Representing the phenomenon of HIV/AIDS in developing countries: a case study from Mozambique

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Abstract. AIDS is a disease with profound effects on the global society, as it affects the individual lives, communities, societies and even nations. As governments try to gear up on the war against this pandemic, an issue of importance pertains to the use of information systems to collect data on the prevalence of the disease, analyse and transmit the data from the lower levels of the health administration where the testing is done to the higher levels of national policy making where different kinds of interventions are designed. In this paper, we argue that the manner in which the representation of the disease is constructed is an important area of concern as it shapes the picture of the disease prevalence, and influences how these statistics then get used for the planning of interventions such as supplying drugs and pro-health campaigns. Drawing from the domain of Science and Technology Studies, with a focus on Bruno Latour’s ideas of “circulating reference”, we firstly develop the theoretical notion of representation, and then apply it to an empirical analysis of the reporting systems, both paper and computer based, of HIV/AIDS in Mozambique. The successive movements of information about HIV/AIDS prevalence across the various administrative levels are seen as translations that are being constructed through the communication and work practices of the health workers at different levels, and are shaped by the political interests of the different stakeholders involved, including international agencies and national health authorities. Latour’s notion of circulating reference is drawn upon to analyse the question of “what is lost, what is gained, and what remains invariant through the successive stages of translation in the construction and use of the representation?”

Key words. Representation, translations, circulating reference, Latour, HIV/AIDS epidemic, Mozambique

1. Introduction

The Acquired Immunodeficiency Syndrome, AIDS as it is popularly known, is increasingly being recognised by national governments, international agencies, non-governmental organisations, and citizens all over the world as being a deadly epidemic that is threatening the social and economic life of individuals, families, communities, societies and even nations. AIDS is the only disease to have a dedicated United Nations (UN) organisation, the Joint United Nations Programme on HIV/AIDS (UNAIDS), aiming to confront it. In 2003, this global epidemic killed more than 3 million people. An estimated 5 million people have been infected with the human immunodeficiency virus (HIV), raising the global estimate of people infected to around 40 million human lives [1].

As argued by Peter Piot, Executive Director of UNAIDS in November 2001, “HIV/AIDS is unequivocally the most devastating disease we have faced, and it will get worse before it gets better”. Moreover, many influential people are now leading the campaigns against the disease and are trying to expand the network and attract other people to join this war. “We are called to join the war against HIV/AIDS with the same and even greater resolve than was shown in the fight against apartheid” - former South African President Nelson Mandela told a host of music celebrities in Robben Island, Cape Town, as part of an appeal to fight AIDS in November, 2003. The President of the World Bank, James D. Wolfensohn, addressing the UN Security Council in January, 2000

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said “AIDS is turning back the clock on development. In too many countries the gains in life expectancy won are being wiped out. In too many countries more teachers are dying each week than can be trained. We will mainstream AIDS in all World Bank work”.

The influence of this global epidemic is especially dramatic in the developing world. In Sub-Saharan countries, it represents the leading cause of adult illness and death. In 2003, an estimated 26.6 million people in this region were living with HIV (66.5% of worldwide cases) and approximately 2.3 million have already died due to AIDS (76.7% of all AIDS deaths). Katjavivi and Otaala [2] argue that HIV/AIDS is not just about numbers, though staggering and frightening these are, rather it is about our lives: “Those who have died with AIDS were fathers and mothers, brothers and sisters, dear friends; even doctors and nurses; primary school teachers, electrical engineers; community leaders; finance managers; entrepreneurs, researchers, and communal farmers trying to lift their families out of poverty. No section of society has been spared from this deadly disease” (p.5).

The primary focus of national governments’ efforts to fight AIDS has been on preventive measures targeted towards individuals and institutions. Currently, the availability and access of anti-retroviral drugs, especially to pregnant women, has become a major issue heavily influencing the politics of funding, and the debates over the rates of growth of the disease. However, what is often missed in existing efforts is the recognition of the informational component required in the handling of the disease. The informational component refers to how the prevalence of the disease in local communities is being represented by government authorities, what information systems (IS) are being used to construct these representations, and what kind of heterogeneous networks - comprised of people, work practices and artefacts - influence the design and use of these IS and with it the evolving representations. The politics around how these representations are used by authorities to mobilise funds, plan intervention programmes, and report the existence of the disease to the world outside are also usually missed. Representation of HIV and AIDS cases is usually presented in the form of prevalence rates, implying the percentage of the population which carries the virus or exhibits the disease in a particular time period. This prevalence rate is an important indicator to track the epidemic over time and across populations, and discern trends about the scale of the problem and how the epidemic is distributed by age, gender, mode of transmission and geographical area [3].

In this paper, we argue that this prevalence rate should be seen as a representation, an informational construct created through the information systems that register, report, and analyse these figures. Also important is the manner in which these figures get used by the relevant authorities. As it has been forcefully argued by various researchers, especially from the domain of Science and Technology Studies (STS), representations, and how they are constructed and used, are influenced by various social, political, and cultural conditions. Unpacking how these representations are constructed and used becomes important for at least two reasons. Firstly, it helps to understand how effectively these representations reflect the state of prevalence of the disease on the ground. For example, recent reports from Mozambique (a Sub-Saharan country, categorised by UNDP as one of the poorest in world) [4], have estimated the HIV prevalence rate in 2002 at 13.6% for the population aged 15 to 49 years [5]. We argue that this figure should not be taken at face value as the “truth”, and the question should be raised of “how well does this percentage represent the HIV/AIDS situation of the Mozambican people?” Secondly, such unpacking helps to analyse how effectively these representations are used or not used by the authorities to intervene with the prevention and management of the disease, for example through the allocation of drugs and other resources.

The objective of this paper is to develop the theoretical concept of representation, and to apply it to an empirical analysis of HIV and AIDS reporting systems in Mozambique. Specifically, the focus of this paper is on answering the following questions:

- What is the nature of the information systems used for representing the HIV/AIDS phenomenon in Mozambique?
How do the socio-political-organisational context and the existing work practices of health staff shape the construction and use of the representations arising from the HIV/AIDS reporting system in Mozambique?

We examine these questions through an empirical analysis of the HIV/AIDS reporting systems in selected districts in Mozambique.

The paper is organised as follows. In the next section, 2, we explore the theoretical notion of representation drawing upon relevant literature from the domains of IS and STS research. In section 3, the research method is described followed by the case study from Mozambique in section 4. Section 5 provides an analysis of the case, drawing upon the theoretical notion of representations dealt with in section 2. Finally, some brief conclusions are presented in section 6.

2. Theoretical Considerations: Representations, Work Practices, and IS Research

The question of representation has been and continues to be of central importance in IS research. Any IS designed to represent work incorporates, to different degrees, more or less explicit assumptions about how work is or should be carried out. As Kyng [6] argues, IS are tools developed to represent both current and future work practices, as well as associated system design possibilities. System development methodologies prescribe representational techniques, for example the creation of prototypes and flow charts to make visible workplace practices. However, such methodologies tend to be narrowly limited to design concerns [7]. Early work in computer science in the seventies and eighties, grounded in a positivist cognitive science tradition, sought to create representations in the form of models that were a mirror of reality. The challenge then was to create stronger representational forms through richer notations and techniques that could abstract and formalise the real world in more precise ways [8].

The primarily positivistic perspective of representation has been challenged by various researchers as reflected in issues of the Communications of the ACM dedicated to participatory design (June, 1993), Social Computing (January 1994), requirements gathering (May 1995) and representations (September 1996). Some of the key perspectives that these critiques have successfully introduced to the debates on representation are discussed below, followed by further extensions to this debate through the works of STS researchers like Bruno Latour [9].

Sachs [10] criticised the “organisational, explicit” view of representation that sought to model well defined tasks and operations through for example, workflow modelling techniques. Instead, she argued for a more “activity oriented” view “which suggests that the range of activities, communication practices, relationships, and coordination it takes to accomplish business is complex and continually mediated by workers and managers alike” (p.38-39). This activity based view thus emphasises the need to examine how people communicate, how they think about problems and solutions, and how they form alliances and negotiations to get things done. While the organisational view assumes that people make errors, the activity perspective focuses on how and why people solve problems [10].

Suchman [7] has emphasised the political dimensions of representations, and the implications that arise from making certain forms of knowledge and work practices visible. She argues that “in the case of many forms of service work, we recognise that the better the work is done, the less visible it is to those who benefit from it” (p.58). Viewed from this perspective, she describes representations as “interpretations, in the service of particular interests and purposes, created by actors specifically positioned with respect to the work represented” (p.58). The challenge this perspective raises for researchers is to examine the intimate and deeply embedded relations between work, their representations, and the politics of organisations.

Maps can be seen as a representational device of the terrain and how particular resources are distributed over it, for example trees or roads. In recent years, maps are being generated through Geographical Information Systems (GIS); and are being subject to serious scrutiny through a
deconstruction of the political and social influences in their construction. For example, Harley [11] has emphasised how political, religious, and social forces, representing a form of power, have played a significant role in the context of cartography. Such arguments have led to critiques against the use of GIS as producing maps that reflect perfect correspondence with reality [12]. Goodchild [13, p.56] has remarked, “…it is GIS’s supreme conceit that one can structure a useful representation of geographical knowledge in the absurdly primitive domain of the digital computer, just as it is cartography’s conceit that one can accomplish the same objective with pen and paper.” The political nature of map based representations is captured nicely in the quote below:

The new map of Jammu and Kashmir recently released by the CIA significantly described the region east of the Line of Control as the “Indian State of Jammu and Kashmir” while it designates the territories to its west as “Pakistan controlled areas of Kashmir.” In the past, the US treated the whole state as disputed. There are other notable changes from the past which would no doubt make many people wonder at the political agenda implicit in the map.

These critiques have been taken on board by Puri [14] in his empirical analysis of GIS applications for land management in India. Puri has argued that the political and intellectual interests of scientists shape the construction of models that are designed to represent the problem of land degradation. Puri describes maps as boundary objects that circulate between different communities including scientists, farmers, and administrators. In the process of circulation, they carry in more or less explicit ways the agenda of different groups, and inscribe power relations that shape the possibilities of communication and interaction between the groups.

Another form of representation concerns the construction of categories. From the kinds of categorisation systems that are developed, certain forms of representations become visible and others invisible [15]. Examples of classification schemes include the International Classification of Diseases, the Nursing Interventions Classification, Race Classification under apartheid in South Africa, and the classification of viruses and tuberculosis. Similarly, the Munsell code is a classification scheme for colours, where the different nuances of colours in a spectrum are represented by a number. This classification scheme represents a common standard for painters, car manufacturers, cartographers and pedologists [9]. Classification schemes help to provide a degree of comparability, visibility (and simultaneously invisibility) and control [15]. STS researchers have emphasised the political nature of such representation schemes and how they underlie interests of different groups to make certain representations visible or not.

In the context of IS, Walsham [16] describes representations to include activities of sense reading (when we make meanings of activities) and sense giving (when we convey our meanings to others) through different media including the use of technologies, databases and videoconference. In the context of the Lotus Notes based system for sales management, Walsham poses some key questions that researchers should ask: why was this particular form of representation chosen?; What types of representations are considered valuable by the users (in his case, the salespeople) themselves?; what knowledge of the sense-giver is useful in order to aid the reader’s sense creation process?; who required all this (the creation and use of representations) to happen and for what purpose?, and what incentives (or disincentives) were provided to use the representations? Addressing these questions, Walsham provides theoretical and practical implications around questions of what representations should be used and how can better representations be made (ibid).

In the health care domain, in recent years, the use of formal tools (computer-based decision tools) to represent the work of the medical practitioner has been a topic of debate. Berg [17], who has emphasised the tensions between the use of representation tool and medical work, writes:

Both critics and advocates want to judge the actions of formal tools in comparison with those of human experts, and query whether the tool is an adequate representation of the structure of medical practice, of the physician’s decision making, or of an optimal doctor’s performance” (p.162).
On one hand, critics of the use of tools argue that computers are unable to access the tacit knowledge humans have, and computer-based representations will be fundamentally inadequate. On the other hand, there are arguments made about how tools can be effective in representing the medical practitioners’ work, which has a significant information-processing component. It is thus argued that scientific methods can be used to develop certain computer-based representations of medical work [17].

Berg argues that formal tools change both the content and the context of the medical practitioner’s work and vice-versa. The representation of the practitioner’s practice through the use of formal decision-support tools may be shaped by either the current imperfections of the tools (practical or design constraints) and by psychological and socio-economic barriers inherent in the practice itself [17].

The above mentioned critiques to the traditional perspectives on representation grounded in a positivist tradition of either cognitive science or cartography, emphasises the need to examine the relations between the normative accounts of how work gets done and the actual practice [7]. The question then is not on whether a particular formalisation or representation is possible or desirable, or whether stronger techniques can be designed to capture what is left out, but on how representations provide resources on particular occasions for particular groups of people, and how through this process other groups of people get excluded. Such a perspective emphasises the heterogeneity of representations, and the challenges and opportunities created as representations circulate through groups of people with different backgrounds and interests, and when these representations get used in place of the work itself.

A theoretical and empirical apparatus to apply such a perspective in practice is provided by Bruno Latour’s concept of circulating reference [9]. Latour argues the creation and use of particular forms of representation does not imply one giant leap but a series of incremental steps of translation. At each step, some aspect of the phenomenon being represented is lost or reduced, and simultaneously other aspects are gained or amplified. What gets lost are the locality, particularity, materiality, multiplicity and continuity of the phenomenon, and simultaneously what is gained concerns compatibility, standardisation, text, calculation, circulation and relative universality. This dialectical process of reduction and amplification leads Latour to ask the interesting question of ‘what is gained, what is lost, and what remains invariant in the process of translation?’ This question which is articulated through the notion of circulating reference is described aptly through the following quote:

… [A] reference is not simply the act of pointing or a way of keeping… rather it is our way of keeping something constant through a series of transformations… What a beautiful move, apparently sacrificing resemblance at each stage only to settle again on the same meaning, which remains intact through sets of transformations (ibid. p.58). … [The] rupture at each stage [of] the ‘thing’ part… and its ‘sign’ part… (ibid. p.60). [The details are often lost, and what remains is the] horizon, the tendency. Reduction, compression, marking, continuity, reversibility, standardisation, compatibility with text and numbers – all these count infinitely more than adequatio [does this mean resemblance] alone. No step – except one – resembles the one that precedes it, yet in the end when I read the field report, I am indeed holding in my hands the forest of Boa Vista (ibid. p.61).

As our theoretical basis, we draw upon this Latourian perspective of representation, as it helps to emphasise the socio-political and cultural processes that go into the construction and use of representation. We draw upon this concept of circulating reference to try and address some of the questions around representation posed by Walsham. We apply this theoretical perspective to study the manner in which the phenomenon of HIV/AIDS is represented through the IS to the health authorities, how they circulate and get used in the management of the epidemic.
3. Research Methods

This paper is based on an interpretive study with data collected in selected districts from two of the three Mozambican southern provinces (Gaza and Inhambane) in addition to the extensive analysis of existing literature relevant to HIV management within the broader context of the health care sector in the country.

The research was performed in three different time periods: September 2002, March 2003, and August to September 2003. The empirical investigation was carried out in the health facilities, and district, provincial and national directorates of health. The facilities were selected in order to obtain a representative picture of the work practices surrounding HIV/AIDS in the testing facilities and infirmaries, with a particular focus on understanding the information flows, i.e. in each province how data were gathered first from selected health facilities (health centres and district hospitals) and its flow and quality from the district to the provincial and national levels. Another focus was to explore both rural (usually more distant to their district offices) and urban health facilities (usually more crowded) because of the varying demographics of people visiting the health facilities and the different levels of resources that existed there.

In order to analyse the multiple flows of information across different levels, data was gathered at the four organisational levels (facility, district, province and national), and in three different kinds of units (Ante Natal Clinics, Laboratories and Blood Banks and Voluntary Counselling and Testing Centres) where testing for HIV/AIDS was being performed. A summary of the break up of units by locations is provided in Table 1. At the National level, data was gathered in the HIV/AIDS Programme headquarters and in the Departments of Epidemiology and Endemics (National Health Directorate) and of Health Information (Planning and Cooperation Directorate).

<table>
<thead>
<tr>
<th>Testing facility</th>
<th>Health facility</th>
<th>District</th>
<th>Province</th>
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<tbody>
<tr>
<td><strong>Antenatal clinics regularly surveyed</strong></td>
<td>Chokwe Health Centre</td>
<td>Chokwe</td>
<td>Gaza</td>
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<td></td>
<td>Maxixe Health Centre</td>
<td>Maxixe</td>
<td>Inhambane</td>
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<tr>
<td></td>
<td>Zavala Health Centre</td>
<td>Zavala</td>
<td>Inhambane</td>
</tr>
<tr>
<td><strong>Laboratories and Blood banks</strong></td>
<td>Chicuque Rural Hospital</td>
<td>Chicuque</td>
<td>Gaza</td>
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<td></td>
<td>Maxixe Health Centre</td>
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<td>Inhambane</td>
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<td>Zavala Health Centre</td>
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<td>Urbano Health Centre</td>
<td>Urbano</td>
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<td>Chokwe Rural Hospital</td>
<td>Chokwe</td>
<td>Gaza</td>
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<tr>
<td></td>
<td>Carmelo Day Hospital</td>
<td>Carmelo</td>
<td>Gaza</td>
</tr>
<tr>
<td></td>
<td>Chicumbane Rural Hospital</td>
<td>Xai-Xai</td>
<td>Gaza</td>
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<tr>
<td><strong>Voluntary, Counselling and Testing (VCT) centres</strong></td>
<td>Chicuque Rural Hospital</td>
<td>Maxixe</td>
<td>Inhambane</td>
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<td></td>
<td>Urbano Health Centre</td>
<td>Urbano</td>
<td>Inhambane</td>
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<td></td>
<td>Chokwe VCT</td>
<td>Chokwe</td>
<td>Gaza</td>
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Note: In the rural hospitals generally seen as district hospitals, the infirmaries were also included in the study visits.

Data were gathered primarily through the conduct of 62 semi-structured interviews with staff performing different functions including doctors, laboratory workers, nurses, personnel dealing with statistics. The list of people interviewed is summarised in Table 2 below. Interviews were carried out in Portuguese primarily by the first author of the paper, a Mozambican and a medical doctor by profession. The summary of the interviews were later discussed by him in English with the second author, a non-Portuguese speaking person. Interviews typically took place in the work site of the respondent (for example the office of the doctor or the laboratory where the testing was being carried out), and varied from 15 minutes to an hour depending on how busy the staff were. Sometimes, interviews took place as people were working, for example breaks in between seeing patients or during the coffee breaks. Sometimes, with the consent of the respondents, the interviews were recorded, and other times when the person did not feel comfortable, hand written notes were taken. In the interviews, respondents were asked questions about their work loads, clinical
practices, counselling and testing procedures, AIDS patients’ management and treatment, the use of register books, the use of statistics, the usefulness of data reported, and the relationship between the people responsible for statistics and programme managers. Laboratory workers and blood bank workers, often located in the same building, were asked similar questions relating to the procedures followed in laboratory work, testing, quality control, and reporting. The persons working on statistics and the managers were asked questions pertaining to collation of data and forms, data usefulness, data quality control, use of software for statistical analysis, the use of reports and nature of managerial decisions. At the provincial and national levels, the focus of interviews was different from the lower levels with questions asked relating primarily to how the data was being used, the kind of statistical reports being generated and to whom they were being sent. A research diary was maintained to document relevant notes, and to record the interviewer’s own impressions of the interviews.

In addition to the interviews, primary data were also collected through participant observation, where various aspects of work were studied, for example how the testing was done, where the reagents were stored, the numbers of patients visiting the clinics, the various forms, registers and books that were used to enter the data etc. This observation helped to develop a richer understanding of the work practices and its context. For example, we could better understand how because of heavy patient-loads, the lab workers would sometimes not have the time to change their gloves before attending to the next patient. A significant amount of secondary data was also collected, for example formats of data registration forms and some monthly reports which was useful to get further insights into the practical details of the work that had to be done. Study of government reports and guidelines helped us to understand the significant gaps between the government statements and realities on the ground.

<table>
<thead>
<tr>
<th>Working level</th>
<th>Persons dealing with testing</th>
<th>Clinicians</th>
<th>Persons responsible for statistics</th>
<th>Managers</th>
<th>Total</th>
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<tbody>
<tr>
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<tr>
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<td>1</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>6</td>
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<tr>
<td>Zavala health centre</td>
<td>1</td>
<td>1</td>
<td>1</td>
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<tr>
<td>Inharrime health centre</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>4</td>
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<tr>
<td>Urbano health centre</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>4</td>
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<tr>
<td>Chicuque rural hospital</td>
<td>3</td>
<td>3</td>
<td>1</td>
<td>1</td>
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<td>Maxixe District Office</td>
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<td>Inhambane-City District Office</td>
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<td>1</td>
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<td>2</td>
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<td>2</td>
<td>2</td>
<td>4</td>
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<tr>
<td><strong>Gaza Province</strong></td>
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<tr>
<td>Chokwe-Sede health centre</td>
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<td>2</td>
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<tr>
<td>Chokwe rural hospital</td>
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<td>2</td>
<td>1</td>
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<td>5</td>
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<td>Chokwe VCT centre</td>
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<tr>
<td>Chicumbane rural hospital</td>
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<td>3</td>
<td>1</td>
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<td>8</td>
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<tr>
<td>Chokwe District Office</td>
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<tr>
<td>Xai-Xai District Office</td>
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<td>2</td>
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<td>Provincial Directorate of Health</td>
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<td>2</td>
<td>4</td>
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<tr>
<td><strong>National Level</strong></td>
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<td>1</td>
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</tr>
<tr>
<td><strong>Total</strong></td>
<td>12</td>
<td>15</td>
<td>19</td>
<td>16</td>
<td>62</td>
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</table>

The analysis of data gathered took place through an interpretive process [18] involving a continuous process of data collection in the field, its study to identify important themes, and relating these themes to theory. Typically, the first author who conducted the interviews created summary statements of a batch of interviews in English and sent it electronically to the second author who did not live in Mozambique. Then both authors would compare their notes and impressions and share with each other by email or face-to-face if the situation permitted. Initially,
the analysis was concerned with understanding and documenting the health information flows across the various levels and the challenges being experienced. The first author also discussed his impressions with some of the respondents to clarify the correctness of the interpretations. As time went on, we were struck by how the flows of information were being shaped by the different kinds of activities at the various levels, and how through this process the representations themselves were changing. To understand the “why” of this process, we started to read relevant literature, and slowly focused our attention to the writings around IS and representations which we felt helped to develop insights to the case. The socio-technical perspective adopted in this research made us understand the limitations of the technical perspectives on representations, and focus more strongly on the STS domain, more specifically the ideas expressed by Latour around circulating reference.

The description of the case study and its analysis now follows.

4. HIV/AIDS prevalence rate in Mozambique: Representation and use

In Mozambique, data on HIV/AIDS are collected from four key population segments. These are:

- Pregnant women
- Patients visiting health facilities and showing symptoms of AIDS
- Blood donors donating blood in blood banks
- Individuals voluntarily checking their HIV status in voluntary testing centres

We now discuss separately each of these population segments, focusing on the issue of representation of the disease prevalence. More specifically, we focus on three issues which relate to our research questions. The first relates to “how each of these population segments is being represented” which questions the adequacy of the sample being tested and reported. The second relates to “how does the context shape the process of representation”. This emphasises how the context and work practices, including the use of IS, shapes the representation. The third concerns “how are the representations being used”. This question brings to light the adequacy and legitimacy of what is represented in relation to the requirements for managing the disease.

4.1. Pregnant women

How is the disease amongst pregnant women being represented?

In largely heterosexually driven epidemics where there is evidence that men and women in the general population have become infected with HIV in significant numbers, as is the case of Mozambique, HIV surveillance is based on testing pregnant women (15 to 49 years old) attending antenatal care facilities in sentinel surveillance sites [19]. The HIV status of those tested is then used to extrapolate the disease incidence and to develop estimates for the provincial, regional and national prevalence of HIV.

Antenatal clinic attendees provide a good sample of the disease incidence because they are sexually active and adult. The baseline assumption is that pregnancy is the result of unprotected sexual intercourse, which is the dominant mode of HIV transmission in many parts of Africa.

These surveys of pregnant women have been motivated by the UNAIDS engagement with national health authorities in many countries in the developing world to make more reliable estimates of national HIV prevalence using standardised methodologies. Similar guidelines have also been made available to other countries so as to enable UNAIDS to be able to develop global estimates of the prevalence of the disease.

In Mozambique (a country consisting of 144 rural and urban districts), surveys of HIV testing of pregnant women are carried out in selected district sites by the Multi-Sectoral Technical Group consisting of several experts, especially epidemiologists from the Department of Epidemiology and Endemics in the Ministry of Health, and statisticians from the National Institute of Statistics.
During the survey period, data are collected between the months of September and November. Each sentinel site, corresponding to one antenatal care facility that was assigned to one of the few selected districts, gets blood samples from 300 pregnant women who are seen in their first antenatal consultation.

Four surveys have been successively implemented in the years 1998, 2000, 2001 and 2002. The first survey (1998) was based on data collected in only five antenatal care facilities (one in the northern region, three in the central region and one in the southern region). Given the limited availability of data at the time, the Multi-Sectoral Technical Group has considered this survey non-representative, and stipulated that the resulting estimations should only be used only as indicative to guide the process of improving the national response [20].

To try to correct some of the problems of non-representatives of the sample in the first survey, the sentinel sites were expanded from five to twenty in the second survey (2000), (one each in the eleven urban and nine rural districts). Thus the coverage was around 14% of the districts (20/144) in the country. In addition to the increased sample, processes to improve the quality control of the testing methods were also introduced. For example, on a daily basis all positive and two negative samples were sent to the reference laboratory for retesting, and regular supervision was done to observe the testing and ethical procedures being followed.

The third and fourth surveys performed successively in 2001 and 2002 further expanded the number of sentinel sites sampled from twenty to thirty-six, aiming to improve the sample covered (25% district coverage). The spread of these sites were ten in the southern region, sixteen in the centre and ten in the north. Through the 2002 survey, a total of 10,788 pregnant women were sampled, 2,990 in the south, 4,799 in the centre and 2,999 in the north [5]. According to the projections of the last census (1997) in 2002 there were 904,126 pregnant women, meaning that the 2002 survey covered only 1.2% of the target group (with variations around 1.3% in the south, 2.1% in the centre and 1.0% in the northern region).

How does the context influence the process of representation?

In the antenatal clinic where the survey is carried out, the HIV status of an individual (input) moves through a series of sequential translations, from an individual with a name and demographic details to an anonymous statistic of HIV positive or negative, which then contributes to the sample base that is used to make statistical generalisations of HIV prevalence in the entire Mozambique population. Shaping and constituting this process of translation is a complex and heterogeneous network comprised of various groups of people including health managers, epidemiologists, statisticians, nurses and laboratory technicians, and the use of artefacts such as data forms, test tubes, and reagents.

On a routine basis, various pregnant women approach the antenatal care facility to determine their pregnancy status and its follow up. Follow up includes periodic antenatal check-ups, receiving individualised health promotional messages, and managing pregnancy risks. A major advantage in performing the survey in these antenatal facilities is that blood is routinely taken from women attending these clinics for a number of standard tests, which makes it relatively easy to also use these blood samples for repeated testing. This means that blood specimens are collected originally for purposes other than HIV testing, e.g. screening for syphilis disease and determination of the haemoglobin level (checking for eventual anaemia), but then are also used for conducting HIV tests. The strategy adopted for HIV testing is based on anonymity, and informed consent is not taken from the clients (pregnant women).

The *determine HIV test*, that is a rapid or simple immunoassay, is performed after all the identification information of the client is removed and replaced by a code such that the HIV test result cannot be traced back to the client. To ensure patient anonymity, one nurse collects the specimen, and the laboratory worker performs the test. During the specimen collection, the nurse places an aliquot of blood into a new tube, and labels the tube with a new code not linked to any personal identifying information. At the time of specimen collection, the nurse also separately
collects demographic information (e.g. age, marital status, residence), which is registered in another HIV surveillance form using another coding scheme which again cannot be traced back to an individual (see Figure 1).

As schematically illustrated in Figure 1, *Ana Zimo* (a hypothetical name of a pregnant woman) is an expectant mother, 18 years old, living in Maxixe district. She approached the antenatal clinic only to check her pregnancy status. Because it was her first antenatal consultation, she was unknowingly included in the HIV study, and she was not informed that her blood sample would also be used for conducting the HIV test. Through a series of steps, the name *Ana Zimo* disappeared, was replaced by a code, and later became a single HIV positive case. The unlinked anonymous HIV test result was then matched using new code with her demographic information for analysis. In Figure 1, we give a schematic depiction of the translations involved in the process of testing an individual client.

![Figure 1: Capturing HIV cases, pregnant woman being turned into HIV case through a series of translations](image)

**How are the representations used?**

The HIV test results, which can be seen as the output of the system of individual case testing from individual sites in each of the thirty-six districts' sentinel antenatal care facilities, are aggregated and then transmitted to the national level for processing by an HIV manager, who by training is an epidemiologist or statistician.

The 10,788 sampled cases (both HIV negative and positive), coming from the 36 districts surveillance sites were first used to estimate the number of HIV cases from the remaining 108 districts which had no sentinel sites. This extrapolation was done by the Multi-Sectoral Technical Group, who identified common characteristics that could allow comparisons across districts. These included factors like population mobility, road access, health services, presence of population groups with high risk for HIV infection, culture and tradition, economic situation and education level [5, 20]. Based on these assumptions, districts with similar characteristics were assigned to districts with sentinel posts and given the same HIV prevalence rates. For example, the districts of Chibuto and Manjacaze from Gaza province were assigned to the sentinel post of Zavala district from Inhambane province, because of similarities in cultural traditions related to gender, social taboo, and socio-economic dynamics [5].

Having obtained the surveillance data by districts, two computer programmes distributed by UNAIDS/WHO specifically designed to prepare national HIV/AIDS estimates, were used by the authorities. These two computer programmes or models are referred as EPP (Estimation and Projection Package) and SPECTRUM. In Figure 2, a schematic is presented which depicts how the two programmes are used. The EPP is used to estimate and project adult HIV prevalence rates using surveillance data in countries with generalised epidemics (e.g. Mozambique). The input to EPP is surveillance data from various sites and years showing HIV prevalence among pregnant
women. The EPP programme is used to fit a simple epidemic model from data from urban and rural sites. The national prevalence projections produced by EPP can subsequently be imported into the *SPECTRUM* programme to calculate the number of people infected, AIDS cases, and AIDS deaths [21]. The calculations in the *SPECTRUM* programme are based on population estimates provided by the United Nations Population Division and model patterns prepared by the UNAIDS Reference Group that describes the progression from infection to death, the distribution of infections by age and sex, transmission from mother-to-child and the effect of HIV infection on fertility [21]. The *SPECTRUM* programme is thus described as a policy modelling system. It contains modules for a number of reproductive health areas and for the purposes of making a national HIV estimate. Two *SPECTRUM* models are used: *DemProj* (for making demographic projections) and the *AIDS IMPACT MODEL* (AIM, for making epidemiological projections) [21]. These computer calculations are based on the ‘well-known’ natural course of HIV infection which determines the relationship between HIV incidence, prevalence and mortality. Estimates for mother-to-child transmission and HIV mortality in children are calculated from countries’ age-specific fertility rates and documented region-specific rates of mother-to-child transmission [19].

![Flowchart](image.png)

*Figure 2 - Estimation and Projection of National HIV Prevalence Models*

*Source: UNAIDS [20]*

The resulting projections from the 2002 survey data have provided an estimate of the national prevalence rate in adults (15 to 49 years old) at 13.6%, with variations across the provinces as summarised in Table 2 below.

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<tbody>
<tr>
<td>Niassa</td>
<td>916,672</td>
<td>5.9%</td>
<td>25,419</td>
<td>3,813</td>
<td>29,232</td>
<td>2.3%</td>
<td>1,900</td>
<td>1,754</td>
</tr>
<tr>
<td>C Delgado</td>
<td>1,525,634</td>
<td>5.0%</td>
<td>35,852</td>
<td>5,378</td>
<td>41,230</td>
<td>3.3%</td>
<td>2,680</td>
<td>2,474</td>
</tr>
<tr>
<td>Nampula</td>
<td>3,410,141</td>
<td>7.9%</td>
<td>126,619</td>
<td>18,993</td>
<td>145,611</td>
<td>11.5%</td>
<td>9,465</td>
<td>8,737</td>
</tr>
<tr>
<td>Zambézia</td>
<td>3,476,484</td>
<td>15.4%</td>
<td>251,628</td>
<td>37,744</td>
<td>289,372</td>
<td>22.9%</td>
<td>18,809</td>
<td>17,362</td>
</tr>
<tr>
<td>Tete</td>
<td>1,388,200</td>
<td>16.7%</td>
<td>108,960</td>
<td>16,344</td>
<td>125,304</td>
<td>9.9%</td>
<td>8,145</td>
<td>7,518</td>
</tr>
<tr>
<td>Manica</td>
<td>1,207,332</td>
<td>18.8%</td>
<td>106,680</td>
<td>16,002</td>
<td>122,682</td>
<td>9.7%</td>
<td>7,974</td>
<td>7,361</td>
</tr>
<tr>
<td>Sofala</td>
<td>1,516,166</td>
<td>18.7%</td>
<td>133,256</td>
<td>19,988</td>
<td>153,244</td>
<td>12.1%</td>
<td>9,961</td>
<td>9,195</td>
</tr>
<tr>
<td>Inhambane</td>
<td>1,326,848</td>
<td>7.9%</td>
<td>49,266</td>
<td>7,390</td>
<td>56,656</td>
<td>4.5%</td>
<td>3,683</td>
<td>3,399</td>
</tr>
<tr>
<td>Gaza</td>
<td>1,266,431</td>
<td>19.4%</td>
<td>115,473</td>
<td>17,321</td>
<td>132,794</td>
<td>10.5%</td>
<td>8,632</td>
<td>7,968</td>
</tr>
<tr>
<td>Maputo P</td>
<td>1,003,992</td>
<td>14.9%</td>
<td>70,310</td>
<td>10,546</td>
<td>80,856</td>
<td>6.4%</td>
<td>5,256</td>
<td>4,851</td>
</tr>
<tr>
<td>Maputo C</td>
<td>1,044,618</td>
<td>15.5%</td>
<td>76,100</td>
<td>11,415</td>
<td>87,515</td>
<td>6.9%</td>
<td>5,899</td>
<td>5,251</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>18,082,518</strong></td>
<td><strong>13.0%</strong></td>
<td><strong>1,099,563</strong></td>
<td><strong>164,934</strong></td>
<td><strong>1,264,497</strong></td>
<td><strong>100.0%</strong></td>
<td><strong>82,192</strong></td>
<td><strong>75,870</strong></td>
</tr>
</tbody>
</table>

*Source: INE et al. cited in MISAU DPC [22]*
As stated earlier, the core assumption of the UNAIDS model in Sub Saharan Africa is that the primary mode of transmission for HIV/AIDS is through sexual intercourse within the heterosexual population. This assumption is implemented in the model by using statistics on pregnant women tested for HIV, as the key independent variable to statistically extrapolate to computing HIV Prevalence rate for the population of Mozambique. The following practical biases arise from these modelling assumptions which bring to question the adequacy of the current estimates:

♦ Overrepresentation of younger women as they are more sexually active and thus likely to become pregnant;

♦ Exclusion of other forms of HIV transmission which may also be important, such as: unsafe blood transfusion (a phenomenon common in deprived settings, especially where malaria is endemic with complications related to anaemia mainly among children); injecting drug use; and, homosexual male population.

Moreover, the efficacy of these models is often undermined by the quality and the amount of the data collected on the ground. An example of data related manipulation comes from Zimbabwe. At the end of 2001, this country had released HIV prevalence estimates of 34%, however, figures released in 2003 placed these estimates at 25% (a decline of 9%). In 2004, the UNAIDS report commented on this manipulation as follows:

“Unfortunately, this did not correspond to a real decline of 9% in prevalence. The new figure represented a statistical correction of the 2001 estimate, which had relied on antenatal data that included a significant proportion of testing irregularities...The corrected estimates, although lower, therefore show no actual decline in HIV prevalence in the country”[1, p.12].

Based on similar modelling exercises, the Mozambican HIV prevalence rate is computed and compared globally. UNAIDS publishes reports in which these national estimates are compared with those of other countries (see Table 3). Although Mozambique is still below the average Southern African HIV prevalence, this region is the world’s most severely affected by HIV/AIDS. In at least seven countries - Botswana, Lesotho, Namibia, South Africa, Swaziland, Zambia, and Zimbabwe - more than one-fifth of the adult population is infected with HIV. In four of these countries, HIV/AIDS prevalence exceeds 30 percent; and Botswana’s rate is nearly 40 percent [23]. Modelling assumptions which lead to the systematic exclusion of certain groups of population thus leads to inaccurate estimates of HIV prevalence. These inaccuracies then “circulate” from the local level of the community where the phenomenon is prevalent through the various levels of the national health administration hierarchy to the global level where cross-country comparative reports are published by agencies like the UNAIDS.

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<thead>
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<tbody>
<tr>
<td>Angola</td>
<td>13,527,000</td>
<td>350,000</td>
<td>5.5%</td>
</tr>
<tr>
<td>Botswana</td>
<td>1,554,000</td>
<td>330,000</td>
<td>38.8%</td>
</tr>
<tr>
<td>Lesotho</td>
<td>2,057,000</td>
<td>360,000</td>
<td>31.0%</td>
</tr>
<tr>
<td>Malawi</td>
<td>11,572,000</td>
<td>850,000</td>
<td>15.0%</td>
</tr>
<tr>
<td>Mozambique</td>
<td>18,644,000</td>
<td>1,100,000</td>
<td>13.0%</td>
</tr>
<tr>
<td>Namibia</td>
<td>1,788,000</td>
<td>230,000</td>
<td>22.5%</td>
</tr>
<tr>
<td>South Africa</td>
<td>43,792,000</td>
<td>5,000,000</td>
<td>20.1%</td>
</tr>
<tr>
<td>Swaziland</td>
<td>938,000</td>
<td>170,000</td>
<td>33.4%</td>
</tr>
<tr>
<td>Zambia</td>
<td>10,649,000</td>
<td>1,200,000</td>
<td>21.5%</td>
</tr>
<tr>
<td>Zimbabwe</td>
<td>12,852,000</td>
<td>2,300,000</td>
<td>33.7%</td>
</tr>
</tbody>
</table>

Source: USAID [23]

Table 3
HIV prevalence in Southern Africa by country (end 2001)

Southern Africa Over 30% of worldwide HIV/AIDS cases
Sub Saharan Africa Over 70% of worldwide HIV/AIDS cases (about 26.6 million people)
4.2. Patients visiting health facilities and showing symptoms of AIDS

How are AIDS patients being represented?

Patients hospitalised due to AIDS related diseases are routinely reported on a monthly basis through two parallel ‘standardised’ reporting systems from the district hospitals. These are AIDS inpatients reporting system and the monthly summary for inpatients from district hospitals. These parallel channels contribute to duplication of effort, consume large amounts of time and contribute to low validity, incorrectness and incompleteness of data. The more advanced hospitals (central and provincial) report the data in a largely ad hoc manner because no formal system has been set up to report AIDS cases. These are therefore not part of the officially reported data [22] and are thus not explicitly addressed in this paper.

The AIDS inpatients reporting system, includes both the confirmed cases from the laboratories and the clinically suspected AIDS patients admitted in the medicine, paediatrics or surgery wards. Clinical AIDS is defined according to the Bangui criterion, that is a set of standardised clinical signs and symptoms proposed by the WHO in 1986 for the establishment of AIDS diagnosis in Africa without the use of laboratory tests [24]. The report is sent on a monthly basis in a paper format from the infirmary and successively goes to the District, Provincial and National levels respectively (National Department of Epidemiology and Endemics). In the national level at Maputo, the paper reports are entered in the computer (Epi Info system) before they are sent to the National HIV/AIDS Control Programme.

The monthly summary for inpatients is an integral part of the main health information system within the National Directorate of Planning and Cooperation. The form was created in order to provide data from inpatient wards in categories such as surgery, maternity, paediatric and medicine including the important causes of admitting patients e.g. malaria, diarrhoeas, AIDS, tuberculosis, anaemia, etc. These data are first aggregated in a paper format in the district and are computerised at the province level to be sent electronically to the National Department of Information for processing and analyses.

How does the context influence the process of representation?

Similar to the picture in other developing countries, the representation of AIDS patients is shaped by a range of factors. Here we discuss some of them.

Most of the Mozambican people do not seek the public healthcare services; but instead prefer to visit traditional healers or even perform self treatment by buying medicines on the black market. Health care is available to only around 50% of the Mozambique population, partly due to the destruction of physical and communication infrastructure during the civil war (1976 – 1992), physical distances, and high costs of medicine [25].

The few AIDS patients visiting the district hospitals may not be recognised or misdiagnosed as the disease is often conflated with the associated opportunistic disease (e.g. chronic diarrhoea). This misdiagnosis arises from the fact that many of the clinicians are not adequately skilled and extremely overworked with a district hospital possibly serving an average population of about 40,000 in a district. Currently there are only 17,000 health workers in Mozambique, of which 11,000 are trained. Only 6 percent are doctors, consequently less than 50 percent of the districts are served by a doctor [25].

When an AIDS condition is suspected, the admission of a patient is dependent on the severity criteria. This means that the non-severe patients usually are treated as outpatients and typically referred to the Voluntary, Counselling and Testing services or to the day clinics that provide specific follow up services to the HIV/AIDS patients. So, these patients are excluded from the registration system for the purposes of reporting. The ones admitted to the hospitals are guided to the infirmaries. In the infirmaries, the majority of “AIDS patients” are not objectively confirmed in the laboratories due to resource constraints on testing facilities, and the clinical Bangui criterion to
set up AIDS diagnosis is the most used. The small group being tested is usually those that do not clearly fulfil the AIDS clinical diagnosis and therefore the clinician is uncertain about the cause of the clinical pattern. The majority of health centres and district hospitals frequently lack adequate HIV test kits, so in general, the assays available are primarily for screening blood donors and clients tested in Voluntary Counselling and Testing services.

In the cases where the clinician requests the laboratory test, he/she fills in a paper form request identifying the patient’s name, age and the clinical diagnosis. A nurse collects the blood specimen and both the request form and the specimen are sent to the laboratory. In the laboratory, the blood specimen is tested, using the determine method, and the result is translated into the same paper form request that then becomes the laboratory report. The report is then sent back to the infirmary where the patient’s HIV result is registered in the individual’s clinical records and later on it becomes a part of the monthly statistics.

Additionally, AIDS cases are not being adequately reported. For example, in 2001 the total number of AIDS cases reported was by far less than the projections made from the survey data where there were an expected 82,192 new AIDS cases. The AIDS patients system had reported 10,772 cases which represented only 13% and the monthly summary for inpatients had only reported about 2,600 cases (3%) [26]. More than 50% of the cases reported were from one province (Maputo-city) and the percentage rose to above 75% if the Gaza province was included in the sample. This implies that the remaining nine provinces in the country were reporting nearly no AIDS cases.

We studied in more detail the specific AIDS reporting system and found that it exhibited a range of inconsistencies and incompleteness, including problems that many data items were not being filled in, and very often AIDS confirmed cases were reported falsely, higher than the suspected cases (Chilundo, Sahay and, Sundby in review). As a result many AIDS cases got lost or the reports were not forwarded.

**How are the representations used?**

The few AIDS patients’ data being sent from the district hospitals and health centres are further aggregated at the provincial level in one form by the person responsible for HIV/AIDS data, and then sent to the Department of Epidemiology and Endemics to be entered into the EPI Info application for analysis. However, the use of these data is primarily limited to reporting purposes. Some of the managers we interviewed confirmed that these reports were of limited value as they were obviously under reporting the disease. These reports were contrary to the reality observed of a progressive increase in AIDS inpatients which were increasing the bed occupation and reducing the possibility to admit new patients with ailments other than AIDS to the facility wards.

4.3. **Blood donors donating blood in blood banks**

**How is the disease prevalence amongst blood donors being represented?**

The aim of donating blood is to save the life of someone who is lacking it (e.g. patients under surgery, children with anaemia due to malaria, etc.). Blood donors are thus categorised as benevolent (voluntary charity, usually attracted by campaigns) and also restorers (replacing the blood used to treat some relatives). The former tend to be the group with low risk to have HIV (e.g. youth in the schools) because organisations collecting blood try to exclude HIV positive people. The later group, usually representing the family members of someone in need of a blood transfusion, come from different settings and cannot be easily related to risk behaviour. Regardless of its origin, all blood collected in blood banks needs to be routinely screened prior to blood transfusion. So, in general blood donors constitute a particular low risk HIV sample group. Their HIV status is reported by the blood banks on a quarterly basis in summary reports without individual names. The reports include details about blood bank activities’ such as number of blood donations, blood derivates, blood requests, screening tests performed for infectious diseases like
syphilis and HIV and the amount of discarded unsafe blood. The report is sent from the district level blood banks that are physically located within health centres or district hospitals to the next level of hierarchy of blood bank management which is the provincial hospital. The provincial blood bank manager is the person responsible for data aggregation per health facility into one form to send to the National Programme of Blood Transfusion where the data are computerised.

**How does the context influence the process of representation?**

The blood bank facility is where blood is collected from donors (both benevolent and restorers) for the purposes of transfusion. By the time he/she donates blood, there is prior explanation regarding the internal procedures that are followed in relation to the blood collected. These include information about the tests performed to screen for infectious diseases (HIV and syphilis) before proceeding to further processing steps towards transfusion. The blood donor is advised that if his/her blood is considered inappropriate (unsafe) for transfusion it will be discarded without informing him. If he/she intends to know the HIV result, then is referred to the Voluntary, Counselling and Testing service for adequate counselling. All samples collected are identified by names and registered in specific register books. In many of the health facilities visited, the register books being used were seen to be improvised from ordinary exercise books, with no clearly defined report formats. As a result, there were many mistakes in the report books caused by illegible handwriting, the spread of ink blots, and incomplete entries. The absence of standardised reporting formats led to a number of problems such as blood donation data being reported without HIV screening data, and discrepancies between the totals of HIV and syphilis positive cases and that of discarded blood. These totals should theoretically be equal.

Furthermore, the reports were observed to not be sent on a timely basis to the national level, especially from the district blood banks. In contrast, the province and central level blood banks were seen to be sending more reliable and timely data.

**How are the representations used?**

Again, the national blood bank managers are concerned with the negative influence regarding the manner in which data are captured and reported. So, for instance, in order to compensate for the estimated errors in the figures sent from the district blood banks, the national managers applied a correction factor of 40% to the reported data to add to the province and central blood bank data at the time of compiling the annual report. This ad hoc correction distorts the representational picture of the HIV prevalence rates from blood donors.

**4.4. Individuals voluntarily checking their HIV status in Voluntary Counselling and Testing Services (VCT)**

**How are the volunteers being represented?**

The last sample group is represented by individuals who voluntarily seek Voluntary, Counselling and Testing (VCT) services to check their HIV status. The VCT services are provided as a result of a collaborative strategy between government, bilateral agencies and NGOs, launched in 2001. People, from both the rural and urban areas, have been strongly advised by health authorities to seek VCT services. This advice has been conveyed through the media (mainly local radio stations), campaigns in schools, churches and other popular institutions. However, although there are advantages to know the HIV status (e.g. avoid transmission to others, chance to earlier combat opportunistic diseases, chance to receive anti-retroviral therapy specially for pregnant women, etc), people have been resistant in complying to the advise. Except during campaigns, e.g. organised by churches, the average work load is low, with a number of 4-6 suspected cases a day. This is because it is generally known that there has not been any treatment possibility for HIV and the social stigma associated with the disease is significant.
In 2003 there were 40 VCT centres unevenly spread out in both rural and urban areas countrywide. For example, while there were 11 VCT centres only in the capital, Maputo City, there were none in Cabo Delgado. The regional distribution of VCTs (60% in the south, about 30% in the centre and the remaining in the north) is an issue of representational concern since it makes it likely that the disease prevalence gets reported more from certain regions than others because of the sampling techniques employed. During the year 2003, 104,392 people were reported to have sought VCT centres.

**How does the context influence the process of representation?**

When a volunteer comes to a VCT, he/she is first given information about the aims and advantages of taking the test. The counsellor has a register book (daily register for counselling activities), which identifies the client using a numerical code instead of the name. In this book, the gender, age group, test result, education level and the status of pregnancy is also registered. These data items are aggregated on a monthly basis in another form (monthly summary for counselling activities) and the total for each variable is written at the bottom of the form. On the fifth day of each month, the monthly form is sent to the province, where the HIV manager aggregates and sends a copy of the report to the national level. We were not given any indication that there were regular systems in place for data validation or analysis.

The VCT services appear to be well resourced, e.g. equipped with new computers, but they are not necessarily well run. In many of the facilities we visited, we found many VCT workers experiencing several constraints in entering data into the existing database (based on Epi Info 6) called “Data System for VCT in Mozambique – A Local System for Collection, Analysis and Data Processing”. Moreover, the use of the Epi Info application for routine data management has been strongly criticised and it is seen as inappropriate by some health information systems specialists [27].

**How are the representations used?**

In 2003, the prevalence rate from VCT units was 25.4% (26,135/102,896). Nevertheless, this number will have to be interpreted with caution, because quite a significant number of the “volunteers” seeking the VCT is mainly represented by highly selected groups such as patients already manifesting AIDS symptoms (14.7%), people considered of risk behaviour (23.7%) and that related to prevention of mother-to-child transmission (20.9%), who were advised or sent by the health authorities or doctors to perform the test.

Moreover, opposing the prevalence estimates arising from pregnant women and projected through the computer models (referred to in subsection 4.1), the VCT units have registered quite a significant number of cases (18.3% = 372/2026) of HIV amongst children aged 5 to 14 years. For heterosexually pattern like that of Mozambique, the models predict almost no cases on this age group (also called “a window of hope”). This fact suggests the existence of different ways of HIV transmission other than sexual which may also be important.

Current policies are considering providing for Highly Active Antiretroviral Therapy (HAART) to the infected people, especially the pregnant women in order to prevent the mother-to-child transmission. These may change the currently negative incentive to voluntarily test one’s HIV status. Based on the current strategic framework (2004-2008), the expected coverage to provide HAART treatment will be cumulatively as follows: 7,924 (in the year 2004); 20,805 (in the year 2005); 57,954 (in the year 2006); 96,418 (in the year 2007) and 132,280 (in the year 2008). Considering that 25.4% representing the volunteers as the potential targets to benefit HAART, the estimated coverage for the period 2004 will only be around 8%. 
**Summing up**

We have described how HIV/AIDS prevalence data are collected, analysed and transmitted across four population segments (pregnant women, patients visiting district hospitals and showing AIDS symptoms, blood donors donating blood in blood banks and individuals voluntarily checking their HIV status in VCT services).

Data on pregnant women (aged between 15 to 49 years) is captured through regular antenatal surveys. Typically, a small sample of 1.2% of the pregnant women is used to determine the HIV prevalence of the entire population (including children and men). This is done through the use of several assumptions of commonality of socio-cultural-economic features and mathematical calculations inscribed in the UNAIDS computer models (EPP and ESPECTRUM). This representation is then used by national authorities for planning, advocacy and prevention campaigns, and at the global level by UNAIDS to make worldwide country reports.

The AIDS patients admitted in hospitals constitute another significant population, but a range of social, ethical and economical constraints significantly influence the representation of the disease for this segment. This influence is especially pertinent because most of the diagnosis is based on clinical suspicions and not on “objective” laboratory tests leading to frequent misdiagnosis. Also, a majority of the AIDS patients admitted in the central or provincial hospitals are not included in the two parallel reporting systems leading to a distortion of the representation of the disease to the national authorities.

The blood donors’ segment should largely be considered as the representation of a segment with low risk group, especially in the benevolent category. The poorly designed reporting system and the absence of standard procedures contributes to distorting the quality of the representation.

The volunteers seen in VCT services are the third population segment. This system seems to provide a better representation of the disease because it is based on men, women, and children voluntarily showing up to check their individual status. However, the representation of the disease is to some extent masked by social stigma which serves as a strong deterrent for people to opt for testing. This reluctance to volunteer is also amplified by the fact that people largely feel that there is limited benefit to obtain their HIV status because they cannot be treated due to the lack of anti-retroviral drugs. Evidence from these services suggests the existence of different ways of HIV transmission other than sexual which may also be important, thus questioning to some extent the adequacy of the UNAIDS models used in Mozambique.

In Table 4, we provide a summary of the issues related to representation across the four population segments.

Also, we found no evidence of the national authorities trying to take the representations of the disease as emerging from the four distinct segments, and aggregating or reconciling them in order to compute a consolidated total of the disease prevalence in the country.

From the picture presented we have revealed that all kinds of prevalence representation have their own weaknesses. The political, social, ethical and economical aspects are heavily shaping the representation of HIV/AIDS in Mozambique.
<table>
<thead>
<tr>
<th>Questions</th>
<th>How this population segment is being represented?</th>
<th>What is the influence of the context?</th>
<th>How are the representations being used?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Surveys (pregnant women)</strong></td>
<td>Pregnant women are periodically surveyed in selected antenatal clinics.</td>
<td>There are series of translations using several artefacts (e.g. testing tubes and pads, paper forms), actors (e.g. nurses, lab workers, managers) and codes to meet unlinked, anonymous HIV testing which is matched with personal demographic data</td>
<td>The HIV status coming from pregnant women provide the baseline to generalise to the entire population through a series of assumptions of commonalities to allow comparisons across districts; Mathematical projections inscribed in UNAIDS computer models are used to estimate people HIV infected, AIDS cases by sex, age, etc.</td>
</tr>
<tr>
<td><strong>AIDS Inpatients</strong></td>
<td>Two parallel reporting systems contribute to duplication of efforts, underreporting, and poor data quality.</td>
<td>Few AIDS patients are captured due to: low health care coverage; Lack of skills to perform clinical AIDS diagnosis; Lack of test kits; Unwillingness to report AIDS cases associated with stigmatisation; Data reported with inconsistencies and incompleteness</td>
<td>AIDS data are processed in Epi Info application, but their use is only limited for reporting;</td>
</tr>
<tr>
<td><strong>Blood donors</strong></td>
<td>All blood collected is supposed to be screened for HIV prior to transfusion processing. A quarterly reporting system for blood bank activities include HIV status data of the donors</td>
<td>The lack of clear design and standards contribute to shape the representation of the HIV from blood donors: Register books and forms used are often improvised and not uniform across different blood banks; Errors in reporting forms with blood donations reported without HIV screening data; Discrepancies between the totals of HIV and syphilis positive cases with the amount of discarded blood.</td>
<td>HIV data from blood donors is used: To get an idea of the people with low HIV risk captured to donate blood; To plan for reagents and spares necessary for the blood banks daily activities. However, data from district hospitals have been of poor quality and delayed. National managers had to use correction factors shaping the representation of the HIV phenomena.</td>
</tr>
<tr>
<td><strong>Volunteers (VCTs)</strong></td>
<td>This seems to be an effective medium for reporting HIV data as it captures data from men, women and children from varying social segments. The VCT services are unevenly distributed (60% in the southern region) and mostly in urban areas; This is the only computer and paper reporting system based at the facility level</td>
<td>The stigma is minimised by the use of codes to the voluntary people; however, even so, few people have sought the services except during campaigns; Services well resourced with standardised collection systems; Most counsellors lack skills to adequately explore the existing software for local collection, analysis and data processing</td>
<td>HIV prevalence from these settings (25.4%) get masked by the AIDS patients referred by clinicians to perform the test; Evidence (HIV amongst children 5 to 14 years of age) suggests the existence of different ways of HIV transmission other than sexual which may also be important, thus questioning to some extent the adequacy of the UNAIDS models used in Mozambique</td>
</tr>
</tbody>
</table>
5. Discussion

In this section, we draw upon some of the key ideas from Latour presented in section 2, to provide a deeper analysis to the case. Two key issues are analysed: the nature of translations; and, what is gained and lost in the process of translation.

5.1. Nature of translations

In the Actor Network terminology translations refer to the processes by which attempts are made to build and stabilise a heterogeneous system of allies composed of both humans and non-humans [28]. Translation thus refers to the process by which “technology changes hands” and new actor networks are created in this process of reconfiguration. In Pandora’s Hope [9], Latour cautions about looking at translations as not one big leap, but a series of small and incremental steps, involving different kinds of translations, and in each step, there are aspects being simultaneously gained and lost in the process.

The processes through which the HIV/AIDS representations are created, transmitted and used can be seen to involve a number of small translations, which then together contribute to create the “national HIV/AIDS prevalence rate” for Mozambique. Latour’s argument here would be that this prevalence rate calculation has not come up suddenly involving one big leap, but in fact has been constructed and transmitted through various, inter-connected and incremental steps.

In our analysis, the process starts at the health unit or the laboratory or blood bank service where the patient is clinically diagnosed or the first blood sample is tested. Various translations are then set into motion such as the human being is first translated into a record, mostly paper based, sometimes formal but often informal and locally improvised. This record should contain demographic and clinical data of the patient. Another example of a translation concerns the taking of the blood specimen taken, often without informed consent, marking it by a code, and separating it from the demographic details to maintain anonymity. The blood test, leading to a positive or negative HIV status serves as a point of reference, which allows comparison with other people in the population “with” or “without” HIV, both in the local region where the person is based or in some global context through for example inter-country report comparisons.

In addition to the translations within a facility, there are translations across levels. At least four levels exist in the case of the health sector of Mozambique: district, provincial, and national, and international. The representation of the HIV phenomenon, so constructed, then circulates both within and across these levels and both loses and gains certain of its properties in the process. We discuss this using the notions of reduction and amplification presented by Latour.

5.2. What is gained and lost in the process of translation?

In this process of circulation, representations loses certain of its properties in some cases (for example assigning a code to make the person anonymous), and in other cases gets amplified (for example, through the statistical generalisations to the population). It is these simultaneous processes of reduction and amplification that lead to the question of what is left behind in a translation. For example, the HIV immunoassay test is used to identify the presence or not of the virus in the blood sample by the detection of antibodies to HIV in serum, plasma or the whole blood from infected individuals. This test is governed by global standards, but local translations are shaped by contingencies such as availability of reagents and workloads. The test results are made universal by making it compatible with other tests being performed in other places. This potential for comparison creates amplification by making the local result part of a sample that is used for statistical generalisations to the population, and secondly, the result helps to make comparisons, at the local, provincial, national and also global levels. What remains constant in the simultaneous processes of reduction and amplification described, is the UNAIDS and WHO guidelines on which these tests are based and supposed to be carried out.
As the test result is translated across different levels (say district to province) there are again both amplification and reduction ongoing. For example, the HIV positive cases detected in each facility are aggregated to provide province wide figures. In this process of aggregation, the details of the particular facility where the results come from are lost. There is thus reduction. Also, as we described, in some cases, the Manager at the National level, who believes that the number of HIV cases is grossly under represented, adds a correction factor of 40%, leading to an amplification of the representation. Various other local issues also contribute to the reduction and amplification such as forms being lost and data being wrongly recorded. At each level, through aggregation, the locality and particularity is lost, and simultaneously through comparison and statistical generalisation, universality, comparability and standardisation is gained. The UNAIDS statistical package, built as per global requirements, enables the construction of inter-country comparison estimates, presented in global reports, and further circulated for readership.

We conceptualise this simultaneous process of amplification and reduction through the schematic in Figure 3, which is adapted from Latour (1999). From individuals to HIV prevalence, are represented using two isosceles triangles, implying reduction and amplification respectively. As the representation “changes hands” both within and between facilities, the details of the individual’s (drawn from different population segments) interests and particularities are lost, and to it is added details of a particular facility, and the doctor or nurse who performed the diagnosis or laboratory test. Simultaneously, with the reduction there is amplification.

![Figure 3 - The transformation at each step of the reference may be pictured as a trade-off between what is gained (amplification) and what is lost (reduction) as each information-producing step. Adapted from Latour [9], p.71.](image)

In summary, Latour’s ideas provide at least two deep analytical insights. Firstly, it helps to look at HIV prevalence rate figures not as taken for granted “facts” but as representations that are constructed and shaped by socio-technical aspects including various local contingencies such as availability of reagents for testing. A practical implication of this insight is the need for managers to not take these figures for granted, and to ask searching questions about its adequacy, even though it may have been generated using the UNAIDS programme. A second conceptual insight comes from the notion of translation or what can be also seen as the steps by which the representation “changes hands.” This metaphor of changing hands is interesting as it helps to emphasise how ownership changes at different stages, and with this, networks get redefined, representing both the old and new. This process of redefinition has been described by the ideas of
amplification and reduction, and can be drawn upon also by other researchers to study other IS phenomenon involving representation and their processes of construction.

6. Concluding remarks

In this paper, we have argued that the representation of the HIV/AIDS phenomenon is constructed and used within a complex socio-political heterogeneous network. Grounded within the Science and Technology Studies tradition, we have drawn specifically upon Latour’s concept of circulating reference to explore the various translations that take place as the HIV/AIDS status is confirmed or not confirmed, and data about it is circulated through the various reporting systems reaching local, provincial, national and international audiences.

There are multiplicities of interests shaping the translations at different levels. The political interests of UNAIDS and various donors help to establish standardised procedures through the use of computer models to estimate the national prevalence of HIV. At the national level, the managers who do not rely on data reaching them from the lower levels add a “correction factor” of 40%. This correction also helps them to represent the disease in a way in which they believe it should be reported. Even artefacts like registers and forms shape the construction of the representation. For example, the non availability of standardised reporting forms leads to blood bank workers writing the activities’ data (including the test results) in improvised pieces of paper which contribute distorting the quality of the representation to the higher level of the hierarchy.

Understanding the dynamics of the complex heterogeneous network which shapes the representations of the HIV prevalence rates has important implications for both research and practice. With respect to research, the analysis expands our understanding of the notion of translations and how they are constructed. As Latour argues, we have described translations to be made up of a number of incremental and intermediary steps, involving a simultaneous process of amplification and reduction. Such a perspective provides us with a conceptual apparatus to unpack the construction of a representation, and the politics that surround it. In this way, we also respond to Suchman’s (1995) call to understand the inter relationship between representations and the organisational politics within which they are shaped. From an epidemiological perspective, we underline the need for efforts to have adequately sized samples, but also emphasise the difficulties of getting them in practice. As argued by Lee and Barkerville [29], an increase in the size of a sample implies an increase in the reliability of the estimate. This is also an issue of concern for UNAIDS who has emphasised that an effective representation of the HIV/AIDS is heavily dependent on the size and quality of the data collected on the ground [1].

Some implications for practitioners are now discussed. The study has highlighted how the HIV/AIDS representation is shaped by a range of socio-ethical, economic and political aspects. Improving the reporting systems which circulate the representation is this a fundamental task for the programme managers. More specifically, managers and designers should consider overcoming parallel AIDS patients reporting systems from district hospitals into an integrated system so as to avoid conflicting and incorrect representations. Efforts should be made to increase the availability of HIV tests to all suspected AIDS patients. The blood bank reporting system should also be redesigned and standardised in order to enhance the quality of evidence based on the system. The Voluntary, Counselling and Testing services need to be represented evenly throughout the country and a certain degree of integration of diverse HIV/AIDS information systems seems to be a key strategy for rational planning of the resources and needs. We believe that some constructive change is possible to existing systems representing the HIV/AIDS phenomenon, and hope that our paper offers a contribution to considering such change in terms of both research and practice.
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