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# Biomedical Science's Embodiments in Contemporary Laos

## Informal Caregivers and Children Living with HIV

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### INTRODUCTION

Children living with HIV remain a “blind spot” in the management of the HIV epidemics in low-resource countries (Hejoaka 2009: 870). The factors associated with the disclosure process and its impact on treatment adherence have been widely discussed in the literature; yet, little is known about the lived experiences and the family, community and social environment within which these children are raised, both before and after HIV status disclosure (Krauss et al. 2016). Who looks after and cares for others, how and under what conditions? Born in the United States in the 1980s, the perspective of care is developing in many countries and regions, in the “North” and then in the “South”. The care perspective provides a lens to articulate social phenomena generally addressed separately (for example,

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the division of labour within the family, society and care migrations) (Borgeaud-Garciandia et al. 2020; Hollinrake 2013). Within various domains as elderly care, cancer, mental health, palliative care and more recently Covid-19 care, research on informal care has been concerned with the following questions: Who provides informal care? What kind of help informal caregivers do provide? What motivates family members to provide informal care? The burden of informal care comes as a recurrent matter (Bragstad, Kirkevold & Foss 2014). This paper aims to approach this issue in the context of the HIV epidemic in Laos.

1.8 million children are living with HIV worldwide, including 110,000 in Asia Pacific (UNAIDS 2017). About 90% of HIV infections in children happen during the perinatal period and result from mother-to-child transmission (MTCT) (De Cock et al. 2000). HIV-related deaths in children can be prevented by 1) testing pregnant women for HIV; 2) prevention of mother-to-child transmission of HIV through antiretrovirals; 3) early diagnosis of HIV infection in newborns of HIV-positive mothers; 4) early antiretroviral treatment of children diagnosed as infected (World Health Organization 2012). Although access to treatment has improved in the past decade, half of the children in need still don't have access to antiretroviral drugs (UNAIDS 2017). Children living with HIV (CLWHIV) are facing multiple social, emotional, and health vulnerabilities, but have historically been given little attention by policymakers and scholars. In giving the voices to the informal caregivers of children living with HIV, this contribution aims to analyze how, in Laos, the HIV epidemic prevention and treatment, global policies and care practices are embodied locally. Our lens is to examine the materiality of its technologies (here understood as HIV test and antiretroviral treatment) and how they are embedded in the everyday and the ordinary. It aims at questioning the historical bonds and frameworks governing the contemporary logics and practices in the health domain. Retracing the local interpretations of global health agendas and their unfulfilled desires implies describing the main actors; the ways and the means by which healthcare is accessed and delivered; and the types of networks and bonds that users and caregivers mobilize (Ailio 2017; Papparini & Rhodes 2016). In other terms, our goal is to underline the active entrapment between bodies, spaces and devices in a pandemic. What are the standards conveyed in this area during the construction and implementation of HIV prevention and treatment programs? How do individuals negotiate them in a context of rapid social change?

Lao People's Democratic Republic (PDR), usually called Laos, is an ethnically diverse country of South-East Asia, bordered by China, Vietnam, Cambodia, Thailand and Myanmar, with an estimated population of seven million people (United Nations 2015: VII). It is classified as a lower-middle income economy and has one of the highest rates of human poverty among ASEAN countries as 17% of the population living below the standard poverty line (The ASEAN Secretariat 2017). Laos is one of the two countries in the Mekong region that has lowest HIV prevalence among population aged 15-49. The first person with HIV was diagnosed in 1990 and the first with AIDS in 1992. The commitment of the Lao Government and its partners in responding to HIV started in 1993 when the Lao Government

formalized a response to HIV. The political will to fight AIDS emerged more clearly in 2001 with the adoption of a National Policy. Under the impetus of International and Non-Governmental Organizations, the Lao Government expressed the will to limit the spread of the virus. In 2006, the Minister of Health finally recognized the existence of an epidemic. HIV epidemic remained limited among the so-called “most at-risk populations” (men who have sex with men, sex workers, and intravenous drug users). However, recent data point a sharp increase in cases of the general population, including housewives infected by their spouses (Hancart Petitet & Sychareun 2018). To counter the epidemic, the government, thanks to international agencies and the resources provided by the Global Fund, is developing a multi-sectoral response through the Ministry of Health, chaired by the National HIV/AIDS Committee (CHAS). Whereas in neighbouring countries, except in Vietnam where HIV prevalence is similar as Laos, HIV prevalence are higher, Cambodia counted 0.5%, Myanmar 0.7%, and Thailand 1.0% among population aged 15-49, prevalence remains low in Laos. It is 0.3%, with about 12,000 people living with HIV (The World Bank 2019). The majority of HIV cases is found in border provinces along the Mekong River: Vientiane Capital (40.5%), Savannakhet (21.1%) and Champasak (13%), where rates of cross-border migration are particularly high, both for Lao citizens and external migrants (UNAIDS 2016).

In Laos, people mostly call HIV infection “*luk AID*” (it means “AID disease” in Lao language) and the difference between HIV and AIDS is rarely known. HIV testing and counselling services have been scaled up to cover all 18 provinces for free of charge for the Lao population. The free access to antiretroviral therapy (ART) services is available in some urban sites in seven provinces. Also, Lao migrant workers working in Thailand have access to free antiretroviral treatment and other laboratory examination in the Thai hospitals, only if they have a work permit and Thai Health Insurance. However, the majority of Lao migrants in Thailand are working as illegal workers with low-paid salary. Consequently, their access to the Thai Hospital for HIV test and antiretroviral treatment is very restricted and most of them are sent back to Laos in such case (UNAIDS 2016).

Knowledge about mother-to-child transmission (MTC) among Lao pregnant women remains poor and the prevalence of HIV through mother-to-child transmission have increased in Laos, from 2% in 2003 to nearly 5% in 2010 (Hancart Petitet & Sychareun 2018). The related prevention and treatment activities have started in 2006 in Laos, but remain localized in large hospitals and in the main urban centres. These activities include mostly an HIV test during antenatal consultation and the provision of antiretroviral therapy during the pregnancy and delivery in order to limit the mother-to-child transmission. There are eleven hospitals providing antiretroviral treatment in Laos (three in the capital, three in the southern and five in the northern provinces) (Sanaphay et al. 2014). However, those activities reach few numbers of women. Only 11% of HIV-positive pregnant women had received antiretroviral treatment before delivery and 26% of infants born from HIV-positive women had received a HIV virology test in the first two months (UNAIDS 2016). The literature highlights that in rural areas, many women

are still giving birth at home; according to the 2005 Lao National Reproductive Health Survey, 85% of women gave birth at home, with only 28.5% of children being born from a mother who had visited health facilities for antenatal care (Sanaphay et al. 2014). In addition, access to HIV tests remains overall limited in antenatal care; as an example, only 55% of pregnant women benefited from a HIV test at antenatal care in 2013 (UNAIDS 2016:31). Some women receive the medical prescription for HIV tests but do not go to the lab to be tested or do not come back to take the HIV test results. Also, many men and women in bearing age are migrant workers facing various issues in accessing to sexual and reproductive health information and care (Phetchanpheng et al. 2020; Sychareun et al. 2021).

Our fieldwork in Champasak Province between 2013 and 2015 highlighted the low level of knowledge about HIV of traditional birth attendants. It also pointed out the risks some obstetrical home practices may represent in terms of horizontal and vertical transmission<sup>1</sup> (Hancart Petit et al. & Sychareun 2017). Finally, as outlined by previous studies, the use of improper breast milk substitutes causes a threat to child survival. Our home visits revealed the extent to which formula feeding is mostly a socio-economic issue in Laos, for which women do not receive enough financial support. Women often had little knowledge and understanding of this solution, and often lacked access to a proper water sanitation system and clean drinking water to prepare milk bottles (Barennes et al. 2012; Hancart Petit et al. 2015).

In 2016, the Centre for HIV/AIDS and Sexually Transmitted Infections in Laos reported that 235 children under 15 years old were on antiretroviral treatment, mainly in Vientiane Capital (103 cases), Savannakhet (44 cases) and Champasak Province (45 cases). However, it is likely that the number of children living with HIV in Laos is much higher (Centre for HIV/AIDS and STI 2016). While the experiences of the informal caregivers of children living with HIV have been documented in Thailand (Wattradul & Sriyaporn 2014) or Vietnam (Harris & Kim 2014), little is known about their profiles, experiences and perspectives in Laos. Until 2016, a community-based care and support model for children and families living with HIV or affected by AIDS was implemented. With the Ministry of Health support, it was implemented by the associations LPH (Living Positive HIV) and PLWA (People Living with Aids). The program has been active in six provinces and in Vientiane capital, operating through a network of self-help groups reaching over a thousand recipients. The model included five aspects: covering transportation costs to enhance access to antiretroviral treatment sites; peer counselling through people living with HIV self-help groups; home visits and follow-up activities by people living with HIV self-help groups; financial support through several funding facilities; outreach activities for the reduction of stigma and discrimination (UNAIDS 2016). According to literature, the present model for the most part proves effective in support for continuous treatment, care, and in responding to the needs of children and families living with HIV. However, several gaps and priority areas for further interventions were identified. Some of the families were living in extreme poverty, and while the support model provided several funding avenues, respondents still experienced great difficulty in paying

transportation for testing, counselling, treatment and check-ups. Beyond medical care, HIV infection requires a constant and crucial socio-psychological follow-up. This represents significant emotional, cognitive, and behavioural challenges for the parents of children living with HIV or for those who take care of them in case of illness, death, migration or issues with the parents (Matsuoka 2011).

This paper aims at capturing and analyzing the burden endorsed by the informal caregivers of children living with HIV. We wish to highlight the patterns of such burden and to encapsulate all of its aspects. The first part of the paper describes how, and under which circumstances, the informal caregivers of children living with HIV in Laos came to fulfil this role. The following parts address the constraints created by caregiving responsibilities, and the issue related to HIV disclosure, stigma and discrimination. The last section interrogates the informal caregivers' conflicting feelings and anxieties with regards to the child, which reveal the depth of their emotional fatigue.

## METHODS

The paper is based on a long-term research related to HIV epidemic issues in Laos. From 2013 to 2016, we documented various issues related to the prevention of mother-to-child transmission (MTC) of HIV (Hancart & Sychareun 2018). For this paper, we partly mobilize both this corpus and the results of a recent study examining the issue of children living with HIV (Viphonephom 2018).<sup>2</sup> This qualitative investigation tackles the notion "informal care" given to these children. It documents the responsibilities and the load this role comes with, in a context of unprecedented migrations. Phonevilay Viphonephom conducted data collection from October 2017 to August 2018, in the paediatric antiretroviral therapy (ART) centre of Mahosot Hospital in Vientiane Capital, and in the ART centre of Champasak Provincial Hospital. She interviewed participants at their homes in both areas. Study participants were the informal caregivers of children living with HIV (between ages 0-15). Vientiane Capital and Champasak provinces were chosen as study sites given the high HIV prevalence rate and of the magnitude of cross-border migration in these areas.

The informal caregivers included both parents and non-parents; they had to be 18 years old or above, to be responsible for a child living with HIV for at least one year and to be picking up antiretroviral medicine at antiretroviral therapy centres for their child. Thirty informal caregivers of children living with HIV participated in the study: fifteen from the ART centre at Mahosot Hospital and fifteen caregivers from the ART centre at Champasak Provincial Hospital, both from in-patient ward and out-patient wards. Among them, thirteen were external migrants (including two who also had an experience of internal migration), seven were domestic migrants and ten were non-migrants. All but one participant had family ties with the children living with HIV; fifteen were mothers, four were fathers, five grandmothers, three aunts, two uncles and one was a non-biological father. All informal caregivers were informed about their HIV status: seventeen

caregivers had an HIV-positive status and thirteen were HIV-negative status; all the mothers enrolled in the study were living with HIV. The most frequent educational level of caregivers was primary school (sixteen caregivers); five had attended high school, three college and two secondary school. Four caregivers were illiterate. Following ethical procedures required for research implementation and the specific clearances required by the hospital administrations, participants were introduced to Phonevilay V. by the medical team in the two antiretroviral therapy centres.

The informal caregivers described the child-rearing practices of thirty-three children living with HIV (three caregivers were taking care of two children), including seventeen boys and sixteen girls. Almost all children were aged 10 years old or younger (twenty-seven children) and were non-migrants (twenty-nine children), two children were internal migrants and two external migrants. Eight children had separated parents, eleven were single orphans and one was a double orphan; all but one of deceased parents was reported having died of AIDS-related illness.

Semi-structured interviews were conducted with participants and took place at first in a private room at the ART centre. The following interviews were conducted either at the house of the participant, either at the ART centre. Interviews were conducted in Lao language, recorded and transcribed. Data was later translated into English and coded. Triangulation technique was used after the interview through discussions with peers (antiretroviral therapy medical team) and participants' confirmation. Interviews aim at encompassing the demographics of caregivers and at collecting information about access to HIV medication and treatment and to HIV status disclosure issue. Lastly, the coexistent child and caregivers' dynamics in the household and in the community (HIV stigma and discrimination, caregivers' emotional relationship to children living with HIV) were discussed. Participants were invited to sign a consent form before the interview and all names were changed to protect their anonymity.

## BECOMING AN INFORMAL CAREGIVER

Caregiving implies the provision of numerous services and activities, including physical, medical, emotional, spiritual, material and financial support. It is part of an invisible economy embracing childcare, elder care and care for the infirm, which has historically been a highly gendered activity, with women representing the large majority of informal, unpaid and unrecognized caregivers (Schiller 1993). Caregiving responsibilities become even more demanding when raising a HIV-infected child, and notably encompass responsibility for antiretroviral treatment, the management of HIV status disclosure and "concealment strategies" if secrecy is maintained (Hejoaka 2009: 869-876). In high-resource countries, literature has shown that informal caregivers of children living with HIV are oftentimes single mothers. Mostly overwhelmed with child-rearing and caregiving responsibilities, they face many issues including family disruption, child behaviour problems and



socio-economic ostracism (Demmer 2011). Similarly, caregiving in South-East Asia tends to fall largely in the hands of financially insecure mothers and wives (Wattradul & Sriyaporn 2014).

In our study, we explored from an emic perspective the social and contextual determinants in which people endorse the role of informal caregivers. We gave a voice to them and examined how and why they faced difficulties, and the way they gave meanings to their failed attempts or day-to-day fulfilment. In other terms and following Everett Huges (1996), we explored informal care as an ongoing process in which the person sees her life as a whole and interprets their attributes, actions and things that happen to him or her. We observed three situations through which individuals came to fulfil the informal caregivers' responsibilities. First, nineteen of the thirty informal caregivers we interviewed were one of the child's biological parents, fifteen of them being their mothers. Some mothers became aware of their HIV status as they got tested during antenatal care. Others, especially those living in rural areas and who gave birth at home did not receive a HIV test. The HIV status was revealed both for the mother and for the baby, as the baby was brought to the health facility because of respiratory problems or because he or she was not gaining enough weight. Blood tests were conducted, and, depending on the age of the baby, were followed by a DNA testing<sup>3</sup> or a HIV antigenic testing, which resulted in a final diagnosis and the HIV status disclosure by the medical staff. As one participant explains:

We knew it first from this girl. She had fever and diarrhoea for several years starting when she was 8 months old. Her parents had still stayed together. When we came to know that she got infected by HIV, then her parents got tested. (53-year-old grandmother of 5-year-old girl.)

Given the restrictive access to HIV tests, the situation of these mothers who didn't get tested during antenatal consultation and who learned about their HIV-positive status through their child's early disease, is common in Laos. We recall here the story of a family who got HIV tested when the father got sick. The mother said:

At first, I was stressed. When I came to know that my son also got infected, I couldn't accept it. I cried; it was so stressful for me at that time. (34-year-old mother of 3-year-old boy.)

Other informants had kinship ties (grandparents or parents' siblings) with children living with HIV and became informal caregivers as the biological parents could no longer fulfil their role. Some had migrated to another area, had alcohol or drugs addictive practices, or had died.

She [her mother] had stayed in Thailand for several years and sent money to support us and built a house. She left her son here, then she went back to work in Thailand. Before she died, she told me "Mother, please don't leave my son, you should go take medicine and follow doctors" advice. Without medicine, I'm afraid my son may die. (65-year-old-grandmother of 12-year-old-boy.)



Finally, in a few cases such as divorce, caregiving responsibilities were arbitrarily granted to community members by the local authorities. In Laos, when divorce is happening, the family members (usually parents or elder relatives) of both the man and the woman will be called. All will meet the head of village with the objective to decide who will take care of the child. The decision is usually made depending on both parents' behaviour, financial status and availability. When parents can't find an agreement, they have to declare it and ask the judge in court to decide. We present here the case of a 5-year-old girl's grandmother. Her son and her daughter-in-law had two children. When they got the divorce approval from the head of village, neither of them wanted to take care of the two children. The head of village hence decided that each father and mother should take one child. The little girl was given to the father, but he couldn't take care of her himself. He was a drug addict often absent from home and was even jailed for several months. His mother therefore had to take care of the little girl. She said:

We didn't ask to look after her. The head of the village gave her to us. They had given her to her father, but he couldn't look after her, so they gave the child to me. I had to do so. (53-year-old grandmother of 5-year-old girl.)

## INFORMAL CAREGIVING RELATED CONSTRAINTS

The disease daily management and the related constraints imposed on informal caregivers often added to existing precarious socio-economic conditions. The discrimination and stigmatization faced in daily life were added to the burden of care, and *created situations of multiple stresses* (Demmer 2011). These life stressors have been classified in four categories: at first, illness management (medical appointments and decisions, hospitalizations), and stigma associated with HIV infection and its social impact. Communication with health care providers and social service agencies, and the experience of multiple deaths from AIDS are also mentioned (Mellins et al. 1994). These life stressors are complicated by the lack of material, emotional and financial support for children living with HIV and their informal caregivers received from their community and their families. The latter having poor information about HIV transmission and having the fear of being infected themselves (Mchenry et al. 2017).

All tasks and activities related to informal care comes with many obligations and constraints which affect everyday life, life choices and future plans. The routine medical appointments, the provision of the antiretroviral treatment and the frequent child school disruptions requires a lot. The informal caregiver must indeed ensure a constant availability and a flexible schedule, which is particularly challenging for employees or self-employed people. As a result, several of them had to quit their job, creating situations that further weakened the financial security of the household. For example, the uncle of one HIV-infected child had to quit his well-paid and stable job, others had to adapt their jobs; some women stopped their activities at the market to sell merchandise from their home.

His grandfather used to look after him, but he died when the boy was one year old. I used to work and my wife used to sell things. I quitted my job to look after him, otherwise no one would do it. (27-year-old uncle-in-law of 6-year-old boy.)

Informal caregiving also affected and sometimes restrained some long-term life projects. One informant, who had been granted the responsibility of caregiving, reported how this position tangled her project of migration.

I'm planning to migrate to Savannakhet. This house will belong to my daughters. My husband, my son (who is her father) and I will migrate. I have no idea for this little girl yet. (53-year-old-grandmother of 5-year-old girl.)

The limited access to antiretroviral treatment for children living with HIV appeared as a main constraint regarding the life projects for informal caregivers. For example, one family wanted to move and settle in the Northern Province but had recently been given the responsibility of a 4-year-old girl living with HIV. The 30-year-old aunt of the girl said:

I used to discuss with my husband, but he wouldn't let her go. He said she could die if she goes there, because she wouldn't have medicine to take over there. It's only available here in Vientiane capital. (30-year-old aunt of 4-year-old girl.)

## BUILDING TRUST AND EMOTIONAL BONDS

Establishing rapport and building trust is a crucial component of the informal caregiver ethos. The psychosocial support they provide is all the more critical to build resilience, meaning and reconstruct the self-esteem of children living with HIV (Barenbaum & Smith 2016). In our study, the informal caregivers emphasized how the nature and the intensity of the relation they had built with the child were context-specific. This relationship largely depended upon their kinship ties to the child, the frequency of parents' presence in the household, and on any antecedent that could have affected the parent-child bond. Also, in a few cases, parents were sharing their commitment to always answer positively to the child desires, even in the case of out-schooling demand.

If he wants to quit the school, I'll allow him. I'll be understanding, I know that he has this disease, I don't want to force him. (38-year-old mother of 11-year-old boy.)

When parents had been absent over significant periods of time, children sometimes had a stronger relation with their caregiver.

He hasn't called me mother, he just calls my name since he was a little kid, because I have not looked after him. He calls my parents his "parents" because they have looked after him, not me. (34-year-old mother of 14-year-old boy.)

Several non-biological informal caregivers emphasized the depth of the relationship they had with the child. Providing care comes with solid complicity and profound intimacy, such bonds they never built with their other children.

I wouldn't give her to her mother, I love her for being my child already, and her mother can't look after her. (34-year-old-non-biological father of 7-year-old girl.)

My husband said no matter what happens, he will grow him up himself, he wouldn't give him to anyone. He feels pity for them to be separated. He loves them all the same, although he mostly cares for this son. He also loves those two children, but this son is more important. (35-year-old-mother of 11-year-old-boy, who has both children with and without HIV infection.)

The construction of these intimate ties could also confront some informal caregivers with their health conditions, ages and own death, and toward the uncertainty of the child's nursing and of treatment management afterwards.

I'm already above 60 years old, whether I can see my grandson growing up until he becomes an adult or not, that I don't know. I just keep looking after him like that. (65-year-old grandmother of 12-year-old boy.)

I was just talking to him, asking: "If I die, with whom will you stay?" Then, he replied: "Oh! I might not be here after you". (70-year-old grandmother of 8-year-old boy.)

The biological parents of the HIV-infected children often mentioned the bond they had with the child and their commitment to accompany them as long and as good as they could at the time of the HIV infection disclosure.

## HIV STATUS DISCLOSURE AND NON-DISCLOSURE

WHO recommendations state that children should be told their HIV-positive status and/or that of their parents and informal caregivers by the age of 12 years old. Younger children should be gradually prepared for full disclosure, while "[accommodating] their cognitive skills and emotional maturity" (World Health Organization 2011). Disclosure should, however, not be considered an one-time event. It has to be implemented as an ongoing dialogue able to respond to the feelings of social isolation and to the anxieties that such "biographical disruption" (Bury 1982) may trigger (Vaz et al. 2010). Children affected by HIV shall be cared for by their family and should not be isolated from other children and society. Furthermore, the correlations between HIV status disclosure and treatment adherence have been highly discussed in the literature especially in sub-Saharan Africa, with divergent findings (Haberer & Mellins 2009). It is usually assumed that disclosure leads to positive psychosocial outcomes, including enhanced self-motivation, hope for the future and feelings of normalcy (Blasini et al. 2004). Baker et al. (2018) observed that quickly after HIV-positive status disclosure, children rejected it, they felt depressed and they changed their behaviour. However, after they received some support and more knowledge about HIV, they considered it a life challenge they could overcome. Beyond patterns showing increased treatment adherence and retention after disclosure, previous research reported that the benefits of HIV status disclosure include a better ability to protect oneself and others and

to reach social support and enhanced coping skills and resilience (Gerson et al. 2001, Gyamfi et al. 2015). Children living with HIV, who had already known their HIV-positive status, reported that they wanted to be told their status earlier (Baker et al. 2018).

The recommendation related to HIV disclosure applied by health caregivers in Laos mostly followed the international guidelines (UNICEF 2004). HIV disclosure is to be made when the child is 12-15 years old when he/she is considered responsible and before his/her first sexual intercourse (World Health Organization 2011). However, outside health institutions, HIV status disclosure to infected children may be influenced by several factors, including the living environment (household, communities and society) of factors both from the informal caregivers and the children. Moreover, the law related to HIV status disclosure to children living with HIV has been issued in the article 31 and article 43 decreed by the President of Laos. The *Law on the Protection of the Rights and Interests of Children* mentions that the "Disclosure of the HIV/AIDS status of children is forbidden". The State creates conditions for children affected by HIV to receive education and to participate in various activities in school without discrimination (National Assembly 2007). This law highlights the fact that informal caregivers, and children living with HIV themselves have their right to non-disclose and keep their HIV status confidentially from their teachers, neighbours and community members.

In our study, the disclosure numbers of HIV-positive status by informal caregivers were as follows. Twenty-seven children were not aware of it, four of them already knew their HIV status (two of them were 8 years old, one was 14, and one was 15). Informal caregivers of two children (aged 10 and 12) were uncertain if HIV status disclosure had been done. They had never asked whether their children knew their HIV status but assumed that they might know it.

Most informal caregivers gave a small one-time announcement and provided a short explanation. A 32-year-old mother of a 9-year-old girl mentioned that she didn't want to explain yet fully HIV infection to her daughter. She said:

I haven't told her with many details, I just told her that she has AIDS, she has not asked more. She has taken it [her medicine] at the time before going to school. I just told her that she has to take it for her whole life, that she can't miss it.

When becoming older and having more interaction with other people, some children may learn their HIV status from other people living in their community.

He's just known it. Maybe some people told him, or maybe his relatives or nearby people. I don't know that he could understand it or not, but I think he knew it. I don't want to ask because I don't want to mention anything. (42-year-old father of 5-year-old girl.)

Informal caregivers who were not the biological parents of the children living with HIV tended to feel more comfortable discussing the topic with children, since they had less personal anxiety or guilty feelings.

His uncle who is staying in Savannakhet [another province] was the person who told him. My sister had looked after me and my brother [his uncle] had looked after my son when I was admitted in the hospital. When my son first knew it, he could accept it without any problem. His uncle told him everything, he said that he has AIDS. (34-year-old mother of 14-year-old boy.)

We observed that disclosure of HIV-positive status to children appears both a condition and a determinant of family bonds, and hence represents an additional stressful responsibility. One of our informants told:

I will always follow here until she learns about her HIV status. If that time comes, I will tell her by myself. It may be fine, I will softly tell her that she got infected when she was born, and still she survives. (40-year-old father of 11-year-old girl.)

When HIV Status was not disclosed, informal caregivers explained that children were too young and not mature enough to learn about their HIV status. They were also told by the medical team that they shouldn't disclose HIV infection to children too early. Informal caregivers assumed that children would not necessarily understand what it means and what it entails.

She's not aware because she can't understand anything yet. She knows that she's taking medicine, but she doesn't know what this medicine is for. (42-year-old father of 5-year-old girl.)

We shouldn't tell him yet, he's still a little boy. If we tell him, he might feel inferior, because today he lives with an inferiority. Children tend to repeat everything they learn. I'm afraid that other people might victimize him, and they mightn't dare to play or study with him. (44-year-old aunt of 10-year-old boy.)

Besides, the high levels of social control in rural communities in Laos were often cited as a factor limiting HIV status disclosure. Informal caregivers feared that the constant underlying surveillance of relatives and neighbours would create a climate of stigmatization and discrimination for children living with HIV if awareness of the HIV status was generalized.

I haven't told anyone because I worry that after people know about this disease, they won't talk with them [my children], I feel pity for them. I'm afraid that they [people in the village] might victimize my children. (45-year-old mother of 9 and 7-year-old girl.)

Our informants also explained that if children knew their status, they would be likely to disclose it to others. From their point of view, disclosure would lead to stigmatization. This was another reason behind their will to maintain secrecy.

We will tell her the day where she will be able to know. Now, she's still small, we won't tell her soon. Maybe when she can understand, later around 10 years old. If I tell her now, she may tell it to several people, I don't want to tell her yet. (27-year-old mother of 5-year-old girl.)

Some informants also cited deep anxieties and nervousness as reasons to maintain secrecy, fearing that HIV status disclosure could have consequences on the mental health of their child and implications on their relationship with him/her. Biological parents mentioned their difficulties and anxieties in dealing with this situation and they felt they were responsible for the direct or indirect transmission of the virus to their child.

I feel discouraged. I'm afraid that my daughter may not be able to accept it. I worry that she will be bad to us when she grows up. I'm afraid that she won't be able to accept it when she grows up, that we won't be able to control her; she might have suicide thoughts, something like that. (27-year-old mother of 5-year-old girl.)

Maintaining secrecy did not come without challenges for informal caregivers. Children had to take medicine daily, once in the morning and once in the evening; this raised inevitable questions from the child about the why and wherefore of the treatment. Most informal caregivers then lied to ensure compliance to treatment, arguing that the medicine was vitamins, were helping to relieve fever, enriched their blood or acted as medicine that helps them grow.

She asks me all the time, "Mother, why do I always have to take medicine?" I just tell her that "it's a vitamin, taking it will make you grow up faster. You see, your elder sister has grown up quickly, because she also takes this vitamin." (30-year-old aunt of 4-year-old girl.)

When she sees her elder brother taking medicine, she asks: "Mother, what is my brother's medicine, why don't I take it too?" I answered, "why do you have to take it? You have nothing"; then she continued: "So what does my brother have? He does not have a fever!" I feel pity for her when she asks questions like that, but I don't tell her. (35-year-old mother of 11-year-old boy.)

HIV status disclosure to children is an important challenge for informal caregivers. Most of our informants had chosen not to disclose HIV status to the child they were in charge of. The educational level of informal caregivers, their openness about their HIV-positive status along with considerations about the child's age and ability to understand the HIV infection have been cited as factors influencing disclosure. While fear that the child would openly disclose HIV status to others, concerns about her/his emotional and physical health and anxieties related to stigmatization tend to push informal caregivers to delay the disclosure (Vreeman et al. 2013).

Moreover, informal caregivers were worried about the social effect disclosure could have, given recurring instances of stigma and discrimination happening both in the family and in communities. Feelings of anxieties and guilt also pushed them to maintain secrecy, with biological parents being particularly reluctant to discuss this topic as they feared resentment from their child. These attitudes of informal caregivers towards disclosure are similar with those from previous studies (Hejoaka 2009; Hayfron-Benjamin et al. 2018; Biadgilign et al. 2011; Brown et al. 2011; Kallem et al 2011; Ekstrand et al. 2018; Mchenry et al. 2017; Bertrand & Loubaki 2013).

## STIGMA AND DISCRIMINATION

In Laos, people living with HIV and their children are provided antiretroviral drugs free of charge. However, transportation and hospitalization costs still represent a heavy financial burden for families, hampering healthcare access, adherence and antiretroviral drug efficacy, while having significant implications on their professional activity (Barenes et al. 2015). People living with HIV must also cope with high levels of stigma and discrimination. They mostly had to face diffusion of rumours, the exclusion from family activities, community events or work, the verbal insults and physical violence (United Nations Programme on HIV et al. 2012). Discriminatory attitudes are observed within health care facilities, predominantly correlated with health staff's poor knowledge and limited experience in working with HIV-positive patients (Vorasanee et al. 2017). Our study highlights the salience of these negative attitudes towards people living with HIV and their informal caregivers within families and villages. Informal caregivers were reluctant to disclose the HIV status of their child to them mostly to protect the children and themselves. They often mentioned that they feared them and their children being exposed to acts of stigma and discrimination, losing their job, or their friends or even not being able to send their children to school. This sustains the findings of T. Chanvilay, Y. Yoshida, J. A. Reyer and N. Hamajima who found that stigma issues, along with confusions about HIV infection and low perception of the symptoms, coined obstacles to early access to ART (Chanvilay et al. 2015).

Information about HIV/AIDS infection, prevention and treatment issues, and questions related to the care of HIV-infected children were usually provided to caregivers during the training they received at antiretroviral therapy centres. They were exposed to the messages and guidelines of the medical staff every two-three weeks as they visited the centre. Most informal caregivers knew the three main modes of HIV transmission. However, they frequently mentioned that they were afraid of potential HIV transmission risks to family members. Some implemented prevention practices which were not necessarily relevant and could be detrimental to their mental health and that of the child. For instance, one mother assumed that transmission could occur through saliva, and therefore made sure that food and dishes were not shared during meals between children living with HIV and family members.

I warn my children about meals. I don't want them to eat together. I also don't want them to drink water together, I have separated their glasses. I am afraid that it [HIV] may be transmitted to the older son through the saliva. I told him that anything he already ate should not be shared with others. (30-year-old mother of 11-year-old boy.)

I told my children that if they get some wound and if it bleeds, they should not stay close to each other. Because children's immunity is not strong, so I don't want them to be too close. (38-year-old uncle-in-law of 8-year-old boy.)



Nevertheless, within the family, awareness of child's HIV status went oftentimes hand in hand with stigmatization and discriminatory practices. This revealed the extent to which health information messages were far from being uniformly circulated in families, and how this falsehood and popular representations of HIV infection sustain negative attitudes towards people living with HIV and their informal caregivers. As one mother explained:

Whenever someone touches him, they're afraid. They haven't touched him. I feel hurt because it's very rare that my siblings touch him [...]. It's like they love my sister's children more than my son. (27-year-old mother of 2-year-old boy.)

Our interviews revealed the extent to which stigma was internalized by informal caregivers and children, and the tensions within the family these prejudiced patterns could create.

They are afraid of being infected. They separated the utensils they use from the ones I touch. They prevented me to use the same soap for taking a bath. It is fine, I'm also afraid that I might transmit it to them. (27-year-old mother of 2-year-old boy.)

Stigmatization affected the everyday life of informal caregivers and children; the discriminatory practices had damaging consequences toward physical and mental health of both children living with HIV and their caregivers.

When he was small, whenever he ran inside, they told him to run out immediately, then they closed the door. I don't know the reasons why they hated my son. They don't want him to play with their grandsons. They might be afraid that he could transmit HIV, I don't know. (27-year-old uncle-in-law of 6-year-old boy.)

The quotes shed light on the stigmatization and discrimination faced by the children and their informal caregivers experience in their communities, and on their interplay with HIV status disclosure and family dynamics. Our informants mostly suffered from being harassed by recurring gossips in the village. They recounted how the discrimination they frequently suffered from, affected not only their well-being, but also sometimes their professional activity and thus their financial security. The fear of the infection appeared central to discriminatory attitudes, and was oftentimes reproduced by informal caregivers themselves, as they were afraid that children living with HIV could transmit HIV to other children. Some therefore implemented prevention practices to avoid HIV transmission, which were not necessarily relevant to the three major HIV transmission modes.

## CONFLICTING FEELINGS AND ANXIETIES

We observed that informal caregivers oscillated between various inner feelings. Sometimes, they felt a sincere unbounded love or intimate affection for the child, the respect owed to a parental or family duty of protection. Some, especially if they were the biological mother or father responsible for the HIV transmission of the virus to their child, felt guilty and shame. Most of them talk about the frustra-

tions and the emotional fatigue created by the burden of care and the heaviness of the antiretroviral treatment. Similar to mothers living with HIV loneliness and isolation in Burkina (Hejoaka 2009), our study shows how child-rearing habits and care trajectories are entangled with a “conceptual incongruity” (Blystad & Moland 2009). The conceptual incongruities in our cases are the ideals of care, love, resilience and tenacity, and, on the other hand, deeply entrenched anxieties related to death, guilt, shame, despair and feelings of injustice.

Our informants who were not the parents of the child mainly expressed a sense of frustration and abandonment. They were the solution of last resort for a child whose parents could not take care of, although they had not necessarily desired to fulfil such a role.

If I didn't look after him, what would he become? Who may want to look after him? I don't want to look after him either! I had to look after my daughter, so then why do I have to look after my grandson again? (70-year-old grandmother of 8-year-old boy.)

Sometimes, I'm in a bad mood, I get angry at him. I tell him that I might die and leave him here. He says: “if you die, I'll take your bone ash back. If they burn you, I'll hold your bone ash with me.” When I am exhausted, I tell him: “if I am too tired, I will die, with whom will you stay?” Then, he says: “OK, I'll stay with your bone”. He loves me more than his father. (46-year-old grandmother of 6-year-old boy.)

Even if they previously mostly ignored how HIV could be transmitted, the informal caregivers who were the biological parents of the child were tinged with a strong feeling of guilt. The blame was mostly much more reinforced in case of undesired pregnancies. This negative feeling could lead informal caregivers to experience depression and suicidal tendencies, similarly to what has been observed in a study conducted in Nigeria (Abasiubong et al. 2011).

I feel like I am the only one who constantly overthinks it. If I were the only one infected, it would be better, why is there mother-to-child transmission? Why did he get infected by me? Daily I blame and hurt myself. I constantly think about the day I will die. (34-year-old mother of 14-year-old boy.)

When I first knew it, I had a suicide thought: “If you die, how can your children live?” But it is not like there is only you, there are still other people. You have to keep fighting, they can also relieve you from it, and as long as they are in good health they can stay with your children. People who're not infected may still die before us, my sister said. (35-year-old mother of 11-year-old boy.)

These sentiments coincided with anxieties related to the HIV-related health issues caused for the child, and hence for his/her uncertain future and life expectancy.

I only worry about her. Growing her up is a burden, it's difficult because she's blind. And by the way it's caused by me, so she got infected and she suffers from this blindness; We are also poor. It's like a destiny, I don't know how it will be in the future. (40-year-old mother of 5-year-old girl and 3-year-old-boy.)

Troubled family situations tended to severe these circumstances, especially if the partner of the caregiver was not aware of his/her spouse HIV status. This is the case of one serodiscordant couple (one partner is infected by HIV and the other is not) we met. They had stayed together for more than three years and have one-year-old-boy (HIV-negative) together. The mother got HIV infection from her previous husband. Her new husband came to know about her HIV status when she got pregnant. He said:

My wife didn't tell me that she got infected. I was so hurt. If I had known before that she was a person living with HIV, I wouldn't be in a relationship with her. I knew it when we already had a son. If I didn't have him, I wouldn't bear with it. (34-year-old non-blood-related father of 7-year-old girl.)

High numbers of participants suffered from complex family and conjugal situations and from socio-economic marginalization. These difficulties, significantly hampered their access to medical care and hence to the provision of antiretroviral treatment. They were at the core of prolonged frustrations and anger. The informal caregivers who were subjects of the conflicting feelings previously described expressed negative and violent comments towards their child.

Sometimes, I wonder how the situation would be if I could not earn any more money, or if she got sick. In these moments, I even tell her that I would kill her. I once say things like that to my daughter. But in normal times, I wouldn't say something such words, I know it. (42-year-old father of 5-year-old girl.)

Several studies have pointed to the mental health issues encountered by informal caregivers of children living with HIV, notably symptoms of depression, anxiety, stress (Santiesteban et al. 2012; Lanchman et al. 2014; Lentoor 2017; Osafo et al. 2017). These psychosocial challenges may seriously affect informal caregivers' capacity to engage in meaningful parenting practices, with potential long-lasting impacts on children's neurocognitive and socio-emotional development (Lentoor 2018). The initial guilt due to the HIV transmission, the coercive imposition of endorsing the informal caregiver's role and responsibilities, the burden of care combined with its financial, social, and psychological effects, had severe impacts. It created an emotional fatigue and resulted in deep anxieties regarding their bond and daily interactions with the child.

## CONCLUSION

Taking care of children living with HIV creates several constraints. The recurrent medical appointment and parental responsibilities' caregivers have vis-à-vis the children require a significant availability which may be prejudicial to professional careers and employability and hence may threaten financial situations often already fragile. Establishing mutual trust and building intimacy with the child also depend on the conditions through which informal caregivers started to assume this role. Most biological mothers discovered that they were HIV-positive and

had transmitted the virus to the child at antenatal care or as the child grew up. These situations create a strong sense of shame and culpability for mothers. Other informal caregivers started to look after children living with HIV as a form of family obligation, following the death, illness, or migration of the child's parents or as the latter were no longer able to take proper care of them. In other cases, village chief assigned informal caregiving responsibility to people who had in no way expected or chosen to endorse it.

Our exploration of the lived experiences of the informal caregivers of children living with HIV has never been documented in the Lao context. These caregiver's narratives emphasize the dual, oxymoronic and contradictory feelings and ideals that turns them apart. It also offers a lens to observe the distribution of power in HIV public health domain from policy making to program delivery and from various points of view. This study underlines the needs of children living with HIV and their caregivers to get better attention both in health settings and in the communities. In 2012, Arthur Kleinman wrote a call "for a serious discussion about caregiving and a reconsideration of its place in medical education, medical practice, and medical research, on the one side, and its significance for patients, families, and communities, on the other". He also pinpointed the need to "open the door to the democratic implications of caregiving as moral and political practices" (Kleinman 2012: 1551).

In our research settings, the implementation of community interventions and programs addressing issues of stigma and discrimination is a key issue. Increasing efforts to improve pregnant women access to antenatal care and HIV testing during their visit, especially in rural areas, would significantly reduce the risks of HIV mother to child transmission. Finally, improving the link between informal caregivers and health staff and structures, and thinking other alternative dedicated to the day care to children living with HIV would relieve the burden of informal caregivers. Some projects have been implemented in this field. Nevertheless, short-term global health agenda and unstable donors' priorities mostly shaping Lao public health policy priorities do not reinforce the actor's capacity and neither guarantee sustainability of their activities.

Our exploration of informal care as the consequences of the logics and the practices in the HIV prevention and treatment domain has to be seen as a social form of the "perpetual present" (David Lewis in [Sweet 2017]) often engendered by the development sector. The projects implemented both in mother and child health and in infectious health were implemented first by the colonial regime, then by the Lao governments, with short term technical and financial supports from multiple and an ever-changing international donor (Sweet,2017). Further research would broaden our analysis. The organization, division and distribution of care work for vulnerable children within families, institutions and local, national and transnational institutions provide a lens to trace the history of medicine in Laos. Situated at the crossroads between the history of colonialism, modern South Asia and medical pluralism, this history scrutinizes how the social and gender health inequalities shape, reproduce and legitimize informal care, both intertwined with, and too often disregard by biomedical science.

## Notes

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1. The vertical transmission is the predominant route for acquisition of HIV infection in children, either in utero, intrapartum, during delivery or postnatally through breast feeding. The horizontal transmission route may occur via the community-associated routes as of the surrogating of breastfeeding or “wet nursing” by a woman with HIV, pre-mastication of food, and sexual abuse, as well as the healthcare routes regarding the infusion of HIV-contaminated blood products, use of contaminated needles, syringes and medical equipment (Myburgh et al. 2020).
2. This master study was a part of an overall research project entitled “Migration, Mobility and HIV/STI Vulnerabilities. An Interdisciplinary & Community-Based Participatory Research in Laos (2016-2018)”. This research combined a quantitative study launched in nine antiretroviral therapy centres in Laotian provinces including 600 patients, and five qualitative sub-studies including 100 participants.
3. DNA stands for deoxyribonucleic acid. A DNA HIV testing measure the HIV genetic material.

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## **Conflict of interest**

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The authors declare no conflicts of interest.

## **Compliance with Ethical Standards**

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The protocol of the research *Migration, Mobilities and HIV/STI Vulnerabilities Participatory Research Project in Laos* received ethical clearance by the National Ethical Committee of the Lao Ministry of Health on 9 January 2017. All participants gave oral consent before interviews.

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**Abstract:** Who provides informal care? What help informal caregivers do provide it and at what costs? This contribution examines the Biomedical Science's Embodiments in Contemporary Laos in looking at the materiality of its technologies in the everyday and the ordinary. We aim to tackle this issue in approaching the daily lives of children living with HIV from the point of view of the people who are taking care of them, the so-called informal caregivers. The paper highlights the constraints created by caregiving responsibilities, and the emerging issues related to HIV disclosure, stigma and discrimination and conflicting feelings. The informal caregivers' narratives underline how families, institutions and local, national and transnational institutions are assigning care work. Informal care offers a lens to explore the social and gender health inequalities, both interrelated with, and too often disregarded by the biomedical science.

### *Les incarnations de la science biomédicale dans le Laos contemporain. Aidants informels et enfants vivant avec le VIH*

**Résumé:** *Qui fournit des soins informels ? Quel type d'aide et de soutien les aidants fournissent-ils et à quel prix ? Cette contribution vise à décrire les déclinaisons contemporaines de la science biomédicale au Laos en examinant la matérialité de ses technologies au quotidien et dans l'ordinaire. Nous aborderons cette question en analysant la vie quotidienne des enfants vivant avec le VIH du point de vue des personnes qui en prennent soin, les aidants. L'article met en évidence les contraintes créées par les responsabilités de soins, les problèmes liés à la révélation de l'infection à VIH, à la stigmatisation et à la discrimination et aux sentiments contradictoires qui émergent de ce travail de care. Les récits des aidants donnent à voir comment le travail de care pour les enfants vulnérables est pensé et distribué au sein des familles, des institutions et des institutions locales, nationales et transnationales. Les soins informels constituent un prisme pour analyser les inégalités sociales et genrées en matière de santé, à la fois corrélées et trop souvent ignorées par la science biomédicale.*

**Keywords:** biomedical science, children living with HIV, informal caregivers, Laos.

**Mots-clés :** *science biomédicale, enfants vivant avec le VIH, aidants, Laos.*

