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Addressing Adherence to Antiretroviral Therapy in Ouagadougou, Burkina Faso: Insights from hospital ethnography

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Addressing Adherence to Antiretroviral Therapy in Ouagadougou, Burkina Faso: Insights from hospital ethnography

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RÉSUMÉ

L'épidémie de l'infection au virus de l'immunodéficience humaine (VIH) constitue une crise majeure en santé publique de nos jours. Les efforts de la communauté internationale visent à rendre les traitements antirétroviraux (TARV) plus accessibles aux personnes vivant avec le VIH, particulièrement dans les contextes à ressources limitées. Une observance quasi-parfaite aux TARV est requise pour tirer le maximum de bénéfices thérapeutiques à l'échelle individuelle et à l'échelle populationnelle. Cependant, l'accroissement de la disponibilité des TARV s'effectue dans des pays africains qui disposent de systèmes de santé fragiles et sous-financés. Ceux-ci souffrent également d'une pénurie de personnel de santé, lequel joue un rôle central dans la mise en oeuvre et la pérennité des interventions, notamment celle du soutien à l'observance thérapeutique.

La présente étude ethnographique relate l'expérience de personnel de santé dans la fourniture des services de soutien à l'observance dans un contexte de ressources limitées et d'accroissement de l'accès aux TARV. L'étude a été menée dans deux centres hospitaliers de la capitale du Burkina Faso, Ouagadougou.

Trois conclusions principales sont mises au jour. Tout d'abord, une bonne organisation – tant logistique que matérielle – dans la provision de services de soutien à l'observance est capitale. L'infrastructure d'observance doit aller au-delà des unités de prise en charge et s'intégrer au sein du système de santé pour assurer un impact durable. De plus, la provision des TARV dans le cadre d'une prise en charge médicale exhaustive est essentielle pour un soutien à l'observance efficace. Ceci implique la présence de professionnelles de santé en nombre suffisant et disposant d'outils pour soutenir leur pratique clinique (tests de laboratoire, traitements pour infections opportunistes), ainsi que des mécanismes pour leur permettre d'aider les patients à gérer la vie quotidienne (gratuité des services, programmes d'alphabétisation et soutien psychosociale). Enfin, une amélioration de la coordination des programmes VIH au niveau national et international est nécessaire pour assurer une prise en charge cohérente au niveau local. La programmation conçue dans les pays étrangers qui est incomplète et de courte durée a un impact majeur sur la disponibilité de ressources humaines et matérielles à long terme, ainsi que sur les conditions de travail et de prestation de services dans les unités de soins.

Mots-clés: virus de l'immunodéficience humaine, traitement antirétroviral, observance thérapeutique, Afrique subsaharienne, personnel de santé, systèmes de santé, ethnographie hospitalière.

ABSTRACT

The human immunodeficiency virus (HIV) epidemic is the most pressing public health crisis of modern times. Present international focus targets expanding access to life-saving antiretroviral treatment (ART) for people living with HIV/AIDS – referred to as treatment scale-up- in contexts with limited resources. Near perfect adherence to ART regimens is required to maximize individual and public health outcomes. ART is being scaled-up in African countries with under-funded, fragile health systems. These health systems are further plagued by a shortage of health professionals who play a critical role in the implementation and sustainability of ART programmes, including the provision of adherence support.

This ethnographic study sought to explore the experience of health providers in addressing adherence to ART in settings of limited resources where ART is being scaled-up. The study took place in two hospital centres in the capital city of Burkina Faso; Ouagadougou.

The study led to three broad conclusions. First, good organization is imperative in the delivery of adherence support services, both in terms of logistics and materiality. This infrastructure must extend beyond the level of the hospital ward, to the level of the health sector in order to ensure a sustainable impact. Second, the provision of ART within a comprehensive package of care is an essential component of effective adherence support. This involves equipping providers with tools to assist them in their clinical practice (laboratory monitoring, treatment for opportunistic infections, and additional staff) as well as mechanisms for them to help patients negotiate the trials of daily life (gratuity of care, literacy support, psychosocial support). Third, there is a need for improved coordination of nationally and internationally-led HIV programming for coherent service provision at the local level. Limited and short-term external funding affects the long-term availability of material and human resources, as well as working conditions and service provision on the wards.

The results of the study contribute to the existing academic literature on ART adherence, to the design of future research projects, and to the organization of adherence support services.

Key words: human immunodeficiency virus, antiretroviral treatment, adherence, Sub-Saharan Africa, healthcare providers, health systems, hospital ethnography.

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LIST OF ABBREVIATIONS AND ACRONYMS

AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral treatment
ARVs	Antiretroviral drugs
ATARAO	*Appui aux traitements antirétroviraux en Afrique de l'Ouest*/Supporting Antiretroviral Treatment in West Africa
CAMEG	*Centrale d'achat des médicaments essentiels génériques et des consommables médicaux*
CHUM	*Centre hospitalier de l'Université de Montréal*
CMA	*Centre medical avancé*
CMLS	*Comité ministériel de lutte contre le Sida*/Ministerial Council on HIV/AIDS
CSPS	*Centre de santé et de promotion sociale*
DIU	*Diplôme inter-universitatire*/Inter-university diploma
ESTHER	*Ensemble pour une solidarité thérapeutique hospitalière en réseau*
GDP	Gross domestic product
GFATM	Global Fund for AIDS, Tuberculosis and Malaria
HAART	Highly Active Antiretroviral Therapy
HIPC	Highly-indebted poor country
HIV	Human immunodeficiency virus
LMIC	Low and middle income countries
NGO	Non-governmental organization
PAMAC	*Programme d'appui au monde communautaire et associatif*
PEPFAR	President's Emergency Plan For AIDS Response
PMTCT	Prevention of mother-to-child transmission

PNDS	*Plan national de development sanitaire*/ National Health Development Plan
SMI	*Santé materelle et infantile*/ Mother and infant health
SP/CNLS-IST	*Secretariat Permanent du Conseil national de lutte contre le Sida et les infections sexuellement transmissibles/*Permanent Secretariat of the National Council for the Struggle against HIV/AIDS and STIs
STIs	Sexually transmitted infections
TRIPS	Trade-Related Aspects of Intellectual Property Rights
UN	United Nations
UNAIDS	The Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Plan
VCT	Voluntary counselling and testing
WHO	World Health Organization

For Alex, Sara, Margaret, Mickey and
others for whom treatment never
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CHAPTER ONE: INTRODUCTION

RELEVANCE OF THE STUDY

The human immunodeficiency virus (HIV) epidemic is the most pressing public health crisis of modern times. The magnitude of the HIV epidemic requires informed, comprehensive and effective action at all levels of society. Present international efforts aim to expand access to life-saving antiretroviral treatment (ART) for people living with HIV/AIDS – often referred to as treatment scale-up. A number of large - scale ART distribution programmes have been implemented in sub-Saharan Africa, rendering lifesaving treatment available to an ever-increasing number of individuals. Increased access to treatment has been credited with prolonging the lives of individuals for whom an HIV diagnosis was equated with a death sentence just a few years ago.

Despite the positive implications of these treatment programmes, in general little attention has been paid, until now, to monitoring of patient adherence. Near-perfect adherence to ART is essential for positive treatment outcomes, including improved clinical status of the individual. Sub-optimal adherence compromises treatment success and fosters the development of HIV strains that are resistant to current ART regimens. These resistant strains can be transmitted between individuals. Lack of emphasis on adherence support in scale-up programmes thus poses a serious threat not only to individual patient outcomes, but also to public health.

ART scale-up is being carried out in African countries with largely under-funded and fragile health systems. These health systems are further plagued with a chronic shortage of health professionals due to lack of resources and emigration to more favourable job markets in higher-income countries. This deficit in health professionals is especially devastating to the health sectors of low-and-middle-income countries (LMIC) that are heavily reliant on manpower to implement health interventions, including adherence support for patients on ART. Despite the crucial role of the health provider in such contexts, human resources are an often-overlooked component in health system planning.

Healthcare professionals across Africa are faced with the logistical challenge of treating the massive influx of HIV patients that accompanies the increased access of ART and providing them with a continuum of care (including adherence support) that is essential for positive treatment outcomes.

This ethnography aimed to study the question of adherence support for patients on ART from the perspective of the health provider. It is important to examine this issue from the health provider's perspective for several reasons. First, there have been recent calls by the international HIV/AIDS community for more operations research to assess the impacts of treatment scale-up on health systems. A description of how adherence to ART is currently being addressed provides practitioners and policy-makers with an evidence-based understanding of the present context. Second, an in-depth understanding of the difficulties faced by health professionals in their daily work caring for HIV patients helps to highlight barriers to adherence support and identify possible targets for improvement and further research. Third, a survey of recommendations on how adherence support for patients can be improved valorizes the perspectives of healthcare providers and fosters a more participative approach to health system development.

CHAPTER TWO: LITERATURE REVIEW

Human Immunodeficiency Virus

In 2007 there were 33.2 million people around the world infected with human immunodeficiency virus (HIV) - the virus that leads to acquired immune deficiency syndrome (AIDS) - including 2.5 million new infections (UNAIDS/WHO, 2007). In the same year 2.1 million AIDS-related deaths were reported. While HIV is present in all regions around the globe, it disproportionately affects Sub-Saharan Africa. This region alone accounts for more than two thirds of all infections; that is 22.5 million cases.

The magnitude of the epidemic makes it the most significant public health problem in recent history (Harries, Nyangulu, Hargreaves, Kaluwa, & Salaniponi, 2001). The International Federation of Red Cross and Red Crescent Societies recently released a report identifying HIV and AIDS as “a global disaster” (International Federation of Red Cross and Red Crescent Societies, 2008). HIV produces devastating impacts on individual health by suppressing the immune system and leaving the body vulnerable to opportunistic infections – a sign of progression toward AIDS and, ultimately, death. HIV is transmitted between individuals through blood and bodily fluids during sexual intercourse, from mothers to infants (during pregnancy, childbirth and breastfeeding), and contact with contaminated blood (for example, through blood transfusions and the sharing of intravenous drug needles). The highly transmissible nature of HIV poses a substantial threat to population health and sustainable development.

The impacts of the HIV epidemic are far-ranging. Over 10 years ago, Danzinger identified several areas of impact of HIV and AIDS on low and middle income countries (LMIC), on individual, household, social, and economic levels (Danzinger, 1994). Despite improvements in treatment access, HIV continues to wreak havoc on societies across Sub-Saharan Africa. It has been shown to negatively impact macroeconomic development in highly affected countries. Modelling studies have shown that HIV has a detrimental effect on the gross domestic product (GDP) of countries where it is endemic, adding a further barrier to sustainable development in some African countries (Ventelou, Moatti, Videau, & Kazatchkine, 2008). For example, in four African countries (Angola, Central African Republic, Cameroon and Côte d'Ivoire) the HIV epidemic was estimated to account for a 1% loss in GDP growth per year between 2000 and 2010 when compared to a scenario without the HIV epidemic (Ventelou, et al., 2008).

A sizeable amount of resources at the international, national and community levels has been invested to counteract the HIV pandemic. Investments have targeted a range of activities; from preventive to therapeutic. In recent years, much effort has been attributed to rendering treatment for HIV available in LMIC (WHO, 2008b). A number of large-scale antiretroviral treatment (ART) distribution programmes have been implemented in sub-Saharan Africa to respond to the HIV epidemic, rendering lifesaving treatment available to an ever-increasing number of individuals.

Antiretroviral Treatment

There is now widespread acceptance at the international level that access to ART is essential in mitigating the impact of HIV/AIDS. ART functions by halting the replication of HIV, thus reducing the amount of virus in the body (viral load) and the destruction of CD4 cells (an integral component of the immune system and the virus' preferred target) (WHO, 2002). The main goal of ART is to slow the individual's clinical progress from HIV to AIDS and, ultimately, death. Treatment allows HIV positive individuals to live longer, more productive lives and to care for their children (Harries, et al., 2001).

ART is not only essential in treating HIV, but also in preventing its spread. Findings from studies in African settings have shown that individuals on ART engage in less sexual risk behaviour (Kennedy, O'Reilly, Medley, & Sweat, 2007). Increased availability of treatment may encourage individuals to seek voluntary counselling and testing (VCT) services and to disclose their HIV status to their sexual partners

(Harries, et al., 2001). A study in Bostwana recorded a five-fold increase in voluntary HIV testing after decentralization rendered ART locally available (Warwick, 2006). Evidence also exists that as ART decreases the viral load of infected individuals, the possibility of transmission may also be reduced (Quinn, et al., 2000). In 2008, a group of Swiss physicians released a controversial statement declaring that HIV positive individuals who are adherent to ART and who do not suffer from any other sexually transmitted infections (STIs) cannot sexually transmit HIV to their partners (Vernazza, Hirschel, Bernasconi, & Flepp, 2008). Projections made in 2005 estimated that if a quarter of patients in Africa were placed on treatment, up to 1.3 million new infections could be prevented after just five years (Akileswaran, Lurie, Flanigan, & Mayer, 2005).

There are several global initiatives that seek to improve access to ART in resource-limited countries. In 2003, the World Health Organization (WHO) announced its innovative "3 by 5" initiative; a programme aiming to provide three million people infected by HIV in LMIC with ART by 2005 (WHO, 2003b). The WHO "3 by 5" initiative was founded upon a public health approach that aimed to develop treatment programmes that reach as many people in need as possible (WHO, 2006b). Although the target was attained after the 2005 deadline, the initiative is credited with contributing to substantial improvements in access to treatment by increasing visibility and political pressure on donors. Other renowned donors that drive ART access initiatives include the Global Fund for AIDS, tuberculosis and malaria (GFATM), launched in 2002, and the President's Emergency Plan for AIDS Response (PEPFAR), initiated in 2003 (UNAIDS, 2007). Various governmental, non-governmental and faith-based organizations also play key roles in broadening ART accessibility.

The current goal dominating the international donor scene is "universal access to HIV prevention, treatment, care and support by 2010" (UNAIDS, 2007). The commitment was first established at the Gleneagles Meeting of the Group of Eight countries in 2005 and reaffirmed at the 2005 United Nations (UN) General Assembly World

Summit (UNAIDS, 2007). Significant progress in ART availability and access has been achieved since the adoption of the universal access goal; between 2006 and 2007 alone, one million more individuals in LMIC were prescribed ART (De Cock & De Lay, 2008). Attainment of this goal, however, will be compromised in the absence of increased financial pledges from the international community (UNAIDS, 2007).

The adoption of these grand objectives would not have been possible without the drastic decline in prices of antiretroviral drugs (ARVs) over the last few years. Activist groups and NGOs have maintained pressure on governments and pharmaceutical companies to render ART more accessible to impoverished populations (Buvé, Kalibala, & McIntyre, 2003). In Burkina Faso, for instance, the monthly price of ART paid by patients dropped from around US$800 at the end of 1998 to about US$100 by June 2001 (V.-K. Nguyen, Grennan, Peschard, Tan, & Tiendrébéogo, 2003). Today, ART in Burkina Faso costs patients approximately US$3 per month (Sanou, 2008).

International trade regulations protecting intellectual property initially constituted a significant barrier to accessibility of ART in LMIC. Competition from generic ART manufacturers in India, Brazil and Thailand, as well as the activist pressure just mentioned above helped to bring down prices and reform those international regulations. The World Trade Organization adopted the Doha Declaration on the Trade-Related Aspects of Intellectual Property Rights (TRIPS) Agreement on Public Health November 14, 2001 stating that Member countries had a “right to protect public health and, in particular, to promote access to medicines for all” (World Trade Organization, 2001). This agreement allows countries without the capacity to manufacture pharmaceuticals domestically to import lower-cost generic ARVs in the interest of public health. In 2002, several ARVs were added to the WHO Essential Medicines List, affirming HIV as a public health priority (Laing, Waning, Gray, Ford, & Hoen, 2003).

Adherence to Antiretroviral Treatment

The attainment of the positive health benefits of ART is contingent not only on the availability of drugs, but also on near-perfect adherence to medication regimens. Indeed, as Kim and Gilks once stated in an editorial to the New England Journal of Medicine: "Adherence support, rather than regimen potency, may be the single most critical determinant of long-term success" of treatment programmes (Kim & Gilks, 2005).

The WHO provides the following definition of adherence: "the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes - corresponds with agreed recommendations from a health care provider" (WHO, 2003a). The definition of "adherence" distinguishes itself from that of "compliance" in its reflection of the active role played by the patient in the treatment process.

No gold standard exists for measuring adherence. Patient self-report is the most commonly used method; patients are asked to recall how many doses they missed over a certain period of time (Goudge, Ngoma, & Schneider, 2004). Pill counting, provider assessments, pharmacy records, and the medication event-monitoring system (a system whereby a microchip in the pill container records information about the date and time the container is opened) are also used. These methods all have drawbacks and thus can only serve as proxies for measuring actual adherence rates.

There is no consensus in the literature on optimal levels of adherence (Walsh, Pozniak, Nelson, Mandalia, & Gazzard, 2002). Some researchers consider adherence to more than 95% of doses to be essential in maximizing virological outcomes (Paterson, et al., 2000). More potent antiretroviral drug combinations with a higher "genetic threshold" for resistance, as well as more long-acting drugs, have been introduced from the late 1990s (V.-K. Nguyen, personal communication, August 3, 2008). It is now thought that these more potent regimens are more "forgiving" of lower adherence, although an optimal threshold has yet to be identified.

Suboptimal adherence has been associated with poorer patient outcomes and the appearance of mutations in HIV strains that render them resistant to current medication regimens (Sethi, Celentano, Gange, Moore, & Gallant, 2003; Weiser, et al., 2003). The academic community has published appeals for more pro-active monitoring of patients on ART that aims to identify adherence problems before treatment becomes ineffective for a particular person (Bangsberg, 2008). Of grave importance to public health is that these resistant strains have the potential to be transmitted to uninfected partners (Hecht, et al., 1998). Harries and colleagues, therefore, cautioned that treatment scale-up must be carried out within a structured framework in order to optimize positive benefits and to avoid "antiretroviral anarchy" – that is, "widespread and unregulated access" to ART (Harries, et al., 2001). Integral to this perspective is the concept of excellent patient adherence to treatment and medical follow-up (Harries, Makombe, Schouten, Ben-Smith, & Jahn, 2008)

Despite the importance of adherence support in ensuring treatment success, most large-scale ART programmes have, until recently, paid little attention to the issue, focusing instead on the numbers of people accessing treatment. A review of ART monitoring by international, regional and national institutions in Southern African countries suggested that adherence is a largely neglected indicator (Shamu, 2004). UNAIDS and WHO monitoring of population adherence rates is limited to a quantitative indicator of adherence to measure the number of people still on treatment at certain time points. Furthermore, a recent WHO update on the goal of universal access only briefly broached the subject of adherence to treatment (WHO, 2008b).

The WHO recommends that the scale-up of ART programmes be implemented within a public health approach, summarized as follows:

> "The public health delivery of ART focuses on maximizing survival at the population level through standardized sequencing of the available ARVs, delivered to individuals by means of simplified approaches and supported by

> clinical and basic laboratory monitoring. It encompasses the guiding principles of chronic disease management with a strong focus on ART adherence and integrated, decentralized health care delivery linked to reduction of HIV transmission." (WHO, 2006a)

Four guiding principles have been developed in line with this approach to minimize drug resistant HIV strains: "(1) appropriate ART access, prescribing and usage; (2) fostering adherence; (3) supporting prevention of HIV transmission; and (4) appropriate action based on surveillance and monitoring results" (WHO, 2006c).

The public health approach in South Africa was compared to an individualized approach in Switzerland (Keiser, et al., 2008). The authors reported similar outcomes in both cohorts of patients newly initiated to ART. They recommended, however, that patients, particularly in South Africa, would benefit from more precocious prescribing of ART.

It has been found that ART scale-up programmes in Africa have been successfully implemented and have achieved positive outcomes (Akileswaran, et al., 2005; Touré, et al., 2008), including high adherence rates (Akileswaran, et al., 2005). A meta-analysis reported that adherence rates in Sub-Saharan Africa compare favourably to those in North America and surpass them in some contexts (Mills, et al., 2006). Most of such studies, however, include relatively small numbers of participants and little emphasis on monitoring (Akileswaran, et al., 2005) and adherence (Harries, et al., 2001). Furthermore, many of the treatment programmes studied benefited from technical and financial resources from partners in Northern countries, which differentiates them from the actual context of scale-up in many African countries (Boileau, et al., 2008). A study on ART adherence in Mali and Burkina Faso by the pro-ARV group revealed that only 58.5% of the sample was optimally adherent (Aboubacrine, 2006). ART programmes in Africa have also reported significant numbers of patients lost to follow-up (Ndiaye, 2008; Touré, et al., 2008).

Determinants of Adherence to Antiretroviral Treatment

Adherence is a multidimensional issue that goes far beyond the individual characteristics of the patient. The WHO has outlined five dimensions of adherence for chronic conditions: patient-related factors, condition-related factors, therapy-related factors, health system/healthcare team factors, and social/economic factors (WHO, 2003a).

Patient-related factors

Patient characteristics have often been reported as significant determinants of adherence to ART (Malcolm, Ng, Rosen, & Stone, 2003; Singh, et al., 1999). Several adherence studies have focused on demographic factors. In a longitudinal study of American HIV patients, African-American ethnicity, low income and education levels, and substance use were independently associated with lower levels of adherence (Golin, et al., 2002). Similar findings were reported elsewhere (Catz, McClure, Jones, & Brantley, 1999; Gordillo, del Amo, Soriano, & Gonzàlez-Lahoz, 1999; Moatti et al., 2000). Other studies, however, have found demographic factors to be unreliably associated with medication-taking behaviour (Holzemer, Bakken Henry, Portillo & Miramontes, 2000) and suggest that they not be used as predictors of adherence (Lerner, Gulick & Neveloff Dubler, 1998).

Research has suggested that adherent patients differ from their non-adherent counterparts in terms of health beliefs and attitudes (Malcolm, et al., 2003; Smith et al., 1997). Adherent patients have been found to have higher perceived self-efficacy concerning medication-taking ability (Catz, Kelly, Bogart, Benotsch, & McAuliffe, 2000).

Psychosocial factors have also been found to influence patient adherence to ART. In a cross-sectional study, depression was found to be more prevalent among non-adherent patients than adherent patients (39% versus 17%) (Starace et al., 2002). Similar findings were later supported in a longitudinal study (Spire et al., 2002).

Social support (Catz, et al., 2000) (Holzelmer et al., 1999, DiMatteo, Lepper & Croghan, 2000), coping behaviour (Singh et al., 1999), quality of life (Holzelmer et al., 1999), level of education and awareness of health issues (Kalichman, Ramachandran, & Catz, 1999; Smith, Rapkin, Morrison, & Kammerman, 1997), and drug or alcohol use (Moatti et al., 2000) have also been associated with adherence behaviour.

Despite this considerable pool of research on individual attributes, few personal factors have been found to be consistently associated with adherence (Ammassari, et al., 2002).

Condition- related factors

Few studies have been carried out on the impact of illness-related factors on adherence (Garcìa & Côté, 2003). Evidence suggests that the duration of illness and severity of symptoms may have an impact on adherence, but diverging findings from different studies imply that the direction of the effect is unclear (Garcìa & Côté, 2003). For example, a cross-sectional study showed that patients with lower CD4 levels were less adherent to treatment (Gordillo, del Amo, Soriano, & Gonzàlez-Lahoz, 1999). This finding, however, requires further investigation of the directionality of the effect due to the cross-sectional design of the study.

Therapy-related factors

Complexity of medication regimen has often been found to affect adherence to ART, with more complex treatment schedules acting as a deterrent (Ammassari, et al., 2002). Indeed, ART regimens are considered to be among the most complex prescribed to control chronic conditions (Chesney, Morin, & Sherr, 2000). The complexity of these regimens is due to several factors, including: “pill burden, dosing, dietary instructions, number and type of different medications prescribed, convenience, and ability to incorporate the treatment regimen into a daily routine” (Trotta, et al., 2002). Unpleasant side effects have also been cited by patients as a reason for missing doses (Sullivan, et al., 2007). It has been suggested that in order to optimize adherence to ART treatment regimens should be made as simple as possible, dosage scheduling should be adapted to the patient's lifestyle, and patients should be equipped with information to effectively anticipate and manage side-effects (Trotta, et al., 2002).

Healthcare Team & Health System Factors

Healthcare Team Factors

Health providers play an essential part in the implementation of health interventions, particularly in limited resource settings (Rowe, de Savigny, Lanata, & Victoria, 2005). ART distribution programmes are no exception.

The positive effects of a good patient-provider relationship on adherence behaviour have often been discussed in the academic literature (Maddigan, Majumdar, & Johnson, 2005; Sajatovic, et al., 2005). The influence of the patient-provider relationship is particularly important in the context of HIV where adherence to ART is crucial to positive treatment outcomes (Ickovics & Meade, 2002). Several qualitative studies on factors that favour ART adherence cite the necessity of a good quality patient-provider relationship (Lewis, Colbert, Erlen, & Meyers, 2006; Murphy, Johnston Roberts, Hoffmann, Molina, & Lu, 2003; Stone, et al., 1998). Russell et al. (2004) found that seropositive patients who were more satisfied with the quality of their relationship with their provider were more adherent to treatment regimens. In one South African study examining adherence to tuberculosis treatment, the presence of caring health professionals who offered emotional support was found to favour adherence (K. A. Rowe, et al., 2005).

While the central role of the provider in promoting patient adherence to ART has been demonstrated through research, it is less clear whether this knowledge has translated into clinical practice. A qualitative study conducted in the United States showed that most physicians discuss adherence to ART with their patients (Johnston Roberts & Volberding, 1999). In another qualitative project, researchers found that most physicians believed that promoting adherence was part of their role, however the majority surveyed decried the fact that work conditions did not allow them to spend an adequate amount of time on this task (Golin, Smith, & Reif, 2004). Physicians have reported patient non-adherence to treatment recommendations to be a significant challenge to clinical practice (Malta, Petersen, Clair, Freitas, & Bastos, 2005).

Due to the importance optimal adherence to ART, it is fundamental that an open and culturally acceptable dialogue on this subject exist between the patient and the provider (Malta, et al., 2005). It has been suggested that interventions to promote ART adherence should include a multidisciplinary team of providers (Stone, 2001).

Health system-related factors

Health systems can influence patient adherence to long-term therapies in a variety of ways, including: cost of health services, provider availability, continuity of care, and modalities of communication with patients (WHO, 2003a). An ethnography of tuberculosis patients in urban Bolivia found that structural determinants of the health system such as hidden costs, poor access, discrimination, and maltreatment were factors associated with non-adherence to treatment (Greene, 2004).

Despite the importance of health system determinants, little research has been carried out on the subject with respect to adherence to ART. For instance, in a review of adherence specific to ART, only health system aspects related to the provider were discussed, with a brief mention of poor programme implementation (WHO, 2003a). Thus, factors in the health system that affect adherence to ART need to be further clarified. The following determinants could serve as potential starting points: health-care infrastructure, drug stock shortages, and financing mechanisms (including user fees) (Castro, 2005).

Social and economic factors

In an essay on studying adherence from a biosocial perspective, Castro suggests studying the following contextual factors: socioeconomic factors (e.g. poverty, cost of treatment, transportation costs), social capital (e.g. social status, social support), and cultural models of health and disease (e.g. transmission, healers) (Castro, 2005).

A review conducted by the WHO on adherence to long-term treatments showed that several social and economic factors affect adherence, including:

> "Poor socioeconomic status, poverty, illiteracy, low level of education, unemployment, lack of effective social support networks, unstable living conditions, long distance from treatment centre, high cost of transport, high cost of medication, changing environmental situations, culture and lay beliefs about illness and treatment, and family dysfunction." (WHO, 2003a).

Few social and economic determinants of adherence have been studied in relation to ART. A cross-sectional study was conducted on the social, cultural, economic and structural determinants of adherence to ART in a population of HIV patients in Botswana (Weiser, et al., 2003). The investigators found treatment cost to be the most significant barrier to adherence, with 70% of the patients surveyed citing it as a problem and 44% claiming that it prevented them from effectively adhering to treatment regimens. Frequent gaps in treatment were also attributed to financial barriers.

Addressing Adherence to Antiretroviral Therapy

Low-cost adherence interventions have been found to be cost-effective in terms of healthcare utilization and health outcomes (WHO, 2003a). A comprehensive strategy to ensure adherence to ART should address a range of determinants across the above-mentioned categories (Stone, 2001). To date, most adherence interventions have focused on patients characteristics and ignored broader systemic determinants of adherence (Goudge, et al., 2004). It is important to avoid placing a disproportionate amount of responsibility for adherence on the patient as many personal determinants of adherence are beyond the control of the individual (Malcolm, et al., 2003). "A stronger commitment to a multidisciplinary approach is needed in order to make progress in this area. This will require coordinated action from health professionals, researchers, health planners and policy-makers" (WHO, 2003a).

Antiretroviral Therapy and Health Systems

HIV cases were first detected across Africa in the 1980s. This was also around the time when structural adjustment programs championed by the International Monetary Fund (IMF) and the World Bank in an effort to stabilize volatile economies in LMIC were forcing African governments to drastically reduce social spending, including in the health sector (Peabody, 1996). One of the direct impacts of these policies was a reduction in national investments in health, resulting in disastrous consequences for public health systems (Ridde, 2007). HIV, therefore, arrived at a time when health systems across the continent were already struggling to meet the needs of their populations.

The Alliance for Health Policy and Systems Research defines a health system as “all the organizations, institutions and resources that are devoted to producing health actions and whose primary intent is to improve health”(Alliance for Health Policy and Systems Research, 2004). A health system has four essential functions: service provision, resource generation, financing and stewardship.

Health systems in LMIC currently face a multitude of barriers to effective functioning, ranging from organizational to financial (Travis, et al., 2004). Years of constrained budgets have left public healthcare systems across Africa in a state of decay (Ridde, 2007).

The scaling-up of health interventions first requires a thorough understanding of “the range and intensity of constraints that apply in specific contexts” (Hanson, Ranson, Oliveira-Cruz, & Mills, 2003). With the advent of expanded access to ART through national and international funding, precarious health systems with limited human resources are now faced with the logistical challenge of responding to the treatment needs of an influx of HIV patients (Kober & Van Damme, 2004b). Concern has been voiced that ART scale-up will divert scarce resources away from other health priorities and negatively impact the overall provision of health services. On the other hand, some believe that scale-up has the potential to strengthen weakened health systems if appropriately implemented (El-Sadr & Abrams, 2007).

Global health interventions, such as ART scale-up, face the logistical decision of taking a vertical, disease specific approach or a more horizontal approach that seeks to integrate existing health services (Travis, et al., 2004). If ART programmes are integrated into the public health system, they can improve overall service delivery as well as working conditions for staff (El-Sadr & Abrams, 2007; Pfieffer, et al., 2008). Such an approach, while more beneficial in the long-term, may be more complex to implement initially. A more vertical approach, on the other hand – that is, HIV services that are implemented in parallel to existing health services- may accentuate existing inequities in healthcare, weaken the public health system, and divert scarce resources away from the public health sector (Chopra, 2005; EQUINET, 2004). Furthermore, such approaches are unlikely to contribute to the attainment of long-term objectives such as the Millennium Development Goals (Travis, et al., 2004).

It is important to clarify, however, that the distinction between vertical and horizontal programmes is rarely dichotomous (Oliveira-Cruz, Kurowski, & Mills, 2003). The definition is rather based on a continuum that is highly contingent on factors such as "internal organization and structure of the health system, for instance levels of decentralization; health system capacity and dependence on donor support for funding of basic infrastructure; demographic and epidemiological profile; and international priorities and politics" (Oliveira-Cruz, et al., 2003).

Much advocacy exists to ensure that ART distribution programmes are implemented in a way that strengthens health systems (EQUINET, 2004). This implies not only ensuring a steady supply of antiretroviral drugs but also training of staff, strengthening of laboratory capacities, and ensuring psychosocial and adherence support for patients (Buvé, et al., 2003). As one WHO Knowledge Management Advisor put it, "we must rebuild health systems as we confront the epidemic" (Bailey, 2004).

There is an overall dearth of academic literature on approaches to strengthening health systems (Travis, et al., 2004). Limited research on this subject, as well as the recent implementation of many ART scale-up initiatives, means that the impacts of the programmes are yet to be determined (El-Sadr & Abrams, 2007; Wyss & Wiess, 2005). “The roll-out of HAART in Africa represents a gigantic experiment as many of the important determinants for its possible success or failure are unknown; these need to be explored through research at the same time the roll-out is occurring” (Jaffar, et al., 2005). One major concern is the sustainability of ART programmes once international funding - including that of such massive donors as PEPFAR and the Global Fund to Fight AIDS, TB and malaria - ceases (Wyss & Wiess, 2005). There have been increasing calls from the international HIV/AIDS community (most recently at the XVII International AIDS Conference in Mexico City) for more operations research – defined as “applied research focused on specific problems to give specific operational answers” – to assess the implementation of ART scale-up with an objective of improving it through the use of available resources (De Cock, 2008). Inherent to this type of research is the need to assess *how* ART services are presently being dispensed.

ART and Human Resources for Health

One facet of health systems that has been the focus of much research in recent years is human resources for health. The global importance of this issue was highlighted in 2006 when it was chosen as the theme of the WHO annual report. Health providers play an essential part in the implementation of health interventions, particularly in limited resource settings (A. K. Rowe, et al., 2005). In a report jointly published by UNAIDS and PEPFAR (2007) it was acknowledged that the goal of “universal access to comprehensive prevention programmes, treatment, care and support” by 2010 would not be attainable without strengthening health systems and significantly expanding the health workforce (UNAIDS & PEPFAR, 2007). ART scale-up is highly dependent on “well-skilled and motivated personnel with clinical, nursing, counselling, laboratory and/or pharmaceutical skills” (Wyss, 2004).

Despite the recognized importance of health human resources at the global level, health policies of LMIC often pay insufficient attention to this integral component of the health system (Dussault & Dubois, 2003; Wyss, 2004). When it is taken into account it is usually incomplete and of limited scope (Dussault & Dubois, 2003). This oversight threatens the ability of the health sector to put international donor contributions to effective use. “Millions of dollars, for example, have been invested to ensure the availability of AIDS and tuberculosis drugs but hardly any funding has been committed to ensure that there is a sustainable workforce to administer these drugs” (O'Neil, 2008).

The attainment of health goals in LMIC is further compromised by the current worldwide shortage of health professionals. The WHO estimates that the world is presently lacking over 4 million health workers. Nowhere is the situation as dire as in Sub-Saharan Africa (WHO, 2006d). This region alone accounts for 24% of the global burden of disease but disposes of only 3% of the world’s health workforce, with most of these professionals concentrated in urban areas.

Global Crisis in Human Resources for Health

The current crisis in health human resources in many LMIC has been attributed to the expansion of the global job market, which has facilitated the move of health professionals from rural to urban areas and from impoverished to richer countries (WHO, 2006d). Movement toward developed countries has been further facilitated due to health professional shortages in those countries (Stilwell, et al., 2003).

There exists a plethora of literature on the individual reasons for the migration of health workers (Eastwood, et al., 2005; Gilson & Erasmus, 2005). Salary is by far the most common reason invoked as motivation for migrating to a high-income country (Astor, et al., 2005; L. Nguyen, et al., 2008). Not only is salary considered insufficient, but its allocation often delayed and sporadic (*Health Workforce*

Challenges: Lessons from Country Experiences, 2004). However, many other factors are influential in the decision process, including dissatisfaction with the work environment. Muula and Maseko (2006) describe the lamentable working conditions of health centres in Malawi: overload of work, limited resources, lack of career advancement, non-stimulating work environment, lack of access to continuing education possibilities, and discriminatory recruitment practices. It is these conditions that lead to stress, burnout, depression and demotivation, ultimately pushing health professionals to leave their jobs and often to migrate abroad (Industrial Health Research Group and the South African Municipal Workers Union, 2005).

The HIV epidemic further aggravates the crisis by increasing the demand for health services and by directly impacting health professionals, many of whom are infected with HIV themselves (UNAIDS & PEPFAR, 2007). In a qualitative study conducted in Cape Town, South Africa to assess the experiences of nurses dealing with an influx of HIV patients, low morale and frustration were rampant among the staff (Lehman & Zulu, 2005). Nurses also reported an expansion of their roles to deal with the multifaceted nature of HIV, unbearable workloads that negatively influenced quality of care, inadequate training to deal with HIV, and negative psychological impacts such as guilt, depression and fear of exposure.

Addressing Human Resources for Health in Health Policies

Reformed health sector management and leadership are crucial in addressing the current health professional crisis in LMIC (O'Neil, 2008). Not only must human resources be taken into account in health sector policies, it is equally important to consider the motivation of the health professionals themselves (Franco, Bennett, & Kanfer, 2002). Motivation of health workers, or lack thereof, can have a profound impact on the attainment of goals in the health sector, including quality of care. Health worker motivation can be affected by organizational factors, but also by greater sociocultural determinants (Franco, et al., 2002).

A comprehensive plan to address low morale among health professionals (and, in turn, the threat of migration from the workforce) should involve a mix of financial and non-financial incentives (Mathauer & Imhoff, 2006). A qualitative study carried out in Benin and Kenya among health professionals supported the theory that non-financial incentives such as recognition, professional development and training opportunities, and ensuring a well-resourced and organized work environment can positively impact morale in the health workforce (Mathauer & Imhoff, 2006). "Clinical workers require management and administrative systems to work if they are to be effective" (McCoy, PcPake, & Mwapasa, 2008). ART programs have particular management needs in terms of drug procurement, laboratory capacity, and information (McCoy, et al., 2008).

Proposed health sector reforms should include an analysis of the potential impacts of the reforms on the health workforce. Equally important is the communication of reforms to health professionals in a transparent manner so that the greater organization goals may be clearly understood (Franco, et al., 2002). Health sector reforms should also take into account the interdependence of different categories of health professionals (Dussault & Dubois, 2003). This requires a systemic perspective of health human resources (Dussault & Dubois, 2003) taking into account characteristics of the health system as well as greater contextual factors. A multisectoral response to human resources for health is crucial for the scale-up of ART (Wyss, 2004).

SUMMARY

Unprecedented amounts of international funds have been attributed in recent years to improve availability of ART for individuals living with HIV across Africa. To date, these programmes have not invested sufficiently in adherence support for patients on treatment, despite the fact that research has shown suboptimal adherence to be detrimental to both individual and public health outcomes.

Patient adherence to treatment is influenced by multiple factors from the individual to the societal level. While individual determinants of adherence have been relatively well studied, there is a dearth of information on health system-related factors and adherence. Studies have shown that a good relationship between the patient and the provider can have a positive influence on patient adherence behaviour. This is likely to be a key area for targeting the improvement of adherence support provided to patients.

With the expansion of treatment access, fragile health systems in LMIC are coping with an increase in HIV patients seeking ART. It is unclear how these health systems are responding to this scale-up of ART services. Health systems in most Sub-Saharan African countries are further constrained by a critical shortage of health professionals. As healthcare providers have been shown to be an integral component in health interventions, the implementation of adherence support services may thus be compromised.

CHAPTER THREE: CONTEXT

General

Burkina Faso is a small landlocked country bordered on the south by Côte d'Ivoire, Ghana, Togo, and Benin and to the north by Mali and Niger. The country's Sahel climate implies that it is often plagued by devastating droughts (World Bank, 2003), though in 2007 heavy rains and flooding caused widespread damage and several lost lives (IRIN, 2007). Both types of severe climate conditions wreak havoc on Burkina's agriculture-based economy and, in turn on food security among the population (World Bank, 2003).

Burkina Faso (formerly known as Upper Volta) became an independent nation from the colonial rule of France in 1960. The country is divided into administrative regions of provinces, departments and villages (Ministère de la santé du Burkina Faso, 2000). It is among the poorest countries in the world, ranking 176 out of 177 countries on the human development index with a score of 0.370 (UNDP, 2008). The country's 14 million inhabitants live mainly in rural areas. The urban population represents only 18% of the total, though this proportion is growing, consistent with the global trend of urbanization. Nearly 30% of the population scrapes by on less than a dollar US a day and over 70% survives on less than two dollars US per day.

Quantitative indicators paint a bleak picture of the population health status in Burkina Faso. The overall life expectancy at birth is 52 years (UNICEF, 2008). The under-five mortality rate is 204 per 1000 live births and the infant mortality rate is 123 per 1000 live births. Burkina is a high fertility country with a national average of 6.4 live births per woman pending survival of childbirth – no easy feat with an adjusted[1] maternal mortality rate of 700 per 100 000 live births. Only 25% of the adult population is literate and primary school net enrolment is 45% of school-age children.

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[1] UNICEF, WHO and UNFPA evaluate the country reported maternal mortality ratio on a periodic basis and make adjustments to account for problems of underreporting and misclassification of maternal deaths and to develop estimates for countries with no data. The reported maternal mortality ratio for Burkina Faso from 2000-2006 was 480 maternal deaths per 100 000 live births.

Despite a low human development index, it cannot be overlooked that Burkina Faso benefits from a relatively stable socio-political context as compared to other West African nations. The country's current president, Blaise Compaoré, took power in October 1987 following a coup d'état. Since the 1990s, however, the country has engaged in a democratization process (World Bank, 2003). Blaise Compaoré was elected for a third presidential term in 2005 with an overwhelming 80% of the popular vote in an election that was deemed free and fair by most international observers (U.S. Department of State, 2008).

The country is enriched by its cultural, linguistic and religious diversity (World Bank, 2003). The predominant cultural group, found mainly in and around the capital city of Ouagadougou, is Mossi and comprises about half of the country's population. Three major religions are practiced in Burkina Faso: Islam (52%), Christianity (21%) and Animism (26%) (Nougtara, et al., 2008).

Recent social unrest in the country was sparked by the rising prices of food and oil, a phenomenon observed in several low-income countries around the world. *Les manifestations contre la vie chère* (Protests against the high cost of living) began in February 2008 in Bobo-Dioulasso, the country's second largest city, and quickly spread to Ouagadougou (RFI, 2008). Intermittent protests and strikes were held over the following months to highlight what the protesters interpreted as government inaction over the rising cost of basic necessities.

Health sector

Health services in Burkina Faso remain largely under public control despite a growing number of private health centres (mainly in urban areas) and a continued reliance on traditional medicine (World Bank, 2003). The non-governmental sector also plays a non-negligible role in providing health and social services to the population. NGOs, other organizations (faith-based and secular) as well as twinning initiatives (e.g. the French ESTHER project) work in parallel with the state and provide a range of health services, mainly targeted at vulnerable populations (World Bank, 2003).

Care in the public sector is dispensed on a cost-recovery basis and these fees often act as a barrier to accessing healthcare for the poorer segments of the population (Nougtara, et al., 2008). Medication costs present a further economic burden on households. A 2003 household survey found that 75% of household health expenditures went toward purchasing medications (Ministère de la santé du Burkina Faso, 2005a).

Public health services are organised into three levels (Ministère de la santé du Burkina Faso, 2005a). Primary care is dispensed at the district level through *Centres de santé et promotion sociale* (CSPS- Health and social promotion centres). At the second level, more advanced care is available at *Centres médicales avancés* (CMA – Medical centres with surgical ward). The tertiary level of care consists of referral hospitals at both the regional (9) and national (3) levels. These centres provide the most advanced care in the country and also serve as training and research centres.

Like many African countries, Burkina Faso suffers from a deficit in human resources for health. The most recent WHO health workforce data from 2004 indicate that the country has 708 physicians (5/100 000 inhabitants), 6 557 nursing and midwifery personnel (50/100 000 inhabitants), and 343 pharmacists (3/100 000 inhabitants) (WHO, 2008a). Bodart et al. (2001) reported that 95% of health personnel and institutions are part of the public sector, but these numbers hide the stark inequalities in geographic distribution of the workforce. A 2003 World Bank report found that despite accounting for merely 10% of the country's population, the major cities of Ouagadougou and Bobo-Dioulasso benefited from 54% of doctors, 33% of nurses, 57% of midwives and 59% of pharmacists (World Bank, 2003).

The deficiencies in health manpower reflect a lack of planning and management of the health workforce (World Bank, 2003). The country's training centres graduate insufficient numbers of health workers on a yearly basis. Furthermore, lack of continuing education opportunities and specialized training mean that personnel are often maladapted to the changing health contexts in which they are working. Health professionals who wish to further their education are usually obliged to leave the country to study elsewhere.

Burkina Faso implemented a series of health sector reforms as of 1992 (Nougtara, et al., 2008). Health sector reforms were broadly grouped into four categories: decentralization, liberalization of health services, reform of the pharmaceutical sector, and hospital reform. A retrospective study was conducted looking at the impact of macroeconomic adjustment policies on health resources and the consequences of health policies initiated between 1983 and 2002 (Haddad, Nougtara, & Fournier, 2006). The findings suggest that while both physical access to health services and the availability of generic drugs improved, financial barriers still greatly hindered utilization, particularly among the poor. Though reforms led to an increase in recruitment across all categories of health professional (except pharmacists), this augmentation benefited mainly urban areas and perpetuated urban-rural disparities. The study also found that public health services are plagued by poor quality rendering them unappealing to the population, a finding echoing Bodart et al. (2001). An in-depth socio-anthropological analysis highlighted that the poorest of the poor were most penalized by the reforms and no effort had been made to integrate concepts of equity in the changes (Ridde, 2008).

A study on factors contributing to Burkina Faso's poorly performing health system concluded that reforms have been largely unsuccessful in inspiring confidence in public health services among the population, as attested by a continuous drop in service utilization over an extended period of time (Bodart, Servais, Mohamed, & Schmidt-Ehry, 2001). The authors made the following recommendations to redress the situation: 1) make human resources for health a priority; 2) adjust the health expenditure budget such that more funds are directed toward rural areas; 3) strengthen decentralized administrative structures; and 4) redefine the role of the Ministry of Health (Bodart, et al., 2001).

In 2000, the government adopted the *Plan National de Développement Sanitaire 2001-2010* (PNDS – National Health Development Plan 2001-2010) to address the poor performance and quality of Burkina Faso's health sector (Ministère de la santé du Burkina Faso, 2000). The PNDS includes eight intermediary objectives: increase national health coverage, improve quality and utilization of health services, strengthen action against transmissible and non-transmissible diseases, reduce transmission of HIV, develop human resources for health, improve the efficacy of the health sector, increase financing of the health sector, and strengthen the institutional capacities of the Ministry of Health. The implementation of the PNDS is financed by the government, debt relief funds, external donors, and the country's population through cost-recovery mechanisms (Ministère de la santé du Burkina Faso, 2005a).

HIV and AIDS

Like most countries in the African sub region, Burkina Faso has been affected by the HIV pandemic. Prevalence data from 2005 suggest that 2% of the adult population is living with HIV (WHO/UNAIDS, 2008). According to a 2001 UNDP report the driving factors of the epidemic in the country are poverty, migration, rapid population growth, urbanisation, sexual behaviour, and poor reproductive health.

National Response to the HIV Epidemic

Government recognition of the HIV epidemic and response to it has grown since the first cases were detected in the country in 1986 (SP/CNLS-IST, 2005). Since 1998 the government of Burkina Faso has made clear its commitment to fighting the HIV epidemic (UNDP, 2001). The national response is coordinated at the highest level of government; that is by the Permanent Secretariat of the National Council for the Struggle against HIV/AIDS and STIs (SP/CNLS-IST – *Secrétariat Permanent du*

Conseil national de lutte contre le SIDA et les IST) under the Office of the President (UNDP, 2001).

In 1998, a strategic planning committee was assembled which led to the development and adoption of the Strategic Framework of the Fight Against HIV/AIDS 2001-2005 (*Cadre stratégique de lutte contre le VIH/SIDA 2001-2005*) (UNDP, 2001). The Framework called for a multisectoral response to the epidemic, including actors from the public sector, the private sector, the community sector and religious groups. A Round Table of donor organizations was held in June 2001 in order to discuss financing possibilities to implement the Strategic Framework (Presidence du Faso/CNLS-IST, 2008). This meeting led to a commitment of 90% of the resources necessary to implement the Strategic Framework which included four strategic axes: (1) strengthening of strategies to curb the transmission of HIV and STIs; (2) strengthening of epidemiological surveillance of the epidemic; (3) the improvement of the quality of care of persons infected and affected by HIV; and (4) the expansion of the response, the promotion of partnerships and multisectoral coordination.

A second Strategic Framework was elaborated for 2006-2010 period and adopted in 2005 (CNLS-IST/Secretariat Permanent, 2005). Another Round Table of donors led to almost complete financing of the 160.6 billion fCFA (approximately US$380 million) plan. The framework is in line with the Strategic Framework for Poverty Reduction, the country's 2001-2010 National Health Development Plan (see previous section), as well as the Millennium Development Goals and New Partnership for African Development (NEPAD) objectives. It contains the following strategic axes: (1) strengthening of prevention strategies and promotion of voluntary counselling and testing; (2) strengthening of access to care and comprehensive medical and community care for people living with HIV; (3) strengthening of the protection and support for people living with HIV and those affected by HIV/AIDS and other specific groups; (4) strengthening of partnership, coordination, and mobilisation of resources; and (5) strengthening of epidemiological surveillance of the epidemic, monitoring and evaluation and the promotion of research.

Antiretroviral Treatment in Burkina Faso

ARVs first became available on a very limited basis in the early 1990s (V.-K. Nguyen, et al., 2003). These brand name drugs were sold at private pharmacies in Ouagadougou at an extremely high cost to the individual. The cost of ART not only acted as a barrier to access for the majority of HIV patients, but those who could afford to buy drugs often did so in an "irrational" manner; that is, buying them sporadically and/or taking them in inefficient doses.

During the same period, some HIV positive individuals were able to access ARVs through drug donations (V.-K. Nguyen, et al., 2003). Drug donations occurred on an individual-to-individual basis, through the burkinabè diaspora, or through group-to-group donations. These exchanges occurred mainly in the community sector and also did not guarantee a continuous supply of medications.

In an effort to regulate the supply of ARVs in the country, in 1999 the government licensed ARVs and authorized the *Centrale d'Achat des Médicaments Essentiels Génériques et des Consommables Médicaux* (CAMEG) to import them (V.-K. Nguyen, et al., 2003). The CAMEG began in 1994 as a pilot project in response to the devaluation of the national currency, the franc CFA (fCFA), that was carried out as part of the country's structural adjustment programme (CAMEG, 2008). As a country that relies primarily on imports to supply its pharmaceutical needs, the devaluation of the currency had a profound impact on the health sector. Prior to the CAMEG's implementation, the country's pharmaceutical portrait could be characterized as follows: inadequate supply of medications in the health sector, low accessibility to medications for the poor, and regulations limiting the adoption and integration of generic medications into the market.

In December 1997, an evaluation commission composed of national and international experts deemed the pilot project a success (CAMEG, 2008). The commission recommended that the CAMEG be registered as a non-profit association with financial and judicial independence. The actual mandate of the CAMEG has three main objectives:

1. To provide both public and private health structures with generic medications, medical and laboratory materials, dental material and products, and other medical materials;
2. To acquire pharmaceutical products under the best financial circumstances;
3. To guarantee the availability of these products according to the quality norms in place.

In order to obtain the best possible market prices, the CAMEG issues calls for tenders from pharmaceutical companies. The procurement process takes place in two phases: the pre-selection of suppliers and the consultation of suppliers. This procedure is continuous and distributors and brands often vary. A tangible outcome of this procedure is the frequent changing of packaging and appearance of the drugs that are distributed to patients, despite the fact that the chemical composition remains essentially the same.

Since the CAMEG began importing ARVs in 1999, prices have dropped dramatically, largely as a result of international pressure on pharmaceutical companies to reduce prices and the increased availability of generic forms of the drugs (V.-K. Nguyen, et al., 2003). Accessibility to the drugs has increased considerably as a result. Between 2002 and 2005 the number of people receiving treatment improved significantly from 675 to 6 666 (SP/CNLS-IST, 2005). According to the most recent WHO/UNAIDS data, 13 000 people are currently receiving ARVs in Burkina Faso, representing approximately 39% of people living with HIV in need of treatment in the country (WHO/UNAIDS, 2008).

Funding for the purchase of ARVs by the CAMEG is provided largely by international donors. Government financing of treatment actually reduced from 64.3% in 2002 to 35 % in 2004 (SP/CNLS-IST, 2005). Financial support is provided by a variety of multilateral donors, including, but not limited to, the following: the highly-indebted poor country (HIPC) initiative, *Ensemble pour une solidarité thérapeutique hospitalière en réseau* (ESTHER), the World Bank, and the GFATM.

A three-country case study – including Burkina Faso- on the impacts of the GFATM on health systems was published in 2005 (Wyss & Wiess, 2005). The report found that financing from the Global Fund allowed for more collaboration of stakeholders at the national level, capacity strengthening of tertiary and referral health structures, and increased availability of ART, among other things. Funding, however, did not alleviate shortages in human resources for health. Due to the brief nature of the report, additional research is required to elaborate upon several findings.

On August 28, 2007 the SP/CNLS-IST signed a second grant agreement with the GFATM under the sixth round of HIV/AIDS grants (The Global Fund to Fight AIDS, 2008). The total amount requested was approximately US$71.4 million. The grant came into effect on October 1, 2007 and as of August 2008 about US$8.4 million had been disbursed. One of the main objectives of the grant is to “Improve accessibility and quality of therapeutic treatment and care, and the follow-up of PLWHAs, including co-infected people (TB/HIV)”, which includes ensuring the availability of ARVs (SP/CNLS-IST, 2006). The proposal estimates that the grant will “allow ARV care and treatment for 20 000 PLWHA by the end of 2010”.

At the time the present study was carried out, patients were asked to pay a contribution of 5 000 fCFA (about US$10) per month for their ARV treatment, an amount fixed in 2005 (Wyss & Wiess, 2005). According to a brief case study conducted in 2005, at the time there was no clearly defined plan as to what the sums collected would eventually be used for (Wyss & Wiess, 2005). Exemptions for those determined to be indigent (see “Results” section) are common. The monthly contribution per person for ART has since dropped to 1 500 fCFA (about US$3) (Sanou, 2008).

Though treatment is highly subsidized, the contribution requirement has been highly contested by groups advocating for gratuity of ARVs (Association Actions traitements, 2004). In June 2008 a symposium was held in Ouagadougou on the lessons learned about access to ART in the country (*Livre des résumés*, 2008). Several papers were presented that discussed the financial barriers to accessing ART. A heated debate ensued among participants – researchers, government and NGO representatives – on the feasibility of ART gratuity in Burkina Faso (V.Ridde, personal communication, June 2008).

CHAPTER FOUR: OBJECTIVE AND CONCEPTUAL FRAMEWORK

Objective of the Study

A significant amount of national and international resources have recently been invested in Burkina Faso (most notably through GFATM) to improve ART availability for HIV patients in the country. As mentioned in the "Literature Review", the success of ART is dependent on more than just drugs and must be delivered within a comprehensive package of care. Adherence support services are a central component of this package. Little is known about the context of ART provision at the site of distribution in Burkina Faso and which support services are provided to patients.

The government and its partners rely mainly on the public health system to dispense ART. The available literature has shown that health systems in sub-Saharan Africa are fragile and under-resourced. Burkina Faso is no exception. Studies demonstrate that the public health system performs poorly and inspires little confidence in its users. Health services are dispensed on a cost-recovery basis that hinders access for the country's largely impoverished population.

While the government has shown a strong commitment to addressing the HIV epidemic, it has not shown the same commitment in the past towards human resources in the health sector. Like many countries in sub-Saharan Africa, Burkina Faso suffers from a critical shortage of health manpower due in part to poor planning at the national level. Given that the dispensation of HIV-related services, including adherence support, is heavily dependent on healthcare providers, it is unclear how scale-up of ART has affected service provision at the level of the ward.

The objective of the present ethnographic study was to explore the perspectives of healthcare providers on the issue of adherence support at two hospital sites (three wards) in a context where ART availability is being scaled-up.

This objective lead to the formulation of the following research question: What are the experiences of healthcare providers in addressing patient adherence to ART in a context of treatment scale-up?

CONCEPTUAL FRAMEWORK

Ethnographic research implies the firsthand exploration of a particular setting by the researcher (Atkinson, Coffey, Delamont, Lofland, & Lofland, 2001). It is an inductive process that seeks an in-depth understanding of an issue through the use of various methods (see "Methods" section). In recognition of this, the conceptual framework adopted was large in scope and acted largely as a guideline rather than a structured approach to allow for considerable flexibility in both the data collection and analysis phases.

Hospital Ethnography

The hospital as an object of ethnographic study has been discussed in academic journals (Long, Hunter, & van der Geest, 2008; van der Geest & Finkler, 2004). Interest in hospital ethnography developed in the post-colonial period of the 20th century, when anthropologists began to turn a reflexive gaze toward their own societies (Long, et al., 2008).

There are two opposing perspectives in the field as to how the hospital should be perceived in relation to greater society. According to one paradigm, the hospital is viewed as a world apart from the prevailing context, an island in itself (van der Geest & Finkler, 2004). An alternate viewpoint suggests that life within the hospital is as an extension of life outside the institution.

> *"The authors contend that life in the hospital should not be regarded in contrast with life outside the hospital, the ''real'' world, but that it is shaped by everyday society. The hospital is not an island but an important part, if not the 'capital', of the 'mainland'."*(van der Geest & Finkler 2004)

The second approach was maintained in the present ethnography. The hospital is recognized as a setting where a panoply of factors inherent to a range of different levels – individual, hospital, health system, societal, and international – influences the behaviour of healthcare providers and patients on the ward.

This conceptual framework guided the data collection and the resulting analyses by compelling the ethnographer to interpret interviews, observed events, and document sources from a reflexive perspective that recognized individual behaviour as infallibly linked to the prevailing context in which it occurred. The results thus take into account the broader context and attempt to explain how the interplay of determinants both within and outside the hospital compound penetrate the ward and influence the provision of adherence services for patients on ART.

CHAPTER FIVE: METHODS

Study Design

The present project is an ethnographic study looking at the experiences of health providers in addressing adherence to ART in a context of limited resources where ART is being scaled-up. Savage (2000) has argued for greater inclusion of ethnography in health research. Ethnography is a highly contextualized and reflexive approach that seeks to understand phenomena in a natural setting from the perspectives of both the researcher and the researched (see "Conceptual framework"). This method can be particularly useful in health research in studying the organisation of health services. It has been further argued that qualitative methods are currently underused in the study of adherence and can be particularly useful in providing in-depth information about adherence such as access and reasons for non-adherence (Sankar, Golin, Simoni, Luborsky, & Pearson, 2006).

Context of the study and the ethnographer's position

The choice of setting for this study – two hospitals in Ouagadougou, Burkina Faso - was motivated in part by ease of access, and in part by familiarity.

The initial objective of the study was to look at human resources in the field of HIV/AIDS, with a particular emphasis on the role they play with respect to patient adherence to ART. As my fieldwork progressed, however, it became apparent that to understand adherence in this context, it was necessary to look beyond individual patient and provider interactions and study the influence of more systemic determinants of adherence support such as availability of resources (including drugs), socioeconomic and other external pressures (such as research projects).

I joined the *Appui aux Traitements Anti-rétroviraux en Afrique de l'Ouest* (Supporting Antiretroviral Treatment in West Africa – ATARAO) research group in November 2006. The group is a partnership between researchers in Canada, Burkina Faso, and Mali. Over the ten-month period prior to my departure for Burkina Faso, I participated regularly in group meetings and email correspondence of the Montréal team. In this way, I followed the progress of the project from the planning to the implementation phase.

The ATARAO cohort study was officially implemented in January 2007 in both Burkina Faso and Mali. The main goal of the project was to prospectively follow 400 HIV patients newly prescribed ART in each country. A subsidiary objective was to build research capacity among the African team members and junior Canadian researchers, including students like myself. While the funding for the project is provided entirely by a Canadian donor (Canadian Institutes of Health Research), teams of local researchers were established in both study countries. The study was preceded by a pilot study which took place in 2005 in partnership with the same local principal investigators. A longstanding relationship thus exists between the Canadian and the African partners.

The ATARAO study distinguishes itself from many North-South collaborations by the fact that there are no Canadian team members stationed permanently in the field and African partners work for national research centres (Costello & Zumla, 2000). Each country team is responsible for the management and implementation of the project at the country level while the Montreal team coordinates the overall project and the bulk of scientific production. The Montreal team periodically carries out training and monitoring missions. Two public health doctoral students studying at the *Université de Montréal* each spent five months in the field assisting with project implementation. In theory, the present study could have been carried out anywhere in Africa where ART is being scaled-up. However, the established relationship and the presence of the ATARAO country team meant that access to the field was greatly facilitated by the African partners.

I chose to conduct my fieldwork with the ATARAO project in Burkina Faso instead of Mali as I had previously visited the country for a brief period in 2006 while I was living in the neighbouring country of Ghana. As time and financial constraints permitted only for a relatively short fieldwork period of three months, I considered it prudent to go to a city that I was already somewhat familiar with. This proved to be a wise decision as my familiarity with Ouagadougou quickly afforded me the independence necessary to move between study sites with ease.

Prior to my arrival in Burkina Faso, it was made explicitly clear to both me and to the local team by the Canadian principal investigator of the study that my role in the project would be that of a student researcher. This implied being exempted from all coordination and administrative duties related to project implementation. This decision, taken with good intentions, proved to be largely unrealistic due to the unpredictable factors at play on the field (described below).

The ATARAO project in Burkina Faso was implemented at three participating study sites: two wards at a major public referral hospital and one ward in a small, non-profit medical centre. A fourth site in the community sector desisted from the project at an early stage of project implementation due to conflicting interests.

Site One is classified as a *centre medical* (medical centre), which means that there are no surgeries conducted (aside from caesarean section deliveries) and no hospitalisations (aside from paediatric and deliveries). Founded in the 1960s by Italians of a Catholic religious order, it is now run by an Italian paediatrician (Vice-Province Camillienne du Burkina Faso, 2007). The centre specialises in maternal and infant care and services mainly people of lower socioeconomic status. ART has been available for adults since 2003 and for children since 2004. Site One receives technical support in HIV care from hospitals and a university in Italy through the ESTHER project.

Site Two is a referral and teaching hospital. There were two participating study wards at this hospital: Ward A and Ward B. Both wards receive a significant number of HIV patients and are involved in the prescription of ART. Since 2002 the hospital has benefited from the technical support of the French-led ESTHER project. The initial goal of the ESTHER collaboration was to support the development of a specialized HIV centre and, eventually, the implementation of a day hospital.

At each site there was one ATARAO interviewer, aside from Ward B at Site Two where there were two (a second interviewer was transferred there after the desistance of the fourth site to help address the large influx of patients). The interviewers, along with a designated physician in the ward, were responsible for recruiting patients for the study and conducting interviews at three-month intervals over a one-year period. As will be discussed later on, the interviewers were quickly integrated into life on the ward and were often asked to carry out tasks other than those for which they were explicitly hired. Two project coordinators were responsible for overseeing activities on the study sites and responding to any issues raised by the interviewers. The coordinators were also responsible for managing logistical and financial issues and reporting back to the burkinabè principal investigator who is himself a senior physician at Site Two.

Shortly after my arrival in the field, it became apparent that the designated coordinators were much too occupied with their full-time positions[2] to adequately support the work of the interviewers. As I was present on the study sites on a daily basis, particularly at Site Two, I naturally became the relay person between the interviewers and the coordinators. This turn of events accorded me the added advantages of establishing credibility among hospital staff and providing me with duties other than those related to my personal research – in some ways affording me with a point of entry to conduct a certain degree of "negotiated interactive observation" (Wind, 2008).

Van der Geest and Finkler have addressed the complicated nature of the role of the ethnographer in hospital ethnography (van der Geest & Finkler, 2004). The nature of work in a hospital setting often confines the ethnographer to one of two roles: health

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[2] One coordinator held a full-time position in government as part of a team overseeing the activities of a major international HIV funding initiative. The other coordinator was a full-time nurse at one of the study sites.

professional or patient. Studies investigating the perspective of the health professional most often involve the ethnographer adopting the role of health provider. While not a trained healthcare worker, my ad-hoc role as middle-woman between the interviewers and the coordinators provided me with the legitimacy to spend several months on the project sites interviewing professionals and interacting with patients. On a more personal level, the small contribution I made toward the overall project functioning assuaged my guilt of carrying out research in an environment where no able hands remain idle.

Ethical Considerations

Ethics board approval for the ATARAO project was obtained from *le Comité d'évaluation scientifique et de l'éthique de la recherche Équipe Hôpital Notre-Dame du CHUM* (ND 07.013) and the *Centre Hospitalier National* in Burkina Faso. Ethical approval for the present study was also obtained from *Comité d'éthique de la recherche de la Faculté de medicine* of the *Université de Montréal* (CERFM 85(07) #257). There were no expected negative consequences for study participants. Particular attention was paid to render the identities of the participants anonymous in the present document.

Participants and Recruitment

The strategy used in the selection of participants was based on the premise that in order to understand the phenomenon under study a diverse array of perspectives needed to be collected (Giacomini, Cook, & for the Evidence-Based Medicine Working Group, 2000). Interview participants were selected using a judgement approach. The judgement sample implies recruiting those individuals who will most efficiently contribute to answering the research questions (Marshall 1996). This selection may be based on practical knowledge of the context, available literature and information gained through the study itself (Marshall 1996).

Participants of the study were HIV/AIDS healthcare providers working at one of the two study sites. With the help of one of the ATARAO project coordinators and senior physicians on the wards, health providers who were known to play an active role in the care of HIV patients were approached by the researcher to take part in the study. The selection process aimed to ensure that the perspective of each type of provider implicated in HIV care was represented. Often the participants themselves suggested individuals who they felt could offer an informed opinion on the subject matter – which contributed to a snowballing effect. There was one instance where a potential participant was approached and later declined an interview; one doctor in Ward B was approached and consented verbally to an interview but was transferred to a hospital in a rural region before an interview date was scheduled. The final sample of interview participants included physicians (7), nurses/midwives (5), pharmacists (2), lay counsellors (2), research interviewers (4), and one NGO representative. Two participants were approached for second interviews. Thus, a total of 23 formal interviews were conducted (see Appendix 1 for a breakdown of participants by site).

Instruments & Sources of Data

Semi-structured interviews

A semi-structured questionnaire with open-ended questions was used during the interviews (Appendix 2). The design can be characterized as a focused interview since it allowed the interviewer to broach a series of predetermined themes while leaving participants considerable freedom in terms of responses (Boutin, 2000). A process of respondent validation was undertaken; after each interview, information that was unclear or needed to be further expanded upon was compiled in a list to be discussed in subsequent interviews (Pope & Mays, 2000). This technique was used as a method to improve the quality and rigor of the study. Two participants who were particularly informative were each interviewed a second time – a nurse and a lay counsellor.

Observation

Observation was also undertaken in the three study settings. Observation is a valuable complement to semi-structured interviews (Grawitz, 2001). It is often used in qualitative research as a method of confirming data collected by other means - referred to as methodological triangulation (Pope & Mays, 2000). The necessity of adding an observation component to qualitative studies is aptly highlighted by the following quote: “Questioning the validity of checklists and the prevailing methodological orthodoxy in qualitative research is useful, but of greater relevance is the need to promote (and teach) a more observational paradigm for qualitative health research” (Power, 2001).

I observed activities in the wards, often engaging in informal conversations with those present (staff, patients, family members, other visitors). Observations were recorded in a logbook. This allowed me to gain a better understanding of the logistics of the ART distribution programme (i.e. layout of the setting, patient pathway, ambiance, etc.). Questions arising from observations were recorded and addressed to participants during formal interviews. Likewise, information provided during interviews was often confirmed through observation. These two methods were thus highly complimentary.

As mentioned previously, my presence on the study sites was legitimized by the role I played in the ATARAO research project. The tasks I carried out aimed to ease the workload and improve the work situation of those involved in the project: transferring materials and information between the sites, transporting blood samples to the laboratory, conducting quality control of the data, directing patients, and providing psychosocial support to the interviewers. These activities – which often had me running around the hospital – helped me to integrate the daily life of the sites, particularly at Site Two where I spent most of my time[3]. This shift in my role occurred naturally, though perceptively, and also marked the transition from non-

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[3] This was due to several factors, namely: there were two participating wards at Site Two, a higher patient volume, and a greater number of staff to interview.

participant observation to “negotiated interactive observation” (Wind, 2008). “The concept of negotiated interactive observation captures what happens when you are doing fieldwork without at the same time assuming that you become one of ‘them’”. Wind (2008) introduced this concept, arguing that it is an alternative to the more contentious concept of participant observation. Participant observation implies that the observer participates, that he integrates himself into the group; “that he is almost forgotten as an observer, but remains present as an individual” (Grawitz 2001). Participant observation is the Achilles’ heel of hospital ethnography as playing the role of patient or healthcare provider is often impossible or ethically questionable (van der Geest & Finkler, 2004). While my integration was clearly limited by several barriers (language, ethnicity, and short time-frame), these minimal tasks, consistent with the concept negotiated interactive observation, greatly enriched my understanding of the context.

Document review

Written documents were used to corroborate and elaborate on ideas raised in interviews and observation periods, acting as a third complimentary method. Aside from traditional academic sources (PubMed, Medline, etc.), media sources, government documents and donor reports were consulted to add depth and context to the findings. A variety of local sources of documentation was collected through contact persons on the field and internet searches. Examples of documentation used include: national guidelines for the care of HIV patients, prototypes of patient files and monitoring cards, grant proposals, national strategic plans on HIV/AIDS, and conference proceedings. These sources mainly served to contextualize data obtained through interviews and observation, adding historical, political and sociocultural depth to the study.

Data Collection Procedure

Interviews and observation were performed over a three-month period, from September to December 2007. Each participant was asked to give his/her informed consent prior to participating in the study (Appendix 3). Interviews were conducted by the ethnographer and took place at the work-site during regular work hours. All interviews were carried out in French, the official language of Burkina Faso and one spoken fluently by the participants and myself. As all health care providers in the three settings are fluent in French, no potential participants were excluded due to language barriers. Interviews lasted between 20 minutes and an hour and a half. An audio-recording device was used with the participant's permission to allow the interviewer to interact more fluidly with the provider. Interview data was transcribed by the researcher for use in the analyses. Citations used in the present document were translated free-hand by the ethnographer. Actual participant names were omitted to preserve confidentiality.

A logbook was used to record observational data and the ethnographer's reflections on the research process. Each logbook entry includes date and location.

Data Analysis

Once all interview data had been transcribed, a narrative analysis was conducted for each of the settings studied: Site One, Ward A, Ward B, the Day Hospital, and the Pharmacy. Four main reasons for conducting a narrative analysis in ethnographic research have been described: "concern with the meaning of experience, voice, human qualities on personal or professional dimensions, and research as a story" (Cortazzi, 2001). The narratives were based on typical situations that I had observed on the wards and were supported by interview data, informal conversations, and document review. Each narrative was designed to illustrate a set of themes that were particular to the setting and recurrent throughout the interviews conducted at the respective sites. The five narratives range between approximately 1 800 words to 4 500 words.

Once the five narratives were complete, they were first analyzed separately to extract recurring themes at each site. The themes were then compared and contrasted across sites. The final analysis, elaborated upon in the following "Results" section is the synthesis of themes common to all sites (e.g. ARV lifecycle) and particular to each setting (e.g. adherence infrastructure).

CHAPTER SIX: RESULTS

OVERVIEW

The present Results section is a product of the analysis of the provider's perspective on the provision of adherence support for patients on ART. While a more complete discussion of the study question would include the patient's perspective, this was beyond the scope of the present ethnography.

Several determinants emerged from the study that affect the provision of ART support by providers. The main factors that emerged were not individual such as provider behaviour, but rather determinants of more macro systems; ranging from the ward, to the health system, to the socioeconomic context, and finally to the international level. These I have termed "systemic adherence inhibitors" to reflect how they have the potential to impede the adherence support provided by the health professional to the patient and, ultimately, the adherence behaviour of the patient himself.

Systemic adherence inhibitors have been grouped into three categories that are each elaborated upon in the sections to follow: ART supports, daily life, the ARV lifecycle, and external pressures. The results section will conclude with a discussion on the evolving context of HIV care in Burkina Faso.

The results section is schematized in the following diagram where concentric circles depict the increasingly macro systems that impact the provider's provision of adherence support to patients on ART.

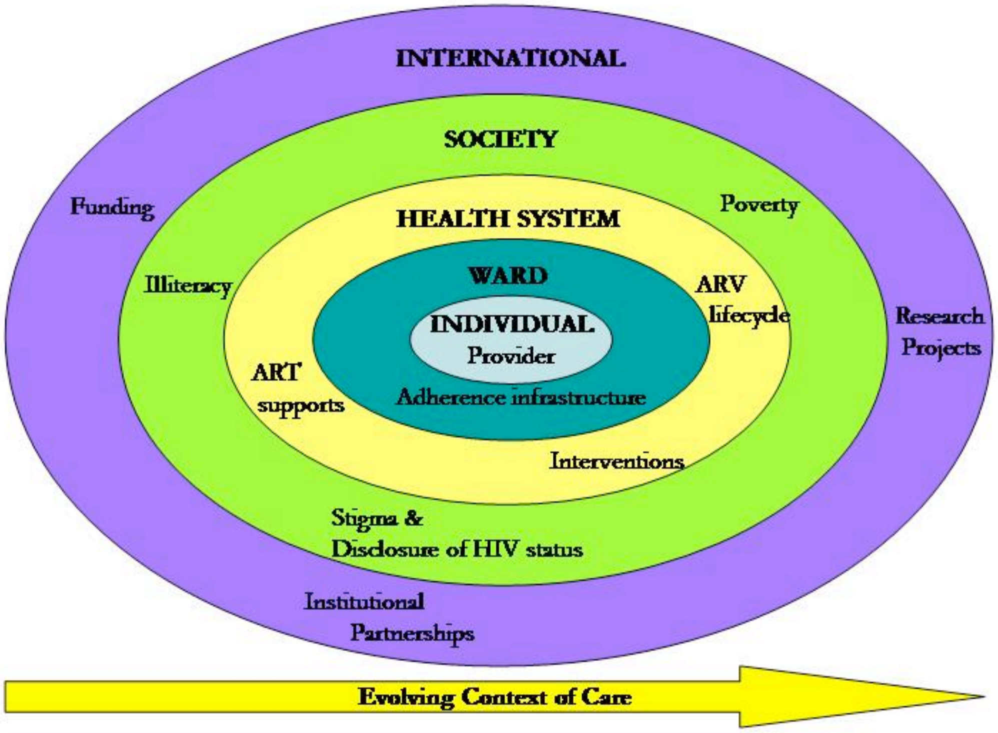

Figure 1. Schematic representation of results

Prior to delving into the above-mentioned themes, it seems à propos here to provide a brief description of the context of HIV care at each of the three sites.

Context of Care

This section will discuss the contexts of care at each of the three sites. Although each ward specializes in HIV care, they differ in terms of patient characteristics, entry point for care, the patient pathway of care, and human resources, among other things. The following descriptions seek to provide the reader with the necessary background information that will assist in the contextualization of subsequent results.

Site One

Prevention of mother-to-child transmission (PMTCT) is the main door of entry for HIV care at Site One. About 600 PMTCT-referred patients are followed here, three-quarters of whom are already receiving ART. Women are referred to the adult ward after testing positive for HIV at the VCT centre of the *Santé maternelle et infantile* (SMI - Mother and Infant Health Unit). One doctor described the care provided at Site One as follows, "*it's actually like a continuity*" (Doctor, Site One), referring to how women who receive prenatal care at the centre often continue consulting for other services for themselves and their children.

VCT services began at the SMI in May 2002 (Vice-Province Camillienne du Burkina Faso, 2007). During the morning prenatal consultations, two midwives educate pregnant women about HIV and the importance of getting tested. Those who wish to be tested then go to the VCT office (located just down the hall from the SMI waiting room) where they undergo an HIV test free of charge, administered by one of two midwives.

> "*Now those who wish come do their test. The test is free…and voluntary. We don't force them."* (Midwife, Site One)

The midwife concedes, however, that not enough women come forward voluntarily to be tested. Indeed, a study conducted at Site One between May 2002 and April 2004 found that less that one fifth of pregnant women at the SMI accepted VCT after group counselling (Pignatelli, et al., 2006).

> "*Not many. For now there are not many who adhere to it. Not as many as we would like."* (Midwife, Site One)

If the HIV test is negative, the woman is asked to return in three months for her regular prenatal follow-up. If it is positive, she is sent to undergo laboratory tests (CD4 count, haematology, etc.) - which are also provided free of charge to pregnant women - and is referred to the adult HIV care ward. The woman will continue consulting the midwives for pregnancy-related issues, but will receive HIV care, including ART, from a doctor in the HIV ward.

If the woman's CD4 count indicates that she does not yet require ART she is seen every three months by one of the doctors in the HIV ward for monitoring. At the 27th week of pregnancy, a midwife at the SMI gives her Zidovudine tablets. The pills are to be taken twice daily. Three additional pills are given in a separate pouch, to be taken at the onset of labour. The midwives insist upon the importance of adherence to the medication in order to protect infants from HIV. At each subsequent prenatal visit the midwife counts the number of remaining pills in the box to ensure the woman is taking her Zidovudine tablets correctly. If adherence problems are detected, a discussion between the woman, the doctor and the midwife ensues to determine how the situation can be remedied.

Three physicians share the consulting responsibilities of PTMCT-referred patients in the adult ward: a senior Italian doctor who is in charge of the ward, a young female burkinabè doctor who has been working there for less than a year, and a young female Italian intern. There are no nurses in this ward so it is the midwives – two of them – who assist the doctors during consultations. It is an arrangement born of necessity; the Italian doctors depend on translators to communicate with their mainly Mooré-speaking patients. Over time it has become the norm of care and the midwives assist the local doctor as well, though only for the PMTCT-referred patients.

> "*Otherwise, we help. We consent, we take the pressure, we look at the conjunctiva. Otherwise, the medical visit, it's the doctor who examines the patient. But we're there. If there is the pressure to be taken, we take it. The weight we take. We look at the conjunctiva…The medication as well, we can explain to the woman how to take them. Give the medications. But only in the presence of the doctor.*" (Midwife, Site One)

There is another local male doctor in the ward who sees adult HIV patients who are not referred by the PMTCT, of which there are approximately 220. These patients are referred mainly from the general adult consultation ward. This doctor sees patients alone; that is, without the help of the midwives. Nonetheless, he works in "*close*

collaboration" with the senior doctor on the ward and consults him regularly with respect to difficulties and other issues that arise in patient care.
An ATARAO interviewer is present on the site to conduct interviews and occasionally assists the doctors with the psychosocial counselling of patients.

Site Two: Ward A

Since 2003, HIV care at the hospital has been regular in the internal medicine ward. Until recently, all HIV patients who arrived at the hospital were referred there. They have the largest patient roster at the hospital, totalling over 2 000 patients (1 500 on treatment), and the most experience in HIV care. Most patients are referred here, either from the NGO sector, smaller health centres, or the hospital emergency ward.

Ward A was created in 2005 as a subdivision of internal medicine specifically for HIV/AIDS patients. It is located on the third floor of the main building of the hospital, across from the general internal medicine ward. Ward A caters to both inpatients and outpatients with HIV. In November 2007, all outpatient services were transferred to a brand-new Day Hospital, a separate building in the inner courtyard of the hospital grounds. In-patient services remained on the third floor.

The core staff on the ward consists of the following: six doctors, three nurses (two of whom are specialized in adherence counselling and ART prescription renewals), four mediators (lay counsellors), three part-time psychosocial counsellors, and five orderlies. One ATARAO interviewer is also present for the duration of the research project.

Prescription renewal was added to the duties of nurses trained in the *Diplôme Inter-Universitaire* (Inter-University Diploma - DIU) in 2006 to help manage the large influx of patients arriving for treatment. The DIU was initiated in 2004 with the assistance of various national and international partners (WHO, ESTHER, *Sidaction*, the *Société française de lutte contre le Sida* and the CFAO) and presided over by the Chief of Internal Medicine of Site Two (Sidwaya, May 17, 2004). The programme aims to contribute to an improvement in medical care for people living with HIV in francophone Sub Saharan Africa. The month-long course is attended by professionals, community workers, and people living with HIV across francophone Sub-Saharan Africa.

When the nurses are busy, the psychosocial counsellors sometimes renew prescriptions, though they are not authorized to do so unless a nurse is present. The psychosocial counsellors were recruited from the NGO sector specifically for another research project taking place on the ward. They are considered "*patient experts*" as they themselves are HIV positive and have experienced many of the situations encountered by the patients. Until the end of 2007 they were responsible for only the 80 or so patients taking part in the research project. As the project was coming to an end and the participants were to be integrated into the regular patient roster, the psychosocial counsellors were asked to assist in the adherence counselling of all the ward's HIV patients.

The four women mediators are lay counsellors hired under the French-funded ESTHER project. One senior doctor described them as follows: "*they are the bridge between the patients and the doctors*". Their duties on the ward include booking appointments and taking out patient files, arranging for the meals of the hospitalized patients, psychosocial counselling of patients and their caregivers, adherence counselling, and occasional home visits. They are the first point of contact for patients on the ward. The mediators also play a central role in tracking patients who are lost to follow-up. I was told by several people that the ESTHER project will be coming to an end in the coming years and no one seemed quite too certain whether or not the mediators would remain on the ward thereafter.

Site Two: Ward B

Care of HIV patients is somewhat new in Ward B. As mentioned above, all HIV patients were previously transferred to Ward A. In 2004, according to the head nurse, the ward was officially recognized as an HIV care centre. At the time, most HIV patients treated here presented with dermatological problems and later tested seropositive.

The core of the ward’s staff consisted of the following: the Chief of Ward B (present only on Wednesdays), a senior doctor in charge of HIV patients and the ATARAO research project, a specialist doctor, five nurses, four medical interns, four orderlies, and a secretary. Two ATARAO interviewers, both women, were also present on the ward on a daily basis. A third doctor who cared for HIV patients on Friday afternoons accepted a position at a hospital in a rural region shortly after my arrival on the ward, as mentioned in the “Methods” section.

At the time the fieldwork for this study was conducted, none of the nurses and only one of the doctors had participated in the DIU programme on HIV care. All providers involved in patient care had, however, received some form of in-house training in the care of HIV patients.

There are two types of HIV patients cared for in Ward B: those with dermatological problems and those referred by HIV care NGOs, whether or not they have dermatological problems. The number of patients in the second category increased dramatically in the initial months of my fieldwork and tapered off by the end for reasons that will be discussed shortly.

Adherence infrastructure

Patient adherence to ART was a central preoccupation of all health providers interviewed. My initial interview guide was composed of two sections: questions relating to the general care of HIV patients and questions relating specifically to how ART adherence among HIV patients is addressed. I quickly realised, however, that the two were so closely entwined that trying to separate them was unfeasible.

Each of the three sites had implemented, to varying degrees, procedures to monitor patient adherence to treatment – an “adherence infrastructure” as I have dubbed it. Site One provides an example of a tight-knit circuit where patient care is both familiar and easily monitored. Ward A, on the other hand, disposes of a fairly elaborate adherence infrastructure integrating various tools and types of providers for monitoring patient adherence. Ward B disposes of a limited adherence infrastructure and struggles to track its recent influx of patients.

This section will provide an in-depth discussion of the adherence infrastructure at the three sites. It aims to illustrate that how the differences in the contexts of HIV care led to variations in the organizational structure of adherence services implemented on each ward. Despite these variations, each ward had invested in some form of adherence infrastructure.

Site One

Site One provides a continuum of care to patients and their families. For instance, if a patient is followed here for HIV, she usually also receives free formula milk for her baby from the neonatology ward. When the patient picks up her supply of formula milk, the nurse will ask her when the last time she saw her doctor was and when her next appointment is scheduled for. Nurses and midwives from neonatology also conduct home visits as a means of patient follow-up. If a patient misses several appointments, it is usually relatively easy to track her.

> "*But also, as the centre is large: we have the weigh-in for the pregnant women in Mother and Infant Health, we have the neonatology ward, where the milk is given. So, we always manage to track our patients*". (Doctor, Site One)

Each patient is given a blue *carte de suivi* (monitoring card) once she is referred to the adult HIV ward and is added to the patient roster. The cards are an initiative of the Ministry of Health. They are used in a slightly different manner at Site One as compared to Ward A and not at all in Ward B. One side of the card indicates patient information such as file number, name, sex and year of birth. The other side displays a table of months across the top and years down the side. Each cell is subdivided into two: one section indicates the date of the appointment and the second the date that the patient actually came. The card is used at Site One to monitor patient adherence to medical appointments. The first month that a patient begins treatment, she is seen every two weeks. From months two until six she comes once a month, and thereafter every two months. Each time she goes directly to the doctor, without passing through an intermediary.

Patients are informed early on in the process of HIV care about treatment.

> "*Every six months you will monitor your CD4s, until the time when you start treatment. He knows for now he won't start, but he knows that one day he may start…The person is already prepared psychologically*" (Midwife, Site One).

Patients meet with the doctor a minimum of three times before ART is prescribed. The first time, the physician performs a clinical exam and assesses the patient's WHO clinical stage of HIV. At this point the doctor also prescribes laboratory tests for the patient to complete, including CD4 count. When the patient returns with her results, the doctor can then assess whether or not she is ready to begin treatment.

> *"It's the CD4 count that will determine whether you put the patient on ARVs or whether you don't put him on ARVs. Even if the person is stage 1 or 2 (WHO) but his CD4s are under 200, we recommend that the person be put on ARVs. And the patients who are stage 3 and 4, no matter what the CD4 count is, we automatically put them on ARVs."* (Doctor, Site One)

Before prescribing ART, however, the doctor first prescribes cotrimoxazole (an antibacterial drug used to prevent and treat opportunistic infections) for a period of two weeks. Following this trial stage, the patient returns and together they determine whether she is ready to begin treatment; that is, whether she will be adherent.

Pill counting and questions about pill-taking behaviour are the main strategies used to monitor patient adherence to ART. The process is transparent and shared between the patient, the doctor and the midwife.

> "*Because there are some who will initially say, 'no, I've never forgotten'. But when we base ourselves on pill counting we realise that there were some misses.*" (Midwife, Site One)

If problems are detected they try and find a solution together. Similarly, if the ATARAO interviewer detects adherence problems during one of her interviews she advises the doctor.

> "*If there is a problem like that, of adherence, that is serious enough, even if it is not serious, if there is a problem that I detect during my interview, from what he is saying, then I signal it.*" (Interviewer, Site One)

One doctor says patients display few adherence problems in the beginning. Problems arise once the patient has been on treatment for some time, a phenomenon also observed by the other local doctor who treats HIV positive adults not seen in the PMTCT circuit.

> "*From six months onwards. Six months, one year. Because the first six months, even the first year, generally the patients are adherent. Because of the benefits of the treatment, life has changed. They try to be maximally adherent. But after a year they are a little tired of always taking the products. They have already forgotten what they have lived before as well*". (Doctor, Site One)

According to the doctor, most of the adherence support is provided by an NGO initiated by Site One patients in 2004. The organization caters particularly to the needs of HIV positive mothers and their children and offers a range of services, including counselling and adherence support clubs. The hospital staff members readily extol the role the NGO plays in ensuring patient adherence to ARVs. “*The brunt of the work is done by the association*” (Doctor, Site One). Women patients, particularly expectant mothers, are systematically informed about the NGO when they begin receiving care at Site One and are encouraged to join the organization.

> “*The problem is that we don’t have a psychologist to see. Because they have done the test, it’s positive, morally they are not well, they have to, well…The advice that we give them is that they have to join an NGO. We have had to give that advice often, to show them where the organization is.*” (Midwife, Site One)

> *“And so, usually, those patients who have difficulty accepting their state, we refer them directly to the NGO where they chat with other people who are like them, who have had negative babies. It stimulates, it helps them to easily adhere to the therapy.”* (Doctor, Site One)

In summary, the adherence infrastructure at Site One is mainly built around close relationships and centralized care. Medical follow-up, ART, and adherence counselling are all dispensed at the same time, in the comfort of the doctor’s office, and this for both PMTCT-referred patients and other adult HIV patients. The centre’s family-focused care also means that patients can easily be traced since in general they use services in more than one ward; this is particularly the case for patients with children. The health providers have responded to the gap in psychosocial services at the centre by systematically referring patients to NGOs where they receive additional support.

Site Two: Ward A

As described previously, Ward A is a specialized HIV ward in one of the country’s major referral hospitals. Not only do they have significantly more patients on their roster than Site One (about 2000 versus over 800), but more staff is involved in the care process. Patients must follow an elaborate circuit of care that involves meeting with diverse categories of healthcare providers and – before the advent of the Day Hospital in November 2007 – visiting several offices around the hospital.

As at Site One, patients receive their first prescription for ART from their doctor after clinical and laboratory exams have assessed readiness for treatment. As a general rule, those persons with a CD4 count of less than 200 are eligible for ART. This process usually involves a minimum of two visits to the doctor and laboratory tests in between. Once the doctor has written the prescription, the patient is sent to one of the two nurses trained in adherence counselling for their pre-ART counselling session. If the nurses are busy, the doctors sometimes call upon the ATARAO interviewer, one of the psychosocial counsellors, or even one of the mediators, to conduct the pre-ART counselling sessions.

During the pre-ART counselling session, the patient is encouraged to choose two daily medication times, twelve hours apart that are conducive to his schedule. He is advised about adherence, side effects, nutrition and positive living. One of the nurses referred to this as "*therapeutic education*." This is not the first time the patient will have heard about treatment. In the HIV care circuit, starting with VCT, the patient is often informed about treatment options. According to the ATARAO interviewer, the patients arrive ready to begin treatment.

> "*When we refer a patient, it is with the goal of beginning treatment. We see that the patient himself will come prepared. He comes for this, to have treatment.*" (Interviewer, Ward A)

Following the pre-ART counselling session, the patient must go and pick up his medication. If he is considered too poor to pay the monthly fee for treatment, he first visits the Social Services office of the hospital. There he will receive a stamp on his prescription indicating that he is exempted from payment (see section on "ARV Lifecycle"). He then goes to the ARV pharmacy to pick up his prescription.

There are two ARV pharmacies at the hospital where all HIV patients go to pick up their prescriptions: a central one where the pharmacists have their office (located on the first floor of the main hospital building), and an auxiliary one. When I began my fieldwork, the auxiliary pharmacy was located on the third floor of the hospital, just outside Ward A. The door leading to it was unmarked to preserve the confidentiality of the HIV patients (see section on "Daily life"). At the time, the patients were referred to one of the two to pick up their prescriptions, depending on the pharmacy schedule. In November 2007, the auxiliary pharmacy was transferred to the Day Hospital along with the rest of outpatient services. Thereafter, patients were able to procure themselves of their monthly supply of ARVs at one location. According to the ARV pharmacist, patients receive information about their medications and adherence at the level of the pharmacy. This claim, however, was not corroborated by observation data and seemed unlikely given the long queues of patients outside the pharmacy door on renewal days.

Patients receiving a supply of ARVs for the first time are asked to return to Ward A to the nurse or the doctor (depending on availability) where together they go over the modalities of pill-taking. The patient is asked to return in 14 days to see the nurse. At this time they discuss how he is responding to treatment and if he is experiencing side effects. If all is well, the nurse will give him a second prescription for the remaining 14 days in the month. In case of problems, he is referred to the doctor. The patient will return again in two weeks for his third prescription. From this point onwards, he will come once a month to have his prescription renewed by one of the nurses. If a problem arises in the meantime, however, the patients are encouraged to return to the doctor on the ward as soon as possible.

> "*As soon as they have a problem, they just have to come back.*" (Nurse, Ward A)

Prescription renewal sessions are scheduled for Tuesday and Thursday mornings, though it seemed patients came in most mornings (aside from Wednesdays which were reserved for the rounds of hospitalized patients). Patients go directly to the Adherence Room – an office reserved mainly for the nurses and psychosocial workers, though sometimes the mediators worked there as well - and place the blue carbon copy of last month's prescription at the bottom of the pile that grows steadily throughout the morning. The patient then goes to wait in the cramped hallway. One of the two trained nurses then copies out a new prescription on a prescription pad. The date on the old prescription is used to verify whether or not the patient is refilling his medication on time – a strategy for monitoring adherence. The renewal appointment is set for one week before the supply of medication runs out. The patient receives two copies of the prescription: a white one to be given to the pharmacist and a blue one to be used for next month's renewal. A third pink copy remains in the prescription pad and is thrown out with the pad once it is full. While one nurse is busy copying out prescriptions, the other nurse (or sometimes the mediators) calls out patient names to come forward and retrieve their new prescriptions.

When all the patients have been attended to, the old blue prescriptions are used to fill out the blue stock-card monitoring card. Only patients on treatment receive this card, unlike at Site One where all patients, regardless of treatment status, receive a card. The cards are kept in a long wooden box on a table in the Adherence Room instead of with the patient as is done at Site One to avoid the possible stigmatization of HIV patients (see section on "Daily life").

The monitoring card is the same as the one used at Site One. Here, the table is used to track the prescription renewal date and the date the patient actually came to renew. Along with the blue prescriptions it is another strategy used to monitor patient adherence to treatment. The process was not as thorough as the nurses and mediators would have liked it to be. According to the mediator I interviewed prior to the move to the Day Hospital, she and one of the nurses planned to overhaul the system once they were settled in the new building. Indeed, within the first month at the Day Hospital I witnessed her meticulously going through the cards.

> *"(He) confirmed to me that when we move we will take everything out, to find the mistakes, to put everything in order. Otherwise, I can see on the cards that they didn't check them. The patients came, but they didn't check them. But since I arrived, I have been trying. Each patient who comes, I go, I check, I go I check. Because if we don't check them, we can't know if the patient comes."* (Mediator, Ward A)

Every trimester, the ART pharmacist and assistant pharmacist send out an Excel file to each ward containing the names of all patients in the hospital on treatment. The nurses, with help from the mediators and the doctors, are asked to update the file with information on patient deaths and transfers. Like the monitoring cards, it is a way to determine which patients have been lost to follow-up. The mediators will occasionally be given funds to contact these patients by phone or even to conduct home visits, although this is quite rare.

The nurses, and sometimes the doctors, take the time to counsel patients who have manifested adherence difficulties - detected mainly by missing doctor or prescription renewal appointments. They will first try to "*diagnose*" what the problem is – how many pills he has skipped, since when, etc. They will then counsel him and suggest solutions, taking into consideration his personal situation. These individualized counselling sessions were the main adherence support strategy used at all three sites studied.

> *"Really, the recommendations depend on the difficulty we discover"* (Doctor, Ward A).

The two nurses trained in the DIU are the professionals officially designated to address adherence in the ward. Indeed, everyone I interviewed said that adherence was largely their responsibility. Most, however, also maintained that everyone in the ward plays a role in supporting patient adherence.

> "*They work together. That's not to say they do the same thing. But, it's all a framework. Therefore, it's a system…Therefore, really, they are people who work together…. I want to say that (adherence support) is not a detached role here that we are able to say 'that person completely takes care of adherence'. Like I told you, it's all within a framework (system). That is to say it is at different levels that we can talk about adherence."* (Interviewer, Ward A)

> "*Well, everyone is involved in the organization. Often, well, we guide the patients, everyone is involved.*" (Nurse, Ward A)

> *"Well, everyone takes care of it. Because when you follow the…for example, when we give the appointments, the day of the consultation you realize that there was a patient who was supposed to come and didn't, you signal it first to the mediators so that they can try and find out. And then you go to see at the level of the pharmacy if he goes to get his medications. And when he doesn't come and get his medications, well, the mediators look for him and when he comes back we say, well, we have to go talk to him a bit."* (Doctor, Ward A)

The doctor is ultimately the person who takes the final treatment decision if the adherence problem is serious enough, for instance if a patient has stopped taking his treatment altogether.

> *"We talk to him here. We tell him of the risk he is running if he continues. Now, if the length of time is long, we send him to the doctor. Or if he did it (missed appointments/doses) up to two times, we send him to see the doctor."* (Nurse, Ward A)

The outpatient services were transferred to the Day Hospital in November 2007, as mentioned previously. The adherence infrastructure remained largely the same but the centralization of most services in one location greatly facilitated the patient circuit of care. Patients are now able to consult their doctor, renew their prescriptions, benefit from adherence counselling and fill their prescriptions at the pharmacy on the same floor of one building. There are also plans for the staff of the Social Services to train the mediators in providing exemptions for treatment costs, which would avoid patients having to go to the Social Services in the main building. Eventually, the only services that will not be available at the Day Hospital are laboratory tests, for which the patient will continue to go to the main hospital test centre.

In summary, the adherence infrastructure in Ward A is a highly developed system dependent on various types of health providers and monitoring tools. This system was developed over time as the patient roster increased with improved availability of ART in Burkina Faso. The ward benefits from the added support of personnel hired with the funds of externally funded (both national and international) projects (i.e. mediators and psychosocial counsellors). Despite the large number of patients who consult in Ward A the infrastructure allows the staff to at least target those patients who clearly manifest adherence difficulties.

Site Two: Ward B

The patient circuit in Ward B is similar to that of Ward A but much of the adherence infrastructure is missing. One of the most noticeable differences is the absence of the mediators. At Ward B it is the nurses and, recently, the ATARAO interviewers, who are responsible for most duties ranging from prescription renewal to psychosocial counselling.

As mentioned in the section on “Context of care”, until recently most HIV patients in Ward B were receiving treatment for dermatological problems. At the time I conducted my fieldwork, however, patients were avidly being recruited to initiate treatment (and to participate in the ATARAO research project) from NGOs where treatment was no longer available[4]. As a result, staff were adjusting to a change in

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[4] During the same period, many NGOs were struggling with funding uncertainty. According to one NGO representative, this uncertainty was largely due to the approaching end of the World Bank-funded Treatment Acceleration Program (TAP) which had financed the initiation of ART for many HIV patients. As a result, many NGOs stopped accepting new patients and began referring them to medical centres. Through conversations at the XVII International AIDS Conference with an employee

both the number and the type of HIV patients they were seeing; patients (with or without dermatological problems) now arrive with a referral sheet from an NGO or other health structure indicating his HIV status and type. The nurse then completes a form for the patient to undergo laboratory tests, including CD4 count if required. As some organizations conduct CD4 tests, a patient may arrive with these results. This procedure diverges from that of Ward A where it is the doctor who prescribes the laboratory tests after meeting with the patient for the first time. Laboratory test results are usually ready within 72 hours.

Once the patient has the results of his laboratory tests, he comes back to the ward to see the doctor. At this point, he will be prescribed ART if he is eligible (according to the same criteria used at the other two sites). He is then directed to either the nurses or the ATARAO interviewers for pre-ART counselling. The information provided to the patient during pre-ART counselling is theoretically the same as described for Ward A. Once that is complete, he goes to the pharmacy to pick up his prescription (detouring by the social services if he is determined to be indigent) before coming back to have the dosages explained for a second time by a nurse or an ATARAO interviewer.

The whole process of treatment initiation is completed rather quickly as compared to the other sites and two of those interviewed expressed concern that this rapidity negatively affects patient adherence. As will be discussed in a later section, these two respondents blamed the ATARAO research project for an increased speed of ART prescribing. This concern about adherence may have been compounded by the fact that an “adherence infrastructure” was not in place here as it was in Ward A. Ward B did not have mediators or psychosocial counsellors to provide psychosocial support to patients, nor did they have the blue monitoring cards to tangibly monitor patient adherence to prescription renewal. Indeed, these “tools” were suggested by the providers I interviewed as a way that adherence support could be improved.

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of the SP/CNLS-IST in Ouagadougou, who works on the GFATM portfolio, and an employee of Sidaction in France, I learned that GFATM had agreed to cover the funding of TAP. NGOs were, therefore, beginning to accept new patients again.

Furthermore, only one of the doctors and none of the nurses had participated in the DIU on HIV care (though they had all received some HIV training at the level of the hospital). Adherence was monitored mainly through the verification of the date on the previous month's blue copy of the prescription (as in Ward A) and individualized counselling sessions.

In summary, Ward B had the least developed adherence infrastructure of the three sites studied. This lack of infrastructure was aggravated by a recent influx of HIV patients (see section on "External pressures") and an insufficient number of staff who had not received specialized training in the care of HIV patients.

Systemic Adherence Inhibitors

The term "systemic adherence inhibitor" was coined in the present study. It implies determinants at the ward (hospital), health system, societal, and international levels that can potentially obstruct the adherence support provided by individual health providers, and that ultimately may prevent patients from being optimally adherent to treatment regimens. As illustrated by the diagram at the beginning of the results section, these determinants range from the micro level of the ward to the macro societal and international contexts.

This section presents four broad themes: ART supports, daily life, the ARV lifecycle, and external pressures. Two of the four themes discuss systemic adherence inhibitors with respect to a particular system (i.e. ART supports and daily life); the other two include determinants that initiate at a particular level but produce impacts on other systems (i.e. the ARV lifecycle and external pressures).

ART supports: not only a matter of giving drugs

New international funding for treatment means ART is more accessible in Burkina Faso now than ever before. The difficulty lies in ensuring that providers and patients have all the necessary tools to maximize treatment efficacy, ranging from laboratory tests to psychosocial support, from medication for opportunistic infections to sufficient health professionals.

This section will discuss "ART supports" - the auxiliary tools that the health system must supply in order to ensure effective adherence monitoring - and their present scarcity in the three sites studied.

Laboratory tests

Several of the providers interviewed cited availability and access to laboratory tests such as CD4 counts and viral load testing as a main difficulty in efficiently monitoring patients on treatment. Such tests are not available free of charge to patients which means that the majority cannot afford to have them done on a regular basis. (Exemptions for tests may be granted from the Social Services, but apparently they are not as easy to obtain as for ART and not all tests are eligible.)

> *"At times we are missing resources, in particular, you can ask for a test and the test does not come. When it's like that, you as a doctor, it puts you, it limits your actions. You wait for the test to be able to do something."* (Doctor, Ward A)

Furthermore, even when patients are able to pay for the tests, they are not necessarily available. In the past, there have been supply breaks in CD4 testing as a result of lack of reagents or even- as two doctors mentioned - a lack of forms to prescribe the tests. Viral load testing was either non-existent at Site Two or sporadic; it was never quite clear to me what the situation was.

> *"Presently we can't even do the viral load. That has also stopped. I don't know if it's a problem of materials, what's going on, but there are patients who have been waiting for months and still don't have their results…We want to know if the medications they are taking are still working, or if they have developed a resistance."* (Doctor, Ward B)

At Site One, viral load testing was available, but again access was contingent on the patient's ability to pay.

> *"And now, after six months we redo all the exams. And now, if possible, if the patient has the financial possibility to do the….viral load, we ask him to do the viral load."* (Doctor, Site One)

Lack of these laboratory exams made it difficult for doctors to make clinical decisions about treatment and compromised continuity of care as a result.

Psychosocial care

Several providers interviewed cited social problems as the main barriers to patient adherence to ART.

> *"Generally, there is always something that explains it, particularly social factors and also not having enough to eat, or the patient is hospitalized somewhere."* (Doctor, Ward A)

> *"…it's mainly social problems that cause patients to not be adherent. It's true that a small number of patients who haven't shared their serology with their partners which poses problems, work, but it's really social phenomena that cause patients to be non-adherent."* (Doctor, Ward A)

Ward A benefited from the presence of the mediators and psychosocial counsellors who, along with the specially trained nurses, were responsible for psychosocial counselling on the ward. Due to the high volume of patients, however, providers were not able to spend a sufficient amount of time on psychosocial counselling.

> *"It's mainly the number of patients. We have lots of patients…and we don't manage to follow the entire group of patients, as we would like to. That, really, is a weakness. We don't really manage to get our hands on all our patients. Well, put our hands on is perhaps too harsh. What we would have*

> *wanted is that each patient has an (adherence) consultation appointment, where we would get to discuss with him. But we are not able to do so because there are too many patients. What we manage to do, during renewals, the patients who are in trouble, of adherence, or just in trouble, we try to discuss with them. With them in particular. But, we should be doing it even with those for who the treatment is working; normally we should be talking to them because you never know."* (Nurse, Ward A)

In Ward B, as there were no mediators or psychosocial counsellors, psychosocial support was provided mainly by the nurses and the ATARAO interviewers. The presence of the ATARAO research project on the ward had the positive impact of rendering psychosocial counselling more available to patients, despite increasing the workload on the ward overall (see "External Pressures" section).

> *"Yes, there is an impact – it's positive. Because the support that we provide to the employees on the ward, we help them as well. There's that. There's also the fact that we cheer up the patients during our interviews. We contribute to adherence."* (Interviewer, Ward B)

At Site One the psychosocial support deficit was managed by developing a close relationship with an NGO, as discussed previously. According to one doctor, most of the adherence support is provided by the NGO through a range of activities, including: counselling, support groups, adherence clubs, nutritional support, and income-generating activities. Adherence clubs are led by members of the organization who have special training in ART and adherence from one of the national NGOs[5]. At adherence club meetings, members – both those who are on ART and those who are not – ask questions and discuss their concerns relating to treatment.

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[5] Five members of the NGO had been trained either by the *Programme d'appui au monde associatif et communautaire* (PAMAC) or the *Centre d'information, de conseil et de documentation sur le Sida et la tuberculose* (CIC-doc), two NGOs operating at the national level.

All those interviewed across the three sites considered that one of the ways adherence care could be improved is by introducing more psychosocial activities on the ward: support groups, adherence clubs and home visits. Many of the providers interviewed at the hospital suggested hiring more lay counsellors like the mediators to respond to the psychosocial needs of the patients. In settings of limited resources, however (such as the ones studied), additional services are contingent on funding.

> *"If we have (grants) we will add (activities)"* (Doctor, Ward A)

Medication for opportunistic infections

One of the main difficulties faced by the pharmacists and, in turn, by the doctors, is the supply of medications to treat opportunistic infections. Supply problems are the result of both breaks in supply and actual unavailability.

> *"Well, the difficulties are only at the level of certain products. Certain products. For the ARVs, really, it's ok. But at the level of medications for opportunistic infections, we have many supply breaks. The demand is very high."* (Assistant pharmacist, Site Two)

The ART pharmacist at Site Two reported that international and national organizations often donate a limited shipment of medications to treat opportunistic infections on a periodic basis. This contributes to rendering the supply irregular as the donations inevitably run out.

The range of products available is also limited and even further constricted by the patient's socioeconomic status. This ultimately impacts on the provider's ability to efficiently treat patients.

> *"Well, the difficulties related to patient care are especially tied to treatment because we are often confronted with patients who are financially destitute. So, when you prescribe a treatment, he comes back to say that he was not able to buy it. So, already at the level of prescriptions we are limited because we*

> *have to take into account the socioeconomic status of the patients and see what medications are available, are made available free of charge for opportunistic infections. And to see if among these medications we can prescribe for the pathology we want to treat. It's not always possible because there are not a lot of things that are free of charge."* (Doctor, Ward B)

Both the ART pharmacist and assistant pharmacist believed that adherence support could be improved by making medications for opportunistic infections more available and accessible to patients. Recommendations by several providers, particularly physicians, echoed this claim.

Insufficient healthcare providers

As discussed in the literature review section, the healthcare provider is an integral, but often overlooked component of any health intervention. Several of those interviewed found that the number of personnel was insufficient to respond to the needs of the increasing number of HIV patients on their wards.

> *"In terms of doctors we are not many which means that the workload is enormous."* (Doctor, Ward A)

The number of HIV patients consulting at Site Two has drastically increased over the past few years with improvements in availability of ART. "Taskshifting" (UNAIDS & PEPFAR, 2007) has been used as a method to address this situation. For example, specially trained nurses at Site Two are responsible for ARV prescription renewals and adherence counselling, rather than doctors. In Ward A there are only two nurses who are authorized to renew prescriptions.

> "*...in the beginning it was the doctors who did it themselves. They saw that it was really...That it was a bit difficult because there were many patients. They had to renew before they began consulting. I believe it was, yes, it was in February 2006 that I began this."* (Nurse, Ward A)

Since one nurse began renewing prescriptions in 2006 the number of patients on ART has more than doubled; from 600 to about 1500.

According to one of the nurses, one of the difficulties of the added task of prescription renewal is that they are still expected to carry out regular nursing duties on the ward – including nightshifts. On days when there are dozens of patients waiting for their prescriptions, if one nurse comes off night duty he is expected to stay and help his colleague until the flow of patients has ebbed somewhat. He suggested that work conditions would be better if the two DIU-trained nurses were discharged from regular nursing duties to concentrate on adherence counselling and prescription renewal. This, of course, implies hiring further nursing staff to replace them. After the transfer to the Day Hospital one of the two nurses was discharged from regular nursing duties to concentrate on "*therapeutic education"* but it is unclear whether or not another nurse was hired to replace him on the ward.

The staff on Ward B ward came to rely heavily on the ATARAO interviewers for tasks ranging from counselling to appointment scheduling to prescription renewal.

> *"Well, I think that it's mainly due to their workload; their workload because there is not enough personnel. Also, I think that it's the different trainings I've received because firstly through ATARAO I received training in counselling and also, under Ward B, I participated in a training session on adherence."* (Interviewer, Ward B)

As mentioned in the previous section on psychosocial support, a critical lack of personnel impacts on the quality of care patients receive. This is particularly the case with respect to adherence support which, in the present adherence infrastructure, is highly dependent on provider availability. With the current number of patients, doctors do not have enough time to properly counsel patients about adherence.

> *"Really, if it's concerning adherence, each time we meet a patient we at least ask him 'are you taking your medication properly?' At least that question. Each time we meet the patient we at least ask him that question. But now we don't have time to go into detail."* (Doctor, Ward A)

The deficit in staff becomes even more marked when part of the adherence infrastructure goes awry. One doctor at Site One talked about how patients who miss their appointments and arrive unexpectedly throw her whole schedule off kilter, leaving her with insufficient time to conduct proper consultations.

> *"And then those who miss appointments are obliged to come another day either because the products (ARVs) are finished or to restock before the products are finished. Then it swells the queue waiting in such a way that the time you spend with each patient is insufficient. I can recognize it myself, but I can't do otherwise because if I want to give more time I'll never finish. So you are obliged to go fast, and it is when you go fast that problems arise. You need a lot more time, to chat with the person, so that the person opens up. It also contributes to good adherence (to treatment)."* (Doctor, Site One)

A lack of personnel not only compromises current quality of care but impedes the ability of wards to introduce new services for patients. The pharmacist, for instance, proposed that adherence monitoring could be improved by using pill-counting as a strategy. She thinks this would be ideal but the current patient load makes it unrealistic.

> *"I think we want to but with the number…it's not easy. (laughs). Unless they send us personnel."* (Pharmacist, Site Two)

Several providers interviewed maintained that in order to respond to the psychosocial needs of the patients more personnel needed to be hired. As mentioned previously, they recommended hiring lay counsellors highlighting the notion that added personnel need not be highly trained.

Summary

The majority of the interviews and observation periods conducted revealed that accessing ART itself was not the main problem in ensuring adherence support for patients. Rather, this support was compromised by a lack of "ART supports" in the health system such as laboratory tests, psychosocial supports, and medications for opportunistic infections. Furthermore, a critical lack of all categories of personnel across the sites meant that the quality and degree of implementation of both present and proposed adherence interventions was jeopardized.

Daily life: the socioeconomic and cultural context of Burkina Faso

The conceptual model of the present study was founded on the premise that health care centres are not distinct from the world outside their gates. Rather, they are microcosms of society where existing socioeconomic, political, and cultural forces are at play. In the previous section it was discussed how the health system (in collaboration with the NGO sector) must ensure more than just access to drugs in order to efficiently support and monitor adherence to ART among patients.

In this section it will be argued that even more macro societal factors have an impact on both the ability of the health provider to care for the patient and patient adherence behaviour. In the present study, these factors include: poverty, illiteracy, and stigma and disclosure of HIV status. In North American studies on ART adherence, such determinants are often classified under patient factors (Golin, et al., 2002). In this study, however, it was considered more relevant to consider them societal factors, as they are broadly distributed throughout.

Poverty

Poverty among patients is one of the main challenges those interviewed face in the accomplishment of their daily duties. According to several participants, it is the major underlying force compromising adherence to ART and impacts on all the aspects of care, from accessing drugs to medical follow-up. Impoverished socioeconomic status affects both prescribing practices (as noted in the above section on medications for opportunistic infections) and continuity of care (discussed in the sections on the ARV lifecycle and ART supports).

> *"Now, for the difficulties we face, it is the poverty of our patients. That is to say, it's not all medications that are exempted downstairs…at the hospital pharmacist. We have difficulty prescribing other medications which means that on the therapeutic action plan we often have problems."* (Doctor, Ward A)

> *"It's not all exams that the Social Services exempt. We have difficulties at that level. Especially, especially at that level we run into problems."* (Doctor, Ward A)

Poverty, of course, leads to numerous other problems. Food security was mentioned by providers as a challenge faced by numerous patients.

Poverty is widespread in Burkina Faso and the state does not possess an elaborate social security infrastructure. In this setting, it is the NGOs who have stepped in to provide much-needed socioeconomic support to impoverished HIV patients. Most patients at both sites are referred to organizations where they often benefit from nutritional support, psychosocial counselling services, and occasionally income-generating activities. This is well illustrated in the example provided by Site One.

Many of those interviewed suggested that similar activities be implemented at the hospital level, though a few conceded that perhaps a hospital is not an appropriate setting for such programmes. Instead, they suggested improved collaboration with the NGO sector.

> *"We really need to resort to the organizations. Resort to the organizations. And if it was up to me to put in place a programme, it would be a programme that works in collaboration with the organizations."* (Interviewer, Ward A)

As will be elaborated upon below, however, access to services provided by NGOs is often hindered by the patient's fear of stigma and discrimination if their serostatus is exposed.

Illiteracy

Illiteracy is endemic in Burkina Faso; three out of four adults in the country are unable to read. This is a potential challenge to a patient's ability to be adherent to ART. Many cannot read the time, making strict respect of ART dosage times difficult for some.

> *"The problem of non-adherence is also tied to illiteracy. There. That is to say we have a lot of people who are not educated, so they don't know how to read or write. Often it is very hard to be adherent."* (Interviewer, Ward A)

Despite this challenge, providers adapt to this constraint by finding creative ways of helping patients remember the times to take their medications.

> *"There are also patients who have not gone to school…Well, we can explain how to take the products on time…There are some who are Muslim. We can point out prayer time in the morning at seven thirty, in the evening at seven thirty…We ask them about the activities they do. The women who get up at seven to go to the garden, or those who watch a soap opera at 10pm, we try to find out how they can manage not to miss (a dose)."* (Mediator, Ward A)

> *"Often it is illiterate women, who don't have watches. Well, they manage like that, they listen to the radio. They still try to take (their ARVs), maybe not at exact hours, perhaps a few minutes early or a few minutes late"* (Midwife, Site One)

Despite the problem of illiteracy being evoked in several interviews, only one person – an ATARAO interviewer – suggested that literacy support should be included in a programme designed to support adherence.

> *"So, if the programme could also put an emphasis on training, literacy, education even. Or else training. We can no longer take them to school but we can teach them what is necessary, just to know the time, to read the prescriptions, and so on."* (Interviewer, Ward A)

Stigma & Disclosure of HIV Status

The issue of stigma and discrimination still greatly impedes access to services for HIV patients and, in turn adherence to treatment. Anecdotes of patients who pick up their prescriptions straight from the doctor, go directly to the distributor to have them filled, and then take their drugs in hiding were common. Patients often refuse to join NGOs despite the range of services they provide for fear of being labelled as HIV positive.

> *"There are those who do not want to go to the NGOs because then many people will know (that they are HIV positive): 'when they see me go inside the organization they'll know that I am…', and so on'.* (Doctor, Site One)

Helping patients disclose their HIV status to their partners – referred to as 'partner notification' in the public health literature - was a difficulty cited by providers at both sites.

> *"And the other difficulty is serodiscordant couples. There are couples where, well, the woman is on treatment and she does not want to reveal her status to her husband. So often it creates a problem because if we explain prevention through condom use how will she explain to her husband?"* (Doctor, Ward A)

One midwife talked of feeling helpless when her pregnant patients are too afraid to notify their partners that they are HIV positive.

> *"Sometimes it's hard because you find yourself in a situation where you really don't know how to resolve a problem. The woman says 'Ah! I don't know how to tell my partner that I'm HIV positive' and 'my husband told me that if I do the test and I am seropositive he will kick me out.' So often we are at home thinking about this, how to resolve the problem. It's the main difficulty in this line of work. You test the woman, she's there, and she doesn't know how to tell her partner who is threatening to kick her out. Or else she tells him and he says 'get out'. We've had cases like that many times."* (Midwife, Site One)

Recognition of existing stigma and discrimination in society against people living with HIV ultimately affects the way care is organized, in particular at Site Two. This was illustrated by the following three examples: patient monitoring cards are kept on the ward so patients would not be labelled if seen carrying them around; an annex ART pharmacy existed behind an unmarked green door near Ward A (prior to the move to the Day Hospital); and home visits were rarely conducted partially due to difficulties in obtaining patient consent.

> *"But here, in the beginning, they told us to give the cards to the patients. But, when people see certain patients they automatically know which category of patients he belongs to."* (Nurse, Ward A)

Shortly after outpatient services were transferred to the Day Hospital, I questioned one nurse about whether the issue of stigma had been raised by patients. The centre is a distinct structure from the main hospital building and despite being officially labelled as part of Internal Medicine, I wondered how long it would take before it was tagged as a ward for HIV patients.

> *"Even if they are used to coming to the hospital, well, upstairs it's true that the ward was labelled (an HIV ward) but as it was part of the big building and, well, it was internal medicine over there; there were many types of patients. Well, they didn't feel too self-conscious. But here, the fact that it's*

> *isolated, they say that maybe – some, not all, but some – say that it will be a bit stigmatising…But the majority of patients find that they will be better off here because there is enough space, there are enough resources."* (Nurse, Ward A)

Patients I spoke with in the days following the transfer of services to the Day Hospital were very pleased with the new centre and preferred it to the third floor ward. In any case, plans were underway to build a wall around the new centre with an entrance at the back allowing patients to avoid passing through the main hospital gates.

> *"There will be a wall. Well, it's certain patients that wanted it to be that way."* (Nurse, Ward A)

Summary

HIV patients face a number of difficulties imposed by their socioeconomic context. These factors impact both the provider's ability to care for the patient, as well as the patient's capacity to access essential services in HIV care. These societal determinants also influence the logistical organization of care.

The ARV lifecycle: from manufacturers to patients

Ensuring the supply of drugs from manufacturer to patient is a complex feat and one of the main systemic inhibitors of adherence support that became evident during interviews. The "ARV Lifecycle" refers to the pathway ARV drugs follow from entry into the country until they reach the patient (Reynolds Whyte, Whyte, Meinert, & Kyaddondo, 2006). Several issues related to the ARV lifecycle were raised in interviews at both the Site One and Site Two. However, as I had the chance to interview both the ART pharmacist and assistant pharmacist at Site Two, most of the data in this section is based the information they provided.

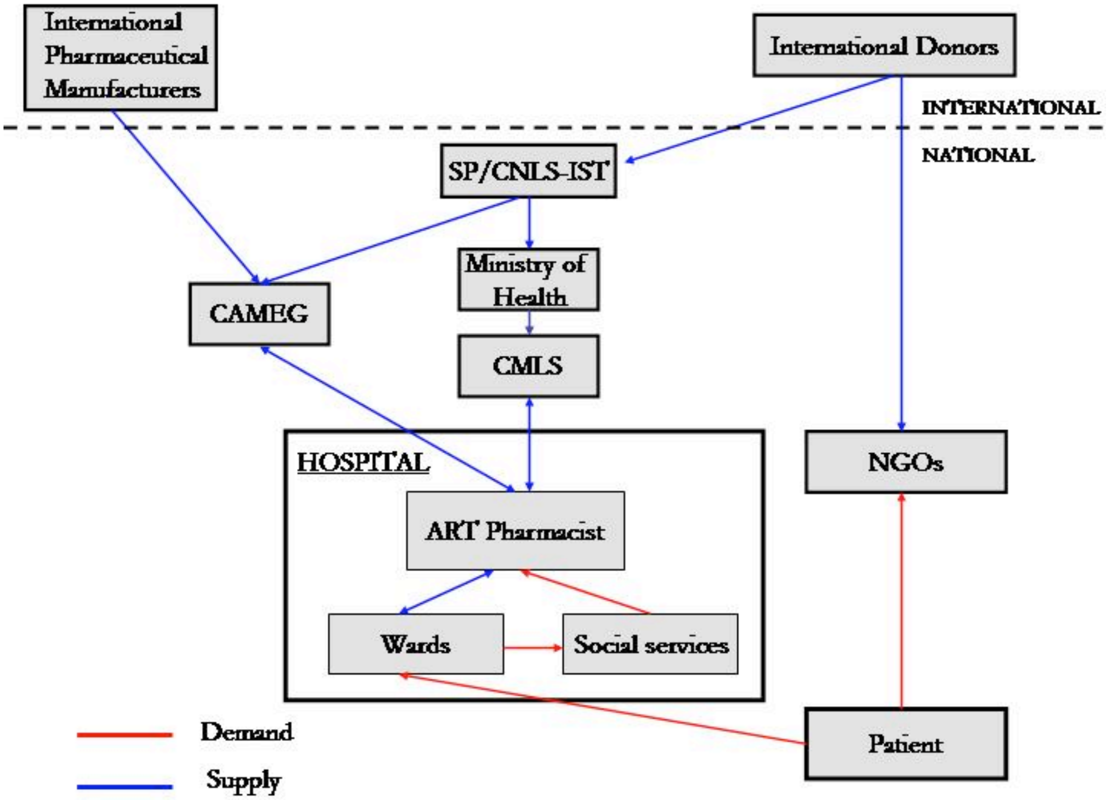

Figure 2. The ARV lifecycle in the public health sector

The majority of ARVs in Burkina Faso are presently financed by the GFATM, whose current round comes to an end in 2011 (The Global Fund to Fight AIDS, 2008). When I asked the assistant pharmacist what will happen afterwards, he responded:

> *"We don't know. We'll have to wait and see (laughs)."* (Assistant pharmacist, Site Two)

Both the pharmacist and the assistant pharmacist maintain that there have been no supply problems with ARVs since they began working at Site Two in 2006. However, as will be discussed below, the procurement process is a complex procedure for both providers and patients and a delay at any one of the steps along the way may compromise a continuous supply of ARVs for the patient.

The present section has been divided into "Supply" and "Demand" in order to discuss the procurement process for both the provider and the patient. The Supply side discusses the procurement procedure providers must follow to ensure adequate stocks of ARVs at the site of distribution. The Demand side, on the other hand, clarifies the trajectory of the patient in accessing drugs each month, according to the provider's understanding. The aim of this discussion is to show how ensuring an uninterrupted supply of ARVs – an essential condition to optimal adherence – is an issue that extends beyond the responsibility of the patient and the provider and depends on facilitating factors at the level of the hospital, the health system, as well as the greater international context.

Supply Side[6]

The main task of the ART pharmacists at the Site Two is to make medications for HIV patients available. These include both ARVs and drugs for opportunistic infections. To do so, they must first have the correct information from each ward about how many patients are on treatment, how many new patients are expected to be prescribed treatment and which regimens of medication are required.

In the wards where HIV care is undertaken, a senior doctor is responsible for submitting a request for ARVs for new patients to the pharmacy each trimester. ARVs for patients already receiving treatment ("*old patients*") are ordered automatically by the pharmacists as they are already included on the pharmacy roster. The request includes the predicted number of new patients who will be put on treatment over the next four months and is based on the patient roster of each ward. A senior doctor is responsible for predicting both the number of patients who will begin treatment and the types of medications that are required.

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[6] This is the ARV supply chain observed in Burkina Faso's public health sector in urban areas. An employee of the CMLS informed me that the procedure is slightly different in rural areas; due to decentralization initiatives, requests for patients already on treatment are addressed to the district level and only requests for new patients are forwarded to the central CMLS. In the private sector, some NGOs continue to receive a portion of their drug supplies directly from generic pharmaceutical companies in Brazil and India (via France).

If a ward has not requested a certain regimen, it should not be prescribed to a patient. During an interview with the assistant pharmacist, an employee from the maternity ward came in to collect ARVs for one of her patients. The pharmacist chastised her because she requested drugs that were not included on the list of regimens of the maternity ward. It was not her fault – the patient was referred to the ward with this prescription. He reluctantly gave her the medications but told her that the patient must be transferred to the patient roster of Ward A to continue receiving those particular ARVs.

The head ART pharmacist assured me that if more patients than predicted are prescribed treatment in a trimester they normally do not run into supply problems - the supplier (CAMEG) usually stocks up to a month of drugs as a buffer. The doctor I interviewed at Site One does not have the same luxury; near the end of a trimester she sometimes ends up with a list of treatments that are not compatible with patient needs. For instance, she may find herself with a list of regimens containing Efavirenz and none containing Nevirapine. Efavirenz is potentially teratogenic and cannot be prescribed to the pregnant women that make up a significant portion of her patient roster.

The requests from the wards, coupled with the existing pharmacy patient roster, are sent to the *Comité ministériel de lutte contre le Sida* (Ministerial Council on HIV/AIDS - CMLS) to be approved. The CMLS is under the direct supervision of the Ministry of Health. Its mission is to organize, coordinate and strengthen the activities in line with the fight against HIV/AIDS and sexually transmitted infections across the country (Ministère de la santé du Burkina Faso, 2005b). "*It acts as a bridge between the Ministry of Health and the Permanent Secretariat of the National Council for the Struggle against HIV/AIDS and STIs*" (Ministère de la santé du Burkina Faso, 2005b).

I once visited the CMLS, housed in a small building adjacent to the hospital. There I met with the person who handles the orders, a pharmacist by profession. He informed me that before agreements are signed with donor organizations, consensus is reached on the number of new patients who can begin ART each year. When the CMLS receives requests for new patients, he must ensure that donor funds can accommodate them.

Once the order is approved by the CMLS, the pharmacist can go pick it up at the CAMEG, the country's non-profit pharmaceutical distributor (see "Context" section). Approval, however, is not automatic. Doctors sometimes request certain types of medications that are no longer available, or have been substituted with equivalent drugs. The assistant pharmacist gives the example of Viracept that was recalled because "*it was badly produced*". In such a case, the patient is changed to an equivalent regimen. Furthermore, he tells me "*There are many problems between the CMLS and the CAMEG that we don't know about"* (Assistant pharmacist, Site Two)

As the CAMEG's procurement procedure requires international tender with contracts awarded to the lowest bidder supplying high quality pharmaceuticals[7], distributors and brands often change. This results in frequent changes in the packaging of the medications and even the number and appearance of pills one must take, despite the equivalent chemical composition. The pharmacists and other providers are constantly required to explain these changes to the patients. For instance, if a patient is used to receiving Duovir but the CAMEG has replaced it with Combivir, they write "Duovir" on the package so that the patient knows it is the same product. The pharmacist considers these variations to be problematic.

> *"You always have to explain that the box has changed, that it's the same product, the box has changed. So it's a problem, we always have to explain…It inconveniences us because we always have to explain to the*

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[7] According to the CAMEG's website, quality assurance of products is a top priority. A rigorous quality control process is carried out at the level of the supplier, the distributors, and the CAMEG itself. When new stocks of drugs arrive, they are tested for quality in large part by a quality-control laboratory in Belgium (SGS LABO SIMON) as well as by the *Laboratoire Nationale de Santé Publique au Burkina Faso*.

> *patients. It even bothers the patients. They think that the products aren't good and that's why they are being changed."* (Pharmacist, Site Two)

While a couple of nurses I consulted on the wards did not find these frequent changes to be particularly problematic, they admitted often having to explain the substitutions to the patients. Some patients, they told me, will not ingest a new medication they receive from the pharmacy before confirming with the provider that it indeed corresponds to their prescription.

The pharmacists find out a brand has been changed when they arrive at the CAMEG to pick up the order; no information is communicated by either the CMLS or the CAMEG to advise them about product changes.

> *"If we say 'Crixivan' and they give us Indinavir, we know there is no Crixivan [left in stock]. Yes, it's the same product."* (Pharmacist, Site Two)

There is also the risk that some patients will believe that a certain product is better than its equivalent. The assistant pharmacist recounted the story of a patient who believed that Duovir was superior to Lavocom even though both contain the same active drug combination of AZT and 3TC.

> *"What did we do? We took the Lavocom and we poured it into a Duovir box. We gave it to him like this saying 'the box is open but we counted and the number of pills is correct.' He left and then came back the next month saying 'with Duovir there is no problem!'"* (Assistant pharmacist, Site Two)

The issue of medications that are appropriate to the African context is also raised by the assistant pharmacist as being a barrier to adherence.

> *"There are also certain products that we had here, like Kaletra and Norvir that should be kept in a cool place. For the patients who travel, the cold chain will break at some point..."* (Assistant pharmacist, Site Two)

He tells of patients who deliberately leave their ARVs behind when they travel for a few of days because they know they will not be able to store them in a cool place.

> *"We need products that are adapted to our climate. If we could have Norvir that does not need to be stored in the fridge that would be good."* (Assistant pharmacist, Site Two)

While the pharmacists know the products well, other health professionals may not. The assistant pharmacist confides in me that an intern may prescribe one brand and when the patient returns with another brand he will send the patient back to the pharmacy thinking it is a mistake, despite the fact that they are equivalent. It also happens that errors are made in the prescriptions because some doctors do not master the chemical composition of the medications. The pharmacy staff members try to catch these errors at the level of the pharmacy. On the wall near the door there is a list of ARVs that cannot be prescribed together.

While procurement of ARVs at the hospital pharmacy is a logistical juggling act for the health provider, and most notably for the pharmacist, ensuring that one has a continuous supply of drugs is a daunting task for Burkina Faso's mainly impoverished HIV patients. The following section discusses the obstacles the patient faces in ensuring his monthly supply of drugs; the second half of the discussion on the ARV lifecycle.

Demand side

At the time this study was carried out, patients were asked to pay a monthly contribution of 5000 fCFA (about US$10) for their supply of ARVs – a prohibitively expensive amount for the vast majority of HIV patients in the country.

A patient may be exempted from payment if he is determined be indigent. At both Site One and Site Two the exemption process is largely subjective and determined by the healthcare provider. At Site One, for instance, as the patient receives all HIV care from the doctor, it is he who decides if she is indigent or not.

> *"Well, here it is done by the doctor. In the worst cases, the patient confides in you (that he does not have the money). Otherwise, once they are starting therapy we tell them that there is a contribution. Now, if they balk already 'well, if it's like that it will be hard, I won't be able to' and so on it's up to the doctor to see. Sometimes also the NGO tells us, 'that one used to pay 5000 and take (his drugs) but if you could give them to him today because he lost his job', or some other concern."* (Doctor, Site One)

At Site Two, patients who tell their health provider that they are unable to pay for their drugs are sent to the Social Services to receive an exemption. At Ward B especially, this seemed to be almost an automatic detour. For instance, I observed that even patients who did not look especially poor (a subjective judgement to be sure) were referred to the Social Services. One nurse in Ward A estimated that at least 80% of patients are exempted from payment. One of the ATARAO interviewers explained the exemption process in Ward A to me as follows:

> *"So, if it comes out of the (pre-ART) counselling session that the patient is not able to each… to give out 5000 fCFA each month for ARVs, we refer the patient. The patient is referred to the social services downstairs to take what we call an exemption. The exemption allows the patient to come and take his products for free."* (Interviewer, Ward A)

The Social Services office at Site Two is a dimly lit, small, cluttered room on the main floor of the hospital, beside the central ART pharmacy. There was often a queue of patients waiting outside the door of the Social Services; the office is not exclusive to HIV patients and any category of patient requiring an exemption is referred there.

There, the patient meets with one of the two women employees and pleads his case as an indigent. If the exemption is granted, the patient receives a stamp on his prescription and his name is recorded in the large ledger that sits on the desk in front of the woman. The exemption process at Site Two is tiresome and requires the patient to visit yet another office in the hospital. It can also be humiliating as the staff of the Social Services often mistreats them, as one psychosocial worker told me (I did not have the chance to validate this claim with other providers or patients). As discussed previously, Ward A staff hoped that the social services for HIV patients would eventually be added to the duties of the mediators at the Day Hospital.

Normally, a patient who is labelled indigent does not have to return each month to the Social Services for an exemption. However, according to the assistant pharmacist those who are not considered to be *very* poor may only be exempted one out of every two months - a practice that impacts negatively on adherence.

> *"There's the example of those who are not too poor. The social services does them a favour, exempts one box (of ARVs) every two months. That is, if he takes one box, it is exempted, if he comes back the next month, it is not exempted. So, what does the patient do? The month he is exempted, he comes, the month he has to pay, he doesn't come."* (Assistant pharmacist, Site Two)

To avoid the issue of cost and exemptions, some patients take advantage of the NGOs that provide ART free of change on an occasional basis. It happens that a patient will do the rounds of the different organizations and come to the hospital only when those other sources have dried up.

> *"Often there are patients who we see in their files; in our files…we say that they are not adherent. But, they are adherent. They are with the NGOs. They take products here, they take products at such and such organizations, they take at another organization. You see?... So they are in fact adherent in the process, but here they are not adherent."* (Assistant pharmacist, Site Two)

> *"…they didn't understand why at certain NGOs it was free when in state structures they say you have to pay 5000. They didn't understand that. So, people prefer to go to the organizations."* (Nurse, Ward A)

This practice is considered problematic not only for continuity of care, but for therapeutic outcomes. One nurse in Ward A told me of patients who arrive on the ward with resistance to all classes of available ARVs in the country.

> *"For instance, he goes to the NGOs because he heard it is free there. In the meantime, he decides that over there doesn't meet his needs, so he goes to another organization…As soon as he changes organizations, he doesn't tell them 'I've taken such and such a product.' No. 'It's the first time I'm coming (for treatment).'…So, it came to a time, I think we had to do a resistance test, we found that he was resistant to every ARV available in Burkina here!"* (Nurse, Ward A)

It is not only gratuity of care in the NGO sector that poses problems; particular cohorts of patients within the hospital itself may receive ART free of charge for a limited amount of time under certain projects. One such programme – a research project - was coming to an end during my time at Site Two. About 80 patients had been receiving treatment for free for the past three years but as the project came to a close, they had to be integrated into the regular patient roster. This did not necessarily imply that they would now have to pay for their ART but they would have to learn the Social Services exemption process. This meant that the doctor and psychosocial counsellor in charge of these patients were required to carefully explain the procedure to each patient. One of the psychosocial workers interviewed believed offering ART at no cost for a certain period of time poses a serious problem.

> *"It is such a serious problem because the outcome of the project is anything but (free)…It's the same problem that we have in all the NGOs with the TAP*

> *(Treatment Acceleration Programme) World Bank*[8] *project…It's the aftermath of TAP that poses problems. What can you do about it?"* (Psychosocial worker, Ward A)

Patients who are newly prescribed ART are required to go back to see the nurse on the ward to have the doses explained once they get their drugs from the pharmacy, as discussed in the section on "Adherence infrastructure". This procedure can also be a way of ensuring at the ward level that the patient received the same medications that he was prescribed. I once witnessed one of the ATARAO interviewers catch such a mistake in Ward B. A woman had returned from the pharmacy with two different medication boxes, as prescribed. When the interviewer took the containers out of the boxes to explain the dosage to the patient, however, she realized they were the same. The interviewer then returned to the pharmacy with the woman to have the problem corrected. In this example the checks and balances of the adherence infrastructure worked efficiently. This procedure, however, is only used for the first prescription. At subsequent renewals the onus is on the patient to verify that the contents of his pill containers comply with his prescription, a considerable challenge given that the brands and, in turn, the appearance and number of pills often change.

Summary

The complexity of the ARV lifecycle in Burkina Faso – getting drugs from the pharmaceutical manufacturers to the patients – poses a challenge for both healthcare providers and patients. Deviations in this lifecycle – from inadequate needs assessments at the level of the hospital to availability of ARVs and their equivalents, and from payment exemptions to appropriate medications – pose a threat both to the provider's ability to support patient adherence and the patient's capacity to adhere

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[8] During the same period, many NGOs were struggling with funding uncertainty. According to one NGO representative, this uncertainty was largely due to the approaching end of the World Bank-funded Treatment Acceleration Program (TAP) which had financed the initiation of ART for many HIV patients. As a result, many NGOs stopped accepting new patients and began referring them to medical centres. Through conversations at the XVII International AIDS Conference with an employee of the SP/CNLS-IST in Ouagadougou, who works on the GFATM portfolio, and an employee of *Sidaction* in France, I learned that GFATM had agreed to cover the funding of TAP. NGOs were, therefore, beginning to accept new patients again.

successfully to his medication regimen. As illustrated, these factors extend far beyond the individual to the greater hospital, health sector, and international systems.

External pressures: interventions with the best intentions

The response to the HIV epidemic in Burkina Faso has been largely driven by external funding (see “Context” section). Interventions aimed to increase the availability of ART (ESTHER, HIPC, World Bank, GFATM), reinforce the capacities of the health structures to respond to the HIV epidemic (ESTHER), and conduct essential research (ATARAO) are well intentioned and ultimately seek to improve the lives of people living with HIV in the country. Nonetheless, these programmes often produce unintended phenomena: uncertainty with respect to funding and project longevity, increased workload for providers, and flooding of the system by HIV patients leading to a divergence of scarce resources away from non-HIV patients.

This section will highlight the potential impacts on the local context of an externally-funded multi-country project through use of the ATARAO research project as an example.

Achieving externally-defined objectives

The main doctor responsible for HIV care in Ward B is the Burkina Faso principal investigator of the ATARAO project. One of the two project coordinators is also a nurse on the ward. Project activities officially began in March 2007. In practice, however, recruitment on the wards only started almost six months later, near the end of August 2007. The objective of the project was to recruit 400 patients newly initiated on ART over a one year-period at three sites in Ouagadougou. This implied recruiting over 100 patients at each site. The late start to recruitment significantly delayed the project in terms of recruitment objectives as the initial project deadlines were maintained.

In an effort to recruit more patients to meet the project objective, the nurse coordinator did the rounds of HIV care NGOs where he had contacts and encouraged them to refer their patients in need of treatment to Ward B[9]. This procedure was an initiative of the country team leaders and was not communicated to the Montreal team (I myself only became aware of it through interviews when the practice was mentioned by a doctor and an interviewer on the ward, as well as an individual on another ward who headed one of the NGOs). This active recruitment meant that Ward B quickly surpassed the other two sites in numbers of participants recruited, despite not being particularly specialized in HIV care.

> Ethnographer: "*If ATARAO didn't exist, there wouldn't be such a large number of (HIV) patients here?*"
> Interviewer: *"No. Because, in fact, we would have limited ourselves to the cases requiring more advanced medical care or those who came with dermatological problems and who are then diagnosed with HIV. We would have been limited to those cases."* (Interviewer, Ward B)

The patient normally arrives in Ward B with a referral sheet indicating his HIV status and type. The nurse then prescribes laboratory tests and asks the patient to return with the results. As mentioned in the section on "adherence infrastructure", this procedure differs from that of Ward A where it is the doctor who prescribes the laboratory tests after meeting with the patient for the first time. One doctor I interviewed believed that this was done to speed up the prescribing process, although the head nurse maintained that the system had been in place since they began caring for HIV patients.

> "*In this study (the nurses prescribe laboratory tests) to go faster, I think. I think. I don't quite understand the whole study."* (Doctor, Ward B)

ART is prescribed by the physician if the patient is determined to be eligible through clinical and laboratory assessment. The time between the patient's first visit to Ward B until he leaves with an initial supply of ARVs can take as little as 72 hours. A

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[9] See footnote on pages 93.

doctor and one of the nurses interviewed were extremely frustrated at the speed of this process and blamed it on the ATARAO research project.

> *"I prefer to proceed more slowly. The first time I see a patient I do not want to be obliged to prescribe because I do not even know if he has already had a counselling session, if we have already told him what ARVs are, how long they last, what they do and all. I do not know what happens before and after the patient arrives in my office."* (Doctor, Ward B)

Both of these interviewees also had strong reservations about the impact that precipitated prescribing had on adherence.

> *"Well, now we don't have the time to converse well with the patient. Because ARV treatment is not an emergency. So, time is really needed to converse with the patient, before he consents (to initiate treatment). As a result of wanting to include the highest number of patients (in the study) I question whether adherence will be good. That's my worry."* (Nurse, Ward B)

> *"If we are not sure the patient will take the medications all the time, we shouldn't prescribe. We first have to be sure of this; if his social milieu will allow it. Intellectually, morally do we feel that the person is ready to do it? The first consultation does not allow us to know that. Even…when I prescribe, even if the nurse did the adherence counselling, I get the impression that it's only once and there you go. He takes the prescription and the voucher and goes to get served at the pharmacy, the same day. I think we really have not taken the time to evaluate the adherence capacity of the patient. It's my opinion. And the proof is that many come back to say things aren't going well, they stopped because…Now there's at least three or four. There was even one who came back right away."* (Doctor, Ward B)

This concern about adherence may have been compounded by the fact that an "adherence infrastructure" was not as developed here as it was in Ward A, as discussed in the section on adherence infrastructure. Furthermore, the objectives of the study had not been clearly communicated to all staff members on the ward, which fostered confusion and resentment.

Coupled with the frustration of being pressured to prescribe was a general sense among those interviewed on Ward B that the project was greatly adding to their workload. This rapid flooding of the system by HIV patients was perceived by some as an infringement on the care of Ward B patients without HIV. Initially, a special consultation time was reserved on Friday afternoons for HIV patients without dermatological problems. It seems, however, that with the increased recruitment of HIV patients that they soon began to come most days aside from Wednesdays.

> *"The way we manage the HIV patients is really in a manner such that we abuse the consultation days, the consultation hours for the regular patients…You take the appointment schedule and you see that there are maybe 15 patients registered for appointments. You go to consult and there are 30 patients…There are 15 registered, but 30 patients. And you know the other 15 who come are often HIV patients that we add to the roster."* (Medical intern, Ward B)

> Ethnographer *"So, in July (2007) was the recruitment as fast?"*
> Doctor: *"No, not as fast."*
> Ethnographer: "*So now…*"
> Doctor: *"It's since September. October even when there are some every day. Every day I include patients in the study. Before it was Friday afternoons. Now it's every day, at each consultation."* (Doctor, Ward B)

Though I had been advised not to involve myself too heavily with the ATARAO cohort project as I was there to carry out my own sub-study, distancing myself from it was difficult, if not impossible in Ward B. Out of six interviews I conducted, five participants took the opportunity to voice their concerns about the ATARAO project. As a result, my impressions of the ward are ambiguous and challenging to reconcile – the research project grew to be so entwined with regular ward activities that it was problematic to distinguish the two. Furthermore, as the research situation deteriorated over the months that I was there, so did my morale. I often left Ward B feeling discouraged and exhausted at the state of affairs and my relative powerlessness to improve the situation, despite the unvoiced expectancies that I could read in the imploring eyes of the staff (and sometimes the patients).

To be fair, ATARAO's impact on the ward was not entirely negative. In fact, one of the main positive outcomes of the study was the increased psychosocial support of HIV patients provided by the two ATARAO interviewers, as discussed in the section on "psychosocial support". Both interviewers were readily available to meet with patients who manifested a need to discuss their problems, even those who were not part of the study. In a way, it seems as if the interviewers progressively filled the gap in psychosocial support in the ward and became their own version of the coveted mediators in Ward A.

Summary

Resources to respond to the HIV epidemic in LMIC are largely provided by national and international programmes – programmes that must themselves provide justification and results to the agencies that fund them. Continued financial support is frequently contingent on reaching objectives defined in terms of quantitative indicators. The obligation to reach pre-determined objectives is often translated into added pressure for those implementing projects on the field, as was seen in the case of the ATARAO research project.

It must be noted, however, that this pressure to recruit was not felt at the two other study sites. In those sites, the research project remained peripheral to the ward's main activities, as intended. In Ward B, the pressure seemed driven by the fact that the study co-investigator and one coordinator worked on the ward, compounded by the fact that they did not have the appropriate "adherence infrastructure" in place to respond to the increased number of patients that the project drew to the ward and had not sufficiently engaged staff members in the research process.

The evolving context of care

As the HIV epidemic continues to evolve throughout Burkina Faso, so too does the industry of care surrounding it. Only a few short years ago, ART in the country was only available in private health centres at costs prohibitive even for the well-off, or through drug donations from western friends (see "Context" section). Today, access to ART and an associated continuum of care continues to expand throughout Burkina Faso. Despite the shortcomings discussed in the previous sections, the magnitude of such improvements was not lost on the providers; most of whom had seen the HIV care situation evolve from palliative to therapeutic.

This final section of results will illustrate the evolving context of HIV care with a concrete example: the implementation of the Day Hospital at the Site Two as an outpatient centre for HIV patients.

New and improved physical infrastructure

The transfer of outpatient HIV services to the Day Hospital greatly facilitated the patient circuit of care by centralizing most services in one location, as mentioned in the section on adherence infrastructure. The new building also provided much-needed workspace for the staff. Despite the insufficient number of health providers at Site Two, the workspaces available to them were formerly inadequate and often cited as a major problem in both Ward A and Ward B. Positive reactions by the staff at the new building were unanimous among those I spoke with.

> *"Ah! Really, the new building, we are comfortable. The place is big, we do as we please. So, in any case, it's good."* (Mediator, Ward A)

> *"There have been lots of changes. First, we are in brand new offices…It's a pleasant environment. Much more adapted. Not only for the personnel, but especially for the patients because when they come there is a waiting room, it's a nice building."* (Nurse, Ward A)

The Day Hospital also includes two waiting areas for patients – a luxury as compared to the tight, standing-only corridors of the "*other side*", as people began to refer to the third floor wing of Ward A. Within days of the move, I noticed a distinct change in socializing behaviour among patients sitting in the waiting room, an observation that was not lost on one mediator.

> Mediator: "*I noticed. In any case, I noticed."*
> Ethnographer: *"It does them good; they are no longer all squeezed into the hallway!*
> Mediator: *"On the other side space was tight. They are there; we also need to get through. They are turning around, around to see how they can manage to move between themselves. In any case, yesterday in the garden they were paired up, talking. Each one was explaining how they experienced the illness."*
> Ethnographer: *"They were talking about their illness?"*
> Mediator: *"Yes! They were talking about their illness. They talked about how it's been since they found out they had HIV. Others talked about the day they did the test and it turned out positive. There was one beside me who said, 'really, my main concern now is that I want a child'. The other one said 'no, you already have one, you must be patient.' They were giving each other ideas. I was sitting beside them listening (laughs)."* (Mediator, Ward A)

Resistance to change

Not everyone is pleased with the Day Hospital, however. Patients from an ambulatory care centre were infuriated by the news that they would have to transfer there to continue receiving treatment. A petition was submitted to the Ministry of Health, to no avail. Funding for their centre had run dry and was forced to close. The patients –

approximately 3000 of them – and some staff, were to be transferred to the Day Hospital at the beginning of 2008. As of December 2007 staff at the Day Hospital was not quite sure of the logistics of the transfer.

> *"The (Chief of Internal Medicine) told us that when we moved here we would have lots of duties, more duties to take care of...Here, we don't know how we will do it, because there is a project, a team who will come from the other side (Ambulatory Care Centre). When they come, we will know how we'll organize it. For now, we don't know. But it's in January."* (Mediator, Ward A)

Enhanced organization of care

Once the staff had settled into the new building, several changes were made to the organization of care. The mediators developed a new system of overseeing patient appointments at the behest of the Chief of Internal Medicine: each day one mediator is assigned to a doctor. She is then responsible for that doctor's patients for the day. A schedule is posted on the door of the filing room. The mediators also created numbered tickets out of card stock for each doctor. When a patient arrives for an appointment, he is given a number with the doctor's name on it. This way the mediators only have to call out numbers to keep track of patient order. One of the mediators began going through the wooden box of blue patient monitoring in an effort to make the adherence monitoring system more efficient.

There was one change the mediators were concerned about: they will be required to work full day shifts due to an increase in the number of consulting hours (formerly they only worked mornings). Prior to my departure, they were discussing ways of organizing their new schedule amongst themselves and planned to meet with the Chief of Internal Medicine to reach a solution.

There were also changes to the nurses' duties. One nurse was completely detached from regular nursing duties related to the hospitalized patients. In 2008, he was to become the Coordinator of Therapeutic Education and had registered for an online degree on the subject. His role will be to oversee all those involved in patient adherence (aside from the doctors); that is nurses, psychosocial counsellors and mediators. His vision is to better integrate therapeutic education into the ward's activities to improve adherence.

> *"Well, therapeutic education is very broad. It takes into account the patient information, learning about health problems, treatments…well, it's a set of activities. Everyone involved in patient care (will be involved). So, once everyone is trained in therapeutic education, I think that with the personnel that we have, we'll be able to follow all the patients."* (Nurse, Ward A)

Room to grow

One of my last interviews was with a senior doctor of Ward A. Like his colleagues, he seemed generally content with the care of HIV patients on the ward. According to him the Day Hospital offers the advantages of more space and day hospitalisations, but care will continue much as before.

When questioned about whether he thinks it is necessary to add more activities to enhance patient adherence to ART he responded that they are limited only by available funds. "*If we have (grants), we will add (activities)*". For him, what is important is to build a solid foundation of care provision.

> "*We need a base to take root. If we are well-rooted we will be able to evolve correctly. We can add activities. We can get rid of other activities that are less efficient*." (Doctor, Ward A)

Summary

The context of care for HIV patients continues to evolve in Burkina Faso, despite the above-mentioned systemic adherence inhibitors. Improvements in physical infrastructure, service organization, and service availability affect not only the quality of care that patients receive, but health worker satisfaction and motivation. Though they were largely pleased with these improvements, the providers nonetheless, recognize that there is still room for improvement; improvement that is largely contingent on the availability of external financial support.

CHAPTER SEVEN: DISCUSSION

OVERVIEW

The findings discussed in the above section suggest three main conclusions that can be drawn from the provider's perspective on the provision of adherence support to patients on ART. First, organization is important in the delivery of adherence support services. Second, providing ART within a comprehensive package of care is an essential part of adherence support. Third, there is a need for better coordination of nationally and internationally-led HIV programming in order for coherent service provision at the site of ART distribution.

These three broad conclusions are elaborated upon in this section, supported by both the results of the present study and previously published findings.

Conclusion One: The importance of organization in the delivery of adherence support

ART scale-up must be carried out within a functional infrastructure in order to be sustainable. This warning, voiced by Harries (2001) in the initial years of the expansion of treatment availability across sub-Saharan Africa, is as pertinent today as it was then.

The results of this study indicate that ART distribution sites need to invest in some form of "adherence infrastructure" in order to effectively support patients on treatment. The organization of adherence support is essential both in terms of logistics and materiality. Furthermore, this infrastructure must extend beyond the level of the ward and permeate the level of the health sector where policies are often more deterministic of ensuing realities on the field, rather than vice-versa.

Logistics of adherence infrastructure

Adherence support was one of the main tasks of most providers interviewed and all were aware of its importance in ensuring positive treatment outcomes. Each of the three wards had developed a particular adherence infrastructure. Site One offered family-oriented HIV care in a community medical setting. Site Two, on the hand, disposed of a more elaborate infrastructure, reflecting its status as a national hospital centre with a high patient volume. Comparisons between Ward A and Ward B at Site Two reflected the difference between a site experienced in care for a high volume of HIV patients and one unaccustomed to a sudden influx of HIV patients.

The organization of adherence infrastructure must take into account available resources on the ward. Site One, for instance, developed a close relationship with an NGO in order to fill the deficit in psychosocial resources at their centre. Ward A took advantage of additional human resources (lay counsellors) to respond to the psychosocial needs of patients. Ward B, on the other hand, lacked the necessary human resources to provide comprehensive care to their patients. As a result, they developed a highly dependent (and unsustainable, given the project's limited duration) relationship with the research interviewers who came to play a significant role in patient adherence counselling.

In the context of Ward B, a different model of adherence infrastructure than Ward A would perhaps be more appropriate, given human resource constraints. For instance, group adherence counselling has been used elsewhere in Africa with some success (Tu, Kos, Culbert, Migabo, & Amisi, 2004). A group approach to adherence is common in the NGO sector in Burkina Faso, often referred to as "*clubs d'observance*" (adherence clubs). In Mali, where the other half of the ATARAO project is carried out, patients receive group adherence counselling prior to treatment initiation at certain centres (M.Sicotte, personal communication, July 21, 2008). The findings from this study indicate that adherence infrastructure is not a "cut-and-paste" concept and should be tailored to the particular needs of each ART distribution site.

Though the adherence infrastructures of the three settings varied in scope and available resources, they nonetheless shared certain similarities: uniform prescribing criteria (consistent with national and WHO guidelines), an individual-based counselling approach, and patient monitoring cards (except in Ward B). All three sites attempted to address patient-related factors of adherence by adapting adherence advice to the individual's condition (e.g. recall strategies for those who could not read, referral to NGOs). This patient-focused approach is consistent with WHO recommendations on adherence to long-term therapies through improving the efficacy of interventions targeting patient-related factors: "Patients need to be informed, motivated and skilled in the use of cognitive and behavioural self-regulation strategies if they are to cope effectively with the treatment-related demands imposed by their illness" (WHO, 2003a).

The three wards rely on providers to actively seek out adherence problems among patients and to formulate recommendations based on individual needs. This strategy is emphasized in the national guidelines of care for HIV patients (Groupe d'Experts Burkinabè, 2003). It is also reflected in Burkina Faso's 2006-2010 Strategic Framework on HIV/AIDS. Under the second main objective of strengthening access to medical and community care for people living with HIV, "organization of adherence to treatment support" is listed as one of ten priority areas and is described as follows:

> "Respect of the medical prescription and of the therapeutic plan by the patient is the principal indicator of treatment success…The actions of health system actors and community actors should be reinforced and improved for a better follow-up of patients. This will consist in particular of strengthening the capacities of actors, of promoting positive experiences in relation to adherence to treatment, as well as new practices in health structures." (Secretariat Permanent CNLS-IST, 2005)

This strategy places the onus for adherence support on individual capacities – both patient and provider – and overlooks more systemic issues such as the availability of resources and the socioeconomic context. Furthermore, the impact of such a strategy on the work condition of the provider must be considered. Several providers interviewed bemoaned the fact that the current patient volume does not allow them to spend an adequate amount of time counselling each patient on adherence. Lehman and Zulu (2005) have reported low morale and frustration among nurses in South Africa trying to deal with a rise in the number of HIV patients. Given the already critical shortage of health professionals in Sub-Saharan Africa, it is important to take into account the impact of health services organization on the working conditions of staff so as not to increase the possibility of burnout or migration from the workforce (Industrial Health Research Group and the South African Municipal Workers Union, 2005).

The importance of material infrastructure

Material resources played an important role in detecting adherence problems among patients and, as a result, acting to address these problems. Site One and Ward A both used the blue patient monitoring cards to ascertain whether patients were seeking care and renewing their supply of ARVs in a timely manner. Patient rosters at the level of the wards and the pharmacy were also used to identify patients who were either late for appointments or lost to follow-up. Prescriptions from the previous month's ARV renewal were another method employed at Site Two to detect timeliness. There was a clear difference in patient monitoring at Site Two between Ward A, where a variety of material monitoring tools were used, and Ward B, where only patient prescriptions and, presumably (though I never witnessed this) the pharmacy roster were used.

A prime example of the impact of material infrastructure in supporting patient adherence is the opening of the Day Hospital at Site Two. As discussed previously, the patient circuit was greatly facilitated in Ward A following the transfer of outpatient services to the Day Hospital. Furthermore, the new physical infrastructure had a visible positive effect on the morale of the health providers – a finding that has been previously reported elsewhere (Mathauer & Imhoff, 2006). Comfortably installed in their new quarters, the health providers undertook plans to strengthen the adherence infrastructure: overhauling the monitoring card system, developing a new method of organizing patient appointments, and making plans for a revamped "*therapeutic education*" procedure.

In settings of limited resources, the success of health interventions is largely dependent on health workers, as discussed in previous sections (A. K. Rowe, et al., 2005). The effects of enhancement of organizational infrastructure – both logistical and material - on the morale of health providers should not be undervalued. Such improvements may ultimately contribute to the provision of higher quality services to HIV patients, as well as to worker retention (McCarthy, O'Brien, & Rodriguez, 2006).

Adherence infrastructure beyond the ward

ART distribution programmes are complex endeavours requiring concerted action at various levels, from the site of distribution, through the health system, to higher national and international policy levels. Factors inherent to the health system have been found to have an impact on the adherence capacity of patients to long-term therapies (WHO, 2003a), though little research has been done on this subject in the context of ART. The need for a commitment at all levels to ensure that systemic determinants facilitate, rather than impede, patient adherence is cogently illustrated in this study by the discussion on the ARV lifecycle.

The findings of the present study illustrate that the provision of a continuous supply of ART to HIV patients – a fundamental prerequisite in ensuring adherence to treatment - is a complex process. The convoluted nature of ART distribution in an African setting has been discussed elsewhere (Reynolds Whyte, et al., 2006). In Burkina Faso, efforts have been made to regularize the supply of ART in the country with the implementation of the CAMEG. Access to ART has markedly improved since the publication of a historical perspective of the situation by Nguyen and colleagues (2003) in which difficult decisions had to be made by health providers as to which individuals should access limited quantities of antiretroviral drugs.

This study found that patients in Burkina Faso continue to negotiate a logistical maze in order to access their monthly supply of treatment. The patient pathway at Site Two is particularly ridden with complexity; requiring individuals to visit doctors, nurses, the social services, and the pharmacist (with varying waiting periods at each stop along the way) before finally leaving the hospital with a plastic bag of drugs. Some patients, discouraged by cost and bureaucracy, procure themselves of treatment at NGOs when possible, rendering continuity of care ever more precarious.

The procurement process described by the pharmacists is a logistical obstacle course, requiring providers to predict treatment needs on each ward, to update the hospital patient roster, to communicate needs to the CMLS, to obtain approval by the CMLS (who ensures that demands are consistent with national resources), and finally to procure the drugs at the CAMEG where the brands ordered may not be the ones available. This complex procedure is not particular to Site Two, having been developed at the national level (Sanou, 2008). In fact, complexity is a theme consistent throughout Burkina Faso's response to HIV/AIDS.

Nonetheless, the pharmacist and assistant pharmacist interviewed maintained that there had been no breaks in supply since they began working there two years ago. This finding is consistent with evidence reported in a recent WHO update on ART scale-up where the majority of 66 LMIC surveyed reported no disruptions in ARV stocks (WHO, 2008b). As scale-up is a relatively new process in most African countries it will be essential to monitor the procurement procedure over the coming year to ensure its sustainability. This issue will become more pertinent as the current round of GFATM nears its end (Wyss & Wiess, 2005).

Summary

In order for health professionals to provide adherence support for patients on ART, investments must be made at various levels into ensuring that certain facilitating conditions exist. At the ward level, the organization of adherence services needs to take into account existing resources and health provider capacities. Furthermore, the physical organization is an often-overlooked factor that has been found to affect both the morale of health providers and service provision. This study suggests that physical infrastructure should be arranged, if possible, in such a way that responds to provider space needs and facilitates the patient pathway. At the health system level, measures need to be taken that recognize the role of systemic determinants of adherence such as ARV procurement policies and financing mechanism, among others. Finally, advocacy at the international level must continue in an effort to facilitate acquisition of generic ARVs for LMIC and reduce the surrounding bureaucracy of the procurement process. Castro (2005) has pressed for more studies that assess the effects of such systemic determinants on patient adherence to ART.

Conclusion Two: The provision of ART within a comprehensive package of care is essential to effective adherence support

The strengthening of health systems has often been cited in the literature as a prerequisite to the scaling up of ART (Buvé, et al., 2003) and much advocacy exists to ensure that ART distribution programmes adopt a horizontal approach to the implementation of expanded treatment access (Chopra, 2005; EQUINET, 2004). Such an approach has the dual benefit of improving health service provision for the entire population as well as ensuring that HIV patients receive a comprehensive care package. As mentioned in previous sections, a comprehensive package of care is crucial to effectively responding to the HIV epidemic (Harries, 2002). This involves equipping providers with tools to assist them in their clinical practice (laboratory monitoring, treatment for opportunistic infections, and additional staff) as well as mechanisms for them to help patients negotiate the trials of daily life (gratuity of care, literacy support, psychosocial support). The delivery of these services is, of course, dependent on effective management and administrative systems (McCoy, et al., 2008).

The findings of this study support the perspective that expanding access to ART must involve more than just the provision of HIV drugs by demonstrating that some of the main challenges faced by providers were not ARVs themselves but a lack of peripheral adherence supports in the health system, such as laboratory tests, medications for opportunistic infections, psychosocial services for patients and staff.

The national guidelines for the care of HIV patients in Burkina Faso recognize the need for certain pre-existing conditions in order for ART to be successful, including: trained and competent prescribers, the availability of complementary laboratory tests, authorized treatment centres, a continuous supply of antiretroviral drugs, patient adherence, and optimal conditions for patient adherence (Groupe d'Experts Burkinabè, 2003). The findings of this study, however, imply either a gap in implementation, a lack of resources, or both.

Tools to Assist Clinical Practice

The providers interviewed in the present study face a number of difficulties in their clinical practice related to a lack of resources, not least of which is a shortage of health professionals themselves to assist in the follow-up of HIV patients. The following section relates these findings to the current literature, reinforcing the perspective that peripheral supports in the health system play an essential role in the delivery of a comprehensive package of HIV care.

Laboratory monitoring

There is a debate in the academic literature on the need to provide laboratory monitoring for patients on ART in settings of limited resources, such as CD4 and viral load testing, in order to better inform clinical decision-making. The current state of laboratory capacities in Sub-Saharan Africa requires considerable investments in both material and human resources to improve services (Petti, Polage, Quinn, Ronald, & Sande, 2006). A computer simulation modelling study suggested that CD4 and viral load monitoring were only marginally more successful in predicting patient survival than clinical observation alone (Phillips, et al., 2008). The authors concluded that these techniques were not cost-effective in resource-limited settings where emphasis on expanding access to ART should continue to be the priority of funding. In a comment to the editor that appeared in the same journal issue as the above study, Moore and Mermin responded favourably to these findings, adding that it is unclear that better monitoring would translate into improved clinical outcomes (Moore & Mermin, 2008). Others have also argued that costly laboratory monitoring should gradually be improved over time but should not divert resources away from the more important goal of making treatment available to a greater number of individuals (Koenig, et al., 2006).

On the other side of the debate, researchers advocate that improved laboratory capacity can translate into better diagnoses and monitoring, leading to improved clinical outcomes (Bates & Maitland, 2006; Petti, et al., 2006). Although the WHO encourages prescribing ART on the basis of clinical indicators when CD4 count tests are unavailable, it states "wider availability of appropriate and affordable CD4 testing and plasma viral load testing should be advocated in order to guide decision-making on when to switch ART regimens in resource-limited settings" (WHO, 2006a). Results from Mali and Burkina Faso from the Pro-ARV group support the implementation of more widespread availability of viral load monitoring for HIV patients (Pirkle et al., 2009). It has also been recommended that drug resistance be monitored at the population level in all ART programmes (Harries, et al., 2001). In a study of 97 treatment naïve individuals in Burkina Faso, 8% were found to have mutations associated with drug resistance (Vergne, et al., 2006). Similar findings were also reported in Mali by the ATARAO group (C. Tremblay, personal communication, June 11, 2008).

These findings, combined with those of the present study, suggest that effective laboratory monitoring for patients on ART is an integral component of a comprehensive package of HIV care. Investments in laboratory capacity can contribute to more informed decision-making by healthcare providers about treatment options for their patients, ultimately favouring better clinical outcomes.

Medication for opportunistic infections

Several providers, namely the pharmacists and doctors, cited lack of an appropriate, inexpensive and continuous supply of medications to treat opportunistic infections as a difficulty. Interview data implied that this problem extended beyond the hospital system to the national health sector and was also sometimes contingent on international donations. Treatment of opportunistic infection is yet another component considered to be part of the continuum of care required for the holistic treatment of patients with HIV (Harries, 2002).

Improving the availability of such medications is listed as one of the secondary objectives in the 2006-2010 National Strategic Framework to Fight HIV/AIDS and STIs (Secretariat Permanent CNLS-IST, 2005) and is listed under the second main objective of Burkina Faso's proposal to the sixth round of the GFATM (SP/CNLS-IST, 2006).

> *"The efforts already underway for acquiring and making available medications to fight opportunistic infections in health centres and care associations should continue."* (Secretariat Permanent CNLS-IST, 2005)

It remains to be seen, however, how this conceptual objective will translate into practice. Close monitoring of national implementation of the objective is necessary to ensure increased availability and affordability of medications for opportunistic infections at the level of the hospital.

Human Resources

Human resources are recognized as a critical factor in the implementation of ART programmes (and all health programmes for that matter) (UNAIDS & PEPFAR, 2007). This study found that health professionals were generally pleased with the quality of care provided to HIV patients (aside from in Ward B). Furthermore, almost all providers interviewed across the three sites reported significant satisfaction in caring for HIV patients. Similar results were described in a South African study where ART roll-out had inspired and motivated staff to provide comprehensive care to their patients (Stein, Lewin, & Fairall, 2007).

The findings of this study nonetheless indicate that the existing basin of human resources at the three sites studied is inadequate to respond to the needs of a growing number of HIV patients on ART. This echoes a study in four Southern African countries that found lack of human resources to be the single greatest constraint to treatment scale-up (Kober & Van Damme, 2004a). The fact that the providers at Site Two considered there to be an insufficient number of staff to deal with the patient load is particularly worrisome given that this institution benefits from the highest concentration of health workers in the country by far (Ministère de la santé du Burkina Faso, 2005a). This finding reinforces the recommendation Bodart et al. (2001) made several years ago that human resources for health be considered a priority issue in health reforms in Burkina Faso.

A frequent response to the issue of human resources has been to implement various training activities (Chopra, 2005). Indeed, it was observed in this study that most providers in contact with HIV patients had participated in a variety of training opportunities. The country also benefits from a regional HIV care training programme (DIU) run by the Chief of Internal Medicine at Site Two through which several providers in Ward A had already been trained. It has also been reported that staff training in the context of ART roll-out has contributed to improved morale by providing workers with new skills and professional opportunities (McCarthy, et al., 2006). There is limited evidence, however, on how such training initiatives impact clinical outcomes for patients (McCarthy, et al., 2006). Furthermore, training activities should not replace the strengthening of supportive supervision and feedback procedures in the workplace (Chopra, 2005).

Another response to the lack of human resources for health in LMIC has been to delegate certain tasks to personnel who are less highly trained. This approach, referred to as “taskshifting” has been advocated by UNAIDS, PEPFAR and others as a way of “strengthening and expanding the health workforce to rapidly increase access to HIV and other health services” (UNAIDS & PEPFAR, 2007). The strategy involves shifting duties traditionally undertaken by highly qualified health workers to less qualified personnel who are more easily and rapidly trained and has been found to be effective in a number of LMIC contexts (Ivers, 2008; Kamoto, 2008). Taskshifting was observed at Site Two where nurses were assigned prescription renewal duties and lay counsellors (mediators) played a significant role in providing psychosocial support to patients. Providers believed that the hiring of lay counsellors could improve the quality of psychosocial care offered to patients. This finding is pertinent as it indicates acceptability of a relatively inexpensive taskshifting approach by providers.

Concern has been raised, however, about the assurance of quality of care when employing a taskshifting approach (Philips, Zachariah, & Venis, 2008). Taskshifting implies increased supervision requirements to monitor the actions of providers carrying out tasks that were formerly not part of their work description. It has therefore been suggested that taskshifting "must be part of an overall strategy that includes measures to increase, retain, and sustain health staff" (Philips, et al., 2008).

The findings of the present study indicate that considerable investments need to be made in the area of human resources in the burkinbè health sector. Despite the adoption of a taskshifting approach, healthcare providers are still struggling to meet the needs of an ever-increasing number of HIV patients. Training and taskshifting alone will not solve this deficit. These strategies must be a part of a larger, national level human resources for health strategy.

Mechanisms to help patients negotiate daily life

It has been suggested that while health systems cannot be expected to completely remove the barriers of adherence posed by the greater socioeconomic and political context, mechanisms may be developed to moderate these effects (Travis, et al., 2004). Chopra suggests that the current predominantly biomedical approach to the HIV epidemic through ART scale-up may ignore "political, social, and economic determinants of poverty and the AIDS pandemic" (Chopra, 2005).

Social factors were considered by providers to have a profound impact on both their ability to adequately care for patients and the patient's capacity to adhere. This finding diverts from a previous study on systemic determinants of adherence among patients in Bolivia in which the providers were not sensitive to such issues (Greene, 2004). A review of the contextual relationships of adherence included the following remark: “Individuals cannot be separated from their social context, which is a powerful influence on their lives” (Goudge, et al., 2004). This passage aptly summarizes the findings of the present study.

Gratuity of Care

The impoverished socioeconomic status of patients was one of the main difficulties faced by providers in carrying out their work. Similar findings were reported from a study of health providers involved in ART distribution in South Africa (Stein, et al., 2007). Poverty was also considered by providers to be the main socioeconomic barrier to adherence. Comparable results were found in a quantitative investigation of patients and their health providers in Bostwana (Weiser, et al., 2003). The researchers predicted that adherence levels would increase from 54% to 74% if cost was removed as a barrier.

Castro maintains that the majority of studies conducted in poor contexts do not take into account direct and indirect financial impacts on households of ART (e.g transport and medical exams). “Although these costs may seem minimal to health professionals and decision makers, bearing these costs often translates into difficult household decisions about who eats, who works, or who goes to school” (Castro, 2005). The opportunity costs of buying ART for impoverished Ugandan families was described as follows:

> *“The long-term commitment of buying ARVs is difficult for individuals and families to maintain in situations where needs are so abundant. The medical consequences of these family dilemmas are nonadherence to treatment regimens and the possibility of ‘antiretroviral anarchy’ with dangers of developing resistance that experts fear”* (Reynolds Whyte, et al., 2006).

Food security has been found to be particularly problematic for HIV patients (Bukusuba, Kikafunda, & Whitehead, 2007). A study in Accra, Ghana, found the cost of food to be a financial barrier in ensuring adequate nutrition among a sample of 50 HIV patients (Wiig & Smith, 2007). The vulnerability of HIV patients may be attributed to both the high cost of accessing HIV medical care and decreased economic productivity, resulting in less disposable income to purchase food (Bukusuba, et al., 2007). Food security is a particularly worrisome issue in Burkina Faso where in 2008 mass public demonstrations were staged to protest the rising costs of basic necessities (see “Context” section).

Papers presented at a symposium in Burkina Faso on “Access to Antiretroviral Therapy: Lessons Learned” (24-25 June 2008, Ouagadougou) discussed significant financial barriers to accessing ART for patients. Despite the fact that at some sites of HIV care 80% of patients receive exemptions for monthly treatment payments, 64% of patients claimed that costs related to treatment were problematic for them (Bocoum Yaya, 2008). These included complaints of high costs related to nutrition (90.7%), medications to treat opportunistic infections (84.7%) and transport (74.5%). These findings were also supported by a qualitative study (Bila, 2008).

Interestingly, in the national guidelines on care of HIV patients, non-adherence due to cost barriers is listed as an acceptable reason to alter treatment regimens, though this point is not elaborated upon further (Groupe d'Experts Burkinabè, 2003). Free HIV (including testing, laboratory monitoring, and associated drugs) care has been advocated as being an essential factor in achieving universal sustainable access to ART (Souteyrand, Collard, Moatti, Grubb, & Guerma, 2008; Whiteside & Lee, 2005).

Several providers in the present study recommended gratuity of care as an essential factor in supporting patient adherence to ART. The above-mentioned symposium of politicians, researchers, community experts, and health providers recently debated the necessity of providing ART free of charge in Burkina Faso (*Livre des résumés*, 2008). Though there is strong advocacy for gratuity of HIV care that is supported by local research results, resistance persists at the political level to implement the policy (V. Ridde, personal communication, June 2008). It must be recalled that public health services are dispensed on a cost-recovery basis in Burkina Faso and that user-fees have been found to act as a significant barrier to access for poorer households across all categories of patients (Nougtara, et al., 2008). As such, it can be expected that granting gratuity of care for HIV patients will have wide-ranging policy repercussions across the health sector. Nonetheless, the findings of the present study and those mentioned above consider it an essential step toward achieving both equity in access to ART and positive, sustainable treatment outcomes.

Literacy Support

Illiteracy was considered by several providers to act as barrier to adherence for patients. Some also reported that it added difficulty to their task of adherence support as they spent more time explaining dosage procedures to these patients. Previous studies in the United States have found that low levels of education and literacy were associated with lower levels of adherence (Kalichman, Ramachandran, & Catz, 1999).

Providers in the present study dealt with this challenge by helping patients to develop innovative medication recall strategies, such as listening to the radio and abiding by Muslim prayer times. In a context of such endemic illiteracy, such as in Burkina Faso, it may not be feasible to implement large-scale literacy interventions in the health care setting. A more realistic option, perhaps, is to develop time-efficient interventions designed specially to assist illiterate patients to adhere to ART. Diagrammatic representations, for instance, may be useful for such a population.

Psychosocial Support

Several providers reported that social issues were the root cause of adherence problems among patients and presented a significant challenge to their work. For instance, widespread stigma of HIV in burkinabè society affects how services for HIV patients are organized (e.g. monitoring cards, pharmacy) and can impede providers from carrying out certain tasks (e.g. home visits). Fear of stigma, discrimination, and abuse also prevented many patients from disclosing their HIV status to their sexual partners – a challenge to providers both in terms of care and prevention.

The deleterious effects of stigma and discrimination of HIV in Africa have often been discussed in the literature (Rankin, Brennan, Schell, Laviwa, & Rankin, 2006). Rowe et al. (2005) reported fear of stigmatization as one of the barriers to adherence to tuberculosis preventive therapy for HIV patients in South Africa (K. A. Rowe, et al., 2005). A study of HIV providers in South Africa likewise found that stigma and disclosure were particularly challenging issues and time-consuming to address in clinical practice (Stein, et al., 2007).

The providers interviewed in the present study expressed concern about their inability to spend adequate amounts of time responding to the psychosocial needs of patients. This finding supports a previous study that reported psychosocial demands of clients to be the greatest challenge to healthcare providers (Stein, et al., 2007). The national HIV care guidelines of Burkina Faso stipulate that nurses and midwives should be attentive to all needs of patients.

> *"The global care of people living with HIV is complex and may require multidisciplinary interventions. The care provided should be holistic (global)"* (Groupe d'Experts Burkinabè, 2003)

The adherence activities reported in this study are highly dependent on the ability of the nurse/midwife to spend appropriate amounts of time with each patient, identifying difficulties and solution strategies adapted to the patient's individual condition. Given the high patient volume and lack of personnel identified in this study, effective implementation of this approach may not be realistic. The providers interviewed recommended that further psychosocial services were required to help patients deal with stigma, disclose their HIV status to their families and sexual partners, as well as address other social problems. Several participants suggested working in closer collaboration with the NGO sector. This recommendation was recently put forward by a leading HIV researcher in Burkina Faso who recommended formalizing the complementarity between the NGO sector and medical centres so that patients may benefit from more comprehensive care, ranging from medical to community services (Kouanda, 2008).

Summary

The majority of the population struggles to meet daily needs in the impoverished socioeconomic context of Burkina Faso. Findings from this study and others support the idea that HIV patients are a particularly vulnerable group as financial and social barriers compromise access to comprehensive HIV care, including adherence support. In order to support patient adherence to ART, providers must be equipped with tools to effectively carry out their tasks and to help patients negotiate the greater socioeconomic context in which they live.

It is recognized that a comprehensive care package contributes to greater probability of treatment success.

> "The availability of a system through which patients who miss clinic visits can be promptly identified, an organized patient medical record that includes a description of a patient's clinical as well as psychosocial status, and mechanisms for tracking patients in the community are all components of an effective HIV care programme" (El-Sadr & Abrams, 2007).

Such a system is more compatible with an integrated (horizontal) implementation approach. Not only does this approach have the capacity to strengthen health services for all patients, but also it avoids scarce health providers being diverted toward specialized HIV care. Though integrated HIV care tends to be more complex to implement initially and may not yield immediate results, findings from the present study indicate that it may be more sustainable and apt to providing appropriate conditions to supporting patient adherence to ART.

Conclusion Three: The need for improved coordination of nationally and internationally-led programming for coherent service provision at the local level

Unprecedented amounts of money from national and international donors have been invested to render life-saving ART more accessible to individuals across Sub-Saharan Africa (WHO, 2008b). Despite the positive implications of these commitments, nationally and internationally-led interventions have their setbacks. A limited amount of funding over short time periods means that HIV programmes are often implemented in a vertical, patchwork manner within existing health and HIV services, as was observed in this study. As a result, ART programmes are plagued by uncertainty, limiting the ability to make long-term plans in service provision. This issue was highlighted particularly well in the present study on three occasions: first, the long-term availability of material and human resources on the wards; second, the patchwork exemption process for indigent patients; and third, the impact of an external project on working conditions and service provision.

Long-term uncertainty

Uncertainty about the long-term availability of resources was a common thread in several interviews. For instance, most, if not all, providers seemed aware that current funding for ARVs had been made available through international donors for a limited time-span. When questioned about what would happen when the funding period expired, none had an answer. This concern has also been voiced in academic journals (Wyss & Wiess, 2005). The pharmacists at Site Two attributed supply breaks in medications for opportunistic infections to irregular donations by international partners. Ward A benefited from both mediators and psychosocial workers through an international partnership and a research project, respectively. Though it was widely recognized that the mediators had a positive impact on the delivery of psychosocial services for patients, it was questionable whether their contracts would continue beyond the lifespan of the project. It is unclear however, whether this information was unavailable or simply not shared with the lower categories of health professionals. Ridde (2008) has described the Mossi culture – predominant in the study area of Ouagadougou - as a strict hierarchy. Though this factor may have contributed to the lack of insight about long-term plans among the staff members interviewed, uncertainty with respect to funding in HIV programmes is a perpetual problem, even at the international level (UNAIDS, 2007).

The patchwork indigent exemption process

The selection process for the exemption of fees for indigent patients further exposes how patchwork provision of services is not sustainable. It was reported in the present study that the majority of patients were granted exemptions for ART, a finding which has been corroborated by other national studies (Bocoum Yaya, 2008). However, this exemption process is ambiguous, subjective and often a logistical challenge to the patients. Furthermore, the assistant pharmacist raised the issue of “not-very-poor” patients who were not consistently exempted from payment. He maintained that this strategy had a negative impact on patient adherence. It also compromises the continuity of care by pushing patients to seek free services in the NGO sector on an irregular basis. This is indicative the phenomenon of “irrational” use of ARVs described by Nguyen et al. (2003) that perpetuates in Burkina Faso to this day and justifies concern about “antiretroviral anarchy” (Harries, et al., 2001).

In a context of endemic poverty, the identification of indigents is a complex issue. One research project in Burkina Faso is currently studying the use of specific criteria established by community members for the selection of indigents by nurses at local health centres (Ridde, in press). Similar research may prove useful in the context of HIV care. Nonetheless, the negative effects of non-standardized, irregular fee exemption procedures on patient adherence behaviour provide further argument for the implementation of gratuity of care as a national policy put forward in the previous section.

The impact of external interventions

External interventions – both nationally and internationally led must be sensitive to the local contexts in which they are implemented. In the present study, this issue was illustrated through the discussion about the impacts of the ATARAO research project.

Despite being led by a local team of HIV experts and of a relatively small scale, the project exerted a significant amount of pressure on the settings in which it was implemented, particularly in Ward B. Staff complained of increased workload and came to rely heavily on the research staff to help dispense care. Two providers also reported concern about the effects of precipitated prescription of ART on patient adherence. Given how crucial optimal adherence for positive individual and public health outcomes, the WHO recommends delaying treatment initiation until the patient fully understands the demands of ART and feels ready to begin (WHO, 2003a). This finding illustrates how the use of quantitative indicators (in this case the objective of 400 patients newly initiated on ART) may inadvertently negatively impact both the working conditions of providers and patient care. The observational study design of ATARAO meant that there should have been no pressure on the local researchers to recruit participants. Nonetheless, it was clear for many of those interviewed that for the project to continue, donor expectations would have to be met – and this meant increasing the rate of recruitment.

Apprehension was voiced by providers in the Ward B where a substantial increase in HIV patients occurred over a short period of time as a result of the recruitment efforts for the research project. Two providers expressed concern that the growing number of HIV patients infringed upon the time spent attending to non-HIV patients. The concern about HIV programmes diverting scarce resources away from other health problems has been expressed elsewhere (Chopra, 2005).

ART scale-up is a relatively new phenomenon in Africa and the effect of increased availability of ART on existing health services is currently under-studied (El-Sadr & Abrams, 2007; Wyss & Wiess, 2005). As this study illustrates, vertically-implemented external interventions may unknowingly add considerable pressure to fragile health services by encouraging an influx of HIV patients. This may not only translate into reduced quality of care for HIV patients – including attention paid to treatment adherence- but also compromise the care received by non-HIV patients. The deleterious impacts on service provision observed as a result of the relatively small ATARAO research project provide grounds for concern about the effects of larger HIV programmes, with respect to both intervention and research.

An integrated approach to ART distribution that strengthens existing health services has been put forward as a strategy to avoiding these pitfalls (Chopra, 2005; EQUINET, 2004). This echoes the discussion in the above section on providing a continuity of services for HIV patients. As discussed previously, this requires investing in range of resources, both material and human. An investment in research on the scale-up process has also been cited as essential in comprehending how programmes are functioning (Jaffar, et al., 2005).

Efforts are already underway in Burkina Faso to coordinate the donor response, a condition required for financial support by the GFATM. As the second round of funding is currently in its early stages, it remains to be seen how this will play out on the ground. Furthermore, it is unclear whether improved coordination will extend beyond the provision of HIV services to include other areas of service delivery, including research.

CHAPTER EIGHT: CONCLUSIONS

CONTRIBUTIONS OF THE STUDY

Ethnographic studies in hospital setting often provide evidence upon which to build future research and interventions (Savage, 2000). Qualitative methods have been found to be useful in clarifying the dynamics of adherence (Sankar, et al., 2006). The findings of the present study have led to several research and practice recommendations.

Contributions to Practice

The findings of the present study have the potential to make modest contributions to clinical practice, mainly at the three sites studied, and potentially in other settings in Burkina Faso. First, interviews allowed providers to express their perspectives on adherence and work conditions. Two participants explicitly thanked the ethnographer for this "auto-evaluation" opportunity.

> *"We've never been evaluated. I think that over time, at a certain point you need to evaluate to see how the components work. It's important. It allows (us) to really confront what should be done with what is done and the difficulties people face to implement their programmes."* (Psychosocial worker, Ward A)

The second participant mentioned the importance of an outsider's perspective of a phenomenon but insisted that in order to be useful, the results must be shared. In response to these concerns, a research report summarizing the findings (in French) will be presented to the co-researchers of the ATARAO project. Based on these two positive reactions to the study, it is recommended that feedback mechanisms be implemented on the wards that allow providers to express their experiences and concerns to supervisors on a regular basis. This suggestion is consistent with previous recommendations in the literature (Chopra, 2005).

Second, consistent with the first conclusion of the study, the adherence infrastructure at each site should be revisited. Efforts could be made both to facilitate the patient pathway and adapt the infrastructure to available resources on the wards. This may imply redefining the roles of all actors along the way to ensure efficacy and coherence. As of the end of 2007, a group of experts had met to revise the national care guidelines (S. Koala, personal communication, November 2007). Once the new guidelines are formalized, it will be important to communicate any changes in protocol or tasks in a transparent manner to the health providers. This could be accomplished either through a ward or a hospital meeting. This recommendation recalls the importance in transmitting information to staff to promote greater organizational awareness (Franco, et al., 2002). It goes without saying that communicating changes to the patient pathway to the patients themselves in a clear and timely manner is essential.

Third, the study identified potential areas for improvement in service provision. As discussed in the results section, these primarily involve ensuring the necessary support services (laboratory, psychosocial) at the level of the hospital. The results provide evidence to advocate for the greater inclusion of such tools by demonstrating the challenges health providers face in working without them. The findings also clearly communicate a need for improved human resources for health planning at the national level.

Fourth, in designing future adherence interventions, particular attention should be paid to ensuring the peripheral supports in the health system are available, as well as tools for providers to assist patients in negotiating their socioeconomic condition. This recalls the need for an integrated, comprehensive approach to ART scale-up (Buvé, et al., 2003), as discussed previously. Furthermore, responding to the difficulties evoked by the providers shows concern for their work conditions and has the potential to positively impact staff morale. Consideration for the well-being of the health workforce is of utmost importance given the crucial role it plays in the success of health interventions such as ART scale-up (Wyss, 2004), particularly in the context of the human resources for health crisis (Stein, et al., 2007).

Fifth, given that the main recommendation of providers was to reinforce psychosocial care of patients, a more clearly defined protocol for these types of services should be elaborated. For instance, referral to NGOs is presently a verbal recommendation and largely based on the provider's awareness of available services in the community sector. Referral to medical centres, however, is accomplished with a form specially designed for this purpose. It is therefore suggested that the referral procedure to the associative sector be formalized along with a review of current psychosocial services in view of improving them. This recommendation has been echoed by other burkinabè researchers (Kouanda, 2008).

Sixth, the national body spearheading the response to HIV/AIDS, the SP/CNLS-IST, along with other national and international organizations should pursue plans to improve coordination of activities. This has been included as an objective in Burkina Faso's present grant agreement with the GFATM (SP/CNLS-IST, 2006). Such coordination has the potential to contribute to more coherent service provision at the level of ART distribution and avoid the patchwork nature of care observed in the present study.

Contributions to Research

Results from the present study will serve to inform both present and future research. First, as the ATARAO study is still continuing in Mali, these findings can serve to inform data analyses, as well as future phases, by accentuating the importance of an in-depth understanding of the context of research; that is, a comprehension of the interplay of factors at various levels of the system that influence both the research process and subsequent results.

Second, findings may influence future study designs on adherence. Interestingly, in a study by Weiss et al. (2003), patients who were non-adherent to medication due to barriers in drug procurement or access to alternate regimens – factors that are described as systemic determinants in this study- were categorized apart under "gaps in treatment". This is an important distinction to recall in future study designs since classification of determinants of non-adherence may ultimately improve the design of future interventions.

Third, results from this study indicate that the process of selecting indigent patients for payment exemptions is largely subjective and based on the health provider's interpretation of the patient's socioeconomic situation. This question requires further study with respect to ART scale-up. The impact of treatment costs on households has previously been studied in the burkinabè context and found to be detrimental (Bocoum Yaya, 2008)

Fourth, the findings reported validate the argument that further research is required on how ART scale-up is carried out - including which services are made available and which are overlooked – as well as how it impacts on existing health services (El-Sadr & Abrams, 2007).

Limitations of the Study

There are several limitations to this study. First, the scope of the present study is limited to the provider's perspective. A more complete discussion on adherence support could be obtained through the inclusion of the patient's viewpoint.

Second, cross-cultural research presents particular challenges. The researcher may be oblivious to certain cultural practices and beliefs that impact the findings. As a white woman in an African, patriarchal society, many of my interviews and observations were likely coloured by gender and racial expectations conjured by the study participants and myself. This barrier was addressed by adopting a reflexive approach to data collection (Giacomini, et al., 2000) and attempting to triangulate findings using several methods and sources of information (Mays & Pope, 2000).

Third, providers may have felt as though they were being evaluated, leading them to be more inclined to provide socially desirable responses. In response to this challenge, I paid careful attention to the formulation of my questions. For instance, instead of questioning which improvements participants considered necessary on the ward, I asked them to describe the components of an ideal adherence support programme. Reluctance to appear as an evaluator occasionally prevented me from delving deeper into certain issues. This was particularly the case with respect to the question on the difficulties faced by health providers in their daily work.

Fourth, three months of fieldwork is a relatively short time period during which to conduct ethnography. As a result, there are several ideas discussed in the above results section that warrant further study, including: the identification of indigents, higher-level systemic factors that impact on adherence support (e.g. international funding, national decision-making), and cultural barriers to adherence. The drawbacks posed by a limited time-frame were attenuated somewhat by the fact that this was not my first trip to West Africa, including to Ouagadougou. Also, I have been a member of the ATARAO research group since November 2006 and participated in weekly discussions on activities and challenges in the field. I was thus relatively well-informed as to the overall circumstances of the project in Burkina Faso.

Fifth, language posed a significant barrier during many of the observation sessions. Most of the conversations between patients and staff, and often among staff, were carried out in the local language Mooré. As such, much of my observation of patient-provider and provider-provider interactions was limited to body language. Though this evidently posed certain challenges in understanding, it also provided a unique perspective, as I was obliged to pay particular attention to non-verbal cues. This allowed me to triangulate verbal and non-verbal information.

Finally, due to the discontinuation of the study in Burkina Faso, triangulation of results with the burkinabè partners was less feasible than desired. Ideally, results would have been corroborated with the principal co-investigator in Burkina Faso, project coordinators, interviewers and key informants. In the absence of this possibility, results were discussed with the Montreal principal investigator and coordinator, both of whom have spent a considerable amount of time working on the issue of HIV and ART in Burkina Faso.

Rigor

There are three views on how ethnographic research should be evaluated: (1) using the same set of criteria as quantitative studies, implying a global set of indicators upon which to judge research; (2) employing a separate set of criteria compatible with the distinct character of qualitative research; and (3) avoiding the use of criteria since the notion of set criteria is discordant with the qualitative approach (Hammersley, 1992). Mays and Pope propose a set of criteria upon which to evaluate qualitative research based on the premise that all research seeks to represent a certain reality (Mays & Pope, 2000). From this perspective, the quality of research may be assessed in the common terms of validity and relevance, adapted to the needs of the type of research (i.e. qualitative or quantitative). The relevance of this study has been previously discussed in this document. Six criteria have been suggested to assess validity: triangulation; respondent validation; clear exposition of methods of data collection and analysis; reflexivity; attention to negative cases; and fair dealing. Each of these will be discussed in relation to the present study with the caveat that this is not an attempt to reduce the notion of quality to a simple “checklist” (Barbour, 2001) but rather to assure the reader that a just representation of the reality of the topic of study was of utmost concern to the researcher.

Triangulation refers to the use of two or more data collection methods, or two or more data sources (Mays & Pope, 2000). The results of this study are based on a mix of interview, observation data, and document review. When possible, more than one person belonging to a particular category of professionals on each ward was interviewed in an effort to triangulate data sources. For example, two nurses were interviewed in both Ward A and Ward B.

Respondent validation seeks to confirm the researcher's findings through consultation with study participants (Mays & Pope, 2000). As mentioned in the limitations section above, this method was not employed to the extent that the researcher had hoped. Nonetheless, certain findings were corroborated through informal interviews as well as two second interviews during the research process.

The present document includes an elaborate description of the methods and analysis used, as well as the researcher's position, in an effort to elucidate the entire research process for the reader.

Conducting fieldwork requires the researcher to reflect on how her presence in the setting may influence her findings, a process referred to as reflexivity (Giacomini, et al., 2000). This approach is especially apparent in the account of the ethnographer's position, as well as in the section on "External pressures: interventions with the best intentions" of the results. As mentioned in the limitations of the study, my white, student, female identity, likely influenced how people responded to my presence on the wards. In general, I felt that my identity was helpful in integrating the setting, as providers did not view me as a threat. I also made a considerable effort to not appear as an evaluator during interviews, as discussed previously.

If information arose during an interview that was contradictory to data obtained from another participant I sought to clarify the issue either by asking the participant to explain himself/herself further or by confirming the information with another participant. No great disparities in information collected were noted.

"Fair dealing" aims to ensure that a variety of perspectives is included in the analyses. This method was ensured by both the objective of the study – that is, to collect the viewpoints of a variety of healthcare providers – as well as in the data collection approach described previously.

In summary, several measures were taken to ensure the rigor of the present study. Needless to say that given the above-mentioned limitations to the study there is room for improvement. Nonetheless, it is the researcher's contention that the present findings provide a realistic illustration of the phenomenon studied.

CONCLUSION

The objective of this ethnographic project was to study the perspectives of healthcare providers on the issue of adherence support for HIV patients on ART. In doing so, it addressed several gaps in the literature. Primarily, it responded to the call for more operations research on how treatment scale-up is affecting service provision at local sites of distribution.

The study led to three broad conclusions. First, good organization is imperative in the delivery of adherence support services. Second, providing ART within a comprehensive package of care is an essential component of effective adherence support. Third, there is a need for improved coordination of nationally and internationally-led HIV programming for coherent service provision at the local level. The study findings are innovative in that they draw attention away from the individual provider behaviour and instead focus on factors that inhibit adherence support at various levels of society – the ward, the health system, society and the international context. This perspective thus avoids placing a disproportionate amount of responsibility on the individual and attempts to identify areas for improvement at macro levels that are often overlooked.

It is clear from the study findings that it is only through the sustained engagement of actors at all levels of society that the effective provision of adherence support services for patients on ART can be ensured.

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APPENDIX 1. STUDY PARTICIPANTS BY SITE

Category of Health Professional	**Site One**	**Site Two: Ward A**	**Site Two: Ward B**	**Site Two: Pharmacy**	**Total**
Doctor	2	3	2		7
Nurse		2	2		4
Midwife	1				1
Pharmacist				2	2
Lay Counsellor		2			2
Research interviewer	1	1	2		4
NGO representative	1				1
TOTAL	**5**	**8**	**6**	**2**	**21**

APPENDIX 2. SEMI-STRUCTURED INTERVIEW GUIDE

Questions démographiques

1. Quel est votre âge?
2. Quelle est votre profession?
3. Où avez-vous complété votre formation?
4. Depuis combien de temps pratiquiez vous cette profession?
5. Depuis combien de temps pratiquiez vous dans ce service?

Prise en charge générale

1. J'aimerais que vous me décrivez comment la prise en charge des patients VIH se passe à/au ____________ (lieu : Médecine C, Dermatologie, Ste Camille) (Imaginez qu'un patient VIH sous traitement entre dans le service. Qu'est-ce qu'il fait?)
2. Quel est votre rôle dans cette prise en charge?
    a. Quelles sont vos tâches?
3. J'aimerais que vous me parliez de comment vous vivez cette prise en charge.
    a. Quels sont les aspects positifs?
    b. Quelles sont les difficultés auxquelles vous faites face?

Prise en charge de l'observance

Maintenant, j'aimerais que vous me parliez de la prise en charge **de l'observance** aux ARV chez les patients VIH.

1. Quels sont les services offerts aux patients pour répondre aux questions d'observance aux ARV?
    a. Qui est/sont la/les personne(s) qui gère(nt) ces services?
2. En tant que ______________ (catégorie de professionnel de la santé), quel est votre rôle par rapport à l'observance des patients aux ARV?
    a. Pouvez-vous me lister les tâches reliées à ce rôle?
3. De quelle manière aborder-vous le sujet de l'observance avec vos patients qui prennent les ARV?

   a. À quel(s) moment(s) les patients reçoivent-ils des informations sur la prise de médicaments?
   b. Pouvez-vous me donner des exemples de recommandations que vous offrez à vos patients concernant l'observance aux ARV?
   c. Si vous percevez qu'un de vos patients exerce des difficultés avec l'observance aux ARV, quelles recommandations offrez-vous?
4. Selon vous, qui est la personne/catégorie de professionnel de la santé qui devrait être principalement chargé d'assister les patients avec l'observance aux ARV? Pourquoi?
   a. Quelles seraient les tâches de cette personne?
5. J'aimerais que vous me parliez de la communication entre les professionnels de la santé au sujet de l'observance aux ARV.
   a. Par exemple, parlez-vous au __________ (une autre catégorie de professionnel) à propos de l'observance des patients aux ARV?
6. Si on vous demandait de planifier et d'implémenter un programme pour répondre aux besoins d'observance aux ARV, quels genres de services prévoyez-vous?
   a. Qui serait chargé à gérer ces services?
      i. Quelles seraient les tâches de cette personne?
   b. Qui seraient les autres professionnels impliqués?
      i. Quelles seraient les tâches de chacun?
7. Avez-vous d'autres commentaires à ce sujet que nous n'avons pas abordés?

APPENDIX 3. INFORMED CONSENT FORM

FORMULAIRE DE CONSENTMENT

Rôle que jouent les professionnels de la santé dans l'observance des patients aux traitements antirétroviraux

On vous invite à participer à cette étude en tant que participant. L'objectif de ce projet de recherche est de mieux comprendre le rôle que jouent les professionnels de la santé dans l'observance de leurs patients aux traitements antirétroviraux (TARV). Ce projet s'effectue avec une collaboration entre le Centre hospitalier national Yalgado Ouédraogo, le Centre Oasis, et l'Université de Montréal.

Description du projet

Ce projet de recherche tente de mieux comprendre le rôle que jouent les diverses catégories de professionnels de la santé dans l'observance des patients aux TARV. Dans ce but, différentes catégories de professionnels de la santé seront interviewées.

Procédures

Les thèmes qui seront discutés porteront sur le rôle que jouent les professionnels de la santé dans l'observance des patients aux TARV, incluant des mesures qui pourraient être prises pour améliorer les services rendus. La durée de l'entretien est d'environ une heure. Un endroit et une heure appropriée seront convenus selon votre disponibilité et vos préférences. Un appareil d'enregistrement de la voix sera utilisé avec votre permission. La chercheuse principale dirigera l'entrevue.

Résultats attendus et bénéfices pour participants et pour la société

Participants: Il n'y a pas de bénéfices directs de votre participation dans l'étude. Cependant, au terme de l'étude, les résultats seront partagés avec vous.

Société: Les résultats attendus contribueront à une meilleure compréhension du rôle que jouent les professionnels de la santé dans l'observance des patients aux TARV. Ces résultats pourront mener à des interventions pour mieux répondre aux besoins des patients par rapport à l'observance aux TARV, ainsi que des changements dans l'organisation des services de la santé.

Risques et inconvénients

Il n'y a pas de risques attendus pour le participant. Cependant, il sera demandé de partager son temps avec la chercheuse.

Confidentialité.

Les entretiens seront enregistrés avec un appareil d'enregistrement de la voix, avec la permission du participant. Postérieurement, l'information sera transcrite à un système informatique. Un code numérique sera assigné à chaque participant pour assurer que l'identité de chacun reste confidentielle. Les codes numériques ne seront pas partagés à l'extérieur de l'équipe de recherche. Les données informatisées seront gardées sur l'ordinateur portable de la chercheuse principale (Kimberly Munro) et un mot de passe sera nécessaire pour y accéder. Seulement la chercheuse principale et les investigateurs principaux auront la permission de consulter les documents. Les données, incluant les enregistrements et les transcriptions, seront détruites 5 ans après la fin de l'étude.

Éventualité d'une suspension de l'étude

La participation à cette étude peut être interrompue par la chercheuse si elle croit que c'est dans l'intérêt du participant ou pour toutes autres raisons.

Liberté de participation et liberté de retrait de l'étude

Votre participation à cette étude est tout à fait volontaire. Vous êtes donc libre d'accepter ou de refuser d'y participer et vous pouvez vous retirer de l'étude en tout temps, sans conséquences. Si vous retirer votre participation de l'étude, toute information déjà transférée sur l'ordinateur sera supprimée.

Compensation

Il n'y a pas d'incitatifs offerts pour votre participation dans l'étude. Cependant, l'entretien s'effectuera durant les heures de travail et vous ne serez pas pénalisé.

Personnes ressources

Si vous avez des questions concernant l'étude, vous pourrez contacter :

<u>Personne-ressource neutre au Burkina Faso</u>
Dr. Marcel Lougué
Chargé de programme au Programme d'appui au monde associatif et communautaire de lutte contre le SIDA

<u>Personnes en contact direct avec les participants</u>
Kimberly Munro- Chercheuse principale

Abdoul Kadre Kargougou- Coordinateur de recherche au Burkina Faso

<u>Investigateurs de recherche associés</u>
Pr Pascal Niamba, MD
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Département de médecine sociale et préventive
Université de Montréal

Rôle que jouent les professionnels de la santé dans l'observance des patients aux traitements antirétroviraux

Déclaration du participant
J'ai lu et compris le contenu du présent formulaire. Je certifie qu'on me l'a expliqué verbalement. J'ai eu l'occasion de poser toutes les questions concernant ce projet de recherche et on y a répondu à ma satisfaction. Je certifie qu'on m'a laissé le temps voulu pour réfléchir et prendre ma décision. Je sais que je pourrai me retirer de ce projet en tout temps.

Je, soussigné(e), accepte de participer à cette étude

____
Date

_______________________________ __________________________
Nom du participant Signature du participant

Je consens à ce que les entretiens soient enregistrés: oui ___ non ___.

Je certifie a) avoir expliqué au signataire les termes du présent formulaire de consentement; b) lui avoir clairement indiqué qu'il reste à tout moment libre de mettre un terme à sa participation et que je lui remettrai une copie signée du présent formulaire; et je m'engage à préserver la confidentialité de l'identité du participant

_______________________________ _______________________
Nom de l'intervieweur Signature de intervieweur

Je certifie avoir expliqué au participant les objectifs de l'étude et j'accepte de garder confidentiel l'identité de tous participants recrutés.

____________________________ _______________________

Nom du recruteur Signature du recruteur

Information additionnelle
Une copie sera fournie au participant et une autre sera gardée par l'équipe de référence.
Ce projet à été approuvé par le CERFM de l'Université de Montréal (comité d'éthique) le (date et numéro de certificat). Dernière révision du formulaire de consentement: le 2 août, 2007.