART restart. And yet, in the case of Runako, who actually lived with her aunt in a staff house within the hospital premises, the immediate access to the ART clinic clearly facilitated her ART restart, once she was psychologically ready. The other patients lived 30 to 50 kilometres away from the hospital. Transport costs were a major obstacle that clearly prolonged ART interruption for some of them. Pfuma was overwhelmed by logistical problems during the process of her ART initiation:

*I was initiated in February and I was supposed to go back to the hospital on the second of February and it coincided with a funeral in my family and my aunt was critically ill. So after attending to these emergencies I came to the hospital and they said it was too late so they referred me to health centre. I didn't have bus fare so I went to ask from my sister and she told me she couldn't help as she had tried her best to help before. We were also expecting that my husband would send me some money from South Africa but he didn't. So I am planning that when schools close I will take my children with me and drop them off at my parents' home and proceed to the hospital. It's troubling me, I really want to restart treatment but I don't have the money. [interview with Pfuma, ART patient currently interrupting treatment]*

Nashe and Chikonzi also claimed that they stayed away from ART because they could not afford transport costs to attend ART follow-up consultations at the district hospital. Nashe and his wife lived close to a health centre which already provided ART follow-up consultations. Transport to the hospital and back cost US\$24 per person. Depending on which services were available at decentralized sites, patients were required to travel to the hospital for pre-ART sessions, CD4 cell count and other lab tests, ART initiation, and first follow-up after two weeks - up to 5 consultations within a short period of time. As Farai, the Primary Care Counsellor at Nashe's health facility emphasized, many patients made great efforts and walked 30 kilometres to the hospital. In Nashe's case, however, the swollen leg and his general health condition did not allow him to walk. Nurse Chenai remembered that the situation affected more patients before CD4 testing was decentralized:

*Many people opted in to test HIV. We discovered a lot of problems because we could test people if they were positive they did not go to the hospital. Most of these people were in stage 3 or 4. They did not have bus fare and they walked very long distances for CD4 registration and counting and also for HIV lessons. After the HIV tests we did post-test counselling then we would tell them to go to the hospital but these people did not come back because they walked long distances and eventually, some of them died.* [interview with nurse Chenai]

Chikonzi's story, whether it is true or not, also tells a story about an ART patient struggling to adhere to appointments:

*I went there on the 10<sup>th</sup> of February and was told to come back on the 6<sup>th</sup> of March, when I got there they said I was late and didn't consider the walking distance from where I was coming from. They gave me another appointment on the 27<sup>th</sup> of April, that time I had money and so I boarded a mini-bus, but it had a breakdown on the way. But still I didn't arrive there very late, they would have assisted me but they didn't, I was given another date.* [interview with Chikonzi, ART patient]

It is noteworthy, however, that Nashe's and Chikonzi's wives who were both on ART managed to adhere to the appointments, sometimes walking the 30 kilometres to the hospital with a baby on their back. Edzai who was medically (deteriorating health) and socially (hiding status from husband) highly vulnerable, lived 50 kilometres from the hospital and 20 kilometres from the main road, but did not mention the distance as a reason why she did not restart ART. Neither did Linda, who returned to care in spite of a large distance from her home to the hospital, and her walking impairment.

Maidei and Batsirai were linked to the ART programme through the prevention of mother-to-child transmission programme, but with different outcomes. Maidei restarted ART for her own health through this programme when she was pregnant. Maidei lived near an ART providing health centre, but was not eligible to be decentralized. Maidei kept walking to the hospital, but complained:

*I collect at the hospital and my next appointment is 14 June. We have however suffered a lot because it's too far and we have to walk. When we leave this place just before 7am we arrive at around 4pm and sleep there and I go there alone mostly because my husband would be out searching for menial jobs. [interview with Maidei, ART patient]*

### **Patient – health worker relationship: personal relationship versus shame of “defaulting”**

Tomupeishe and her husband were both on ART. They were wealthy, well educated, and member of a church that encouraged members to adhere to ART. The couple had three healthy children, and, as her husband said, a “*bright future ahead of us*”. As the couple lived in a house close to the district hospital, they had immediate access to ART – and still interrupted ART for seven months. What had happened? Tomupeishe and her husband had been travelling and returned to their home place a week after their scheduled ART appointment. Out of fear of being “*shouted at*” [interview with Tomupeishe, ART patient], they did not approach the ART clinic to explain their situation. Instead, and despite their knowledge about the consequences of ART discontinuation for their health, they stayed away from the ART clinic for many months.

Feelings of shame and guilt after interrupting ART emerged as a frequent pattern throughout the interviews and focus group discussions. Even though health workers generally acknowledged genuine access barriers, there were strong and judgemental perceptions among some individual health workers about patients who missed their ART appointment. Missing an ART appointment was socially unacceptable.

Health worker Farai, who was on ART himself, had strong doubts about Nashe’s reasons for not re-initiating ART. He argued that retention on ART required a good attitude; patients like Nashe “defaulted” because they lacked a sense of responsibility for their own lives and those of their families:

*In fact, many people do not default because of the distance. Some people don't tell the truth, as far as we observe here. Because you find that there are chaps who are quite strong, physically fit, but who do not go for ART initiation. (...) I told you that I am a*

*widow, I am a single parent with three children. So if I do not go for treatment, and I cannot work, then the children will suffer. So it is one of the things, if you are concerned about your family, you have to make an effort and go for treatment. But if you are negligent, you don't even care about your children...* [interview with health worker Farai, ART patient]

Nurse Robert emphasised that retention was a matter of knowledge and attitude, “defaulting” in turn a matter of lacking knowledge and having the wrong attitude, as this section shows:

*Some default because of lacking knowledge about how ART works so this should be stressed on pre-ART sessions and health workers should be knowledgeable and also be capacitated on educating patients during pre-ART lessons.* [interview with nurse Robert]

The stigma of “defaulting” was a frequently perceived and stated barrier to ART restart among the study participants. Besides the above presented case of Tomupeishe and her husband, Chido, Chikonzi, Jayaguru and Nashe talked about feelings of shame and anger in relation with their status as “defaulters”. As a “defaulter” who had not been on ART for long enough, Chido did not qualify for decentralized ART. She felt bitter about what she perceived a “*punishment*” by the nurse, and about how she was treated. Chido’s report of the insensitive behaviour of one particular nurse at hospital B, as portrayed in section 7.3, was not an isolated account. During participatory observation at the ART clinic of hospital B, we witnessed the particular nurse by-passing the triage desk, talking in an unprofessional way to waiting patients, and picking selected patients from the queue. Other ART nurses felt uneasy about his behaviour, and the nurse-in-charge was aware of the problem:

*Tadisa: Yes. It is happening. I encountered about five who were given one-month supply. It was from the same nurse. They were punished because they had (laughing) skipped some days before coming, so they were told ‘I am going to give you one month, in the next month you come’.*

*Interviewer: Like a policeman?*

*Tadisa: Ya, like a policeman. So I encountered these patients. And they were from one nurse. So I told this nurse you are causing a lot of congestion in the clinic and you are causing actually the withdrawing of patients from taking their drugs if you punish them this way.* [interview with nurse Tadisa]

Jayaguru interrupted ART because he ran out of drugs whilst working on a farm 200

kilometres away from home. Having missed his follow-up appointment, he feared returning to the hospital:

*When I returned I feared going back to the hospital in fear that I could be shouted at. (...) I had never heard of anything that could have happened to anyone who missed an appointment but I knew that when I was initiated I was told that I am not supposed to default so I felt guilty of doing that. I even had thoughts of going and starting afresh from blood tests as if I was a beginner. [interview with Jayaguru, ART patient]*

Whether real experience or perceived fear, the stigma of “defaulting” showed that the quality of the patient-health worker relationship was an important determinant of adherence and retention on ART. In contrast to the quoted cases, the stories of Ega, Fungisai, Meso and Runako showed that a continuous, close and trusting relationship can facilitate ART restart. Fungisai’s brother worked as an ART nurse at the local health centre where he facilitated decentralized ART restart for his sister. Meso and Runako were familiar with ART nurses who were good friends of their late mothers. Even for Chido, who claimed that the offensive behaviour of an ART nurse contributed to her prolonged ART interruption, it was eventually thanks to her close relationship with nurse Chenai that she restarted therapy.

### **Tracing: safety net versus confidentiality**

Nine out of the sixteen portrayed ART interrupters were visited at their homes by community health workers through the SMART tracing programme: the other patients were not aware of the programme. In the cases of Jayaguru, Meso and Simbisai, tracing facilitated their return to HIV care.

Jayaguru was considered lost to follow-up when the hospital sent CHASA Kutenda to trace him. Jayaguru expressed how grateful he was that Kutenda encouraged him to return to HIV care before he fell ill:

*My guilty conscience made me think I would be questioned and even when the CHASA came to call me I thought I was going to be put under interrogation but we had a nice discussion and I was reinitiated. [interview with Jayaguru, ART patient]*

Batsirai, Chikonzi, Edzai, Nashe and Pfuma were traced by CHASAs during the present research project and recruited to participate in the study. Pfuma said on tracing that “*having someone to talk to in such situations would be very helpful*”. They all restarted ART after the tracing intervention and the study interview, except Batsirai whose condition deteriorated further until her death a few months after the interview.

Tracing of patients who discontinued ART was generally perceived as a useful and acceptable intervention, as the following quotes illustrate:

*Participant 1: I was once followed up when I had stopped ART...*

*FGD facilitator: Is it right or bad to be followed up?*

*Participant 1: It is good. You might have problems or even just decide to stop due to circumstances or facing other problems. Those who follow up may give you advice.*

*Participant 2: It's good because they know what would have caused us to miss our appointment and would provide help if they can.*

*Participant 3: Tracing is a good activity because even in the bible there was Noah who advised people about the coming flood and that they should prepare for that. So it's good to inform one another and to remind each other. Someone who reminds you and talks to you are good because they are concerned about your life, they love you.*

[Focus group discussion with young female ART patients]

There were, however, some study participants who do not think health workers should trace them at their homes. In the case of Edzai, for example, the village health worker approached her husband who did not know that Edzai was HIV-positive and enrolled on the ART programme. Confidentiality was a delicate issue and potential concern related to tracing, as the following study participant expresses:

*At times they do not even know where I stay then they get lost and walk around asking people.* [participant of a focus group discussion with male ART patients]

Tracers reported various cases of ART patients whom they successfully encouraged to return to care.

*When we trace them and get the reasons why they defaulted, we then give them correct information. For example, someone defaulted because they did not like the feeling of hunger that they felt after taking the tablets. Tracing helps as CHASAs give them information about how they can cope when they do not have adequate food supplies. Another example is that of a person who defaulted because he had been told in their church that he has been healed and is free from HIV, when we traced him and learnt that, we quickly gave the person the right information and convinced him to restart ART until he agreed.* [participant of a focus group discussion with ART patient tracers]

Tracers also reported that their activity helps understand the reasons why patients interrupt treatment:

*Through tracing, we learnt about a lot of causes for defaulting. We learnt that people default due to religious beliefs and this is very common around this place. [participant of a focus group discussion with ART patient tracers]*

Tracers also reported that they found many patients who were identified as suspected interrupters but in reality never stopped ART. Documentation errors at the ART clinics were the major reason for these cases that were misclassified as lost to follow-up. Some patients complained about being classified as “defaulters” without having missed an appointment, as the following quote shows:

*We started tracing of lost to follow ups last year and we have found it an effective way of learning exactly what’s happening to those suspected defaulters. Sometimes when we get there we discover that the patient is adherent and it was just an issue of flawed documentation. So tracing creates a platform for the correction of mistakes within the system. Sometimes you get to know that the patient died. (...) [interview with CHASA Shorai]*

*The documentation process is flawed: some people are documented as defaulters yet they are retained patients. So when we follow up such people we realise that it does not go down well with them, as we would be unnecessarily bothering them. [participant of a focus group discussion with ART patient tracers]*

Hence, tracing was identified as useful intervention to improve the ART programme:

*Tracing and doing follow-ups has helped the hospital to know the actual people who are still on ART and excluding those who are deceased. This has helped them enrol more cases. (...) Tracing is good because it helps the hospital update its patient records and realise faults in the system. [participant of a focus group discussion with ART patient tracers]*

Tracers emphasised that following-up patients only after 90 days was far too late:

*Tracing should start maybe within 5 days to 7 days so as to save lives. If tracing starts after 7 days of defaulting, it might take the tracer 3 days before finding the patient and another week to convince them to restart ART and by then the person would have defaulted for over a month, so time should be of essence, trace them early and get them back on ART before they default for longer. [participant of a focus group discussion with ART patient tracers]*

Who should be the tracers had been a controversial discussion between the SMART programme and the health authorities. During the pilot, all health worker cadres including trained and supervised community health workers were at the ART nurses' disposition to trace patients lost to follow-up at their homes. ART patients generally welcomed any tracer who was supportive and who protected their confidentiality. Based on the CHASAs' individual conduct and his or her relationship to the patients, participants from different focus groups in different areas had different experiences and views of the CHASAs as tracers, as the following quotes show:

*FGD facilitator: Who do you think is the best cadre to do tracing?*

*Participant 1: I think it should be the CHASA because the CHASA has got an understanding of such issues and can talk about these issues better than anyone else.*

*Participant 2: I think it should be a CHASA because they were specifically trained for that. They know exactly how they were trained regarding that job and they probably have better knowledge in these approach issues even better than nurses themselves.*

*Participant 3: CHASAs are better placed because some can even approach you and talk about such confidential issues in public but the CHASA was trained on that.*

[Participants of a FGD with male and female support group members]

Another focus group of support group members also preferred CHASA as tracers, but were critical about confidentiality breaching behaviours they experienced in their area:

*Participant 1: The CHASA is ok if he is a decent person because they know better about HIV issues and every CHASA is HIV-positive so he is the right person to visit and talk to such people.*

*Participant 2: There is a problem with CHASAs because they can't keep people's issues confidential. It goes to an extent where they offer counselling using a patient's name as an example.*

*Participant 3: CHASAs should be given lessons on keeping confidentiality because no one would want to go to the hospital and the next thing they hear people talking about the drugs they are taking having been told by the CHASA.*

[Participants of a FGD with male and female support group members]

## **7.7 Discussion: medical and social vulnerability after treatment interruption**

There is a variety of reasons why patients interrupted ART. Long-term retention on ART was essentially influenced by their ability to return to care after a temporary treatment gap. In this section, I will discuss the qualitative study findings and compare it with other studies. The implication of the results will be presented as well as the strengths and weaknesses of this study component. Table 7-4 shows the framework matrix – a tool for qualitative data analysis introduced in section 7.2.3 – that gives an overview on the sixteen cases and the identified reasons for ART interruption and restart.

**Table 7-4:** Framework matrix on reasons for ART interruption and facilitators and barriers to ART restart in sixteen cases

THEMES	Reasons for ART interruption	Facilitators for and barriers to restart after interruption			
		ART status	Health status during ART interruption	Social capital marriage family and kinship networks support groups	Health system access to ART follow-up patient-health worker relationship patient tracing
<b>CASES</b>					
<b>Batsirai, f, 22</b>	stigma in marriage	stopped 1 year ago, no restart (died few months after interview)	severely ill with TB; on CTX prophylaxis	<i>Facilitators:</i> mother her only support, but at a late stage only <i>Barriers:</i> husband left her when she fell ill after stopping ART; lived with in-law family who rejected her	<i>Facilitators:</i> CHASA traced her and brought her back to care temporarily <i>Barriers:</i> distance to ART clinic; rigid down-referral policy at hospital;
<b>Chido, f, 36</b>	mobility	restarted 5 months after ART interruption	healthy, feeling ill after 4 months (diarrhoea)	<i>Barriers:</i> competing interests, family members expecting monetary support from her since she is employed	<i>Facilitators:</i> restart thanks to personal relationship with local nurse who intervened at hospital asking for down-referral <i>Barriers:</i> collecting drugs at hospital, 40 kilometres away, in spite of local health centre being ART follow-up site (rigid down-referral policy); felt “punished” after having “defaulted” due to travel by getting small ART drug supplies only, causing frequent travel to hospital, ultimately causing repeated ART stop
<b>Chikonzi, m, 35</b>	mobility	stopped more than 1 year ago, no restart	healthy but depressed according to his wife; previous TB; on CTX prophylaxis	<i>Facilitators:</i> married with Maidei who is supportive <i>Barriers:</i> no supportive family or kin in the district; no community networks, considers support groups as closed savings and credit groups	<i>Facilitators:</i> traced by a CHASA <i>Barriers:</i> transport costs to the hospital prevent him from re-initiating ART; rigid down-referral policy at hospital; felt blamed to be a “defaulter” by a hospital ART nurse, complained about favouritism at ART clinic
<b>Edzai, f, 32</b>	stigma in marriage	stopped 7 months ago, no restart	deteriorating health since ART interruption; pneumonia; suffered herpes zoster; on CTX prophylaxis	<i>Facilitators:</i> her parents and sibling are supportive and look after her child, but they do not know she stopped ART <i>Barriers:</i> husband does not know her status and does not want to test HIV himself	<i>Facilitators:</i> traced by a community health worker <i>Barriers:</i> resides 20 kilometres from health centre and 50 kilometres from hospital, cannot afford transport

<b>Ega, m, 74</b>	religious authorities	restart 3 months after ART interruption	feeling weak, stopped working in his garden	<i>Facilitators:</i> supportive wife (herself on CTX) and son; embedded in religious community, supported by other ART patients in religious community; support group member (despite “leadership problem”) <i>Barriers:</i> feels neglected by relatives	<i>Facilitators:</i> good relationship with health worker at hospital who convinced him to restart <i>Barriers:</i> 30 kilometres distance not a problem due to relative wealth
<b>Fungisai, f, 35</b>	failed initiation	restarted 6 months after failed ART initiation	mental illness episode, suspected HIV encephalitis	<i>Facilitators:</i> restart thanks to supportive brother (who is a nurse at the local health centre); member of support group, which she considers an income-generation project <i>Barriers:</i> widow living with her mother who did not provide adequate treatment support	<i>Facilitators:</i> lives near a local ART initiation pilot site; direct link to health centre and ART programme through her brother <i>Barriers:</i> 30 kilometres distance to hospital not a problem due to local health centre a pilot treatment initiation site
<b>Jayaguru, m, 57</b>	mobility	restarted 6 months after ART interruption	healthy	<i>Facilitators:</i> supportive wife (on CTX prophylaxis); supportive brothers; member of religious community <i>Barriers:</i> Member of Apostolic Church which discouraged members from biomedicine	<i>Facilitators:</i> lives in short distance to hospital; CHASA traced him and brought him back to ART <i>Barriers:</i> felt ashamed about having missed follow-up appointment, feared to be blamed as “defaulter”
<b>Jekuche, m, 57</b>	religion	restarted 6 months after ART interruption	became severely ill 4 months after interruption: rash, wounds, fever, “shake-ups” and “mild stroke” (Jekuche)	<i>Facilitators:</i> supportive wife (on CTX) who persuaded him to restart ART after getting ill <i>Barriers:</i> member of religious community; sceptical about support group due to leadership issues	<i>Facilitators:</i> lives near hospital A, no physical access barriers; restart after tracing by CHASA who he was acquainted with
<b>Linda, f, 48</b>	religious authorities	restarted more than 1 year after ART interruption	physically disabled due to a stroke after interrupting ART	<i>Facilitators:</i> strongly supportive sister who made her restart ART; a network of people with whom she made business and whom she supported in the past; <i>Barriers:</i> religious community discouraging her from ART	<i>Facilitators:</i> - <i>Barriers:</i> disability; distance to hospital, local health centre not yet a decentralized ART site
<b>Maidei, f, 36</b>	failed initiation	restarted 2 years after failed initiation	felt healthy after completing TB treatment; alcohol	<i>Facilitators:</i> husband Chikonzi supportive after release from prison <i>Barriers:</i> no support from relatives, in-laws of former husband blaming her for death of him and the 8-year old child	<i>Facilitators:</i> returned to care through PMTCT during latest pregnancy <i>Barriers:</i> distance to hospital, delayed decentralisation

<b>Meso, f, 20</b>	stigma in marriage	restarted 12 months after ART interruption (died few months after the interview)	wasted and severely ill with TB	<i>Facilitators:</i> her late mother had close relation to ART nurse at hospital; supportive aunt desperate to take her and care for her <i>Barriers:</i> recent loss of husband and baby; lost parents, lived with brother's family, keeping her as labour force, not giving care and support to her	<i>Facilitators:</i> access to ART follow-up; lived near hospital; personal relationship to ART nurse <i>Barriers:</i> appears not having received adequate care at hospital
<b>Nashe, m, 38</b>	mobility	stopped 2 years ago, no restart	deteriorating health since interruption; diarrhoea and swollen leg; on CTX prophylaxis	<i>Facilitators:</i> supportive wife who is on ART <i>Barriers:</i> lived in emigration (South Africa) before illness, has, seems therefore socially isolated in Zimbabwe; not member of support group	<i>Facilitators:</i> gets CTX at local health centre; restart after tracing / study <i>Barriers:</i> hospital 50 kilometres away; rigid down-referral policy at hospital; fear to be blamed for "defaulting"
<b>Pfuma, f, 26</b>	failed initiation	ART initiation failed 7 months ago, no restart	feels healthy; CD4 of 151; on CTX prophylaxis	<i>Facilitators:</i> sister, paternal aunt and aunt's daughter are supportive <i>Barriers:</i> polygamous marriage with husband in South Africa, discourages her from ART	<i>Facilitators:</i> traced by CHASA <i>Barriers:</i> very long distance to initiation clinic (hospital); long walking distance and no transport means from home to ART follow-up site
<b>Runako, f, 18</b>	failed initiation	restarted 1 year after failed initiation	admitted at hospital after getting ill	<i>Facilitators:</i> lived with paternal aunt who was close to mother; knows some other adolescent ART patients, meets them informally at hospital <i>Barriers:</i> orphaned; adolescence	<i>Facilitators:</i> resided in hospital compound with aunt who worked at hospital; immediate access to ART clinic thanks to good contacts to nurses
<b>Simbisai, f, 18</b>	mobility	restarted 12 months after ART interruption	wasted and severely ill with TB	<i>Facilitators:</i> lived with grandmother who took her home from Harare and brought her to hospital <i>Barriers:</i> mother died, father (on ART) not supportive; sister discouraged her from ART on religious grounds	<i>Facilitators:</i> lived near ART initiation pilot site <i>Barriers:</i> prompt tuberculosis treatment at hospital A after return from Harare, but failed referral from tuberculosis programme to ART programme; restart of ART at health centre after tracing by a CHASA
<b>Tomupeishe, f, 36</b>	mobility	restarted 7 months after ART interruption	good health	<i>Facilitators:</i> supportive husband who was on ART, decided together to restart ART before getting ill as they were before starting ART	<i>Facilitators:</i> lived near hospital <i>Barriers:</i> felt ashamed for having missed follow-up appointment, had experienced insults by a nurse in the past, feared to be blamed as "defaulter"

ART=antiretroviral treatment; TB=tuberculosis; CHASA=Community HIV/AIDS Support Agent; CTX=co-trimoxazole;

### **7.7.1 ART interruption despite strong motivation to remain in care**

There is a broad range of reasons why patients interrupt ART, some of them strongly connected with the local context such as the limited drug supply given to ART patients by a particular health facility, others rooted in more general issues, such as gender relationships in Zimbabwe. We found four main reasons for ART interruption. First, many ART patients dropped out at an early stage of therapy. Strictly, they should not be considered interrupters since they never really initiated ART. Mental and psychological conditions as well as losses during referral were underlying reasons for failed ART initiation. A second reason for ART interruption was women who stopped taking drugs to hide their HIV status from their new partner or husband and his family. This phenomenon revealed a deep gender conflict in the studied communities: women complained that men commonly refuse HIV testing before marriage, whilst men blamed women for hiding that they are HIV-positive. In the context of extreme poverty, marriage was for many women an imperative for social and economic survival. It appears that for many women, striving for social survival in everyday life prevailed over their longer-term desire for good health. Our findings on the impact of gender conflicts on ART confirm research from Zimbabwe and other sub-Saharan countries (Skovdal, 2011a). Mobility was a third and probably the most frequent reason for ART interruption – a relevant aspect of retention which has rarely been studied by qualitative research. As the Zimbabwean ART programme is a fragmented system of individual and often different hospital and district ART programmes, prolonged travel and migration often led to treatment gaps due to failed referrals, short drug supply or missed appointments. Fourth, some patients stopped ART as they found themselves caught between religious and biomedical authorities. In contrast to other studies, traditional African medicine and “witchcraft” did not emerge as a contradictory health system to biomedicine. Some Apostolic Churches were much more powerful and radical in promoting magic and spiritual healing in opposition to ART. Whilst there is a rich literature of qualitative research on the potentially conflicting cultural models of traditional and biomedical healing, the impact of the growing evangelicalism across sub-Saharan Africa on ART retention has not been studied.

In their qualitative study on ART interruption, Ware (2013) distinguished between intentional and non-intentional ART interruption. Related to the findings of this study, stopping ART due to failed initiation, HIV stigma in marriage and religious authorities would be considered intentional, whilst stopping ART due to migration or travel would be non-intentional. The authors argued that patients who unintentionally stop ART due to logistical or financial reasons usually return to care after a temporary interruption

thanks to their “willingness” and “motivation” (ibid.). Our study does not support the concepts of “intention” and “willingness” with regard to adherence and retention. The patients who missed their ART appointment due to prolonged travel or unexpected incidents stayed off ART for a longer period. Our study rather supports the findings of the systematic review of Merten (2010), arguing that patients are highly motivated to adhere to ART, yet struggling to balance competing moral, social and medical interests and demands in their social lives than losing will and intent to stay healthy. Temporary ART gap turned into prolonged disengagement for other reasons than those causing the treatment interruption.

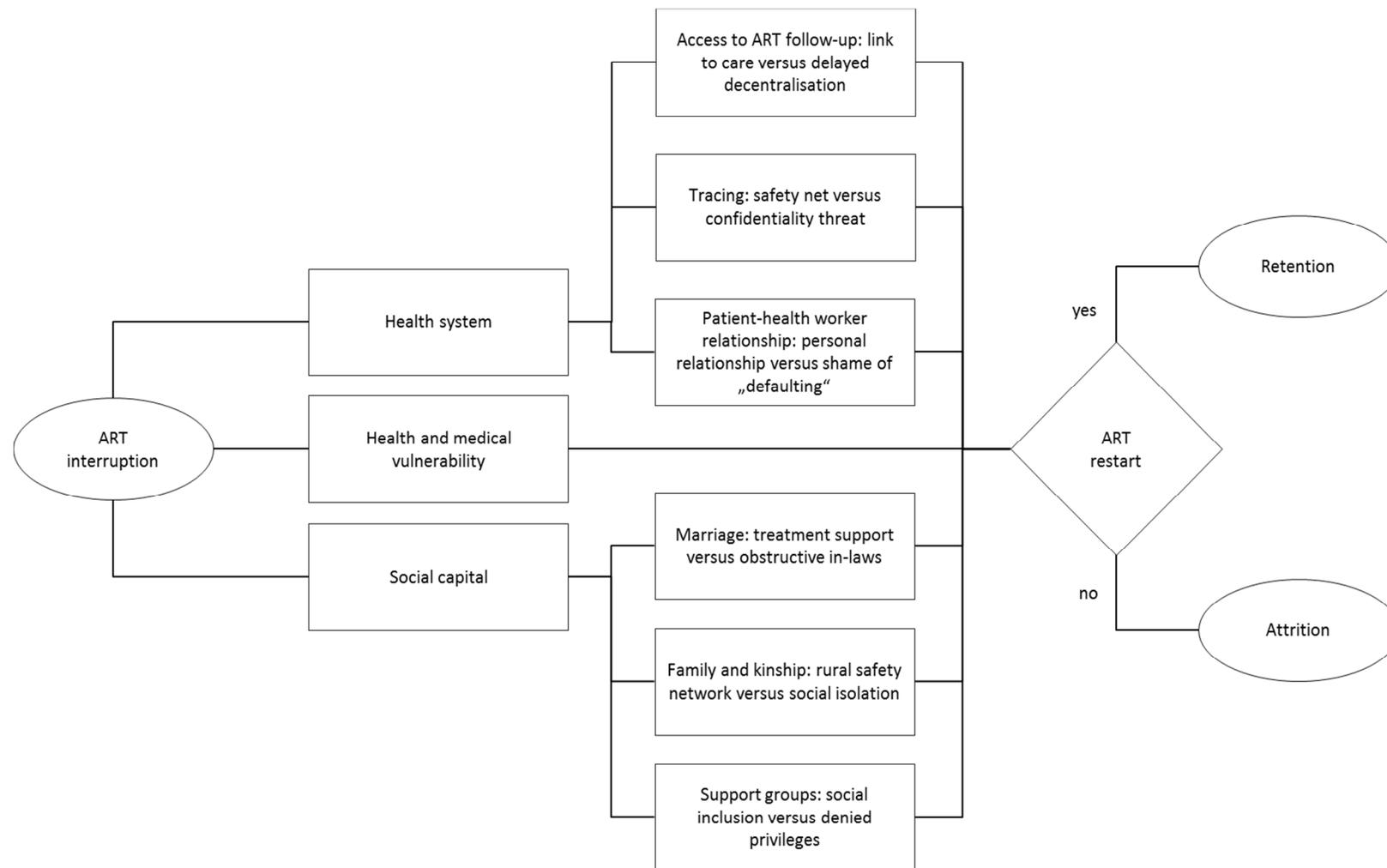
The two above cited influential studies by Merten (2010) and Ware (2013) focused on individual and social determinants influencing adherence and retention, largely ignoring reasons engrained in the health system and ART programme itself. Other qualitative studies, such as the monographs by Nguyen (2010) and by Mattes (2011) provided rich and critical insights into inclusion and exclusion mechanisms of ART programmes; their findings though were limited due to quality issues.

### **7.7.2 Safety nets after interruption key for long-term retention**

Whilst there is a large literature on reasons for ART interruption, our study adds new insights on what happens after patients drop out of the ART programme. Preventing attrition from ART thus is less a matter of getting lost than of getting found. Patients who interrupt ART enter into a time window of medical and social vulnerability with unknown outcome. Figure 7-6 shows a flow chart summarizing the patient’s scenarios and choices after treatment interruption which either lead to ART restart and retention or to prolonged therapy discontinuation and attrition.

ART interrupters have three potential safety nets that can prevent them from permanent disengagement: their own health, their social capital, and the health system. From a Practice Theory point of view, the function of these safety nets is to help the patient regain agency: his or her capacity to take action, as for example to return to the ART programme.

**Figure 7-6:** Flow chart on facilitators of and barriers to ART restart after interruption



### 7.7.3 Kinship networks: a key source of social capital

Patients whose health status deteriorated had good chances of resuming ART if they possessed sufficient social capital through marriage, family and kinship networks. Descent was the primary supportive relationship. Lack of social capital in these primary networks, however, increased the patient's social vulnerability, defined as susceptibility to social harm and exclusion (Allotey, 2012), bearing high risks of attrition from ART. This was predominantly the case for female ART patients who stopped ART to hide their HIV status from their partners and in-laws. Even if they disclosed their status, they often lacked family support as long as they stay with their partner and in-laws. Their (rural) parental home was a critical safety net for HIV-positive women who separated from their partners.

Our findings on the paramount importance of kinship for long-term adherence and retention confirm insights from other studies, investigating extended family as a source of social capital in Zimbabwe. The studies of Parsons (2012) and Zagheni (2011) explored how kinship networks cope with the immense number of orphans due to HIV/AIDS deaths in Zimbabwean society. The authors argued that paternal aunts and uncles as natural care-takers were not able to absorb the mounting number of orphans in Zimbabwe. In the course of the HIV epidemic, grandmothers, adolescent siblings, those often in urban or semi-urban settings, and maternal aunts and uncles became involved in care of orphaned children. Parsons (2012) stressed that in the framework of Zimbabwean's patrilineal kinship system, the mother's kin, especially her brother, play a key role in the event of a mother's death. Zimbabweans imply a strong affective and spiritual bond with their mother's brother, which is often explained with the power of the dead mother's spirit (*ibid.*). For this reason, Zimbabweans consider all female maternal relatives of mother's generation *mai* (mother). Thus, in the case of a child whose mother dies, the two complementary concepts of patrilineal kinship on the one hand and the power of the maternal spirit lead from the child's point of view to a separation, and thus to a potential competing influence between *baba* (the principle of descent) and *mai* (the principle of the spirit) and their respective extended families. Parsons (2012) illustrates this notion of "competition" by telling the story of an orphaned girl. The father's family decided that the girl would live with her mother's relatives as long as she remains unmarried. The author showed that that care – in a sense of "loving motherhood" – was delegated to the maternal relatives. When the time of marriage came, the patrilineal kinship claimed her back. In the Zimbabwean society, bride price payment is a prevailing regulation of customary marriage. Marriages of female kin thus

represent a potential source of income compensating the extended family's loss of her productive and reproductive working capacity (ibid.).

The Zimbabwean kinship structure has not only absorbed the tremendous need for orphan care. Our study showed that it also serves as a supportive safety net for ART patients in need of care and assistance, particularly in the event of a personal crisis, such as after a treatment interruption. The case stories presented in this study demonstrate that marriage, family and kinship are powerful structures of inclusion and exclusion.

In the last ten years, the concept of social capital has gained the attention of policy makers (Scott 2011). OECD (2001) and World Bank (2002) explored the potential impacts and benefits of social capital for social and economic development. In the public health domain, the social capital approach has been used in a variety of study topics, including ART. Ware (2009) showed the importance of social capital for long term ART adherence. The authors argued that obligations, responsibility and reciprocity within social networks were the driving factors why patients in sub-Saharan Africa make tremendous efforts to adhere to ART. Our findings support the importance of social capital for adherence and retention, however largely limited to family and kinship. Whilst community resources represent an important resource for ART patients to adhere to ART drugs and appointments, we found that vulnerable ART interrupters who are most in need are not supported by the community. Socially-vulnerable ART interrupters are rarely members of HIV/AIDS support groups. In fact, the missing link to a support group makes them socially vulnerable. Support groups, frequently found in the study area, were a way of collective self-determination among ART patients with social capital. Support groups were strongly connoted with an identity creating discourse of social inclusion and exclusion, both by members and non-members. Members tend to blame non-members for being in denial about their HIV status, whilst non-members often consider support groups as exclusive clubs.

#### **7.7.4 The need for a supportive health system**

ART interrupters in a deteriorating health condition who lacked supportive partner, family and kinship relationships were at high risk to permanent disengagement from ART, especially if they were confronted by barriers in the health system. Intricate re-initiation procedures not responding to their needs were a main reason why ART interrupters delayed therapy restart. Our case studies showed that vulnerable patients who were most in need of support did not have the resources and confidence to embark on a renewed initiation process simply because they could not afford it or did

not have the physical strength for multiple visits to the district hospital. These findings confirm the existing literature on ART client satisfaction and retention obstacles from Zimbabwe that identified long waiting times, high visit frequencies, and unpredictable clinical pathways major issues affecting ART patients (Campbell, 2011a).

In addition to the system barriers, ART interrupters often felt ashamed and guilty for having “defaulted”. Many patients reported they were blamed and offended by health workers for missing their ART appointment; others feared hostile reactions when returning to the same ART clinic where they “defaulted”. The notion of “defaulting ART” had a strongly accusatory connotation. It had been used in tuberculosis programmes with a stigmatizing association for many years, and it appears that its condemnatory meaning has been taken over in the ART programme. ART patients started complaining not only about the negative perception, but also about offensive behaviour of health workers in relation to missed appointments. Patients internalised the stigma of “defaulting” to such an extent that they did not dare return to the clinic. It appears that the source of the stigma of “defaulting” was the health system itself. The existing qualitative evidence on health system related determinants suggests that besides decentralised ART provision, the patient-health worker relationship is key to adherence and retention throughout sub-Saharan Africa, as Kagee (2012), Dahab (2011) and Gusdal (2009) reported from South Africa, Agnarson (2010) and Mattes (2011) from Tanzania, Sanjobo (2008) from Zambia, and Campbell (2011a) from Zimbabwe. There is, however, further research needed to understand the human resources challenges of chronic care integrated in primary health care systems. Innovative interventions are required to strengthen trusting and continuous patient-health worker relationships in ART.

On the other hand, our findings suggest that ART interrupters have good chances of returning to care if the health system provides conditions where the patients can regain agency. Three facilitating approaches appear particularly relevant: first, decentralised ART initiation and follow-up makes restart easier. Physical proximity to the ART site obviously reduces the patient’s financial burden to the household. Decentralised preparation, initiation and follow-up of ART also allow the patient to locally reconcile competing interests within family, kinship and community, potentially supported by the familiar health facility, the community health workers or a support group. Our study showed that concealment of ART is not an option in the setting of rural Zimbabwe. Socially-vulnerable patients, such as newly married women, require a locally-accessible supportive safety network. The local primary health care facility is an ideal gateway not only for “one-stop” primary health services including ART, but also for

information sharing, peer education and social networking. Integration of ART into primary health care would require full decentralisation of ART.

Trusting patient-health worker relationships are critical for ART restart. Instead of blaming patients for missing their appointment, health workers can assess the patient's social vulnerability and structural adherence barriers. Again, health workers in the local health facility might be in a better position to understand the reasons why the patient interrupted ART, and propose potential ways to resume treatment. A trusting patient-health worker relationship is particularly important in the event of a crisis, such as a treatment interruption. Health facilities should therefore put the quality and continuity of this relationship in the centre of the ART programme.

Community-based adherence support should be targeted to reach medically- and socially-vulnerable ART interrupters who do not have family and kinship networks. Patients who need it most are usually not part of community support groups. Community-based tracing is highly accepted and demanded both by professional health workers and patients. However, the study results suggest that community-based tracing should be, firstly, initiated at an early stage after a missed appointment, and secondly, targeted to patients considered medically and socially vulnerable. It appears that patient tracing is most feasible, efficient and effective in a decentralized ART programme. Local health facilities are in a better position to identify interrupters than hospitals because they oversee fewer patients and because the health personnel and community workers often know them personally. Interrupters can be promptly and easily identified provided the facility uses an appointment system; tracing can be organised through existing working relationships between professional health staff and mobile community health workers on bicycles.

#### **7.7.5 Strengths and weaknesses**

Most qualitative studies on ART retention have explored reasons for therapy interruption. The major strength of this study was its focus on patients who restarted ART after interruption. Our focus on patients who interrupted ART allowed documentation of lived experience of therapy disruption. The approach to reconstruct case stories contributed to a better understanding of failed retention in the context of the treatment career and the immediate social environment of the patient. The teamwork with Zimbabwean researchers and translators allowed me to get insights into cultural concepts around HIV and ART. The interviews with patients and relatives and the focus group discussions were conducted in Shona, and the English transcripts were discussed with the translator and with a third Shona-speaking person who was in

charge of checking the quality of the transcript. Geographical clustering and combing methods and techniques were an additional strength of the study. Rather than sampling individual cases in a large geographical area, the focus on four study sites allowed a deeper familiarisation by the study team with the local environment, the social networks and the everyday lives of patients and health workers in the health facilities. Interviewing not only the patient, but one or two close relatives allowed reconstructing the narrative on the basis of perceptions from different angles. Interviews, focus group discussions and participant observation were conducted at the same four geographically-limited study areas. Hence, the study team members were able to link accounts collected across the three methods with each other, and to frame individual statements in the local context. The perceptions of partners and relatives added valuable insights into contextual circumstances under which the interrupter cases managed or failed to restart ART. Focus group discussions and participant observation served to validate and critically discuss themes and concepts that emerged from the cases.

There were inconsistent or even conflicting responses related to some cases and themes. For example, good health was in some cases a barrier to and in other cases a facilitator for ART restart after interruption. Support groups were considered instrumental for some patients and inaccessible for others. Treatment interruption was an issue of attitude and moral failure in the view of some health workers, and a consequence of poverty for others. Interviews bear the major weakness of self-reporting. I did not aim at reconstructing an “objective truth” to why exactly the patients interrupted and restarted ART. Putting the participants’ responses in the context of their own history of ART or role in the ART programme often helped resolving inconsistencies. In the case of Nashe, for example, there were a number of parallel narratives as to why he did not return to ART after coming back from South Africa. His nurse suspected an issue with his family in-law, his counsellor found he had a negligent attitude on life, his wife said he was depressed, and he himself claimed he did not want to spend his family’s money for transport to the hospital. Interviews do not reveal how things are in the real world, but they reflect how people talk and think about things. I tried to resolve inconsistent responses by reconstructing the history and the context that might have influenced the participants’ perception of ART interruption and restart. Nashe’s health seeking behaviour was clearly shaped by his migration history and the feelings of shame and guilt related to his failure as bread winner. His counsellor’s view on Nashe’s “irresponsible behaviour”, on the other hand, reflected a general pattern of some health workers judgemental views on patients who did not adhere to their instructions.

There are a number of limitations to the qualitative study findings. Given the restricted geographical area of the study, the generalizability of the study is limited. The specific social and economic circumstances in rural Zimbabwe and the characteristics of the health system and ART programme in Zaka and Bikita do not allow the transfer of the findings to other settings. It would have been advantageous to choose a comparative design, for example by selecting two distinct districts. Comparing qualitative data from the two neighbouring districts Zaka and Bikita under the same ART programme did not provide any relevant insights. Furthermore, the patient cases were analysed in retrospect. As lived experience is critical to better understand ART restart after interruption, it would have been beneficial to undertake a prospective qualitative study. Patients were only interviewed once. In a prospective design, the five interrupters who had stopped ART at the time of the interview could have been followed-up for a certain period and interviewed several times. On the one hand, this might have deepened insights; on the other hand, this approach would have raised ethical concerns if no action had been taken to help those whose disengagement from care posed a threat to their health. In a number of cases, it was thanks to the intervention of the study team that the participant resumed ART. In two cases, I learnt that the participants died a few months after the interview. Whilst following-up these cases, I might have had to assist the participant to access life-saving hospital care.

I conducted large parts of the data analysis on my own after returning to Europe. Whilst coding was partly done in collaboration with study team members, the analytical framework was not established by multiple researchers. Involvement of other researcher in the analysis might have strengthened the credibility of the study findings.

## **8 Discussion and conclusions**

I chose a mixed-methods study design to explore the magnitude and the underlying reasons of ART programme attrition in a rural setting in Zimbabwe. This final chapter presents a discussion of the integrated qualitative and quantitative findings (8.1) and of the strengths and weaknesses of the study (8.2). The thesis ends with a reflective commentary (section 8.3) and with recommendations on programming and research (section 8.4).

### **8.1 Discussion of main findings**

A synthesis of the quantitative and qualitative research resulted in three overall study findings that are presented in this section: firstly, ART re-engagement after interruption is a key to long-term retention; secondly, early tracing of vulnerable interrupters could reduce mortality on ART; and thirdly, retention has improved over calendar time, possibly thanks to earlier therapy initiation and to decentralisation of ART provision. The mixed-methods integration matrix below (table 8-1) shows how the findings of the quantitative and qualitative components were integrated in the course of data analysis: results of each component were translated into questions to be explored by the complementary component, as indicated by the arrows.

**Table 8-1: Mixed-methods integration matrix**

Quantitative findings	Emerging questions for complementary investigation	Qualitative findings
75% retention 3 years after ART initiation	What were the reasons for good retention?	strong motivation to adhere to drugs and appointments district ART programme supported by NGO project (SMART)
12-months retention increased from 77% (2006 cohort) to 85% (2010 cohort) median CD4 baseline increased from 55 (2006 cohort) to 151 (2010 cohort)	Besides the fact that patients initiate ART earlier, what were the reasons for improved retention over time?	SMART gradually strengthened supportive interventions at health facility level (decentralised ART provision) and community level (CHASA programme and tracing)
86% tracing coverage 62% traced by professional health workers, 38% by community health workers median time between missed appointment and tracing 461 days	How was tracing performed by SMART and perceived by the involved parties? How did monetary incentive influence tracing performance?	tracing feasible and well accepted by patients and health workers time of tracing perceived too late high numbers of patients traced by professional health workers on motorbike when tracing was incentivised community health workers took over tracing on bicycles after monetary incentives were ceased
17% LFU incorrect due to documentation errors	What are the causes and consequences of erroneous losses?	high patient workload, chaotic organisation and management failures at hospital level caused missing and erroneous recording by ART nurses tracers blamed by misclassified ART patients for suspecting them to be “defaulters”
62% LFU found to be dead; only 4% found alive mortality 1.8 times higher than officially reported 64% early mortality (during first 6 months of ART) baseline characteristics: 73% WHO stage III or IV, median CD4 of 149; 19.5% on tuberculosis treatment	How do patients and health workers perceive and explain death on ART? What was the role of health status in interruption and restart?	health workers and patients perceived death as a result of late testing and ART initiation tracers perceived death as a consequence of non-adherence and ART interruption deteriorating health after interruption perceived as a dominant reason why patients restarted ART, wives and family playing a facilitating role tuberculosis perceived a major obstacle for retention local health centres know their patients and are better

			informed about event of and reasons for losses or deaths than hospitals
30% moved away without reporting transfer moved	Why do people not obtain an official transfer letter?	→	local health centres not issuing transfer letters patients reluctant to attend hospital consultation to obtain transfer letters national ART programme not harmonized
54% deaths before, 46% after last scheduled appointment 47% of deaths after interruption occurred within 30 days		←	How large is the time window for tracing between missing an ART appointment and death? patients' health deteriorated after treatment interruption patient tracing for ART restart was well accepted by health workers and patients
43% patients interrupted ART for more than 7 days at least once		←	How common are treatment interruptions? main reasons for treatment interruption: women hiding their HIV status to their partners, religious authorities discouraging patients from ART, and missing an ART appointment due to travel early interruptions occurred due to failed initiation, caused by illness, including mental and psychological conditions
52% interrupters resumed ART (median interruption of 32 days), 48% did not		←	What proportion of interrupters restarted ART and what is the average length of interruption? temporary ART interruption turned into prolonged disengagement from ART due to lack of safety net in social environment and disconnection from health system, caused by high transport costs and negative attitudes by health workers on "defaulting" restart after interruption was facilitated by family and kinship networks and a supportive health system, such as good patient-health worker relationship, local access to ART, and physical tracing

### **8.1.1 Return after interruption key for improved retention**

More than one out of four retained patients had a treatment gap of at least seven days. Given the frequent incidence of temporary ART interruption in the SMART programme, the question to understand long-term retention is not just why patients interrupt, but, even more importantly, under what circumstances they restart ART.

Stopping ART cannot be interpreted as a lack of adherence motivation. Our qualitative findings rather suggest that patients are confronted with social and cultural conflicts in their immediate family, kinship and community environment which are so powerful that they are prepared to put their health and, ultimately, their lives at risk. Two main reasons for therapy interruption were women hiding their HIV status from their partners, and religious authorities discouraging patients from taking ART. ART interruption appeared as a symptom of deep gender conflict and the influence of the Apostolic Church in Zimbabwean society. Patients also interrupted ART because they missed an ART appointment due to unexpectedly prolonged travel or due to migrating away from the ART initiation site. Like all Zimbabweans, ART patients are mobile. 8% of all enrolled SMART patients moved away from where they initiated therapy, many of them without a formal transfer to another clinic and thus classified as losses to follow-up. In what appears to be a fragmented national ART programme with weak links between ART sites, moving from one site to the other bears the risk of treatment interruption. Our case studies show that in a new social environment, patients can have great difficulties to undergo a new process of disclosing their HIV status. If the health system does not facilitate a smooth transfer from one site to another, the patient can fail to reconnect to the ART programme. A harmonized information system would not only reduce the proportion of silent transfers, but could ultimately contribute to improved retention. Providing patients with a reserve supply of ART drugs for an extra month would be another measure to prevent treatment interruptions.

ART restart after interruption has been a neglected phenomenon in previous retention studies. With a temporary therapy interruption, ART patients enter a period of vulnerability. According to our quantitative data, around half of the interrupters returned to care after a median interruption of 32 days, whilst the other half permanently disengaged from ART. In the setting of our study, as an ART interrupter, the patient's capacity to determine his or her treatment career is constrained by numerous factors in the patient's environment. Merten (2010) characterised ART adherence as the outcome of the patient's permanent evaluation of beneficial versus harmful effects of adhering to ART drugs and appointments, balancing out medical, moral and social imperatives in his or her environment. After therapy interruption, this struggle is

aggravated and becomes existential. Temporary interruption became prolonged disengagement from ART predominantly if patients became ill and lacked a safety net in marriage, family or kinship. In rural sub-Saharan Africa, family and kinship networks are the paramount safety network, substituting non-existent governmental social welfare and security, as pointed out by sociological and anthropological studies, such as Zagheni (2011) and Parsons (2012) on kinship resources for orphan care in Zimbabwe and Mattes (2011) and Nguyen (2007) on the conflicting value to the individual between biomedicine and a kinship-based social organisation. Besides the lack of social capital, ART interrupters remained disconnected from the health system for two main reasons rooted in the health system itself: firstly, distances were too long and opportunity costs for transport too high to undergo the ART re-initiation procedures at the district hospital; and secondly, ART interrupters did not return to the ART clinic because they feared being blamed as “defaulters” by health workers. Shame about “defaulting” caused by negative attitudes of health workers about patients who did not adhere to ART appointments was a strong and frequent pattern of conflict between patients and health workers.

Having a partner, female sex, older age and less than 6 months ART interruption were identified as factors associated with ART restart in studies from Uganda (Mills, 2013) and South Africa (Kranzer, 2010). We found three major facilitators for ART restart after interruption: access to ART at the local health facility; a trusting and stable patient-health worker relationship; and early physical tracing after missing an appointment. Given the fact that therapy gaps are inevitable, a better understanding of the facilitators of and barriers to ART restart will be crucial to improve retention.

### **8.1.2 Mortality on ART: the need for early tracing**

Two thirds of the patients who dropped out of the SMART programme were classified as losses to follow-up, their treatment outcome remaining unknown. Only after tracing the lost patients at their homes, SMART found that death was the major reason for programme attrition. Tracing revealed that deaths were 1.8 times more frequent than initially reported by the programme, accounting for 76% of all patients who had dropped out of the programme after three years. 45% of all deaths were unreported, their causes unknown. The magnitude of hidden deaths raised the question who these patients were and under what circumstances they died. Comparing unreported with reported deaths showed that patients whose death was not reported were on ART for a shorter period of time and were more likely to be female. Of note, deaths were more likely to remain hidden if they occurred after the patient had missed his or her ART appointment. Half of the deaths occurred *before* the patient missed his or her ART

appointment. Whilst these deaths occurred as the patient was theoretically still in possession of ART drugs, the other half of deaths occurred *after* missing an ART appointment. This temporal aspect of death on ART has not been investigated by programmes and research so far, probably due to the fact that the date of unreported deaths usually remains unknown, unless ART data is matched with death register data. Both our quantitative and qualitative findings suggest that early tracing of vulnerable ART interrupters could improve retention. Yet, tracing after the 90 days threshold is too late: half of the deaths after interruption occurred within 30 days. The SMART tracing intervention, therefore, did not improve retention: only 4% of the lost patients were found alive; four of them participated as cases in the qualitative study component. Professional and community health workers considered tracing of losses after 90 days as ineffective and frustrating.

The qualitative study findings suggest that early tracing of vulnerable ART interrupters could reduce mortality and, thus, attrition from ART. Research on ART patient tracing in Malawi (Tweya, 2010) and Kenya (Thomson, 2011) and from a systematic review (McMahon, 2013) showed a high proportion of patients restarting ART after tracing and an overall improvement of retention in ART programmes with tracing compared to programmes without tracing. However, the cited programmes were substantially supported by NGOs and research projects, and their outcomes thus not necessarily transferable to resource-poor public ART programmes. As physical tracing of ART interrupters is a potentially costly undertaking, ART programmes need to target tracing to medically and socially vulnerable patients. The fact that most of the deaths after ART interruption were not reported to the health facility suggests that social isolation and disconnection from the health system might have played a role why these patients did not restart ART. A lack of partner and family support is clearly a key warning indicator for attrition after interruption.

Our qualitative results suggest that local health centre nurses know their patients better than hospital nurses, and are better and earlier informed about losses or deaths. Physical tracing was a successful intervention of SMART to improve the accuracy of assignment of ART outcomes and to update the electronic patient database. The present study showed that tracing is feasible and can be implemented at relatively low cost. The qualitative research also showed that physical tracing is well accepted both by patients and health workers, as long as the tracers are trained and supervised by the local health centre nurse, and that the patient's confidentiality is protected. The qualitative enquiry found that early tracing is most feasible in a decentralised setting where health workers and patients knew each other and patient numbers allowed to

quickly identify interrupters on the basis of a well-kept appointment book. As shown in the systematic review by Wouters (2012), lay community health providers have contributed to increased coverage of ART programmes, adding extra human resources to overwhelmed health systems. Recent large-size observational studies such as Lamb (2012) and Fatti (2012) confirmed earlier findings of a cluster-randomized trial from Uganda that showed substantial retention gains in programmes with community-based adherence support (Chang, 2010). Our study showed that actors who are familiar with their local community, like the CHASA, can incorporate physical tracing of ART interrupters into their broader sensitization and adherence support activities.

Whilst tracing could potentially provide a safety net for vulnerable interrupters, it also serves to improved quality of patient data management and programme monitoring. Our study revealed that 17% of patients who were classified lost to follow-up in the medical records were not genuinely losses. Participant observation at the two hospitals in Zaka and Bikita showed that high patient workload, chaotic organisation of patient flow and medical records, as well as failures in human resources management in the ART departments, caused missing and erroneous recording by ART nurses led to misclassification of retained patients as lost to follow-up. Nonetheless, the SMART electronic patient database contributed to substantial data quality improvements, since SMART data clerks continually verified whether medical records were consistent and complete before capturing the data electronically. ART nurses confirmed that the tracing intervention was a major data cleaning and updating exercise. The findings on medical record keeping confirm earlier research on electronic medical record systems. Like most national ART programmes in sub-Saharan Africa, ART records are kept in paper-based systems. NGO projects like SMART introduced their own electronic system which has led to what Forster (2008) called “antiretroviral database anarchy”, lacking data uniformity and standardized ART outcome categories. As the authors found in their review, electronic ART databases contribute to reduced losses to follow-up, especially if they are accompanied by patient tracing and checking of death registry data.

### **8.1.3 Improving retention over time**

With 75% of the enrolled ART patients retained at 36 months, the SMART partnership achieved better outcomes than similar programmes in Zimbabwe and in the region, such as for example a large government ART programme in South Africa, reporting a 36-month retention proportion of 64% (Cornell, 2010b). In the existing retention literature, there is no clear trend in retention on ART over recent years. Some studies report improving retention (Fox, 2012), other studies report increasing attrition

(Mutevedzi, 2013). In the case of SMART, 12-month retention has improved from 77% in the 2006 cohort to 85% in the 2010 cohort. The findings suggest two major reasons for this trend. Firstly, patients initiated ART earlier over time, as the increase of the median CD4 baseline from 55 (2006 cohort) to 151 (2011 cohort) among all enrolled patients shows. Secondly, SMART gradually decentralised the supportive interventions from hospitals to rural health centre and to the community level. Confirming growing evidence from other studies, such as Fatti (2010) and Long (2011), our findings suggest that besides the fact that patients initiate ART earlier, decentralisation of ART provision has contributed a lot to improved ART outcomes in the SMART programme. ART provision at the local health centre can serve as a critical safety net for interrupters who lack economic and social capital to restart therapy.

Earlier qualitative research, such as Nam (2008), Ware (2009) and Merten (2010) showed that ART patients in sub-Saharan Africa are highly motivated to adhere to ART drugs and appointments. This study confirms that in spite of competing interests and high opportunity costs in their immediate social environments, ART patients commonly manage to stay on ART or to restart after a temporary interruption. The SMART programme demonstrates the resilience of ART patients even during a severe economic and humanitarian crisis. Our cohort analysis shows that patients who initiated ART in 2009 during political turmoil, hyperinflation, epidemic outbreaks and a breakdown of public infrastructure, were only slightly more likely to drop out of care.

## **8.2 Strengths and limitations**

The methodological strengths and weaknesses of the quantitative and qualitative study components were discussed separately in sections 6.3.6 and 7.7.8. In addition, our study had a number of strengths and limitations with regard to the overall mixed-methods approach.

### **8.2.1 Strengths**

This research project was one of the rare mixed-methods studies on ART retention in sub-Saharan Africa. The literature on quantitative research on retention is vast, and there is also a rich body of qualitative literature on adherence to ART, including a research project on social capital and HIV/AIDS in Zimbabwe (Campbell, 2011b). Yet, as shown in the literature review, we only found one mixed-methods retention study from sub-Saharan Africa (Miller, 2010), investigating a relatively small cohort (n=528). In our study, we were able to offer more comprehensive insights into ART retention than if we had focused on a solely quantitative or qualitative approach. Our cohort was

comparatively large (n=8425) and, owing to a cluster sampling strategy and multiple interviews concerning single cases, we consider our qualitative data saturated.

Researching across and between the two methods allowed us to translate results from one component into new research questions for the complementary component. We explored the quantitative and qualitative data concurrently, allowing integration of the findings. As shown in table 8-1, quantitative findings raised new research questions that were subsequently explored in the qualitative data analysis. At the same time, emerging qualitative findings led to additional quantitative queries that had not been foreseen in the study protocol.

The multidisciplinary composition of the study team was probably the most important asset of the mixed-methods approach. Sampling strategy, recruitment of study participants and reconstruction of the case stories were discussed between social science researchers, programme managers, community facilitators, data officers and health workers. At a workshop towards the end of field work, the team members presented and discussed their personal analysis and interpretation of the collected data. I incorporated my notes on the workshop discussion as valuable extra information into the qualitative data set. Even though mainly informally (see limitations below), the study team was the driver of the interactions between the qualitative and quantitative research components, and eventually, of the integrated findings.

Another strength of the study was its operational research design. As described in chapter 5, SMART supported the existing government ART programme without adding parallel ART services. As an operational study embedded into the public ART programme, we investigated ART retention under “real world” conditions. The ART programme managers had initiated the tracing intervention to address loss to follow-up which they considered a growing concern. The three parties – the government ART programme, the NGO support project SMART, and the research project – agreed to implement the intervention as a learning exercise and defined a strict division of roles: SMART developed the tracing scheme and provided the extra funds, the government programme implemented the intervention, and the research team observed the process and analysed the outcomes of the intervention. Since the programme managers were involved in developing the research questions, this study was able to bridge the often cited gap between research and practice (Zachariah, 2009). Moreover, the operational research approach worked well in this study thanks to a functioning programme monitoring scheme. Without the SMART patient data base providing good quality cohort data, this study would not have been possible.

### 8.2.2 Limitations

The study did not exploit the full potential of the mixed-methods approach. As O'Cathain (2010) pointed out, mixed-methods studies are often carried out as two separate studies. The lack of interaction and conversation between the qualitative and quantitative components often limits the additional knowledge that could be generated through the combined approach. Integration of the quantitative and qualitative study components was not systematically established in the study protocol. During data collection in the field, the two study components were not formally interlinked; integration was rather performed through informal interactions in the study team, as mentioned above. A reason for the lack of formal integration during data collection was that we did not collect primary quantitative data. Data collection in the quantitative component was largely cleaning, preparing and linking of electronic secondary data provided by the SMART programme. Integration was also limited during data analysis because I largely analysed the data sets on my own only after returning from field work.

There are limitations with regard to the generalizability of the study findings. Two faith-based district hospitals were the backbone of the ART programmes in Zaka and Bikita. As explained in chapter 5, faith-based hospitals in Zimbabwe benefit from additional resources for infrastructure, equipment and personnel, compared with government district hospitals. The ART programme in the study area did not only benefit from moderate NGO support through the SMART project, it also benefitted from the long-standing partnership between the two mission hospitals with foreign health organisations and donors, such as SolidarMed, which have regularly provided physicians to fill vacant positions. The study findings on retention, loss to follow-up and death are therefore not generalizable for the rest of Zimbabwe, but can serve as benchmark, since the support has been moderate and SolidarMed, in contrast to other NGOs, has supported existing public services and not established its own ART services. However, the high proportion of deaths amongst patients classified lost to follow-up is with no doubt generalizable to other areas of Zimbabwe and probably to other countries in the region, as well as the need for early tracing. A number of locally specific factors made patients interrupted ART, for example, the influence of the local Apostolic Church or the degree of ART decentralisation in a given district. As mentioned before, ART is not a uniform programme in Zimbabwe. The capacities of the local health system strongly influence the performance and outcomes of vertical programmes, such as ART. Whilst reasons for ART interruption are to large parts influenced by the local context, I argue that the main study finding on the medical and social vulnerability of ART interrupters, hinting at the need of targeted early tracing, are generalizable to other ART programmes in Zimbabwe and the region.

### 8.3 Reflective commentary

Conducting this study was a balancing act in two ways: between research and implementation on the one hand and between the quantitative and qualitative paradigms of social science on the other hand. What I experienced as the biggest challenge in mixed-methods research was the fact that quantitative and qualitative research approaches were not just two different methods, but represent two different epistemological paradigms: the positivist and the interpretative paradigm (Ulin, 2005). Researching across the methodological boundaries, I occasionally found myself “between and betwixt” two positions (a status referred to as being neither here nor there in cultural anthropology). Whilst the positivist world view takes the assumption that there is an objective truth out there which can be described and analysed by a researcher who is independent of his research topic, the interpretative model conceives the social world as constructed and interpreted by the observer, who perceives the world from his subjective perspective. In the positivist paradigm, the researcher is neutral and does not impact on the world he is observing. In the interpretative paradigm, the researcher’s presence influences the research process; his or her perspective and interest inevitably shapes the research subject and the study findings. The world of social science has been polarised between the two approaches to an extent that some researchers argue the two paradigms were incompatible (ibid.). In my role as Principal Investigator and study team leader, I was not supposed to advocate for one of the two world views. During field work, I was wearing the interpretative hat of the anthropologist, in meetings with the hospital data clerks and the study statistician, I took the role of an epidemiologist. I believe that mixed-methods is a powerful approach because it stimulates the researcher to think out of the box and to critically reflect the research findings in the light of the two paradigms. Provided there are sufficient technical and methodological skills from both approaches in a study team allowing good quality quantitative and qualitative research, I would argue that mixed-methods is probably the most appropriate design for implementation research, since real world interventions require both a clear picture on both the magnitude and a holistic understanding of public health problems.

The question to what extent my own role as previous programme manager “biased” the research findings, is problematic. In quantitative research, bias represents a systematic error in the measurement, for example in the way data was collected, causing a deviation of a measured value from the “true” value, whilst the interpretative paradigm rejects the assumption of an objective truth. In the qualitative research process, the

subjective patterns of perceiving, thinking and interpreting by the study team members obviously influenced the flow and outcomes of the interviews, focus groups discussions and participant observation. In qualitative research, the fact that different researchers might have come to different results does not necessarily mean that the qualitative results are not reliable. As Ulin (2005) suggest, the quality of qualitative research should be assessed rather by the “dependability” than “reliability” of the findings. In qualitative research, the question is not if the findings but rather if the research procedures can be replicated, if the pathway from data collection to analysis and interpretation was consistent and transparent, and if interpretations were critically discussed between researchers (ibid.) – quality criteria which I consider were met in this study.

Following the interpretative paradigm of social science, I believe that there is no “objective truth” in the social world, and that researchers cannot take an “external” view on their research subject. I understand that research is always influenced by the researcher’s perceptions, values and interpretations. The research interest, the theoretical approach, and the choice of methods are always influenced by individual preferences, the status, and even by the personal background of the researcher. Many journals require the researchers to declare any conflict of interest that might have influenced their research findings. Whilst “no conflict of interest” suggests that the researcher had an objective view on the topic, I guess the researcher’s scientific description, analysis and interpretation of the world was still influenced by his or her personal perspective. A critical reflection of my own role in the present study is therefore needed to strengthen the credibility and accountability of the research findings.

As mentioned in the introduction, I had been SolidarMed programme manager before entering the Doctor of Public Health programme. The commitment to equitable access to HIV care was an important value when I contributed to the development of the SMART programme. From an early stage of the SMART programme, I advocated for decentralised ART provision, task shifting and community participation – such as the CHASA programme – which I thought were appropriate strategies to tackle access barriers related to high transportation costs and shortage of qualified staff. To what extent ART should be provided by nurses instead of doctors and by health centres instead of hospitals, and whether or not community health workers should be included were issues passionately debated in the SMART programme. Medical doctors and government health officials were concerned about the quality of care if ART was provided by unskilled personnel and the risk to confidentiality if patient information was

shared with non-professionals for the purpose of adherence counselling and tracing. I was convinced that the public health and equity gains of decentralised ART provision would outweigh the potential losses caused by the absence of medical and laboratory treatment monitoring. Yet, advocating for evidence-based programming, I switched from implementation to research to investigate if the SMART partnership in Zimbabwe was on the right track.

Practice Theory, as outlined in section 7.1, was the underlying conceptual framework of the study, influencing the methodology and analysis of the qualitative study component. The study findings confirm that ART retention is influenced by the interplay of “agency” and “structure”. Our study shows that ART patients who interrupt their therapy are generally highly motivated to return to care. In the event of a treatment interruption, when patients become medically and socially vulnerable, structural barriers prevail and the patients’ capacity to determine their own action deteriorates. During this critical passage of an unstructured therapy interruption, we found family and kinship networks to be the key intermediate domain between agency and structure, providing a safety net to the patient. Our findings suggest that the most vulnerable patients who would be most in need do not benefit from community support. Vulnerable and isolated ART interrupters do not have access to HIV/AIDS support groups. This aspect confirms that social capital gains require previous investments in social relationships. Yet, being socially excluded is exactly what makes ART interrupters vulnerable to prolonged therapy discontinuation, for example in the case of women hiding their HIV status to their partners and in-laws or migrants living separated from their parental family. As descent-based relationships require less social capital investment than community-based ties, they can be considered the last resort for ART interrupters to regain agency, especially as therapy interruption continuous and the patient’s health deteriorates. As the patient’s self-determination and resilience decline, he or she becomes dependent on structural forces, in our case the health system. Practice theory contributed a comprehensive conceptual framework to this study that guided us to equally explore individual and structural influences on retention on ART.

#### **8.4 Recommendations for programming and research**

On the basis of the results of this study, the following interventions to improve retention are recommended to the Zimbabwean ART programme and NGO support projects, such as SMART:

1. Decentralise provision of the full package of ART and tuberculosis treatment from hospitals to primary health care facilities, including CD4 cell count, pre-ART adherence consultations, treatment initiation, and follow-up.
2. Simplify ART initiation procedures and reduce referrals to prevent early losses.
3. Prevent early mortality through active screening for tuberculosis prior to ART initiation, and through early tracing of patients in an advanced stage of the infection, especially during the first six months after initiation.
4. Roll-out community-based adherence support including early tracing focusing on medically- and socially-vulnerable ART patients by well trained, supervised and incentivised community health workers to prevent deaths after ART interruption.
5. Develop the capacities of the health workers at primary health care facilities in such a way that they are motivated and skilled to engage in trusting and stable relationships with their ART clients, supporting instead of blaming patients in the event of a therapy interruption.
6. Strengthen and harmonize the ART medical record system and simplify transfer modalities to allow mobile ART patients to easily access ART drugs at multiple sites nation-wide, and to reduce documentation errors leading to false losses to follow-up.

Unstructured treatment interruptions have significant public health implications. A better understanding of the critical period after ART interruption is required to improve long-term retention. Further quantitative and qualitative social science research is needed to learn more about death on ART, to understand the implications of patients “cycling in and out” of ART (Kranzer, 2012), to determine the social indicators of prolonged ART interruption, to assess the outcomes of fully decentralised ART provision, and to develop cost-effective community-based tracing interventions for medically- and socially-vulnerable patients.

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## Appendix 1: Criteria to assess study quality

For the quantitative studies, I used the following nine quality criteria for critical appraisal of observational studies, as proposed by Petticrew and Roberts (2006):

- description of study participants,
- similarity of control group and intervention group,
- description of the intervention,
- validity and reliability,
- relevance of the measures,
- drop-outs in follow-up studies,
- duration and size of the study,
- statistical methods,
- blinding.

I assessed the qualitative studies using the checklist questions of the licensed Critical Appraisal Skills Programme tool (CASP, 2013):

- Was there a clear statement of the aims of the research?
- Is a qualitative methodology appropriate?
- Was the research design appropriate to address the aims of the research?
- Was the recruitment strategy appropriate to the aim of the research?
- Was the data collected in a way that addressed the research issue?
- Has the relationship between the researcher and the participants been adequately considered?
- Have ethical issues been taken into consideration?
- Was the data analysis sufficiently rigorous?
- Is there a clear statement of findings?
- How valuable is the research?

## Appendix 2: Ethical approval letters

Telephone: (263)-4-791792/791193  
Telefax: (263) - 4 - 790715  
E-mail: [mrcz@mrczimshared.co.zw](mailto:mrcz@mrczimshared.co.zw)  
Website: <http://www.mrcz.org.zw>



Medical Research Council of Zimbabwe  
Josiah Tongogara / Mazoe Street  
P. O. Box CY 573  
Causeway  
Harare

### APPROVAL LETTER

Ref: MRCZ/A/1650

19 January, 2012

**Thomas Gass**  
London School Of Hygiene and Tropical Medicine  
LSHTM, Keppel Street,  
London WC1E 7HT, UK  
United Kingdom

**RE: Reasons for Non-Adherence, Treatment Interruption and Loss to Follow up in a Decentralized Antiretroviral Treatment Program in Rural Zimbabwe. A Mixed Methods Study**

Thank you for the Application for Approval to carry out Research Activity that you submitted for review to the Medical Research Council of Zimbabwe (MRCZ). Please be advised that the Medical Research Council of Zimbabwe has **reviewed** and **approved** your application to conduct the above titled study.

This approval is based on:-

- (a) Protocol Summary
- (b) Protocol LFTU Study version 1.1 dated 6 January, 2012
- (c) English and Shona Informed Consent Forms version 1.1 dated 6 January, 2012
- (d) English and Shona Information Sheet for Patients version 1.1 dated 6 January, 2012
- (e) English and Shona Information Sheet for Participants of a Focus Group version 1.1 dated 6 January, 2012
- (f) English and Shona Information Sheet for Health Workers version 1.1 dated 6 January, 2012
- (g) English and Shona In-depth Interview Guides version 1.1 dated 6 January, 2012

**APPROVAL NUMBER : MRCZ/A/1650**

This number should be used on all correspondence, consent forms and documents as appropriate.

- **APPROVAL DATE** : 19 January, 2012
- **EXPIRATION DATE** : 18 January, 2013
- **TYPE OF MEETING** : EXPEDITED REVIEW

After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the MRCZ Offices should be submitted one month before the expiration date for continuing review.

**SERIOUS ADVERSE EVENT REPORTING:** All serious problems having to do with subject safety must be reported to the Institutional Ethical Review Committee (IERC) as well as the MRCZ within 3 working days using standard forms obtainable from the MRCZ Offices.

**MODIFICATIONS:** Prior MRCZ and IERC approval using standard forms obtainable from the MRCZ Offices is required before implementing any changes in the Protocol (including changes in the consent documents).

**TERMINATION OF STUDY:** On termination of a study, a report has to be submitted to the MRCZ using standard forms obtainable from the MRCZ Offices.

**QUESTIONS:** Please contact the MRCZ on Telephone No. (04) 791792, 791193 or by e-mail on [mrcz@mrczimshared.co.zw](mailto:mrcz@mrczimshared.co.zw).

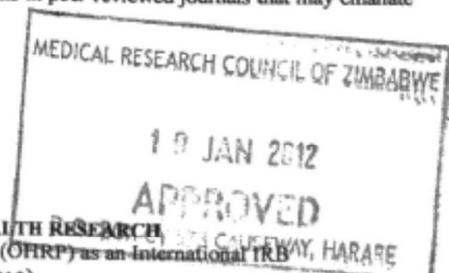
**Other**

Please be reminded to send in copies of your research results for our records as well as for Health Research Database. You're also encouraged to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study.

Yours Faithfully,

  
MRCZ SECRETARIAT  
FOR CHAIRPERSON  
MEDICAL RESEARCH COUNCIL OF ZIMBABWE

PROMOTING THE ETHICAL CONDUCT OF HEALTH RESEARCH  
Registered with the USA Office for Human Research Protections (OHRP) as an International IRB  
(Number IRB00002409 IORG0001913)



**OBSERVATIONAL/INTERVENTIONS  
RESEARCH ETHICS COMMITTEE**

LONDON  
SCHOOL of  
HYGIENE  
& TROPICAL  
MEDICINE



28 March 2012

Thomas Gass

Dear Thomas

**Study Title:** ART Retention Study Zaka/Bikita: Reasons for non-adherence, treatment interruption and loss to follow-up in a decentralized antiretroviral treatment program in rural Zimbabwe. A mixed methods study

**LSHTM ethics ref:** 6140

**Department:** Infectious and Tropical Diseases

Thank you for your email of 26 March, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

**Conditions of the favourable opinion**

Approval is dependent on local ethical approval having been received, where relevant.

**Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>	
LSHTM ethics application	n/a		
Protocol	V1.0	13/02/12	
Information Sheet	V1.0	13/02/12	
Consent form	V1.0	13/02/12	

**After ethical review**

Any subsequent changes to the application must be submitted to the Committee via an E2 amendment form.

Yours sincerely,

**Professor Andrew J Hall**  
Chair

# Appendix 3: SMART patient data base (screenshot)

**Patient**

Country  Site  ART Patient Number  0000 National Patient Number

Date of birth  Sex  Height adults cm

First positive HIV test  ART Pre-Exposure

WHO stage at first visit

Diagnoses at first visit

1	<input type="text"/>
2	<input type="text"/>
3	<input type="text"/>
4	<input type="text"/>

Previous TB tt completed

Place of ART start  Date of ART start outside

Date of death

CD4 Baseline  at initiation of ART

**New Visit**

**Save**

**Back to Menu**

<Ctrl>+<M>

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**Visits**

Facility	Type of facility	Name of facility	Transfer	VisitNumber
Visit	Visit Type	Actual Date	Next Date	Adherent
Clinical	Weight in kg	Height children cm	BMI	Pregnant
Laboratory	CD4	Viral Load	CD4%	Haemoglobin
		Sputum TB test	ALT	Creatinine
OI prophylaxis	Co-Trimoxazole or Dapsone			
ARV drugs	3TC	TDF	NVP	AZT
	ABC	d4T	ddI	LPV/r
	IDV	NFV	RTV	ATV
				FTC
TB / KS	Tuberculosis		Reason for ARV drug switch	
			Kaposi Sarkoma	
New opportunistic infection	New Diagnosis 1			
	New Diagnosis 2			
	New WHO Stage			
Side effects due to ART	Side effects Y/N		Side effect 1	Side effect 2

Record: 1 of 1

No Filter  Search

## Appendix 4: SMART patient tracing form

ART Client Tracing Form (CTF)		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	Type of tracing	F <input type="checkbox"/> Field tracing	P <input type="checkbox"/> Phone tracing			
2	Name / Function patient tracer					
3	Date of tracing					
<b>Patient Information</b>						
4	Sex	M <input type="checkbox"/> Male	F <input type="checkbox"/> Female			
5	Date of birth					
6	Ward / Village					
7	Date ART started					
8	Date of last ART visit					
9	Facility name of the last ART visit					
10	Last appointment date					
11	Nearest rural health clinic					
<b>Tracing Results</b>						
12	<input type="checkbox"/> <b>Patient found (one answer possible from a to f)</b>					
	a <input type="checkbox"/> Patient refusing to answer					
	b <input type="checkbox"/> Patient was initiated but never started taking ARVs					
	c <input type="checkbox"/> Patient is on ART					Last visit date:
	d <input type="checkbox"/> Patient is on ART, official transfer out					Specify site:
	e <input type="checkbox"/> Patient is on ART, silent transfer out					Specify site:
	f <input type="checkbox"/> Patient stopped ART					
13	If patient stopped ART, reason(s) for stopping ART ( <i>multiple answers possible</i> )					
	a <input type="checkbox"/> Illness / symptoms	Specify:				
	b <input type="checkbox"/> Transport costs (bus fare, food, etc.)					
	c <input type="checkbox"/> Treatment costs (lab, drugs, fees)					
	d <input type="checkbox"/> Religious belief					
	e <input type="checkbox"/> Preferring not to disclose HIV status					
	f <input type="checkbox"/> Pregnancy / Breast feeding					
	g <input type="checkbox"/> Doctor's decision (official stop)					
	h <input type="checkbox"/> Belief that ARVs do not work					
	i <input type="checkbox"/> Drugs out of stock					
	j <input type="checkbox"/> Health worker behaviour					
	k <input type="checkbox"/> Household / Family / Partner not supportive					
	l <input type="checkbox"/> Employer not supportive					
	m <input type="checkbox"/> Travel / Migration					
	n <input type="checkbox"/> Other reason	Specify:				
14	<input type="checkbox"/> <b>Patient not found</b>					
15	Source of information (e.g. Family member, etc.)					
16	<input type="checkbox"/> Patient is not known					
17	<input type="checkbox"/> Patient died, specify date of death					
18	<input type="checkbox"/> Patient moved away					
	a <input type="checkbox"/> Out of village					Specify where:
	b <input type="checkbox"/> Out of district					Specify where:
	c <input type="checkbox"/> Out of the country					Specify where:
19	<input type="checkbox"/> <b>Status reported post tracing</b>					Date of reporting:
20	<input type="checkbox"/> Patient re-started ART					Date of re-start:
21	<input type="checkbox"/> Reported transfer out					Date of transfer out:
22	<input type="checkbox"/> Reported death					Date of death:

# Appendix 5: Participant Information Sheets & Informed Consent Forms

## London School of Hygiene & Tropical Medicine

Keppel Street, London, WC1E 7HT, United Kingdom



### INFORMATION SHEET FOR HEALTH WORKERS

#### STUDY TITLE

Reasons for non-adherence, treatment interruption and loss to follow-up in a decentralized antiretroviral treatment program in rural Zimbabwe. A mixed methods study.

#### INVESTIGATOR

Thomas Gass

#### INSTITUTION

London School of Hygiene and Tropical Medicine

#### CONTACT

Email: [thomas.gass@lshtm.ac.uk](mailto:thomas.gass@lshtm.ac.uk)

---

#### 1. INTRODUCTION

My name is Thomas Gass, I am a researcher of the London School of Hygiene and Tropical Medicine. I would like to invite you to participate in my research study. The question of my study is: What are the reasons of ART patients in Zaka and Bikita to interrupt or stop the therapy? Before you agree to participate, it is important that you read and understand the following explanations on this study. This information sheet is to help you decide if you would like to participate. You are entirely free to decide whether you would like to take part or not.

- You should fully understand and be satisfied with the procedures before you agree to take part in this study.
- If you have any questions, do not hesitate to ask me.
- If you decide to take part in this study, we will ask you to sign this document (consent form) to confirm that you understand the study.

- It is your right to withdraw from the study at any time and with no explanation.

## **2. PURPOSE OF THE STUDY**

I am undertaking this study to obtain a scientific degree at the University of London. The results of the study will help the hospitals and clinics of Zaka and Bikita to improve the ART program in such a way that as many ART patients as possible can be retained on therapy.

## **3. LENGTH OF THE STUDY AND NUMBER OF PARTICIPANTS**

My research in Zaka and Bikita district lasts from February until June 2012. The study includes interviews with 15 health workers who are involved in the delivery of ART services. I will also conduct interviews with ART patients, conduct group discussions and analyze computerized, anonymous data of about 8000 patients at the hospital.

## **4. PROCEDURES**

If you agree to take part in this study, I will ask you to sign a consent form to be interviewed. If you are willing to take part but unable to be interviewed at this time, we will arrange an appointment at a later date.

In the interview, I would like to ask you about your experiences and opinions regarding

- your every day activities and workload with ART patients;
- the strengths and weaknesses how the ART programme is organized;
- the management of opportunistic infections, including TB;
- ART initiation and follow-up consultation;
- the ARV drugs and their effects on the health and wellbeing of patients;
- side effects of ART;
- adherence and how patients manage to stay on ART;
- why some patients do not manage to adhere;
- ways to improve adherence and retention.

The Interview will be face to face and take between one and two hours. It will take place in a private or professional setting of your choice.

If you are willing, I am going to audio-tape the interview. This will help me remember and verify particularly interesting aspects you mentioned during the interview. In addition I will take notes on paper. Your name and contact details will not be included on any audiotape or notes, instead a study code, unique to you will be used.

## **5. CONFIDENTIALITY**

All information obtained during the course of this study, including personal data and research data (transcripts and notes) will be kept strictly confidential.

Your name will not be included on any audiotape or notes, instead a study code, unique to you will be used.

Your name and study number will be kept in a separate notebook which will be stored securely and separately from other data.

In this type of study it is helpful to quote in reports some of the exact things people have said in the interview, and we would like your permission do this.

Data from this study that may be reported in scientific journals or reports will not include any information that identifies you.

Data will be kept for at least six years after the study is finished for possible checking or further analysis. It will then be destroyed.

#### **6. RISKS OF TAKING PART**

Being involved in this study should not involve any physical, psychological or professional harm for you. If there are any questions you do not want to answer, it is ok not to answer them.

#### **7. BENEFITS OF TAKING PART**

There will be no other direct benefit for you. However, the results of this study will be shared with the health authorities, the hospitals and the clinics of Bikita and Zaka district. I will include recommendations into my report how the ART could be improved so that all patients can be retained on ART.

#### **8. ETHICAL APPROVAL**

This study was approved by the Medical Research Council of Zimbabwe. Contact: Medical Research Council of Zimbabwe. P O Box CY573 Causeway, Harare Zimbabwe Phone: +263-4-791792.

MRCZ No. ....



**INFORMED CONSENT FORM**

**AUTHORIZATION** YOU ARE MAKING A DECISION WHETHER TO PARTICIPATE OR NOT IN THIS STUDY. ENSURE THAT THE INTERVIEWER HAS APPENDED HIS SIGNATURE ON THIS FORM TO INDICATE THAT YOU HAVE READ AND UNDERSTOOD THE INFORMATION PROVIDED ABOVE, HAVE HAD ALL YOUR QUESTIONS ANSWERED AND HAVE DECIDED TO PARTICIPATE.

The date of enrolment in this study, that is today's date, MUST fall between the dates indicated on the approval stamp affixed to each page. These dates indicate that this form is valid when you enrol in the study but do not reflect how long you may participate in the study. Each page of this Informed Consent Form is stamped to indicate the form's validity as approved by the MRCZ.

I have been informed by the researcher Thomas Gass about the nature, conduct, benefit and risks of this study.

I have read the information sheet concerning this study (or have understood the verbal explanation) and I understand what will be required of me and what will happen to me if I take part in it.

My questions concerning this study have been answered.

I understand that at any time I may withdraw from this study without giving a reason.

I agree to take part in this study Yes  No

I agree the discussion to be audio-recorded Yes  No

I agree for comments I made to be quoted in the study report. My identity will not be revealed. Yes  No

**PARTICIPANT**

Printed Name Signature Date

**RESEARCHER**

I confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

Printed Name Signature Date

# London School of Hygiene & Tropical Medicine

Keppel Street, London, WC1E 7HT, United Kingdom



## INFORMATION SHEET FOR HEALTH WORKERS

MRCZ No. ....

**STUDY TITLE**                      Reasons for non-adherence, treatment interruption and loss to follow-up in a decentralized antiretroviral treatment program in rural Zimbabwe. A mixed methods study.

**INVESTIGATOR:**                      Thomas Gass

**INSTITUTION:**                      London School of Hygiene and Tropical Medicine

**CONTACT**                              Email: [Thomas.gass@lshtm.ac.uk](mailto:Thomas.gass@lshtm.ac.uk)                      Phone: 077 300 14 77

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### 1. INTRODUCTION

My name is \_\_\_\_\_. I would like to invite you to participate in a research study on antiretroviral treatment. The study is conducted in collaboration with the Ministry of Health and Child Welfare. The question of the study is: What are the reasons of ART patients in Zaka and Bikita dropping out of the ART program? Before you agree to participate, it is important that you read and understand the following explanations on this study. This information sheet is to help you decide if you would like to participate. You are entirely free to decide whether you would like to take part or not.

- You should fully understand and be satisfied with the procedures before you agree to take part in this study.
- If you have any questions, do not hesitate to ask me.
- If you decide to take part in this study, we will ask you to sign this document (consent form) to confirm that you understand the study.
- It is your right to withdraw from the study at any time and with no explanation.

### 2. PURPOSE OF THE STUDY

The results of the study will help the hospitals and clinics of Zaka and Bikita to improve the ART program in such a way that as many ART patients as possible can be retained on therapy. In addition, this research project is part of an educational program Thomas Gass is undertaking at the University of London.

### **3. LENGTH OF THE STUDY AND NUMBER OF PARTICIPANTS**

This research project in Zaka and Bikita district will take place in 2012 and last approximately 4 months. The study includes interviews with approximately 40 ART patients, treatment partners, health workers and health officials. We will also conduct group discussions with approximately 50 ART patients and analyze computerized, anonymous data of approximately 1000 ART patients at the hospital.

### **4. PROCEDURES**

If you agree to take part in this study, I will ask you to sign a consent form to be interviewed. If you are willing to take part but unable to be interviewed at this time, we will arrange an appointment at a later date.

In the interview, I would like to ask you questions about the following topics:

- Reasons why patients continue or discontinue ART;
- What helps people to stay on ART , and what makes it difficult to stay on ART, looking at things in the family, community and health center;
- What does the clinic do well that helps people stay on ART, and what it could do better;
- Enabling and limiting factors of ART retention in the family, community and health facility;
- Strengths and weaknesses of the ART program regarding retention of patients;
- Tracing patients who miss their appointments.

The Interview will be face to face and take between one and two hours. We will agree on a suitable place where you feel comfortable to speak freely.

If you are willing, I am going to audio-tape the interview. This will help me remember and verify particularly interesting aspects you mentioned during the interview. In addition, or if you refuse audio-taping, I will take notes on paper. Your name and contact details will not be included on any audiotape or notes, instead a study code, unique to you will be used.

### **5. CONFIDENTIALITY**

All information obtained during the course of this study, including personal data and research data (transcripts and notes) will be kept strictly confidential.

Your name will not be included on any audiotape or notes, instead a study code, unique to you will be used.

Your name and study number will be kept in a separate notebook which will be stored securely and separately from other data. In this type of study it is helpful to quote in reports some of the exact things people have said in the interview, and we would like your permission do this. Data from this study that may be reported in scientific journals or reports will not include any information that identifies you.

Data will be kept for at least five years after the study is finished for possible checking or further analysis. It will then be destroyed.

### **6. RISKS OF TAKING PART**

Being involved in this study should not involve any physical, psychological or professional harm for you. However, if you feel psychologically stressed during the interview, you can withdraw at any time. If there are any questions you do not want to answer, it is ok not to answer them.

If you are an ART patient, please be assured that your routine care is not affected if you join or do not join the study.

#### **7. BENEFITS OF TAKING PART**

We pay a compensation for the time you spend with us for this interview. If you are an ART patient, we can reimburse transport costs for one medical consultation or counseling at any health facility in the district. The results of this study will be shared with the health authorities, the hospitals and the clinics of Bikita and Zaka district. I will include recommendations into my report how the ART could be improved so that more patients can be retained on ART.

#### **8. ETHICAL APPROVAL**

This study was approved by the Medical Research Council of Zimbabwe. Contact: Medical Research Council of Zimbabwe. P O Box CY573 Causeway, Harare Zimbabwe Phone: +263-4-791792.

You will receive a copy of this information sheet.

MRCZ No. ....

**INFORMED CONSENT FORM**

Participant number

**AUTHORIZATION** YOU ARE MAKING A DECISION WHETHER TO PARTICIPATE OR NOT IN THIS STUDY. ENSURE THAT THE INTERVIEWER HAS APPENDED HIS SIGNATURE ON THIS FORM TO INDICATE THAT YOU HAVE READ AND UNDERSTOOD THE INFORMATION PROVIDED ABOVE, HAVE HAD ALL YOUR QUESTIONS ANSWERED AND HAVE DECIDED TO PARTICIPATE.

The date of enrolment in this study, that is today's date, MUST fall between the dates indicated on the approval stamp affixed to each page. These dates indicate that this form is valid when you enrol in the study but do not reflect how long you may participate in the study. Each page of this Informed Consent Form is stamped to indicate the form's validity as approved by the MRCZ.

I have been informed by the researcher \_\_\_\_\_ about the nature, conduct, benefit and risks of this study.

I have read the information sheet concerning this study (or have understood the verbal explanation) and I understand what will be required of me and what will happen to me if I take part in it.

My questions concerning this study have been answered.

I understand that at any time I may withdraw from this study without giving a reason.

I agree to take part in this study Yes  No

I agree the discussion to be audio-recorded Yes  No

I agree for comments I made to be quoted in the study report. My identity will not be revealed. Yes  No

**PARTICIPANT**

Printed Name Signature or Thumb print Date

In case of thumb print Name and Signature of a witness

**RESEARCHER or INTERVIEWER**

I confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

Printed Name Signature Date

## Appendix 6: Topic Guides

IDI Participant Number:

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<p>Retention Study Bikita &amp; Zaka</p>  <p><b>Interview Topic Guide for Interrupters</b></p>	<p><b>London School of Hygiene &amp; Tropical Medicine</b>          Department of Clinical Research          Faculty of Infectious and Tropical Diseases          London School of Hygiene &amp; Tropical Medicine          Keppel Street, London WC1E 7HT</p> <p>Thomas Gass  <a href="mailto:thomas.gass@lshtm.ac.uk">thomas.gass@lshtm.ac.uk</a>          Phone Zimbabwe: 0778 326 217          Phone Europe: +41 79 681 05 53</p>	 <p><b>Improving health worldwide</b></p>
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Name of the interviewer .....

Tracing number of the participant.....

Date of the interview.....

Start Time..... End Time.....

Location of the interview.....

Date of last ART visit.....

Period(s) of ART interruption.....

## **A. Introduction, personal information & warm up**

- Greet the participant & establish positive rapport

*My name is XXX, I am from XXX, I work as an interviewer in this research project.*

- Briefly describe the procedure of the interview.
- Present and explain the Informed Consent Form and get it signed.
- Start the audio recorder
- Verify Informed Consent verbally while recording.
- Inform the participants that they are free not to answer any questions that they are not comfortable with.

*To start, please tell me a little about yourself.*

*How are you? How is your family? Where were you born?*

*What is your education? What is your profession / occupation?*

## B. Interview

Topic	Discussion Points	Probe Questions
Health now	<p>How is your health condition at present?            Are you presently under any treatment (biomedical, traditional or any other treatment)?            When did you interrupt ART?            Why did you interrupt ART?</p>	<ul style="list-style-type: none"> <li>- To what extent does your health problem affect your everyday life and activities?</li> <li>- Have you had any health problems during the last 12 months?</li> <li>- Are you currently taking any drugs?</li> <li>- Have you recently visited a health facility or a traditional healer?</li> </ul>
Experience and perception of ART and ART discontinuation	<p>What made you start ART?            How has ART affected / changed your life?            How did the partner, family, kin, community, employer cope with you taking ARVs?            What do you think does ART to you and your health?            Have you ever interrupted ART before?            If yes, for what reasons?            What made you restart?            How has discontinuation of ART affected/changed your life and your health?            What do you think happens after discontinuation of ART?</p>	<ul style="list-style-type: none"> <li>- Whom did you involve in decision making? With whom did you share your decision to start ART?</li> <li>- How many pills per day did you have to take? What was the name of the drug?</li> <li>- During your ARV treatment, did you seek for other treatment? Other drugs? Against which disease?</li> <li>- If someone feels ill in your household, what do you do for recovery?</li> <li>- How do TB treatment and ART interact in your experience?</li> <li>- Did you experience side effects? What kind of? What do you think is the reason for these side effects?</li> <li>- How was your health condition when you stopped?</li> <li>- Did you involve other people in your decision to stop ART? With whom did you discuss? What was there advice?</li> </ul>
Retention and	Have you ever missed your ART appointment?	<ul style="list-style-type: none"> <li>- Are there times during the year when you find it</li> </ul>

adherence	<p>Why? Under what circumstances?          Who is most helpful and supportive to keep you ART appointments?          How do you manage to remember taking your pills every day – life long?</p>	<p>easier or more difficult to keep going to the ART appointments?          – Are you satisfied with the health workers providing ART services?          – When it comes to ART appointments, what is the role of your treatment partner, CHASA, village health worker, ART nurse, family members?          – Do you know other patients who discontinued ART?          – For what reasons?</p>
Being HIV positive	<p>How does HIV affect / change your life?          How has HIV affected your health?          Did you disclose your status? When? To whom?          How does the partner, family, kin, community, employer cope with you being HIV positive?          Have you ever experienced harassment or insulting based on the fact you are HIV positive or on ART?</p>	<p>– How was your health condition at that time?          – Did you share the results with other people? With whom?          – After you received the test result, what advice were you given at the health facility?          – Who else gave you advise what to do next?          – Do many PLHA suffer TB?</p>
Role of the health facility	<p>How is the relationship to the health workers at your health facility?          Were they supportive or not? In what way?          Are you satisfied with the medical service you get?          If you compare ART provision at hospital (Musiso and Silveira) with ART provision at rural health centres, what is the difference?          How could the health facility improve ART service?          What should be changed in the future?</p>	<p>– Did you discuss / inform your health facility about stopping ART?          – What could the health facility do to support you in a better way?          – Under what circumstances would you stay on treatment, return on treatment?          – Which is the nearest health facility? How far is it? How often do you there? How do you travel there?          – Are you satisfied with their service?          – Do you have to pay for health services?</p>
Role of family & kin	<p>Do your family and kin support you in taking ARVs?</p>	<p>– Who lives in your household?          – Who brings income home?          – How is the health of your family members?          – What do your family and kin members think and</p>

		<p>believe about ART?</p> <ul style="list-style-type: none"> <li>– Who supports you most? Was there anybody who disapproved you are on ART?</li> </ul>
Role of support group	<p>Are you member of a PLHA support group? Why? What is your experience with the support group? Do you know a CHASA? What do they do?</p>	<ul style="list-style-type: none"> <li>– Any positive and negative experience with support groups?</li> <li>– Why are some PLHA member and others they are not member?</li> <li>– How many people are member of the group?</li> <li>– Do you think PLHA groups and CHASA can help improve ART and adherence? In which way?</li> <li>– Can the CHASA collect the ARV drugs for you?</li> <li>– When was your last meeting? What did you discuss?</li> <li>– What happens if a member is in trouble? Can you remember such a case?</li> </ul>
Partnership and gender relations	<p>How has HIV affected your partnership and marriage? How do HIV and ART affect your plans for having children?</p>	<ul style="list-style-type: none"> <li>– How did your spouse react when you tested HIV positive?</li> <li>– Do you know the status of your spouse?</li> <li>– Does he know your status?</li> <li>– What does your spouse think about ART?</li> <li>– Since you tested HIV positive, have you had sexual intercourse with more than one partners?</li> <li>– Do you use contraceptives? What kind? Since when?</li> </ul>
Cultural Concepts	<p>In your village, what do the people know about HIV/Aids? What is people's attitude on people with HIV? What do you know about how HIV? How is it transmitted? What are the most frequent symptoms of HIV/Aids? What is the purpose of a CD4 test? Do you know side effects?</p>	<ul style="list-style-type: none"> <li>– What name do people give the disease? What does it mean?</li> <li>– Has the attitude changed in recent years? How and why?</li> <li>– What do people think and believe about ARVs? What do people think is the effect of ARVs? What do you know about ARVs?</li> <li>– What do people think and believe about side effects</li> </ul>

		<p>of ARVs? What do you know about it?</p> <ul style="list-style-type: none"> <li>- If someone is sick, is he/she being supported in your household/community? Does it happen that sick people are left alone? In what cases?</li> </ul>
Tracing	<p>After missing an ART appointment, have you ever been approached by a health worker? Do you know someone who has been contacted either by phone or at home? If not, how would you feel about this? What would be the advantages and disadvantages of such as system? What do you know about what happens if an ART patient interrupts treatment? How can this best be prevented? Do you think tracing would be a good solution for the future? Under what circumstances?</p>	<ul style="list-style-type: none"> <li>- Whom would you accept to approach you if you miss an appointment?</li> <li>- What do people think about tracing?</li> </ul>

## **C. Closing**

- Do you want to add or correct something you have told me?
- Do you have questions?
- Thank you very much for taking part in this discussion!

## **Field Note (observations & informal conversations)**

IDI Participant Number:

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Retention Study Bikita & Zaka

# Interview Topic Guide for Health workers

**London School of Hygiene & Tropical Medicine**

Department of Clinical Research  
Faculty of Infectious and Tropical Diseases  
London School of Hygiene & Tropical Medicine  
Keppel Street, London WC1E 7HT

Thomas Gass  
[thomas.gass@lshtm.ac.uk](mailto:thomas.gass@lshtm.ac.uk)  
Phone Zimbabwe: 0778 326 217  
Phone Europe: +41 79 681 05 53



Improving health worldwide

Name of the interviewer .....

Tracing number of the participant.....

Date of the interview.....

Start Time..... End Time.....

Location of the interview.....

Period(s) of ART interruption.....

## **A. Introduction, personal information & warm up**

- Greet the participant & establish positive rapport

*My name is XXX, I am from XXX, I work as an interviewer in this research project.*

- Briefly describe the procedure of the interview.
- Present and explain the Informed Consent Form and get it signed.
- Start the audio recorder
- Verify Informed Consent verbally while recording.
- Inform the participants that they are free not to answer any questions that they are not comfortable with.

*To start, please tell me a little about yourself.*

## B. Interview

Topic	Discussion Points
1. Background	<ol style="list-style-type: none"> <li>1. What is your professional background?</li> <li>2. Please describe this health facility and the HIV services of this health facility.</li> </ol>
2. ART programme in general	<ol style="list-style-type: none"> <li>1. In your experience, what are the strengths and weaknesses of the ART programme in the district.</li> <li>2. What is your experience with support and supervision for your HIV services by the DHE?</li> </ol>
3. ART patients	<ol style="list-style-type: none"> <li>1. What are your experiences with ART patients at your health facility?</li> <li>2. What are the strengths and challenges of decentralization?</li> <li>3. How are your patients doing? Do you see side effects? Defaulters? Deaths?</li> </ol>
4. Retention	<ol style="list-style-type: none"> <li>1. In your experience, what are the main reasons for deaths on ART and for defaulting on ART?</li> <li>2. How could retention be improved in the future?</li> </ol>
5. Support groups	<ol style="list-style-type: none"> <li>1. What are your experiences with PLH support groups in the area of your health facility?</li> <li>2. How do you collaborate with support groups?</li> </ol>
6. CHASA	<ol style="list-style-type: none"> <li>1. What are your experiences with the CHASA?</li> </ol>
7. Cultural Concepts	<ol style="list-style-type: none"> <li>1. In the area, what do the people know about HIV/Aids? What is people's attitude on people with HIV?</li> </ol>
8. Tracing	<ol style="list-style-type: none"> <li>1. Are you tracing defaulters? How? Who traces?</li> <li>2. Is tracing useful? Why?</li> <li>3. Did you manage to bring people back to care after tracing them?</li> </ol>
9. Various	<ol style="list-style-type: none"> <li>1. Would you like to add something?</li> </ol>

## **C. Closing**

- Do you want to add or correct something you have told me?
- Do you have questions?
- Thank you very much for taking part in this discussion!

## **Field Notes (observations & informal conversations)**

FGD Number:

Retention Study Bikita & Zaka	<b>London School of Hygiene &amp; Tropical Medicine</b>	
Topic Guide	Department of Clinical Research Faculty of Infectious and Tropical Diseases London School of Hygiene & Tropical Medicine Keppel Street, London WC1E 7HT	Improving health worldwide
<b>Focus Group Discussions</b>	Thomas Gass <a href="mailto:thomas.gass@lshtm.ac.uk">thomas.gass@lshtm.ac.uk</a> Phone Zimbabwe: 0778 326 217 Phone Europe: +41 79 681 05 53	

Name of the facilitator .....

Name of the assistant / record taker .....

Date of the focus group discussion .....

Start Time..... End Time.....

Location of the focus group discussion.....

### Participants (no names)

	Sex	Age	Date ART start	Ever interrupted ART?	Name of health facility at last ART visit
1					
2					
3					
4					
5					
6					
7					
8					
9					
10					
11					
12					
13					
14					

## A. Introduction, information & warm up

- Greet the participants & establish positive rapport
- *My name is XXX, I am from XXX, I work as a facilitator in this research project. This is my assistant XXX. He/she takes notes.*
- Explain the procedure of the focus group discussion.
- Present and explain the Informed Consent Form and get it signed by all.
- Inform the participants that they are free not to answer any questions that they are not comfortable with
- Start the audio recorder
- Start with an introduction round. Everybody who wants can tell his / her ART story in a nutshell.

## B. Focus Group Discussion

Discussion Topics	Discussion Points	Probe Questions
Being HIV positive	<ul style="list-style-type: none"> <li>- How does HIV affect / change your life?</li> <li>- How has HIV affected your health?</li> <li>- How does the partner, family, kin, community, employer cope with you being HIV positive?</li> <li>- Have you ever experienced harassment or insulting based on the fact you are HIV positive or on ART?</li> </ul>	<ul style="list-style-type: none"> <li>- How was your health condition at that time?</li> <li>- Did you share the results with other people? With whom?</li> <li>- After you received the test result, what advice were you given at the health facility?</li> <li>- Who else gave you advise what to do next?</li> <li>- Do many PLHA suffer TB?</li> </ul>
Treatment	<ul style="list-style-type: none"> <li>- How has ART affected / changed your life?</li> <li>- How does the partner, family, kin, community, employer cope with you taking ARVs?</li> <li>- Did you experience side effects? What kind of? What do you think is the reason for these side effects?</li> </ul>	<ul style="list-style-type: none"> <li>- Whom did you involve in decision making? With whom did you share your decision to start ART?</li> <li>- How many pills per day did you have to take? What was the name of the drug?</li> <li>- During your ARV treatment, did you seek for other treatment? Other drugs? Against which disease?</li> <li>- If someone feels ill in your household, what do you do for recovery?</li> <li>- How do TB treatment and ART interact in your experience?</li> </ul>
Retention	<ul style="list-style-type: none"> <li>- Have you ever missed your ART appointment?</li> <li>- Why? Under what circumstances?</li> <li>- Who is most helpful and supportive to keep you ART appointments?</li> <li>- How do you manage to remember taking your pills every day – life long?</li> </ul>	<ul style="list-style-type: none"> <li>- Are there times during the year when you find it easier or more difficult to keep going to the ART appointments?</li> <li>- Are you satisfied with the health workers providing ART services?</li> <li>- When it comes to ART appointments, what is the role of your treatment partner, CHASA, village health worker, ART nurse, family members?</li> </ul>

		<ul style="list-style-type: none"> <li>- Do you know other patients who discontinued ART?</li> <li>- For what reasons?</li> </ul>
Interruption of ART	<ul style="list-style-type: none"> <li>- Have you ever decided to stop taking ARVs?</li> <li>- Why did you decide so?</li> <li>- What effect had the ARV interruption on your health? On your everyday life?</li> <li>- Have you re-started? Do you consider doing so? Why?</li> </ul>	<ul style="list-style-type: none"> <li>- How was your health condition when you stopped?</li> <li>- Did you involve other people in your decision to stop ART? With whom did you discuss? What was there advice?</li> </ul>
Role of the health facility	<ul style="list-style-type: none"> <li>- How is the relationship to the health workers at your health facility?</li> <li>- Were they supportive or not? In what way?</li> <li>- Are you satisfied with the medical service you get?</li> <li>- If you compare ART provision at hospital (Musiso and Silveira) with ART provision at rural health centres, what is the difference?</li> <li>- How could the health facility improve ART service? What should be changed in the future?</li> </ul>	<ul style="list-style-type: none"> <li>- Did you discuss / inform your health facility about stopping ART?</li> <li>- What could the health facility do to support you in a better way?</li> <li>- Under what circumstances would you stay on treatment, return on treatment?</li> <li>- Which is the nearest health facility? How far is it? How often do you there? How do you travel there?</li> <li>- Are you satisfied with their service?</li> <li>- Do you have to pay for health services?</li> </ul>
Role of family & kin	<ul style="list-style-type: none"> <li>- Do your family and kin support you in taking ARVs?</li> </ul>	<ul style="list-style-type: none"> <li>- Who lives in your household?</li> <li>- Who brings income home?</li> <li>- How is the health of your family members?</li> <li>- What do your family and kin members think and believe about ART?</li> <li>- Who supports you most? Was there anybody who disapproved you are on ART?</li> </ul>
Role of support group	<ul style="list-style-type: none"> <li>- Are you member of a PLHA support group? Why?</li> <li>- What is your experience with the support group?</li> <li>- Do you know a CHASA? What do they do?</li> </ul>	<ul style="list-style-type: none"> <li>- Any positive and negative experience with support groups?</li> <li>- Why are some PLHA member and others they are not member?</li> </ul>

		<ul style="list-style-type: none"> <li>- How many people are member of the group?</li> <li>- Do you think PLHA groups and CHASA can help improve ART and adherence? In which way?</li> <li>- Can the CHASA collect the ARV drugs for you?</li> <li>- When was your last meeting? What did you discuss?</li> <li>- What happens if a member is in trouble? Can you remember such a case?</li> </ul>
Cultural Concepts	<ul style="list-style-type: none"> <li>- In your village, what do the people know about HIV/Aids? What is people's attitude on people with HIV?</li> <li>- What do you know about how HIV? How is it transmitted? What are the most frequent symptoms of HIV/Aids? What is the purpose of a CD4 test? Do you know side effects?</li> </ul>	<ul style="list-style-type: none"> <li>- What name do people give the disease? What does it mean?</li> <li>- Has the attitude changed in recent years? How and why?</li> <li>- What do people think and believe about ARVs? What do people think is the effect of ARVs? What do you know about ARVs?</li> <li>- What do people think and believe about side effects of ARVs? What do you know about it?</li> <li>- If someone is sick, is he/she being supported in your household/community? Does it happen that sick people are left alone? In what cases?</li> </ul>
Tracing	<ul style="list-style-type: none"> <li>- After missing an ART appointment, have you ever been approached by a health worker? Do you know someone who has been contacted either by phone or at home? If not, how would you feel about this? What would be the advantages and disadvantages of such as system?</li> <li>- What do you know about what happens if an ART patient interrupts treatment? How can this best be prevented? Do you think tracing would be a good solution for the future? Under what circumstances?</li> </ul>	<ul style="list-style-type: none"> <li>- Whom would you accept to approach you if you miss an appointment?</li> <li>- What do people think about tracing?</li> </ul>

## **C. Closing**

- Do you want to add or correct something you have told me?
- Do you have questions?
- Thank you very much for taking part in this discussion!

**Field Note (observations & informal conversations before and after the FGD)**

## Appendix 7: Narratives of patients who interrupted ART

### **Batsirai, the abandoned young mother**

Batsirai was 22 years old, mother of a four months old baby, and severely ill. She looked wasted, had difficulties breathing and speaking and her voice was faint. We recruited Batsirai through CHASA Shorai who traced her. We collected Batsirai, her baby and her mother at their home around 50 kilometres from the hospital and took them to the ART clinic, where Batsirai was supposed to collect her CD4 results and to restart ART. Some of her answers were confusing, and it was only possible to establish her case consistently after the interview with her mother, who was a widow with very poor knowledge about ART, as the following quote shows:

*She's taking some drugs but I don't know the name or what they are treating but she's taking them properly. There were times when she would forget to take the drugs but of late she has been taking them properly.* [interview with Batsirai's mother]

Batsirai tested HIV and started ART when she was married with her first husband, with whom she had no children. After his death, Batsirai married again and became pregnant. She dropped ART because she feared her husband's and his family's reaction.

CHASA Shorai said Batsirai has been chronically non-adherent; each time she was registered in HIV care and tested CD4 she would throw away her card. Batsirai admits that she *did not adhere to what I was told at the hospital*. During pregnancy, she did not take the drugs she was prescribed to prevent vertical transmission because she did not like their taste, as she put it. Batsirai's husband worked in another town and she stayed at the abandoned homestead of her first husband's parents. After the birth of the baby, Batsirai became ill. Her in-laws started rejecting her, until her husband left her, as she explains in the following quote:

*He was perverted by his parents, (they) interfered. They said to him you are keeping a sick person what for? And he left me.* [interview with Batsirai, ART patient who interrupted treatment]

Her mother took her and the baby to her home. This is where CHASA Shorai traced her. Batsirai's tragic case is a combination of various factors contributing to a steady decline of her health status, and, as we were informed later, led to her death a few

months after the interview. In her second marriage, Batsirai suffered under the resentment of her in-laws. To hide her HIV status, she had to stay away from ART. Stopping ART made her sick, and being sick she was considered a burden to the family-in-law, and her husband neglected and eventually abandoned her. After CHASA Shorai found her for the first time, she sent her to the hospital where she was taken blood for a CD4 cell count. She was sent home with an appointment to re-initiate ART. Batsirai never re-initiated ART.

### **Chido, the primary school teacher**

Chido was a mother of three children. Her husband died, and the 9-year-old boy was HIV-positive and on ART. It worried Chido that she had not yet managed to tell him that he was HIV-positive. As a primary school teacher, she had a regular income, yet she was using most of her salary to support relatives, and there was not much money remaining at the end of the month. It was nurse Chenai at the local health centre who diagnosed Chido's HIV status. Since then, the two women had kept a warm relationship, as the nurse expressed in the following quote:

*She knew I was never going to tell anyone so that is why we clicked. (...) I know her history, I understand her. [interview with Chenai, nurse]*

Chido had been on ART for two years when she travelled to Harare. At that time, life was rough in Zimbabwe; hyperinflation devalued the cash in Chido's pocket, fuel became short, and public transport collapsed. Chido was not able to return to her home as planned. Without a referral letter from the hospital, Chido was not able to access HIV care at the public ART clinic in Harare. Stuck in the country's capital city for a couple of weeks, she ran out of drugs, and an interruption of a few weeks turned into a serious crisis for Chido. She finally returned home to her ART clinic at the hospital with a treatment gap of a month. As a "defaulter", she was given a two-week drug supply only instead of the routine two- or three-months. Yet, the economic crisis did not allow Chido to spend US\$24 for transport there and back every two weeks, so she stayed away from ART for another 4 months. When her stomach started troubling her she felt desperate because of her son who also needed ART. She felt guilty and, eventually, went to nurse Chenai to ask for help. At that time, nurse Chenai's health centre had become a decentralized ART site. Many ART patients comfortably collected their drugs locally. Yet, as a "defaulter" who had not been on ART for long enough, Chido did not qualify to be decentralized. She felt bitter about what she perceived a punishment by the nurse at the hospital, and about how she was treated:

*They don't want people to default, so when you do that they punish you by giving you small supplies like two weeks or one month while others are getting supplies for three months. They don't deny your drugs but they just give you small supplies so that you have to come again and again. (...) If only they could use polite words even if one defaults, because there are certain words that you cannot use when talking to people. Even other staff members know that he is rough. When patients are not behaving they say we will call him to come and deal with you or close down this place. He sometimes send people out of the consultation room and says I will serve you later if you just have a small misunderstanding in answering his questions. I was once offended when I had my child and they said those with children come this side. I went there but was not given the food package others were being given because they said I am a teacher. I have heard some saying there is a bus fare fund for children but I am afraid to ask the nurse because he is scary. [interview with Chido, ART patient]*

Chido was re-initiated on ART only after an intervention of nurse Chenai through the hospital's sister in-charge. Chido has fully recovered since and never missed a pill or an appointment again.

### **Edzai, the brave widow**

We interviewed Edzai in a counselling room at the local health centre. It would have been impossible to visit her at home because her husband did not know that she was HIV-positive. Edzai was 34 years old and had a very poor socio-economic background; she dropped out of school early, not used to write nor read and not able to recall the year when she started ART. She had no income and stayed many walking hours away from the main road in her husband's homestead where they lived from subsistence farming. At the interview, she looked wasted and her voice sounded feeble. Edzai had two boys aged 13 and 6 years from her previous marriage. After her first husband's death, Edzai and her children returned to her parental home where they lived until Edzai remarried. After re-marrying, she moved to her new husband's home and left her children behind. The older son was taken by the family of her first husband. The younger remained with her parents. Edzai was on ART, she used to collect the drugs for herself and for her son. She said she had always taken her drugs when she lived with her parents. But she feared that her new husband would want a divorce if she told him that she was HIV-positive. She hid the drugs outside the house for a while, but soon stopped taking them. She thought that her husband was HIV-positive too, because his former wife died and four children all died. Before they married, she suggested they could test for HIV together. But he refused saying he would only get

tested when he fell ill. Edzai did not have anybody to whom she could talk about her desperate and burdening situation. She could not even turn to her parents, who have been supportive to her, as she explained in the following interview section:

*Interviewer: So how do you plan to deal with your husband and your ARVs?*

*Edzai: I wish he could agree that we get tested together. I had planned to just come and take drugs and show him that this is what I have done.*

*Interviewer: Why are you having such thoughts?*

*Edzai: I fear that if I continue not taking ARVs sooner or later I will fall sick and I won't know where to start from if that happens. (...)*

*Interviewer: Does your family know that you stopped ART and what do they say about that?*

*Edzai: To be frank they don't know that I am no longer taking my ARVs and they wouldn't be happy that I stopped taking drugs. (...) It is difficult because I should have told my parents that I stopped but it's not an easy thing to do. Sometimes I would come here at the clinic prepared to restart ART, prepared to take whatever comes, this is my way, even if it means divorce.*

A couple of months before the interview, health centre nurse Chamunorwa realized that Edzai was overdue and sent a village health worker to trace her at her home. She was found ill and the tracer encouraged her to resume treatment. She came to the health centre and was diagnosed with herpes zoster and pneumonia. The nurse said he treated her and advised her to urgently re-initiate ART. Edzai kept refusing. At the time of the interview, six months had elapsed since Edzai stopped ART. Her health had deteriorated and the fact that she was hiding her HIV status both to her husband and to her family members disconnected her from any social and psychological support. Edzai's refusal to restart ART in spite of her ill-health and in spite of feeling guilty in front of her family underscores the power of HIV stigma in marriage, representing both a cause and a consequence of the colossal gender inequality in Zimbabwe's society.

### **Ega, the old man with the beautiful garden**

Ega was married and had seven children. He was an old man and proud of his garden "that beats everyone's garden even those who are not on ART" [interview with Ega, ART patient]. His wife was also HIV-positive and on CTX prophylaxis. She said she was due for a CD4 cell count recently, but she would only go to the hospital during the

school holidays when the children were at home to watch the garden, so the baboons would not take the chicken.

Ega was nearly 70 years old when he became seriously ill. He said he had tried everything to get healed, including accusing relatives for having bewitched him. In 2008, his son and his wife encouraged him to test HIV, and when he was tested positive, he was initiated ART. Ega had been on ART for four years, when he stopped. Whilst he did not give any plausible reason in the interview why he interrupted ART, his wife bluntly told us the church elders said he was healed and he should stop taking ART drugs. Ega and his wife were members of an Apostolic Church community. Ega's wife said her husband truly believed that he was healed because he felt strong and he would spend the whole day working in his garden. So he stopped ART and felt embarrassed about it, as the following quote shows:

*When I was asked why I defaulted, I lied saying I had gone to Mozambique because I didn't have a good reason for defaulting. [interview with Ega, ART patient]*

Three months after stopping, he started feeling ill and developed a rash. In the meantime, other church members who were on ART had started opposing the church leaders' order to abstain from ART. Ega's wife and the nurse in-charge of the local health centre convinced him to re-initiate treatment. Ega recovered well from this episode:

*My relatives and friends were saying I would die the next day. When I was in the hospital they kept saying let's dig his grave he will come back dead, but they are the ones dead now and I am alive because of the drugs. [interview with Ega, ART patient]*

### **Fungisai, the woman who saw flames**

Fungisai was the sister of the nurse in-charge of a rural health centre. She said since the nurse was her brother, every health worker at the centre treated her like a relative. Fungisai was 45 years old and had two children; she recently became grandmother. She was married and left her husband during her second pregnancy. He later died. In 2005, Fungisai tested HIV-positive and was put on CTX prophylaxis. During a stay in South Africa in 2008, she became ill and returned to her parents' home in the district. She was admitted at the hospital and given the starting supply of ART. But Fungisai had become mentally ill to an extent that did not allow her to adhere to the drugs, as she explains in the following quote:

*I came back from South Africa very ill, I came to the clinic and I couldn't even eat so I survived through drips. I went to the hospital and was initiated ART. I was given the*

*starter pack first. But I confused the drugs and when I went to the ART clinic and explained everything to the nurse she said what has happened has happened but I must be careful next time, then she gave me my second supply. I took it home and suddenly I started seeing the flames of fire turning blue. I went mad and from that time I interrupted ART. I was mentally disturbed for the whole year and I was admitted at the hospital so they would force me to take the drugs even in my madness.*

Later Fungisai was told that she "would beat people such that they would run away from me where ever I approached them." [interview with Fungisai, ART patient] Her mother and brother only found out after a few months that she was not taking her drugs. With assistance of her brother, Fungisai was admitted at the hospital again and diagnosed HIV encephalitis. She was successfully treated and restarted ART.

Fungisai's case raises the issue of HIV related mental illness impacting adherence and retention. Fungisai did not adhere to ART whilst her health deteriorated in spite of home care by her mother and direct access to the health system through her brother. Even though she was diagnosed an opportunistic infection, Fungisai still thinks that she became mentally confused because of the ART drugs.

### **Jayaguru, the wealthy farmer**

CHASA Kutenda brought us to Jayaguru's farm where we interviewed him. The farm was a few kilometres from the hospital, and Jayaguru had lived there with his family since 1974. Jayaguru, who was 57 years old, was a relatively wealthy farmer. He had a nice piece of land, cattle and irrigated vegetable plantations; and he was well-known in the area for his tasty and affordable tomatoes. In 2010, Jayaguru became ill of tuberculosis. His brother advised him to test HIV. Jayaguru and his wife tested both HIV-positive, he started ART and she was put on CTX prophylaxis. The couple was member of an Apostolic Church community. Contrary to some other church members (see the case of Jekuche), Jayaguru and his wife did not follow the local church leader's plea to abstain from ART. Jayaguru's wife admitted that there was a time when she hid her status from the church community:

*Sometimes they discouraged us from taking drugs and later they said we can take drugs. At one time they said those who take drugs will be ordered to take down their garments (be excluded from the church). At that time I went to another another clinic so that I wouldn't be seen by those who know me. [interview with Jayaguru's wife, patient in HIV care]*

Jayaguru himself did not talk about his faith and whether it influenced his adherence to

ART. He interrupted ART because he ran out of drugs whilst working on a farm 200 kilometres away from home. Having missed his follow-up appointment, he did not dare returning back to the hospital:

*When I returned I did not want to go back to the hospital in fear that I could be shouted at. (...) I had never heard of anything that could have happened to anyone who missed an appointment but when I was initiated I was told that I am not supposed to default so I felt guilty of doing that. I even had thoughts of going and starting afresh from blood tests as if I was a beginner. [interview with Jayaguru, ART patient]*

Jayaguru was on ART for more than a year when he stopped ART. He expressed that shame about being a “defaulter” was the reason why a delay of a few weeks developed into a treatment gap of six months. He was already classified lost to follow-up when the hospital sent CHASA Kutenda to trace him. Jayaguru expressed how grateful he was that the CHASA encouraged him to return to HIV care before he would have fallen ill:

*My guilty conscience made me think I would be questioned and even when the CHASA came to call me I thought I was going to be put under interrogation but we had a nice discussion and I was reinitiated. [interview with Jayaguru, ART patient]*

### **Jekuche, the religious teacher**

Jekuche was a 57 years old and a secondary school headmaster. He had been married for nine years and had six children from two marriages. Jekuche’s first wife left him when he married his current wife because she did not want to live in a polygamous marriage. In 2007 Jekuche became seriously ill, with diarrhoea and stomach pain. He “tried everything to get healed” [quoting Jekuche] but it did not help. Eventually, his wife encouraged him to test for HIV. He tested positive and initiated ART. His wife tested negative. Three years later, during one of her pregnancies, Jekuche’s wife tested again, but she was now HIV-positive.

Jekuche was deeply religious. He and his wife were members of different Christian churches before they joined the African Apostolic Church in 2009. At a public ceremony of the church in June 2011, an Apostolic leader encouraged HIV-positive church members to stay away from hospitals and to stop ART, as he explains in the following interview section:

*It was at a church function when we were misinformed. We were told that we have all been healed. And I accepted that and I went home, including my wife. After some time (...) I started feeling ill. Shaking and what and what. Then in January, it got worse, I*

*started experiencing real shake-ups and a mild stroke. And I had wounds in the back which were serious and deep. So I had to come to the hospital. Then when I came to the hospital, they restarted me and I explained to them I had learnt my lesson, I will never ever drop these things again, for whatever reason. Now even our church leader explained that no, hospital was made by God, so people are healed by God (...).*

Jekuche was a wealthy and well educated Zimbabwean. As headmaster of the secondary school, he was a locally well-known and respected personality. He had been on ART for four years and he knew that ART saved his life. And yet, the announcement of the religious leader made him stop ART. Jekuche said he restarted ART after changing his mind. However, his wife underlined that he did not want to return to care as long as the church did not withdraw the announcement. It was her who ultimately convinced him that “he would die and leave me alone yet we have a lot of children” [interview with Jekuche’s wife] and took him to the hospital. Jekuche explained that after he restarted, the church reconciled spiritual healing with biomedicine by stating that hospitals were made by God. Jekuche enthusiastically defended his church, underlining that it was a misinformed leader who made the announcement without consulting his superiors:

*A lot of people died. And a lot of people are ill right now because of this problem. Now after this announcement was made, the church leader, he made the public announcement that people should go back to the hospital. Because this is wrong. Hospitals were made by God to assist people. This announcement was wrong. It was misplaced. It meant to kill people. And to make people stay away from the church.*  
[interview with Jekuche, ART patient]

At the time of the interview, the SMART programme considered Chido and Jekuche as retained patients, whilst Edzai was classified lost to follow-up. The cases of Chido and Jekuche show that retention does not indicate persistent adherence to ART drugs and appointments. They both had treatment interruptions of several months before restarting ART. The same was the case with eight other cases. Edzai, like four other cases, has been away from ART for many months without returning to care. Whilst Edzai and two others (Nashe and Chikonzi) restarted ART after the interview, Batsirai and Meso did not manage to return to care, and died a few months after our encounter. The narrative analysis of the cases suggests that understanding the determinants of long-term retention requires an investigation of two critical passages in the treatment career of an ART patient: firstly, the reasons why patients interrupt treatment, and secondly, under what circumstances patients return to care or turn a temporary ART interruption into a prolonged and potentially fatal therapy discontinuation.

### **Linda, the widow with the stick**

Linda was walking on a stick. She recovered quite well from a stroke she had five years ago, but she remained handicapped and had a minor speech difficulty. Her sister said she wished Linda had physiotherapeutic care. Linda travelled to hospital B every three months to collect her ART drugs, always escorted by her sister, who was her most important treatment supporter. Linda had no children. She lived with her sister's family and her mother.

Linda and her sister have always been very close to each other. They grew up in a family of 16 children in the countryside of Masvingo Province. Whilst her sister married in rural Masvingo, Linda became an international trader. She married, moved to Harare and got involved in cross-border trading with Namibia and Zambia. Buying consumer goods in bulks in the neighbouring countries and selling them on the market at home was a popular way of earning income in Zimbabwe. In her thirties, Linda made good business. After 6 years in marriage, she became ill. As her health deteriorated, her sister came to Harare to look after her. She took her to the hospital, where Linda tested HIV-positive and started ART. Linda's life changed abruptly. Her husband left her and her sister took her back to their mother's home in the village. Around half a year after starting ART and returning home to Masvingo, Linda became involved with a Pentecostal Church community. The bishop told her that drugs were not allowed, and that she would be spiritually healed. So Linda stopped ART. In February 2008, whilst she was staying with the bishop, she had a stroke. Linda's sister took her away from the bishop and brought her to her own home. She took her to the hospital where Linda restarted ART in 2010. Linda survived thanks to her sister, as the following quote of Linda's sister shows:

*When she had stroked they called me because it was difficult, she couldn't go to the toilet or bath alone, she messed herself, I had to go and wash her, and she messed herself again. She then resumed ART and she got better but she still had the stroke. I am always on the look-out to check if she takes her pills at eight in the morning; if she leaves her sadza, I heat it and feed her. If there is no sadza we make porridge and she eats and then takes her pills. If I am there everything is ok. [interview with Linda's sister]*

Like many other ART patients, Linda quit ART due to the influence of her religious leader. In Linda's case, interrupting ART made her particularly vulnerable because it concurred with a cerebrovascular accident. Linda became entirely depending on her sister. As her sister points out, Linda also had a network of friends and relatives whom

she had done business with or whom she had helped out in the past. Thanks to her social network, she had a safety net assisting her whilst recovering from the stroke and restarting ART:

*She was very kind to everyone when she was strong; she was very generous and she supported everyone through her businesses. So people send her blankets, shoes or clothes from Harare. Since she was a nice person she is getting help. She didn't have a child, and she supported everyone even during funerals and she paid fees for children of our deceased family members so they take care of her. She has shown appreciation; she gave me one sheep and told me to sell it. (...) [interview with Linda's sister]*

Not all family members were happy about the fact that Linda needed treatment, care and assistance. As her sister pointed out, the brother who lived with them in their family's homestead considered Linda a burden to the family.

### **Maidei, the mother who stopped drinking beer, and Chikonzi, the former prisoner**

Maidei was an illiterate 36-year old woman who grew vegetable and gathered insects for sale. She was once married with a man with whom she had five children. The man died in 2008, and one of the children from that marriage died very recently; the boy was eight years old and HIV positive. During the funeral, the child's late father's family accused Maidei for bringing HIV into the family, and causing the death of the boy and his father. Maidei was tested HIV-positive several times at antenatal care, and she was given ART to prevent vertical transmission as well as drugs for CTX prophylaxis. She only started ART after her first husband's death, when she became ill with tuberculosis. After completing tuberculosis treatment and recovering, she dropped ART because she felt healthy. She started drinking.

*It was the devil. I wasn't thinking clearly, I used to drink beer by then and taking ARVs together with beer would make me feel a burning sensation in my chest so I decided to stop the ARVs. I was later taught at the clinic that ARVs and beer don't get along so when on ARVs one should stop beer, but by then I didn't know. (...) All the money I got from the sale of garden produce and termites, I used to buy beer. [interview with Maidei, ART patient]*

Maidei was not only addicted to alcohol, she also lacked treatment literacy. She found it difficult to distinguish the different drugs.

In 2010, during the time when she was drinking beer, Maidei married Chikonzi. He had just been released from prison, where he got infected with tuberculosis and started

ART. Access to ART was not a problem in prison and they had enough food, he said. Upon his release, the prison clinic referred him to the hospital to continue ART. Chikonzi moved to Maidei's. After a first visit at the hospital's ART clinic, he decided to drop therapy. He said he stopped ART because he did not have the money to pay for the bus fare. Chikonzi complained about the nurses at the hospital:

*I went there on the tenth of February and was told to come back on the sixth of March. When I got there they said I was late and didn't consider the walking distance from where I was coming from. They gave me another appointment on the twenty-seventh of April, that time I had money and so I boarded a bus, but it had a breakdown on the way. But still I didn't arrive there very late, they would have assisted me but they didn't, I was given another date. I wouldn't mind walking there to get drugs but I have a problem when people do favouritism and serve people who came after me first before they have served me. You see a nurse actually coming to the queue to collect a card for a certain person who is at the end of the queue. They favour those who pay them while some of us without money to pay them are skipped in the queue.*

Maidei eventually initiated ART before the birth of her last child. She stopped drinking beer and she wished Chikonzi could also restart treatment. She heard that their local health centre recently became an ART site, so that it would not be far and expensive to collect drugs in the future. She said that Chikonzi needed ART now because "*he has gone dark in complexion and this shows that he is not well.*" [interview with Maidei, ART patient]

### **Meso, the maltreated orphan**

We interviewed 18-year old Meso at the hospital when she came for her follow-up consultation. Meso had the appearance of a stunted child. She was skinny and wore untidy clothes that were far too large for her size. She was ready for the interview though not feeling well. She did not talk much, so that we reconstructed Meso's story largely from the interview with her aunt.

Meso grew up with her mother who had left her husband because she did not want to live in a polygamous marriage. Meso did not remember her father; he died when she was a baby. She had three older brothers who had different fathers. Her mother became ill when Meso was in grade 5. Meso dropped primary school to care for her dying mother. She does not know if she was vertically transmitted or if she was infected during childhood. Her aunt, a sister of Meso's late mother, said that Meso might have been infected when she was raped at primary school age. She said it might as well

have happened when Meso cared for her mother's open wounds. Meso's mother died of AIDS in 2007 when she was 13 years old. She was taken by another sister of her mother's who by then worked as a maid for a nurse. The nurse happened to be the in-charge of the newly established ART clinic. Meso became ill with tuberculosis and it was this nurse who tested Meso, put her on treatment and later initiated her on ART. When Meso had recovered, her brothers claimed their father's spirit said they should look after Meso. They took Meso away from her aunt's and she had to work in one of her brother's households. Her aunt says Meso was maltreated there and they did not give her proper food. Although her brothers told her not to marry due to her HIV status, Meso found a partner and married at the age of 18. This is when she stopped ART because she feared that her husband would leave her when he knew that she is HIV positive. Meso not only hid her status to her husband, as she explains in the following quote:

*Meso: I feared that I they (brothers and aunts) would ask me why I stopped. I was afraid they would be mad at me.*

*Interviewer: why do so many women stop ART because of marriage?*

*Meso: In fear that if he discovers he will dump you if he knows about your status. In my case, my brothers were discouraging me from getting married, saying you are HIV positive and no one will ever marry you. [interview with Meso, ART patient]*

Ironically, Meso's husband became ill, tested HIV-positive and was initiated on ART himself. When they married, Meso was already pregnant. Before the baby was born, in December 2011, Meso's husband died in a car accident. A few days later, Meso gave birth to a baby, but the baby died after three months. Still without ART, Meso became very ill and was admitted at the hospital, where she was kept with tuberculosis for one and a half months, and re-initiated on ART by the nurse whom she had known before. After being discharged from the hospital, she went back to live with her brother's family. Meso said she felt like a burden to that family and she wished she could leave the place to get some employment to be on her own. But her brother did not let her go. Meso's aunt was worried about Meso's situation at her brother's, as the following quote shows:

*People just rush into marriage. If Meso had not been married maybe she wouldn't have stopped or fallen sick. Right now we are not happy about her staying there with her brothers. They are not taking good care of her; they make her work hard and don't give her good food. Recently she was complaining that she has got chest pains after they had made her carry a twenty litre bucket of water. The other brother's wife once had a misunderstanding with Meso and threw out her clothes. The brother's wife she lives*

*with now is not giving her proper food she sometimes comes here to ask for peanut butter or eggs. [interview with Meso's aunt]*

Meso's case is the story of an HIV positive orphan who was vulnerable in multiple ways. Given her fragile state of health and her minor age, she was in good hands living with her maternal relatives, where she was initiated on ART thanks to her aunt's relation to the nurse of the ART clinic. When she was taken away from her care givers to her brother's family, she got into an environment where she was exposed to maltreatment and hostility. Marriage was an opportunity to escape from her brother's family. Meso's case demonstrates that under circumstances of vulnerability and dependency, marriage can be a reason why women stop ART. Meso restarted ART only after her baby died and she was admitted at the hospital after her health had critically deteriorated. At the time of the interview, she had recovered and returned to her brother's home. Her aunt said she wishes Meso could live with her. She was desperate about Meso's fate and said *sometimes I even wish she would have died with her mother because the situation she is in now pains me* [interview with Meso's aunt].

Meso died three months after the interview.

### **Nashe, the labour migrant**

Nashe was a 39 year old man who grew up on his father's farm. He was a certified steel binder. In recent years, he spent most of his time working on a farm in South Africa. He returned to Zimbabwe two years ago. Back in Zimbabwe, Nashe had no job and no income. Nashe was married and the couple had a two-year old child. We interviewed Nashe in his village at health centre B3. He did not give the impression of being able to handle reinforcing bars or carrying heavy boxes of tomatoes. He was limping, his appearance was fragile, his voice feeble, and he said he had chronic diarrhoea. Like many other Zimbabweans, Nashe worked as a labour migrant in South Africa, where he was tested HIV-positive and started ART at his workplace. In the interview, he did not like talking about South Africa, emphasizing how much he would like to restart ART:

*To tell the truth, sister (addressing translator), ART is good for me, I used it before and I saw its importance. (In South Africa) I got into ART and started gaining weight.*

[interview with Nashe, ART patient who interrupted treatment]

Nurse Chenai and primary care counsellor Farai supposed that he infected his wife and felt ashamed about it. His wife said Nashe did not tell her about his HIV status. She only found out from his stepmother towards the end of her pregnancy, when Nashe

returned from South Africa. She was married before and had three children with her former husband. She tested HIV positive at antenatal care during her last pregnancy with the baby from Nashe. His wife said she had accepted her status and was happy that her baby was tested HIV-negative thanks to the drugs she took to prevent vertical transmission. Because her CD4 cell count dropped from 600 when she first tested to 330, she was recently initiated on ART.

Upon his return from South Africa, Nashe went to the hospital and was initiated on ART. Nashe stopped after two consultations because he could not afford transportation. Indeed, Zimbabwe was in deep crisis in early 2010 when Nashe returned to Zimbabwe, and the health centre was not providing ART services yet. He did temporary farming jobs here and there and thought he would resume ART when the family's economic situation would have improved. But his health deteriorated, the leg got worse and he was not able work anymore. Transport to the hospital and back was US\$24, an amount that the family could not afford:

*It's difficult to channel the little money I get for transport to the hospital when the child is crying because of hunger. I cannot value my life over that of my child. So I would rather save money and buy food for my family than keeping it for bus fare to go to the hospital.* [interview with Nashe, ART patient who interrupted treatment]

Nashe's health workers believed that there were other reasons why Nashe dropped ART. Nurse Chenai – we know her from Chido's case – was an enthusiastic and warm hearted ART nurse who supervised the local HIV/AIDS support group. She was familiar with the background of her patients. She did not know Nashe well because he was in South Africa. But she knew that his parents died and his paternal relatives belonged to a church community that discouraged members from ART. She supposed this could have played a role in Nashe's case. Primary care counsellor Farai was employed at health centre B3 to provide HIV testing and counselling and adherence support to ART clients. Farai himself had been on ART for four years and he emphasized that he had always collected his drugs *at the exact appointment date* [interview with Farai, primary care counsellor and ART patient], even if he had to walk to the hospital in a critical state of health. Farai said that neither the swollen leg nor the transport costs but an *attitude problem* was the true reason for Nashe's non-adherence. He believed that Nashe had not accepted his HIV status because he felt guilty about infecting his wife and having failed to disclose to her while she was pregnant. Farai believed that Nashe felt ashamed to confront himself with the truth.

After the interview, we offered Nashe a ride to the hospital which he accepted. He stayed overnight and the next day, after an intervention of the study team at the nurse

in-charge, Nashe got reinitiated on ART and immediately down-referred to the health centre.

A few weeks later, we accidentally saw Nashe's wife at the ART clinic of the hospital. Whilst Nashe was down-referred, his wife was still going to the hospital for ART follow-up. But that day, she did not come for her scheduled ART visit; she came because nurse Chenai had referred her. After starting ART, she developed a rash all over her body, and it had become painful. At this day, Nashe's wife was not able to walk to the hospital because she was not feeling well. Nashe had sold maize to make US\$24 available for her transport. Normally, ART patients were required to come with their treatment partners. Obviously, Nashe's wife could not afford to pay the bus fare for two. We witnessed the following incident at the OI clinic and present it from the field notes in some detail because it demonstrates how both Nashe and his wife were struggling with distance, indirect treatment costs and referrals. It was Tadisá, the nurse in-charge of the ART clinic, who attended Nashe's wife. Tadisá was a committed and experienced ART nurse who had been among the pioneer nurses providing ART in the district. At the hospital, ART patients were initiated and managed entirely by nurses. Doctors were consulted in very rare cases. In such cases, the doctor did not see the patient in the ART clinic, but the patient was referred to the out-patient department where the patient had to queue a second time to see the doctor. Tadisá did not refer Nashe's wife to a doctor, but prescribed her antihistamine and steroids. She said she was not sure if the rash was a side effect of the ART drug component nevirapine, or an effect of her recent malaria episode, or any kind of eczema. After the consultation with Tadisá, Nashe's wife went to the hospital pharmacy to collect the prescribed drugs. There she was asked to pay US\$13 for the drugs. Since she did not have that money she left the hospital and was about to travel back home, before we found her. She told us the story and we paid for her drugs. We later discussed the episode with Tadisá and she said that payment plans can be negotiated with the hospital administration if the patient cannot pay. Nashe's wife did not know about this scheme and almost went home with her rash and no treatment. Due to our involvement in the case, Tadisá thereafter down-referred her to the health centre.

The cases of Nashe and his wife would have developed in a different way if the study team had not intervened. As far as Nashe is concerned, whatever reason made him stop ART after his return from South Africa, the critical question is why he did not restart for more than two years, in spite of his deteriorating condition. Was it because of the leg or the distance or a guilty conscience or the religious belief of his relatives? Whichever reason is true, it is apparent that Nashe had great difficulties to cope with his status and his wife was his only potential support. As a returning migrant, he was

isolated in the community, his parents were dead, his relatives did not approve of ART, and the adherence counsellor at the health centre considered him an irresponsible person with an attitude problem. The episode of his wife revealed that the hospital's policy to down-refer patients only when they are stable does not necessarily assure good quality and good results of care. In the case of Nashe's wife, she was properly referred from health centre to hospital but not seen by a medical doctor, and her rash would have remained untreated because she could not pay for the medication. The fact that she left the hospital without treatment underlines the critical situation of her family not allowing proper HIV care and treatment for both Nashe and his wife under their current circumstances.

### **Pfuma, the illiterate mother**

It was a 20 kilometer four-wheel drive on a bumpy unpaved track from the rural health centre until we reached an even more remote health centre, where we meet Pfuma. She had been lost to follow-up and traced by a village health worker. It took her three hours to walk from her home to local health centre, where essential health services are provided including HIV testing and CTX prophylaxis, but no ART. Reaching the nearest ART site would have taken her another four hours, adding up to a full day walk from her home to the ART site. Pfuma was 26 years old and lived with her three children (9, 7 and a baby) and with the second wife of her husband and her children in a remote mountainous homestead. Pfuma and her children lived in poverty; she was illiterate, her children did not go to school and her husband was in South Africa and did not send money to his wives. Pfuma made her living from subsistence farming and menial jobs here and there. She and her husband's second wife were not in good terms. Pfuma would not leave her children back when leaving the homestead.

During her pregnancy in 2011, Pfuma's sister gave her money for transport to get to a health centre for testing. Her husband did not join her, as she explains in the following quote:

*When I went to the clinic they advised me to bring him along for testing and when I told him he showed no interest. He said if I feel that I am sick I should get tested myself and leave him out of it. I said to myself this is my life and I have to take care of myself, so I woke up the next morning and I went to the clinic for testing. I didn't tell him about it.*  
[interview with Pfuma, ART patient, interrupted ART 7 months ago, has not restarted]

After being tested HIV-positive, Pfuma's sister gave her again US\$10 for the bus fare to travel to the hospital to register for HIV care. At the hospital's ART clinic, she learnt

that she could have saved the trip to the hospital and instead registered at the health centre, where pre-ART services were provided such as CTX prophylaxis, CD4 test and pre-ART sessions. So Pfuma was given a box of CTX and referred back to the health centre. As Pfuma was tested HIV in a different district, she was not informed about the availability of decentralized HIV care at the health centre. So Pfuma travelled back home, then travelled to the health centre a few days later to give blood, and again a few days later to get the results. Since she had no money to hop on a vehicle on her way to and from the health centre, she walked and stayed at her aunt's place. Pfuma's CD4 cell count was 151 and she immediately received her first pre-ART session. After a second pre-ART session, Pfuma was initiated ART in January 2012 at the health centre by the hospital outreach team. She went home and started taking her drugs. 14 days later, she was due for her first ART follow-up consultation. After another one-day walk, she did not directly go to the health centre, but attended a funeral and visited her aunt who was critically ill. As the funeral lasted until late, Pfuma came to the health centre only the next morning, one day after her appointment date. The nurse told her that her delay was not acceptable. She was informed that the ART initiation outreach team would only come two weeks later. Pfuma gave up and has been on CTX prophylaxis at the health centre since. She said it is troubling her and she wishes she had the means to restart ART. She said her parents, her sister and her aunt's daughter keep reminding her she should get treatment, but she cannot afford the travelling. She said tracing was a good thing since "having someone to talk to in such situations would be very helpful." [interview with Pfuma]

### **Runako, the teenage orphan**

Swiss doctors have been working at the hospital since it was founded by missionaries in the 1940ies. Runako's mother worked as a housemaid in one of the doctor's houses for 23 years. She was married and had five children. In 2004, she became ill. The Swiss doctors encouraged her to test HIV. She and her husband tested positive. At the time, no ART was available at the hospital. In Harare, the drugs were too expensive. Her husband left her and did not want to take the children with him. The housemaid knew she would die. She proposed to the Swiss doctor to employ her husband's sister in her stead, and she asked the sister-in-law to look after Runako and her brothers.

Today, Runako was a 19-year old teenager. She was eleven when her mother died. After mother's death, Runako's father took the children to live with his new family in the neighbour district. She came regularly to the hospital to collect money from the Swiss doctor to pay for her school fees. Runako was not happy at her father's home. After his

death, 14-year old Runako and her four young brothers were taken to live with their aunt in the mission. At the age of 17, Runako fell ill, and she was started on ART. Yet, she did not take the drugs. Instead, she started asking why she was infected with HIV and her brothers were not. Her aunt did not realize that Runako was not taking the drugs, as she explains in the following interview section:

*When she was in form four, she started saying how did I get sick when I am the eldest and my younger siblings are not infected? We told her we do not know. All along we thought she was taking her pills but she was not. (...) The nurses said I am the one who has the problem and I said how come? I told the doctor that the patient was not taking pills and that the nurses were accusing me. (...) I do not have any fault because I'm bringing her to the hospital. So I continued to go with her to the hospital until she started going back on ART. [interview with Runako's aunt]*

The finger pointing on Runako's aunt by the health workers shows the moral responsibility of Runako's aunt to look after her brother's children. From Runako's point of view, the question "why me?" prevailed. At times, Runako would deny she was positive or she would claim that they must all be tested again to prove that it was only her being positive. Runako probably dropped ART and lied to her and the nurses because she was in denial about her status. It appears that during adolescence, Runako found a way to cope with the "why me" question, and this helped her stay on ART, as the following quote suggests:

*I would tell them that we are not the one who looked for the virus, it just came to us and it was not our fault. So we just have to keep taking drugs because that is how we keep alive .[interview with Runako, 19, ART patient]*

### **Simbisai, the rebel orphan**

The interview with Simbisai took place at the health centre, where she was re-initiated on ART only a week before the interview. She was coughing and looked wasted and ill. Simbisai was 18 years old, she lost her mother when she was eleven. Her father was on ART and visited her regularly. She thought that she was either infected at birth or when caring for her mother who was dying. After her mother's death, she and two of her six siblings lived with her grandmother. Only a few months after the death of her mother, in February 2006, twelve year old Simbisai became ill. She was admitted at the hospital and tested HIV-positive. Her health remained feeble, and two years later

Tuberculosis broke out. She was treated and initiated on ART. After completing tuberculosis treatment, she felt strong and she desperately wanted to go and live with her sister in Harare, as she explained in the following interview section:

*I just left them [the ART drugs] when I was called to Harare. I told myself that I had recovered and there was no need to continue taking the drugs. I even told my grandmother that I had finished taking the drugs so that I would be allowed to go to Harare. My grandmother eventually allowed me to go because I was persistent about going and I would actually cry over it until she allowed me to go. (...) I had finished ticking my card and so I told them that I was going to Harare. [interview with Simbisai, ART patient]*

So Simbisai stopped ART and went to Harare where she worked as a housemaid at her older sister's family's home. In the meantime, Simbisai had appeared on the list for ART patients to be traced at hospital A. CHASA Kutenda was sent to Simbisai's grandmother's home where he found Simbisai's brother. He then called Simbisai in Harare and encouraged her to return home and to get back on HIV care. Simbisai refused and said, she would come back only when she falls ill. It did not take long until she did become ill. Her sister – a member of the apostolic church – told Simbisai she would be bewitched when she returned home. Instead, she took Simbisai to a "prophet" who came to her sisters' home to sprinkle holy water for Simbisai's healing. Simbisai's health deteriorated, and eventually when the girl was seriously ill, her sister sent her back to her grandmother's. The first part of Simbisai's story is about an adolescent dropping out of HIV care after moving away from her care giver, the grandmother. The case of Simbisai shows the important role grandmothers play as care givers in a society where many children lost their parents due to HIV/ AIDS. The case also shows the vulnerability of adolescents on ART, especially if they move away from their supporting environment. Simbisai insisted to move to Harare, and nobody could change her mind. Neither did the health system ensure a formal referral of Simbisai to a clinic in Harare, nor did her new care giver, her sister, provide any adherence support.

Back at her grandmother's home, the misery continued. Simbisai went to the hospital and was prescribed tuberculosis treatment again. For unknown reasons, Simbisai was put on tuberculosis treatment at the hospital, but referred to the health centre for ART initiation, which was the nearest facility from her grandmother's home. Only there and half a year after her return from Harare, the nurse realized that Simbisai's tuberculosis was not cured and she was still not on ART. Only a week before the interview, Simbisai was identified and re-initiated on ART thanks to the newly introduced tracing programme. The second part of Simbisai's story is a striking example how re-

integration of a patient in HIV care can be delayed due to failed referrals between the tuberculosis and ART programme, and between the hospital and the health centre.

### **Tomupeishe, the wealthy housewife**

We interviewed Tomupeishe at her home in the district's main town, where she lived with her husband, who was the headmaster of the local primary school, and also on ART. The couple was educated and relatively wealthy with three children in the age of 18, 13 and 3 who were all HIV negative. Tomupeishe and her husband tested HIV and started ART together back in 2005. In their history of ART, the two had always supported each other to adhere to pills and appointments. It was in 2007 when her husband's brother died and they attended the funeral a few hundred kilometres away from home. As they stayed with their relatives longer than planned, they returned home one week too late for their ART appointment. The one-week delay lengthened into a treatment interruption of seven months. The following section of the interview shows the couple's fear to return to the ART clinic after having "defaulted":

*Tomupeishe: It so happened that we were due for ART supply whilst we were still away and so we missed our appointments. (...) We defaulted by seven months because I did not know what to say because those who were dispensing the drugs were strict about dates.*

*Interviewer: Do you think they would not have given you the drugs, what do you mean by "strict"?*

*Tomupeishe: Maybe we just thought so, but when you are working with people you know their attitudes and a small thing like that turns out to be a big issue.*

*Interviewer: Had you ever seen them shouting at other people who missed appointments or had you experienced it yourself?*

*Tomupeishe: I was shouted at and told that we are not giving you any drugs. I was then assisted by another nurse. I was told that we want people who meet their appointments, I don't know if the nurse who attended me would have held on to his word that I would not have been given any drugs. [interview with Tomupeishe, ART patient]*

Tomupeise and her husband interrupted ART for more than half a year simply because they feared repercussions by health personnel for having missed their appointment. It is remarkable that it was a wealthy and well educated couple who decided not to return to HIV care due to their fear of being insulted. Her husband underlined that apart from

the harsh remarks by a nurse to his wife, they had never experienced troubles at the ART clinic. Yet, they were overwhelmed by shame, as the following quote from the interview with Tomupeishe's husband shows:

*It's generally known that most people in the nursing profession are rude to clients. However, we had never experienced that in ART, we were being treated well (...) and they told us that ARVs are life-long. We were just overwhelmed by fear and I feel embarrassed by that as an educated person, how could how I have done that after being told that ARVs are life-long? [interview with Tomupeishe's husband, ART patient]*