UNIVERSIDADE DE LISBOA
Instituto de Ciências Sociais

Unfit bodies:
HIV, care and politics of survival among young people in Maputo

Francesca Cancelliere

Orientadora: Doutora Cristiana Lage David Bastos
Coorientador: Doutor Francesco Vacchiano

Tese especialmente elaborada para obtenção do grau de Doutor em Antropologia, especialidade em Antropologia da Saúde.

2023

Unfit bodies

UNIVERSIDADE DE LISBOA
Instituto de Ciência Sociais

Unfit bodies:
HIV, care and politics of survival among young people in Maputo

Francesca Cancelliere

Orientadora: Doutora Cristiana Lage David Bastos
Coorientador: Doutor Francesco Vacchiano

Tese especialmente elaborada para obtenção do grau de Doutor em Antropologia, especialidade em Antropologia da Saúde.

Júri:
Presidente: Doutora Ângela Maria Barreto Xavier, Investigadora Principal com Habilitação e Presidente do Conselho Científico do Instituto de Ciências Sociais da Universidade de Lisboa.

Vogais:
- Doutora Simona Taliani, *Professori Associati, Dipartimento di Scienze Umane e Sociali, Università L'Orientale di Napoli*, Itália;
- Doutor Luiz Henrique Passador, Professor Adjunto, Departamento de Políticas Públicas e Saúde Coletiva, Universidade Federal de São Paulo, Brasil;
- Doutora Carla Marília Teófilo Braga, Professora Associada, Departamento de Arqueologia e Antropologia, Universidade Eduardo Mondlane, Moçambique;
- Doutora Giulia Cavallo, Professora Auxiliar Convidada, Departamento de Antropologia, Instituto Superior de Ciências Sociais e Políticas da Universidade de Lisboa;
- Doutora Cristiana Lage David Bastos, Investigadora Coordenadora do Instituto de Ciências Sociais da Universidade de Lisboa (orientadora).

Esta investigação foi realizada com o apoio institucional da Fundação para a Ciência e Tecnologia, através da concessão de uma bolsa de doutoramento (SFRH/BD/115356/2016), com a duração de 36 meses.

2023

Unfit bodies

To the members of the *grupinho*

Unfit bodies

Acknowledgements

This work would not have been possible without the support, affection and time dedicated to me by many people I had the opportunity to meet. My sincerest thanks go to all the young people I met and accompanied during the years in Maputo. Thank you to them and their families for allowing me to enter their lives and share moments of joy and suffering together. This work is for you, it is dedicated to you and for those who are no longer with us to honour their memory.

The fieldwork can be a lonely journey, but mine was made up of precious encounters and support. Special thanks go to Irma Rute and Irma Leonir for receiving me at the daily centre, allowing me to take my first steps in the field and always offering support and hospitality. Thanks also to all the technicians of the Clinic team who gave me valuable time and thought. In particular, thanks to Teresa and Ernesto for receiving me in their daily work.

My most sincere gratitude goes to Carla Braga and the Department of Anthropology at the Eduardo Mondlane University in Maputo, for welcoming, supporting and guiding me. Thanks also to Massimiliano Sani for allowing me to understand the complexity of the world of humanitarian aid without losing his enthusiasm.

Special thanks go to Lara, Isabel, Camilo and Cacilda for opening the doors of their home to me and allowing me to have a place in Maputo that I can still call home. Special thanks go to Joana Borges for never making me feel alone during all the difficulties the field had brought. Thanks also to João Morgado, without whom this project would not have started. To Amanda, Joana, Michela, Valeria, Chiara, Alberto, Rosa, Tania, Ruben and Rita and all the friends who accompanied me on this Mozambican journey.

This work has benefited from a grant from the FCT - *Fundação para a Ciência e a Tecnologia* as well as from the support of my host institution the ICS - Institute of Social Sciences. Inside the host institution, I would like to thank the staff of the ICS, especially Dra Maria Goretti, and the members of the *Serviço de Gestão Académica*, who have been patient and supportive from the beginning. My sincere and profound thanks go to my tutors Cristiana Bastos and Francesco Vacchiano for their support, generosity and encouragement. Discussing with them was invaluable and fundamental during the fieldwork and writing process. Besides my tutors, my greatest thanks go to Maria Concetta Lo Bosco, for her friendship, for listening, understanding and guiding me with a patience and dedication that allowed me, personally and professionally, to grow and reflect.

Deep gratitude also goes to João Vasconcelos, Giulia Cavallo, Paulo Granjo, Irene Rodrigues, Nuno Domingos, Simone Frangella, Chiara Pussetti , Ricardo Roque and Patricia Hilario for their comments and questions that allowed me to reflect and write with greater depth.

Special thanks go to my PhD colleagues: Elisio Jossias, Francesca de Luca, Inês Galvão, Giorgio Gristina, Rita Kantu, Madalena Rolim Patricia, Murilo Guimarães, for their support, suggestions and encouragement.

Special thanks go to Simona Taliani and Roberto Beneduce for opening the path to medical anthropology and continuing to accompany me with their reflections and kindness.

This journey would not have been possible without the support of many people, but in particular endless thanks to my parents, Chiara and Giorgio for their support and patience over these long years and for always believing in me and in my trajectory. Thanks to João Picão for his love and patience. Finally, thanks to my friends who have always supported me Chiara, Amanda, Valerio, Andrea, Ines, Margherita, Maria, Roberto, Daniele, Turi, Teo, Lapo, Giulia and Rocco.

Abstract

With my research project, I aim to investigate the politics of care and adherence in the biomedical setting related to antiretroviral therapy and how they have affected young people living with HIV. My goal during fieldwork, and the purpose of this work, is to adopt a political dimension in the study of AIDS (Fassin et al. 2007). In other words, to try to maintain two attentive gazes – one on history at work on the global level and another on history as lived in the local space; to observe and analyse the state policies and the politics of subjects (Fassin et al. 2007). I sought to explore the everyday lives of young people between eleven and twenty years old who contracted the virus through mother-to-child transmission (vertical transmission) and who manifest difficulties in complying with treatment.

My understanding of patients' life histories, their interactions with the policies of care and theirs experiences with regards to illness episodes allow me to generate associations between the clinical and the social course of the disease, including such themes as health-seeking behaviour, adherence to therapy and agency.

My aim is to explore how care is provided in Mozambique and specifically how adherence to antiretroviral treatment is affected by the social context in which young people live. I address, in particular, the ways in which families understand and negotiate medical services and adherence politics and how emotions come into play during the care process.

Keywords: HIV/AIDS, global health, Mozambique, vertical transmission, care

Resumo

Com o meu projeto de tese, procuro investigar as políticas de cuidados e aderência a terapia antirretroviral no contexto biomédico e como estas afetam os jovens que vivem com o vírus do HIV na cidade de Maputo, em Moçambique. O meu objetivo durante o trabalho de campo, e o objetivo deste trabalho, é adotar uma dimensão política no estudo da SIDA (Fassin et al. 2007). Por outras palavras, tentar manter dois olhares distintos - um sobre a história a nível global e outro sobre a história vivida no espaço local, observando e analisando as políticas de estado e as políticas dos sujeitos (Fassin et al. 2007).

Procuro explorar a forma como os cuidados são prestados e especificamente como a adesão ao tratamento antirretroviral é influenciada pelo contexto social em que os jovens vivem. Abordo, em particular, as formas das famílias compreender e negociar os serviços médicos e as políticas de aderência e como as emoções entram em jogo durante o processo de prestação de cuidados. A tese visa contribuir para o conhecimento antropológico sobre questões relacionadas com cura, seropositividade e políticas publicas em contextos sócio económicos desfavorecidos centrando-se nos casos etnográficos para uma visão que destaca a necessidade de uma atenção maior aos cuidados multidimensional para as pessoas seropositivas.

Através do trabalho de campo - que ocorreu em Maputo, capital de Moçambique, entre outubro de 2016 e fevereiro de 2018 - procuro explorar a vida quotidiana dos jovens entre os onze e os vinte anos de idade que contactaram o vírus através da transmissão de mãe para filho (transmissão vertical) e que manifestam dificuldades em cumprir o tratamento.

Durante o campo, participei em atividades de um centro de dia para pessoas em situação socioeconómica desfavorecida, tendo a oportunidade de acompanhar as atividades de apoio psicossocial e conhecer os jovens participantes na investigação. Lentamente, o campo tornou-se itinerante incluindo outros lugares de investigação como centros de saúde e hospitais. Paralelamente, mantive um olhar nas políticas publicas e realizei uma parte da pesquisa em instituições e ONG que trabalham com questões relacionadas com o HIV/SIDA.

Esta tese encontra-se estruturada em uma introdução, seis capítulos e uma conclusão. No primeiro capítulo vou explorar os desafios enfrentados nos aspetos metodológicos durante o trabalho de campo. A chegada ao campo, os seu tempos dilatados e os primeiros encontros, levaram-me a uma lenta mas constante reformulação e reflexão de possíveis métodos e ferramentas a implementar.

No segundo capítulo, o meu objetivo é mostrar como a narrativa global em torno da SIDA, e as principais campanhas propostas pelos atores globais, apresentam tensões com as respostas à pandemia em contextos locais. Além disso, ao mostrar alguns cenários que tive a oportunidade de observar na Conferência Internacional da SIDA (IAC) em 2018 em Amesterdão, este capítulo serve de enquadramento para os capítulos seguintes, que ilustrarão mais especificamente os desafios no terreno na implementação dos objetivos propostos pela saúde global.

No terceiro capítulo, irei traçar a história do sector da saúde em Moçambique para melhor compreender as «intervenções para o combate a HIV/SIDA». O principal objetivo deste capítulo é fornecer o contexto histórico para melhor localizar as *práticas de saúde e da cura*, tendo em consideração que os legados coloniais e pós-coloniais aparecem no quotidiano dos centros de saúde na perspetiva dos profissionais de saúde e dos pacientes.

O quarto capítulo introduz a *multiplicidade de cuidados* e políticas da saúde no contexto moçambicano atual. Vou explorar de que forma os cuidados de saúde são prestados nos centros públicos e destacarei algumas das dificuldades estruturais que os profissionais de saúde e os jovens pacientes enfrentam diariamente.

O quinto capítulo analisa a ligação entre cuidados de saúde e emoções. Após uma breve descrição de uma clínica coordenada por uma ONG internacional especializada em doentes infetados pelo vírus do HIV com complicações, refletirei sobre a forma como as questões humanitárias lidam com a sobrevivência e a morte na «emergência crónica da HIV/SIDA».

O último capítulo mostra mais uma história em que são delineadas zonas de abandono social e em que as pessoas vulneráveis permanecem presas, deixando pouca esperança de adesão e estratégias de sobrevivência. Através da história de Joana mostrarei como diferentes modelos de cuidados e tratamentos se sobrepõem, criando uma perigosa articulação entre a violência experimentada na esfera familiar (e espiritual) e a praticada pelos cuidados médicos.

Palavras-chave: HIV/SIDA, saúde global, Moçambique, transmissão vertical, cuidados de saúde

Index

List of pictures

List of tables

List of abbreviations

ART - Anti-Retroviral Treatment
CCS - Centro de Colaboração em Saúde
CPR - Cardio Pulmonary Reanimation
DSCM - Maputo City Health Direction
DFID – Department for International Development
FRELIMO - *Frente de Libertação de Moçambique* (Liberation Front of Mozambique)
GDP – gross domestic product
GFATM - Global Fund to Fight AIDS, Tuberculosis and Malaria
GFF -Global Financing Facility
HAART - Highly Active Anti-Retroviral Therapy
IMF - International Monetary Fund
INSIDA - Inquérito Nacional de Prevalência, Riscos Comportamentais e Informação
MSM - Men having Sex with Men
MSF - *Medicos sem fronteiras* (Doctors without Borders)
MoH - Ministry of Health
NGO - Non-Governmental Organization
PEPFAR - President’s Emergency Plan for AIDS Relief (US)
PSI - Population Service International
PTV - Vertical Transmission Prevention
RENAMO - *Resistência Nacional Moçambicana* (Mozambican National Resistance)
SAAJ - *Serviço Amigavel para Adolescentes e Jovens* (Youth Friendly Service)
SAP - Structural adjustment programs
SRH - Sexual Reproductive Health
UNAIDS – Joint United Nations Programme on HIV/AIDS
UNICEF – United Nations International Children's Emergency Fund
UNFPA - United Nations Population Fund
USAID - American Agency for International Development

VL -Viral Load

WHO - World Health Organization

Introduction

Setting the scene

My interest in HIV/AIDS studies began during my psychology training with migrant patients at the Frantz Fanon Centre in Turin. During my internship, I mainly attended patients from Nigeria, among them a young woman who had been a victim of trafficking and was affected by the HIV virus. I remember that listening to the clinical interviews with Carla, a fictitious name, was a decisive moment from where I understood the great difficulties that these patients face. From a theoretical perspective, the challenge was to maintain the dialogue around the therapeutic relationship, at the same time ensuring it was linked to anthropological and ethnographic knowledge in order to be able to create a place of care. However, it was Carla's experience in particular that led me reflect about Africa, in this case Nigeria, the relationship with sorcerers and *Mami Wata* (Mother of Water Spirit), and the migration process that took her to the Italian streets. It was here that Carla was brought, with the illusion of a better future, to become a sex slave. Finding the courage to escape from the trafficking circuit, Carla entered sheltered housing and arrived at the Fanon Centre on the recommendation of a Psychiatric Service for Diagnosis and Treatment (SPDC) following a compulsory health treatment (TSO). This treatment occurred due to an episode in which she stood on a brick praying all night and which was diagnosed as an «acute psychotic episode».

I accompanied her for a long period of time, as a young trainee she used to call me «the little one» with a sweetness that reminded me of a mother's sweetness. Her seropositivity was one of the countless challenges she had to face. Diagnosis and treatment were difficult to explain in interviews, characterised by a fundamental lack of consensus, as if we were talking on two parallel registers. Years later, when I was in Mozambique, I remember receiving news of Carla: she refused to take her medication which eventually resulted in her death.

It was one of the first instances where I realised the challenges faced when dealing with patients with different models of care and illness. This encounter brought me closer to anthropology and, later on in 2011, as part of my master's degree in Psychology, I carried out research on the juvenile perception of HIV/AIDS in the city of Namaacha, Mozambique.

Since I was interested in the subject, Simona Taliani, my tutor at the time, advised me to read Paul Farmer, and the reflections in his work «Infections and inequalities: The modern plagues» has always accompanied me during my journeys (Farmer 1999). I soon realised that the world that revolved around AIDS was much wider than Paul Farmer's writings and that «inequalities» were materialising in front of me every day in Mozambique with a brutality for which, I realize years later, I was not prepared. This first stage of research led to a master's thesis in psychology entitled «Border stories: young people and AIDS in the city of Namaacha». Here I was hosted by an activist of an association of people living with HIV and her family. The encounter with them was central to the research, but in particular was central to my personal growth: not without misunderstandings and conflicts, over the years, a close emotional bond was created and it is they upon whom I still rely when I am in the country (Cancelliere 2015).

On returning to Mozambique a year later, I learned the news that many of the people I had met had lost their lives as a consequence of AIDS. Very naively, but deeply saddened by their deaths, I asked myself how it was possible that young people were still dying of AIDS. I also wondered why I had not been informed about these deaths and this theme will re-emerge in this dissertation.

Subsequently, I have returned to Mozambique several times, always with different projects linked to the world of NGOs. This world allowed me to make numerous contacts and acquaintances through work and friendships that proved fundamental for the development of my doctoral research. In 2015 I started a PhD in anthropology at the Institute of Social Science at University of Lisbon and between 2016 and 2018 I conducted 15 months of ethnographic fieldwork in Maputo, the capital of Mozambique.[1]

With my research project, I aimed to investigate the politics of care and adherence in the biomedical setting related to antiretroviral therapy and how they have affected young people living with HIV. My goal during fieldwork, and the purpose of this work, is to adopt a political dimension in the study of AIDS (Fassin et al. 2007). In other words, to try to maintain two attentive gazes – one on history at work on the global level and another on history as lived in the

---

[1] The research project received funding from FCT (Science and Technology Foundation of Portugal) doctoral program at the Institute of Social Sciences of the University of Lisbon (ref. SFRH/BD/115356/2016) and received the approval of the Bioethical Committee of the Ministry of Health in Mozambique (ref. 1999/ CNBS/17).

local space; to observe and analyse the state policies and the politics of subjects (Fassin et al. 2007). Some of the questions guiding my ethnographic investigation include:

How is care provided in the Mozambican context? How does the social support system influence the adherence to treatment? How do young people deal with a social and family environment lacking in support and emotional resources? How do they understand and negotiate medical services and adherence politics? What are the perspectives of surviving and dying? How do emotions come into play during the care process?

Starting with these premises, I sought to explore the everyday lives of young people between eleven and twenty years old who contacted the virus through mother-to-child transmission (vertical transmission) and who manifest difficulties in complying with treatment. This age range partly breaks out of the childhood/adolescence parameters and conventions with which prevalence rate data is often displayed for understanding the development of the epidemic, which is between children - considered up to 14 years - and adults - 15 years and older. Neither categorisation is of any use for this work, as I believe that this age grouping presents particular difficulties related to seropositivity, which I will show in the course of this work.

AIDS as an object of inquiry in anthropology

Since the 2000s, anthropological studies on HIV/AIDS in sub-Saharan Africa have taken an increasingly broad focus (Dilger 2010). The anthropological literature has tended to focus on studies concerning specific risk groups and issues related to the prevention of virus transmission. Later, research began to focus on the ways in which HIV/AIDS took on meaning in specific cultural contexts and how these changed with the presence of the virus (Dilger 2010). Other authors have instead focused on how the epidemic and its spread in specific regions of the world was correlated with certain political, economic, social and historical factors (Farmer 1990, Farmer 1999; Schoepf 2001).

The vast literature on AIDS and its dynamics reminds us that dealing with it today remains a subject of great interest for medical anthropology, since it provides the opportunity for reflection on the dynamics which go beyond the biological and are inscribed in the social, economic and political for the understanding of the disease.

The starting point that I believe is useful to take into account when reading this work is the experience of illness as understood by Arthur Kleinman (1978). Medical anthropology has always been characterised by the intention of investigating the process through which biological, political, economic and socio-cultural phenomena determine each other (Quaranta 2006). If biomedicine until the 1970s had represented the lens through which anthropologists looked at «other» medicines (Evans-Pritchard, [1937] 2002; Lévi-Strauss [1958] 1966; Rivers 1924; Turner [1967] 1976), with the Harvard school, biomedicine emerges in terms of a specific cultural system. It is here that Kleinman and collaborators propose to consider biomedical categories as cultural categories through which a particular interpretation of illness is constituted (Kleinman et al., 1978).

From this viewpoint, the distinction between «disease» and «illness» (Kleinman et al., 1978), and later on «sickness» emerges. Disease refers to alterations in the functioning and structure of the organism and illness refers to the meaning that the experience of suffering takes on for those who experience it personally. These statements would represent different explanatory models which can be found in particular in scientific language (disease) and in the family and social context (illness) (Kleinman et al. 1978). Furthermore, by sickness, Young means the process by which behavioural and biological signs, particularly those originating in pathology, are invested with socially recognisable meanings: it is a process for the socialisation of pathology (disease) and the experience of illness (illness) (Young 1975).

I believe the issue is more complex than this – for example the same doctor or the same patient may present different explanatory models depending on the contexts in which they find themselves and the positions they hold – but what is helpful to think about in relation to AIDS is that for too long the experiences of patients have been side-lined in favour of a biomedical treatment centred around taking antiretrovirals.

When the ethnographic observation enters the HIV/AIDS clinics of health centres in Maputo, it is noticeable that, because of the different explanatory models used, the doctor-patient interaction is often a source of misunderstandings that may lead to what is defined as «non-adherence», understood as the non-adherence of patients to the therapies indicated by their doctors.

According to some authors, patient misunderstanding of medical communication is one of the main causes of non-adherence. However in my interpretation, understanding the experience of HIV-positive people and the difficulty of adherence to antiretroviral treatment cannot be resolved and understood solely by distinguishing explanatory models. It is certainly important to understand the experience of illness, but in order to do so the investigation and reflection must go beyond the doctor/patient dyad to become part of the context of social suffering in which patients, families and health care workers find themselves implementing this «performance».

The suffering experienced by young people hospitalised for the terminal stages of AIDS has often led me to think about the social, political and economic inscriptions present in their bodies and in their experience of illness.[2] In this spirit, Paul Farmer speaks of structural violence, as that particular form of violence that does not require the action of a subject to be carried out, insofar as it is characterised by its processual and indirect nature (Farmer 1999).

Within this perspective we can conceive AIDS as a social process which is inscribed in individual events principally through the limitations exercised on their capacity for action. According to Farmer, one can grasp the intertwining of individual experience and the forces of social exclusion in an extreme synthesis: structural violence becomes pathological mainly by limiting the subjects' capacity for action (Farmer 1999). In this case, the young patients in the final stages of the illness are united by living on the margins of profoundly unequal social organisations, without the possibility of being able to negotiate the terms of their existence (Quaranta 2006).

An Ethnographic Perspective of the Study of AIDS

My fieldwork occurred in Maputo, the capital of Mozambique, between October 2016 and February 2018. Bearing in mind that the field was not completely new to me, from Portugal I had already made contact with a *daily centre*, run by a religious congregation, for people in a socio-economically disadvantaged situation. This *daily centre* was crucial in getting to know the young participants involved in the research. I began to be included in the centre's activities and in

---

[2] I am referring also to the embodiment paradigm: a paradigm that aims to combine a phenomenological perspective – attentive to the subjectivity and experience of social actors – with an economic-political approach that aims to grasp the action of the broader macrosocial. In the words of Csordas (1990) it is necessary to grasp the relationships that socio-cultural phenomena have with, and on, corporeality.

particular in psycho-social support under the supervision of the psychologist in charge. Slowly, the field became itinerant. I rarely spent more than half a day at the *daily centre* and began to spend time with the participants at health centres they attended, in hospitals during long hospital stays, on the way home and in other daily activities that they considered important. These were all precious moments that gave me a better understanding of how their lives were structured and difficulties were faced. In parallel, I carried out research within institutions working on HIV/AIDS issues, conducting interviews and participating in meetings with NGOs and donors.

Extended case studies and participant observation - often over many years, sometimes even over generations - may establish a privileged viewpoint for the study of AIDS nonetheless the ethnographic approach also contains problems (Colson 2010). Long-term ethnographic work raises a number of ethical questions when asked to stop and reflect on how the disease has changed social realities and communities (Mogensen 2010). How ethical is it to engage in long-term research and academic debates when some of the participant are in last stages of AIDS? How much time we have, and for witch purpose?

According to Dilger (2010) and Farmer (1992), dealing with ethical dilemmas in the field, particularly when field is strongly shaped by situations of chronic illness and death, has a lot to do with the subjectivity of the researcher (Dilger 2010; Farmer 1992). This aspect is also difficult if we think about positionality as a choice between collaborating with aid organisation and agencies or by «simply» accepting to be a «witness» to the suffering in the communities one works with (Farmer 1992). Dilger argues that:

> Approaching fieldwork through ethnography, with its holistic focus and its long-term approach, may play an important role to analyse the various perspectives, practices and power relations that have come to shape the views, actions and experiences of a broad range of actors in global, national and local settings with regard to HIV/AIDS. Individual and collective experiences and actions, in particular in the HIV/AIDS context are best described through the presentation of extended ethnographic case studies in a specific locality (Dilger 2010,7)

Structure of the work

The first chapter of this thesis is dedicated to the challenges faced from a methodological perspective during the field work. The arrival in the field, its extended timeframe and the first encounters, led me to a slow but constant reformulation and reflection of possible methods and tools to implement.

The first part of the chapter addresses the challenges encountered in relation to positionality in the field. I will show how «dancing» between the role of anthropologist and psychologist, with the possibility of maintaining a double gaze in the field, has advantages and disadvantages. Moreover, working with young people with HIV, often in the terminal stages of the illness, presents numerous difficulties from an emotional and relational perspective and an inability to maintain any position of detachment.

The second part of the chapter is a reflection and reformulation of a methodology focused mainly on young people and its possible co-creation and participation in the research. I will present how the creation of a support group and the use of visual techniques, such as photovoice and bodymapping, allowed me to get in touch with aspects of their emotional lives that were hardly accessible. Although it is a methodological reflection, this first chapter will present ethnographic data that will then be discussed in the following chapters.

Through the second chapter my aim is to show how the global narrative around AIDS, and the main campaigns proposed by the global actors, present tensions with the responses to the pandemic in local contexts. In addition at showing some scenarios that I had the opportunity to observe while attending the International AIDS Conference (IAC) in 2018 in Amsterdam, this chapter serves as a frame for the following chapters, which will illustrated more specifically the challenges in the field in the implementation of the goals proposed by global health.

I will investigate how, there is a political and scientific discourse in which the biomedical approach to interventions continues to dominate over the multidimensional one and the voice of experts for the implementation of campaigns prevails over the one of the young «beneficiaries» of the projects. In conclusion, two aspects called my attention: the rhetoric used to talk about AIDS-related deaths in the global health arena and the concerns of implementing a specific campaign, known as «treatment as prevention».

In the third chapter, I will trace the history of Mozambique's health sector. The main purpose of this chapter is to provide an historical background to better locate health practices, where colonial and national building legacies have emerged in the day to day live within health centres from the perspective of health workers and patients. The «AIDS interventions» have to be situated in the long history of which they are part, the history of public health and epidemics, of the health care systems and its professionals. In the first part of the chapter I'll analyse the long-term health policies during colonial rule, which have been used to justify spatial segregation and exploitation of the labour force, linking infectious diseases, such as syphilis, to African sexual promiscuity. In the second part of the chapter I'll analyse health policies after independence. The dream of Samora Machel, about *free health for all,* supported by large agencies such as the WHO, was aborted because of civil war, infrastructural limitations and a corrupt system. In addition I will show how the politics of austerity implemented in the country by the World Bank and the IMF during 1980s, created struggles in managing the multiplicity in the health sector and how this has had an impact on health centres.

In the last section of the chapter I will examine the HIV/AIDS policies in Africa and in Mozambique, tracing the process that, since the introduction of HAART in 2000, has made survival possible for people with HIV. I analyse in particular the so-called «test and treat agenda» and the objective of reaching an undetectable viral load. Powerful institutions and programs like PEPFAR, UN agencies, NGOs and the Ministry of Health are based within different ethical frames of action, yielding contradictory messages with overlapping interventions.

The fourth chapter introduces us to the multiplicity of care and policies in the Mozambican context nowadays. I'll present how health care is provided in the public health centre that I'll call *Centro de Saúde*. Through ethnography within health centres and the histories of young people, I will highlight some of the structural difficulties that health workers and young patients face on a daily basis. The social, cultural and economic complexity of the country does not allow for unique interpretation, forcing us to use multiple lenses of analysis.

The chapter will focus, in particular, on the challenges of a young girl living with the virus of HIV who receives late disclosure of her status. This case study points out how information about health and body is central to good treatment adherence and wellbeing. Emilia's everyday challenges of «being positive» reveal physical issues around her body – a body too thin and then too visible to be unnoticed – and her struggle for love.

The fifth chapter analyses care through the politics of emotion in the daily work with young people living with the virus of HIV. After a brief description of the clinic, which I will call *The Clinic* in this thesis, a centre coordinated by an international NGO and specialising in HIV-infected patients with complications, I will reflect on how humanitarian issues deal with survival and death in the so-called «chronic emergency».

In particular through the story of Pedro’s days in the hospital, in the clinic and at home, this chapter analyses the force of the emotions of Pedro and his caregivers and the question of survival. Overall, this chapter reflects on moments of liminality where the workers of *the Clinic* and of the *Daily Centre* made decisions between life and death, chronic and terminal, survival and annihilation.

The last chapter shows one more story in which zones of social abandonment are outlined and in which vulnerable people remain trapped, leaving little hope for adherence and survival strategies. Through Joana’s story I will show how different models of care and treatment often overlap, creating situations of violence both from a familiar and spiritual angle, as well as from the shortcomings of medical facilities. Joana’s body became a battleground of ancestral conflicts and an illustration of medical failure. In the first part of the chapter I will show Joana’s story and how issues of ancestral conflicts and the world of the invisible come into play in the explanation and treatment of AIDS. Furthermore, I will show how the precarious socio-economic situation accompanied by extreme violence within the family context left Joana in a state of abandonment. In the second part of the chapter I will show the challenges within the hospital context and how the language used by health workers often clashes with the explanation of the disease related to the world of the invisible of which many of the families I met are a part.

Chapter I

Positionality, emotions and methodological dilemmas during fieldwork

Positionality in the field

During the fieldwork I often found myself having to stop and reflect on what I was doing, and how I was doing it. Working in the context of vulnerability and suffering, particularly with young people, meant that I often had to rethink my role and methodology. This is why, in this thesis, I decided to dedicate a specific chapter to the methodological issues that arose (Cancelliere 2019). I believe that my profession and background have allowed me to hold a particular position in the field. Besides being a researcher, I am a psychologist, something that helped me initially to gain the confidence of gatekeepers.

However, my dual perspectives also posed the risk that my role as researcher could be confused or misunderstood by participants. I started my fieldwork by contacting a centre working with people living with the HIV virus. At first, when reflecting on how to participate in the daily centre's activities, it was difficult to define my role: on the one hand, I felt the impossibility of being a neutral observer, but also a certain difficulty in being included in activities as a psychologist.

Also if anthropological literature helped me to think about the tension and positionality of the ethnographer (Bourdieu 2003; Geertz 1974; Borneman and Hammoudi 2009; Crapanzano 1980), I actually realized that, day by day, I was becoming more and more involved, in ways that were very different to the one I had imagined. As I had expected, I was asked by the psychologist in charge, to take on some of the cases of the young people in the daily centre. As I was comfortable with these requests I continually questioned myself whether it was the «right» way to stay in the field and how to become genuinely immersed in the field.

However, as this was a multi-situated research, or rather one that has been carried out in different urban contexts – health centres, NGOs, day centres, and within families – I soon realised that the representations that the people I met in the field had of me were various. I think it is always necessary to ask ourselves what we are representing and what resources we can provide for the people we meet and interact with during the fieldwork, particularly in contexts of extreme poverty, where the privileged position of the white researcher is evident.

While always presenting myself in a very transparent way from the beginning – a researcher in anthropology but also as a psychologist by training – the different contexts and different relationships led people to «categorise» me as an anthropologist (rarely), researcher, expat expert or psychologist (doctor). I could rarely renegotiate this idea, and sometimes the given category was useful for the path of understanding in the field. As an example, during one of the first meetings in the health centre, the nurse on duty immediately sent me to meet a teenager girl to obtain the disclosure of her HIV status. Embarrassed and uncomfortable for never having participated in such a delicate process, I pushed back, questioning the reason for this and it was explained to me that as a «psychologist doctor» they believed that this ability was something intrinsic to the training I had undertaken.

As Francesca Morra argues, during fieldwork I realised that ethnography was indeed something very personal. It was a praxis, informed by theory, or rather by the practice of other ethnographers, always rooted in the interpersonal experience of the researcher (Morra 2021).

As others ethnographies, also mine, rise from personal dispositions, curiosities, and character. During fieldwork I was surprised on how much I actually reflected on my presence and its consequences. Essentially, the ethnographic field is created by the relationships between observer and observed and the uncertainties, tensions and doubts that inevitably occur when encountering the other (Morra 2021). This process of practice reflectivity, was defined by Michael Jackson (2007) as a particular instance of boundary disruption where the ethnographers loses the normal balance between being open to the world of others while protecting their own sense of self (Jackson 2007).

Ethnographical practice has a cost, and as Georges Devereux argued it, is an emotional one (Devereux 1967) where the researchers are deeply upset by the investigation of other human beings. The author affirmed that the unconscious communication between observer and the observed raises anxiety. The researcher could therefore resort to methodology as a «professional defence», to «decontaminate» the research material by removing its emotional content, but when this is employed as a defence, methodology allows the ethnographer to detach themselves from the emotional resonances raised in the research encounter, by simplifying or intellectually systematising material (Devereux 1967). However removing subjectivity, when investigating human behaviour, could only lead to distortions (Devereux 1967). The presence of the observer produces «disturbances» in the field while, at the same time, the field generates unconscious reactions – in psychoanalytical terms, a countertransference – in the observer (Morra 2021). According to Devereux, a «good methodology» reflect on countertransference and disturbances as a research's crucial data (Devereux 1967).

During my fieldwork I found myself dealing with my own anxieties while I was an active witness of suffering, grief and inequalities. Making ethnography can be very demanding and I tried to study the echoes and the reverberations produced in the encounter, the «disturbances» occurring «within» the observer. The ethical encounter «requires for the ethnographer to be vulnerable, to be reached into. Then, her struggles, inquietudes and failures offer an insight that could not be achieved otherwise» (Morra 2021: 38). According to Jackson (2007) the potential of anthropology lies in shifting from personal to interpersonal, anthropology has the capacity to participate in people's struggles, inquietudes and failures, transforming self-centred reflections into research concerning other lifeworlds, and the stakes of existence (Jackson 2007).

Furthermore, positioning for me also meant understanding how to place myself while working in a cultural context very different from my own and how this challenged the pre-defined and comfortable, I would say ethnocentric, vision from which one normally starts.

By «culture» I do not mean, as the initial approaches claimed, something that defines a specific and closed ethnic group, but as one of the possible reference systems that people can use and through which they implement choices and decisions in relation to other possible reference systems, such as family, religious or scientific (Abu-Lughod 1991; Gupta and Ferguson 1992). I think the reflection around ethnocentrism raised by the Kleinmans is interesting, seen as the difficulty of thinking and valuing the lives of others outside our own categories (Kleinman and Kleinman 1991).

As an anthropology scholar, I was aware of my own ambiguous relation with this attitude. As Sjaak van der Geest pointed out, while I can feel the moral and political danger of ethnocentrism, at the same time I acknowledge that ethnocentrism was part of my culture and that no culture could survive without at least some degree of it (van der Geest 2002). Being able to identify and reflect on one's own limits and positions was part of the process of being able to create a sincere analysis of the important therapeutic paths of others. My own cultural practice, in this context as a biomedical-oriented approach, filtered initially my way of representation and discourse. This did not imply, however, an inability to understand local cultural practices. For instance, while firmly convinced that taking antiretroviral drugs was one important aspect to control the virus, over time I learned to understand and analyse other therapeutic pathways implemented by family and patients and recognised the need for the coexistence of all of them.

Emotions in the field

> One evening, around 10 o'clock, the phone rings and it was Joana. She tells me that she feels a strong pain in the middle of her chest, that she wasn't able to breathe well and asks me what to do. We talk on the phone for a while until her breathing calms down. I wondered if it was an anxiety symptom or a respiratory failure and I advised her to call an ambulance in case this crisis returns. When I hang up the phone I start thinking about what I should do in situations like these. I immediately text to the psychologist in charge of the centre who told me not to worry and that emergency calls were very common. She also explained to me the importance of disconnect from the work while being at home. I don't feel particularly reassured after this phone call but I understand my colleague's point. However, I keep thinking about what stopped me from taking the car in the middle of the night and going to see how she was. Should I have done that? The darkness and suburban neighbourhoods of Maputo, where Joana lived, were not particularly recommendable at night. I felt terribly guilty about this awareness of the privileged situation I was in and terribly worried about Joana. I stayed awake all night listening to the sounds of the street. I thought of going to see her the next morning in the early hours of the day, hoping to find her still alive. (Fieldwork diary, 19th March 2017)

Working with children and adolescents living with the HIV virus elicits a very broad range of emotions. Overall, their verbal, but also and especially bodily ability to tell their stories about living (and dying) with HIV was extremely powerful and touching. Inevitably this aroused emotions and actions that I shared with my interlocutors during the research and in the following years.

Deciding to talk about emotions in my thesis and using them as an *ethnographic lens* to help understand the experience was neither obvious nor calculated. Although I was aware that I was dealing with an emotionally and relationally complex field, I think I only started thinking about it when I was already immersed in the field and therefore imbued with feelings, moods and emotional experiences that I initially struggled to identify and define as an essential part of the research. For this reason, I remember that my writings were initially divided into two, a field diary – personal and full of emotions and reflections – and field notes – which tried to describe in objective form what was happening. This division of the *fields*, as subjective and objective, rational and emotional, was carried out during the first two months of the fieldwork. Over time, separating the two experiences became both impossible and counterproductive. The situations I lived, the relationships I had were totally charged with emotional experiences. After all, the experience we have in the world and the memories of this experience – fieldwork or not – are made up of emotions.

A neutral and detached observer, as proposed by the initial anthropological research, immediately lost all meaning for me. I immediately became part of an «emotional ethnography», in which my «being» was felt and experienced both by me and by my interlocutors. I found comfort in the words of Ruth Behar in her 1996 work «The Vulnerable Observer: Anthropology That Breaks Your Heart», where she argues for the importance of anthropologists to embrace their emotions in the field and discredits the theory that scientific credibility implies a neutral observer (Behar 1996).

Recently, a number of authors have analysed the importance of the researcher's emotions within ethnographic practice and how the interpretation of ethnographic data must also take place through the analysis of the researcher's emotions (Lo Bosco 2021; Morra 2021; Stodulka 2015). [3]

Although I do not wish to go into the details of psychoanalytic and psychotherapeutic theories here, it seems appropriate to mention that the history of the anthropological discipline in this sense is similar to that of psychoanalysis. If classic psychoanalysis has always seen the need for the analyst's presence as neutral – a detached observer one might say – the more modern

---

[3] The sense of urgency felt upon returning from the field on the importance of emotions and the feeling that there is still too little debate in academia on the subject, led me and the then co-coordinator of MAYS (Medical Anthropology Young Schoolars) to organise a conference and subsequently a special issue on the subject (Cancelliere and Probst 2021).

theories – particularly relational ones – see the possibility and importance of analysing the therapist’s emotional reactions and experiences in relation to the patient (the so-called countertransference) in order to better understand the patient’s experiences. Ethnographic practice is, like clinical practice in a certain sense, imbued with relational and therefore also emotional aspects to be analysed as an important insight and reflection source (Devereux 1967).

What frames, however, the work in the context of vulnerability is the reflection around one’s own position of privilege. As Simona Taliani, Paul Farmer and Nancy Sheper-Huges remind us, while working within extremely vulnerable contexts, is impossible not to feel this privilege (Taliani 2006; Farmer 1999; Sheper-Huges 1992). During the meetings with the participants, my feelings of anguish and guilt were persistent. The proximity to the daily violence, illness and occasionally even their deaths made me feel sometimes unable to emotionally control similar experiences. As Maria Concetta Lo Bosco affirmed, considering one's own emotions and relating them to those of the people encountered in the field allows for greater understanding and knowledge of the field itself (Lo Bosco 2018).

Working at the margin: dead and dying

> I feel dizzy. How is this possible? Don’t they say that you are now living a normal life with HIV? So what’s the point of working with people who have no hope? I didn’t want this... I can’t handle this. When I chose to work with young people living with HIV I didn’t think it would go this far... I thought I would work with some hope.
>
> I feel cheated! No-one told me that I’d end up working with the most difficult cases of suffering, the ones that have no chance to survive. Am I working with people already given up for death?
>
> Maybe this suffering, this headache, stomach ache and fever, are not food poisoning I am having, but a sign of extreme emotional fatigue, which I need to listen to and respect. I need to stop (Fieldwork diary, 11th November 2017).

Before leaving for Maputo, it had not been my intention, in this doctoral work, to deal directly with death. Very naively – and perhaps also as a form of defence – I wanted to work with the complexity, the vulnerability of life with HIV but I did not think that this choice would bring me so close to working with death and dying. This is why my thesis work was not initially conceived with this in mind, why I have always partly avoided wanting to analyse this issue and it therefore lacks a profound reflection on the meaning of death. I wanted to focus on life, on its possibilities, which turned out to be impossibilities. The death of young people and adolescents is an occurrence considered unacceptable in our society and the suffering it caused me was explicatory.

During a break in Italy I remember being quite worried about Jose. He was one of the members of the support group, perhaps the quietest at the time. José was 15 years old, mother and fatherless, he lived with his aunt, her husband, grandmother and 4 cousins in a two-room tin house (Picture 1).

Picture 1: photo taken by José for the «*quem sou eu?*» project and exhibited at the day centre. José told me that with this photo called «the door of the house, which has fallen down» he wanted to show what he meant by not having privacy with neighbours.

He had stopped going to school a few months before because of the constant nausea and headaches but also because of the second line of treatment he was taking. It was heavy to take but he was worried that the box of medication he had to carry with him was too bulky for him and that his colleagues might see it (Picture 2). José was very concerned about his privacy, which he felt he did not have at home as he claimed that his aunt was always shouting at him to take his medication, making the neighbours hear. When I met him the second line of treatment was giving little results in decreasing the viral load and José, according to the clinic psychologist, was showing symptoms of depression.

Picture 2: The weekly box of Jose's second-line antiretroviral treatment

On my return from a period in Italy I was met with the news I had feared so much. José had lost his life at the end of July. The first thing I thought was how is it possible that no one from the clinic had notified us? It had been two months since his death and no one had asked where he was? No one had gone to look for him? I spend days wondering how this could have happened, and I was blaming myself (for leaving Mozambique), I blamed the clinic staff, the daily centre staff and José's family. I was looking for someone to blame. I thought about the times we spent together during the support group and how, before we said goodbye, he was finally satisfied to have found a job as a mechanic's assistant and he was feeling independent from his aunt who was taking care of him. What was happening to me, however, frightened me: after an initial moment of shock and searching for the «culprit», I felt cold, impassive, without tears. I never cried over his death, which I did for the deaths that followed. Why?

I asked for help to my co-supervisor, Francesco Vacchiano, which helped me to understand what was happening to me. Was I tuning into the emotional reaction I was feeling around me? It was highly likely that I kept thinking about the aliveness that José's family had to feel with his death. I wonder if I was thinking this because it was actually a relief for me too. Every time we talked about him all the doctors seemed to be ready for this event, the resistance to treatment that his body had been developing for years had forced him to undergo several hospitalisations for tuberculosis and to develop a reluctance to take medication. It was not sadness I felt but anger. And when, after a month, José's aunt came to talk to me, my anger increased, as I reported in my diary:

> José's aunt came to visit me as a surprise at the daily centre, and she came to ask me for money. This is something I was told happens frequently after someone dies because the family no longer has the right to food support for the sick person and has to find another survival strategy. She asked me for money for the funeral. They buried him without any ceremony in the «garden of the hospital» and the main problem is that now his spirit haunts her. She sees his face all the time, dreams about him, sees him in the house. She calls herself the reference figure who took care of him. She never took care of him, to the extent that he died alone in hospital and they buried him in a mass grave.
>
> She told me that José was getting worse and worse in the last few days, he could hardly get out of bed, so she decided to take him to church. She put him on the «chapa» (local transportation) and she went on foot because she didn't have enough money to pay for her too. José fainted in the middle of the road alone and someone, after resuscitating him, took him to church. After praying for him the pastor told her to

> take him to the hospital. She did not take him, did not inform the Clinic and took him home. After two days he got sick and they admitted him to the Machava Hospital (where they admitted him for TB). He died alone after three days, refusing to be given oxygen.
>
> She also told me of the importance of rituals, of caring for the dead and the constant presence of spirits, of the invisible life in the visible, during this conversation I was not able to concentrate on this aspect. All I could think about was that Josè was detached and taken to an evangelical church instead of the hospital. The technicians at the clinic told me that in the situation he was in anyway, not much would have changed, but I can't rest (Fieldwork Diary, 6th January 2018).

In her pioneer work on grief, Nancy Scheper-Hughes showed how sadness has different forms of expression– for example the grief experienced by women that have to deal with the death of a child, and sometimes allowing, even helping, some of their children to die (Scheper-Hughes 1992). Following what Scheper-Hughes found did not conform to the conventional biomedical wisdom concerning «normal» grieving following death, a model of «human» behaviour that is, in part, the creation of a few influential psychologists, among them John Bowlby (1961), Elisabeth Kubler-Ross (1969) , and Robert Jay Lifton (1967) .

The psychologists and psychiatrists of mourning (see Freud 1957, 244-245; Bowlby 1980; Lifton 1967) consider the death of a child and infant death in particular, to be among the most wrenching of all experiences of loss. Bowlby (1980, 113-124) for example, described the phases of normal mourning after the death of a young child as follows: numbness and shock, disbelief, anger, depression, disorganisation, and reorganisation.

I agree with Jónína Einarsdóttir who argues against the universality of the neglect thesis, which holds that mothers in societies with high fertility and high child mortality will respond to that situation with selective neglect of young children, in particular weak or disabled ones, and a lack of mourning when they die. The author argues that cultural values and ethical considerations related to religion and kinship ideologies, as well as gender relations and subsistence are all important factors in shaping reproductive practices and, in turn, maternal affection and dedication (Einarsdóttir 2000).

Indeed, reflecting on the different forms of expressing grief can be helpful in understanding the practices and reactions that accompany death in this context, the issue went beyond the expression of suffering.

I think I was particularly struck by the words of José's aunt because of the different types of violence I felt were directed against him. The first form of violence speaks to us of an unbridgeable institutional void. Families surviving on the food of the sick family member. The desperation of this young aunt also had to do with this: her children, one of whom was still in infancy, no longer had access to food support after José's death. This speaks of the cruelty in which some families live, and of something our minds often try to push away – always to (not) remind us of our privilege – that people go hungry.

The second violence was spiritual. Even after death José's spirit could not rest, it floated in the world of the living, disturbing them and reminding them that something was missing, that a ritual had to be performed and a proper burial was necessary. These practices are not seen as «unnatural, inhuman, or unwomanly but rather as reasonable responses to unreasonable constraints and contingencies» (Scheper-Hughes 1992, 400).

It is highly probable that what annoyed and irritated me about Jose's aunt's reaction had to do with this different way of dealing with grief and the emotions that came with it. Different ways of dealing with grief did not mean that suffering was not present. But why then, in front of all this violence and misery, did I not shed tears? Perhaps I was only beginning to realise that expressions of grief were different from my own?

Once I had returned and started to work on my thesis, in the middle of stress and sadness I confessed to a Mozambican friend and colleague that I was feeling bad because I was writing about someone who had already died, and that the timing of my writing was out of sync compared to the timeline of the disease. She suggest to me, that I hadn't engaged enough in the spiritual way of seeing things and that this was happening because I didn't believe in the afterlife. She suggested that I should think in another way: commemorating and speaking about the spirits of those who had died young, prematurely or violently is a good process, not only because we are remembering those individuals but also because we are prolonging their lives through the memories. It was very important for the local culture that the spirits of these young people are evoked. Was I tuning to a new form of experiencing grief?

How do you deal with deaths during the research field? Is there a «pre-conceived» strategy to start with in order to be prepared? Rethinking about the field, the way of dealing with grief and death is not only cultural but also personal and the subjectivity of the researcher inevitably comes into play. It depends on a whole series of mental and emotional constructions that the researcher as a person has made and experienced during his or her own life. This is to say that it is difficult to equip oneself, to prepare for the field when talking about situations of extreme suffering, what we are called to do is to try to make sense of the experience, translating the emotions experienced into something that can be said and reflected. I hope in this work to be able to show how, through the emotional relationship with the young people I support, their families and health staff have been important entry points for me in understanding the politics of care and adherence around HIV.

Negotiating ethics[4]

The starting point for writing about ethics is the recognition that ethical research should favour the good and avoid harm to research participants (Orb, Eisenhauer and Wynaden, 2000; Young and Barrett 2001). As Young and Barrett (2001) point out, ethical research is based on the principle that participants will not suffer any harm in the outcome of the research process and, at best, it is hoped that the results can improve the situation of the participants (Young and Barrett 2001). However, for most researchers, ethical research involves negotiations over institutional and procedural ethical requirements (Guillemin and Gillam 2004).

Research projects should follow the formal protocols developed to guide researchers across disciplines and contexts. While ethical research regulations and protocols have existed within the medical sciences for many years, the last decade has seen the social sciences increasingly governed by these principles with institutional reviews and protocols (Haggerty 2004). The submission process for the National Bioethics Committee of the Ministry of Health (CNBS/MISAU) presented me with some challenges about this in a process that took over six months to approve, accompanied by a major challenge in readapting the research protocol.

---

[4] In this thesis work, all names used for participants, their families and some of the health workers encountered during the fieldwork are pseudonyms.

Finally, the research project received the approval of the Bioethical Committee of the Ministry of Health in Mozambique (ref. 1999/ CNBS/17; annex 1).

A document representative of one of these challenges is that of informed consent, which implies that research participants are provided with the information necessary to assess the risks and benefits involved in participation, thereby making an informed decision (Williamson et al. 2005). Although informed consent was obtained at the beginning of the study from both minors and their guardians, I had to ask myself how different degrees of power may affect the voluntary participation and in turn how this may affect the knowledge derived from the research (Christensen 2004).

Accordingly, informed consent was accompanied by a participatory process of ethical negotiation throughout the research. In line with Bakhtin and Holquist's (Bakhtin and Holquist 1981) conception of the ethical nature of dialogue, research processes and possible socio-ethical implications were discussed and explored in a dialogue between the researcher and the researched. The aims of my research were frequently explained and discussed with the participants and the tutors, and together we outlined the programme of our meetings, defining places, times and topics.

However, the space for such dialogue cannot be created without awareness and reflection on the tensions existing between oneself (as researcher) and the other (the researched) during the research process. The constant process of reflexivity generated by dialogue made it possible to create a healthy and trusting research environment. In fact, working with vulnerable groups led to the conduct of participatory ethnography, where their well-being was a priority in the day-to-day research.

Methodological Dilemmas in working with young people

Looking for «child-centred» research methods, I finally followed the perspective of Bakhtin and Holquist (1981), who argued that both research processes and potential socio-ethical implications should be discussed and explored in a dialogue between the researcher and the people encountered in the fieldwork. Moreover, following Skovdal and Abebe (2012), for whom young people are participants in the research – and not merely «informants» and «respondents» – I encouraged teenagers to establish a dialogue and relationship with me, which in turn enabled them to become active in the research process. Furthermore, dialogue can, therefore, become a tool to create a potential space in which to discuss and explore how the research can be conducted ethically, creating a space in which socio-ethical issues could be renegotiated during the research process (Skovdal and Abebe 2012). As Jovchelovitch (2007) argues, a criteria for an idealised public sphere should be that participants and researchers meet as equals, with arguments being accepted for their intrinsic relevance and power rather than according to which speaker wields the most power (Jovchelovitch 2007).

However, the space for such dialogue cannot be created without an awareness of and reflection on the tensions (for example, power inequalities) that are likely to arise between oneself (as the researcher) and the other (as the participants to the research) during the research process. These tensions are likely to be significantly affected by the socio-cultural context of the research (Skovdal and Abebe 2012). For this reason, reflexivity – as a way through which researchers reflect upon their research practices (Gaskell and Bauer 2000) – became a crucial path in my project.

With this in mind, I reconsidered the willingness of participation in the research as well as the methods that should be negotiated at the beginning and throughout the research process itself. To this end, as Thomas and O'Kane (1998) argue, I sought to ensure that teenagers I was working with were always able to «opt in» – and also «opt out» – by encouraging them to settle every aspect of the research activity in which they chose to participate. For example, some of the young people preferred to take part in photo-essays, others chose to use story-writing and draw-and-tell techniques and others wanted only to participate in group discussions. Teenagers could therefore temporarily withdraw from the research as well as re-join it depending on the available research methods they felt more comfortable with (Skovdal and Abebe 2012).

During the first few months in the centre, it became clear that some of the methods I was employing were not adequate for all participants and visual methods initially attracted my attention because they were considered «child-centred» (Mitchell 2006).

In my research, visual methods like drawings, body mapping, and photographs quickly became crucial ethnographic techniques to work with in the support group. When analysing drawings and their implementation, I followed Rose's (2001) «critical visual methodology», which takes into account not only the content of an image but also the circumstances of its production, circulation, and consumption. The content of the drawings – despite not comprehensively showing nor perfectly mirroring the world view of the participant – is a departure point for the understanding of what they know or think about a particular topic. The attention to the production of an image, to the ways in which drawings are done and the reasons they are done entails consideration of the technologies and social relations that are inextricably linked with these drawings and the embodied or corporeal aspects of producing marks on a page (Rose 2001). During the presentation of their work to the group, not only did the drawings convey something about what the drawer perceives, but the ways in which the drawings were seen and consumed by others became a relevant aspect to discuss (Berger 1972).

From the moment I began using visual methods, some issues of representation, translation, and power started to arise as I became aware that enabling young people's perspectives through drawings and photography required more than giving them the tools. As I mentioned before, it requires an awareness of the conditions under which those visual images are produced and viewed; furthermore, the directions given by an adult to young people raises issues of power concerning the broader adult-child relation in society, as well as to me in my capacity as a foreign researcher.

Following Mitchell (2006), I agree that the power hierarchy, implicit in an interaction where an adult ethnographer asks a child, or adolescent, if s/he would like to draw or take a picture, is impossible to eliminate. The author argues that in this case, «drawing is not an inherently child-centred activity, but one in which relationships of power, authority, and difference need to be acknowledged and integrated into the analysis» (Mitchell 2006: 70). Drawing, understood as worldwide natural form of child expression and as a child-centred activity that allows «children to be children», must be related to the culture of production (Mitchell 2006). The author argues that there might be a potential for bias if we assume that children, for example from North America, who are expected to talk about themselves constantly and at length and who are socialised to express their individuality, are taken as the standard for all children's narratives (Mitchell 2006).

During my experience in Mozambique, the viewpoints of young people were rarely asked for in society – whether it be expression of their feelings, or of their individuality. Drawing was not always seen as a pleasurable activity and sometimes presented the risk of infantilising the teenagers, creating a barrier to youth empowerment. Furthermore, drawings were not a substitute for a youth's voice and the absence, muting or fragmentary nature of explanations of their images should encourage researchers to be particularly cautious about over-interpreting these images (Mitchell 2006).

Making up the group

In the daily centre, run by a Catholic congregations, the nuns expressed the necessity to create a «safe space» where young seropositive people, who reported a very high viral load and HIV-related complications, could express their difficulties and build their self-esteem.

The creation of a successful support group aimed at building trust and intimacy with the participants, so that they would feel confident in sharing their experiences. For instance, during one of our last sessions, Augusto told me: «In the beginning, no one believed so much in this group, but now we do! We're feeling comfortable now». Building a safe context takes time but allows them to talk openly about sensitive issues in their lives – issues they would never discuss or that they struggled to share (Picture 3). While I treasure the many benefits of such a trusting and open context, I found myself questioning whether they were disclosing things they may not have intended to, or about which they were not emotionally prepared to divulge – e.g. the HIV status of other family members (Cree et al. 2002).

During my first months of fieldwork, I realised that in many cases the disclosure of the HIV status had been done in a subtle way and many were still denying their HIV status.[5] Many young people were still confused about their condition and why they were taking drugs every day. Most of them already knew each other's HIV status, as they were taking part in groups in the health centre where they were waiting for a treatment all together instead of doing it individually. I, therefore, initially decided to invite them to speak about pills, without directly using the term HIV.

---

[5] Most of the young people were affected by HIV through vertical transmission. This means that the HIV status is gradually revealed around the age of 10. This has not always happened in the best way, leaving children in a limbo, confused about the real condition they may be affected by.

Picture 3: The group during one of the meetings, a picnic on the beach in Maputo.

I was afraid that the modalities according to which I would set up a support group may increase the stigma. From here with the members of the group, we started a process of deconstruction of the ill body, reshaping identities in an environment created by wishes, expectations and challenges.

Moreover my role, identity and participation in the research was discussed throughout and through our encounters. Though my double position as researcher and psychologist was clear to the nuns of the centre, I was concerned about the group participants' understanding. Although the meaning of «researcher» was not so clear to them, and for most of the time they regarded me as a nun, the fact that they were part of a research project was explicit from the beginning and a formal consent form was signed by them and the family. This understanding was gradually deepened throughout the meetings. Below is an extract from one of the initial group sessions, as we explained to a new member what we were doing in our meetings:

> Researcher: « This is a support group, where we can talk about what is bothering us in our daily lives and try to find a solution together. What I wanted to ask is whether I can then write down some of the things that come up. Do you know what research is? Do you know what research (investigaçao) is?»
> Augusto: Sister, you are a researcher?
> Pedro: A secret researcher (Um investigator secreto)!
> Researcher: Not really a secret one! But I'm not a sister – you know that, right? We can speak about all kinds of things here. If you give me your permission, I will write some of the things you are telling me in a book. What do you think about me writing about it, without using your names?
> Emilia: That's fine, but you will always be a sister to us.

I took a few months before deciding to start our sessions. I was already meeting with children individually and I waited until I was sure that what I was building was a safe space. Many matters worried me: Was I increasing the stigma already present in their lives? Would it actually be useful? Would they participate in the group? Would I be up to it?

I started feeling a sense of inadequacy due to the mere fact of conducting research in a field that involves working and coming into contact with extreme suffering. In my experience, becoming an active participant in my research came naturally and my tendency was to try to improve the lives of the young people encountered; to alleviate their problems and try to avoid avoidable deaths, even if the feeling was not being able to do enough. For this reason, the psycho-social support group that I set up for young people was always a priority with respect to the collection of ethnographic data.

In March 2017, after having confronted me with other psychologists who were following and observing support groups organised by other clinical centres in Maputo, I eventually decided to start the group. Together with the nuns, we decided to start on a Wednesday, since on this day the centre was closed to the public, allowing some privacy and avoiding interruptions or questions from other members of the centre. The group was characterised by flexibility in regards to time schedule and space: members could arrive when they chose to, for instance after school, and attendance was not mandatory. This flexibility proved to be powerful in the creation of a safe space. However, the admission of new members during the following months compelled me to re-explain our rules as well as the different times of access and this often slowed down the activities.

The group meeting started at 9 a.m. and continued until 12.30 p.m. These hours accommodated different school time schedules. Each session had three different moments: the icebreaker, the main topic, and food.

During the icebreaker, we would usually sit in circle. I would invite participants to describe a good thing and a bad thing that had happened that week. Sometimes the conversation began without my intervention. Taking into account the shared stories, we chose a central topic for the session. Below is an extract from an icebreaker moment:

> Researcher: How was the week? How are you feeling?
>
> Augusto: I'm not very well. They [the doctors] told me it's gonna pass – they gave me cough syrup and pills.
>
> Alvaro: I'm feeling a bit better. Yesterday was not a good day. I started feeling dizzy and I started to vomit. I was at school and I asked to go back home.
>
> Researcher: How do you feel when these things happen at school? Does anyone give you trouble? Does this happen often?
>
> Emilia: It's happened a lot to me.
>
> Pedro: I don't go to school the day after.
>
> Alvaro: I didn't vomit in the classroom but I felt a bit ashamed.
>
> Researcher: I'm sorry that you feel bad, but feeling bad is something that happens to everyone. What do other people say?
>
> Augusto: Some of them say bad things.
>
> Pedro: Others feel pity for you, I don't like that. 60 students that pity you! Imagine if someone arrived and told you, «She is sick, I feel bad for her». I don't like that.
>
> Alvaro: I already feel pity for my cousin. In the streets of our neighbourhood people beat her up; she fainted. She is 14 years old. When she woke up she had forgotten everything that had happened, she had lost her memory.
>
> Researcher: Sometimes we forget things that were bad, these things escape our memory. Do you think there are things that you don't want to remember?
>
> Pedro: I have forgotten getting hit. I forgot a lot of things, not everything. When I woke up I was in the hospital.

> Emilia: I was sick, I had headaches and a cough. People in the school told me to go home but I didn't want to, I wanted to study.
>
> Pedro: My week was terrible! I had diarrhoea and headaches. When the weather is cold my head hurts a lot but when it's hot it hurts more! Cold hurts inside and hot outside.

Among the main topics that we discussed there were explications of HIV, CD4 and viral load;[6] treatment and difficulties in adherence; treatment at the health centres; stigma at school and with family; traditional healers, religions and beliefs; reimagining the past, present, future, friendship, love, and sexuality.

The last half an hour of our meetings was dedicated to the important moment of sharing food (Picture 4). As the participants arrived at the meeting immediately after school or they would go to school after the meeting, it was important to eat properly, especially concerning the taking of antiretroviral treatment. During the first session we decided that everyone would be in charge of bringing food and drink for the whole group on an alternating basis. I usually gave a small amount of money to the one in charge to buy the ingredients for the meal – e.g. cake, pasta, chicken. Also if research compensation has been a fundamental, albeit controversial, element of the health research apparatus for decades (Dickert and Grady 1999) in particular for structurally vulnerable populations, in my work it engendered a sense of responsibility towards others in the group, affecting other aspects of group relationships.

---

[6] Viral load and CD4 cell count are the two surrogate markers of ART responses and HIV virus progression that are used to manage and monitor HIV infection. These two tests monitor the trend of the virus. CD4 count is like a snapshot of how well the immune system is functioning. CD4 cells (also known as CD4+ T cells) are white blood cells that fight infection. The more you have, the better it is for your body. These are the cells that HIV kills. As an HIV infection progresses, the number of CD4 cells declines. When the CD4 count drops below 200, a person is diagnosed with AIDS. A normal range for CD4 cells is about 500-1500. Usually, the CD4 cell count increases when the HIV virus is controlled with effective HIV treatment. Viral load is the term used to describe the prevalence of the HIV virus in the blood: the more HIV there is in the blood (and therefore the higher the viral load), the faster the CD4 cell count will fall, and the greater the risk of becoming ill because of HIV. When the virus becomes resistant to a particular ART drug, the patient passes from first line treatment – which consists of one or two pills a day – to a second line treatment – which involves more than 5 pills a day and implies a much more significant collateral effect (http://www.aidsmap.com/Viral-load/page/1327496/).

Picture 4: One of the snacks brought by Augusto and his grandmother

Nobody lost money or failed to fulfil their task. During the convivial setting people talked about food, cooking and in particular about appetite. One of the aspects characterising an advanced HIV-positive state in young people is lack of appetite. Therefore, cooking for oneself and for others, talking about ingredients and recipes, turned into a pleasant experience. One day, while speaking of the positive aspects of the group sessions, Mauro told me, «the good thing about the group is that it gives us an appetite!». Below, an excerpt on the matter of lack of appetite:

> Researcher: Sometimes a headache can come from the lack of food.
> Pedro: …lack of appetite.
> Researcher: What is the difference between lack of food and lack of appetite?

> Emilia: When you don't have food in your house, or when you have food and you don't want to eat – that's lack of appetite. We have food at home; I lose weight from my lack of appetite.
> Augusto: Sometimes I don't have food at home. [Others agree with his affirmation]
> Emilia: If I'm not feeling well, I don't want to eat. I can eat two spoons and I'm full.
> Researcher: Sometimes we don't like eating, sometimes we don't like what we have to eat. That's okay but it's also good to try to eat something to feel better.
> Pedro: Emilia, you are so skinny! We want you to eat these two bananas that are here! Actually, you can have mine too.

«*Quem sou eu*?»

During the research project I was inspired to implement the use of cameras from the auto driven interviews technique used in particular by Clark (1999) and Clark-Ibáñez (2004). I reframed the methodology to adapt it to the group context in Maputo suburbs.

The term «auto driving» refers to an interview that is conducted by the participant, who sees and hears his own behaviour and comments on it (Heisley and Levy 1991). Butler's (1994) research and his studies show that «auto driving» can increase the researcher's access to the experiences of young people. allows the researcher to get a perspective of the respondent's action and the respondent to better express the meaning of his/her material (Heisley and Levy 1991), allowing the participants to retain some control of the interview. Their own photographs shape the topics included and their own commentary of the photographs preserves the youth's right to interpret material in their own way (Clark 1999). Because of its ability to portray behaviours in context, as well as to explore the meaning of those behaviours to the actors, the «auto drive» technique allows children and teenagers to visually show and tell important aspects of their lives (Clark 1999).

For all these reasons I decided to introduce cameras into the project, still being aware that the imbalance of power between the researcher and the young people remained and had to be included in the analysis. While you are giving oral instructions to the child, encouraging her to show what it is like to have an illness through picture-taking, as Clark pointed out, you are also directing the child to take pictures of some part of their world, preventing them from feeling free to take photos of whatever they want (Clark 1999). For example, the photo of where the antiretroviral treatment was being held was my indication. In this case, therefore, we cannot consider this photo as necessarily representing their daily lives.

Although most of the young people had never taken a photograph, they understood the basic principles of operating a camera and required few instructions. Most of them completed the project within two weeks after receiving their camera, others took a while longer and some lost their camera. It was also challenging every attempt to give them as few directions as possible regarding *what* to photograph.

I presented the project «Quem sou eu?» (Who am I?) as a project in which they could show how life was to a stranger through photographs. During the first session, each of us made a roundup of our daily routines in order to think together about what aspects could eventually be important to capture. Two suggestions were given during this session. The first was about taking pictures of where they keep medicines, in order to analyse aspects of treatment, and the second was a discussion about the ethical dilemmas of taking pictures of strangers, which could potentially violate privacy and confidentiality (Gold 1989). In particular, we discussed some of the potential dangers of taking photographs of people without their consent and together we agreed that they should have to ask before taking a picture and to completely avoid taking photographs of people in situations that they believed could be potentially embarrassing for the person photographed. Together we also decided that they should not take pictures in hospitals and if they wanted to take a picture at school, they would always have to ask for permission from the teacher. In the end, they decided unanimously not to take pictures at school out of fear that classmates might steal the cameras. Photographs were eventually presented during the group sessions as a sharing activity that could reveal new meaning and experiences.

In picture 5 for example, Emilia show us a normal meal in her house. While describing the picture (and the situation) she stressed the fact that her lack of appetite might be linked to the lack of food variety presented in the house, in this case *xima* – a polenta made by corn flour and tomato sauce.

Picture 5: This picture taken by Emilia was called 'dinner' for the exhibition at the day centre.

In picture 6, Augusto is showing his drugs table:

> Augusto (showing pictures): Here is where I keep all the medicines; here I am with the medicines (picture 6)
> Pedro: Me and Augusto have the same disease, so we take the same things. My mother told me that I've had it since I was a child, Augusto I don't know. I have been very sick since I was three years old.
> Emilia (speaking about Augusto's picture): This cream here is for the wounds, when you have wounds on your body you apply it after a bath.

Picture 6: Augusto's drugs table

This moment of sharing revealed how some issues and interpretations might have otherwise remained dormant in face-to-face interviews (Clark-Ibáñez 2004). I found that even if the images didn't contain new information, they could trigger meaning for the interviewee to communicate something that might not have otherwise been expressed (Collier 1967; Schwartz 1989).

Edson for example was very shy and not a great speaker; others always joked about how quietly he spoke. During the presentations of the pictures, we all, including Edson himself, realised that he was an amazing photographer. His works show that that he was living in a happy and safe family context – probably also one of the reason for his undetectable viral load (Picture 13,14).[7]

Moreover, I found that showing pictures could function both as a form of advocacy and to mentalise sick states considered transitory. Alvaro showed me two powerful photos that he had

---

[7] The lower the amount the better. The aim of HIV treatment is to reduce the viral load to a level that is too low to be measured by standard tests. This is called an «undetectable» viral load.

decided to take of himself. One showed him very skinny and hunched over, taken in a period of his life when he was very ill with tuberculosis and Kaposi sarcoma. In the other, he was well dressed, listening to music, at the school entrance. He told me that he wanted to capture these two important moments of his life to remember how ill he was and how, with medication, he got better. «It is important for me but also for others, others in my condition. They have to understand that you can get better, you must not break down.»

Body mapping

I step in body mapping during my reflexivity process on methodological challenges in the field and in search of original research methods that would allow greater expression to young people. In this process I started an online Couse of the University of Cape Town, called Art and Medicine where I found much to reflect on. Body maps is defined by Gastaldo et al.:

> As the process of creating body maps using drawing, painting or other art-based techniques to visually represent aspects of people's lives, their bodies and the world they live in. Body mapping is a way of telling stories, much like the way totems contain symbols with different meanings, but which significance can only be understood in relation to the creator's overall story and experience (Gastaldo et al. 2012:5).

Body mapping originated in South Africa as an art-therapy method for women living with HIV/AIDS in 2002 (Devine 2008; MacGregor 2009). The method evolved from the Memory Box Project designed by Jonathan Morgan, a clinical psychologist from the University of Cape Town, South Africa.[8] Jane Solomon later adapted this technique to create body mapping through a narrative process, reflecting on living with HIV/AIDS. Since then, body mapping has evolved as a research methodology but still today there has been no substantive literature to guide the creation and analysis of the rich visual and oral qualitative data that body maps, and body mapping, provide as products and processes, respectively. As Solomon (2002) argues «body mapping has the potential to engage and enable its participants to communicate creatively

---

[8] The Memory Box Project was a therapeutic technique for women affected by the HIV/AIDS to record their stories, providing a keepsake for their loved ones in a handmade memory box.

through a deeper, more reflexive process» (Solomon 2002:7). Body mapping can be used as: a therapeutic tool; a treatment information and support tool; a research tool; an advocacy tool.

I reviewed the body mapping activities found in Solomon's original body mapping guide and selected those which had the potential to illustrate my themes (see Table 1-2).

Table 1: Original Exercises Selected (Solomon 2002)	**Table 2: Readapted body mapping for teenagers in Maputo**
General introduction before you begin Exercise 1: Body tracing Exercise 2: Highlighting your body shape Exercise 4: Personal print	General introduction before you begin Exercise 1: Body tracing Exercise 2: Highlighting your body shape Exercise 3: Personal print
Exercise 8: Creating a personal symbol Exercise 9: Drawing a self-portrait Exercise 11: Marks on the skin Exercise 12: Marks under the skin	Exercise 4: Creating a personal symbol Exercise 5: Drawing a self-portrait
Exercise 5: Painting in your support Exercise 15A: Decorating your body map Exercise 15B: Finishing off	Exercise 6: Marks on the skin Exercise 7: Marks under the skin Exercise 8: Where it hurts, experience with pain
	Exercise 9: Locating emotions Exercise 10: Support network Exercise 11: Imagining the future
	Exercise 12: Painting in your support Exercise 13: Decorating your body map Exercise 14: Finishing off

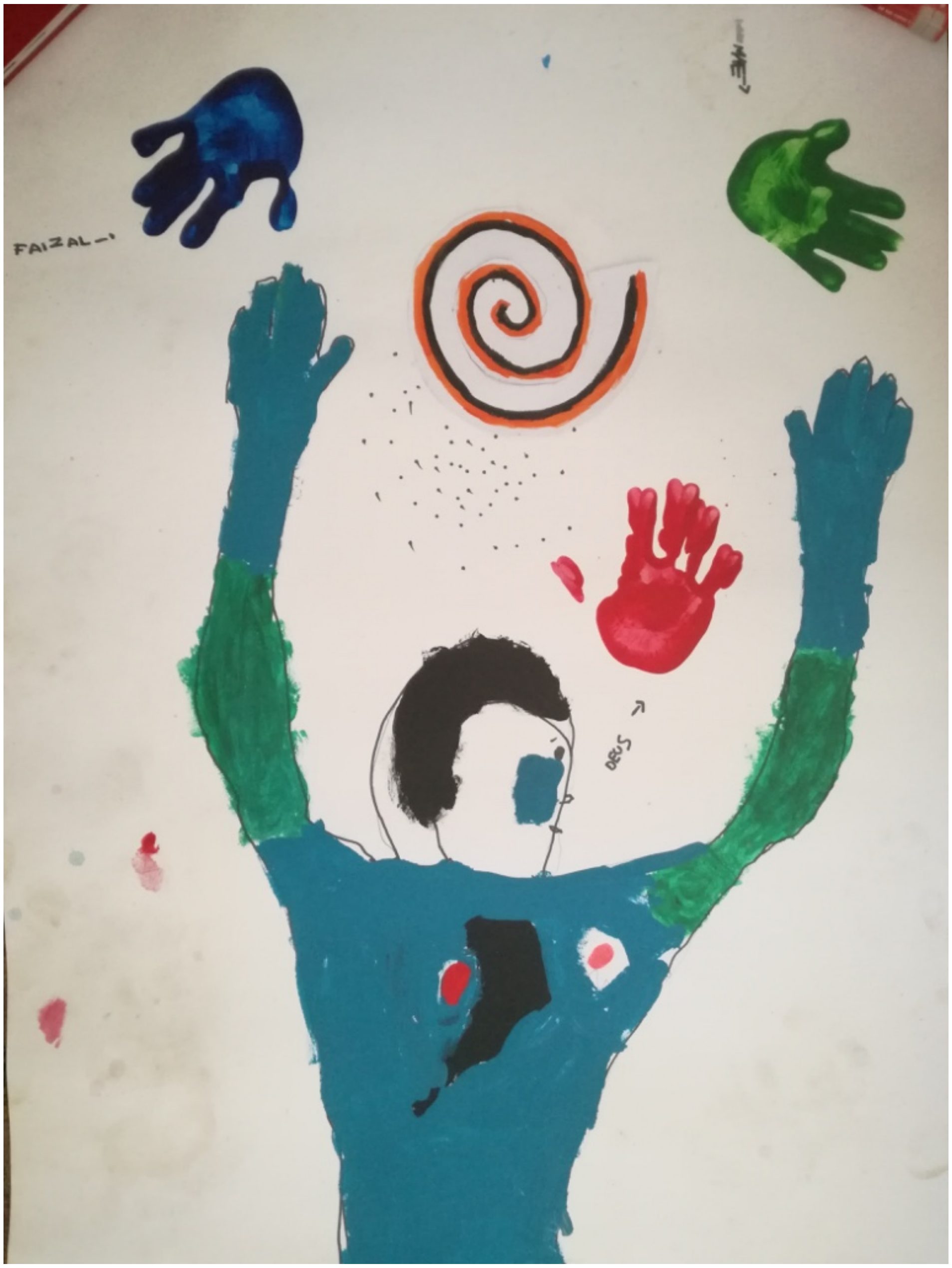
Another crucial aspect of the adaptation of body mapping to my research purposes was time. The original body mapping guide encourages participants to allocate at least five full days of working time, or approximately 30 hours to complete each body map. Since our activities were done once a week, alongside others group tasks, the body mapping exercises therefore continued for a couple of months.

Picture 7. A part of Edson's bodymapping.

In picture 7 these three painted hands represent the support network. I asked participants who they ask for help if they may have a problem related to school, health or other issues. Edson identifies God (Deus), Doctor Ana Gabriela (a doctor of the Clinic) and his aunty (minha tia). Interestingly, he was the only one who identified a doctor as an important figure in the network. As a wish for the future, Edson wished to be together with his family to celebrate at the dinner table. I analysed the story maps in their entirety, including the process of creation (verbatim and field notes), the body maps themselves and the narratives that accompanied them (testimony and key aspects) as Rose's (2007) methodology suggests. As shown in pictures 8 and 9, during the creation process children were able to paint over their body and were free to alter their body shape in whichever way they wanted. In the pictures, the marks on their bodies – related to the HIV status and in speaking about stigma – were covered during the last session, when decorating the body. The young people were attracted to, and initially engaged by, this work. However, during the final discussion about whether or not to show their work in the exhibition, they preferred to ameliorate them first. The fluid, constantly changing corporeity that they proposed during the process of artistic creation also allowed them to understand themselves as evolving and not in a static condition of illness and stigma (Picture 8).

Picture 8: The creative process of Hilario

Picture 9: Carlos's and Edson's body mapping



Picture 10: Augusto’s body mapping

Reflections on methods

The work produced during the support group sessions was exhibited during the International Day of the Fight Against AIDS, on December 1 2017 (Picture 11). The exhibition took place on an open day at the centre, alongside other exhibited works and without specifying which authors were seropositive (Picture 12,13,14,15 are some examples). However, the group members wanted to be active «coordinators of the exhibition» and sought to explain their work to the visitors. This created some concerns on the contradiction that often occurs in the Mozambican society on HIV public disclosure. On one hand, young people are advised to keep their status secret by families and health workers to protect them from stigma. On the other hand they are empowered to have a normal life and not to be ashamed of their status. However, it has been a very important act of giving back, where they had a chance to show their abilities and stories to the public, and consequently also to themselves.

Visual arts are useful if we consider that they mitigate, in part, the often demanding issues that researchers face during fieldwork. Through visual arts, for instance, I was able to gain insight into certain aspects of youth reasoning, thinking, aspirations, desires and ways of handling particular issues. I explored several key themes, including support networks, emotions, and experience with pain through a critical examination of participants' visual and oral narratives. Therefore, it also became an important therapeutic tool, as it helped to analyse and discuss critical aspects related to stigma, adherence, and self-esteem. However, photo voice and body mapping do have some limitations. First of all, they cannot be considered techniques *per se* but instead tools that can complement other research methods, such as individual and family encounters. Secondly, researchers should be cautious in using the «visually arresting» images – e.g. poverty context – rather than focusing on what might be meaningful for the interview participants (Orellana 1999). For example, I noticed my own tendency to prefer images and paintings that, as an outsider, I found unique or aesthetically beautiful but that were with less meaning for the young people I was working with. Finally, I think that during the research process, we as researchers should remain critical and reflective about what actually is *in practice* a «child centred research», and especially avoid any over-interpretation of a youth's art work.

Picture 11: Setting up the exhibition

Picture 12. This photo was titled 'home' by Seba. it was actually his grandfather's house with whom he lived before spending time in a nuns' home to try to lower the viral load and put on weight.

Picture 13; 14. These two photos taken by Edson show the familiar context. The first was titled ‘happy' and the second 'my sisters'. Edson, orphaned of both parents, always showed great affection for his sisters who always took care of him.

Picture 15; 16. These two photos were taken by Carlos on his way to the daily centre. The first with the title "the street where my family lives" and the second with the title "the blue sky above me, a beautiful day".

Chapter II

Speaking global, acting local

Care in the global context

Through this chapter my aim is to show how the global narrative around AIDS, and the main campaigns, present tensions with the responses to the pandemic in local contexts, considering that, as Cristiana Bastos states, each local response to the pandemic is an original combination of international elements and local characteristics (Bastos 1999).

In addition at showing some scenarios that I had the opportunity to observe while attending the International AIDS Conference (IAC) in 2018 in Amsterdam, this chapter serves as a frame for the following chapters, which will illustrated more specifically the challenges in the field in the implementation of the goals proposed by global health.

I will show how, there is a political and scientific discourse in which the biomedical approach to interventions continues to dominate over the multidimensional one and the voice of experts for the implementation of campaigns prevails over the one of the young «beneficiaries» of the projects. Two aspects also called my attention: the rhetoric used to talk about AIDS-related deaths in the global health arena and the concerns of implementing a specific campaign, known as «treatment as prevention».

I had the opportunity to attend IAC 2018, a few months after returning from fieldwork. This is perhaps why I was so impressed by the feeling of greatness and control. Metal detectors acted as separators between the different conference halls where it was impossible to circulate without passing through these controls. At the time I thought it perfectly represented the complex and competing discourses circulating within the global AIDS response and as Adrien Guta argues:

> Conferences show the global HIV industrial complex were governments, NGOs, Big Pharma, biomedical researchers, and funders constitute a global bureaucratic matrix that is committed to promoting biomedical and technological innovations to curb the tide of the epidemic (Guta et al. 2011, 20).

The objective of the 22nd International AIDS Conference in 2018, *Breaking Barriers, Building Bridges*, was to bring attention to the need of rights-based approaches to more effectively reach key populations, including those in Eastern Europe and Central Asia and the North-African/Middle Eastern regions where epidemics have been increasing.

Picture 17: 22nd International AIDS Conference (AIDS 2018) Amsterdam, Netherlands. Copyright: Steve Forrest/Workers' Photos/ IAS

The conference was divided into three main blocks: the panel sessions, pharmaceutical companies and sponsors, and the global village. Only the global village was open to the general public and served as a way of opening up the conference to those who could not afford the substantial registration fee. During the first day, with a bit of excitement while getting lost around the conference blocks, something was bothering me. Enthusiastic activists, big Pharma offering expensive gadgets, and researchers from all over the world seemed to be in harmony, where everything was going exactly as it should. While a group of activists was demonstrating in front of a pharmaceutical display to create awareness for the harm reduction initiative I realized that every activity and demonstration inside the conference was planned and was part of the «show». Activists had a limited amount of time to demonstrate – for example in the case of harm reduction it was from 4.00 pm to 4.30 pm every day – so as not to interfere with the time schedule of the conference. As Guta and colleagues aimed:

> The global HIV industrial complex formed by governments, NGOs, Big Pharma, medical researchers, and funders – that aimed to promote the eradication of HIV and AIDS through programmatic (economic, biomedical, technological, and pharmacological) interventions – is an approach which privileges particular ways of knowing and renders dissent and activism a threat to this rationality. Through both overt and subtle means, this matrix works to silence activists' earlier calls for critical resistance and action (Guta et al. 2011:15).

For instance, the main sponsor of AIDS 2018 was Gilead, followed by other pharmaceutical companies like Johnson&Johnson, MSD, Mylan and VIIV Healthcare. Indeed, these conferences could not happen without the support of governments and pharmaceutical companies. Yet, as observed by Altman, although conferences on the one hand are a meeting to promote scientific knowledge, they seem almost like a trade fair where the stands of pharmaceutical companies are as important as the presentation of papers (Altman 1994).

Everything at the conference, including the global village and the actions of the activists, were placed by the organisers in a sort of circular matrix where international actors, activists and patients depended on each other. I had the feeling that the human element, the subjective experience, was lost between round tables around cost effectiveness, statistics and clinical trials.

The biomedical and scientific discourse was therefore dominant, as Cristiana Bastos reports, stating that from the very beginning of the pandemic there was a certain tension between a «molecular» and a «multidimensional» approach to the disease (Bastos 1999). The biomedical orientation has always been central to the response to HIV/AIDS, although there have been numerous efforts over the years to include the views of activists and civil society. The latter, however, are considered «politically necessary but scientifically irrelevant» (Biehl and Petryna 2014, 377). This was also reflected in Bill Clinton's speech, former president of the United State and founder of the President's Emergency Plan for AIDS Relief (PEPFAR) in 2003, where he tells delegates from around the world the key points about HIV prevention, research, programming, and care. That day, he said:

> There is always a reason to abandon or reduce the efforts and a cause in which you have been involved in which total victory has not been achieved… All I know is that the only really pro life answer is to save as many lives as possible…*You can have a political debate on the side on how the political policies have to be, but save as many lives as possible* …This is not about money it is about life. *Is a possibility business*. You guys are in the possibility business, we made mistakes, we are disappointed, yes but you gotta stay in the possibility business, they can take all from you except from your mind and heart. (Bill Clinton Plenary Session, IAC2018).

As a controversial and polemical gesture, Adrien Guta and colleagues, use the term «biofascism» to describe the conference structure and Clinton speeches over the years. This excerpt from Bill Clinton's speech shows how there is a vision of a single truth in the name of science that saves lives, and how the scientific community is predominant over political criticism of the general community (Guta et al. 2011).

As past international conferences on HIV/AIDS illustrate, the delivery of health technologies (usually new drugs or devices), also called the magic-bullet approach, has for many years been the norm in humanitarian health interventions. However, this has not taken into account all those factors, social, political and economic, that influence the success of interventions (Birn 2005; Enserink 2010; Stepan 2011).

The first AIDS conference happened in 1985 in Atlanta and was organised by the Centers for Disease Control and Prevention (CDC), the World Health Organization (WHO), and Emory University. More than 2,000 scientists and public health officials gathered in the city to share information on the emerging new disease. The structure of the conference was designed to provide information on the changes and lines of modification during the year, showing the «trend» of AIDS responses throughout the world. Initially ignoring the broad community, the conferences were mainly scientific forums (Guta et al. 2011). However, conferences quickly became the stage where everything happened, from statement of new scientific findings to claims from activists. Even though the first conferences had been aimed at the scientific community, as a result of activist pressure, the conference was eventually opened to the public in 1990.[9] As Adrien Guta and colleagues reported perhaps one of the most memorable moments of activism was in 1989 during the IAC in Montreal, when a protest by 300 activists invaded the VIP delegation of the conference with the message «Silence=Death» (Guta et al. 2011). The discovery of the agent that caused AIDS, was announced to the American public media by the Secretary of health and Human services Margaret Heckler in 1983. She refered to the discovery made by the Gallo's team's as «another miracle in the long honor roll of American medicine and science» (Bastos 1999).[10]

Indeed, as Cristiana Bastos argued during the first decade of the epidemic, AIDS remained a leveller that killed both rich and poor, left and right. The treatment did not exist, so it was a killer that could potentially hit anyone, regardless of financial possibility (Bastos 2008). Nor was there enough accumulated knowledge that could be readily capitalised into the development of new drugs, even if there had been enough awareness or funding, AIDS was first compared to cancer (the «gay cancer») in its unpredictability and ability to defeat modern medicine (Bastos 2008).

As an infectious disease AIDS indignation increased even more among those not used to that sort of vulnerability as the gay population, drug users and people from the Carribean and parts of Africa (Bastos 1999). The fact that almost two decades elapsed between the discovery of the HIV virus as a medical problem (early 1980s) and a medical/pharmaceutical response (in 1996) showed from the beginning that there was a rare encounter between two different perspectives, medical and social (Bastos 1999). A first wave of activism developed in order to supply what seemed to be missing: through the raising of funds and awareness, it tried to promote public acknowledgement, intense research, rapid solutions, treatments and drugs – a cure (Bastos 2008).

Actually, the inequality between Western and non-Western countries was already evident. For those who were living in sanitised environments, using informed behaviours to avoid ailments, doing their best and striving to keep illness at bay, a new incurable disease appeared as a galvanising shock; for those who had been surrounded by preventable yet prevailing endemic

---

[9] https://www.iasociety.org/Web/WebContent/File/30_Years_of_AIDS_A_History_of_HIV_and_IAS.pdf.

[10] Meanwhile, other medical teams made significant progress in isolating the virus, namely the French team led by Francoise Barr-Sinousi and the Californian team led by Jay Levy (Bastos 1999).

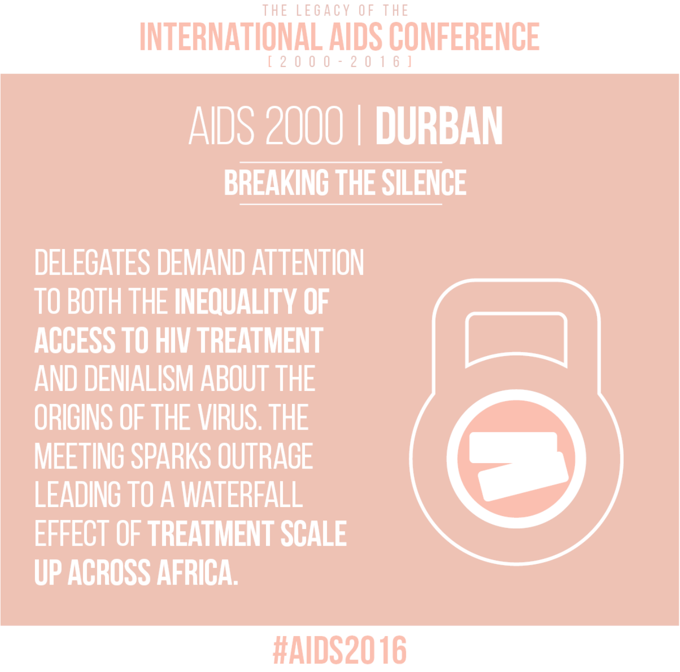
diseases like malaria, tuberculosis, pneumonias and gastro-intestinal disorders, AIDS came as another disruption and another terrible disease in an all too well-known scenario, unbeatable by treatments that were unaffordable to begin with (Bastos 2008). In the words of Cristiana Bastos to describe the epidemic:

> This epidemic simultaneously resulted in homogenization – the bringing together of people from developed and underdeveloped countries – and heterogenization – that is, intensifying existing differences in class, gender, nation, race, and sexual orientation, trought differences in acess to care and risck for disease (Bastos 1999, 8).

In 1996, the ninth IAC in Vancouver marked a watershed moment in the history of the epidemic. Finally, but too late for many, right on time for many others, after years of activism, struggles, clinical trials and many failures, the news of an efficient therapy finally broke (Bastos 1999). In this year, researchers reported on successful studies of a highly active antiretroviral therapy, which would transform HIV/AIDS from a fatal, incurable disease to a chronic condition which could be managed with proper treatment. The overall atmosphere in Vancouver among scientists and activists was one of hope and excitement (Guta et al. 2011).

However, inequalities were evident between those who could reach, purchase, and use treatments, making AIDS a somehow manageable disease (in spite of its costs) and those who, unable to pay for the new treatments, remained under the collective and individual stresses of the devastating epidemic (Bastos 2008). While this could be real for the north of the globe, for the huge part of the seropositive population that live in disadvantaged conditions it remains a relatively impossible situation (Dilger 2010).

In 2000, the IAC was held in Durban and marked another very significant moment as South Africa was one of the countries with the highest prevalence tax in the world and it was the first time a conference was held in an African country. The inequalities in access to treatment around the world was one of the central themes of the conference.



THE LEGACY OF THE
INTERNATIONAL AIDS CONFERENCE
[2000 - 2016]

AIDS 2000 | **DURBAN**

BREAKING THE SILENCE

DELEGATES DEMAND ATTENTION TO BOTH THE **INEQUALITY OF ACCESS TO HIV TREATMENT** AND DENIALISM ABOUT THE ORIGINS OF THE VIRUS. THE MEETING SPARKS OUTRAGE LEADING TO A WATERFALL EFFECT OF **TREATMENT SCALE UP ACROSS AFRICA.**

#AIDS2016

Picture 18: One pamphlet at AIDS 2000, Durban

The Durban conference was preceded by a major controversial debate around what is called the «Presidential Panel». In this document, Thabo Mbeki, current president of South Africa, supported by researchers and scientists, questioned the causes of the virus and the usefulness of treatment claiming that antiretrovirals were responsible for the deaths of many patients) (Fassin 2007).

The publication of this letter, a few months before the opening of the conference, by the Washington Post called into question the participation of many specialists. With the opening speech for the conference by the president, in a sign of disagreement, many participants got up and left.

Didier Fassin, in his analysis of the micro and macro-politics of AIDS in South Africa tries to show how the speech of president Thabo Mbeki can be analysed from different angles. On the one hand, Thabo Mbeki’s speech was about something significant, that had to do with the history of the country and the fact that for a society to be fair, it has to remember the past, in this case specifically related to the apartheid regime (Fassin 2007). The AIDS epidemic in South Africa, the president emphasised: «does not all resemble the one in Western Countries: the disease is transmitted above all through heterosexual relations and spreads much more quickly; and whereas the situation seems to have stabilised elsewhere, in Africa it continues to worsen dramatically.» On the one hand, therefore, the president's speech was intended to show that the African context needed specific and targeted responses and that Western experience could not be used in the African reality. His thesis, however, was clearly influenced by dissent and conspiracy theses, such as invoking that AIDS was caused by malnutrition and his refusal to make anti-retroviral commercially available (Fassin 2007).

As shown in the picture 18, denialism and ideas of pharmaceutical conspiracy about the origin of the virus was on debate and the South African President Thabo Mbeki declared he doubted that AIDS occurred in South Africa and that, if so, it was caused not by HIV but by poverty.

One of the other statements, which stunned public and scientific opinion, concerned the side effects of antiretrovirals that were banned in the prevention of vertical mother-child transmission. The response was not long in coming with 5000 scientists publishing the Durban Declaration' validating the overwhelming scientific evidence about the aetiology of AIDS and a closing keynote speech by Nelson Mandela criticising the South African government for its irresponsibility in relation to HIV/AIDS policies (Fassin et al. 2007).[11] Access to anti-retroviral treatment for many African countries was only possible in 2002, thanks to intense activism and corporate philanthropy in the pharmaceutical sector (IAS 2017).

Thanks to strong public interest and the intense work of activists in 2004 in Bangkok, a new part of the conference arose, referred to as the Global Village and it was open to the public and was created to work as a bridge with the aim of acting as a network between activists, community leaders, health professionals and researchers (IAS 2017).

The conference has served as a peculiar stage that has offered the possibility of analysing the discourse around AIDS and the predominance of the scientific approach. As identified by Altman:

---

[11] For an anthropological analysis of President Mbeki's positions and AIDS policies in South Africa, Didier Fassin published one of his most interesting works «When bodies remember. Experiences and politics of AIDS in South Africa».

> The conference circuit becomes an arena where far more than «objective» information is exchanged. It becomes a focus where dominant paradigms and individuals are established, where contacts are made and where a new class of international AIDS «experts» reinforce each other's importance. Most significantly, the Conferences reinforce a particular «scientific» approach, as discussion is squeezed into predetermined categories. What has become a regular division, into areas, of discussion at both international and national conferences – Basic and transnational research, clinical research, epidemiology and prevention research; Social and political research; Implementation research, economics, systems and synergies with other health and development sectors – has come to suggest that this is the natural way of conceptualising the epidemic. ... which has the effect of other topics, particularly with political or cultural content, appear[ing] peripheral (Altman 1994, 47).

Voices

One of the main objectives of the conference in 2018 was to give more voice to the young people. One of the daily digests affirmed that young people were a central component in ending the epidemic and therefore their participation in the conference was of crucial importance. As reported by conference organisers, youth and junior investigators made up more than one-third of the submissions presented at the conference, and their work garnered attention in every conference track. Events that included young speakers or showed the great success of projects with a focus on policies made by and for young people were dozens. Among them the «youth quake» aimed at «addressing innovative strategies to overcome barriers to access for young people and sharing strategies to amplify meaningful youth leadership for the HIV response».[12]

Youth voices were present, and I'm not questioning the effort made to involve youth voice in the conference and in many case the testimony was truly felt and touching. Rather, I'm interested in how much these voices are actually heard in the implementation of global health policies and whether or not they mirror humanitarian rhetoric, which take a particular kind of biosocial activism as their main form of collective mobilisation.

As Adrien Guta and collegues suggested, we are reminded that at the beginning of the epidemic, activists and critical scholars provided some of the loudest voices (Guta et al. 2011).

---

[12] https://www.aids2018.org/Media-Centre/The-latest/News/Article

The author affirms that «activists and critical scholars need to raise their voices in the post-HAART era in response to the failed promise that providing treatment can wash away all the injustices and forms of structural violence that lead to new HIV infections» (Guta et al. 2011:24). For the author it looks like as if, in the post-HAART era, the main objective has been reached and there is no more space to fight and disappoint (Guta et al. 2011) or at least, those blatant gestures that were initially raised, no longer take place.

The presence of young activists was nevertheless very much felt during the conference, as in the case of a speech by 18-year-old Yana Panfilova leader of Teenergizer a youth organization from Ukraine, presented the purpose of the global village (Picture 19):

> I'm a lot more than HIV… Health care systems cannot simply ignore us, we are not just bodies, we are complete, powerful and independent human beings, we need doctors to trust us. We must be able to ask any questions and receive clear answers in a friendly way. We are equals partners in health…We must give young people the opportunities to get involved and participate. We must be part of the solution and not a decoration. Leaving no one behind is about a call to action.

Youths like Yana, asked to be seen and heard as part of the change and as policy implementers and not just as HIV-positive patients. Hers was also an important claim on her own body and identity.

Picture 19:: 22nd International AIDS Conference (AIDS 2018) Amsterdam, Netherlands Copyright: Marcus Rose/IAS Photo shows: Plenary Session. Leaving no one behind: a call to action Yana Panfilova, Teenergizer, Ukraine.

However, in some plenary sessions at the conference and on other panels, PLWHA were taking part in the speeches and biosocial citizenship took a different shape. Young people were presented more as «beneficiaries» or «victims» to use Fassin worlds, than as possible policy implementers (Fassin 2013).

«The power of peer-led HIV services: Adolescent and youth treatment success in Kenya, Lesotho, Tanzania, and Zimbabwe» was one of the first panels I attended. Supported by the Elisabeth Glaser Foundation project for HIV teenagers in Africa, the panel started with the touching testimony of Jake Glaser, and was followed by the testimony of four teenagers from South Africa, Lesotho, Ghana and Tanzania.

The efforts they made to reach the conference were evident. They had taken their first flight, settled in a new country and had to speak in front of a lot of people about their HIV status.

The sense of inadequacy that they were probably feeling was concerning me: I had the feeling they were considered «testimony bodies» showcasing the success of the NGO project as «beneficiaries». I had the feeling that they were saying exactly what they supposed to say with total standardisation of their speeches, decided by others.

Testimonies like these were particularly common during the panel sessions of the conference: «testimony bodies» were part of youth participation. I find it more significant to refer to them as «useful youth» in the main scope of the conference: producing (great) results. Here Fassin warns us: we must be careful to place young people and children in a condition where humanitarianism speaks for them. This will tend to deprive them completely of their agency and leave them in the position of victims (Fassin 2013). As João Biehl and Adriana Petryna argues:

> «Among the powerful players of Global Health, the supposed beneficiaries of interventions are generally lost from view and appear as having little to say or nothing to contribute» (Biehl and Petryna 2014, 376)

The authors stressed the importance of making the case for a more comprehensive and people-centred approach in Global Health in which people are not merely seen as a problem, as victims, as patients or vectors of disease. People's practical knowledge is instead of central interest to the value of health and well-being (Biehl and Petryna 2014).

A certain kind of rhetoric, used by some activists and members of civil society, to activate the attention of the media and the scientific community was the humanitarian tone of victimhood. To show this aspect called my attention in particular «Dudu's speech», founder of Mothers for the Future, an NGO that supports sex workers who have children. In her speech she highlights the difficulties in creating legitimacy outside of the humanitarian complex because this sets the agenda and also the rhetoric to be used. As shown by various authors, «victims» tend to appropriate the humanitarian discourse to be legitimate and to stay in the circuit (Fassin 2012; McKay 2019; Pandolfi 2006):

> Let me bring you to my work for a moment. I'm a sex worker, I am a mother I am a session organizer, an advocacy lobbyist, I'm the ambassador of a college of children living with HIV/AIDS in South Africa, I work with sex workers in South Africa. Our children are not getting anywhere. We do not have enough money to get our children to the clinic. We cannot afford to give them food they need to stay healthy. We cannot afford the uniform and material for the schooling. We cannot keep them safe while we are going out to work. We have to leave our children and babies at home, by themselves, because we need enough to feed them, even when we have the money we still have to protect our children around the

> discrimination for HIV. But we cannot do this alone, our money does not go far enough. The support from this prize will help mothers. We are mothers (pause) and we like all mothers, our children come first. I'm now asking you to put us first when you are thinking about who to help. Put them first when you are making your plans. Put them first when you want to make the difference. And all above, remember, what keeps other children save from HIV, may not work for children of sex workers. We love our children and they deserve a better life. What you do today could be the life line (Duduzile (Dudu) Dlamini, founder of Mothers for the Future, Amsterdam 26th July 2018)

Picture 20: 22nd International AIDS Conference (AIDS 2018) Amsterdam, Netherlands. Copyright: Marten van Dijl / IAS. Photo shows: At the conference: sex workers protest

As Fassin argues beyond the cultural and literary code of supplication, which should not be reduced to a «neo-colonial» relationship, it is remarkable that this speech uses, throughout, the language of humanitarian reason, the language of suffering and aid («put them first when you are making your plans. Put them first when you want to made the difference»), the language of life and sacrifice («many of us die from HIV and violence, if we die, our children are forgotten and they are out of the system»), within humanitarian reason's own field of engagement («what you do today could be the life line») (Fassin 2012).

Following Fassin thoughts, the presence of humanitarian reason in the speech expresses how the aid complex governs the precarious lives and how « precarious lives» have to use the humanitarian reason language to be heard (Fassin 2012). Humanitarian government is indeed a politics of precarious lives and «it pays more attention to the biological life of the destitute and unfortunate, the life in the name of which they are given aid, than to their biographical life, the life through which they could, independently, give a meaning to their own existence while depoliticising sufferance» (Fassin 2012, 254).

While Dudu spoke, another aspect grabbed my attention. As Cristiana Bastos affirmed, the general public and media, make a distinction between the «innocent» victims of AIDS (as children and blood transfused) and the «guilty» (as drug users and prostitutes), with their distinction made on moral judgment as the «deserving and underserving poor» (Bastos 1999). A sort of «scale of innocence and vulnerability was implicitly established among the three categories of individuals with the virus» (Fassin 2013, 119). On this scale of victims, first of all were the HIV positive children, then the others. As Fassin claims, a «hierarchies of moralities» where «children are depicted as innocent of the fate that is apt to cruelly fall upon them: they become passively infected at birth; they are born doomed to die early» (Fassin 2013, 119).

The issue of priority victims and being placed in certain categories to benefit from funds and projects is crucial to humanitarian intervention. Sometimes this is an issue of life or death and to survive you have to be in one of the lowest categories. Children, born infected, were considered the mark of innocence. Behaviours play no role in the misfortune they have suffered. Babies born positive are considered victims on several fronts: they are victims of inappropriate parental behaviour, of mothers who decide to have a child even though they are HIV-positive, of governments as laggards in introducing programmes to reduce mother-to-child transmission (Fassin 2012).

The main perpetrators were generally considered to be men, often blamed for paternal irresponsibility, conjugal infidelity, but also of violent episodes. Often supported by epidemiological and sociological investigations, the stereotype of the rapist was often invoked. Women, on the other hand, were considered in an ambiguous position: while on the one hand they were the victims of men's violence, on the other hand they represented sexual promiscuity as a cultural trait of the African population (Fassin 2012).

This is certainly both important and true. Orphans of HIV face more difficulties than others, such as stigma, social exclusion and drug adherence and resistance. However, it is problematic for the other «categories» to have a scale of victims, because this means that majority of funding will go in one direction. Furthermore the humanitarian reason of doing good, of «they can take all from you except from your mind and heart» as Clinton said, tends to depoliticise sufferance.

As people become specific population targets in global health we are faced with glaring contradictions:

> We find ourselves face-to-face with profound disconnections between campaign designs and intentions and the complex ways in which those campaigns are actually received and critiqued. The counter-knowledge of the people who are at the centre of interventions is thus integral to assessing their actual impacts and to mitigating against blind spots and the repetition of history (Biehl and Petryna 2014, 380).

Death and dying

One of the aspects that had particularly marked my research field was its proximity to the experience of the end of life and death. Therefore, during the conference I tried to figure out if there were some sessions dedicated to this last topic but soon realised that this was a piece that was missing in the «arena» of IAC 2018. During one of the first panels that I attended, a man from the public asked «why are we not speaking about death and dying?» and this was also my concern. In reality, deaths from AIDS are talked about, but always through graphics and numbers which result in the creation of a process of depersonification. What was missing was hearing about the experience of suffering and dying. It must be acknowledged that the spectre of certain death in the past has created a wave of positivity in the general environment of the conference in recent years, but I observed that this created a political anaesthesia around the consequences of AIDS and death.

Nowadays, as pointed out previously, the turning point on the global response to AIDS came in 1996 with access to antiretrovirals which gradually changed the chances of living with HIV. However, while in many countries of the northern hemisphere, a positive HIV status can be considered a chronic state of life and average life expectancy, this still does not happen in places like Mozambique where, in my opinion, people die in the shadows as a result of the consequence of AIDS.

Speaking of death and the various forms of dying creates a fracture both in the researcher, as I reflected in the previous chapter, and in the world of humanitarian aid. While for me it was an ethical fracture where the research must stop or change direction and time, for the humanitarian complex it is a design failure, in which deaths are analysed through statistics and drugs resistance, rather than through the trajectories of people's life stories. This tends to dehumanise the event of death by not allowing for reflection and self-criticism of the fact that there is no qualitative (I would even say ethnographic) analysis of the failure of AIDS treatment and prevention projects. I had the feeling that there was a great disparity between what emerged in the reports and speeches of the NGOs and the reality observed in the Maputo hospitals. They were dying in invisibility.

«**Treatment as prevention**» **challenges and concerns**

The goal of this paragraph is to analyse the growing relevance of viral suppression in the management of HIV at the global level to understand the challenges in the Mozambican context, when it started in august 2017. Firstly I will analyse how the campaign «treatment as prevention» works and how the term «undetectable» appeared as a new category in the community. Secondly I'll show the difficulties in taking this approach all over the world, from individual to community-level discourses.

Picture 21: 22nd International AIDS Conference (AIDS 2018) Amsterdam, Netherlands. Copyright: Matthijs Immink/IAS. Community march in Amsterdam

Historically, since the identification of HIV in the 1980s, treatments were slow to be developed and often had severe side-effects (Arno and Feiden 1992). The availability of new classes of drugs in the 1990s – that slowed the replication of the HIV virus – radically reduced HIV-related morbidity and mortality (Sepkowitz 2001).

The discover of a new treatment improved health outcomes although these drugs also presented some toxicity (Burgoyne and Tan 2008). However, the production of affordable options in a global scale was restricted due to the trade of patents (Walwyn 2013), producing debates about whether to focus «limited» resources on HIV prevention or treatment. However a series of clinical trials demonstrating the efficacy of early antiretroviral therapy initiation to reduce HIV transmission in serodiscordant (or mixed-status) couples (Cohen et al. 2012).

Until 2010, antiretroviral therapy was only to be started if the CD4 cell count fell below 350 cells per mL, thus beginning to feel the decline in the body for HIV-related aspects. Following the revision of the WHO guidelines in 2013, the start of TARV was indicated for a CD4 below 500, thus avoiding irreversible decline (WHO 2013b).

Treatment as prevention refers to taking HIV medication to prevent the sexual transmission of HIV: «It is one of the highly effective options for preventing HIV transmission. People living with HIV who take HIV medication daily as prescribed and get and keep an undetectable viral load have effectively no risk of sexually transmitting HIV to their HIV-negative partners.»[13]

As Doctor Anthony Fauci, director of the US National Institute of Allergy and Infectious Disease, affirmed during the pre-conference U=U (Undetectable=Untransmittable) 2018, there should be a focus of attention on the importance of the community correlation on viral load and regular viral testing:

> When you introduce any retroviral drugs into the community the community incidence goes down. This is treatment as prevention. As you increase the percent of people on TARV the percent of virus in the community goes down.. U=U…but only when U is really U. This is the individual responsibility to make sure that they are undetectable…[14] U=U only happens when you control your viral load. If you do the test now and you do it three years from now, you cannot be 100% sure you are still U (undetectable). For the CDC you have to repeat the viral load test every 3 to 4 months and if you go well you can repeat every 6 months. You cannot go for a viral load once and then you are fine for 5 years, that is not what you want to do, you wanna follow it (Anthony Fauci, Presentation at U=U preconference, 22th July 2018).

---

[13] https://www.hiv.gov/tasp.

[14] «The PARTNER study was a prospective observational study done at 75 sites in 14 European countries. The first phase of the study (PARTNER1; Sept 15, 2010, to May 31, 2014) recruited and followed up on both heterosexual and gay serodifferent couples (HIV-positive partner taking suppressive ART) who reported condomless sex, whereas the PARTNER2 extension (to April 30, 2018) recruited and followed up gay couples only. At study visits, data collection included sexual behaviour questionnaires, HIV testing (HIV-negative partner), and HIV-1 viral load testing (HIV-positive partner). Results provide a similar level of evidence on viral suppression and HIV transmission risk for gay men to that previously generated for heterosexual couples and suggest that the risk of HIV transmission in gay couples through condomless sex when HIV viral load is suppressed is effectively zero. Our findings support the message of the U=U (undetectable equals untransmittable) campaign, and the benefits of early testing and treatment for HIV.» (Rodger 2019: 2428)

The treatment-as-prevention approach is based on reducing the promotion of new infections (Johnston et al. 2010). In other words, there has been a shift from the use of antiretroviral therapy to avoid virus replication to the specific goal of maintaining an «undetectable» viral load (usually defined as under 50 copies per millilitres and as little as 30 copies per millilitres) (Widdrington et al. 2011).

Beyond the scientific community, the notion of «undetectable» has made its way into individual and community-level discourse (Grace et al. 2015). During IAC 2018, one of the main campaigns that caught my attention was the «prevention access campaign» founded by Bruce Richman, a charismatic Northern-American HIV-positive activist. The campaign focuses on the U=U message, which means Undetectable equals Untransmittable. With research confirming that people on effective HIV treatment cannot pass on the virus to sexual partners, U=U aims to pass this powerful message, to transform HIV prevention and care and to liberate people from stigma and fear. As Bruce Rickman, founder of U=U movement said:

> U=U sets us free. System fears, prejudices and paternalism give permission to the HIV providers including its positive leaders to decide for us rather to educate us, to control people living with HIV, rather that trust people living with it, especially those communities neglected by the health care system. We believe people living with HIV have a right to accurate information about social, sexual and reproductive health. Withholding that information from us is an act of violence against us. It is your body and right to tell the truth or we will tell it for you, and we will do it all over the world… Treatment guidelines are updated in Vietnam and Uganda. Many activists are risking lives and reputations to speak about it… Challenge authorities, is an active revolution, many powers structures and leader that meant to protect us, didn't. If they are not using every platform to get the message out, urgently tell them to do their jobs. leave no one behind, it is a revolution that must include all (Bruce Rickman, March speech, 24th July 2018).

Picture 22: 22nd International AIDS Conference (AIDS 2018) Amsterdam, Netherlands. Copyright: Matthijs Immink/IAS. The U=U 2018 dance party.

U=U is not a new discovery reason why during IAC 2018 activists affirmed that U=U was considered the «big secret» in HIV.[15] Some issues that arose from the statements made by Doctor Fauci and Bruce Riechman also concern the scientific community and social researchers. While «test and treat» with earlier initiation may delay the deleterious health effects of HIV, it requires people who perceive themselves to be asymptomatic to commit to a drug regimen that may cause physical side-effects. As Rosengarten has noted, what the success of antiretroviral therapy «does not convey so well is the potential toll, borne by those engaged in a most intimate corporeal relation with the drugs» (Rosengarten 2004, 92). Encouraging people to start treatment immediately after a positive test, raises doubts in both the community and the scientific population with respect to individual biophysiological cultural and socio-economical differences between patients (Guta et al. 2016; Strub 2010).

The second aspect that concerns the scientific community deals with the tension between the individual and community levels when speaking about viral load suppression (undetectable).

---

[15] https://preventionaccess.org/news-title-02-lorem-ipsum-dolor-sit-amet-6/

Speaking within the north American context, Guta and colleagues highlight that, for people living with HIV, the treatment-as-prevention emphasis on individual and collective viral load is transforming the performative dimensions of embodied risk, affect, subjectivity and sex (Guta et al. 2016). The risk is to send contradictory messages that are not accessible to different socio-cultural contexts. One aspect is that this campaign takes it for granted that sex is stable and monogamous, which for different reasons - social, economic, cultural - is not the case.

Furthermore, it is important to analyse the possibility of individual choice, individual responsibility and viral load testing in some countries around the word. Can we introduce the U=U campaign in countries, like Mozambique, where viral load test are weak and fragile? During one of the U=U sessions at IAC2018, doctors and activists were discussing how to bring the message to the «south». An activist from South Africa expressed her concerns in bringing the U=U message to a country where people still confuse CD4 count and viral load. Another activist from Burundi underlines the impossibility of doing the viral load test properly U=U: «usually we receive the result of the first viral load test when we have to do the second test».

The doubts raised at the conference, those that health workers have encountered in the field, and my own, are similar. If in western countries the U=U campaign raises some concerns about restigmatisation and the use of new categories for example, in countries like Mozambique the problem is still more complex and has to do with the third U, unequal. In countries where access to health still faces many barriers, how can we not recreate a scientific apartheid, where some countries are prevented from having certain types of information? But at the same time, how is it possible to introduce a similar campaign in countries where the health system does not allow it?

While U=U, with all our concerns, changes the way of living with HIV in the seropositive population in the northern hemisphere, this is still not happening in the global south, were people have been left in a «scientific apartheid» and, in the words of William Matovu, a seropositive activist of Love to Love Organisation in Uganda «we have to decolonize HIV». This is more evident in the «south» of the world.

On the one hand I think that U=U conveys an important message which speaks of a history of paternalism in public health services where certain issues are kept «secret» and away from people living with HIV, particularly in marginalised countries. On the other hand, transmitting the message from the individual to the community is a matter of practice. I believe that the lack of health facilities and the impossibility of controlling the viral load create an impossibility in transmitting the message and concerns in implementing the campaign.

Chapter III

Health sector and the politics of AIDS

Health in colonial times

The main purpose of this chapter is to provide an historical background to better locate health practices, and address how colonial and postcolonial legacies have emerged in the daily life of health centres from the point of view of health workers and patients.

The establishment of the Portuguese Empire at the end of the 19th century on the one hand created the conditions for the military and administrative occupation of Angola, Guinea and Mozambique, but also for the extension of public and private health services to the occupied territories (Havik 2014).

During the early 20th century, it was already evident that Portuguese rule was consolidated in the southern part of Mozambique and in the following years Lisbon gained nominal control of the entire colony. As Isaacman and Isaacman stated, colonial rule transformed the basic fabric of Mozambican society (Isaacman and Isaacman 1983).

Despite the broad continuity of colonial policy, as Allen and Barbara Isaacman note, three discrete periods can be identified in Mozambican occupation by the Portuguese state (Isaacman and Isaacman 1983). The first period, which lasted until the mid-1920s, was characterised by a government steeped in corruption and highly disorganised and decentralised. Mozambique's economic dependence on South Africa also dates from this period (Isaacman and Isaacman 1983). It is a period that Claudia Castelo summarises as characterised by isolated measures that envisaged the creation of agricultural colonies. Indeed, at the end of the 19th century there were attempts to promote white settlement, which often came up against a shortage of resources and a lack of state planning (Castelo 2009).

The second period was when the Salazar regime came to power in 1933, imposing a highly centralised authoritarian regime. Its aim was to stimulate the development of the colonial cities and to give the industrial and capitalist class more and more importance (Isaacman and Isaacman

1983, 1983). After the Second World War, a period began in which Portuguese colonialism resorted to new forms of legitimation as a way of circumventing racial submission and the coercive recruitment of workers, characteristic of the exploitative economy it had practised until then. Thus, it was under the auspices of Luso-tropicalist ideology that the political power projected the rapid and intense populating of the colonies with natives of the metropolis (Castelo 2009).

The last period was characterised in particular by growing opposition and the creation of the FRELIMO party, officially founded in 1962, forcing the Portuguese regime to create illusory remnants and promote the myth of multiracialism (Isaacman and Isaacman 1983, 1983).

The health services in the colonial period in Mozambique were administered by the Provincial Directorate of Health Services and Assistance in 1968 and texts highlight the «civilizing» importance of these services (Gomes Morais 2014).

One of the objectives of the Portuguese colonial regime was at that time to bring civilization to the indigenous population through health and education, at the same time fighting beliefs and the use of traditional healers. Mozambique health policies dialogue very strongly with the ideology of the «civilizing mission», being considered as privileged forms of intervention in everyday life of the population (Gomes Morais 2014).

As Cristiana Bastos argues, attempts at subjugation to biomedical knowledge existed in Mozambique even before colonial power was formalised. However, efforts and attempts to promote biomedicine had limited impact. After 1890, however, with the establishment of colonial rule, biomedical knowledge became to all intents and purposes an instrument of domination, attempting to counter traditional healing practices. This project met with considerable resistance. Yhe local populations "continued to fear and flee from European-style hospitals and colonial medical care" (Bastos 2007, 766). During the 1920s, some Portuguese doctors argued the importance of adopting some of their customs to achieve results (Bastos 2007).

Health care before independence was typically distorted in favour of the white urban settlers. Discrimination against black Mozambicans and those too poor to pay for medical treatment was marked. When preventive services existed, they were basically aimed at ensuring a minimum standard of hygiene and protecting the settlers from the spread of infectious diseases. In the last year of colonial rule, this attitude was also reflected in the investments, mainly directed towards the central hospital in Maputo. (Segall and Noormahomed 1994). As a result, more than two thirds of the doctors were in the capital and working in private practice in the three main cities, where 10% of the population resided (Walt and Cliff 1986). In the words of Antonio Rebêlo, Magude's health sub-delegate: «The best medical care to be provided to the indigenous and the one we have an imperative duty to do in Africa, if we are to play our civilizing role, is undoubtedly preventive assistance.» (Direção dos Serviços de Saúde e Higiene 1942, 56) .

As Megan Vaughan argues, in colonial discourses the African continent has always been considered a «disease contender», where violent epidemics also punished settlers at great risk (Vaughan 1991). Disease control was one of the important conditions for colonisation in the African territory from the late nineteenth century. While colonial medicine was concerned with protecting colonists from disease, the other attention was also directed to protecting the labour force (Dube 2009). Medicine in colonial times highlights the political role used to justify and legitimise the domain replacing even the military apparatus (Beneduce 2010). Surveillance post-control was created to control the movement of natives with the aim of preventing the spread of disease (Beneduce 2010; Dube 2009). In the most violent forms, control was done through the creation of segregation camps where the spread of diseases due to difficult conditions often made the epidemic situation worse leaving the local population in a «sanitary apartheid» (Beneduce 2010).

The assistance of official medicine was provided by different institutions: military organisations, religious institutions (Protestant and Catholic missions), private companies, private clinics and the state through the Health Services. This diversity of private and public institutions was characteristic of medical care until the end of the colonial period (Gomes Morais 2014).

As Dube points out, medical complexes elicited multiple responses from the natives – adherence/repulsion of interventions – but even though they fought the intrusive and discriminatory methods of colonial preventive medicine, they remained interested in using the health complex, in particular for the available treatments (Dube 2009).

What actually emerges nowadays is that some of the reluctance on the part of people to embrace is linked to social memories and perceptions of the state, and its legitimacy (Dube 2009). This is particularly relevant when we draw a line between the system, methods and rhetoric used by doctors in the colonial time for infectious diseases like syphilis and in recent times for infectious diseases like HIV/AIDS.

African Sexuality and colonial medicine

During colonial times, a particular image of «African morality» resonated in Europe (Packard and Epstein 1991). The idea was that the «primitive native» was having particular difficulties in adapting to the industrialised and civilised world (Packard and Epstein 1991). Related to the lack of civilisation was also the explanation for tuberculosis in Africa for example. In fact, being particularly susceptible to tuberculosis had to do with the failure to adapt to the conditions of civilisation and the inability to observe European customs, diet and health habits. (Packard and Epstein 1991). On the other hand, it was argued that Africans who lived in the countryside and worked in an outdoor environment tended to be healthy (Packard and Epstein 1991).

Focusing on the inability of Africans to adapt to civilisation, as a basis for the creation of a theory on health and disease in Africa, places the responsibility for the adverse conditions in which they live on themselves. Consequently, it makes the victim responsible for the disease (Packard 1987).

The history of syphilis in East Africa, illustrated in a work by Marc Dawson, shows another example of how explaining the peculiarities of diseases in Africa through a theory of behaviour, leads to the creation of specific medical response patterns (Dawson 1983). As with tuberculosis, also for syphilis, there was initially a certain lack of understanding in the Western medical context during the first decades of XX century. Specifically, the epidemiological and pathological differences between yaws, venereal syphilis, and endemic or non-venereal syphilis had yet to be sorted out around syphilis took over, intrinsic to racial stereotypes (Packard and Epstein 1991). Confusion among medical personnel working in Africa led European observers to see differences between the African and European experience in relation to syphilis and to look for causes for these differences. As with tuberculosis, theories of behaviour around syphilis took over, intrinsic to racial stereotypes (Packard and Epstein 1991).

There were established theories and stereotypes in relation to the sexuality of Africans, on which colonial medical evidence was based. For example, the extreme sexuality of Africans was the main cause of the high rate of spread of syphilis, assumptions for which they had virtually no empirical evidence. Moreover, as Sander Gilman points out, the association between African sexuality and disease has a long history in Western thought (Gilman 1988).

As Megan Vaughan argues, African sexuality in the colonial period has always been perceived as «primitive», uncontrolled, excessive, representative of the darkness and danger of the African continent. Metaphorically, Africa was a continent of female conquest, although the settlers were mainly interested in the male population for forced labour (Vaughan 1991).

Female sexuality was a concern of colonial administrations for its control, and containment was one measure of the effectiveness of an indirect rule policy in shoring up the existing system of social control. But male sexuality was a more immediate problem because men more than women populated the colonial cities and constituted the labour force (Vaughan 1991). The issue of natives' sexuality was tending to control female sexuality so as not to infect the workforce of men and of colonists with sexually transmitted diseases (Vaughan 1991).

In *Black skin, White mask*, Franz Fanon describes the objectification of the black as a sexualized «other». The myth of black sexuality was a myth of excessive sexuality. Female sexuality was a danger that took centuries of «civilization» to tame (Fanon 1986). African female sexuality was doubly dangerous, being both African and wild and female and wild, in line also with the medico moral discourse about sexuality in Britain during the early twentieth-century where «race» and sexuality were explicitly linked (Vaughan 1991).

There was a general consensus during colonial times that female sexuality was the cause of many syphilis epidemics – called «the disease of immorality» – in African countries. For instance, as Vaughan argues, in Colonel Lambkin's reports on syphilis in the Uganda protectorate, the moral problem of the epidemic was seen to stem from the disintegration of «traditional» patriarchal authority – introduced in particular by Christianity – unleashing an uncontrolled female sexuality. Again, the inability of African women to get used to the «civilized society». Female sexuality was seen everywhere as a danger but the male medics saw it controlled in a «civilized» country. Polygamy was seen as being responsible for the rapid transmission of the disease and morality through missionary education for controlling it and the creation of the «African Christian family» was considered the solution (Vaughan 1991).

Between forms of population control, as reported by Francis Dube, *Chibeura*, which literally means «forced to open the legs for inspection», has often been described by women as another violent practice implemented by the colonial medical system in Mozambique (Dube 2009). The crudity of gynaecological inspections was shamefully recognised as a central element of this control (Jackson 2002).

Inspection, control, segregation and surveillance were typical actions and expressions of medical reports during the colonial period. The political space that colonial medicine creates in the colonies was vastly expanded, legitimising domination and replacing military action (Beneduce 2010). For instance, to prevent the spread of smallpox, orders were given to burn all Mozambican houses in Mozambique. It is not difficult, argues Beneduce, to imagine what effect this vocabulary and violence had on the colonised and what image of «white medicine» was produced in the indigenous mind (Beneduce 2010). For instance in Mozambique, the forms of subjugation enacted on the native populations were contrasted with forms of resistance. During vaccination campaigns for smallpox, village chiefs were often called upon by the Portuguese authorities to convince the local population to vaccinate, but resistance to vaccination campaigns took various forms, including concealing a smallpox outbreak to avoid vaccination, hiding in the bush to avoid vaccination teams, or outright refusal to be vaccinated (Dube 2009)

From Independence to the civil war

25 September 1964 marked the beginning of the the Mozambican War of Independence, an armed conflict between the guerrilla forces of the Mozambique Liberation Front or FRELIMO (*Frente de Libertação de Moçambique*), and the colonial regime of Portugal, which ended with a ceasefire in 1974 and the negotiation of independence in 1975. President Samora Machel (a former nurse) and FRELIMO made the creation of a national health system a top priority and at independence, health care was accorded the basic right of every citizen, effectively free to all (Pfeiffer 2019).

Samora Machel dreamed of a health system without segregation and for all classes, with a restriction on the activities of religious missions that had long been central actors in the provision of medicine, and an important commitment as a «political medicine» was part of his plan as he argued in one of his speeches in front of the central hospital in Maputo in 1976:

> Let's speak about health – heath as a service to the people. If we say that we want to politicize health services, someone will say: politicize medicine? Politicize instruments? Medicine is intimately linked to community, intimately linked to society, intimately linked to people's lives. That's why we need to politicize medicine […] Health is indispensable for the fulfilment of our revolutionary tasks. Without health we are unable to fulfil our task, our body does not respond to

> the demands of the struggle and the community is harmed (Machel 1976 citation in Ministério dos Combatentes 2016, 156)

After independence, as Ramah McKay argues, the lingering influence of Mozambique's charismatic first president, Samora Machel was an important factor in the creation of the public health system (McKay 2018).

Primary health care (PHC) initially intended to focus on the scaling up of basic services to its largely rural impoverished population. With the nationalisation of the health system in July 1975, the situation was chaotic. Indeed, out of 550 doctors in the country, more than 85% left, with rural health centres and clinics left to neglect. Only a few health centres remained functional, run by unqualified staff who did their utmost to learn from experience. Primary healthcare was instead guaranteed in the liberated areas in the north of the country, although technicians were often sent on training courses (Walt and Cliff 1986).

The health programme presented at the Third Congress of FRELIMO (and essentially unchanged at the Fourth Congress) made the organisation of a health system and health access for all Mozambican people a fundamental task of the Party. The aim of the Party was to «preserve and improve continuously the immense revolutionary capital constituted by the health of the masses». Extending coverage and giving priority to preventive measures was seen as the health sector's means to this end (Ministério dos Combatentes 2016).

In 1977 the Ministry of Health established the basic health infrastructure for the country. The national health service was to consist of a network of village health workers, health posts, health centres, rural, district and provincial hospitals and three central hospitals. The primary level of this health network had to be constructed from almost nothing. One year after independence, the country had a significantly low number of doctors: 60, as opposed to 289 four years earlier (Vio 2006). FRELIMO, therefore decided to invest in the expansion of rural health posts and at the same time focus on training for mid-level medical staff and community health workers. This resulted in Mozambique being recognised as a model of primary health care by the World Health Organisation in 1980 (McKay 2018).

Health worker training expanded enormously. Between 1975 and 1988, over 1,000 health centres were built or renovated and approximately 2,000 nurses, 110 X-ray technicians, 290 pharmacists, 272 mid-wives and 1,000 village health workers have been trained (Walt and Cliff 1986; Pfeiffer 2019).

As McKay notes, there is a rhetoric around the «glorious days of Samora» in the discourses of health workers. This period is remembered as a time of great inspiration for efforts to expand public health in Mozambique and make it an example to the world (McKay 2018).

The political engagement of health workers and their «role» and objectives were considered part of the «revolution», as Samora argues:

> It is necessary for health personnel to determine and consider as a victory what they have already done: merging the hospitals, eliminating certain discriminating wards, eliminating indigenous, European and other maternity wards… now it is necessary to fight for their consolidation. Without fight there will be no consolidation. Fight requires the complete abandonment of the comfort zone. Where there is war there is no comfort. And our people now wage war to consolidate their victories. It is therefore necessary that all health personnel consciously accept and engage in the fight that our people continue to fight to consolidate their victory. Without a fight there will be no victory (…) We need to create Health Workers with a new mindset – The mindset of serving the people (Machel's speech in 1976, citation in Ministério dos Combatentes 2016, 158)

Nowadays workers' inspirations and expectations are still informed by historical legacies. During a lunch break at a conference organised by PEPFAR, I was at a table with Mozambican colleagues and they were discussing the «Samora time». Some of them were speaking somewhat melancholically about how times have changed. One lady told me when working in health care at the time of the war had become a kind of opportunity to get training and experience. Informal comments show how this melancholy of a hopeful period in history has influenced the history of medicine in Mozambique to the present day (McKay 2018).

However, due to the Cold War context, after an initial post-independence phase of great success and enthusiasm, the RENAMO (Mozambique National Resistance) party was formed with the support of Rhodesia and South Africa. In 1977 a war of destabilisation began, with attacks on government infrastructure, health posts, roads, schools and rural communities (Cliff and Noormahomed 1988).

After a decade of conflict, Mozambique was virtually bankrupt, and its public services were weak. In the midst of the ongoing war (the late 1980s), the government was heavily indebted leading it to sign onto a SAP (Structural Adjustment Program) in 1987 that imposed austerity measures on the ravaged public sector introduced through a World Bank/IMF with health workforce cut and salaries reduced (Cliff 1993; Pfeiffer 2003; Cliff and Noormahomed 1988).

USAID and European bilateral donors began to channel aid through international non-governmental organisations to implement those projects that often functioned independently of MoH plans or finances. Throughout the 1980s and into the early 1990s, political-economic reforms dismantled key features of the public health system, enacting fee-for-service health plans and moving away from the primary health care goals that had structured the post-independence health system. This also opened new spaces for nongovernmental intervention in public health (Pfeiffer 2003).

SAP was pressed for the privatisation of public services and industries, cuts in the budgets for health and education, removal of price subsidies for food and fuel, the scaling back of other social safety nets, and cutbacks in social services (Cliff 1993; Fauvet 2000; Hanlon 1996). Rapid class differentiation (in contrast to the post-independence socialist period), glaring economic disparities, and growing corruption emerged over a very brief period (Pfeiffer 2019).

At the same time a large proportion of health-sector aid from donors was being redirected to NGOs as state services were contracted under the SAP. More than 100 agencies were present in the country in the early 1990s to support the health sector (Hanlon 1996). The landscape in the early 2000s was of hundreds of projects in the health sector, mainly run by NGOs with a superficial link to the national public system (Pfeiffer 2019).

When Apartheid ended in South Africa, RENAMO agreed to a cease-fire in 1992 followed by elections in 1994, won easily by FRELIMO. By the end of the war in 1992, continued political reform had further relaxed state controls on non-governmental actors and interventions, and transnational organisations had become central to the provision of health services in Mozambique. At first providing war relief (Hanlon 1996), many NGOs later went on to take enduring roles in the provision of health services through the Ministry of Health or through verticalized programs targeting specific diseases (Pfeiffer 2003). In light of these transformations, scholars of Mozambique have argued that sovereignty over core governmental functions appeared to be «ceded» to nongovernmental and transnational organisations (West 2005).

The spread of NGOs and the emergence of global health and humanitarian interventions as primary modes of administering life in much of Africa has enabled new structural, institutional and clinical practice of care and enacted new temporalities of care and labour (McKay 2018). Cohen pointed out that one can speak of a «humanitarian gift» when talking about medicine and that it is «increasingly organized less around a future promising access to basic clinical and preventive care and more around a present demanding the urgent supply of lifesaving medication or emergency supplies» (Cohen 2012, 87).

During the meetings with health workers and patients, the humanitarian rhetoric of «request» and «gift» was often present, creating a break with what had been the socialist ideal of medicine as a «sacrifice» for the people. As McKay states, people make clear how humanitarian goods and practices are historically informed through connections between politics and aid, between past and present (McKay 2018).

The AIDS epidemic in Africa

As shown in the previous paragraphs for the case of Mozambique, in order to understand the history of Africa and consequently its dynamics today, we must always take into account how power and economic systems were shaped. The slave trade, dependency in colonial days, wars of independence, military coups and Cold War interests have all affected the post-colonial era (Barnett and Whiteside 2002). Recently IMF and the World Bank with structural adjustment have created a new economic, political and social shape in Africa, in which HIV/AIDS policies are also played out (Barnett and Whiteside 2002, 124-56). To understand the presence of the humanitarian apparatus in the context of the HIV/AIDS epidemic in Africa, one has to examine the continent's history in depth (Barnett and Whiteside 2002; Iliffe 2006).

Medical researchers in Africa quickly realised that the epidemiology of the disease was different from that in the west. While the ratio of male to female cases was 13:1 in the west, the ratio in Africa was nearly 1:1. This aspect and the apparent absence of risk groups such as drug users and homosexuals made the researchers hypothesise a different kind of transmission than in

Western contexts. This led researchers to ask what it was about Africa and Africans which accounted for its peculiar pattern of transmission. One of the issues that made it difficult to understand was the lack of medical knowledge and the idea that the explanation and origin of AIDS was in Africa led researchers to a great deal of speculation with little available data. In line with colonial medical thinking, it is not surprising that stereotypical images of Africa and Africans began to emerge in relation to the epidemiology of AIDS (Packard and Epstein 1991).

This quickly led to two theories. On the one hand, it was thought that AIDS had existed on the African continent for a longer period than in the West and had consequently reached a different epidemiological stage. In line with this theory were the virological theories of the Essex group, which argued that AIDS originated in Africa from the green monkeys (Gallo 1987). This first theory outraged African governments and was seen as imperialist. In response, the governments' coverage of the policies and research proposed by the West to fight the spread of the virus were often scarce.

The second theory explains the heterosexual transmission of HIV in Africa by focusing on a theory of the sexual behaviour of Africans. Again in line with historical explanations of syphilis and tuberculosis transmission, Africans were again blamed for promiscuous sexual behaviour or in the language of social science research on AIDS, for having 'poly-partner sexual activities'. The middle class businessman or bureaucrat with a string of lovers, truck drivers, prostitutes were immediately identified as the main vectors of HIV in Africa (Packard and Epstein 1991).

However, Jaques Pepin, in his comprehensive work on the origins of AIDS, put forward another view, namely that in many African countries colonial medicine often reused syringes and needles in campaigns against tropical diseases, creating a development of HIV-1 and a cross-species transition with chimpanzees. In his theory, Kinshasa became the early HIV epicentre from which subsequent global dissemination occurred, mainly through sexual transmission (Pepin 2011).

However, by the 1980s, the Western media had already defined and associated AIDS with aberrant lifestyle behaviours in the west. Therefore, it was not difficult to look for «deviance» also in the African context. However, this search for «behavioural risks» focused in particular on the issue of Africans having multiple partners, increasing the impression that sexual promiscuity is culturally determined, while excluding from discussion broader patterns of everyday sexual activity which in many cases are both less exotic and more monogamous in character (Packard and Epstein 1991).

Farmer, for instance, suggested that the AIDS epidemic has less to do with culture and more with an imbalance of power: to explain the AIDS pandemic, for the author, we have to consider some axes that could increase the risk for extreme human suffering in «multi-axial models of suffering» like gender, ethnicity («race») and socioeconomic status, where each may be shown to play a role in rendering individuals and groups more vulnerable to extreme human suffering. Furthermore, continued the author, as social scientists we have to be aware of the conflation of structural violence and cultural difference (Farmer 1999). The political disruption of family life generated by wars and migrations – and health policies that have little taken into account the social, cultural and economic differences of the continent, have had a major influence on behaviours considered «deviant», such as polygamy.

On the other side the Mozambican population created an heterogeneous system of representation and explication of the AIDS pandemic. For instance an HIV-positive activist tells me that in the first place during the 1990s, it was common to believe that AIDS was an invention to control polygamy. The meaning of the acronym SIDA was therefore transformed into «Sistema de Diminuição de Amantes» (System to reduce lovers). In this regard, Marianna, one traditional healer says:

> «AIDS is not a disease that has always been there. A long time ago, white people arrived in Mozambique by plane carrying suitcases with them. They came from afar and brought AIDS» (Marianna, Cocomela, February 2018).

In situations of domination such as that of Mozambique, rumours of virological conspiracy and illness brought by whites or from outside were often recurrent (Fassin et al. 2007; Quaranta 2006). The idea of the international introduction of the virus, the possibility that the HAART could be dangerous for populations, or that public health programmes would contribute to discrediting African societies and their governments, have had a particularly strong echo in African public opinion (Fassin 2010). The possibility that the HIV virus was used for sinister purposes is not entirely unfounded. As Fassin (2007) and Usdin (2003) write for South Africa, Dr. Wouter Basson, also known as Dr. Death, who was the scientific director of the chemistry and biological warfare programme, was hired to eliminate political enemies using chemical methods such as sterilisation. During the trial that took place in Pretoria between 2000 and 2002 it was admitted that among the infectious agents considered for this project, the AIDS virus had been the subject of experiments which consisted in sending black spies to motels to infect the population (Usdin 2003; Fassin 2007). In light of these facts, therefore, a persecutory interpretation of AIDS is not surprising, where the suspicion of science and medicine, of their discoveries and their remedies, seen as tools of white domination, takes on a tragic dimension, aggravated by colonial memory (Fassin 2007).

Politics of AIDS in Mozambique

Over three decades have passed since the identification of the first cases of HIV/AIDS in the country. If until 1992, the civil war had restricted circulation within and outside national borders. The return of refugee movement who had fled the war, as well as the intensification of economic and commercial activity, has since contributed to the rapid increase in prevalence levels in Mozambique. The new millennium inaugurated the inclusion of the country and the African region to which it belongs – sub-Saharan Africa – into the group of countries with the highest levels of HIV and AIDS in the world (Manuel 2011).

Data from 2018 estimates that 2,200,000 people were living with HIV in Mozambique, of which 140,000 were children. The HIV incidence rose from 11.5% in 2009 to 13.2% in 2015 in the age group 15 to 49 years (PEPFAR 2018). HIV remains the major cause of deaths in the country and the second leading cause of disability.[16] With 356 new infections per day, out of which 28.7% are related to key populations (MISAU 2015), and 70,000 HIV/AIDS-related deaths, Mozambique still struggles with an HIV emergency. The country also has one of the highest vertical transmission rates from mother to child, at 14% (MISAU 2015).

In terms of national policies, 1986 marked the beginning of a concern about the problem in Mozambique when the first AIDS case was diagnosed in a Haitian doctor who was in the country (CNCS 2004). The World Health Organization (WHO) had taken a central role in coordinating efforts to discover and combat the epidemic globally. The implementation of the

---

[16] http://www.healthdata.org/mozambique.

global strategy by WHO implied the collaboration of this organisation with the countries in the design of national plans to fight AIDS that would translate into policies for managing the disease (Mann and Kay 1991; Matsinhe 2008).

The remarkable intervention of WHO in these processes, as part of its strategy of globalisation of the response structure was proudly mentioned in its documents, which indicated that, in 1991, around 157 countries had a plan to fight AIDS; however, «it says nothing about the contents, degrees of ownership and implementation of these plans» (Matsinhe 2008 39). It is also noticed that, from the beginning of the epidemic management process, Mozambique had already been following an imported model with a top-down character, since the specialists, the model of the policies to be implemented in the fight against AIDS, as well as health and AIDS education materials, were imported. Such a process reflected humility and the lack of local expertise in managing the new epidemic. However, as mentioned by Crisitano Matsinhe, there were responses that, although discreet, had a very significant character in the stages of structuring the Mozambican response to AIDS (Matsinhe 2008).

The idea of achieving «changes in behaviour» as the main objective, permeates the Mozambican reaction against AIDS in all its stages. And it is repeatedly invoked throughout the interventions of the different actors, in different tones and different ways (Matsinhe 2008, 45).

From 1992, the emphasis was placed on condoms. The focus was on concentrating efforts so that their distribution entered a more dynamic phase, thus creating the need to design a marketing strategy and improve the distribution network (MISAU 1992). To implement the condom's social marketing strategy, MOH hired Population Service International (PSI), with funds made available by the American Agency for International Development (USAID) (Manuel 2011).

This strategy embraces the so-called ABC approach: «Abstinence, Be faithful and use Condom», arguing that its emphasis on «primary behaviour change» would reduce HIV prevalence. USAID later embraced the message, and PSI also began to promote the ABC approach while continuing its campaigns. As some authors claim, basing prevention policies on a «theory of change» shifts the discourse from medical to moral in treating a disease (Passador 2009; Gune 2008). The ABC model, crystallises the notion of a behavioural disease associated with improper, censurable behaviour. Guidelines in recent years based their initiatives in particular on fidelity and abstinence, considering them more feasible than the use of condoms (Passador 2009; Gune 2008).

In 1996, UNAIDS was created and started to take on the response to HIV and AIDS, previously coordinated by WHO. In 1999, the World Bank launched the Ideal Strategic Plan model, which prescribes that the fight against HIV and AIDS must start at the highest level of political leadership (Manuel 2011). It is within this scenario that, in 2000, the National Council for Combating HIV-AIDS and a national strategic plan – a guide for action and change were created.

Multi-sectoral response was reflected in the central objectives of the first National Strategic Plan to Combat HIV and AIDS - PEN I (2000-2002), to reduce the spread of HIV infections and to mitigate the effects of the epidemic through a multi-sectoral response with a focus on prevention actions (UNAIDS 2009).

Non-governmental interventions in medicine expanded dramatically again following Mozambique's 2004 decision to make treatment for HIV/AIDS universally available through the National Health Service[17]. This brought new organisations to intervene in public health policy creation and implementation. Organisations such as the International Coalition for Health, a «care and treatment» organisation, provided clinical staff, health worker training, and access to medications.

The Mozambique experience suggests that a primary goal of new approaches should be the creation of frameworks for long-term dialogue between health workers and communities to establish trust and channels of communication, rather than focusing on the top-down imposition of a packaged message, whether it is sex positive or ABC oriented (Pfeiffer 2003).

Concerted HIV testing efforts were only initiated in 2001, while prevention of mother- to-child transmission (PMTCT) services began in 2002. The scale-up of antiretroviral treatment (ART) in Mozambique finally began in 2004, using the WHO «public health» approach, with support from PEPFAR, the Clinton Foundation, the World Bank, and the Global Fund, among numerous other donors (Pfeiffer 2013).

---

[17] Until then, access to antiretrovirals was almost non-existent and only in a few specific exceptions and with exorbitant prices was it available. One of the first and few institutions to deal with HIV-positive people and access to treatment in Mozambique was the Community of Sant'Egidio, which in 2002 started the DREAM project (Disease Relief through Excellent and Advanced Means) and now has more than 13 centres in Mozambique.

One of the initial characteristics of the PEPFAR project was verticality, focusing on HIV-related services and not on improving the broader health system (Pfeiffer 2013). Vertical and horizontal approaches to health have some fundamental differences. Vertical programs often have a preventive focus but they stem from a curative care model. As such they employ a western problem solving approach, and are often disease or health issue specific, such as AIDS or malaria. In essence, they focus on a health problem and develop strategies to reduce or eradicate it. On the other hand, horizontal programs seeks to tackle the over-all health problems on a wide front and on a long-term basis through the creation of a system of permanent institutions commonly known as «general health services».

Most visibly and dramatically, the vertical approach, managed primarily by NGOs, resulted in twenty-three new ART-focused «day hospitals» constructed beside crumbling primary health care infrastructures in existing public urban health system compounds, however these were disruptive. Day hospital staff were often paid better than other health workers, NGOs often used expatriate doctors to provide clinical care, and basic materials and equipment were plentiful compared to the other sections of the health system (Pfeiffer 2013).

In principle, the ART scale-up was being grafted onto the public-sector national health system, but in practice each NGO partner tasked with the scale-up in their region had a different approach to collaborating with the Ministry, staffing clinics, collecting data, selecting a geographical focus, and providing services. The result was a fragmented approach that as Pfeiffer and Chapman affirm, has been typical of PEPFAR countries across Africa. In response to these challenges, the Ministry began in 2006 to promote «integration» of HIV testing and ART into other primary health care services in Mozambique (Pfeiffer and Chapman 2010).

The WHO guidelines changed over the years. Whereas in 2010 antiretroviral therapy was only started if the CD4 dropped below 350 cells per mL, from 2013 onwards the recommendations were to start treatment as early as below 500 cells per mL to prevent the effects of the virus' decline on the body (WHO 2013).

From august 2016 with the «test and treat» recommendation, antiretroviral therapy was started immediately after testing positive, regardless of the CD4 counts. This was followed by the Treatment as prevention policy, which refers to taking HIV medication to prevent the sexual transmission of HIV.

Health sector in austerity times

For understanding the fragmentation of humanitarian aid and how it directly affects the daily life of health centres, another aspect to be considered in the context of HIV in Mozambique is the way in which the flow of foreign funds is managed and organised by NGOs and the Government.

In 2015 the Mozambican health system still has one of the lowest ratios of health worker-to-population in the world, with only three doctors and twenty-one nurses per 100,000 population (MISAU 2015). Furthermore, there were recurrent themes of shortages of fuel to transport patients and drugs at the district level, a lack of meals for inpatient departments, and poor maintenance of vehicles and equipment, a lack of payment for electricity, water and human resources management such as salaries and allowances, all of which impact directly on the patients, increasing the poor access to services.[18] In addition, the recent scandals – see below - have created a situation of further precarity and austerity that has also affected the health system.

The scandal dates back in 2013, with a $2bn loan from the Mozambican government asked to Credit Suisse and a Russian investment bank. The purpose of the loan was to create a tuna fishing company. Although nothing unusual so far, the request was kept secret and out of parliament's hands. The accounts did not add up initially for two reasons: 2bn was a colossal sum for Mozambique and represented more than 12% of GDP (Gross Domestic Product); the debt was made on the assumption that fishing would yield $200m worth of fish every year. Even if such ambitious goals were achieved, they would still fail to match the annual repayments (including interest) of $260m. These irregularities only made the debt public in 2016. Moreover, most of the debt was not used in fishing vessels but naval supplies, three Ocean Eagle, 43 military vessels were purchased, each capable of launching unmanned aerial vehicles and dispensing machine gun fire. After the news and the resulting loss of confidence, the IMF and World Bank suspended humanitarian aid.[19]

Due to the country's debt burden, devaluation of its currency and increased inflation, the 2017 State Budget was worth US$3.86 billion. Austerity measures began to be implemented by the government and touched various sectors including agriculture, health and education, with the

---

[18] Data collected by CIP in 12 districts during QI 2018.

[19] https://www.worldfinance.com/special-reports/the-mozambique-debt-crisis.

restriction of new contracted people, and the reduction in state spending on travel and fuel (MEF 2017).

The Health Sector was allocated US$300.1 million. Overall Government budget expenditure in the health sector has decreased in relative terms from almost 13.4% in 2006 to about 7.8% in 2014 and 9% in 2015 to 7.8% in 2017. As Pfeiffer states, funding remains far from the standards recommended for funding basic public health by the World Bank and WHO, and far from the Abuja target (a pledge by African Union countries to increase government health funding) of 15% (Pfeiffer 2019).

As previously mentioned, since structural adjustment was introduced in the late 1980s, Mozambique's health sector has been financed by a range of donors, agencies, and foundations managed in varying degrees of collaboration with the MoH's local government funding (Pfeiffer 2013; Pfeiffer 2019).

There is an important distinction between on-budget funds, which go directly into the public budget, and off-budget funds, which go directly into the health sector and are spent separately from the MoH. Most resources that flow to NGOs for specific projects are off-budget.[20] Nearly all funding that goes to NGOs is considered vertical and off-budget and generally not used for long-term system building. After this wave of low trust in the government a handful of donors decided to stay away from local government initiatives and continued funding NGOs rather than the health system (Pfeiffer 2019). Among the most important vertical funds, US government funds and the Global Fund to Fight HIV, TB and Malaria together account for half of the sector's funding sources and are frequently used directly through NGOs.

The contrast between on-budget and off-budget lies at the heart of the austerity project. The SAP placed caps on financing on-budget but allows project specific aid funding to increase substantially as long as it flows to non-state actors, and in the last years public services were downsized while NGOs were upsized (Pfeiffer 2019).

---

[20] Instead, internal resources are collected through taxes, tariffs, duties, internal credits and an insignificant amount collected through user fees. A third source of financing is «In-kind donations» of medicines and medical equipment (UNICEF 2015).

Managing multiplicity in the health sector[21]

To contrast the multiplicity and fragmentation of funds and the proliferation of NGOs in development aid, particularly in Africa, the «sector-wide approach» (Swap) emerged in the 1990s (Pfeiffer 2017; Sweeney and Mortimer, 2015). The objective was therefore to constrain the «anarchy» that was being created in global health (Fidler 2007).

This «anarchy» was constituted, as for the health sector, by a series of humanitarian agencies, NGOs, universities, foundations, and institutional funds, each dealing with the public sector in a substantially different form (Ong and Collier 2005; Garrett 2007; Janes and Corbett 2009).

During the early 2000s, a consortium of European bilateral and UN agencies agreed to pool resources in a «common fund», PROsaúde, to support the health system and manage funds together with the MOH. However, a handful of other donors, including USAID, decided to stay out and continue funding NGOs rather than the health system in part so that government budgets stay below IMF mandated limits.

In contrast to horizontal funds, support and funding for the government's health sector budget has been in steady decline. In 2014, the health sector «basket fund» ProSaúde financed $84 million (25%) in comparison to $23 million in 2017. Although categorised as an external investment, ProSaúde is managed by MoH under national procedures – this means that it has its funds funnelled in a transversal mode, on a budget externally audited, with payment of human resources as one of the components.

---

[21] This paragraph takes its cue from the poster presented at the University of Bern during the conference «Making Medicine in Austere Times: Materialities, Moralities and Policies of Care», MAS-Symposium, University of Bern, Institute of Social Anthropology 11-13 June 2019 and visible in the appendix.

Table 3 : ProSaúde commitments (PEPFAR 2018)

YEAR	COMMITMENTS (USD)
2014	84 million
2015	55.6 million
2016	48.5 million
2017	23 million
2018	20.8 million (estimated)
2019	16 million (estimated)

The dwindling financial support to ProSaúde in 2016 reflects the emerging donor preference to fund the sector through alternative, vertical modalities in the wake of the debts scandal. While DFID, Canada and Holland changed to GFF after the corruption on public debts scandal in 2019, Italy, Spain, Denmark, Flanders, UNICEF, UNFPA, Switzerland and Ireland remained – with Ireland being responsible for more than a half of the total funds (PEPFAR 2018).

Global Financing Facility (GFF) is another important group for financial support and a multi-stakeholder coordination platform to mobilise sustainable financing to support high impact reproductive, maternal, newborn, child, and adolescent health stakeholders. Led by the World Bank, the platform is composed also by DFID United Kingdom, Gavi, GFATM and the government of Netherlands. The GFF total for co-financing the programme is USD253 million for 2018-2023. The start of the investment was in 2016 and in addition to proposing system-strengthening interventions such as improving data collection and monitoring, it began by covering, improving quality and access to essential primary health care services. One essential criteria for its disbursement was the development of a Health Financing Strategy, which details how the government will improve its domestic funding in volume and efficiency. In fact, they applied the Program-for-Results (PforR), a World Bank instrument to advance key systems reforms and build institutional capacity.[22]

In 2004, the United States government introduced major new funding to fight the HIV/AIDS crisis in Mozambique, PEPFAR. It is by far the largest increase in health aid in the country's history. As James Pfeiffer argues, difficulties in addressing the AIDS epidemic can only be understood if one appreciates how twenty years of structural adjustment policies have intersected with PEPFAR initiatives (Pfeiffer 2003). As it was, PEPFAR funding flowed off-budget to NGO «implementing» partners through vertical projects (Høg 2014).

PEPFAR and the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) are key players supporting the Ministry of Health to implement HIV national guidelines in the country within the whole cascade. The donor-funded HIV programme alone receives almost the equivalent financing of the entire ministry of health budget – around USD332 million (PEPFAR 2018). This accounted for approximately 88% of HIV expenditure in 2016 (PEPFAR 2018). As Pfeiffer argues, the application of PEPFAR off-budget funding to help deliver HIV care and treatment services within the public system is a complicated and complex process. NGOs will help pay for health worker training (but not for more health workers), HIV-specific equipment and materials, «technical assistance», and data collection, but almost no funding goes to basic system building blocks such as long-term workforce expansion, transport, and infrastructure. Health workers are therefore asked to do more and more in increasingly crowded facilities (Pfeiffer 2019). PEPFAR financing in COP19 (Country Operational Plan) also depends – as does the World Bank – on the Program-for-Results (PforR) strategy. However, the country is not ready for this kind of system that is centralised and without leadership. Based on this data about the performance presented by the country, PEPFAR will allocate USD90 million less to Mozambique in 2019.[23] PEPFAR's partners are innumerable and range from affiliations with major universities such as Columbia University, the Vanderbilt Institute for Global Health and Health Alliance International at the University of Washington to major NGOs such as Family Health International 360, Elizabeth Glaser Paediatric AIDS Foundation, Abt Associates among others (Pfeiffer 2019).

---

[22] https://www.globalfinancingfacility.org/mozambique.

[23] Meeting with Joana Borges, technical advisor MSF, April 2019.

Comparing the activities and respective budget from COP15 to 18, there was a considerable increase in activities such as sexual prevention (HVAB/HVOP), HIV testing and counselling (HVCT) – both mostly related to key populations – care for co-infection HIV/TB (HVTB), and paediatric treatment, care and support (PDCS). In contrast, adult care and support (HBHC), provision of ARV drugs (HTXD), prevention of Mother to Child Transmission (MTCT), activities related to blood safety (HMBL) and health system strengthening (OHSS) saw a considerable decrease. There are already some visible signs of increasing the space for local organisations. However the most powerful, CCS and Ariel, are two Mozambican organisations originating from the American PEPFAR funded organisation, ICAP and EGPAF respectively. These organisations are examples of a branch of international NGOs that were nationalised and now are able to apply as prime recipients on different financing grants (Pfeiffer 2019). As they were created, trained, supervised and monitored by PEPFAR, as well as being absorbed by their procedures, they have an unfair advantage as local community-based organisations struggle with their basics.[24]

During the implementation of COP17 there was a shift on some PEPFAR implementing partners. The country was divided up geographically, and provinces were allocated to the NGO partners usually without direct MOH involvement in the actual decision-making (Pfeiffer 2019). Since then, there has persisted an environment of insecurity due to a realignment of financing. Some projects that used to have 5-year cycles now have shorter planning strategies focused on expected outcomes that are reviewed quarterly (Pfeiffer 2019). As an example, an organisation that reported that human resources were their highest expenditure, had its new hiring suspended, a reduction in number of staff and a reorganisation of structure.

During COP19 discussions, the focus shifted to retention. This type of turnover priority means dismissing community Health workers and hiring new staff to work inside the health facility as counsellors and clinicians along with funding their respective training.[25]

The «asymmetry of power» between private-sector actors and public interests, and philanthropic efforts to improve health and quality of life may in fact reinforce the very inequities they seek to overcome (Birn 2014).

---

[24] Meeting with Joana Borges, technical advisor MSF, April 2019.

[25] *Ibid*.

Moreover, the local population perceives the large discrepancies that exist between global health policies and their actual implementation on the ground (Han 2013). As Biehl and Petryna affirm:

> We must also engage crucial questions about the role of the state and the market in Global Health design and delivery and investigate what happens to citizenship when politics is reduced to survival — all while maintaining a deep and dynamic sense of people in local worlds (Biehl and Petryna 2014: 386).

In theory, bilateral projects should be coordinated between MoH and donors and their implementation should take place in different modalities. Consistent reporting of donors on budget and expenditure of bilateral projects that are off-budget is one of MoH's greatest challenges for budget expenditure analysis in the sector.[26] Also donors, civil society organisations and implementing partners pointed out as a major challenge HIV and TB verticalisation of funds and activities. The perception is that this fragmentation of aid weakens the health sector as it promotes inequality, prevents planning within the health budget and makes it difficult to trace and account for the money.[27]

What happened in practice, as Follér argues, is that the donors have the power to set the agenda through predetermined programmes and by means of various technologies. Their strongest weapons are audit mechanisms used as control instruments. The donor agenda, with keywords such as effectiveness and outcomes, rather than quality and fresh ideas, is a dangerous path for the author. MISAU has to adapt the request in relation to donor priorities, decided outside the country (Follér 2013). In Follér's study, interviewees stressed that there is a difference between European donors and US-based organisations. The mentality of the US organisations was described as more rigid and as leading to a lack of mutual trust. Project money was delivered for extremely short time intervals (three months was mentioned). They were stricter about what they did or did not support (e.g. salaries, rent for offices and cars), and the audit procedures were more rigid, according to the information received (Follér 2013). While PEPFAR has channelled most of its funding to US-based agencies, it has also imposed major demands on those partners to

---

[26] Meeting with Joana Borges, technical advisor MSF, April 2019.

[27] Meeting with Think-Thank Adolescent, CNCS 2017.

gather enormous amounts of data. Each PEPFAR implementing partner has been required to set up its own parallel health information system that uses separate forms, data entry, data transfer systems, and analysis.

To strengthen efforts, in February 2015 the Joint United Nations Program on HIV/AIDS (UNAIDS), United Nations Children's Emergency Fund (UNICEF), WHO, President's Emergency Plan for AIDS Relief (PEPFAR) and others launched a new platform for action – called All In – to generate better outcomes for adolescents by encouraging strategic changes in policy. The MOH joined with CNCS (National council to fight HIV(AIDS) also have a weekly meeting called «think thank adolescentes e jovens» to try to analyse and harmonise all the projects around HIV and adolescents. All these activities are part of the bigger plan to attempt to harmonize intervention in the health sector.

During my participation in some of the meetings the multiplicity of care and intervention was creating some concerns at different levels. For instance, some Mozambican provinces present a huge presence of NGO intervention and others less so. In addition, some of the strategies implemented by some NGOs were not discussed inside the MOH before the implementation and were not in harmony with the National Strategic Plan for Health. In some cases funding was all directed to vertical programmes about HIV and tuberculosis, dismissing other illnesses as non-communicable diseases.

Another important aspect in «settle the agenda» was the enrolment of what is called in the humanitarian language the «beneficiaries» of the interventions, in my case the adolescent population. The National Strategic Plan IV for the health sector (2015–2019) also mentions the need for children and adolescents (both boys and girls) to be consulted in the development, implementation, monitoring and provision of policies and accounts programs that affect them, to ensure the relevance, appropriateness and ownership of prevention, care and treatment offered – an aspect that was also referred to in Chapter Two. Furthermore, by attending conferences and meetings of young activists during my ethnographic research, I had the feeling of having to deal with a self-referenced system in which the ideas and concepts presented by the young people were part of a pre-constructed discourse of the main funders of HIV/AIDS as in the global arena.

When it comes to the interests of Global Health, Follér argues, it seems that the so-called beneficiaries of interventions have little to contribute with (Follér 2013). As far as the HIV/AIDS response is concerned, there have certainly been improvements to involve activists and civil society, but the biomedical orientation remains central and it seems that their contribution is relevant from a political but not a scientific point of view (Biehl and Petryna 2014).

According to my standpoint, the decades-long dependency of the country on external funding has contributed to a fragmentation of aid with significant sustainability issues. In particular, as Pfeiffer argues, vertical funding like PEPFAR has presented modalities of interventions that failed to fund basic system building blocks, entailing, over the years, an important shift in implementation strategies (Pfeiffer 2019). These measures complicated the work for MOH and for the health centres.

In one especially poignant example of how it works, NGOs often recruit highly qualified doctors and nurses from the health system itself luring them out of the public sector with comparatively very high salaries and benefits (Pfeiffer et al. 2014). A 2012 study of this «internal brain drain» in Mozambique revealed that nearly half of the physicians who had left the health system in recent years had been recruited by PEPFAR-funded projects (Sherr et al. 2012). This brain drain is especially concerning in Mozambique since, as previously mentioned, it still has one of the worst health provider-to-population ratios in the world (MISAU 2015).

Even before the hidden debt, the country presented significant difficulties in managing fund allocation, use and operation of the services. After the hidden debt, the subsequent breakdown in trust caused some of the donors to prefer more scrupulous and complex financial control measures, that are much more difficult to follow, for all the parties (donors, NGOs, MoH) involved. Coordination issues, between NGOs and the Ministry of Health in the implementation of projects, has progressively worsened with a direct impact on the daily life of health centres.

In a functional public health system, without diversion of funds, the ideal solution would have been to directly allocate the funds – which in the past has been addressed in particular by PEPFAR – to MOH. Theoretically, it would have increased the health workforce, the number of people receiving health cover would have increased in many places, and more people would have had access to and the ability to stay on HIV treatment (Pfeiffer 2019).

Chapter IV

Practice of care

Multiplicity of care

This second part of my thesis begins by presenting one of the sites where the research was conducted, a public health centre which I will call «Centro de saúde». The aim is to reflect on the many ways in which care is provided through the voices of the health workers and the young people accompanied during the research.

According to approaches in the feminist tradition, care is seen as a «matter of 'tinkering'» and not so much «as a (preferably 'warm') relation between human beings» (Mol, Moser, and Pols 2010). In this direction, care is seen as a series of interrelational practices that make possible working together to achieve a result with the help of various hands (Mol 2008).

Care refers to a whole series of activities concerning feeding, washing, dressing, but in particular to healing, related to interventions that have to do with the course of an illness (Mol 2008). During my fieldwork, I realised that the processes related to care and cure were actually inseparable. I witnessed countless situations in which the importance of medication, and thus of cure, was closely linked to the presence of a family member who could take care of all aspects of the person's care, such as being able to have an adequate diet or more generally take care of the social aspects of the illness.

The forms of care I encountered during my work had also to do with the technologies that the public health system had at its disposal - such as certain anti-retroviral drugs, laboratory tests and machines - and in particular with the fragilities of these technologies. Moreover, dealing with HIV-related issues has to do not only with the pharmaceutical aspects of taking treatment, but with a whole range of issues related to the social aspect of the disease which I will explore in the course of the next chapters.

According to Ramah Mackay, in the context of AIDS, interventions were commonly known as «care and treatment» programmes and care is «defined as the assemblage of drugs, medical knowledge, nutritional and social support and community interventions constituted through diverse actors, goals, and temporalities» (McKay 2018: 8).

Besides the «logic of care», says Mol, there is also a «logic of choice», which patients must be able to make about their own health. However, the patient's choice may be in conflict with what is the best medical direction, creating what is called in medical terms «non-compliance» (Mol 2008).

The «patient choice» in Mozambique is controversial. In fact, according to the «logic of choice» a patient should be the decision-maker and to make these decisions a patient should be well informed about the advantages and disadvantages of the available options (Mol 2008). Making decisions about one's health is certainly an important ideal when the conditions are present. As I will show in ethnographic extracts throughout this chapter, patients have little decision-making capacity with regards to ART adherence. Indeed, the idea of patient choice remains abstract, and the information and knowledge conveyed by healthcare professionals is often too scarce.

As we have seen in the previous chapter, care policies in Mozambique are characterised by great multiplicity. For McKay (2018) this multiplicity and plurality of relationships can be defined as: «this term can display how diverse, deeply unequal actors and institutions come to be invested in the objects and practices of medical care» (McKay 2018, 10). Care can evidently be at the same time, medical and non-medical, public and non-public (idem). The dependence on external donors and the presence of NGOs and humanitarian agencies inside public health centres, often with the overlap of multiple institutions, is one of the dominant aspects showing the multiplicity of care in Mozambique.

Care becomes a matter of practice, where the practices implemented are partly acted out in healthcare facilities and stimulated by a series of movements related to relationships, salaries, gifts and emotions, entangling care with economic processes and humanitarian interventions (McKay 2018).

In my work I have considered only a few of the places where the practice of care was carried out – the Daily Centre, the NGO clinic, the Public health centre and the Hospital within the background of the family context. With this analysis the aim is to show the complexity of the flows of material goods, categories, relations to institutions, livelihoods and emotions that come into play.

SAAJ

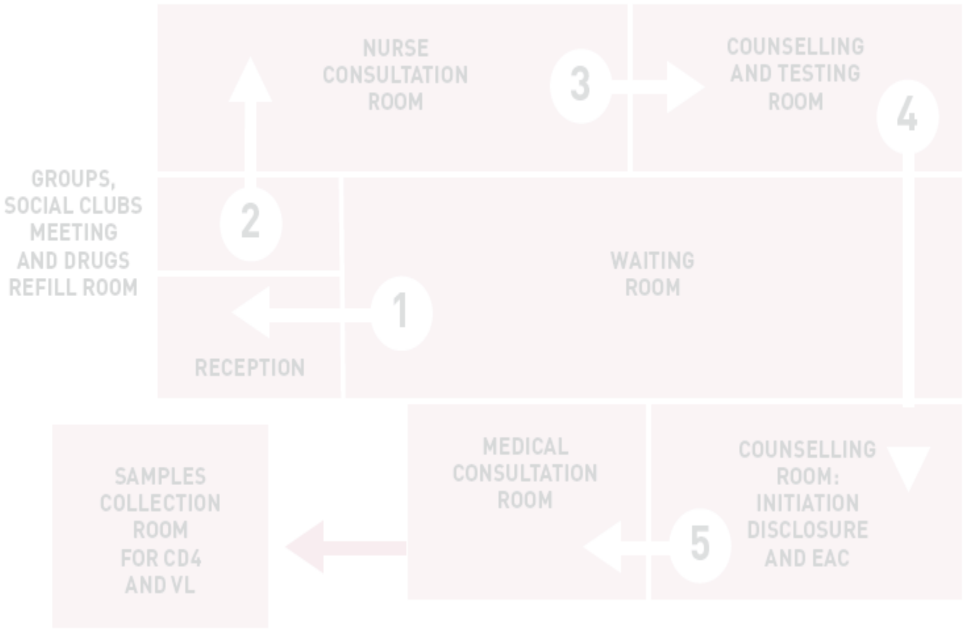
Surrounded by papaya trees, with an impressive colonial style façade, *Centro de Saúde* is located near *Hospital de Mavalane*, in one of the poorest neighbourhoods of Maputo. After passing the reception, the centre is structured around two large courtyards. At the bottom of one of the courtyards there is the SAAJ (*Servico amigos adolescentes e jovens*/ Youth and adolescent-friendly environment service).

SAAJ responds to MoH's strategy to implement a youth-friendly environment inside those health centres dealing with the need to focus on the sexual and reproductive health of adolescents, especially regarding HIV care and treatment. International donors along with the MoH implemented a huge number of activities focusing on teenagers (in particular adolescent girls and peer groups engaged in community and school outreach interventions) that raise awareness of HIV and the stigmatisation of PLWHA. Initially supported by MSF, the SAAJ was considered a model for the MoH providing a full range of SRH (sexual and reproductive health) services – including counselling; contraception; emergency contraception; STI prevention and treatment; HIV/AIDS counselling, testing and care; prenatal care and postpartum/ post-abortion counselling (MSF 2016).

This one-stop model means that adolescents are taken into care entirely within the SAAJ – from reception (where the patient's file, called *processo,* is held) to the dispensing of drugs, including the nurse's consultation, counselling, testing, laboratory tests, and health talks.

As described in the MSF report, the SAAJ must have one nurse dedicated to prescribing antiretrovirals. The clinical component of the programme included competent and empathic staff, informal meetings with adolescents, promoting information in waiting areas and reducing cost barriers (MSF 2016).

The SAAJ where I was conducting research was organised into four consultation rooms, one waiting area, a group session room and a blood collection point (CD4 and Vl) which was no longer working at the time of my research. The drugs were delivered to the medical consultation room. The waiting area was equipped with a TV showing educational health videos (picture 23). The team comprised two nurses, one receptionist, one medical officer and three counsellors.



Picture 23: The SAAJ setting - the organisation of the service and the diverse activities proposed (picture by MSF 2016)

The image shows the layout of the SAAJ setting. Ideally the flux of patients starts in the reception area where the counsellor welcomes the young patient, does triage, takes appointments, directs the patient, opens and manages the patient’s file, and does health talks in the waiting area. If the patient is seropositive, is to the nurse’s room in order to take the drugs and then to the counsellor’s room to have counselling session on living with a seropositive diagnosis.

Due to the test and treatment recommendation implemented in 2017, if the patient tested positive the HAART should start immediately. As said before the WHO guidelines until 2010 recommended starting antiretroviral therapy only when the CD4 cell count fell below 350 (cells per mL). This changed in 2013 when the guidelines recommended starting treatment below 500 (WHO 2013a).

After four years, MSF collaboration came to an end and structural and staff problems began to arise. During my observation in the *Centro de Saúde*, things in the SAAJ were not always working in concurrence with «the best practice» presented in the MSF report, for there existed some structural and technical aspects that, in my view, directly influenced the adherence process of the young patients. It is not my intention to discredit the work of health technicians, but rather to reflect on why providing care in the public sector presents such difficulties and how these shortcomings and deficits that occur can be better understood by taking into account the historical social and economic contexts in which public care interventions are actually accomplished .

The following considerations were also possible thanks to the support of Namati's activists (*defensores de saúde*). Namati is an American NGO that provides legal empowerment to communities specifically on the right to health. The *defensores de saúde*, Namati's grassroots health advocates, not only give recommendations to improve the system, but also empower patients to know their rights as citizens, in other words they try to implement a possible logic of choice. As Feinglass et al. affirmed:

> Health advocates educate patients about key laws and policies, facilitate dialogue between communities and health facility staff to proactively identify and address system failures, and engage in «casework» in order to seek redress for specific violations – walking alongside patients to overcome the social and structural barriers that undermine human dignity and treatment uptake and retention (Feinglass et al. 2016, 1).

Working with them also helped me to relocate myself as an observer in the *Centro de Saúde*. On the one hand, witnessing the testimonies of violation and mistreatment made me feel guilty for not taking action. On the other hand, I felt that my role at that particular moment was not to make a denunciation of irregularities. Notwithstanding, taking any sort of action made me feel frustrated and accomplice. Months later this awareness translated into the impossibility of continuing my observations in the *Centro de Saúde*.

Despite the fact that I initially experienced this stepping back from the fieldwork as a personal failure and inability to deal with the situation, I later realised that it was part of the process and it created a new space for debate on the problems that I had observed. After stepping back, I was able to use the materials, data collected and emotions experienced in the field as a constructive reflection on the daily activities in the centre. Together with two human rights activists we readapted the manual *Direito a Saúde* of the Namati NGO for a younger population and we created a two week workshop on the right to health. The workshop took place for two weeks during my last month of fieldwork in January 2018. It involved 30 participants between the ages of 10-20 and was divided into two groups based on age. The week was structured into different activities. The first day was dedicated to getting to know each other and their knowledge about human rights in broad terms. On the second day, through case studies, participants were accompanied in reflecting on the right to health and thinking together about times when they had been victims of violations inside the health centre. On the third day, the topic was oriented towards sexual and reproductive health and the fourth day was dedicated to the possible creation of an ideal SAAJ with the help of painting, music and a specific letter written by them and addressed to the Minister of Health. On the last day, the dynamic through theatre allowed the young people to put on five different plays that staged five moments of abuse and mistreatment inside the health centre. Some of the reflections in the next section emerge from their testimonies while attached are some photographs depicting some of the moments during the two-week workshop (Annex C).

Emilia's story

Emilia was sixteen years old when I first met her. My first impression was of a thin, shy girl. She contracted the virus of HIV through vertical transmission, but in the first period that we met we never spoke directly about HIV, rather about other concerns that were afflicting her. She actually came to talk to me due to some problems related with the irregularity of her period. She was troubled around the reality of being a «woman» and the possibility of having children. With her weight at 32 kilos the probable reason for her amenorrhea was anaemia, so the social worker at the daily centre decided to do some blood tests in the hospital.

Emilia had been orphaned after the death of both parents, and she was living with her maternal grandparents behind the Mavalane Hospital, in a suburb of Maputo called Xiquelene, not far from the daily centre. Her father died in a car accident when she was a baby and her mother died due to the complication of AIDS when Emilia was six years old. Besides Emilia, the maternal grandparents were also taking care of four other nephews, whose parents left Mozambique for South Africa due to work. Carla and Cesar – the grandparents – were around seventy years old and were bringing with them the life scars of manual labour and the long-lasting after-effects of enduring years of war.

The difficulties that this extended family with a low income have to face are complex and I often had the feeling that they had no way out for a chance of success and well-being. In this case, the concern for Emilia's health adds to the existing concern for one of the younger cousins, recently diagnosed with epilepsy. The family sustenance was possible thanks to some farm land – called in the local language *machambas* – where the family produced corn and peanuts but unfortunately, the last rainy season had destroyed the harvest.

Cezar, who worked as a ship repairer, now receives a small pension. He was seriously injured in the workplace, and can no longer move his left leg. In addition to the small sources of income from pension and the farm land, Carla and Cezar rent out two rooms. These incomes have allowed the family to have at least one meal a day, but the variety of the food was very poor.

Emilia's body weight was a major concern for all. Carla told me that she was a «chubby girl» when she was a baby but after the age of six, she started to lose weight. During that period, she was hospitalised for a while, remembered Carla. Thanks to the help of the food supply known as *cesta basica* from the daily centre and the sachets of supplements received at the hospital, Emilia put on some weight. Actually, the food supply gave rise to tensions in contemporary models of assistance and were often considered by the receivers to be too scarce or insufficient to feed the other members of the family - the basic basket was in fact always shared. Receiving the food basket at the daily centre makes Emilia feel uncomfortable:

> Every month I have to go to Irma Clelia to renew the request. This month they didn't give it to me and I don't understand why, I don't understand why because we have nothing to eat, but he said that grandparents can begin to afford to buy something and therefore I have to become independent (Informal conversation with Emilia, 17th September 2017).

The food supplement in *Centro de Saúde* was requested in the malnutrition room. After a series of questions about family habits, the assistant gave a package of food supplement per day, made of peanut butter plus other nutrients, and scheduled a new appointment for the next month to have more. Unfortunately, due to cuts in funding and delays in supplies, during the following months the supplements had run out and we had to ask a specific MSF contact inside the centre to get them. Emilia's struggle to eat was also due to the lack of variety of food present in the house: she could have only rice or *xima* (a mile polenta) with tomato or cabbage as she shows in picture 5. In this picture from the photo voice project, Emilia shows what she normally has for dinner. As reported in the introduction, within the support group and with the help of visual arts methods, many topics emerged that help both me and the youngsters to create a dialogue around their daily questions and concerns – like, for example, the lack of food.

Carla and Cezar were actually very worried also about giving Emilia freedom and the attempts made to force her to live in a «bubble» were evident. They were very worried about Emilia and imposed many restrictions on her. During our conversations she was speaking about it, confiding that this was the reason she had no friends. Cesar told me once:

> Emilia is not a girl for going out, she, like her grandmother, goes out just to go to the church. She is not allowed to go out for «playing». The problem is that young girls outside the house start to lay with men. I'm not saying that she doesn't have to get married, but the man who will marry her has to be respectful. She doesn't have friends and just after her eighteen birthday she will be allowed to go out. She has to realise that to be a housewife she has to learn women stuff, and you learn them at home (informal conversation with Cesar, 18th September 2017).

During our meeting Emilia expressed her disappointment with these rules and together we started finding solutions that would enable her to have a discussion with her grandparents. What was also troubling Emilia was the fact that she experienced stigma at school and in the community:

> The main problem is not in the family. I do not have friends anywhere. I can not go out in the street to walk, but also at school the situation is difficult. You hear this cough that I always have? When a crisis starts at school I have to get out of the class because they start saying that I have tuberculosis. I try to explain to them that it is not… but no one wants to stay with me (Informal conversation with Emilia, 17th September 2017).

The issue of stigma was often discussed inside the *grupinho* where they tried to find their own way to deal with it. Among the members of the *grupinho* experiencing stigma in society was really common, usually due to health complications and visible scars of the disease, most of the participants had been forced to leave school.

The only place where Emilia felt confident in chatting with some friends was at the daily centre. She loved sewing and some volunteers offered her a sewing machine for Christmas. While we were hanging out with the members of the *grupinho* at the beach she confided that it was the first time she had seen the sea and told me several times that her dream was to be a dressmaker and go around the world. The searching for normality and freedom was also evident in her desire for romantic love. When I left Maputo, she was dating a guy who worked in a shack in front of the house. They had brief conversations and shared small gifts.

Practice of care and adherence in *Centro de Saúde*

When it comes to the logic of care in the context of HIV, one of the first issues to be addressed in health centres has to do with monitoring the progress of the virus. This is done through tests such as the CD4 (or T helper lymphocyte) count, which is a type of white blood cell and a snapshot of how well the immune system is functioning. As an HIV infection progresses, the number of CD4 cells declines. The second exam is of the viral load test, to measure the number of virus particles within a sample of blood.

In the context of HIV/AIDS, structural barriers persist in making it difficult to implement the exams that control the HIV trends. The implementation of viral load as a monitoring tool still faces considerable challenges in Mozambique, with national coverage reported by PEPFAR's (President's Emergency Plan for AIDS Relief - US) implementing partners at 33%. As reported by PEPFAR, the whole process requires improvement, as clinicians rarely make requests on time, the referral system was weak, the equipment maintenance was poor and the technical assistance was scarce – leading to frequent breakdowns and resulting in long waiting lists and turnaround times – and, finally, there is no reliable system to ensure that test results reach patients' files (PEPFAR 2018).

Medical consensus states that to achieve an undetectable viral load and to prevent the development of drug resistance, a person on ART needs to take at least 95% of the prescribed doses on time if this does not happen, the virus may develop a resistance to treatment with the need to switch to a stronger treatment (called second or third line treatment) (Paterson et al. 2000). Rather, I highlight how the politics of ART implementation in Mozambique are both complicated and contradictory.

This latter test detects the level of viral replication, but also treatment success. As shown in chapter two, there is a movement of activists for whom achieving an undetectable viral load means having achieved a personal goal and being proud of it.

The prescribed ideal viral load becomes a sort of norm, a one-size-fits-all approach which has been criticised. As Guta and colleagues have suggested, it is complex to decide on a single goal for viral load as the risk is to ignore socio-cultural and bio-physiological differences between individuals, as well as structural aspects related to accessibility of care and treatment (Guta et al. 2016).

In the clinical context in the health centre where I conducted fieldwork, the inability to take medications after the beginning of therapy was often labelled as «non-compliance» or «non-adherence». Inside the *Centro de Saúde*, non-adherence was usually linked to patient-related characteristics, often ignoring possible social, medical and economic reasons.

Following several authors, a more comprehensive understanding of adherence should be based on a biosocial approach, one that relies on a dynamic analysis of the clinical and social course of the disease and the continuous interaction of biological and social processes over time (Castro and Farmer 2005; Farmer 1992; Kleinman et al. 1995). Adherence differs in time and space and should be comprehended within multifaceted causes in light of the larger social, economic and political context. The use of a biosocial framework grounded on the actual experiences of people diagnosed with HIV is hence essential for understanding adherence, the way in which it changes over time, and the reasons for non-adherence. Through the analysis of people's life trajectories and social contexts (Castro 2005) – especially in resource-poor settings – these reasons are beyond patients' individual responsibility and logic of choice. My understanding of patients' life histories, their interactions with the policies of care and experiences with regards to illness episodes allow me to generate associations between the clinical and the social course of the disease, including such themes as health-seeking behaviour, adherence to therapy and agency.

One of the main concerns for HIV positive teenagers who contract the virus through vertical transmission, like Emilia, is the disclosure of their status to improve adherence. According to the guidelines of the Ministry of Health, the disclosure of the HIV diagnosis should ideally be conducted by a family member with the support of a health centre's medical staff and should take place between the ages of 9 and 11 years old, when the person can understand the disease, even if he or she is asymptomatic (MISAU 2015). The counsellor is responsible for disclosure, which means informing the young patient progressively, step-by-step according to their age, about the disease, following a very precise protocol. Disclosure can be initially partial and then complete. According to the MOH guidelines, medical care and patient support for a child must address three actors: the child, the caretaker and the family. The challenge is to meet the caretakers with the children. On one hand, it is very difficult to disclose to a child who is alone or orphaned – even if the law allows the counsellor to disclose to children of 11 years old in the absence of a caretaker. On the other hand, it's very important to disclose to a child, because he/she needs to understand why they need to take drugs every day, and why regular hospital visits are necessary. As reported by MSF:

> Progressively, the child must be able to know how HIV functions and how drugs help, to explain the different ways of transmission and non-transmission of HIV, and to understand how HIV affects their family. If the adolescent is sexually active, they must be able to take decisions on how to protect themselves and their girlfriend/boyfriend in sexual relationships – for example, by using male and female condoms – explain the male and female reproductive systems, and list common family planning methods (optional) to avoid any new contamination. The counsellors have to prepare and initiate the child and the caretaker for lifelong ART (MSF 2016, 17)

Following the MoH guidelines, the responsibility for children and young adolescents belongs to the caregivers, who are called upon to understand the complexities of the ARVs regime (MISAU 2015). Furthermore, older children or adolescents should feel responsible for managing their own health and understand the essential aspects of the treatment, when the young patient is able to understand the disease, even if it is asymptomatic (MISAU 2015).

In my experience young patients were often orphans and lived with their grandparents. During my fieldwork in the *Centro de Saúde*, I noticed that this aspect complicated the disclosure process within the family. Disclosure was often performed by a health worker, sometimes with a long delay.

During our talks, Emilia showed some confusion about her health condition. Although she was taking antiretroviral medication, she was not sure what for. She was also aware of the existence of the HIV virus and its consequences but did not believe that she could somehow have contracted it. Emilia was visibly concerned about something that had been happening to her for some time but had gone unexplained. I remember that this confusion on Emilia's part alarmed me greatly and made me quite confused. During a meeting, Carla and Cezar clarified this delicate issue:

> When Emilia had her period for the first time, her aunt explained the situation: *you will not be allowed to «play» (brincar) with men from now on, if you do it, you'll die.* She also told Emilia that she had a bug called HIV, and that's why she was taking the drugs. After a while me and Cezar realised that the emotional charge was too much for us and she looked really sad and worried about this discovery. We did a step back and told her that she was taking drugs for asthma (Informal conversation with Carla, 23th November 2017).

The reformulation of Emilia's health situation by her grandparents had legitimately thrown her into a sea of doubts with many unanswered questions. When the family disclosed her status for the second time, Emilia started questioning herself about the responsibility of her health status. A feeling of rage for her mother started to appear and she was asking herself «why did she make me if she knew she was sick?». After the late disclosure, Emilia was not peaceful and if until then doctors had considered her a «good adherent», after that she started questioning the meaning of taking drugs for the rest of her life. One of the big issues lies between the struggle of health workers in the health centre in creating a space where patients can be involved in the practice of managing their own health, is what Mol called «situations of choice» (Mol 2008), and the seeming contradictory use of a more rigid approach, made up of rules to follow and strict schedules:

> You have to take the pills twice a day. One in the morning, when you wake up at 6 am, and one in the evening at 6 pm. It cannot be 6:30, it cannot be 6:15, it has to be exactly 6:00! These pills are for life, not taking them means that you don't want to live. (Counsellor *Centro de Saude*, fieldnotes, 23th April 2017)

As Mattes (2011) points out with regard to the Tanzanian context, technicians have often stressed «self-responsibility», in the sense that adherence to the treatment regime is normally established through a rigid control system that favours patient disempowerment, with mechanisms of reward and punishment aimed at their full subjugation to the medical authorities

(Mattes 2011). One of the ways in which health professionals got young people to remember to take drugs was to link the act of taking them with something they were doing (e.g. they linked it with everyday activities such as watching a *telenovela* or brushing their teeth). This practice, which worked in itself, was, however, loaded with a great deal of individual responsibility and was not accompanied by a solid explanation as to how the drugs work or the possible side effects.

Involving the patient in medical decisions concerning his or her health, thereby implying autonomy in the final decision, was considered a more appropriate practice by medical staff to create medication adherence behaviours in patients. Medical staff were often faced with structural and training constraints which tended to standardise practices related to disclosure and adherence without taking into account the socio-economic context and the individuality of the patient (Braga 2017). As other scholars have mentioned (Hardon et al. 2009; Mattes 2011) the process of guiding patients to become good adherents was about communicating and imposing notions of responsibility. It is not primarily understood in terms of enabling patients to make well-informed choices on the basis of a biomedical understanding of the body and the therapeutic process, but is more directed towards establishing rules and fixing times. For instance, when a patient in his twenties once asked whether it was possible to drink beer while on ART, Maria João, the nurse exclaimed:

> You cannot drink beer! First of all, alcohol is bad for your health. Second, if you drink beer you probably will be drunk and forget your pills. And then imagine if you have promiscuous sexual intercourse while being drunk. You could forget to use condoms, infect someone else or be re-infected. (Maria João, Nurse at *Centro de Saúde*, fieldnotes, 23th April 2017)

Aid funding flow and human resources

Picture 24: The ideal SAAJ painted by Augusto

With this paragraph I want to underline how the provision of care from external donors affects the quality of the service inside the public health centre. During my time inside the *Centro de Saúde*, the presence of an international NGO was visible in the symbolism present on the walls of the buildings, on the doors, on the distributed pamphlets~~.~~ During my participatory observation period, Maria João – SAAJ's nurse – helped me to highlight this aspect. She was 45 years old, she was a single mother of two sons. She had worked as a nurse for 10 years, mostly in the maternity ward, from where she was assigned to provide HAART to children and adolescents.

She has been working at the SAAJ for three years and she was taking care of the treatment of all the young patients. During one of our meetings she explained to me her point of view about donors:

> The situation in the health centre has been getting worse since the MSF (Doctors Without Borders) left a few years ago. They were really good and have doctors and technicians that come here to help us. They were taking care of the Tuberculosis ward, laboratory and SAAJ. Now some of them stay in the TB ward but the majority left. After a while, CCS (PEPFAR) arrived to support us, the Americans. Really don't get what they are doing here. What really happened is that I'm alone and I have to take care of all the patients of the SAAJ (Maria Joao interview, 10th June 2017)

Maria João continued to explain that following the test and treatment policy the patients really increased in number but the centre kept going with the same human resources and without an increase in the salary. This really complicated the amount of work and her economic situation, as with a salary of only 14,000 meticais (approximately 200 euros) it was really difficult for her to survive until the end of the month, so she had had to do *biscatos* (informal business).

The growing number of patients means, for workers like Maria João, an increase in workload and in particular a growing number of bureaucratic forms and paper work in documenting practices that in everyday clinic activities had perverse results (Heimer 2012). As McKay also observes, this was affecting not only the overflow of clinical files into the hallway but also everyday interactions between patients, health workers, and caregivers (McKay 2018). For instance, «the increased workload associated with the documentary demands of AIDS treatment was cited by health workers as a reason they disliked treating patients with HIV» (McKay 2018, 550). While bureaucratic issues were examples of the great difficulty in understanding the clinical situation of many patients, patients with HIV also had separate bureaucratic processes (Hacking 1999).

Maria João was, for most of the time I conducted research there, the only nurse at the SAAJ. It was not uncommon for medical personnel to combine their public work with work in private clinics or other work to increase their income. As McKay affirms, the fact of having multiple professional commitments, besides explaining the difficulties of the middle class, created certain frustrations among the less qualified medical staff who did not have access to these private networks so easily outside the hospital. (McKay 2018).

Furthermore, a health technician told me that it was typical to practice informal work to have extra money. What was worrisome in the health centre was the absenteeism of some of the workers due to the extra work during the opening hours of SAAJ. Although with an official closing time at 3.30 pm, from 1.00 pm, no more patients were taken and from 12.00 pm the nurse – most of the days when I was present – was absent. Patients who appeared after 12.00 pm tend to be chastised by workers about arriving late and are told to show up very early in the next morning (6.30 /7.00 am).

Namati's (2017) annual report shows how absenteeism and mistreatment were two common complaints from patients in the public health centres (Namati 2017). Discussing with the activists of Namati this was also common due to the fact that the MoH has cut benefits for the health workers. Pedro, an activist of the association, talking about the *Centro de Saúde* told me:

> We've addressed complaints related to provider absenteeism and mistreatment. We often receive reports of patients of technicians that are asking for a bribe to receive HAART or other drugs. This is clearly unacceptable. Why does this happen? Surely there is a general dissatisfaction and a charge of work that is too high in the health centres, but it is not only this, it is also cultural (Namaati activist, fieldnotes, 14th February 2017).

Ana Cala of the Department of Humanisation of the MoH suggested another view:

> We have to analyse the facts from the beginning, historically speaking. After independence, people were looking for jobs and that was the first reason for working in the health sector. Salary was not a big thing but was stable. Then people realised that was a lot of work and the salary at the end of the day was poor so they started to ask for subsidies or to start an informal business and they started to treat the clients badly (Ana Cala interview, 13th December 2017)

The human resources issue was complex and depended also on how international aid flows were managed to support some of the human resources at the public health centres. Another example, next to the HAART room was the «psychology room», where young people on treatment received psychological support. Since the psychologist, Sara, was the only one in the whole health centre, she had to deal particularly with psychotic or severe depressive cases and she rarely appeared at SAAJ. The «psycho-social» aspect thus became the responsibility of the counsellor. The counsellor is a community health worker and usually an HIV-positive person, without medical training and with some guidance – normally from an NGO – to support other HIV-positive patients. Initially introduced and financed by NGO projects, only in rare cases, the figure of the counsellor enters into the plan of the MOH with a salary of around 8,000 meticais (110 euros).

During fieldwork the psychosocial room was often empty, with no counsellor in attendance. The counsellor, as she had not been paid since MSF had withdrawn their support, only appeared occasionally, presenting a low-quality service and showing a lack of motivation to support patients.

Other activities were influenced by external donors like the social club, an activity that deals with psycho-social distress of seropositive adolescents. The aim of the social clubs was to ensure better adherence to treatment without directly talking about HIV/AIDS, but by addressing other topics linked to health and by introducing creative activities, and making sure that adolescents are in a position to come to terms with the fact that HIV can be considered like any other disease, which they can control and live with by being positive. During one of our meetings counsellor Delia told me:

> On the last Saturday of the month a meeting of the social group for youngsters who are HIV positive takes place. We do activities, talk about treatment, show them how to take care of themselves and enjoy life. But that does not happen anymore ... it has not happened for the past 6 months. The CCS, an NGO founded by PEPFAR, was the one that provided food and transport for the group members but the funds did not arrive for the last six months and so this activity is not happening anymore. Here, if you are not giving something, people do not show up. We cannot ask the young people to pay for transport, wake up really early and come here with nothing to eat (Delia, informal conversation, 22th October 2017).

These excerpts from my ethnographic experience illustrate one difficult side of how the deluge of there is a certain fragmentation in interventions due to the presence of a large number of NGOs that have contributed to slowing down the central control of health programmes and paradoxically to growing local social inequality (Pfeiffer 2003). As Pfeiffer argues, considering that salaries dropped considerably during the structural adjustment period, health workers found themselves having to choose projects with NGOs where the salaries were higher (Pfeiffer 2003). For example, in 2017 an mid-level doctor in the public sector earned around 35 thousand meticais (varying according to years of experience), roughly EUR 500.[28] Such low wages caused many state workers to switch to NGOs that offered better wage conditions.

The privacy issue

Picture 25. The lack of privacy represented by Carlos at SAAJ

---

[28] https://meusalario.org/mocambique/salario/sector-publico-mocambique/salarios-do-sector-de-saude

This drawing was done by Carlos during one of the activities in the workshop on the right to health in the daily centre. He was particularly upset about the lack of privacy in the health centres, namely in the SAAJ, and he wanted to describe his experience inside one of them.

Although the SAAJ had a special focus on teenager reproductive health in a save environment, the operation and flow of patients through the centre did not always guarantee their privacy. When a patient needs to test for HIV the process involves passing through different rooms. One of the aspects that disoriented me was the fact that in the HAART room a patient was called from the waiting room, by name, for an appointment in the last room on the HIV test circuit. Sakrina, a 20 year old student in sociology appeared in the SAAJ early one morning in June. She entered the HIV test room and then sat again in the waiting room. This meant that the test result was positive and she had to wait to be called into the HAART room. While she was waiting, some colleagues from the university entered the SAAJ and asked her what she was doing. She answered that she was waiting to do the HIV test, and they all agreed about the importance of testing.

If the nurse had called her while the friends were there, the HIV status would have been revealed, without her intention, to some of the community members and it would have been clear for all that she was taking the drugs. Sakrina realised this and she decided to leave, appearing at the SAAJ the day after and this time there were no acquaintances around. I introduced myself in the waiting room and explained who I was, she invited me to enter with her in the medication room. Inside the office she explained to us that the day before was really difficult for her to stay because she did not want her colleagues to know that she was seropositive. She decided to come to this health centre because it was far from her neighbourhood, looking for some privacy.

As reported by Namati and also as expressed by the participants in the workshop on the right to health, the lack of privacy is one of the most relevant barriers in the health system in Mozambique (Namati 2017). In an exciting theatre play performed by the young people of the centre, Rita was a young woman with a small child who entered the health centre for a consultation. When she entered the consultation room she realised that she was not the only patient there and she had to describe all her health issues in front of another patient. When she refused to speak, the annoyed health technician sent her away saying that she had only come to waste his time. As one *defensor da Saúde* of Namati pointed out:

> Surely there is a problem inside the *Centro de Saúde.*. This has been reported many times by patients. What emerges is not only the fact that people are called by name in front of other patients but it is also difficult for the technicians themselves to keep their professional confidentiality once they are out of the health centre. Patients are concerned that when they go for the test, then the health personnel go into the communities and do not keep it confidential (Namaati activist, interview, 24th July 2017).

This aspect became more evident with the progress of fieldwork. One morning in April in *Centro de Saúde.* I met with Carlotta, a patient that I also used to meet outside the *Centro de Saúde*. Carlotta was a 22-year-old woman, married and with a 4-year old baby. She had recently discovered she was seropositive. Although not recommended by the nurses at the beginning of the treatment, she had decided to have another baby and she was pregnant. The decision to have another child before the recommended six months had been much criticised by the nurses who attended her case. Her process passed from the SAAJ to the maternity ward of the *Centro de Saúde* and she was waiting for her CD4 test result. When I met her in the waiting room she was nervous and angry because the nurse had told her that she was too late this morning to ask for the result and that she had to return at 7 a.m. the next day and stand in the queue, but Carlotta kept asking.

The exasperated nurse gave her an envelope of around 100 sheets with all the CD4 counts of the last week. We suddenly realised that we had in our hands the serological test results with the names of over a hundred people who had attended the health centre. I remember this event with a deep sense of distress, as it was one of the moment when I decided to step away from fieldwork at the health centre. I felt like a silent accomplice in a system that did not respect the rights of the patients and a witness to abuses or violations within the health centre and felt all the discomfort of being an observer who was somehow not «called» to denounce such events.

Paperwork

One morning at the *Centro de Saúde*, I accompanied Emilia for a check-up and to collect the results of some laboratory tests. The visit was a routine monthly visit for the prescription of antiretrovirals and the result of the CD4 test. Although these examinations should be a «routine», this was not to be taken for granted. The previous month, I had accompanied Emilia to her previous health centre, which was inside the Mavalane hospital. When I arrived at 8 a.m., I was stunned. There were already at least a hundred people waiting to receive antiretrovirals. Emilia smiled at me and told me not to worry, that she had a contact in the hospital who allowed her to jump the queue, she was a cousin who worked as a health technician. We jumped the queue, went straight to the adults' ward and were given her medication. But because Emilia was not in the right «queue», she had never had her viral load or CD4 checked.

She was later transferred to the *Centro de Saúde* and having looked at Emilia's file, Maria João realised that there were no traces of a CD4 count or viral load test. The last CD4 count had been sent to the laboratory in December 2016 and considering that was already May 2017, it had probably been lost and so she asked for a new test. As Maria Joao affirmed:

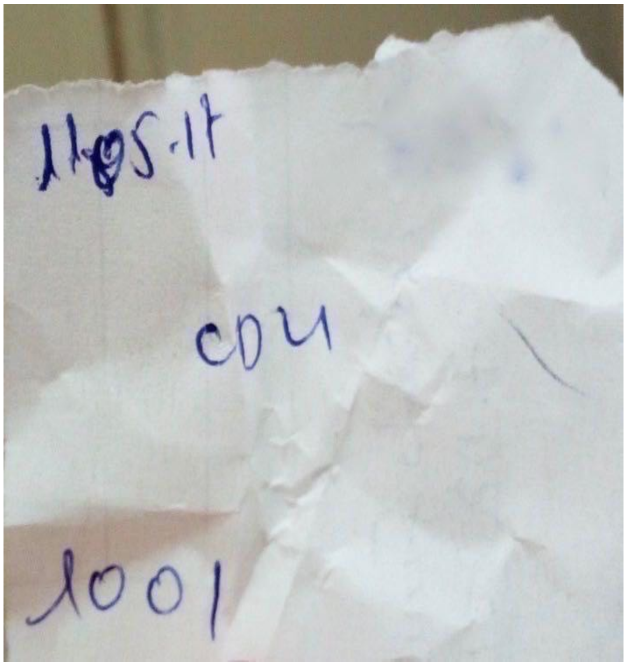
> It is something that happens often here, we are used to it. The CD4 machine of the *Centro de Saúde* is broken and they have to send the samples to the *Hospital Militar*. These processes take a while and the results can be lost along the way (Maria Joao, interview, 25 may 2017)

Actually, young people face innumerable difficulties in carrying out and receiving the results for the CD4 and the VL, from the dislocation in the health centre to the loss of the results in the health system, as Maria João reported. Furthermore, the procedure in health centres was not to give patients copies of their medical examinations but to keep them in a physical archive. Some of the technicians I interviewed argued that the reason for keeping the process in the archive was about not trusting in patients, assuming the files would be safer in the health centre.

Unfortunately, Maria João had to reopen new processes because the previous ones had been lost in the archive. This created various problems in relation to the history of the examinations carried out, the monitoring of the patient's state of health, as well as a lack of confidence in the medical system on the part of patients. With Emilia we asked the nurse of the SAAJ for her CD4 test and considering the new policies on Viral Load test, we insisted on having the latter test too.[29]

---

[29] I would not like the term *insist* to go unnoticed. I wondered during the field when my presence – as a white European researcher – had an influence on the procedures and medical attention that was given to the patients. I think it is important to question the influence one has in the context in which one



11.05.17

CD4

1001

Picture 26. The paper to receive the CD4 count

After a month Emilia went back to *Centro de Saúde* to ask for the results but the answer she received was not comforting:

> I went to the health centre, to ask for the result of the CD4 but it wasn't there, they told me that I have to do it again because it wasn't there, but I told him [health professional] that I'd already done the exam one month ago. He told me I have to do it again. They told me to go to the laboratory to ask but I could not find the place. I want to cry, because how many times do they have to take my blood? They will «end» with my arm! I think I'll no longer go there to ask, there is nothing to do, it is the second time that they lost it. How many times will they lose it again? (Emilia, informal conversation, 28th June 2017)

---

goes to do research. In my case, I sadly found that accompanying young patients for examinations often had a bearing on the attention they were given.

Picture 27. The health centre laboratory in Carlos's bodymapping

The following day, we decided to go together to the health centre to understand why her exams had disappeared. We started to pass from one room to another and ended up getting lost inside the *Centro de Saúde.* Maria João sent us directly to the laboratory (a structure outside the health centre). Here, we delivered the small leaflet needed to recollect the exam but the health technician said that it was not ready. We went back to the SAAJ and a counsellor sent us to an MSF TB room (picture 27). Here, another technician told us to go to the CD4 room, which is where all the tests are kept. In the CD4 room, we found two Namati activists trying to plot numerous medical records of exams of the CD4. There was no trace of Emilia’s CD4 and they decided to request the exam again, this time urgently. Emilia burst into tears during our search «I can’t do it. I don’t understand why it [the result] is not here!»

While we were working inside the *grupinho* about the past and future, Emilia wrote a little essay, where she expresses all her disappointment with some of the health workers and with the laboratory at the health centre. Maria, one of Namati’s activist’s comments:

> It is not uncommon that there is a misplaced clinical file, it always happens. Sometimes patients lose the little sheet (picture 26) but sometimes the health system loses the result or blood sample. In particular, it happens for the examination of the viral load because it is a very complex examination and must be done outside the health centre at the hospital. If it goes well, it takes six months for the result, but often it must be redone (Maria, interview, 24th November 2017).

From the clinical side, as reported by many health workers interviewed, the loss and delay in the return of lab results is worrisome due to the subsequent impossibility of controlling the effectiveness of the treatment. Laboratory exams are normally funded by PEPFAR but controlled and collected by MoH staff. This aspect shows the conflicting relationship between the MoH and the main donor, PEPFAR and shows the plurality of agencies and institutions which come to intervene on documentation practices, measurement, knowledge production, and care in the clinic.

Furthermore, care embraces different levels such as drugs, medical knowledge, nutritional and social support, and adherence is accomplished not only by taking the drugs and checking exams but also by creating a feeling of trust and alliance between the health workers and patients. Trust and alliance were also hard to find due to the loss of exams. Frustration and loss impact how patients manage adherence.

«Culture of silence»

During the fieldwork, I had the opportunity to observe the activities of the SAAJ, from the room where the nurse made the visits to the test room and to circulate in the various areas of the health centre, talking and interviewing health workers, counsellors, doctors and patients. From the very beginning, the willingness of Maria João in sharing information was impressive. She spent a lot of time explaining to me what was happening and how all the medical files worked. However, nurses's kindness and availability were not prevalent when dealing with patients. I remember that I was impressed by the speed with which the patients entered and left the HAART room. If a patient was considered «clinically stable» and was not asking questions about health condition, the nurse just asked some quick questions: «how do you feel this month?»; «Did something happen this month surrounding your health?»; «Are you taking the medication well?». She then checked the last CD4 counts and sent patients away with the drugs for the next month, or every 6 months if they were considered «good' adherent and clinically stable patients».

In many of these meetings, I had the feeling that Maria João's work was mechanical and not focused on understanding whether the patient really had any questions or concerns about treatment. In other words, I felt a lack of effort in listening to the patients. As reported by MSF, many patients, although there is general knowledge about ART, have limited knowledge in understanding what viral load is and the relationship to adherence and treatment failure (MSF 2017).

The participants of the support group were often confused about VL and CD4 counts and have no notion of how to read them. When Maria João read the CD4 or viral load result in front of the patient, she wasn't explaining the numbers and the range of «normality» but only communicated whether the result was «good» or «bad». Maguele – one of Namati's activists – described this trend as the «culture of silence»:

> In Namati we want to end this culture of silence that is present inside the health centre. I'll give you an example about knowledge around HIV status. When you speak with patients they tell you «I know that I am taking the blue pills, and the yellow ones» and then suddenly from one month to another the factory made the pills in different colours and they became really confused. Patients have no idea of what they are taking (the name) and what the CD4 is, they are not able to read the exam, they just know if it is good or not. Patients have the right to know the CD4 count and the right to know the names of the drugs they are taking…The problem here is that they have no idea what their rights are. When a right is violated the patient does not complain. There are few options to complain: you can make a complaint in a box, there is a book on the reception desk of the centre (picture 28).. But people didn't use these channels. They are afraid that the health workers will recognise them and they are worried about the consequences. Is also difficult for us to convince people to speak with us about the difficulties. There is then a problem in the structure of the health centre. People in this country are not prepared to have responsibilities and deal with them. The same accountability system inside the health centre does not take this seriously. There is a lack of responsibility inside the system (Maguele, Interview, 9th of September 2017).

Picture 28. The complaint box in the Centro de Saúde

In some cases, in particular when the CD4 count was low, Maria João took a few more minutes to explain the importance of taking the ART in order to stay well and if the case was considered «complicated» (e.g. minor alone, comorbidity with other illness) she send the patient to the psychology room.

When I participated in some of the conversations in the psychology room I was initially surprised by the lack of mention of emotional states, about «feelings». I felt an impossibility in «feeling talks», since the talks were previously directed around adherence and basic needs. In this context, as in other contexts of the research, I understood from the participants that speaking about feelings with health workers was not so common and considered something «western» and the discussion was basic and material needs oriented. As other authors have suggested (Fassin 2012; Carr 2010; Matza 2012; McKay 2018), in contexts with few socio-economic and medical resources, material issues take precedence over HIV-related psychological issues.

One morning I accompanied Carlota to a session with the counsellor Emma. She had been tested positive a few months before and she decide to bring her husband to the centre. They were what the counsellor called a «discordant couple», which is the term used in health centres to say that one of the two partners is HIV positive and one remains negative, even though they have had unprotected sexual intercourse.

As I mentioned before, the couple expressed their will to have a baby, with Carlota asking how it was possible without infecting her partner. This last question resulted in a silence in the room. Emma suggested that Carlota and her husband wait six months to have a baby without any further explanation about this.

The information itself was not wrong, as the MoH guidelines advise people to wait six months and at least do the first viral load test to make sure that you are undetectable and therefore will not transmit the virus to your partner. Why was this not mentioned? I questioned the counsellor about this practice of «not explaining», and also about «not listening» and the answer was that the patients would not understand the meaning of the explanation and therefore according to her, it was better to give little explanation. Afterwards I had a long talk with counsellor Emma, who told me about her difficulties in dealing with delicate issues such as the pregnancy of HIV-positive women, extramarital relationships and the great concern she had in providing the wrong advice with the risk of infecting the partner. We continued to reflect on the great responsibility of her work and the need to have training to be able to give adequate advice, in her words «safe» advice, to patients like Carlota.

In a context where staff were particularly worried with material assistance, such as food supplies, laboratory results and drugs, the issue in the area of psychology was to find the time and resources to implement careful therapeutic listening.

Clinic staff like Maria João and Emma thus navigated between challenging imperatives: a managerial effort to improve clinic attendance and a therapeutic effort in empathetic communication with the patients, which, due to lack of time and training, were often unable to co-exist. Listening was a difficult practice to acquire because it involved working with evaluation practices and possible distribution of resources and care, as well as therapeutic and empathetic engagement (McKay 2018).

Due to the lack of human resources, the workers in *Centro de Saúde* had to be able to multitask. They had to perform tasks taking into account psychotherapeutic tools, clinical evaluations, and bureaucratic obstacles. Bureaucratic issues had to do not only with patient files, but also with collecting data for research, implementing project management strategies and serving as scripts for medical instruction (McKay 2018). Likewise Magule, Eduardo Malo one of the project's coordinators of Namati believes that:

> Health is seen and lived by the people as a gift that the Party (FRELIMO) and the State provide to you. There is a sort of continuity between the colonial way of providing health and the post-colonial period with a single party. There is an apparent democracy in the state and also in the health sector when in reality it is all a huge oppression machine. The social climate in the country breeds public officials that are created not to complain, therefore there is a prevalence of a silent culture in the whole system (Eduardo Malo, meeting, 24th march 2017).

On many occasions in the Centro de Saúde, the general tendency to pass on little information to patients was associated with a communist or rather socialist legacy (McKay 2018). However, this is a partial explanation that needs to be related also with the rest of the history of public healthcare provision in Mozambique showed in Chapter Three.

Indeed, to better understand this attitude, it is interesting to think not only of the colonial and post-colonial issues in Mozambique's history, but also of the history of HIIV/AIDS policies themselves. Many early AIDS projects brought with them a disciplinary form of counselling in which patients were expected to conform to clinical standards or risk losing their access to treatment and care (Mattes 2011; McKay 2018)

This therapeutic landscape was created by humanitarian projects and shaped to measure adherence outcomes. Indeed, when we talk about creating empathic relationships with patients, we have to consider that health workers were not exactly called upon to perform this task, but rather to control, monitor and evaluate how patients were behaving. The style encountered during the visits was often interrogative and disciplinary and perhaps, as McKay states, was more related to the global health and HIV/AIDS interventions than to a socialist past (McKay 2018).

However, I observed that in healthcare practices common people present an impossibility to complain that come from theirs past history. As shown in Chapter Three, there are some mechanisms in the history of health of Mozambique that are represented in the every-day routine. As Roberto Beneduce affirms «there is no doubt that medicine represents, for the role that it has and had in the territory of the evil, of life and death, a political space» (Beneduce 2010, 101). This mechanism was amplified during the colonial times and it is still present in people's memories. Health facilities are still a place where a «docility construction device» (Beneduce 2010, 101) was present.

In this case, giving people little information about their health condition, became functional in order to ease the difficulties of the health personnel. In a situation where time and resources are lacking, leaving patients in «ignorance» is seen as practical in order to avoid questioning or further explanations to and from the patients.

As emerges in Chapter Two, however, there are not only passive subjects to medical authority, but also activists and HIV-positive people, and efforts are being made in the direction of giving agency to patients so that they understand their rights and ask for more information in the health centre.

Chapter V

Care though the politics of emotions

Because of the precarious health and social conditions that Mozambique faces, some of the seropositive patients still find themselves in a state that is clinically defined between chronicity and terminality. This situation was part of the daily routine at the Clinic. Health workers have to deal with the emotional challenges of working with chronic and terminal patients. In particular, doctors find it especially hard to accept the terminal stage of AIDS when they are caring for young patients. Beyond this, they feel that the idea of terminality reveals the individual failure of the humanitarian purpose.

Thought the story of Pedro, knows in the Clinic as the young boy «that never complained», the aim of this chapter is to show how daily work with young people with the virus of HIV is shaped by emotions. In the beginning of the writing process, when I drew up the index of my thesis, my idea was that this chapter addressed the survival strategies that Pedro adopted to survive. Pedro eventually died in September 2019, an event that made me feel helpless and hopeless. Nonetheless today it has brought distinct, unique and original reflections on what it actually means to fight for survival (and fail) in Mozambique. This is, then, the story of the struggles undertaken by the health workers at the Clinic, who struggled for their patients to survive with a provision of care that was different in space and modalities from the one presented in the previous chapter.

This section is mostly based on the testimonies and interviews with health practitioners, social workers and family members, rather than being narrated in Pedro’s own voice. For the last four months of fieldwork I accompanied Pedro on his care journey through health centres and hospitals, however his personal testimony was difficult to collect. Apart from his fragile health conditions, the difficulties presented in his family environment where he grew up also had an effect on his ability to express himself through biographical details and emotions. For this reason, the collection of his story for my work was done also with the help of other voices. Overall, this chapter reflects on moments of liminality where the workers of the Clinic and of the Daily Centre made decisions between life and death, chronic and terminal, survival and annihilation.

The Clinic

The Clinic was established in 2009 as a collaboration between the MoH and an international NGO in a busy suburb, in Mozambique's capital, Maputo. The Clinic's main objective was to create a better link between primary health care and referral hospitals by creating a centre specialised in treating the complications of HIV-positive patients (such as advanced disease, treatment failure and Kapose Sarcoma - KS) and those with low CD4, therefore considered severely immuno-compromised, at stage III/V AIDS (Fardhdiani et al. 2018). The clinic offers a comprehensive range of services from medical examinations, laboratory tests and psychosocial care, including second- and third-line ART for adults and children, chemotherapy for HIV-associated KS, diagnosis and treatment of OIs (opportunistic infections), and management of side effects of ART. In addition to these services, which are often unique in the country, the clinic offers accompaniment to first-line ART, reproductive health education and adherence counselling. There is a system that identifies patients who do not come to follow-up consultations with the possibility of contacting them by phone and through home visits. Kapose's Sarcoma patients have a dedicated service for wound care and pain therapy (Fardhdiani et al. 2018). It was located behind a public health centre and the structure was partly open air, with the waiting areas in the courtyard around the garden. Normally people have follow-up appointments here because they have been referred by other institutions and doctors as cases that need extra care.

Initially I began to visit the Clinic to assist the young patients from the Daily Centre where I was conducting the research and gradually I became more integrated in the observation of their activities. It was immediately clear that the clinic was a place of care where the intervention was managed differently from the *Centro de Saude,* by staff that was partly Mozambican and partly foreign. As expressed by one of the non-Mozambican psychologists, this condition increased the exchange and knowledge in relation to patient care but it also created tensions due to the different and unequal manners in which the Mozambican staff was treated by the foreign staff (e.g. differentiated salary).

Humanitarian blindness

As Fassin argues, the expression «humanitarian government» designates the deployment of moral sentiments in contemporary politics» (Fassin 2012, 14). For the author, the terms «government» and «humanitarian» must be understood in a broad sense. The first one refers to a set of procedures and actions performed to regulate, control and support human beings. Government is a step beyond the intervention of the state, local administrations and political institutions in general. The second term, «humanitarian», encompasses the two dimensions of the concept of humanity: (Fassin 2012):

> On the one hand the generality of human beings who share a similar condition (humankind), and on the other an affective movement drawing humans toward their fellows (humaneness). The first dimension forms the basis for a demand for rights and an expectation of universality; the second creates the obligation to provide assistance and attention to others: once again we encounter the articulation between reason and emotion that defines moral sentiments (Fassin 2012:2).

Humanitarian reason is based on this intersection of reason for action and emotion in a context where, according to Fassin, the tragedy of the human condition cannot be ignored (Fassin 2012). From this perspective, as Fassin affirmed:

> We consider humanitarian government as the response made by our societies to what is intolerable about the state of the contemporary world. In the face of violence, disasters, and epidemics, and also poverty, insecurity, and misfortune, what is intolerable is not only the presence of the tragic but the inequality with which it is embedded. The suffering of the unemployed man, the refugee, and the disaster victim is not simply the product of misfortune, it is also the manifestation of injustice. Humanitarian reason, by instituting the equivalence of lives and the equivalence of suffering, allows us to continue believing—contrary to the daily evidence of the realities that we encounter—in this concept of humanity which presupposes that all human beings are of equal value because they belong to one moral community. Thus humanitarian government has a salutary power for us because by saving lives, it saves something of our idea of ourselves, and because by relieving suffering, it also relieves the burden of this unequal world order (Fassin 2012, 252).

it is complex to make a critical reflection on the humanitarian reason because it seems morally untouchable (Fassin 2012). Keeping a distance between evaluation and emotions in fact risks falling into relativism, when connecting moral feelings with political and ideological considerations can be seen as cynical (Fassin 2012).

In this respect, the extensive work about MS of Redfield pointed out how the «humanitarian space is a space of life» (Redfield 2013,163). In abstract terms, health professionals do whatever they can to avoid avoidable death at work «against» sacrifice of people (Redfield 2013). But what place might death have within the ethic of life? The author argues that working within a context of linguistic and cultural differences only increases the uncertainty, where death does not have the same meaning; once life stops, assumptions about human commonality became harder to sustain (Redfield 2013). From the perspective of humanitarian aid, death signifies failure rather than an expected passage. This is particularly true for medical organisations that have to deal, on a daily basis, with the outcomes of curable conditions and human cruelty.

In addition, if medicine finds an impassable border in death, doctors are trained to accept death as a possibility. But however peaceful, a patient's demise never stands as a satisfying result, particularly if the cause of death represents something that in other circumstances (e.g. with better technologies, not in war zones) could be treated. Death is, in other words, the failure of practice care. Mortality may be a given, but it remains outside the current vocation of medical humanitarianism (Redfield 2013).

During my fieldwork with the health staff of the Clinic, an issue that emerged during our conversation was about the survival strategies that doctors have to decide to implement so that care is provided at the end of life. Carla, an expat doctor and one of the infectious diseases specialists at the Clinic, refers, during an interview, to the topic from which I would like to begin my reflection on the tensions surrounding the «choice» of reanimation:

> One day we had a very difficult situation here at the clinic, I think one of the most difficult moments that all the members of the team can ever remember. We had a Kaposi patient, that is one of the illnesses affecting patients during the last stage of AIDS. His family abandoned him and he was living on the street. We decided to introduce him to Casa 1, a facility of the Calcutta congregation. We were working on his process. He was lying down on

> the patio of the centre, here (we were on the patio), with a 40 degree fever, in a state of dehydration. The situation was getting worse every minute and he started to have bradycardia. Doctors stabilised him and we decided to send him to the Central Hospital of Maputo. Everyone in the clinic started to follow the situation and help each other to move him, when I realised that his heart rate was dropping… 40, 38, 35 … so I asked the nurse to prepare the adrenaline because in a few seconds we would have lost him. We were exactly in the middle of the patio of the Clinic and we had to start a cardiopulmonary resuscitation (CPR). His heart stopped and we started the CPR. My mistake in this situation was to not ask «should we reanimate him? Or should we leave him in the natural way? (*Deixamos na forma natural*?)» You know, that was my mistake, I did not consider the social part and considered just the clinical one: he was dying in front of me, and I had to reanimate him. After an hour of cardiac massage, it was torture. The team was destroyed, one was crying, another one told me that she was feeling the pulse of the patient, we were looking at each other without an answer. We decided to stop. Someone started saying that he was a palliative patient («*doente paliativo*») but no one said anything during the CPR, I blame myself for what happened, he was not a case for reanimation (Carla, interview, 15th September 2017)

This episode had been reported by more than one of the clinic’s workers as a traumatic moment which raised thoughts about survival. Health workers were ruminating about the limits beyond which it was possible to snatch someone’s life back, as well as what kind of life they were able to offer to the resuscitated patient. As Carla suggests, there exists a liminal moment where the clinician has the «power» and responsibility to choose between life and death. But as a counsellor she asked herself «where are we placing this limit?» and I may add, «Is it a strict limit or is it fluid and subjective?».

Like many other aid groups, they lean on the general Hippocratic precept of avoiding harm and as Carla suggests the humanitarian mind is deeply troubled by the possibility of actively choosing death. As she argues, when doctors save a life through the reanimation process they are saving the «biological body» of the person – overshadowing the so-called social component. In this regard I suggest that what Carla wanted to underline was the importance of considering the patient within a holistic vision.[30]

---

[30] On the holistic view of health and illness, medical anthropology and social sciences broadly approach the topic from different perspectives. Furthermore, despite not having had the time to pursue the issue in this first

In this regard, however, I think it is important to keep the focus on the problems that a binary oppositional logic such as nature and history, bare life and qualified life can produce. When this logic shifts from philosophical, sociological and anthropological theory to the practice of social observation, the risk is to miss many important nuances (Fassin 2010). As Joana Maria – another expat doctor and one of the infectious diseases specialists argues, speaking about the death of another patient with reference to how the binary logic isn't sufficient:

> We (as health workers) are occasionally wrapped up in humanitarian blindness which does not allow us to define a limit between what is a purely biological life and an acceptable social condition. We are so obsessed with the idea of keeping someone alive that we do not have time to stop and reflect on this aspect and often there is no time for that! Or if we do, it can be considered unethical. So should we collocate this limit to make the important choice of saving lives in our everyday life? (Joana Maria, interview, 4th June 2017)

What Joana Maria called «acceptable social condition» is what was I was questioning and what was troubling my thoughts. While knowing that it is related to a different context, I would like to use the metaphor of Agamben's «bare life» (Agamben 1995) to reflect on Joana Maria's words. As Redfield suggests, categories as «state of exception» or «bare life» must first be problematised in order to enter into dialogue with and to be useful for the study with the clinical staff (Redfield 2013). The concept of «life», as Agamben argues, can be perceived in the foundation of contemporary biopower constituted by the state of exception By «life», Agamben refers to two distinct words that could be found in Ancient Greece: *bios* (the form or manner in which life is lived) and *zoē* (the biological fact of life). The risk of not making this distinction is that in particular political contexts, the word «life» goes to refer only to a biological aspect or, more appropriately, to *zoē* with the implication of not dealing with the quality of life lived. For Agamben, considering a life only on the biological level, excluding the analysis of the form in which life itself is lived is described as a «bare life» (Agamben 1995).

In my work, «bare life» is to be understood as the condition in which young seropositive people are in a «state of exception», having been deprived of a series of fundamental rights. First

---

version of the chapter, my intent is to address it following authors from the context of the critical psychiatry as Franco Basaglia (2005). As the author suggests in his struggle for the closure of asylums, he firmly supported the importance of social aspects in the treatment of psychiatric patients, depriving a holistic cure of the patient.

of all the access to health, the impossibility of being cured with dignity and lastly, but not least, all others rights like the right to education, access to food and more in general, children's rights. As has come to light in this chapter they have been deprived of these rights throughout their lives. Therefore the concept of Agamben is helpful if contextualised in a more historical, political and geographical way (Comaroff 2007). The notion of bare life, dialogues well with the concept of necropolitics, introduced by Achille Mbembe, where necropolitics refers to the use of social and political power, through a series of explicit and implicit practices, aimed at exerting control over the life and death of people. In this sense, necropolitics also manifests itself in the legitimisation of the exposure to death of particular human groups and individuals by those exercising power (Mbembe 2006). As Joao Biehl also shows for the Brazilian situation, in what was called by the media the «Africanisation of AIDS», where communities of destitute, undocumented and infected people live like *homines sacri* that belong neither to the living nor to the dead, remaining in «zones of social abandonment» (Biehl 2007, 140).

As the author affirms, zones of social abandonment were prominent in the Brazilian urban context and were identifiable in physical places such as drug rehabilitation centres, but also in specific «categories» of the population considered to be on the margins of the society such as AIDS patients, homeless people with mental health issues, unproductive young people and old bodies (Biehl 2007). Biehl continues: «Neither legal authorities nor welfare and medical institutions directly intervene in these zones. Yet these very authorities and institutions direct the unwanted to the zones, where these individuals are sure to become unknowables, with no human rights and with no one accountable for their condition» (Biehl 2005, 4).

There is a great paradox around areas of social neglect in which the proliferation of deadly places, permitted by public authority, happens at the same time that great campaigns to prevent and treat AIDS are being run (Biehl 2005).

During the home visits, on the peripheral roads, during visits to hospitals, it became increasingly evident to me that there was a population that was not recognised by the formal government, that was not mapped in the population and that lived on the edge of everything and everyone. The presence of these neglected areas created in me a feeling of oppression and bewilderment, leaving me with unresolved questions about the possibility of their existence. For instances, in the streets of the city it was common to meet *moradores da rua* (street dwellers) living in the most miserable conditions, looking for their meals in the dustbin and children sniffing glue so as not to feel hungry. As others *no places* like the psychiatric hospital of Infulene, where bound bodies were abandoned for years in the hope that one day they would escape, but also the hospital of Machava, where people were sent to die of AIDS and which I will describe in the next chapter, the centre of the Sisters of Calcutta, a shelter beside the city's major *lixeira* rubbish dump where Pedro spent a period of his life and which I will describe in the course of this chapter.

In the daily work of the health workers in the Clinic, the condition of *homines sacri* was somehow present and the staff struggled to give back, at the end of life, a civic status to the patients. The assumptions of their work were emphatically based on life rather than death. Likewise, they define life through ethics rather than politics. However, the binary logic of life/death, ethics/politics are mutually dependent. This tension was a sensitive matter in the Clinic's health team, was all of whom were aware of the idea that there was always a choice to be made. For example, a choice on the priority of patients, that implies the exclusion of others patients. Somehow, the work in the Clinic was replacing the one of the State by entering into a whole series of contradictions that can be elicited with the provocative portrayal of the humanitarian mobile sovereignty (Fassin and Pandolfi 2010), in a process where humanitarian organisations reaffirm sovereign power, such as the making of a decision about who to help and consequently who can be left behind.

Still what is relevant for my study and for AIDS studies in general is a critical concern about the complex contemporary politics of exception and the ambiguities of survival (Redfield 2013). Questions of survival and exception do indeed lie at the heart of contemporary humanitarian action, particularly when it unfolds through the form of the medical emergency (Redfield 2013). As Redfield (2013) argues, there is a universal appeal in humanitarian concern to save lives: minimal mortality through emergency care. This is the reason why medicine—particularly emergency medicine—finds an insurmountable border in death, beyond which it cannot reach (Redfield 2013). If the humanitarian focus is on saving patients' «bare» life, then there is a total rejection of «bare death» (Comaroff 2007). Yet – while questioning bare life – health workers' behaviour and feelings at the Clinic fight against «bare death» and what can be called «a chronic dying» in particular with young patients in a practice surrounded by ethics, empathy and more generally, emotions. In the following paragraphs, I will explore in more detail two important aspects: the influence of emotions in shaping the clinical work of providing care, and the ambiguities of the politics of survival, that – as shown by Pedro's story narrated in this section – are strictly connected to the first aspect.

The political force of emotion

The work of health professionals assisting AIDS patients in the last stages of life inherently entails emotional labour. Being confronted with young peoples' pain and loss represents, for me too, one of the main challenges during fieldwork. In this paragraph, then, I want to show how, while implementing strategies of «survival» for themselves in order to handle their patients' suffering and decline, health workers mobilise their emotional labour to increment actions of care and strategies for the survival of their patients too. In this sense, I argue that emotions become a political force within an economy of care and survival.

Emotions experienced by health professionals and their patients show how this emotional component affect us and other people, transforming our way of being in the world and acting within the world (Lo Bosco 2018; Ahmed 2004; Clough 2007). Sara Ahmed, in her work on emotions, asks not so much what emotions are, but what can emotions do.

In this chapter I do not want to go into the social and cultural practice of emotions (see for example Abu-Lughod and Lutz 1990; Lutz and White 1986; Rosaldo 1984), but rather what emotions make us do in order to implement strategies of survival and healing (Ahmed 2004). I consider emotions to be a component that is entirely linked to the context in which we live and/or find ourselves. The ways we experience emotions are also strongly relational, i.e. linked to our experiences and memories (idem).

Following Sara Ahmed's perspective, emotions can be intentional and relational at the same time (Ahmed 2004). The intentionality of emotions is to be recognised in what they tell us about something that has a direction and orientation towards an object (Parkinson 1995, 8). Moreover, they are relational as they imply a re(action) towards and by the object (Ahmed 2004). They create change.

In the biomedical context, emotions are central in the practices of treatment and care concerning the empathic relationships with one's patients (Jensen 2017; Gray and Smith 2008; Smith 1992, Halpern 2001). In this regard, I report below an informal conversation I had with

Joana Maria about the feeling of working with the process of dying. In this extract, she tells me about her strategies to keep strong without losing «her heart»:

> I think I feel in the middle between having a cold heart and a soft heart. Sometimes I'm a bit afraid that it gets too cold. For example, I'm actually working with Kaposi patients and I know that the majority of my patients will die. I started a trial (study) to use better chemotherapy but I know that my patients will all be dead when it's finished. They are all in the advanced stage of AIDS and the last stage is cancer. It's hard, it's hard especially with young people, but working with Kaposi sarcoma helped me so much, because it makes sense, it's a way to alleviate their suffering and give them a better life for the next years (Joana Maria, informal conversation, 24th September 2017).

The possibility of giving a better end of life without pain and through palliative care represents one of Joana Maria's strategy to handle the loss of patients and a way to motivate herself.

As Maria Concetta Lo Bosco argues, it is interesting to analyse emotions not so much for their cultural background, but for how people talk about emotions and how these emotions cause them to act (Lo Bosco 2018). During the research, my young interlocutors displayed a series of affective expressions that influenced the way in which care was provided by doctors, social workers and also by me.

As shown in chapter 1, during the research I had to reinvent new strategies for young people to tell their stories. Communicating emotions through language was complex, making me realise that interviews, conversations, direct questions were useless and counterproductive. The expressiveness of emotions, also linked to the advance of the virus, had another vector, the body. It was through the body, and also through drawing one's own body, that it was possible to enter this world:

> You see, in the head, here where I'm colouring in red (then recolouring in blue), there are the emotions that give you a headache, those if you think too much, that's why you mustn't think too much! If you think too much you go crazy! Here instead, in your heart there are the good ones, the sweet ones, like when your grandmother or mother gives you a hug (Carlos, informal conversation, 13th march 2017).

This example is not intended to be an exhaustive representation of emotional states between young people, but it does help to understand the interconnection between body and mind. As Veena Das argues, language should be considered as an experience and not a vehicle for communication. This can be not only verbal but also bodily and sensory, allowing us to relate and communicate our experiences and memories (Das 1998).

Clough (2007) describes emotions as a way of being in the world that is both expressive and interpretative. In performative actions and in discussions and interactions with others, the author considers individuals as sensual, cognitive and affective beings (Clough 2007). In other words, as Lo Bosco affirms:

> People - as dynamic social subjects - do not just "feel" or "speak about" emotions in socially prescribed ways, they are also performing the emotions they embody. This performativity belongs to discourses and practices, words and actions so that both can illustrate the affective nature or texture of our daily life activities, interests and concerns (Lo Bosco 2018, 205).

The author goes on to emphasise the important link that exists between emotions, motivations and desires and how they penetrate social space, power dynamics and institutions (Lo Bosco 2018). This means, as Gould (2004) argues, that emotions become possible vectors of change, also coming into play in matters of social and political engagement.

The pain that young patients often experienced was both physical and mental. Emilia, Jose, Pedro, Carlos, Sebastião, Joana and the others participants were constantly subjected to terrible and painful physical tests. Their bodies were more «porous» than the others because they were more defenceless. Consequently, skin diseases, open wounds that became infected and did not heal until weeks later were part of their daily routine. I remember that when I met Edson, his body was covered with atopic dermatitis. Edson couldn't concentrate on anything but his skin and the rashes that were battering him. Sometimes during group meetings I could hear him whispering that he was scratching himself and there was nothing to distract him at that moment. If the physical pain decreased over time, or at least disappeared for a while, the scars on his skin made him feel inadequate, making him stop attending school. For this reason, young patients, even if they did not express their pain through words, did so through their bodies, creating in the health workers, in me and in general in the people who cared for them an active and conscious movement to create change, at an individual and political level through care as a political commitment.

Speaking about another young patient, Carla was particularly affected by this aspect:

> Sometimes Pedro and I are crying together. He tells me «Doctor, don't worry I'll not leave you. I'll fight and live». I cry in front of my patients and with them, I think it's important to share with them the feeling of being worried. I don't think we have to speak with them about death, but we have absolutely to speak with them about a life plan (…) I cried with him (Pedro) this week because he has a lot of injuries. In the hospital, the nurses didn't change the drip every three days and so his wrists got infected. This hurts you really a lot. It really hurts! This is unacceptable, because it's a bad health provision from the hospital… This is the Mozambican reality in public hospitals, it's unacceptable as when patients have injuries in their back due to lying down in bed in the same position. So, I saw Pedro and started crying, because he is the one who can die of pain and never complain. He never complains… At that point [of having his wrists infected], the expression of suffering is so huge, please suffer, this has to hurt you somehow and you have to tell me! He tells me that before he feels a bit of pain but not now, now is fine, and he tells me not to cry (…) One time I was with Francisco, he is also another one who never complains. Once I had to see if he had neuro-meningitis, and the exam is really painful, believe me. I had to put a needle in his back and take a sample. I inserted the needle into this small and fragile thing (the body). These children who have so low immune defences take all the diseases in the air, from cats, from pigeons, I had to understand if he had fungal meningitis. When I asked him if it hurts, he said he hadn't felt anything. Please! It's impossible! Please say that it hurts! (Carla, Interview, 4th June 2017)[31]

Indeed, we can see emotions as a communication and sharing channel of our motivations and interests, but also as a *mutual influence* in which an interaction between bodies takes place and that shapes our way of responding to situations (lo Bosco 2018). In my view, emotions flow between Carla and Pedro in a sort of circular movement. The (not) suffering – and the presence of

---

[31] Even if health practitioners call the young patients «children», they are actually teenagers aged 15/16. Besides a common tendency to infantilise patients, this is also due to the fact that their bodies are tiny and fragile so that they usually appear younger than they actually are. The medical staff gives little agency to patients, even to older patients, insofar as they are considered unable to take care of their own health or understand medical indications. For this reason, I witnessed different situations where young adults are treated in a childish way. This issue also concerns with the roles of power between the medical staff who work for the State and what is considered «common people» (*o povo*), as I described in chapter 3.

suffering itself – of Pedro instils in Carla a feeling of concern and sadness, which in turn is expressed by Carla’s tears in her desperate attempt to let him take care of himself. Carla’s tears, for instance, work as an emotional force or as the ultimate impulse able to provide care to Pedro through his understanding on how much she is worried for his life and how important it is for him to take the drugs.

When she is invoking new strategies of adherence or denouncing the health sector’s insufficient strategies, Carla’s emotions are becoming a part of her political life and an act of care. While the pain experienced by Pedro and Francisco eventually undermines their verbal ability to express emotions, the world of the clinical staff is to mobilise emotions in order to help patients to move into action, an issue I will address in the next paragraph. Paying more attention to the emotional burdens of professionals within medical settings serves as a reminder to regard not only patients but also health professionals as individuals, rather than a homogeneous professional group. The emotional aspects of the clinical work should not be disregarded as merely a side effect of the clinical labour or as a disturbing element in «rational» clinical practice. Rather, for health professionals there are emotional challenges that are inseparable from medical decisions and practices in providing care. As such, these challenges influence the experiences of both professionals and patients, and they actively interact with so-called standard clinical practices.

The chronic emergency. AIDS and questions on living

> At first the focus is not to die. Then come other questions of living
> (MSF statement in Redfield 2013, 179)

During conversation with and between the Clinic’s team I realised how the boundaries between chronic and terminal statuses were permeable, subjective and somehow unrealistic due to the clinical situation of young patients. It was almost an ambiguous speech, which Fassin claims is not a contradiction but the psychological response between realism and optimism, between death and an intolerable prospect of life (Fassin 2010).

For sure the picture surrounding the possible path of HIV/AIDS is different if coming from the position of a psychologist, a doctor or a social worker. This is undoubtedly a relevant point, but it is not my intention here to show the divergences between the various interlocutors' views. Rather, I would like to show how the Clinic's workers create a shared narrative of rationality and emotionality, chronicity and terminality. Through my personal experience, I somehow realised how this blurred boundary between rationality and emotions was part of doctors' everyday struggles in the clinic. During the final months of my research, while interviewing Joana Maria, I remember how traumatic it was for me to discover that the life expectation of the young patients in the support group at the Daily Centre in the second line of treatment was a maximum of 5 years:

> 10 years of life expectation? Is too optimistic, probably 5. They are too young to be so sick. These young patients are affected in multiple ways. Their growth, their physical and psychological development, and then the health sector has structural problems, like the country not always having medication. We hope that in a few years the drugs will be a bit better, researchers are struggling to discover new methods and drugs. They are also working on an implant, imagine... It will be fantastic! Because in this way you just have to take care of what is «around» HIV…(Interview with Joana Maria, 13th December 2017)

In light of this, my considerations were imbued with an optimistic feeling of hope and expectation for a fast recovery of the young patients. «Why is death confusing us so much that we have lost our rational thought?» questioned a nurse at the clinic. Aside from the emotional aspect, the progression of the disease is multifactorial as Ernesto, the psychosocial coordinator of the clinic, explains. Speaking about the terminal condition, he affirms:

> I don't like to speak about patients saying that they are in a terminal stage, we are not the ones who can say that they are in the terminal stage. We had patients with a really low CD4 who then recovered. But I have to admit that it's quite difficult, I always have hope but it depends on a lot of factors. There is the drug component; there is the emotional component – you have to stay strong to keep taking drugs; there is the social component (family support), which is the part that is missing for many of our patients, in particular children and adolescents (Ernesto, interview, 7th March 2017) .

In order to address the difficulty of speaking about the «dying process» or «chronic dying», it is worth taking into account how, as Ashforth argued (2010), in many African cultures it is impossible to speak about chronic dying. Speaking about stigma, Ashforth (2010) claims that naming a disease, in many African countries, would be like saying that the person is already dead, as well as calling into question the pollution that this person might represent for others with whom they come into contact. Although never clearly stated by Mozambican clinicians, I felt some resistance in referring to the last stages of life as the last. Furthermore, in many circumstances when I used the expression «to die» (*morrer*), I was always corrected to use instead his/her «loss of life» (*perder a vida*). Clinicians were obviously aware of the usual progression of HIV/AIDS as Carla, the infectious diseases expat doctor, argues:

> HIV can take a long time before evolving to AIDS. When a patient starts to get sick (e.g. with tuberculosis or pneumonia) then the disease is classified as AIDS, there is no going back to the HIV positive stage. AIDS has 4 stages, the third and fourth stages are terminal. AIDS always advances and cannot go backwards, even if the disease is under control. All my patients are at stage 4, they have Kaposi sarcoma and that already defines stage 4. For example, Joana had pulmonary TB and she is already at stage 4, so the prognostic for her and for the others that you are following up is really bad. This is when you do the prognostic with the CD4 count. With a CD4 count of less than 300 I think of pneumonia, with more than 300 I think about tuberculosis. (…) Actually, a person like Joana, with an advanced stage of AIDS and so young, has a really bad life expectancy. Same path for Carlos, he had sarcoma and extra pulmonary tuberculosis and he is in the second line treatment. When you have cancer like sarcoma in his stage that is the more advanced, the normal rate of survival is 30% in three years. But then there are people that can manage it, I had patients with a terrible sarcoma and CD4 counts at 5, and now they are well. There are people that manage it, but it depends a lot on the family context. If the family is responsive and takes care of the patient the situation can be different (Carla, interview, 13th September 2017).

From a different perspective, Maria, a psychologist of the centre affirms:

> We are counting losses, actually we know that, we know that we are working with people that are in a terminal condition. When we check the clinical history of our patient, we know that this person will die soon (…) I believe that there is a huge part [of us that protect

> themselves with] a mechanism of defence. We create an illusion and an optimistic view to have some hope. Today I was chatting with a patient for example. When he first arrived here, his weight was 35 kilos, now he is 78 kilos…that cheers you up a lot (Maria, Interview, 30 July 2017).

While listening to the interview, I realised how it was quite common for the doctors to embody in the same speech «the contradiction» between rational and emotional thinking, which Fassin was speaking about (2010). Somehow, Maria and the other workers, myself included, know that while they are constructing an illusion of hope, they also rationalise this illusion with positive examples of people that recovered: «sometimes we have miracles!» once claimed one of the doctors.

In the Clinic, the work of care is a kind of race against time. «If the disease leaves us some space, we can surround it» affirmed Alfredo, but this is not always obvious. Clinicians deal a lot with the patient's individual responsibility. This refers to what some of them called «the emotional competence of the patients», a sort of personal motivation that relates with self-responsibility, which is considered by them to be one of the crucial aspects of the treatment's adherence, as Maria pointed out:

> When I meet adolescent patients, sometimes they have the sensation of being protected. They feel like superheroes, they think that their body is protected and they will never die, that [HIV] is something that will happen to the others. Also when we do the «shock treatment» [which is] when we say, «if you are not taking drugs, you are going to die!», they say that they will do it, but then a lot of things happen, there are a series of factors that contribute [to this outcome], one of these is their situation of extreme poverty. How can you take the treatment if you have nothing to eat? When working with such kind of vulnerability, as a doctor you always have to take a step back and think…(Maria, Interview, 30 July 2017).[32]

---

[32] It is quite common for children and teenagers not to believe that he or she will die even if they knows or is aware that other children, with the same disease that has been treated in the same way, have already died. Children with chronic, life-threatening illnesses hold out hope and for a very long time may believe, sometimes until within days and weeks of their death, that there are things that can be done to make them better (Bluebond-Langner et al. 2010).

The «shock treatment», as with other technologies of survival adopted was also surrounded by violent rhetoric, as Carla reported:

> Do you want to live? So let's do it' when this admission is done, they know why they have to take the treatment, so the responsibility is individual, sure that the context is multifactorial, it's socio economic, it's familiar…they are adolescents and that's also a difficult phase for them. We can spend hours together speaking about it. Me, (as a doctor) I'm lucky because I have more time than the counsellors to do that. I explained to them what they have to do, the majority of them didn't know the reason why. Then I show them the CD4 line between 0 and 1000. In this case, my patient has 20, that is very low. So I push them to think rationally «You are really near 0. You know what happens when you reach 0? Do you want to live? So, let's do it!» I give trust to my patients. (Carla, interview 13th September 2017)

Clinicians, psychologists and counsellors of the Clinic spend a lot of time speaking with patients about the difficulties that they have in taking the treatment, an issue that is quite uncommon within public health centres such as *Centro de Saúde*. However, this circumstance reveals a paradox: only when a patient's health status is getting worse will she/he receive more or better attention and transferred from a public health centre to the Clinic.

Social and medical workers struggle to find better solutions to improve what stands «around HIV» and affected adherence practice and care. As highlighted by some of them, one of the factors that affects a patient's adherence to the treatment the most is the so-called social component. This usually refers to the family environment, which was pretty worrisome for the young patient with whom I was working. As Maria argues, the family environment represents one of the main challenges in her work:

> When we are faced with a really difficult family context, I feel powerlessness. For us it's really difficult to give them [young patients] the familiar support they need. Sometimes we also have to think about the hypothesis of taking children from families. This is really the last option. Mozambique doesn't have a social safety net for these children so it's really difficult to find a place for them to stay and to recover at least for a few months. Working with the social service here is quite hard but sometimes it works. For example, now we have a mother with three children, we want to place the children for six months in a centre: their

> viral load is really high and one of them was raped, we have to put some pressure on the social assistance to find a centre, but the point is that there are none! (Maria, Interview, 30 July 2017)

A poor family's context and the lack of a social safety net in Mozambique has exasperated clinicians' difficulties in finding a support plan, as I'll show in the chapter dedicated to Joana's case. As Maria reported, often the doctors appeal to their personal resources to deal with situations of extreme poverty. As she did for Albertina, a patient living in conditions of extreme poverty. Maria was really moved by her story:

> Albertina was married to a Portuguese, she spoke English, when the man died the family left her in the street. She lived in the street for 15 years, experiencing blood crossing, prostitution and everything bad that could happen. After a few months of taking care of her in the Clinic we found a way of giving her little cleaning jobs to do inside the Clinic. Although it was common that people after living so many years in the streets would develop psychiatric disorders, Albertina managed to survive and find a room to stay (Maria, Interview, 30 July 2017)

Pedro: The boy who never complains

As mentioned before, in this last paragraph I want to further address how emotions intertwine with the story of a young boy and how they might activate a change process of Pedro's condition because of their peculiar power to transform people's motivations and eventually foster their actions of care. In this sense, I believe that Pedro's story is significant because he is the only one for whom health workers envisaged the possibility of intercontinental travel to save his life.

When I first heard people speaking about Pedro, Sister Rita of the Daily Centre was remarking «he is one of those who relinquished living, like Francisco and Matilde, they are doing quite the opposite of what we are asking them to do. They know that in this way they are giving up, they want to». Her words shocked me at the time. How was that possible? I started questioning myself about the possibility of speaking about giving up and it sounded to me impossible to rationalise. During a clinical supervision meeting, Lara – a counsellor that was taking care of him – reported Pedro's speech at the hospital «Pedro said that he wants to give up, he is suffering too much, he says he wants to die», her words were broken up by tears. Pedro aroused feelings of love and care among the clinic's workers and he was suffering too much. He was in what doctors call the IV stage of AIDS and was showing an acute skin eruption where the blisters on his face prevented him from seeing. Because of this physical issue and of the stigmatisation he suffered for his appearance, he dropped out of school. Five months after I had heard about him, we eventually met. He was one of the members of the support group at the Daily Centre, but his precarious health and the difficult family conditions frequently prevented him from attending the meetings.

He was known in the clinic as the little young boy who was taking care of his family instead of the opposite, and that was one of the main aspects that touched all of us. Emma, a doctor at the clinic commented in this respect: «He is the family man, actually he always has been, even when his father was alive». A few days earlier, he told me during an informal conversation, that he was living with his father, mother and a younger brother, all seropositive and all monitored at the Clinic. As Pedro affirms «we were happy and healthy, I remember that we were going all together at the Clinic to take the treatment». In remembering the time that Pedro was living with his father, the psychologist of the clinic, Maria states:

> He was a hyper-responsible child. He was coming to the Clinic alone to take the treatment for all the family and he checked on them if they were taking [it] or not. He also was the beneficiary of the *cesta basica* (weekly food supply) that he shared with all the family. Pedro is suffering from severe malnutrition and he was sharing the food that was supposed to be just for him with more than 5 family members (…).That's one of the problems. He had a really scrawny body, that's why he looks like a 8 year old child while he is 15 years old. When his father died from cancer related to AIDS, things changed for him. He completely fell down, he was feeling lost and responsible for what happened. He was the one giving pills to him and this death made him think that he was responsible on one side and that the treatment was not working on the other. So, he decided to quit treatment (Maria, informal conversation, 12th November 2017).

As described by the nuns at the daily centre, the situation also changed the family environment and the family split up. Pedro's mother was sent away from the father's grandparent's house and she went back to live with her mother nearby. A family dispute began and the two brothers were separated from each other. Pedro's brother went to live in his aunt's house while Pedro started navigating from the grandfather's house to his mother's house. During one of my home visits, I realised how both Pedro's familiar environments were decisive to his health and well-being.

Pedro's mother came from a really poor environment, and the psychologists of the clinic suspected that she was also presenting mild mental issues. Moreover, all the clinicians were worried about her absence during the child's daily health care. Pedro always showed up alone, for his health check-up at the clinic and at the central hospital. Alfredo was particularly worried about this situation and insisted on the importance of involving Pedro's family, like they do for all the other patients. From his point of view, if Pedro's mom continued to be uninterested in him, they would have to look for an alternative solution.

Another aspect that really worried the health workers was the lack of sufficient food supplies at his mother's house. These issues created some tension among the technicians and created some hesitancy in their decision about the safest place for Pedro to stay. While Pedro's emotional bonds drove him to his mother's house, in another way he needed a steady food supply and a good health environment. Are affects enough to justify a choice? How much does Pedro's voice matter in a context where a choice can lead to life or death? Actually, these were (and still are) major and complicated questions, because we were all aware that adherence to treatment was possible thanks to the combination of emotional, health and social support.

However, in primary survival strategies in HIV treatment, patients need food supply. After a few meetings with the members of the Clinic and the Daily Centre, the psychosocial support team tried to move him into his grandfather's house, being aware that this would worsen his family's already existing conflicts. Pedro's grandfather lived with a new partner of whom Pedro was very afraid. While the house was in better conditions than his mother's house, Pedro was still sleeping on a dusty floor, which greatly aggravated his breathing complications. His grandfather eventually explained to me the reasons for the tension between the two families:

> Pedro's mother would like him to stay with her. But he is my grandson and it is my right to have him to live with me. That lady is crazy and she even called the police to take him away. She also killed my son, she passed him AIDS. Pedro here has everything. We feed him and we treat him well (Pedro grandfather, informal conversation, 20th October 2017).

During this conversation Pedro was sitting in silence listening to his grandfather. However, one day, while we were waiting for the other members of the group, we had a conversation on the patio of the Daily Centre. I gave him a camera for the picture project – unfortunately he lost it and he never had the chance to return it in order to print the pictures. While we were chatting about photos and what he would like to shoot in his family context, he started to speak about his family:

> My father died on the 16th of June, he was sick with HIV. I used to take care of him and to check if he was taking the treatment, but sometimes he used to come back home really late from work, he was a driver and I'm not sure if he was taking the pills. My parents used to live together, everything was fine, we used to go all together to the clinic to take the treatment, but when he died things changed. The problem is between my mother and my grandfather, the father of my father. All the problems are around this *vovo* that lives with him. She turned my grandfather against my mother. She wants my mother's house. When I'm home alone with this *vovo* I'm scared because she bites me and she screams a lot. My grandmother from my mother side said that she had spiritual problems and that she used to go to traditional healers in Inhambane. There she takes some medications and she puts them (traditional remedies) in the house. She did witchcraft on my grandfather, she made him «blind» so he cannot see me nor my family and he just takes care of her (Pedro, informal conversation, 24th October 2017).

Both family's contexts show how, despite his young age, Pedro was responsible for his own health treatment. He spent a period at his grandfather's house but his health condition got worse and his CD4 dropped down to 20. At the clinic, doctors struggled to come up with a solution. In a context where social safety nets are limited or even absent, many health workers confided to me that they were thinking of bringing him to their own home, an eventuality that crossed my mind too. Both I and the health workers were actually watching him dying and feeling a sense of impotence. Likewise in other cases, in the end of October 2017 Pedro disappeared from both the Daily Centre and the Clinic. Being aware that reaching him by phone was really difficult, the health workers decided to arrange a home visit and they eventually found the worst case scenario they could even expect. He was not at home but at the Central Hospital, and they found many jars full of ART pills inside the house.

This time, as many others, he went to the hospital alone to do an x-ray. Knowing that he had always appeared alone and worrying about his condition, the nurses kept him asleep in the hospital. His family did not show up for him in the following days, which increased the concerns of the health personnel. After doing the x-ray, they hospitalised him for pneumonia in the paediatric ward, which from that moment became his second home. This was evident also in his painting where medical presence was considered commonplace. During one of the meetings with the group, the assignment was to paint the family house. Outside of Pedro's house there was an ambulance that normally took him to the hospital.

A few days after his hospitalisation, he had an AVC and his CD4 counts dropped to 1. The central hospital was next to my house and I started to visit him every day. My field notes from this period were dramatic, I was sure he was going to die and after every visit at the hospital I was wondering if it was the last one. I remember nurses of the hospital telling me that it was better to start praying for him. He did not die during that hospitalisation and he managed to survive for the next two years.

One of the main issues arising during his stay at the hospital concerned some structural aspects common to other cases. As with Joana's case, there was difficulty around the access to the antiretroviral treatment in the hospital. Pedro's mother was not able to take care of this part, nor was his grandfather, so Pedro remained at the hospital for many days without treatment. From my diary: «I called his mother when I was with him in the hospital. I told her that he was hospitalised, and she told me she knew. I asked her to bring the treatment and she answered that it was not in her plan to go to the hospital today, and she asked me if the treatment was actually with her.»

Even though these dialogues established conflict and created in me a feeling of anger, I realised that they were also part of a larger plan around adherence to treatment that was not effective.

When I visited him after the AVC, Pedro was not able to properly move the right side of his body. We improvised physiotherapy along the corridor, as I realised that there would be no official physiotherapy for him: another structural lack of support in the public health system.

In this regard and following Fassin's (2010) perspective I argue how – despite the conditions of domination in which they are embedded – people arrange a manifold of subtle tactics thanks to which they eventually transform their bodies into political instruments, moral resources or affective expressions. Pedro, for instance, was able to arouse emotions in all the people that surrounded him, that were struggling to change the situation. The high level of responsibility, the need he felt to take care of the others amplified, in a way, his struggling to complain about his own physical pain. This troubled our hearts. As Carla reported, Pedro never complained about the pain he was feeling when the IV infused him nor about the pain he felt after the AVC. In a way, I felt that by silencing his pain, he was trying to normalise his state. Moreover, I suggest that children, with an existence surrounded by extreme suffering, had to increase their pain threshold in order to cope with life violence.

I think that the flow of his emotions has invested in some way all the people who have accompanied him during the last months of his life. We had weekly meetings where most of the conversation was about him and the life opportunities he would have once he was out of the hospital. Besides the hospitalisation and after one year of moving from one family place to another one, the health workers of the Clinic decided to place him at the *Casa 1*, a foster home where other members of the *grupinho* were spending some months.

Casa 1, run by a religious congregation, was located in one of the city's poorest neighbourhoods, the Hulene landfill site, which has recently become the focus of media attention due to the collapse of part of the landfill and the killing of at least 20 people. As tall as a 10-storey building and with an occupation of 2 KM2, life flows around and inside it. More or less informal collectors and recyclers stand alongside people looking for sustenance and children playing football undisturbed. The visual and olfactory impact of the dump remains impressed and I still remember one of the first times I drove past it on my way to visit Pedro. From the main road I turned left onto a dirt road and started to drive along it. I had seen something similar in another African city, Nairobi, but I was 13 years old and my memories were blurred. The smell did not allow me to keep the window down and the heat of summer did not help. However, the normality of life on the side made it almost «normal». I stopped to look at it, before taking another side street to get to *Casa* 1 and took a photo of a football game.

Entering *Casa 1* was not easy. It was a reception centre for both minors and adults. The presence of orphaned children, the nun explained to me, was a source of great interest for child and organ trafficking, so one had to enter by appointment. There were several sections and the residents were divided according to age and gender. It was almost impossible for males and females to cross paths, except at mealtimes. I went there often, with a mixture of feelings between feeling admired for these nuns and their work and the desperation it must have been to live there. Children were the majority of the guests. In one specific house there were babies in swaddling clothes. Here one of the nuns in charge told me that most of them were AIDS orphans and HIV positive. In one corner were the premature babies, twisted by blankets to look like an incubator. I thought that it was a «God-forsaken» place but Maputo gave no other options at that time.

The decision, taken together with Pedro's mother, made Pedro's grandfather flare up, and he told me that Pedro did not want to be in that place and that doctors and his mother took his grandson away without asking him for permission. After less than two weeks at the *Casa 1*, Pedro was hospitalised for 3 weeks for respiratory problems in the paediatric ward of the Central Hospital. When I met him, he eventually told me that when he had recovered and someone had to come to pick him up (these were the rules of the hospital). He waited a long time at the hospital exit sending messages to everyone, from the social worker of the Clinic to the nuns of *Casa 1* where he slept and to the nuns of the Daily Centre, but nobody went to pick him up. He waited until 6 pm when one of his grandfather's neighbours recognised him and brought him home. This event, as I will explain in Joana's story, did not allow him to return to *Casa 1*.

After a while Pedro's hospitalisations became more frequent and and also my visits to the hospital. I passed by to see him, he told me that he was feeling very well: «I feel well doctor, everything is over! I can go home. They told me they will send me home, but they didn't tell me when.» He always came to us with the most varied food requests: hamburgers, samosas and yoghurts. Following medical supervision, we started spending a lot of time sitting in the garden of the Central Hospital, eating and chatting together. After a while, he always apologised, and told me that he felt tired and preferred to go back to the room and sleep.

Even while he was in the hospital, Pedro was able to share the food I gave him with his mother. One day I asked him if he liked the samosas I brought him the day before: «Very much doctor, I ate one while I gave the other two to my mom and brother, they told me they were very good». I smiled, recognising that it was useless to tell him not to do this, and that the unconditional love for his family was probably one of the aspects that prevented him from understanding that he had to take care of himself before helping others.

The clinicians all agreed that the best solution for him to «live» was to keep him at the hospital. Meanwhile they came up with the idea of sending him to a centre for seropositive children in Portugal. Pedro was entering into the third line of treatment for HIV, which is quite rare in Mozambique. There was no more time. For the international travel he needed to get his ID and passport, but unfortunately the two families never agreed about how to start the process for him to get this documentation, so that the international «saving option» never happened.

In September 2019, while I was preparing another trip to Maputo, sister Augusta video-called me saying that Pedro wanted to greet me. He was hospitalised with an oxygen mask surrounded by the embrace of a health operator. I realised that his body was swallowed like many others I saw in the last stages of AIDS. He asked me when I would come back to Mozambique and when I would go to see him, then the phone line dropped. Shortly after this I was told of his death as a result of kidney failure.

His «chronic dying» tragically lasted a while and the set of actions that health workers undertook to save his life unfortunately didn't succeed. However medical and other survival actions operated by health and social professionals tell something significant. Although, as shown at the beginning of the chapter, their actions are never explicitly politically justified, rather ethically, they were deeply imbued with a political and emotional value. Care as saving a patient's life, or trying to do so, means taking action on the patient's social, family and personal context, trying to take on the responsibility of the State, when absent.

Chapter VI

Drug resistance and ancestral conflicts

Into Joana's story

With this chapter I want to reflect on medical plurality when care reflects local cultures as well as national and global power structures (Olsen and Sargent 2017). Where different healthcare options exist, Joana's story showed how patients and their families display a continuum of healthcare consisting of different medical modalities (Cancelliere 2020). The options chosen may be used concurrently or sequentially and usually treat the same symptoms (Olsen and Sargent 2017).

However, caught between the shortcomings of the health system and a violent family context, Joana's body became a battleground for ancestral conflicts and a stark illustration of medical failure. Moreover, the hospital setting presents a lack of infrastructure that clashes with the emergence of so-called «therapeutic citizenships» and interaction in the provision of care and adherence practice. In addition, Joanna's story showed how other social forces – such as the context of violence present within the family and the accusation of witchcraft worsen an already difficult context.

Joana was one of the first members of the support group. I met her for the first time in March 2017 at the Daily Centre. She was not able to walk, a consequence of severe malnutrition and harassment that had persisted over the last years. She was nineteen years old and her weight was 31 kilos, she was seropositive probably due to vertical transmission and she started ART at the age of ten. Joana was just back from an exhausting and violent journey: as she told me she spent the last year in Gaza Province, kidnapped by the father's family, or that was what they pretended to be.

She told me her story in little pieces, as all the young people that I met used to do. In this section, I will try to show critically important moments of her biography set in a chronological order, to then address them in the next sessions.

Joana was born in a little village near Chibuto, in Gaza Province nineteen years ago. Her mother, a cleaner in a rural hospital, died 6 years ago murdered by her stepfather, who died a few years later in jail. The alleged biological father was hit by a truck and was dead too. She lived for a while in Gaza with an aunt and then moved to Maputo to live with her grandmother in the house where she now lives.

At the time I met Joana, she was also living with her uncle's wife and his daughter. Her uncle Edson died in February as a consequence of AIDS. He was not taking the drugs, blaming Joana as the reason for his illness. The house in which they lived was located on the main road in the direction of Maputo airport. It was uncle Joao's house, with a garage in the front. Relationships with this uncle were complicated, both for Joana and for her grandmother, Clelia. He was considered a rich man: he had a car, he rented apartments and he had a garage. There was whispering among the family members that sorcery was the only explanation for his wealth. Joana often told me that her uncle did not want her at home because she was too sick and she just caused problems. He never helped her with money or food and just wanted her to go away.

She came to the Daily Centre for the first time at the end of 2015, Emilia, the social worker, explained that she arrived with her grandmother Clelia who was very worried about the health of her niece. The grandmother explained that she was «too small and that she always had a cough». She denied that it was HIV and was certain that Joana had problems with her ancestors' spirits. Therefore, she refused to give TARV to Joana, given that Joana never had sexual intercourse and that her mother did not die of AIDS, she thought that HIV could not be an explanation and that only ancestral conflict could have been the answer.

This was one of the reasons why, when one day some people, claiming to be the family of the dead father, asked to take Joana to Gaza – to do a ritual to save her – the grandmother decided to accept. So, Joana went to Gaza. Here, after a ceremony that I describe further on, she lived with her father's family. Joana lived without ART for more than one year and, without an adequate food supply, her health got worse until a neighbour helped her to run away to the police station. After a period in an orphanage, she was able to go back to Maputo to her grandmother's house.

With a CD4 count of higher than 700, her blood exams at the beginning were incredibly good, given the absence of treatment for an extended time. However, after one year she had developed a drug resistance to the first line treatment and she moved to the second line treatment with a CD4 count of 240.

The major medical concern for the staff of the Clinic was her respiratory problems. Joana presented what is called the sequelae of tuberculosis, deep wounds on the lungs which had caused a lung to stop working.

Ancestral conflicts

You have two options when bewitched.
Either you pray a lot for it to go away, or, at the same
time as you receive it, you send it back
(Emilia, social assistant of the daily centre, 2nd March 2017)

When I first met Joana, she was just reappearing at the Daily Centre after a year's absence, and she started her narrative:

> I spent the last year in Gaza (a region in the South of Mozambique), my father's family kidnapped me. One day some alleged relatives of my dead father demanded to take me to Gaza. I did not know who my father was … I was curious. My mother died 6 years ago. My stepfather killed her. He died too, in jail. After all of this happened, I began living with my grandmother from my mother's side and my uncles. We moved to Maputo. Before we lived in Chibuto (Gaza Province). In Maputo, I started living alone with my grandmother. It was better. Some people came here last year. They said they were my father's family. They said they have to take me to Gaza because if not, I would have gotten sicker and sicker and I would have died. They said I had a problem with my father's spirits. My grandmother did not want me to go, but then she let me go: «Take her and bring her back when she is better» she said. But I was sick, I had HIV and tuberculosis. They brought me to Gaza, they told me that I was going to do a ceremony, and I needed to stay there for the whole ceremony. If not, I would die. When I was there, I asked to go back home, but they refused.

> There we did the ceremony. First, they brought me to my dead father's room. But whether he was my real father, I do not know. They told me that I had to sleep alone there. But there were «things» inside the room… this *vovò* (grandmother) was a *Nyanga* (traditional healer). I slept there for three days, then we went to another healer. He told her to buy a goat and a chicken. They cooked it and served the food on the floor where I was sleeping, they gave me something to drink and then they went to another room. They started eating too. After a while, I noticed that I was always sick, that I was not getting better, and I asked this *vovò*, «*Vovò*, I'm not getting any better, can you bring me to the hospital?» They refused. They obliged me to put water on my father's grave…They hit me, this *vovò* and her daughter. They hit me because I was not able to bring water and flour in the house, I was too weak. This *vovò* told me that my father had been her son. He died when I was one year old, he was hit by a truck. They had told my mother that I had to stay there because it is a tradition to stay in the father's family, but my mother had taken me away» (Joana, informal conversation, 7th march 2017)

The brutality of Joana's story speaks of a complex system in which the cruelty of a violent family environment must be analysed in conjunction with different representations of health and illness such as HIV/AIDS.

It is since the beginning of the twentieth century that anthropologists have shown how diseases are culture-dependent as they are constituted as a human reality (Good 1994). The meanings that different symptoms may have in different cultures and classification systems are therefore different. However, it is important to emphasise that African care systems are not only the product of local history, but also of global influences. The frame of reference for diagnosis and treatment is then constituted by local conceptions of disease causation, healing practices and medical institutions (Olsen and Sargent 2017). The different ways of perceiving sickness also have to do with the various causes for which people believe they are sick, and in many African contexts this has to do with mystical forces such as sending sickness via witchcraft (Kleinman 1980).

Ancestor interventions were a constant presence in Joana's life. In southern Mozambique, ancestors are described as «being alive», suggesting their power of intervention in the «real» world and the affairs of living humans. The ancestors represent the dominant supernatural agency that, under the traditional system, is believed to control and condition human existence. The «visible» constitutes or represents a manifestation of the «invisible» and vice versa (Mahumane 2015). It is through dialogue between the living and the dead that the balance of the spiritual forces responsible for prosperity, protection (especially against acts of witchcraft), health, fertility, social prestige, production and so on is guaranteed (Feliciano 1998; Honwana 2002).

As Paulo Granjo argues, there are two fundamental starting points for the system of interpretation of misfortune, health and disease predominant among the Mozambican population. On the one hand, «fate» does not exist, coincidence is not casual, and undesirable events are not limited to «natural» causes. On the other hand, the dichotomy between body and mind does not apply to this system, which does not recognise the dichotomy between individual health and social context either (Granjo 2009).

In other words, Granjo continues, within this system uncertainty is «domesticated», and even if the effect is tangible, for instance with a disease that is biomedically measurable, it is assumed that the reason must be searched in the social and spiritual sphere such as the «bad» behaviour of the victim, the conflict among the living beings, or a lack of harmony with the dead – all of which are considered an integral part of society and the relationships established therein, as we have seen above. If the person manifests the symptoms of a disease, this presupposes the existence of a mental or spiritual imbalance that is affecting the patient. In turn, this imbalance presupposes the existence of social causes (Granjo 2009). According to this holistic perspective, to treat the disease it is necessary to restore social balance, including harmony with the ancestral spirits. If this does not take place, the health problems will continue, because their root cause has not been solved (Granjo 2009).

After the mother's death, according to the predominant patriarchal structure of the Gaza province, Joana should have remained with her father's family. The ritual conducted in Gaza by Joana's father's family was aimed at restoring the balance that had been broken in the past by Joana's absence. This was a family ceremony called *mhamba*, in which, as Luis Passador describes, the whole family should participate. *Mhamba* is always mediated by a traditional healer, a *Nyanga* (Passador 2011). It is the most important family ceremony for the relationship between the living and the ancestors and should occur at regular intervals. The non-fulfilment of the ceremony and non-participation of a family member can lead to punishments by the spirits of the ancestors against their descendants (Passador 2011). Joana's family discourse and representation of her illness and misfortune were consistent with this model.

Due to the severity of Joana's clinical condition, the social workers at the Daily Centre decided to seek a medical opinion at *the Clinic*.

Together with the counsellor Lara, we decided to meet Clelia, Joana's grandmother, to understand her aetiological perspective on Joana's health problems: Clelia argued that if she believes that the cause was witchcraft, we should listen to her and suggest an intervention on the spiritual side. If we gave legitimacy to the spiritual part, this would help her in compliance with the treatment.

The meeting took place in one of the Clinic's rooms. Lara was taking care of the dialogue that was mainly in *changana* (the local language). In an extract of the conversation, Clelia explained to us:

> You get HIV if you had sexual relations without condoms with someone that is infected (by HIV). During the nineties, this happened a lot because no one knew what it was. I got HIV like this. I take my pills and I'm fine. That's because I got it through sex. Joana never had sexual intercourse with anyone and her mother didn't die of AIDS but she was murdered. So Joana's status doesn't depend on HIV. Therefore, before going to Gaza, Joana's health was always bad and she was not getting better. We decided to go to the family *nyanga*, before the Gaza period. After a query with the ancestral spirits, he claimed that the cause of her illness was because Joana had to be a *nyanga* too. The spirit of her great-grandmother from the father's side was bothering her. If she doesn't want to be a *Nyanga*, we can do another ritual to calm down the spirits, but this will cost 7000 meticais (more than 100 euros), and we can't afford it (Clelia, fieldnotes, 3rd May 2017).

As Good argues, «symptoms are given meaning within a cultural system relationally, by the position they occupy within complex symbolic codes» (Good 1994, 99). In this case Clelia gave two different explanations for the same illness. The therapeutic continuum is well illustrated because for her case, treatment was effective because she had contracted the illness by having sexual intercourse without condoms, also explained as an «ordinary HIV infection». In the case of her granddaughter, however, she believed that the treatment was not working because the «real» cause of her illness was due to conflicts with ancestral spirits and therefore probably related to witchcraft. Thus, as I have pointed out before, the «risk» in this case was material (e.g.

being seropositive), but the cause was attributed to a social reason (Joana's neglected «call» to be a *nyanga*) (Granjo, 2009).

In the above story, we may see that Joana, her grandmother, her father's family and the social workers, had all a different aetiology to explain what was happening. Good also argues that «the body, as well as disease, occurs not just in a biological reality. There are also realities taking place in time, in place, in history, in the social world, in nature, and often within a particular mystical setting» (Good 1994, 133).

The different contexts therefore allow different associations to be made between the body and the disease that go beyond the biomedical context. Considering that the body is inscribed in a culture that is dynamic, the interpretation of illness also reflects this non-staticity with a plurality of possible choices (Good 1994).

In Clelia's interpretation of illness, these symptoms would not disappear unless Joana followed her path to become a *nyanga*. Since being a *nyanga* is a matter of lineage, this made sense as the mother of Joana's dead father was also a *nyanga*.

Local explanations of healing offer the advantage of transforming a medical problem into a socially manageable issue. Indeed, this interpretation offers meaningful explanations of the disease by locating it within kin relations, community problems and local history, and thereby also fuelling hope for a cure. This explains much of the ontological force of healing traditions which belongs, as Brigitte Bagnol indicates, to the cosmology of local explication (Bagnol 2017).

During my fieldwork in Mozambique, I had the opportunity to interview traditional healers in the southern region.[33] As other authors observed, HIV/AIDS patients are often diagnosed with a «calling disease» – i.e. sickness due to the unanswered call to become a healer (Bagnol 2017; Wreford 2008). As Dr Pinto, one of the traditional healers I spoke with, argued:

> Becoming a healer practitioner is not a personal choice. The spirits of your ancestors are calling you and you have to follow your path. When you have the «call» to be a healer, you start to be really sick. Sometimes it looks like HIV, sometimes it looks like you are getting crazy (*maluco*). It is normally a very prolonged disease. You have to go to a

---

[33] This was realised thanks to the collaboration in the project «INTEGRA: Between biomedicine and local therapies. Crossed looks on Mental Health in Mozambique» in partnership with the University of Turin, University Eduardo Mondlane of Maputo, and ICS – University of Lisbon.

> traditional healer to do the divination process, and if he tells you that you are having the «call» you have to stay with him to learn to be a healer. The symptoms will disappear only following the suggestions of the healer (Dr Pinto, interview, 18th June 2018)

During my fieldwork experiences in Mozambique, when searching for an explanation, patients with HIV/AIDS often give multiple concurrent or sequential interpretations of their illness. Diagnosis is often associated with the transgression of taboos, the actions of bad spirits and long-lasting diseases that cannot be cured. In particular, for women, the accusation of witchcraft was a common practice (Bagnol 2017; Passador 2011; Ashforth 2002; Rödlach 2006).

As mentioned above and reported by various authors, medical pluralism makes patients, their families and health professionals move in search of therapeutic efficacy between different practices, systems and epistemologies (Feierman and Janzen 1992; Granjo 2009; Janzen et al. 1982; Langwick 2008; Meneses 2004). As McKay points out, this literature has shown health does not stop at physical wellbeing but encompasses other aspects such as relational, spiritual but also financial and domestic. It is important to consider this heterogeneity in representations of health and illness (McKay 2018).

During the whole conversation with Clelia and Lara I was sitting next to Joana in silence when I realised that she was crying. Following Farmer, we clearly see how the fact of her being poor and being a woman, had robbed her of her voice long before HIV appeared to complicate her life (Farmer 1999). This was also evident in the accusations moved against her. As the weak link in the family – young, poor, ill and woman – all the family «evils» were projected onto her.

Joana was considered and condemned by her whole family to be the cause of her own – and her family's – misfortune, since she was not taking up the «call» to become a traditional healer. She was accused of causing the death of her uncle, which was the result of a car accident in which her paternal grandmother was involved. Obviously, she was also accused of her own illness. However, Joana's explanation for her illness was different, and afterwards, as we were having a snack in the garden of the Clinic, I asked her why she had been crying during the meeting:

> I was crying because my grandmother was saying a lot of things that are not true. When my grandmother speaks, I can't say anything. If I do, when we are home she will beat me. She told me to stay quiet before entering the room. She believes in traditional doctors

> and the fact that I am sick from spirits, and that's why she let me go to Gaza! But I know it's not like that! I realised that I got HIV through my mother. They explained it to me at the Clinic. My grandmother does not believe in it. She is very kind to you when she is here, she says she understands, but then when she is at home she completely changes her attitude and begins to accuse me that I am the ruin of the family. (Joana, fieldnotes, 22th May 2017)

After the meeting with Clelia at the Clinic, I discussed some aspects of Joana's case with Lara. Suddenly becoming more cautious when thinking about an intervention using traditional medicine, I sensed fear in Lara's words as she spoke about medical legitimacy, considering it would be better to take care of the biomedical part alone.

As noted by MacCormack, «If we take individual patients as the focus of analysis, we realise that there is already considerable informal integration of scientific and traditional medical systems» (MacCormack 1986, 156). This even though, particularly during the colonial period, but not only, there was a careful effort to try to eliminate practices that were not considered biomedical in order to standardise local medical systems. This is even though the different medical alternatives should not be seen as contradictory, but on the contrary can often represent valid therapeutic interventions in combination. However Clelia demonstrates how, in Mozambique, the dialogue between health workers and traditional healers is still problematic. I believe that biomedical discourse, rather than deconstructing «traditional» conceptions of disease, may even provide elements to ratify them when manipulated by the logic of «traditional» models, even though they work with different assumptions and aetiologies (Passador 2011). Rather than «respecting» the spiritual aspect, I agree with Mariano that it would be useful to create a common sense of spaces, things, thoughts and ideas between patients, biomedical health workers and traditional healers, which would allow patients to say the «unsayable» and to restore the balance needed (Mariano 2018).

Diagnostics in uncertainty: Third floor, bed 43, tuberculosis ward

Due to the worsening of her condition, in May 2017 Joana was hospitalised at the Machava Hospital. As suggested by van der Geest and Finkler, biomedical institutions are reinterpreted by the local culture in which they are located, and this is significant both theoretically and practically (van der Geest and Finkler 2004). This was also the case of the structure where Joana was hospitalised. As the authors argue, life in the hospital should not be regarded as being in contrast to life outside the hospital – the «real» world – but as rather being shaped by it. This was evident in the way in which every day societal hierarchies, inequalities and conflicts were reproduced within the hospital.

My first visit to a hospital was to the Machava Hospital, known between health workers as the place where people in the final stages of tuberculosis (TB) are hospitalised. Joana had already been sent, on several occasions, to the tuberculosis ward to recover. Life here was not easy. Usually, parents and visitors would bring the patients' meals, as the hospital food was neither enough healthy or tasty. However, goods entering the hospital were often noticed by other patients and workers, and as Joana pointed out, people often stole things. Furthermore, Joana was the youngest in her room, and hierarchically she was not in a position to complain. Joana's rooms consisted of 10 beds with a large window on one side that opened onto a common terrace.

As in the ethnography in South African hospitals, described by Gibson, despite the apparent surveillance in the ward, there were instances of patients who appeared to have been «forgotten» or «lost» in transit while in foyers, in waiting rooms, and between wards (Gibson 2004). This was in fact true in Joana case, where surveillance was quite absent: I was able to get in and out of the ward without being questioned. I was feeling a total absence of the medical eye with an absence of action and material practice that was directed at bodies (Foucault 1973).

The lack of economic resources sometimes led to unequal and poor treatment in the hospital, which particularly affected disadvantaged families. There was thus a continuous shifting of patients, services and staff in an attempt to provide redress and equal health services for all. Access to beds was difficult and patients such as Joana were commonly discharged before time.

When I visited Joana at Machava, her body was marked by a severe rash, common in patients in the later stages of AIDS. Doctors explained that Joana was not suffering from TB but from pneumonia. Her CD4 count was low which meant that the virus was starting to become resistant to the treatment. Meanwhile, the gaps were so evident that when we were leaving the hospital, no one noticed that she still had the cannula from the drip in her left hand, and we had to go back into the ward to take it out. I was baffled by the situation. How can an HIV positive immunosuppressed patient with pneumonia be sent to recover on a TB ward, where she risked being infected again? Dr. Carla, part of the Clinic team, tried to explain the situation:

> Joana is a peculiar case. She had TB so many times in her life that now she has what is called «sequelae of tuberculosis». It is not a hopeful prognosis for her, because she is living with just one lung. She will always be like this: she will be fine for short periods and then have long relapse phases. When doctors do an X-ray, the result is so bad that they immediately think it is TB. It will be good for her to have an old X-ray or exam that reports that it is not TB, but this is difficult because patients are not allowed to have their exams… if she could always have a paper with the last diagnosis, she would avoid being so often in the Machava TB ward. Otherwise one day she will get TB again!(Carla, interview, 6th September 2017)

Care in this setting is characterised by bureaucratic difficulties, negligent health care workers, inconsistent record-keeping and imperfect diagnostic techniques that all generate what is referred to as a «technology of invisibilities» (Biehl 2007, 202). This technology transforms patients like Joana and their caretakers into largely absent, discarded «waste» thrown at the margins. As Biehl warned, people become «absent things» through the very processes that involve them as patients (Biehl 2007).

In November 2017, the situation for Joana in her family was becoming unsustainable, as no one was taking care of her. Doctors at the Clinic decided to accommodate her for four months in *Casa 1,* where Pedro was also accommodated. This structure, for people in disadvantaged socio-economic situations led by the Sisters of Calcutta, was one of the very few social safety nets present in Maputo.

Similar to Blake's research in a paediatric oncology ward in South Africa, the young people in my research maintained a distinction between «real» and «temporary» (Blake 2007, 202). Joana never felt that *Casa 1* was the «real world» and she always expressed the wish to go back home and to attend the activities in the daily centre. Indeed, the rules of *Casa 1* were so strict that Joana didn't manage to stay there for a long time.

During the Christmas holidays, Joana left *Casa 1* to be hospitalised for one week due to respiratory issues. When she was released from the hospital, the nurse called her grandmother, who came to pick her up and took her home for a couple of nights. According to the policy of *Casa 1*, however, this was against the rules: if you have a family that can provide food for you, this means you can live there and cannot stay in *Casa 1*. As a result, she was no longer able to re-enter *Casa 1*. The brutality of lack of resources in Maputo's health and social security network created scales of vulnerability in which the few social services that did exist adopted policies that could appear quite cruel and discriminatory, with the result of leaving young people in situations of extreme precariousness with no possibility of choice, as was the case of Joana and many others. Joana received a new diagnosis at the end of January 2018, after a period of suffering that saw her moving back and forth between hospitals:

> She has pulmonary hypertension. She is living just with one lung and this means that she will always have respiratory distress. To circulate more blood, her pulmonary artery works harder. This creates an increase in resistance and hypertension. This flow increase causes swelling in her body. She must start taking diuretics so that this will not happen again. She has been my patient in the past and I have been asking for pulmonary advice, but it takes too long (Joana's doctor, meeting, 25th January 2018).[34]

These difficulties in the transmission of clinical information or «health bureaucracies» (Kleinman 1980, 26), as we observe in Joana's story, are unfortunately a common situation in Mozambique, as Augusto, the psychosocial coordinator of the Clinic, illustrated during an interview:

> Each hospital has a different clinical process. I am talking about the hospitalisation regime. When you are discharged, they give you a discharge guide with a little summary of the diagnosis, which should then be presented to your health facility. With this guide in a health centre, they open a new process or update an old one. The patient should keep a copy of the clinical history given in the hospital. On the other hand, if the hospitalisation reference arrives from the health centre, the health centre will transfer a discharge guide to the hospital, in which the whole clinical condition is explained. However, if you leave your house and go directly to the hospital, you will no longer have this guide. There is no electronic system at the national level, so the hospital will always open a new process with new information, and they would never know what happened before. It would be useful to always take the health card, but no great information is written on it. If you are taking ART, for example, the hospital does not know what kind of regime they have to prescribe you. So,

---

[34] Joana's doctor at Machava hospital, fieldnotes, January 2018.

> for example, Joana stayed without medications for two weeks (Augusto, interview, 29th January 2018).[35]

The impossibility of giving clinical records to patients deserves two levels of attention. On the one hand, their availability would not permit them to reopen new records every time. On the other hand, having these files could give responsibility to the patients and allow them to know more about their health condition in order to make decisions.

Amid the flood of papers, doctors and health workers, as well as other staff, struggle to balance too many patients with too little information about each patient they attended. It sometimes seemed remarkable that patients' clinical files could be found at all; although they usually were, patients were nevertheless exhorted not to rely on what was recorded in the treatment plan but to take responsibility for remembering when blood tests and other exams needed to be done (McKay 2012).

Missing

> Me: «*Vovò*, where is Joana? »
> Clelia: «Joana ran away, she ran away tonight, she opened the door and ran».
> Me: «How is that possible? »
> Clelia: «I am teasing you! (Laughing) She is at Machava Hospital. She was really bad when she came back home from the hospital. Her legs were swollen and she asked me to do a massage, but it did not work, so we went back to Mavalane. They took an XR and blood test and transferred her to Machava» (Conversation with Clelia, fieldnotes, January 2018)

After a few weeks, when Joana had not shown up at the Clinic to get her ARV, a doctor contacted me to ask if I could manage to do a home visit to find out what had happened. Due to the memory of the abduction of the previous year and the concern for her precarious health situation, I decided to go immediately, dropping my previous commitments. Yet, due to the physical and psychological atmosphere of violence prevalent in Joana's family, home visits to her

---

[35] Ernesto, interview, February 2018.

house were always difficult and unconfort for me. Veiled accusations about Joana's health status were commonly made to me and the medical staff of the Clinic, and the presence in the back office of the «dangerous» uncle always made me feel uncomfortable. Upon this visit, Joana's grandmother claimed:

> Joana is at the hospital. She stayed at home two days after the Central Hospital, but then she was getting sicker, she could not breathe. (…) I know she is not getting ART, nobody knows that she is in the hospital. She is in the hospital because she had a cough. I left her at Mavalane, but when I went back there the day after they told me she was at Machava. You see that I'm not able to walk, I can't get there, but I think she is there. (Clelia, fieldnotes, 26th January 2018)

Things were confused, and after a few phone calls to hospitals, we discovered that she was still at Mavalane. Joana had gotten lost in transit from one hospital to another, receiving no treatment and taking no past clinical records with her, another example of «the invisible patient» routine (Gibson 2004). The working conditions at Mavalane hospital reflected the profound resource deficiencies in the health care system in general. The buildings were deteriorating (parts of the electrical and sewage systems were permanently out of order, for instance) and the equipment was faulty or lacking, making it impossible to carry out even basic hospital procedures. An extract from my diary shows the feelings that I had during one of my visits:

> I arrive at the entrance to the adult general practice unit. On the side of the main door, there is a cat that has been bitten by a dog but is still half alive. Why is no one taking care of it?
>
> When I enter Mozambican hospitals, I have the feeling that I need to be in apnoea. It is an apnoea for many reasons, not just because of the strong smell that surrounds the hospital. I need this apnoea to have an emotional numbness and avoid tears, anger and fear of death. When you are so near people who are dying, you can feel it. I try to avoid it, however without great results.
>
> I begin to walk along a dark hall. The silence is broken by the chatter of the nurses, who recreate a state of normality in my mind. In a threatening tone, they tell me that it is not visiting time but, probably thanks to my «whiteness», they let me pass. The day is one of the hottest since the beginning of the year, which didn't help my desire for apnoea. Patients are bedridden and covered only with a synthetic blanket suitable for the winter season. People's

> physical nudity reminds me of another kind of nudity, dictated by deprivation of dignity and social respect, what Agamben calls «bare life».
>
> This time Joana does not run to hug me as usual. She is sitting in the bedroom and she doesn't even look at me. I sit by her side and hug her. She is so full of boils on her body. I am not sure that I want to look around… the room has 8 beds, all full of women, they are all naked. The smell inside the room is heavy and peculiar, I'll never forget it. «I'm feeling better, sis», Joana said. Boils are all over her body, her hands are constantly shaking, wounds all around her mouth, candidiasis. I was sure it would be the last time I would meet her, and somehow I was relieved for the end of her suffering (fieldnotes, 27th January 2018)

Due to her high viral load, doctors from Mavalane explained that Joana had been shifted to second-line treatment for HIV. Meanwhile, Joana was telling me about her journey from one hospital to another and the fact that she had not been taking the ART for two weeks because her grandmother never brought it to the hospital. This was another crucial reason for her non-adherence, which has been mentioned before: if you arrive at the hospital without your ARV, someone from your family will have to bring it to you. The hospital itself will not provide the drugs because there are no electronic files to confirm what you are taking. Joana's case here exemplifies another aspect of the poor operation of the health system.

The day after I returned to Mavalane, ready to hear bad news. Joana was in the same position, seated and playing with the needle of the IV: «They are discharging me from the hospital, sis». How is that possible? I thought. She is not even able to walk. We eat together some boiled eggs and I took her home.

«Where should I go now?»

One day, while we were sitting on her bed in Machava hospital drinking juice, Joana began to talk, with the lucidity and clarity that had always distinguished her:

> I am quite worried about where to go to live when I get out from here. I am sure that I cannot go back home. When I came back from Gaza, they were not happy at all. My grandmother said, «why did you not stay there?». My uncle does not want me at home. He

> said that I did something wrong and they expelled me from *Casa 1*. He said that I cannot live anymore in the house, also my grandma now says that… My uncle refused to come to pick me up at the hospital. He has money, he rents houses in the Zimpeto neighbourhood. When my grandma was hit by the car, the owner of the car gave money to my uncle, he never gave it to my grandma. No one speaks with him, because we are all scared… When I was really ill, he told me: «If you are sick and die, then I have to pay for your funeral. You know that I had to pay for your mother's coffin! I'll not pay for yours too!». I cannot go back to *Casa 1* either, it is not a nice place. They bring you to the hospital, then they leave you there and they never come to visit you. Then, if you come back home, they do not want you anymore (Joana, fieldnotes, 7th February 2018)

While Joana was struggling to find a solution to stay inside the circuits that would legitimate what we can call her therapeutic citizenship, she died in Machava hospital in May 2018. In the months before she passed away, she had a vivid and troubling vision of the situation of abandonment that she was in; even the hospitals did not want to have a patient that was sure to die – in particular from AIDS-related issues – and thus continued to let her stay «in transit». It appeared as if everyone around her was giving up. Nonetheless, she was not prepared to do the same, and kept looking for alternative solutions until the end.

Looking at Joana's story and following the reflections of Farmer, I think that as anthropologists we must be careful to recognise the difference between what is dictated by structural violence and what is an alleged cultural difference (Farmer 1999). Having said that, however, I agree with Simona Taliani who warns us about the danger in seeing this dichotomy. While it is important to understand the differences between «social causes» (violence and misery), «biological causes» (the parasite, the virus) and «cultural causes» (the alterity of beliefs and habits), these are not to be assumed as separate and in contradiction to each other, since this may prevent an understanding of the intersection between factors that are simultaneously at stake in stories of illness and death (Taliani 2006).

Writing stories like Joana's roots ethnographic research in the critical medical anthropological paradigm, to create a more visible whole to those parts of the analysis that are often invisible to the (medical) society. The context of violence present inside the family, accusation of witchcraft together with the shortage of medical care and a social safety net did not give Joana the chance (to choose) to survive.

Conclusions

Carrying out this research, and reaching the end of the writing process, has been a long and tortuous journey, not without difficulties. Working with young people in vulnerable situations, and in some cases accompanying them through the last stages of their lives has been an experience that has allowed me to develop a new outlook on life's difficulties. I felt then, and still feel now, that I have very little understanding of what I was witnessing.

With this work, I don't think I managed to show all the intensity and suffering that they experienced, nor have I been able to describe the complexity of their experiences in their entirety. On my return home, between Milan and Lisbon, the heaviness of the suffering, the boulder of raw reality that these stories showed, was not easy to evocate and my state of mind was for a long time dark and melancholic, surrounded by a sense of injustice for the news of the deaths that arrived from Maputo, but also by the condition of privilege which has been and still is present to me.

During the course of the fieldwork it became increasingly clear that the research would be on the move. After the first month, which was more exploratory and with the days taking place mainly in the day centre, I soon realised that this was only one of the places where they passed through and that the network of care in which they were embedded was much wider. Too wide to investigate everything, I deliberately side-lined some aspects of care that remain central to Mozambique, such as the Pentecostal churches and traditional medicine.[36] However, I was able to understand them and their importance, and although these aspects always come into the research and are constant in the lives of young people, I decided to focus on those places of care that offered a biomedical approach and focused on adherence to antiretroviral treatment. The daily centre, the Centro de Saude, The Clinic and the Hospital are therefore only some of the places where different practices of care were proposed.

The beginning of the fieldwork, while waiting for institutional permission to do research, led me to redefine most of the methodology by making it participatory and reflexive. I also soon realised that the day centre could be the place where everything started but that I had to «follow»

---

[36] The latter is partly discussed in the last chapter, but there is much more to be mentioned.

them from there and accompany them in their daily movements. So I started going with them to health centres, accompanying them to medical appointments and getting to know their homes and families.

While the first chapter of this work seeks to show this initial reconfiguration, the second chapter lays the groundwork for a basic framework for the contexts, interventions and the rhetoric used in global AIDS health. Chapter three provides an understanding of how Mozambique's history can be incorporated in the present interventions and attitudes in the public and private health systems. With this background framework, the following chapters talk about places of care, but in particular about the daily stories of Joana, Emilia, Pedro, Carlos and the others. Here I show how talking about adherence to antiretroviral treatment is a complex work that has to do with several factors, including emotional, social, economic and political aspects, which have little to do with issues related to «individual responsibility» and more with inequalities. Indeed, they embodied inequalities: social abandonment and structural violence in a country where health facilities are weak, and surviving is an everyday struggle.

Most of the young people I met lived in extended families, often orphans of both parents, the main carers being grandparents, uncles or older siblings. When this family network broke down for some reason (e.g. economic issues, death of a family member, internal conflicts), it was evident that Mozambique did not provide a «social safety net» in which these people could be included and accompanied. Reception structures, more or less temporary, were scarce and in extremely precarious conditions. Geographically on the fringes of cities, they are often run by religious congregations that rely on charity or the few subsidies from the state.

This lack of infrastructure, as well as economic and social forces, clashes with the emergence of so-called «therapeutic citizenships» (Nguyen 2010), especially in the case of extremely vulnerable subjects. While in other contexts, the world of activism or the «technologies of confession» about one's HIV status created some «benefit» – social or economic – in the sense of some form of «therapeutic citizenship», that was not the case for the people encountered during the research. The contexts of vulnerability through which they navigated – the lack of medical infrastructure, inadequate economic and food subsidies and non-existent shelters, among other – echo in their stories as a «trap» that left them confined in zones of social abandonment (Biehl 2007). These zones of social abandonment make visible realities that exist through and beyond formal governance and that determine the life course of an increasing number of poor people who are not part of mapped populations (Biehl 2007).

However, the young people encountered tried to implement survival strategies, ranging from finding informal jobs to asking for help and support from religious and NGO centres, but the feeling I had was that the needs and the response they got were separated by a huge gap.

The lack of a support network was also felt in the final stages of the illness, when doctors and relatives knew that there was nothing to be done, and the conditions in the places where they spent the last days of their lives leave a deep moral wound for those who witness it. This moral wound must, however, make way for a political call on the subject of the terminal stages of AIDS. Indeed, as Fassin argues, when one accompanies their stories it is difficult not to fall into an analysis dictated by a moral economy, but it is necessary (Fassin 2013). The moral eclipses the political, overshadowing the structural and social determinants that expose young people to risk and neglect (Fassin 2013). Moreover, if humanitarianism, as I show in chapter two, speaks for them, they will remain confined as victims and deprived of their voice and agency. Furthermore in contexts where structural violence is persistent we have to be cautious and highlight when people cannot choose in an autonomous way. The course of their illness had been dictated by a series of external factors which, and following the work of authors such as Farmer, Biehl and Mol, do not allow subjects to act and actually «choose» (Farmer 1999; Biehl 2007). The forms of suffering and injustice deeply rooted in the ordinary force my reflection to consider Farmer's concept of «structural violence» (Farmer 1999). It is important to recognise the individuality and specificity of each story in order to reflect on possible interventions. It is important to be able to listen to the suffering of individual stories in their uniqueness. In other words, we must learn to listen to our interlocutors during a research, our patients in a health centre by understanding their subjectivity and their experience. This reflection often becomes difficult for the «emergency» situation in which these young people are enrolled and an urgent need to save their lives, getting them to adhere to treatment. It is my opinion that our role as anthropologist and researcher is also to show the limits and strengths of humanitarian intervention through ethnographic cases.

After getting to know theirs's story, the narrative of individual responsibility for non-compliance with HIV treatment loses its force and meaning. The logic behind it, which states that some patients seem to be irrational and resistant to the medicalisation of their everyday lives through the ART regime, becomes irrelevant when we consider the deep history of this behaviour in relation to the cultural, social and medical factors that affect the capacity of life for complying with the ART regime, as well as the general struggle to survive. We have to look behind and beyond self-responsibility and consider that in some contexts there are external factors marked by structural violence which do not allow people to «act their agency» (Farmer 1999). In analysing treatment outcomes among teenagers, it is important to understand the broader family dynamics that influence the possibility of adherence. Indeed, the context of family violence and accusations is a frame where the gaps in the health system, the failure in the dialogue between traditional medicine and biomedicine, and the absence of social safety nets have all exercised their brutality. In a context of multiplicity of care where humanitarian anarchy seeks to be tamed by task forces and coordination groups, on the one hand, the campaigns aim to make young people responsible for their own health, while on the other hand, the medical context tends to leave them unaware, surrounded by uncertainty and misunderstanding.

One of the central aspects of many humanitarian projects that tried to take a holistic view of the situation was to enable them to achieve economic stability for them and their families, but this was often not enough. Young people who struggled to maintain adherence to treatment needed a state of stability, both economic and emotional, that would allow them to return to feeling in control of their bodies and their daily lives, with a possible look to the future.

Working on the individuality of each single story was what was going on in the Clinic for example, avoiding taking into consideration the young people as a generic whole, but giving them the possibility to question strategies and interventions for each single case.

However, this place was peculiar. It was administered by an international NGO and dealt with situations considered in advanced stages of AIDS or tuberculosis. The paradox seems to be that bio-legitimacy in some form is only achieved in cases when the body is brought to the point of exhaustion. It is here that the best treatment and attention is obtained in a desperate attempt to save lives.

I often discussed, with the people in charge of the daily centre, the possibility of creating places, small houses where they could find some stability, small realities that would allow these young people to become stable and then be able to continue life independently. But I also wondered if more attention might be given to the question of end-of-life care. A dignified life, but also a dignified death. I believe this topic, poorly investigated during IAC 2018, is considered a failure, from a biological and humanitarian perspective. It becomes difficult to talk about dignity during the final stages of illness and life, both because of the lack of a dignified life in which these people have often found themselves trapped, and because death is often considered a taboo for the humanitarian reason.

References

Abney, Kate. 2014. *At the Foot of Table Mountain: Paediatric Tuberculosis Patient Experiences in a Centralised Treatment Facility in Cape Town, South Africa*, PhD. diss., University of Cape Town.

Abu-Lughod, Lila. 1991. «Writing Against Culture». In *Recapturing Anthropology: Working in the Present*. Edited by Richard G. Fox, 466-79. Santa Fe: School of American Research Press.

Abu-Lughod, Lila, and Catherine Lutz. 1990. «Introduction: Emotion, Discourse, and the Politics of Everyday Life.» In *Language and the Politics of Emotions*. Edited by Lila Abu-Lughod and Catherine Lutz, 1-23. Cambridge: Cambridge University Press.

Agamben, Giorgio. 1995. *Homo Sacer: Sovereign Power and Bare Life*. Stanford: Stanford University Press.

Ahmed, Sara. 2004. *The Cultural Politics of Emotion*. Edinburgh: Edinburgh University Press.

Alderson, Priscilla, 2008. «Children as Researchers: Participation Rights and Research Methods». In *Research with Children: Perspectives and Practices*. Edited by Pia Christensen and Allison James, 276-90. 2nd ed. New York: Routledge.

Altman Dennis. 1994. *Power and Community: Organizational and Cultural Responses to AIDS*. London: Taylor & Francis.

Arno, Peter, and Karyn L. Feiden. 1992. *Against the Odds: The Story of AIDS Drug Development, Politics, and Profits*. New York: HarperCollins.

Ashforth, Adam. 2002. «An Epidemic of Witchcraft? Implications of AIDS for the Post-Apartheid State». *African Studies* 61, no. 1 (July): 1-21.

—. «Spiritual Insecurity and AIDS in South Africa». In *Morality, Hope and Grief: Anthropologies of AIDS in Africa*. Edited by Hansjørg Dilger and Ute Luig. Oxford and New York: Berghahn Books.

Athanasiou, Athena, Pothiti Hantzaroula, and Kostas Yannakopoulos. 2008. «Towards a New Epistemology: The 'Affective Turn.'» *Historein*, no. 8, 5-16.

Bagnol, Brigitte. 2017. «The Aetiology of Diseases in Central Mozambique: With a Special Focus on HIV/AIDS». *African studies* 76 (2): 205-20.

Bakhtin, Mikhail Mikhaĭlovich. 1981. *The Dialogic Imagination: Four essays*. Edited by Michael Holquist. Translated by Caryl Emerson and Michael Holquist. Austin: University of Texas Press.

Barnett, Tony, and Alan Whiteside. 2002. *AIDS in the 21st Century. Disease and Globalization*. Houndmills: Palgrave and Macmillan.

Basaglia, Franco. 2005. *L'utopia della realtà*. Torino: Einaudi.

Bastos, Cristiana. 1999. *Global Responses to AIDS. Science in Emergency*, Bloomington: Indiana University Press.

—. 2007. «Medical Hybridisms and Social Boundaries: Aspects of Portuguese Colonialism in Africa and India in the Nineteenth Century.» *Journal of Southern African Studies* 33 (4): 767-782.

—. 2008. «From Global to Local and Back to Global: The Articulation of Politics, Knowledge and Assistance in Brazilian Responses to AIDS.» In *Politics of AIDS: Globalization, the State and Civil Society*. Edited by Maj-Lis Follér and Håkan Thörn, 225-41. New York: Palgrave Macmillan.

Baylies, Carolyn. 2004. «Community-Based Research on AIDS in the Context of Global Inequalities. Making a Virtue of Necessity?» In *HIV & AIDS in Africa. Beyond Epidemiology*. E. Edited by Ezekiel Kalipeni et al., 15-28. Oxford: Blackwell Publishing.

Behar, Ruth. 1996. *The Vulnerable Observer: Anthropology That Breaks Your Heart*. Boston: Beacon Press.

Beneduce, Roberto. 2010. *Corpi e saperi indocili. Guarigione, stregoneria e potere in Camerun*. Torino: Bollati Boringhieri.

Berger, John, 1972. *Ways of Seeing*. London: British Broadcasting Association and Penguin.

Biehl, João. 2005. *Vita: Life in a Zone of Social Abandonment*. Berkeley: University of California Press.

—. 2007. *Will to Live: AIDS Therapies and the Politics of Survival.* Princeton: Princeton University Press.

—. 2016. «Theorizing Global Health Medicine». *Anthropology Theory* 3 (2): 127-42.

Biehl, João, and Adriana Petryna. 2014. «Peopling Global Health. A Saúde Global centrada nas pessoas.» *Saúde e Sociedade* 23 (2): 376-89.

Birn, Anne-Emanuelle. 2014. «Philanthrocapitalism, Past and Present: The Rockefeller Foundation, the Gates Foundation, and the Setting(s) of the International/Global Health Agenda.» *Hypothesis* 12 (1): e8.

Birn, Anne-Emanuelle. 2005. «Gates's Grandest Challenge: Transcending Technology as Public Health Ideology». *Lancet* 366, no. 9484 (August): 514-519.

Blake, Rosemary. «Please Keep These Doors Closed». Unpublished Honours thesis, University of Cape Town, 2009.

Bluebond-Langner Myra, Jean Bello Belasco, Marla DeMesquita Wander. 2010. «'I Want to Live, Until I Don't Want to Live Anymore': Involving Children with Life-Threatening and Life-Shortening Illnesses in Decision Making about Care and Treatment.» *The Nursing Clinics of North America*. 45, no. 3 (September): 329-43.

Borneman, John, and Abdellah Hammoudi. 2009. «The Fieldwork Encounter, Experience and the Making of Truth: An Introduction». In *Being There: The Fieldwork Encounter and the Making of Truth*. Edited by John Borneman and Abdellah Hammoudi, 1-24. Berkeley: University of California.

Bourdieu, Pierre. 2003. «Participant Objectivation». *Journal of the Royal Anthropological Institute* 9 (2): 281-94.

Bowlby, John. 1961. «Childhood Mourning and Its Implications for Psychiatry.» *Journal of American Psychiatry*, no. 118, 481-98.

—. 1980. *Loss: Sadness and Depression*. New York: Basic Books.

Braga, Carla Teófilo. 2017. «Producing and Reproducing Inequality: Biopolitical Exclusion, Marginalized Bodies and AIDS Care in Central Mozambique. » *Africa Development / Afrique et Développement* 42, no. 1 (2017): 221–43. http://www.jstor.org/stable/90013907.

Burgoyne Robert W., and Darrell H.S. Tan. 2008. «Prolongation and Quality of Life for HIV-Infected Adults Treated with Highly Active Antiretroviral Therapy (HAART): A Balancing Act.» *Journal of Antimicrobial Chemotherapy* 61, no. 3 (March): 469-73.

Butler, Lenora. 1994. «Autodrive in Qualitative Research: Cracking the Ice with Young Respondents», *Canadian Journal of Marketing Research*, no. 13, 71-74.

Cancelliere, Francesca, 2015, A doença do século: giovani e AIDS nella città di Namaacha, in Intrecci. Quaderni di Antropologia Culturale.

—. 2019. «Visual Arts as Methods of Research: Some Reflections from an Ethnography with HIV Positive Teenagers». *Irish Journal of Anthropology* 22 (1): 262-278.

—. 2020, «The politics of adherence to antiretroviral therapy: between ancestral conflicts and drug resistance». *Dada Rivista di Antropologia post-globale*, speciale n. 2, 2020, Corpo, potere, diritti, 13-41.

Cancelliere, Francesca, and Ursula Probst. 2021. «Being There. Early Career Medical Anthropologists' Perspectives on Contemporary Challenges in the Field». *Anthropology in Action* 28, no. 2 (June): 1-7.

Castro, Arachu. 2005. «Adherence to Antiretroviral Therapy: Merging the Clinical and Social Course of AIDS». *PloS Medicine* 2 (12): e338.

Castro Arachu, and Paul Farmer. 2005. «Understanding and Addressing AIDS-Related Stigma: From Anthropological Theory to Clinical Practice in Haiti». *American Journal of Public Health* 95, no. 1 (January): 53-59.

Castro Arachu, and Singer Merril, eds. 2004. *Unhealthy health policy: A critical anthropological examination*. Walnut Creek: Altamira Press.

Carr, E. Summerson. 2010. *Scripting Addiction: The Politics of Therapeutic Talk and American Sobriety*. Prince ton, NJ: Prince ton University Press

Christensen, Pia Haudrup. 2004. «Children's Participation in Ethnographic Research: Issues of Power and Representation.» *Children and Society* 18, no. 2 (April): 165-76.

Christensen, Pia, and Allison James, 2000. *Research with Children: Perspectives and Practices*. New York: Routledge.

Clark, Cindy D. 1999. «The Autodriven Interview: A Photographic Viewfinder into Children's Experience,» *Visual Sociology* 14 (1): 39-50.

Clark-Ibáñez, Marisol. 2004. «Framing the Social World with Photo-Elicitation Interviews», *American Behavioral Scientist* 47 (12):1507-27.

Cliff, Julie. 1993. «Donor Dependence or Donor Control? The Case of Mozambique.» *Community Development Journal* 28 (3): 237-44.

Cliff, Julie, and Abdul Razak Noormahomed. 1988. «Health as a Target: South Africa's destabilization of Mozambique.» *Social Science and Medicine* 27 (7): 717-22.

Clough, Patricia T. 2007. «Introduction.» In *The Affective Turn: Theorizing the Social*. Edited by Patricia Ticineto Clough and Jean Halley, 1-33. Durham NC: Duke University Press.

CNCS (Conselho Nacional de Combate ao HIV/SIDA). 2004. *Plano Estratégico Nacional de Combate ao HIV/SIDA (2005-2009)*. Maputo: CNCS, https://cncs.gov.mz/wp-content/uploads/2019/08/PENII.pdf.

Cohen Myron S., Marybeth McCauley, and Theresa R. Gamble. 2012. «HIV Treatment as Prevention and HPTN 052.» *Current Opinion in HIV and AIDS* 7 (2): 99.

Cohen, Lawrence. 2012. «Making Peasants Protestant and Other Projects: Medical Anthropology and Its Global Condition.» In *Medical Anthropology at the Intersections: History, Activisms, and Futures*. Edited by Marcia C. Inhorn and Emily A. Wentzell, Durham NC: Duke University Press.

Collier, John, 1967. *Visual Anthropology: Photography as a Research Method*. Newbury Park: Sage.

Colson, Elizabeth. 2010. «The Social History of an Epidemic: HIV/AIDS in Gwembe Valley, Zambia, 1982-2004». In *Morality, Hope and Grief: Anthropologies of Aids in Africa*. Edited by Hansjørg Dilger and Ute Luig. New York: Berghahn Books.

Comaroff, Jean. 2007. «Beyond Bare Life: aiDs, (Bio)Politics, and the Neoliberal Order.» *Public Culture* 19 (1): 197-219.

Conrad, Peter. 1992. «Medicalization and Social control». *Annual Review of Sociology*, no. 18, 209-32.

Crapanzano, Vincent. 1980. *Tuhami: Portrait of a Moroccan*. Chicago: University of Chicago Press.

Crawford, Robert. 1980. «Healthism and the Medicalization of Everyday Life». *Journal of Health Services* 10 (3):365-88.

Cree, Viviene E., Helen Kay, and Kay Tisdall. 2002. «Research with Children: Sharing the Dilemmas», *Child and Family Social Work* 7 (1): 47-56.

Csordas, Thomas J. 1990. «Embodiment as a Paradigm for Anthropology.» *Ethos* 18 (1): 5-47.

Das, Veena. 1998. «Wittgenstein and Anthropology.» *Annual Review of Anthropology*, no. 27, 171-95.

Dawson Marc. 1983. «Socio-Economic and Epidemiological Change in Kenya: 1880-1925.» PhD. diss. University of Wisconsin-Madison.

Devereux, George. 1967. *From Anxiety to Method in the Behavioral Sciences*, The Hague: Mouton & Co.

Devine, Carol. 2008. «The Moon, the Stars, and a Scar: Body Mapping Stories of Women Living with HIV/AIDS», *Border Crossings* 27 (1): 58-65.

Dickert, Neal, and Christine Grady. 1999. «What's the Price of a Research Subject? Approaches to Payment for Research Participation.» *New England Journal of Medicine*, 341 (3): 198-203.

Dilger, Hansjørg. 2010, «Introduction. Morality, Hope and Grief: Towards an Ethnographic Perspective in HIV/AIDS Research» *In Morality, Hope and Grief: Anthropologies of Aids in Africa*. Edited by Hansjørg Dilger and Ute Luig. New York: Berghahn Books.

Direção dos Serviços de Saúde e Higiene. 1942. *Relatórios e estatísticas dos Serviços de Saúde. Ano de 1939*. Colônia de Moçambique: Lourenço Marques, Imprensa Nacional.

Dube, Francis. 2009. «Colonialism, Cross-Border Movements, and Epidemiology: a History of Public Health in the Manica Region of Central Mozambique and Eastern Zimbabwe and the African Response, 1890-1980.» PhD diss. University of Iowa.

Einarsdóttir, Jónína. 2000. *«Tired of weeping»: Child Death and Mourning among Papel Mothers in Guinea-Bissau*. Stockholm: Stockholm Studies in Social.

Enserink, Martin. 2010 «What's Next for Disease Eradication?» *Science* 330, no. 6012 (December): 1736-39.

Epstein, Steven. 1996. *Impure science: AIDS, Activism, and the Politics of Knowled*ge. Berkeley: University of California Press.

—. 2007. «Patient Groups and Health Movements». In *New Handbook of Science and Technology Studies*. Edited by Edward Hackett et al., 499-539. Cambridge, MA: MIT Press.

Evans-Pritchard, Edward E. (1937) 2002. *Stregoneria, oracoli e magia tra gli Azande*. Translated by Roberto Malighetti. Milano: Raffaello Cortina Editore.

Fanon, Frantz. (1952) 1986. *Black Skins, White Masks*. London: Pluto Press.

Fardhdiani V, Molfino L, Zamudio AG, Manuel R, Luciano G, Ciglenecki I, Rusch B, Toutous Trellu L, Coldiron ME. «HIV-associated Kaposi's sarcoma in Maputo, Mozambique: outcomes in a specialized treatment center, 2010-2015. » Infect Agent Cancer. 2018 Jan 19;13:5. doi: 10.1186/s13027-018-0177-6. PMID: 29387144; PMCID: PMC5775566.

Faria, Inês. 2021. «Plans, Changes, Improvisations.» *Anthropology in Action* 28 (2): 18-26.

Farmer, Paul. 1990. «Sending Sickness: Sorcery, Politics, and Changing Concepts of AIDS in Rural Haiti.» *Medical Anthropology Quarterly* 4, no. 1 (March): 6-27.

—. 1992. «New Disorders, Old Dilemmas: AIDS and Anthropology in Haiti.» In *The Time of AIDS. Social Analysis, Theory and Method*. Edited by Gilbert Herdt and Shirley Lindenbaum, 287-318. Newbury Park: Sage.

—. 1999. *Infections and inequalities: The modern plagues*. Berkeley: University of California Press.

Fassin, Didier. 2010. «Ethics of Survival: A Democratic Approach to the Politics of Life.» *Humanity: An International Journal of Human Rights, Humanitarianism, and Development* 1, no.1 (Fall): 81-95.

—. 2012. *Humanitarian Reason: A Moral History of the Present Times*. Translated by Rachel Gomme. Berkeley: University of California Press.

—. 2013. «The Moral Economy of Childhood in the Time of AIDS». In *When People Come First*. Edited by João Biehl and Adriana Petryna, 109-32. Princeton: Princeton University Press.

Fassin, Didier, Amy Jacobs, and Gabrielle Varro. 2007. *When Bodies Remember: Experiences and Politics of AIDS in South Africa*. Berkeley: University of California Press.

Fassin, Didier, and Mariella Pandolfi, eds. 2010. *Contemporary States of Emergency: The Politics of Military and Humanitarian Interventions*. New York: Zone Books.

Fauvet, Paul. 2000. «Mozambique: Growth with Poverty, a Difficult Transition from Prolonged War to Peace and Development.» *Africa Recovery* 14 (3): 12-19.

Feierman, Steven, and John M. Janzen eds. 1992. *The Social Basis of Health and Healing in Africa*. Berkeley: University of California Press.

Feinglass Ellie, Nadja Gomes, and Vivek Maru. 2016. «Transforming Policy into Justice: The Role of Health Advocates in Mozambique». *Health Hum Rights* 18, no. 2 (December): 233-46.

Fialho Feliciano, José. 1998. *Antropologia económica dos thonga do Sul de Moçambique*. Maputo: Arquivo Histórico de Moçambique.

Fidler, David. 2007. «Architecture Amidst Anarchy: Global Health's Quest for Governance.» *Global Health Governance* 1 (1): 1-17.

Follér Maj-Lis. 2013. «Governing AIDS Through Aid to Civil Society: Global Solutions Meet Local Problems in Mozambique.» *African Journal of AIDS Research* 12, no. 1 (March): 49-59.

Foucault, Michel. 1973. *Discipline and Punish*. London: Penguin.

—. 1988. «Technologies of the self.» In *Technologies of the Self. A Seminar with Michel Foucault*. Edited by Luther H. Martin, Huck Gutman, and Patrick H. Hutton. London: Tavistock.

—. 2003. *'Society Must Be Defended': Lectures at the Collège de France, 1975-76*. Edited by Mauro Bertani, and Alessandro Fontana. London: Penguin.

Freud, Sigmund. 1957. «Mourning and Melancholia.» In *The Standard Edition of the Complete Psychological Works of Sigmund Freud*, vol. 14 *On the History of the Psycho-Analytic*

Movement, Papers on Meta-psychology and Other Works (1914-1916), 243-58. London: Hogarth.

Gallo, Robert. C. 1987. «The AIDS Virus.» *Scientific American* 256 (1): 47-56.

Garrett, Laurie. 2007. «The Challenge of Global Health.» *Foreign Affairs* 86 (1): 14-38.

Gaskell, George, and Bauer, Martin W. 2000. «Towards Public Accountability: Beyond Sampling, Reliability and Validity». In *Qualitative Researching with Text, Image and Sound*. Edited by Martin W. Bauer and Georgeaskell, 336-50. London: Sage.

Gastaldo, D., Magalhaes, L., Carrasco, C., and Davy, C., 2012. *Body Mapping as Research: Methodological Considerations for Telling the Stories of Undocumented Workers through Body Mapping*. Accessed xx month 20xx, http://www. migrationhealth.ca/undocumented-workers-ontario/body-mapping.

Geertz, Clifford. 1974. '«From the Native's Point of View': On the Nature of Anthropological Understanding». *Bulletin of the American Academy of Arts and Sciences* 28 (1): 26-45.

Geest van der, Sjaak. 2002. *Introduction: Ethnocentrism and Medical Anthropology Ethnocentrism*. In *Reflections in medical anthropology*. Edited by Sjaak van der Geest and Ria Reis, 1-23. Amsterdam: Aksant.

Geest van der, Sjaak and Finkler, Kaja. 2004. «Hospital Ethnography: Introduction.» *Social Science & Medicine* 59, no. 10 (November): 1995-2001.

Gibbon, Sahra, and Novas, Carlos. 2008. «Introduction.» In *Biosocialities, Genetics and the Social Sciences. Making Biologies and Identities*, 1-18. London: Routledge.

Gibson, Diana. 2004. «The Gaps in the Gaze in South African Hospitals.» *Social Science & Medicine* 59, no. 10 (November): 2013-24.

Gill, Walt, and Julie Cliff. 1986. «The Dynamics of Health Policies in Mozambique 1975-85.» *Health Policy And Planning* 1 (2): 148-57.

Gilman, Sander. 1985. *Difference and Pathology: Stereo Types of Sexuality, Race and Madness*. Ithaca: Cornell University Press.

—. 1988. *Disease and Represemation: Images of Illnessfrom Madness to AIDS*. Ithaca: Cornell University Press.

Gold, Steven. 1989. «Ethical Issues in Visual Fieldwork». In *New Technology in Sociology: Practical Applications in Research and Work.* Edited by Grant Blank, James McCartney, and Edward Brent, 99-112. New Brunswick: Transaction Books.

Gomes Morais, Carolina M. 2014. *Estado colonial português e medicinas ao sul do save moçambique (1930-1975)*. Master Thesis. Casa de Oswaldo Cruz.

Good, Byron J. 1994. *Medical Rationality and Experience*. Cambridge: Cambridge University Press.

Gould, Deborah. 2004. «Passionate Political Processes: Bringing Emotions Back into the Study of Social Movements.» In *Rethinking Social Movements: Structure, Meaning and Emotion.* Edited by Jeff Goodwin and James M. Jasper, 155-75. Lanham, MD: Rowman and Littlefield Publishers.

Grace, Daniel, Sarah A. Chown, Michel Kwag et al. 2015. «Becoming 'Undetectable': Longitudinal Narratives of Gay Men's Sex Lives After a Recent HIV Diagnosis.» *AIDS Education & Prevention* 27, no. 4 (August): 333-49.

Granjo, Paulo. 2009. «Saúde e Doença em Moçambique.» *Saúde e Sociedade* 18 (4): 567-81.

Gray, Benjamin, and Pam Smith. 2008. «Emotional Labour and the Clinical Settings of Nursing Care: The Perspectives of Nurses in East London.» *Nurse Education in Practice* 9 (4): 253-61.

Guillemin, Marilys, Gillam, Lynn. 2004. «Ethics, Reflexivity, and 'Ethically Important Moments' in Research.» *Qualitative Inquiry* 10 (2), pp. 261-80.

Gune, Emídio. 2008. «Momentos liminares: dinâmica e significados no uso do preservativo.» *Análise Social* 43 (2): 297-318.

Gupta, Akhil, and James Ferguson. 1992. «Beyond 'Culture': Space, Identity, and the Politics of Difference.» *Cultural Anthropology* 7, no. 1 (February): 6-23.

Guta, Adrian, Stuart J. Murray, and Marilou Gagnon. 2016. «HIV, Viral Suppression and New Technologies of Surveillance and Control.» *Body and Society* 22 (2): 82-107.

Guta, Adrian, Stuart J. Murray, and Alex McClelland. 2011. «Global AIDS Governance, Biofascism, and the Difficult Freedom of Expression,» *APORIA: The Nursing Journal* 3 (4): 15-29.

Hacking, Ian. 1999. «Making Up People.» In *The Science Studies Reader*. Edited by Edson Biagioli, 161-71. New York: Routledge.

Haggerty, Kevin D. 2004. «Ethics Creep: Governing Social Science Research in the Name of Ethics.» *Qualitative Sociology*, no. 27, 391-414.

Halpern, Jodi. 2001. *From Detached Concern to Empathy*. Oxford: Oxford University Press.

Han, Clara. 2013. «Labor Instability and Community Mental Health: The Work of Pharmaceuticals in Santiago, Chile.» In *When People Come First: Critical Studies in Global Health*. Edited by João Biehl and Adriana Petryna, 276-301. Princeton: Princeton University.

Hanlon, James. 1996. *Peace Without Profit: How the IMF Blocks Rebuilding in Mozambique*, Portsmouth, NH: Heinemann.

Hardon, Anita et al. 2009. «Engaging in Biomedical Hypes and Hopes: Health Activism and Access to ART in Africa.» Paper presented at the workshop *The Authority of Science: On the Relation Between Governance and Biomedicine in Africa*, Max Planck Institute for Social Anthropology, Halle, Germany June 15-17.

Havik, Philip J. 2014. «Public Health and Tropical Modernity: The Combat Against Sleeping Sickness in Portuguese Guinea, 1945-1974.» *História, Ciências, Saúde-Manguinhos* 21 (2): 641-66.

Heimer, Carol. 2012. «Inert Facts and the Illusion of Knowledge: Strategic Uses of Ignorance in HIV Clinics.» *Economy and Society* 41 (1), 17-41.

Heisley, Deborah, and Sidney, Levy. 1991. «Autodriving: A Photoelicitation Technique.» *Journal of Consumer Research* 18, no. 3 (December): 257-72.

Høg Erling 2014. HIV scale-up in Mozambique: exceptionalism, normalisation and global health. Glob Public Health. 2014;9(1-2):210-23. doi: 10.1080/17441692.2014.881522. Epub 2014 Feb 5. PMID: 24499102; PMCID: PMC4066904.

Honwana, Alcinda. 2002. *Espíritos vivos, tradições modernas: possessão de espíritos e reintegração social pós-guerra no sul de Moçambique*. Maputo, Promédia.

Hutchby, Ian, and Moran-Ellis, Jo, eds. 1998. *Children and Social Competence: Arenas of Action*. London: Falmer Press.

IAS. 2017. History of the International AIDS Society (IAS). IAS

Iliffe, John. 2006. *The African AIDS Epidemic: A History*. Oxford: James Currey.

Illich, Ivan. 1976. *Medical Nemesis*. New York: Pantheon.

Isaacman Allen, and Barbara Isaacman. 1983. *Mozambique: from Colonialism to Revolution, 1900-1982*. Boulder: Westview Press.

Jackson, Lynette A. 2002. «'When in the White Man's Town': Zimbabwean Women Remember Chibeura.» In *Women in African Colonial Histories*. Edited by Jean Allman et al. 191-215. Indianapolis: Indiana University Press.

Jackson, Michael. 2007. *Excursions*. Durham, NC: Duke University Press.

Janes, Craig R., and Kitty K. Corbett. 2009. «Anthropology and Global Health.» *Annual Review of Anthropology* 38 (1): 167-83.

Janzen, John M., Charles Leslie, and William Arkinstall. 1982. *The Quest for Therapy in Lower Zaire*. Berkeley: University of California Press.

Jensen, Anja M. B.. 2017. «Guardians of 'the gift': the emotional challenges of heart and lung transplant professionals in Denmark». *Anthropology & Medicine* 24 (1): 111-26.

Johnston, Karissa M., Adrian R. Levy, Viviane D. Lima et al. 2010. «Expanding Access to HAART: A Cost-Effective Approach for Treating and Preventing HIV.» *AIDS* 24 (12): 1929-35.

Junod, Henri. 1996. *Usos e costumes dos Bantu*. Maputo: Arquivo Histórico de Moçambique.

Jovchelovitch, Sandra. 2007. *Knowledge in Context: Representations, Community, and Culture*. New York: Routledge.

Kalofonos, Ippolytos Andreas. 2010. «'All I Eat Is ARVs': The Paradox of AIDS Treatment Interventions in Central Mozambique.» *Medical Anthropology Quarterly* 24 (3): 363-80.

Kanki P. J., Avroy J. and Essex M. 1985. «Isolation of T-lymphotropic retrovirus related to HTLV-III/LAV from wild African green monkeys.» *Science* 230 (4728): 951-54.

Kleinman, Arthur. 1978. «Concepts and a Model for the Comparison of Medical Systems as Cultural Systems.» *Social Science & Medicine, no. 12*, 85-93.

—. 1980. *Patients and Healers in the Context of Culture. An Exploration of the Borderland Between Anthropology, Medicine, and Psychiatry*. Berkeley: University of California Press.

Kleinman, Arthur, Leon Eisenberg, and Byron Good. 1978. «Culture, Illness and Care. Clinical Lessons From Anthropologic and Cross-Cultural Research.» *Annals of Internal Medicine*, no. 88, 251-258.

Kleinman, Arthur, and Joan Kleinman. 1991. «Suffering and its Professional Transformation. Towards an Ethnography of Interpersonal Experience» *Culture Medicine and Psychiatry* 15 (3):275-301.

Kleinman, Arthur, Wang, Wen-Zhi, Li, Shi-Chuo, et al. 1995. «The Social Course of Epilepsy: Chronic Illness as Social Experience in Interior China.» *Social science & medicine* 40 (10): 1319-30.

Kubler-Ross, Elisabeth. 1969. On Death and Dying. New York: Macmillan.

Langwick, Stacey. «Articulate(d) Bodies: Traditional Medicine in a Tanzanian Hospital.» *American Ethnologist* 2008 35 (3): 428-39.

Lévi-Strauss, Claude. (1958) 1966. *Antropologia strutturale*. Translated by Paolo Caruso. Milano: il Saggiatore.

Lifton, Robert Jay. 1967. *Death in Life*. New York: Touchstone.

Lo Bosco, Maria Concetta. 2018. «A Call for a Broader Citizenship: Parent-Led Autism Advocacy Movement in Portugal.» PhD diss. University of Lisbon.

—. 2021. «Fellings in the Field.» *Anthropology in Action* 28 (2): 8-17.

Lutz, Catherine, and Geoffrey M. White. 1986. «The Anthropology of Emotions.» *Annual Review of Anthropology*, no. 15, 405-36.

MacClancy, Jeremy, and Augustin Fuentes. 2013. «The Ethical Fieldworker, and Other Problems.» In *Ethics in the Field: Contemporary Challenges*. Edited by Jeremy MacClancy and Augustin Fuentes, 1-23. New York: Berghahn Books.

MacGregor, Hayley N. 2008. «Mapping the Body: Tracing the Personal and the Political Dimensions of HIV/AIDS in Khayelitsha, South Africa.» *Anthropology & Medicine* 16, no. 1 (April): 85-95.

Machel, Josina Z. 2001. «Unsafe Sexual Behaviour Among Schoolgirls in Mozambique: A Matter of Gender and Class.» In *Reproductive Health Matters* 9 (17): 82-90.

MacCormack, Carol. 1986. The articulation of western and traditional systems of health care. In The professionalisation ofAfrican medicine, ed. Murray Last, and G.L. Chavunduka. New Hampshire: Manchester University Press.

Mahumane, Jonas. 2015 *«Marido Espiritual» Possessão e Violência Simbólica no Sul de Moçambique,* Tese especialmente elaborada para obtenção do grau de Doutor em Antropologia, ICS Universidade de Lisboa.

Mann, Jonathan M., and Kathleen Kay. 1991. «Confronting the Pandemic: the World Health Organization's Global Programme on AIDS 1986-1989.» *AIDS* 5 (S2): 221-230.

Manuel, Sandra. 2005 «Obstacles to Condom Use Among Secondary School Students in Maputo City, Mozambique.» In *Culture, Health and Sexuality*, 7 (3): 293-302.

—. 2011. «Políticas de HIV e SIDA e dinâmicas socioculturais em Moçambique.» In *Desafios para Moçambique 2011*. Edited by Luís De Brito, Carlos Nuno Castel-Branco, Sérgio Chichava, António Francisco, 333-351. Maputo: IESE.

Mariano, Esmeralda. 2016. «The 'Unsaying' of Reproductive Affliction in Mozambique Witchcraft and Local Reproductive Knowledge.» *The Oriental Anthropologist* 16 (2): 303-20.

Matsinhe, Cristiano. 2008. *Tabula Rasa: Dynamics of the Mozambican Response to HIV/AIDS.* Maputo: Kula.

Mattes, Dominik. 2011. «We Are Just Supposed to Be Quiet»: The Production of Adherence to Antiretroviral Treatment in Urban Tanzania.» *Medical Anthropology: Cross-Cultural Studies in Health and Illness* 30, no. 2 (March): 158-82.

Matza, Tomas. 2012. " 'Good Individualism?' Psychology, Ethics, and Neoliberalism in Postsocialist Russia." American Ethnologist 39 (4): 804–18.

Mbembe, Achille. 2006 « Nécropolitique », *Raisons politiques*, vol. no 21, no. 1, pp. 29-60.

McKay, Ramah. 2012. «Afterlives: humanitarian histories and critical subjects in Mozambique». *Cultural Anthropology* 27 (2), 286-309, 2012

—. 2018. *Medicine in the Meantime: The Work of Care in Mozambique*. Durham NC: Duke University Press.

MEF. 2017 Circular No.1/GAB-MEF/2017. "Administração e Execução do Orçamento do Estado para 2017"

Meneses, Maria Paula G. 2004. «Quando não ha problemas, estamos de boa saúde, sem azar nem nada»: Para uma concepção emancipatória de saúde e das medicinas.» In *Moçambique e a reinvenção da emancipação social*. Edited by Boaventura de Sousa Santos and Teresa Cruz e Silva, 77-110. Maputo: Centro de Formação Jurídica e Judiciaria.

Ministério dos Combatentes. 2016. *Samora Machel: na memória do povo e do mundo*. Maputo: CPHLLN.

MISAU. 1992. *National AIDS Control Programme. Plano de Médio Termo 92/93*. Maputo: MISAU.

—. 2015. *Plano estratégico do sector da saúde [Health sector strategic plan].* Maputo: MISAU.

Mitchell, Lisa M. 2006. «Child-Centered? Thinking Critically about Children's Drawings as a Visual Research Method.» *Visual Anthropology Review* 22 (1): 60-73.

Mogensen, Hanne O. 2010. «New Hopes and New Dilemmas: Disclosure and Recognition in the Time of Antiretroviral Treatment». In *Morality, Hope and Grief: Anthropologies of Aids in Africa*. Edited by Hansjørg Dilger and Ute Luig. New York: Berghahn Books.

Mol, Annemarie. 2008. *Logic of Care: Health and the Problem of Patient Choice*, London: Routledge.

Mol, Annemarie, Ingunn Moser, and Jeannette Pols. 2010. Care in Practice: On Tinkering in Clinics, Homes and Farms. Transcript-Verlag.

Morra, Francesca. 2021. «Towards an Ethnograpy of Crisis.» *Anthropology in Action* 28 (2): 36-43.

MSF 2016 *Moz_SAAJ Report*. English, MSF Mozambique.

Namati. 2017. *Recomendações para assegurar o respeito pela privacidade nas unidades sanitárias*. Namati Mozambique

NASCOP. 1998. *National Sentinel Surveillance: AIDS Cases by Province and District*. Nairobi: KNACP.

Nguyen, Vinh-Kim. 2010. *The Republic of Therapy: Triage and Sovereignty in West Africa's Time of AIDS*. Durham, NC: Duke University Press.

Noormahomed Abdul R., and Segall, Malcom. 1994. *The Public Health Sector in Mozambique: a Post-War Strategy for Rehabilitation and Sustained Development.* Mozambique country paper. Macroeconomics, Health and Development nº 14. Geneva: WHO.

Olsen, William, and Carolyn Sargent. 2017. *African Medical Pluralism*. Bloomington: Indiana University Press

Ong, Aihwa, and Stephen Collier, eds. 2005. *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems*. Malden: Blackwell.

Orb, A., Eisenhauer, L. & Wynaden, D. 2000. Ethics in qualitative research, Journal of Nursing Scholarship, 33, pp. 93–96.

Orellana, Marjorie F. 1999. «Space and Place in an Urban Landscape: Learning from Children's Views of Their Social World», *Visual Sociology* 14 (1): 73-89.

Packard, Randall M. 1987. «Tuberculosis and Industrial Health Policy on the Witwatersrand, 1902-1932.» *Journal of southern African studies* 13 (3): 187-209.

Packard, Randall M., and Paul Epstein. 1991. «Epidemiologists, Social Scientists, and the Structure of Medical Research On Aids in Africa.» *Social Science & Medicine* 33 (7): 771-83.

Pandolfi, Mariella. 2006. «La zone grise des guerres humanitaires.» *Anthropologica* 48 (1): 43-58.

Parkinson, Brian. 1995. *Ideas and Realities of Emotion*. London: Routledge.

Passador, Luis H. 2011. «Guerrear, casar, pacificar, curar: o universo 'tradição' e a experiência com o HIV/Aids no distrito de Homoíne, Sul de Moçambique.» PhD diss. Universidade Estadual de Campinas.

Paterson, David L. et al. 2000. «Adherence to Protease Inhibitor Therapy and Outcomes in Patients with HIV Infection.» *Annals of internal Medicine* 133 (1): 21-30.

PEPFAR. 2018. *Mozambique Country Operational Plan 2018*, Strategic Direction Summary. Accessed 6st March 2015 https://mz.usembassy.gov/wp-content/uploads/sites/182/OGAC_COP20-Mozambique-SDS-with-Appendix-C_FINAL.pdf

Pepin, Jacques. 2011. *The Origins of AIDS*. Cambridge: Cambridge University Press.

Pfeiffer, James. 2003. «International NGOs and Primary Health Care in Mozambique: The Need for a New Model of Collaboration.» *Social Science and Medicine* 56 (4): 725-38.

—. 2013. «The Struggle for a Public Sector: pepfar in Mozambique.» In *When People Come First: Critical Studies in Global Health.* Edited by João Biehl and Adriana Petryna, 166-81. Princeton: Princeton University Press.

—. 2019. «Austerity in Africa: Audit Cultures and the Weakening of Public Sector Health Systems.» *Focaal*, no. 83 (Spring): 51-61.

Pfeiffer, James, and Rachel Chapman. 2010. «Anthropological Perspectives on Structural Adjustment and Public Health.» *Annual Review of Anthropology* 39: 149-65.

Prince, Ruth J. 2013. «Situating Health and the Public in Africa Historical and Anthropological Perspectives.» In *Making and Unmaking Public Health in Africa*. Edited by Ruth J. Prince and Rebecca Marsland, 1-51. Athens OH: Ohio University Press.

Prout, Alan, and Allison James. 1997. «A New Paradigm for the Sociology of Childhood? Prevenance, Promise and Problems.» In *Constructing and Reconstructing Childhood: Contemporary Issues in the Sociological Study of Childhood*, 7-34. Edited by Allison James and Alan Prout. 2nd ed. London: Falmer Press.

Quaranta Ivo, ed. 2006. *Antropologia medica. I testi fondamentali*. Milano: Raffaello Cortina Editore.

—. 2006. *Corpo potere e malattia. Antropologia e AIDS nei Grassfileds del Camerun*. Roma: Meltemi.

Rabinow, Paul. 1977. *Reflections on Fieldwork in Morocco*. Berkeley: University of California Press.

—. 1996. «Artificiality and Enlightenment: From Sociobiology to Biosociality.» In *Essays on the anthropology of reason*, 91-112. Princeton: Princeton University Press.

—. 1999. *French DNA: Trouble in Purgatory*. Chicago: University of Chicago Press.

Redfield, Peter, 2013. *Life in Crisis: The Ethical Journey of Doctors Without Borders*. Berkeley: University of California Press.

Rivers, William H. R. 1924. *Medicine, Magie and Religion*. London: Kegan Paul.

Rödlach, Alexander. 2006. *Witches, Westerners, and HIV: AIDS and Cultures of Blame in Africa*. Walnut Creek: Left Coast Press.

Rodger AJ, Cambiano V, Bruun T, Vernazza P, Collins S, Degen O, Corbelli GM, Estrada V, Geretti AM, Beloukas A, Raben D, Coll P, Antinori A, Nwokolo N, Rieger A, Prins JM, Blaxhult A, Weber R, Van Eeden A, Brockmeyer NH, Clarke A, Del Romero Guerrero J, Raffi F, Bogner JR, Wandeler G, Gerstoft J, Gutiérrez F, Brinkman K, Kitchen M, Ostergaard L, Leon A, Ristola

M, Jessen H, Stellbrink HJ, Phillips AN, Lundgren J; *PARTNER Study Group. Risk of HIV transmission through condomless sex in serodifferent gay couples with the HIV-positive partner taking suppressive antiretroviral therapy (PARTNER): final results of a multicentre, prospective, observational study.* Lancet. 2019 Jun 15;393(10189):2428-2438. doi: 10.1016/S0140-6736(19)30418-0. Epub 2019 May 2. PMID: 31056293; PMCID: PMC6584382.

Rosaldo, Michelle. 1984. «Toward an Anthropology of Self and Feeling.» In *Culture Theory. Essays on Mind, Self, and Emotion*. Edited by Richard A. Le Vine and Robert. A. Shweder, 135-57. Cambridge: Cambridge University Press.

Rose, Gillian. 2001. *Visual Methodologies: An Introduction to the Interpretation of Visual Materials*. London: Sage.

Rose, Nikolas. 2007. *The Politics of Life Itself*. Princeton: Princeton University Press.

Rosengarten M. 2004. «Consumer activism in the pharmacology of HIV. » *Body & Society* 10: 91–107.

Scheper-Hughes, Nancy. 1992. *Death Without Weeping: The Violence of Everyday Life in Brazil*. Berkley: University of California Press.

Schoepf, Brooke G. 2001. «International AIDS Research in Anthropology: Taking a Critical Perspective on the Crisis.» *Annual Review of Anthropology*, no. 30, 335-61.

Schwartz, Dona. 1989. «Visual Ethnography: Using Photography in Qualitative Research.» *Qualitative Sociology* 12 (2): 119-53.

Sepkowitz Kent A. 2001. «AIDS. The First 20 Years.» *New England Journal of Medicine*. 344 (23): 1764-72.

Sherr, Kenneth, Baltazar Chilundo, Sarah Gimbel et al. 2012. «Brain Drain and Health Workforce Distortions in Mozambique.» *PLoS ONE* 7 (4): e35840.

Skovdal, Morten, and Tatek Abebe. 2012. «Reflexivity and Dialogue: Addressing Methodological and Socio-Ethical Dilemmas in Research with HIV-Affected Children in East Africa.» *Ethics, Policy & Environment* 15 (1): 77-96.

Smith, Pam. 1992. *The Emotional Labour of Nursing*. London: Macmillan.

Solomon, Jane, 2002. *«Living with X»: A Body Mapping Journey in Time of HIV and AIDS. Facilitator's Guide*. Johannesburg: REPSSI.

Stodulka, Thomas. 2015. «Emotion Work, Ethnography, and Survival Strategies on the Streets of Yogyakarta.» *Medical Anthropology* 34 (1): 84-97.

Stepan, Nancy L. 2011. *Eradication: Ridding the World of Diseases Forever?*. Ithaca: Cornell University.

Strong, Thomas. 2009. «Vital Publics of Pure Blood.» *Body & Society* 15 (2): 169-91.

Strub, Sean. 2010. «Medical Ethics and the Rights of People with HIV Under Assault.» *Poz* (blog). April 28, 2010. Accessed 1st December 2015, https://www.poz.com/blog/test-and-treat/.

Sweeney, Rohan, and Duncan Mortimer. 2016. «Has the Swap Influenced Aid Flows in the Health Sector?» *Health Economics* 25, no. 5 (May): 559-77.

Taliani, Simona. 2006. *Il bambino e il suo doppio. Malattia, stregoneria e antropologia dell'infanzia in Camerun*. Milano: Franco Angeli.

Thomas, Nigel P., and Claire O'Kane. 1998. «The Ethics of Participatory Research with Children», *Children and Society* 12, no. 5 (November): 336-48.

Turner, Victor. (1967) 1976. *La foresta dei simboli. Aspetti del rituale Ndembu*. Translated by Nicoletta Greppi Collu, Brescia: Morcelliana.

UNAIDS. 2009. *AIDS Epidemic Update*. Geneva: UNAIDS Accessed 1st April 2015 https://www.unaids.org/sites/default/files/media_asset/jc1700_epi_update_2009_en_1.pdf.

UNICEF. 2015. *Moçambique: Informe orçamental 2015. Saudé*.

Usdin, Shereen. 2003. *The No-Nonsense Guide to HIV/AIDS*. Oxford and London: New International Publications & Verso.

Valle, Carlos Guilherme. 2015. «Biosocial Activism, Identities and Citizenship: Making Up 'People Living with HIV and AIDS' in Brazil.» *Vibrant: Virtual Brazilian Anthropology* 12, no. 2 (December) 27-70.

Vaughan, Megan. 1991. *Curing Their Ills: Colonial Power and African Illness*. Stanford: Stanford University Press.

Vio, Ferruccio. 2006. «Management of Expatriate Medical Assistance in Mozambique.» *Human Resources for Health* 4 (1).

Young, Lorraine, and Hazel Barrett. 2001. «Adapting Visual Methods: Action Research with Kampala Street Children» *Area* 33 (2):141-52.

Walwyn David. 2013. «Patents and Profits: A Disparity of Manufacturing Margins in the Tenofovir Value Chain.» *African Journal of AIDS Research* 12, no. 1 (March): 17-23.

Walt, Gill, and Julie Cliff. 1986. «The Dynamics of Health Policies in Mozambique 1975-85.» *Health Policy and Planning* 1 (2): 148-57.

Walt, Gillian, and Angela Melamed. 1983. *Toward a People's Health Service*. London: Zed Books.

West, Harry G. 2005. *Kupilikula: Governance and the Invisible Realm in Mozambique*. Chicago: The University of Chicago Press.

Whitehead, Lisa Claire. 2006. «Quest, Chaos and Restitution: Living with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis», *Social Science & Medicine*, 62 (9): 2236-45.

WHO. 2013a. *HIV and Adolescents: Guidance for HIV Testing and Counselling and Care for Adolescents Living with HIV. Recommendations for a Public Health Approach and Considerations for Policy-Makers and Managers*. Geneva: WHO, Accessed 1st December 2016 https://apps.who.int/iris/handle/10665/94334.

—. 2013b. *WHO Issues new HIV Recommendations Calling for Earlier Treatment.* Accessed December 1, 2015, http://www.who.int/mediacentre/news/releases/2013/new_hiv_recommendations_20130630/en/index.html.

Widdrington, John, Brendan Payne, Manjul Medhi et al. 2011. «The Significance of Very Low-Level Viraemia Detected by Sensitive Viral Load Assays in HIV Infected Patients on HAART.» *Journal of Infection* 62, no. 1 (January): 87-92.

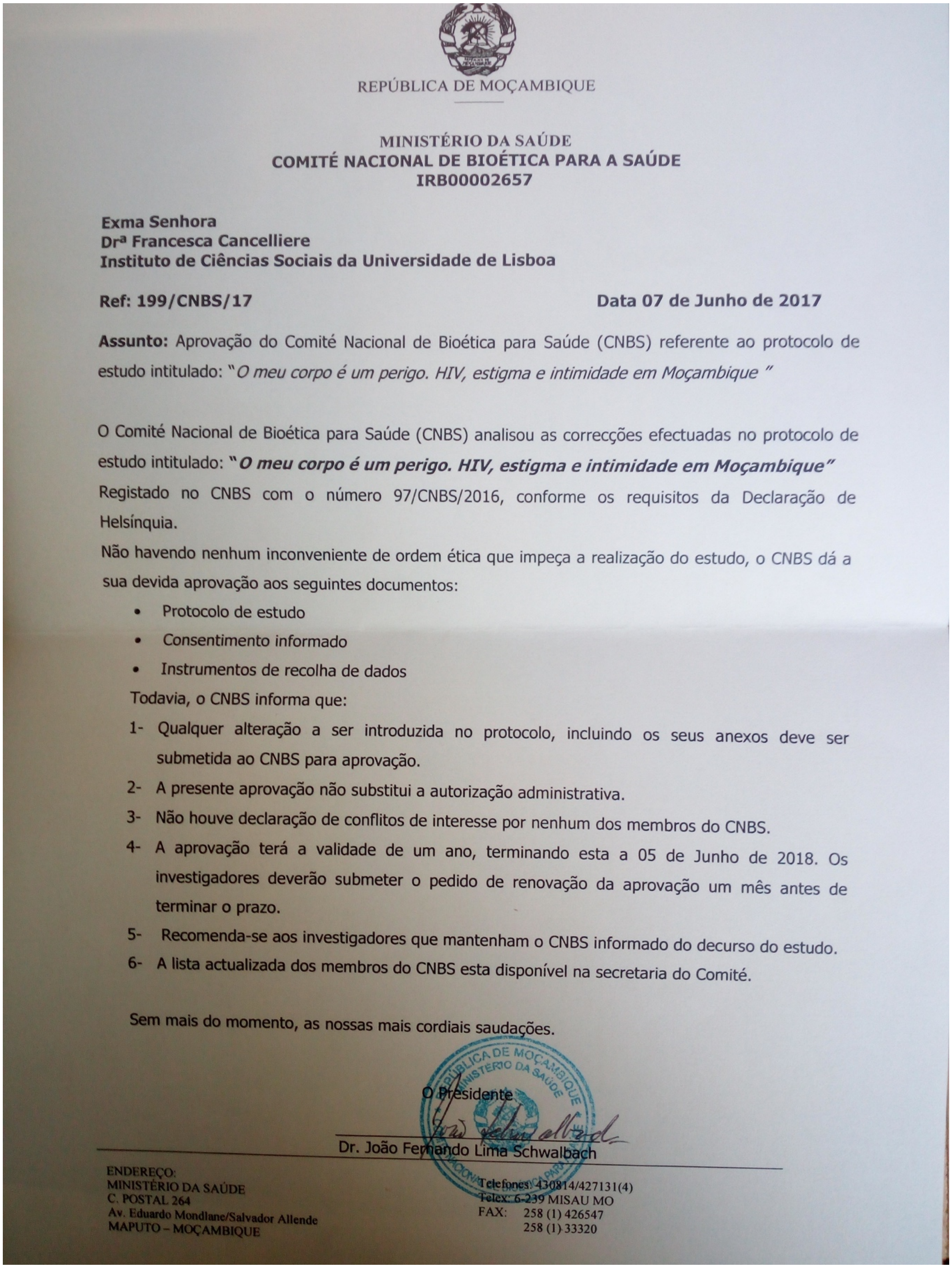
Williamson, Emma, Trudy Goodenough, Julie Kent et al. 2005. «Conducting Research with Children: The Limits of Confidentiality and Child Protection Protocols.» *Children and Society* 19, no. 5 (November): 397-409.

Wreford, Joanne. 2008. *Myths, Masks and Stark Realities: Traditional African Healers, HIV/AIDS Narratives and Patterns of HIV/AIDS Avoidance*. Capetown: Centre for Social Science Research.

Young, Allan. 1975. «Why Amhara Get kureynya: Sickness and Possession in an Ethiopian zar Cult». *American Ethnologist* 2:567–584

Annex

Annex A. Approval of the National Bioethics Committee for Health to conduct fieldwork



REPÚBLICA DE MOÇAMBIQUE

MINISTÉRIO DA SAÚDE
COMITÉ NACIONAL DE BIOÉTICA PARA A SAÚDE
IRB00002657

Exma Senhora
Drª Francesca Cancelliere
Instituto de Ciências Sociais da Universidade de Lisboa

Ref: 199/CNBS/17 **Data 07 de Junho de 2017**

Assunto: Aprovação do Comité Nacional de Bioética para Saúde (CNBS) referente ao protocolo de estudo intitulado: "*O meu corpo é um perigo. HIV, estigma e intimidade em Moçambique* "

O Comité Nacional de Bioética para Saúde (CNBS) analisou as correcções efectuadas no protocolo de estudo intitulado: ***"O meu corpo é um perigo. HIV, estigma e intimidade em Moçambique"*** Registado no CNBS com o número 97/CNBS/2016, conforme os requisitos da Declaração de Helsínquia.

Não havendo nenhum inconveniente de ordem ética que impeça a realização do estudo, o CNBS dá a sua devida aprovação aos seguintes documentos:

- Protocolo de estudo
- Consentimento informado
- Instrumentos de recolha de dados

Todavia, o CNBS informa que:

1- Qualquer alteração a ser introduzida no protocolo, incluindo os seus anexos deve ser submetida ao CNBS para aprovação.
2- A presente aprovação não substitui a autorização administrativa.
3- Não houve declaração de conflitos de interesse por nenhum dos membros do CNBS.
4- A aprovação terá a validade de um ano, terminando esta a 05 de Junho de 2018. Os investigadores deverão submeter o pedido de renovação da aprovação um mês antes de terminar o prazo.
5- Recomenda-se aos investigadores que mantenham o CNBS informado do decurso do estudo.
6- A lista actualizada dos membros do CNBS esta disponível na secretaria do Comité.

Sem mais do momento, as nossas mais cordiais saudações.

O Presidente

Dr. João Fernando Lima Schwalbach

ENDEREÇO:
MINISTÉRIO DA SAÚDE
C. POSTAL 264
Av. Eduardo Mondlane/Salvador Allende
MAPUTO – MOÇAMBIQUE

Telefones: 430814/427131(4)
Telex: 6-239 MISAU MO
FAX: 258 (1) 426547
258 (1) 33320

Annex B. Poster presentation *Austerity measures in a fragile context. The case of seropositive teenagers in Mozambique,* presented at «Making Medicine in Austere Times: Materialities, Moralities and Policies of Care», MAS-Symposium, University of Bern, Institute of Social Anthropology 11-13 June 2019.

AUSTERITY MEASURES IN A FRAGILE CONTEXT

The case of seropositive teenagers in Mozambique

Francesca Cancelliere, PhD Candidate, ICS-ULisboa

How austerity measures affect young patients' life and their routine in public health centres?

Bare. Living with HIV in Maputo
PhD research project explores the challenges of teenagers in Maputo who face a complex and precarious landscape of living with the HIV virus.

HIV overview (IMASIDA 2015)

- Major cause of deaths in the country
- 2.100.000 people living with HIV out of which 170.000 are children
- Prevalence rate from 11.5% in 2009 to 13.2% in 2015 within the age group of 15 to 49 years old
- Prevalence is higher in urban areas (16.8%) than in rural areas (11%)

HISTORICAL FACTS

- 1964-1974 Independence War
- 1975 Independence from Portugal and election of Samora Machel (FRELIMO) with the creation of a national health system as a top priority
- 1977-1992 Civil war between FRELIMO and RENAMO

SAPs (Structural Adjustment Programs)

Austerity is one expression of SAP (Powers and Rakopoulos 2019). In the midst of the war of late 1980s, Mozambique was virtually bankrupt and its government heavily indebted. The signature of a SAP in 1987 imposed by the World Bank/IMF led to austerity measures on the public sector, which resulted in health workforce cut and salaries reduction, removal of price subsidies for food and fuel, the scaling back of social safety nets, and cutbacks in social services (Pfeiffer 2003; Fauvet 2000; Cliff 1993; Hanlon 1996).

NGOs

To reduce public spending on national health systems across the continent SAP was imposed and major donors recruited NGOs to fill in the service gaps (Pfeiffer 2019). By the early 1990s, nearly 100 agencies were spread throughout the country supporting the health sector (Hanlon 1996). By 2000, there were hundreds of health projects managed by NGOs across the country with only superficial linkages to the local health system itself (Pfeiffer 2019).

SECRET LOAN

Back in 2013 the Mozambique Government borrowed $2 billions in order to set up state-backed tuna fishing companies (Ematum), with the loans arranged by Credit Suisse and a Russian investment bank [1].

The request was kept hidden from the country's Parliament

A significant amount of funds were used to buy military vessels

The subsequent breakdown in trust between Mozambique and its creditors caused international donors, the IMF and the World Bank to suspend the financial aid.
General Budget Support was suspended in 2016 and is still suspended (UNICEF 2017)
Due to the country's debt burden, devaluation of its currency and increased inflation the 2017 State Budget was worth US$ 3.86 billion (UNICEF 2017).

HEALTH FINANCIAL OVERVIEW AND FINANCIAL CONTROL

Government budget expenditure in the health sector is moving away from the Abuja target of 15%

2006	13.4%
2014	7.8%
2015	9 %
2017	7.8% - In 2017 Health Sector was allocated US$ 300.1 million

(Pfeiffer 2019; UNICEF 2015)

The country shows one of the lowest health workers-to-population ratio in the world
Three doctors and twenty-one nurse per 100,000 population (MISAU 2014)

On-budget
Foreign aid that flows on budget into the health sector itself on the public and government funding budget

Off-budget
Foreign aid flowing off-budget in the health sector goes directly to NGOs in collaboration with MISAU's (Ministry of Health of Mozambique) funding.

Horizontal funding
Horizontal funding focuses on the strengthening of basic health system building blocks and recurrent costs. This type of funding is nearly always on-budget, where it can be included in long-term planning to maintain or extend the system (Pfeiffer 2019)

Vertical funding
Vertical funding refers to resources used to address a specific disease or health problems (ex. HIV/AIDS, TB, malaria) and generally not used for long-term system building. Nearly all funding that goes to NGOs is considered vertical and off-budget (Pfeiffer 2019)

MISAU MAIN EXTERNAL RESOURCES

Description	Funds		Criticities
Prosaude is a Consortium of European bilateral and UN agencies (Italy, Spain, Denmark, Flanders, UNICEF, UNFPA, Switzerland and Ireland) agreed to pool funding, of which human resources are one of the most important components. (UNICEF 2017)	Year 2014 2015 2016 2017 2018 2019	Committment (USD) 84.0 millions 55.6 millions 48.5 millions 23.0 millions 20.8 millions (exp) 16.0 millions (exp)	The dwindling financial support to Prosaude in 2016 reflects the emerging donor preference to fund the sector through alternative, vertical modalities in the wake of the debts scandal.
Global Financing Facility (World Bank, DfID-United Kingdom, Gavi, GFATM and the government of Netherlands) is a multi-stakeholder coordination platform to mobilize sustainable financing to support RMNCAH. Their Investment Case (IC) started in 2016. (https://www.globalfinancingfacility.org/mozambique)	The program is co-financing USD 253 millions for 2018-2023.		Financial Control (Development of Health Financing Strategy; Program for Results)
PEPFAR - The U.S. President's Emergency Plan for AIDS Relief GFATM - Global fund to fight AIDS, Tubercolosis and malaria (PEPFAR 2018)	PEPFAR Investment (2004-2018): USD +3.6 billions Total Funding per 2018: USD 394 millions PEPFAR financing in COP19: less USD 90 million GFATM for 2018-2020: USD 335 million		No funding goes to basic system building blocks (Pfeiffer 2019). Projects with shorter planning strategies and shift in activities from COP 15 to COP 19. Shift in implementing partners, the country is divided up geographically between NGOs. "Internal brain drain" (Sherr et al. 2012)

ETHNOGRAPHIC VIGNETTES

SAAJ
Serviços Amigos dos Adolescentes e Jovens
Youth Friendly Health Services

SAAJs deals with young people between 10 and 24 years old. Services include: counselling, contraception, emergency contraception, STI prevention and treatment, HIV/AIDS counselling, testing and care, prenatal care and postpartum/post-abortion counselling. The human resources are mainly supported by partners rather than by the MISAU, which led to sustainability issues (Doctors Without Borders, 2016)

#1 Health workers

Clara, the nurse of SAAJ in health centre, has to deal everyday with a high number of patients. Because of the huge amount of work and the low salary she received for it, she is forced to do other unformal jobs:

"The situation in the health centre is getting worse from when MSF (Doctors Without Border) left few years ago. They were really good and have doctors and technicians that come here to help us. They were taking care of the TB yard, laboratory and SAAJ. Now, some of them stay in the TB yard but the majority left. After a while, CCS (PEPFAR) arrived to support us, the Americans. I really don't get what they are doing here. What is really happened is that I'm alone and I have to take care of all the patients. Now with "test and treat" implementation, the sooner the treatment is started the better it is for the person's health, but there is a question that the Americans don't have taken into account. If we start treatment for all patients, they will clearly increase in number. How can we do the same job with the same human resources and with the same salary? MISAU is not giving us more money or new resource and with my salary (14.000 meticais, approximately 200€) is really difficult to arrive at the end of the month, so I have to do biscatos (unformal jobs)."

Speaking about patients difficulties, Marta an activist of Namati NGO (Right to Health) comments:

"We've addressed complaints related to health providers' absenteeism and mistreatment. Patients are saying that the SAAJ didn't accept people after 1.00 pm although its official closing time is 3.30 pm. We often receive reports from patients about technicians asking for a bribe to receive HAART or other drugs. This is clearly unacceptable. Why does this happen? Surely there is a general dissatisfaction and a charge of work that is too high in the health centres, but it's not just this, it's also a cultural issue."

#2 Psychosocial support

Delia is a young counsellor who worked in the SAAJ thanks to NGO funding. Nowadays, she doesn't receive a salary and she is a volunteer showing a low-quality service and a lack of motivation with patients. She was also in charge of the "social clubs", that now are not happening anymore:

"The social clubs of young people who are HIV positive is usually gathering the last saturday of each month. We do activities, talk about treatment, how they take care of themselves and enjoy life. But that doesn't happen anymore ... it has not happened for the past 6 months. The CCS (PEPFAR) was the one that provides for food and transport for the group members but is not working now. Here, if you are not giving something, people didn't show up. We cannot ask the young people to pay for transport, wake up really early and come here with nothing to eat".

#3 Clinical exams

Carol is a 16-year-old seropositive girl waiting for her CD4 exam result (CD4 count is like a snapshot of how well your immune system is functioning). The difficulties in receiving the results of her CD4 exam and Viral Load (the amount of HIV in blood) are different, from the spatial dislocation in the health centre to the structural loss of the results papers inside the health system:

"I went to the health centre to ask for the result of the CD4 but it wasn't there, they told me that I have to do it again because it wasn't there, but I told them that I've already done it one month ago. They told me I have to do it again. They told me to go to the laboratory and ask but I didn't find the place (she bursts into tears)... I can't do it. I don't understand why it's not here!"

Maria, one of the activist of Namati, comments:

"It's not uncommon that there is a misplaced clinical file, it always happens. Sometimes patients lose the little sheet but sometimes the health system loses exam result or blood sample. In particular, it happens for the examination of the viral load because it's a very complex examination and must be done outside the health centre at the hospital. If it goes well, it takes six months to receive the result, but more often it must be redone."

SOME REFLECTIONS

- Mozambique's long-term dependency from external funding contributes to the fragmentation of aid and to significant sustainability issues. In particular vertical funding, like PEPFAR, presented modalities of interventions that didn't fund basic system building blocks, entailing during the years an important shift in implementation strategies. Even before the hidden debt, the country presented significant difficulties in managing funds, their allocation and use. After the hidden debt, the subsequent trust breakdown led some donors to adopt more scrupulous and complex financial control measures that are much more difficult to follow up for all the parties involved (donors, NGOs, MISAU). Coordinational issues between NGOs and the Ministry of Health for projects' implementation has progressively worsened, with a direct impact on the daily life of the health centres. In a more efficent public health system, without diversion of funds, the ideal solution would have been to allocate directly the funds to the MISAU, which in past years have been addressed in particular to PEPFAR and NGOs. It would have ideally increased the health workforce, health coverage would have increased in many places, and more people would have had access to and stay on HIV treatment (Pfeiffer 2019).
- As long as it is understaffed, underpaid, and over-worked, the health workforce could not be more responsive and attentive to patients' needs.
- Community health workers (e.g. counsellors) are essential to provide community-based outreach and they should be trained and paid through a public system prepared to manage them in order to guarantee coverage, equity, and sustainability (Mukherjee and Eustache 2007).
- If the MISAU rations the CD4 test among the population without a structure that supports the Viral Load test, the consequence would be an alarming lack in patients' HIV screening.

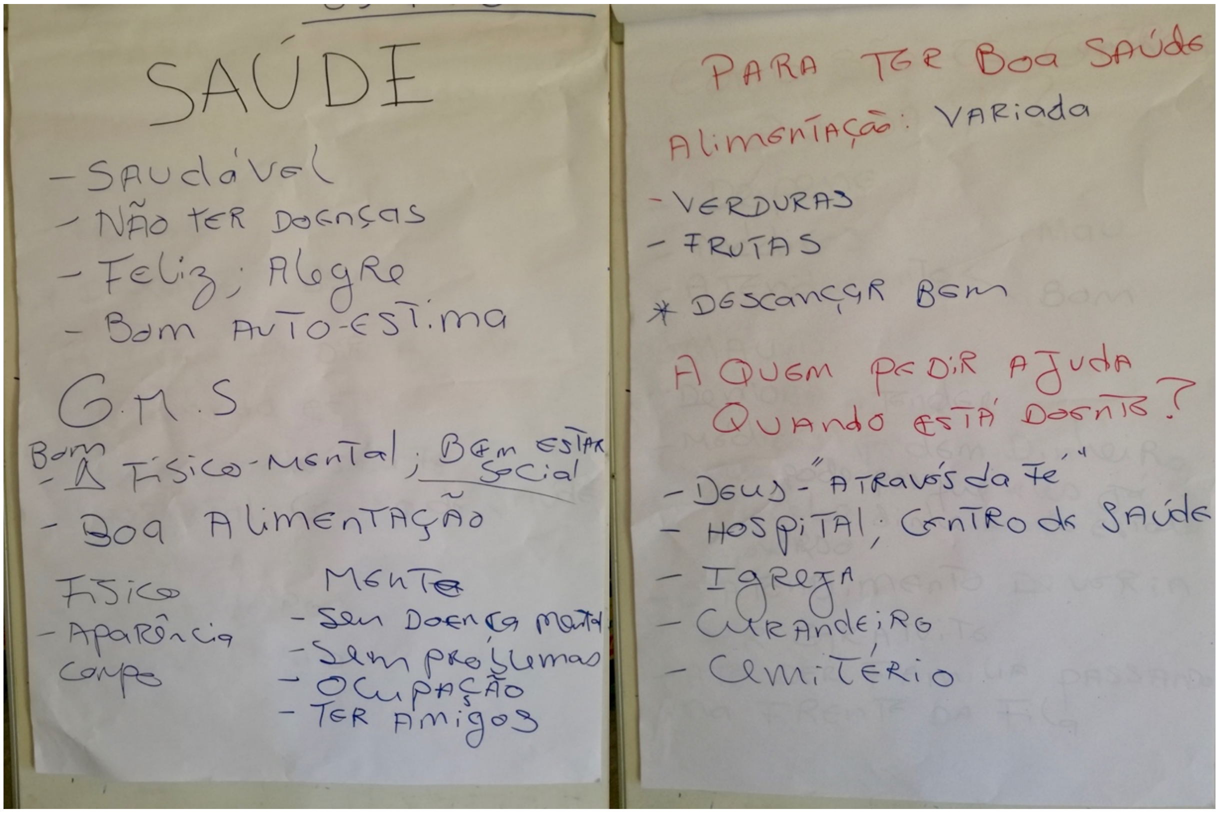
NOTES

[1] https://www.worldfinance.com/special-reports/the-mozambique-debt-crisis

REFERENCES

Cliff, J. (1993). Donor dependence or donor control?: The case of Mozambique. Community Development Journal, 28(3), 237–244.
Doctors Without Borders. (2016). Youth-friendly service providing HIV prevention and treatment.
Fauvet, P. (2000). Mozambique: Growth with poverty, a difficult transition from prolonged war to peace and development. Africa Recovery, 14(3), 12–19.
Hanlon, J. (1996). Peace without profit: How the IMF blocks rebuilding in Mozambique. Portsmouth, NH: Heinemann.
Ministério da Saúde (MISAU), Instituto Nacional de Estatística (INE), ICF Internacional. (2015). Inquérito de Indicadores de Imunização, Malária e HIV/SIDA em Moçambique (IMASIDA) Maputo, Moçambique. Rockville, Maryland, EUA: INS, INE e ICF Internacional.
Ministério da Saúde (MISAU). (2014). Health Sector Strategic Plan PESS 2014-2019.
Mukherjee, J. S., & Eustache, F. E. (2007). Community health workers as a cornerstone for integrating HIV and primary healthcare. AIDS Care, 19(1): S73-82.
Pfeiffer, J. (2019). Austerity in Africa. Audit cultures and the weakening of public sector health systems, Focal, 2019(83), 51-61.
Pfeiffer, J., Gimbel S., Chilundo B., Gloyd S., Chapman R., Sherr K. (2017). Austerity and the 'sector-wide approach' to health: The Mozambique experience.Social Science and Medicine, 187: 208–216.
Pfeiffer, J. (2003). "International NGOs and primary health care in Mozambique: The need for a new model of collaboration." Social Science and Medicine 56(4): 725–738.
Powers, T., & Rakopoulos, T. (2019). The anthropology of austerity, Focaal, 83: 1-12.
PEPFAR. (2018). Mozambique COP2018 Strategic Direction Summary
Sherr K, Mussa A, Chilundo B, et al. (2012). Brain drain and health workforce distortions in Mozambique. PLoS One, 7: e35840.
UNICEF. (2017). Moçambique: Informe Orçamental 2017: Saúde [Mozambique: Budget report 2015-Health]. Maputo: UNICEF.
UNICEF. (2015). Moçambique: Informe orçamental 2015: Saúde Mozambique: Budget report 2015-Health]. Maputo: UNICEF.

Annex C: Some of the moments and outputs of the workshop "*Direito à saúde*"



SAÚDE

- Saudável
- Não ter doenças
- Feliz; Alegre
- Bom auto-estima

G.M.S

- Bom Δ Físico-Mental; Bem estar social
- Boa alimentação

Físico
- Aparência
Corpo

Mente
- Sem doença mental
- Sem problemas
- Ocupação
- Ter amigos

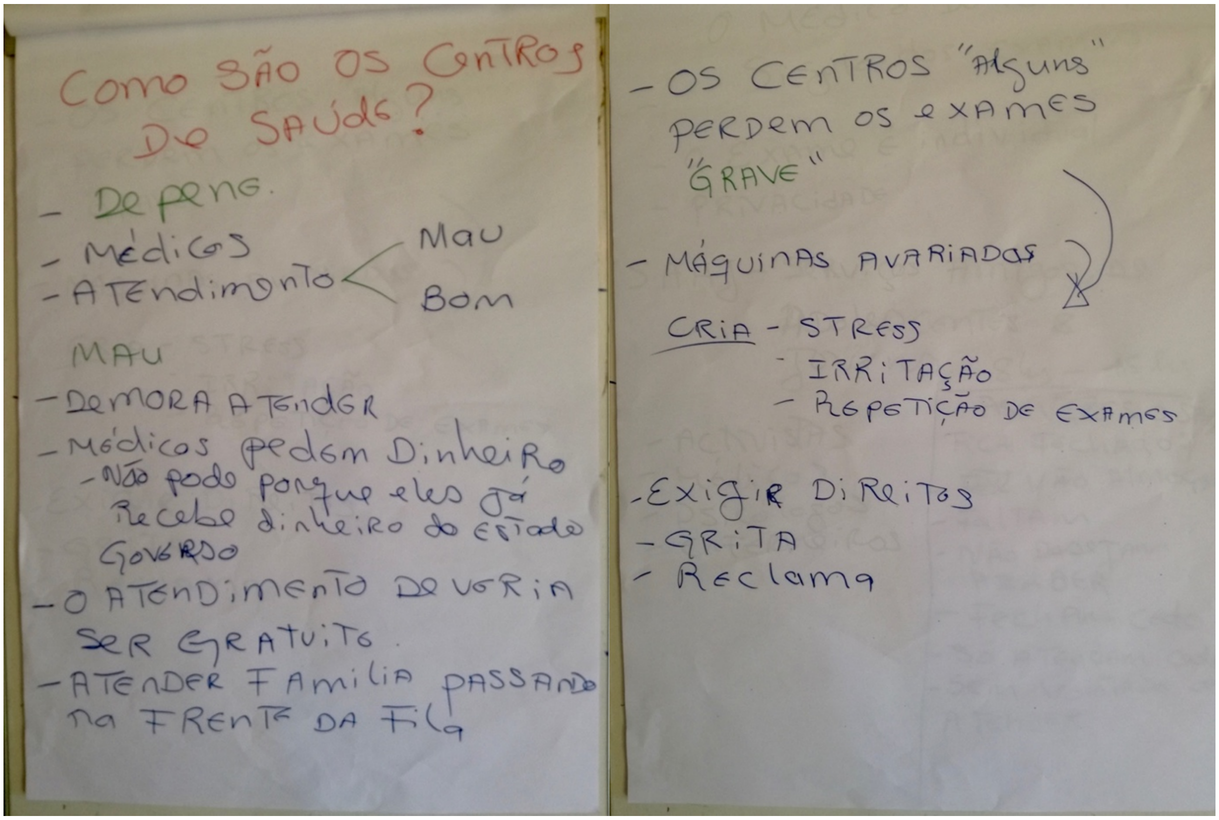
PARA TER BOA SAÚDE

Alimentação: variada

- Verduras
- Frutas
- * Descançar bem

A QUEM PEDIR AJUDA QUANDO ESTÁ DOENTE?

- Deus - "através da fé"
- Hospital; Centro de saúde
- Igreja
- Curandeiro
- Cemitério



Como são os centros de saúde?

- Depende.
- Médicos
- Atendimento < Mau / Bom

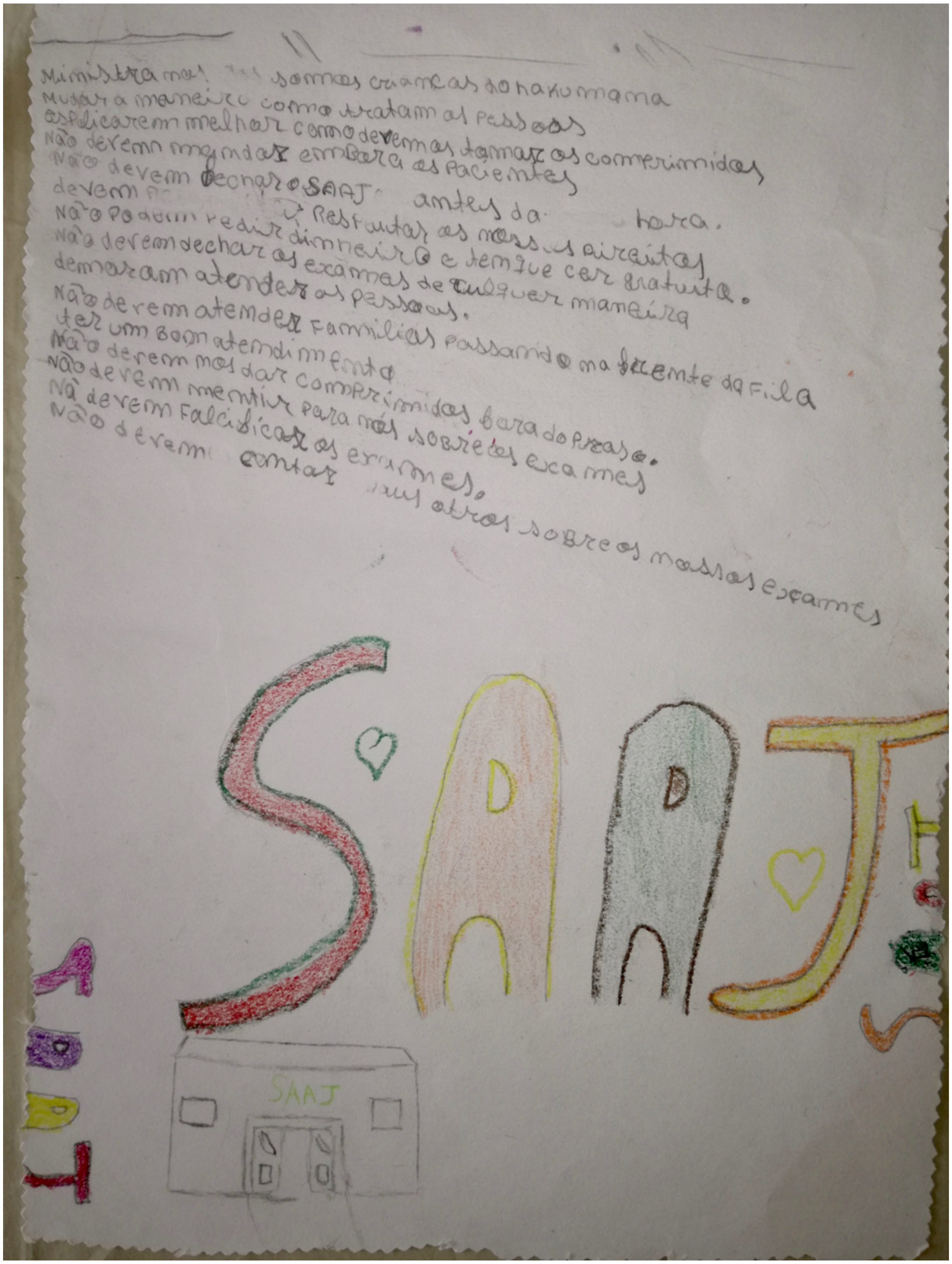
Mau

- Demora atender
- Médicos pedem dinheiro
  - Não pode porque eles já recebe dinheiro do estado governo
- O atendimento deveria ser gratuito.
- Atender familia passando na frente da fila

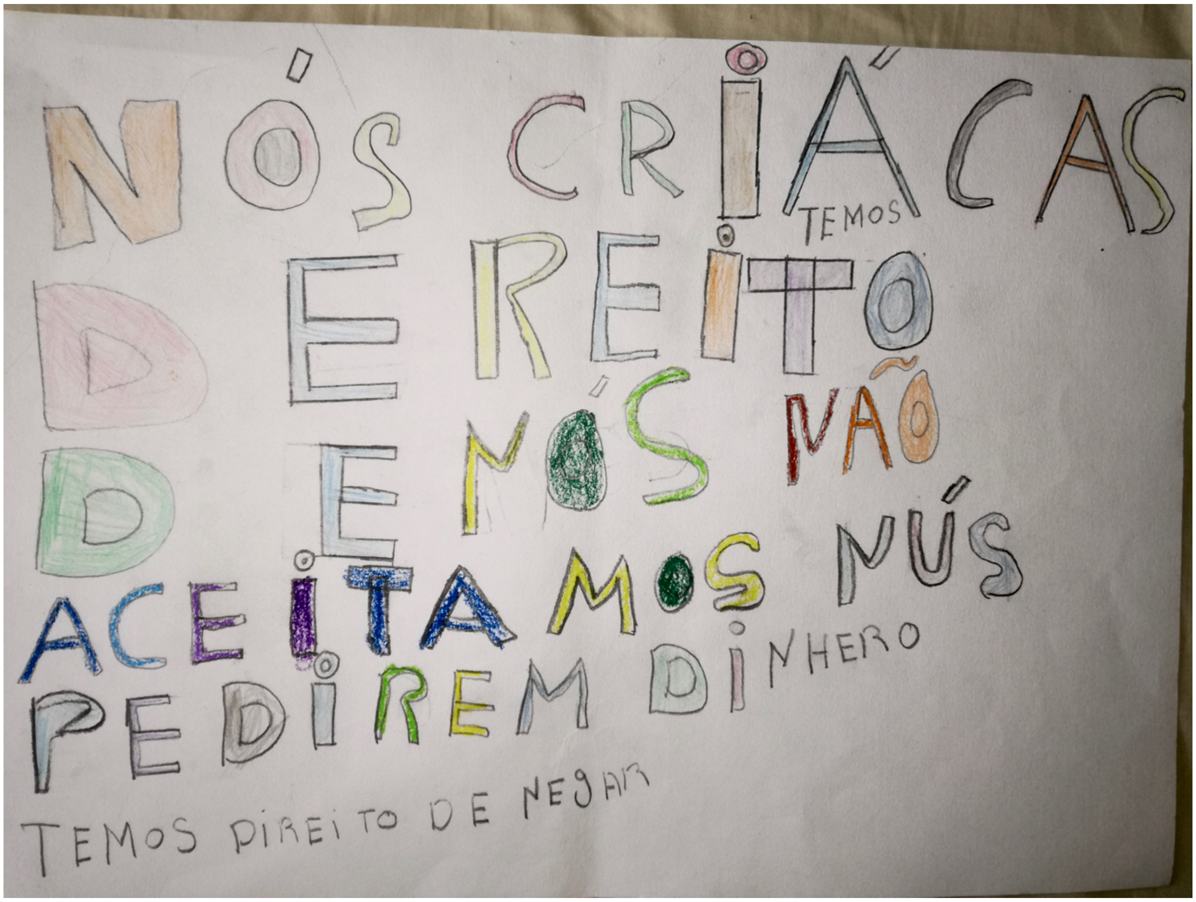
- Os centros "alguns" perdem os exames "grave"
- Máquinas avariadas

Cria - stress
- irritação
- repetição de exames

- Exigir direitos
- Grita
- Reclama

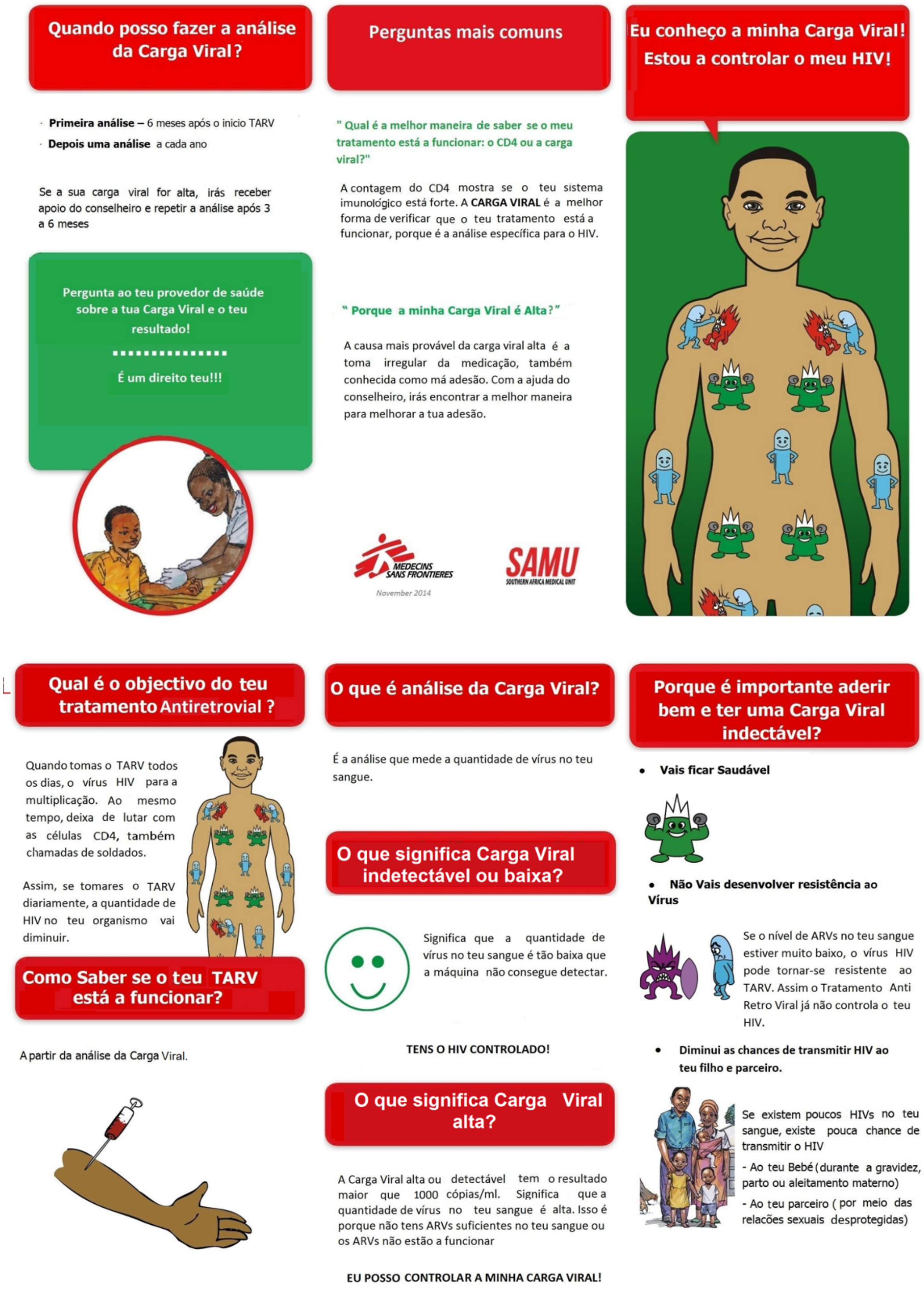


Ministra nos! somos criamças do hakumama
Mudar a maneira como tratam as pessoas
esplicarem melhar como devemos tomar os comerimidos
Não devem mandar embora os pacientes
Não devem fechar o SAAJ antes da hora.
devem [illegible] Respeitar os nossos direitos
Não podem pedir dimneiro e temque cer gratuita.
Não devem dechar os exames de culquer maneira
demoram atender as pessoas.
Não devem atender familias passando na frente da fila
ter um bom atendimento
Não devem nos dar comprimidos fora do prazo.
Não devem mentir para nós sobre os exames
Não devem falcificar os exames.
Não devem contar aos otros sobre os nossos exames



NÓS CRIÁCAS TEMOS
DEREITO
DE NÓS NÃO
ACEITAMOS NÚS
PEDIREM DINHERO
TEMOS DIREITO DE NEGAR

Annex D: Leaflet produced by doctors without borders on viral load



Quando posso fazer a análise da Carga Viral?

- **Primeira análise –** 6 meses após o inicio TARV
- **Depois uma análise** a cada ano

Se a sua carga viral for alta, irás receber apoio do conselheiro e repetir a análise após 3 a 6 meses

Pergunta ao teu provedor de saúde sobre a tua Carga Viral e o teu resultado!

....

É um direito teu!!!

Perguntas mais comuns

" Qual é a melhor maneira de saber se o meu tratamento está a funcionar: o CD4 ou a carga viral?"

A contagem do CD4 mostra se o teu sistema imunológico está forte. A **CARGA VIRAL** é a melhor forma de verificar que o teu tratamento está a funcionar, porque é a análise específica para o HIV.

" Porque a minha Carga Viral é Alta?"

A causa mais provável da carga viral alta é a toma irregular da medicação, também conhecida como má adesão. Com a ajuda do conselheiro, irás encontrar a melhor maneira para melhorar a tua adesão.

MEDECINS SANS FRONTIERES

SAMU
SOUTHERN AFRICA MEDICAL UNIT

November 2014

Eu conheço a minha Carga Viral! Estou a controlar o meu HIV!

Qual é o objectivo do teu tratamento Antiretrovial ?

Quando tomas o TARV todos os dias, o vírus HIV para a multiplicação. Ao mesmo tempo, deixa de lutar com as células CD4, também chamadas de soldados.

Assim, se tomares o TARV diariamente, a quantidade de HIV no teu organismo vai diminuir.

Como Saber se o teu TARV está a funcionar?

A partir da análise da Carga Viral.

O que é análise da Carga Viral?

É a análise que mede a quantidade de vírus no teu sangue.

O que significa Carga Viral indetectável ou baixa?

Significa que a quantidade de vírus no teu sangue é tão baixa que a máquina não consegue detectar.

TENS O HIV CONTROLADO!

O que significa Carga Viral alta?

A Carga Viral alta ou detectável tem o resultado maior que 1000 cópias/ml. Significa que a quantidade de vírus no teu sangue é alta. Isso é porque não tens ARVs suficientes no teu sangue ou os ARVs não estão a funcionar

EU POSSO CONTROLAR A MINHA CARGA VIRAL!

Porque é importante aderir bem e ter uma Carga Viral indectável?

- **Vais ficar Saudável**
- **Não Vais desenvolver resistência ao Vírus**

Se o nível de ARVs no teu sangue estiver muito baixo, o vírus HIV pode tornar-se resistente ao TARV. Assim o Tratamento Anti Retro Viral já não controla o teu HIV.

- **Diminui as chances de transmitir HIV ao teu filho e parceiro.**

Se existem poucos HIVs no teu sangue, existe pouca chance de transmitir o HIV

- Ao teu Bebé (durante a gravidez, parto ou aleitamento materno)
- Ao teu parceiro (por meio das relacões sexuais desprotegidas)