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# **Ethical Dilemmas Raised by HIV-Related Research in Laos. From Scientific Research to Production of a Radio Program**

**Pascale HANCART PETITET,<sup>\*</sup> Vanphanom SYCHAREUN<sup>\*\*</sup>**

Since the late 1990s, Laos has become more open to foreign research, especially in the medical and environmental sciences. However, only a few research departments in Laos are dedicated to social sciences, and anthropology is still not taught at the university level. When we had the idea in 2011 to propose a study documenting reproductive health issues in the context of HIV from an anthropological perspective, we decided to combine the anthropological skills of researchers from the Institut de Recherche pour le Développement (IRD) with the expertise of the team at the Department of Postgraduate Studies at the University of Health Sciences. This team already had considerable experience in leading research programs on this issue from a public health perspective using a qualitative approach. Our study was included in a health research program under the Ministry of Health, which established a department of Training and Research in 2013 to enhance the promotion and overall management of health research. As with all scientific studies, we followed all ethical clearance processes required by the National Ethics Committee for Health Research<sup>1</sup> and obtained the authorizations required to start the project.

This chapter describes and analyzes how and to what extent this research raised ethical issues and required methodological adjustments, and how those adjustments also led to scientific innovations. The chapter first retraces the research project's genealogy, then examines the specific conditions of scientific data production required when collecting personal accounts and facts related to HIV, which is still a sensitive issue in the context of Lao PDR, not unlike many other countries. We then share some preliminary results of this project and explain how these results raised ethical issues for researchers and how it led us to develop innovative ways to share results with the general public.

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1. Since 2014, the ethical clearance requirement must be completed on the Lao PDR Health Research Portal (website: <http://laohrp.com/index.php/hrp/index>).

The University of Health Sciences in Vientiane and IRD developed a research project on the social and cultural aspects of using antiretroviral treatment (ART) to protect children, based on the WHO recommendations for the prevention of mother-to-child transmission (PMTCT) of HIV (PremS ANRS 12271). In 2010, a new PMTCT strategy was adopted at the international level, emphasizing ART initiation during pregnancy and breastfeeding. International agencies targeted the “elimination of mother-to-child transmission” by 2015 as a global goal.<sup>2</sup> Our research programs aimed to produce scientific knowledge related to this public health initiative in the Laotian context. We also wished to contribute to the anthropology of human reproduction in a rapidly changing Southeast Asian society. We collected data in various spaces (local organizations, health institutions, informants’ homes, and coffee shops), and our research raised questions on both the validity of anthropological methods and the local interpretation of internationally accepted ethics principles. We tested innovative ways to collect data and share research results with the general public in Laos. In May 2015, we started a radio program in Lao language to share research results to support efforts to limit mother-to-child HIV transmission.

Drawing from both theoretical and applied perspectives, our research follows the paths of anthropologists who have worked in the field of HIV/AIDS for over 20 years. They have documented social, cultural, and political issues related to HIV during the two main stages of the pandemic—first, during the pre-2000 era when only preventive measures were available, then during the post-2000 treatment era.<sup>3</sup> They have provided scientific arguments (by showing that patients could be adherent) in support of delivering free AIDS treatment in the poorest countries, when treatment was not immediately available in contrast to the more affluent ones.<sup>4</sup> They also showed how AIDS-related stigma could prevent access to health services for infected patients.<sup>5</sup> Since researchers involved in AIDS programs are ethically responsible for the practical consequences of their research<sup>6,7</sup> in

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2. World Health Organization. (2010). PMTCT strategic vision 2010–2015. Geneva: World Health Organization. Retrieved from [http://www.who.int/hiv/pub/mctct/strategic\\_vision/en/index.html](http://www.who.int/hiv/pub/mctct/strategic_vision/en/index.html)
  3. Hardon, A., & Moyer, E. (2014). Anthropology of AIDS: Modes of engagement. *Medical Anthropology* 33(4), 255–62. doi:10.1080/01459740.2014.889132
  4. Desclaux, A. (2002). Impact of access to antiretroviral treatments on health programmes: Challenges, plan of action and scope of research. In J.-P. Moatti, I. Ndoye, H. Binswanger, P. Kahn, M. Grunitzky-Bekele, S. Hiras, & Y. Souteyrand (Eds.), *Improving access to care in developing countries: Lessons from practice, research, resources and partnerships*. Geneva: UNAIDS/WHO.
  5. Songwathana, P., & Manderson, L. (2001). Stigma and rejection: living with AIDS in villages in southern Thailand. *Medical Anthropology*, 20, 1–23. doi: 10.1080/01459740.2001.9966185
  6. Benoist, J., & Desclaux, A. (1996). *Anthropologie et sida. Bilan et perspectives*. Paris: Karthala.

the field,<sup>8</sup> how can anthropologists best interact with actors from other disciplines to improve local public health outcomes?

In Lao PDR, HIV prevalence is said to be low. The official estimate is about 0.3 % among the adult population, mainly through heterosexual transmission. HIV incidence is increasing, with an estimated 1096 cases of new infections in 2015, up from 957 new cases in 2014 and 617 new cases in 2012. HIV prevalence is also increasing in subgroups of key populations such as sex workers; people who inject drugs; and men who have sex with men (MSM), identified as transgender persons who reported selling sex. Heterosexual (88%) and MSM (8%) contact accounted for the majority of HIV transmission from 1990 to 2013. Transmission from mother to child (4%) and injected drug use (less than 1%) account for only a small proportion of cases.<sup>9</sup> HIV cases due to mother-to-child transmission increased from 2% in 2003 to nearly 5% in 2010.<sup>10</sup> According to a 2016 National AIDS Control Committee report, the cumulative number of pregnant women with pre-counseling and testing was 25,456; among these, 24,487 received blood tests and 23,957 received post-HIV-test counseling. Of these pregnant women, 68 mothers tested positive for HIV and were put on ART. However, in rural areas where PMTCT services are rarely available, many pregnant women deliver without being tested for HIV.

Recent studies indicate that many Laotians still know little about HIV prevention and treatment. People, such as housewives or youth who are not primarily identified as among the “most-at-risk groups” (sex workers, drug addicts, etc.) are nevertheless at risk of being infected by HIV. For example, during their investigation in Luangnamtha province, in Northern Laos, Sychareun et al.<sup>11,12</sup> documented the alarming rate of sexual risk behaviors among younger adolescents. The study showed that these risks were related to their curiosity and taste for experimentation, their use of alcohol, and traditional sexual customs.

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7. Dozon, J-P. (1997). L'anthropologie à l'épreuve de l'implication et de la réflexion éthique. In Agier, Michel (Ed.), *Anthropologues en dangers : l'engagement sur le terrain, Cahiers de Gradhiva*, 30, 109–21. Paris: J.-M. Place.
  8. Fassin, D. (2006). *Quand les corps se souviennent. Expériences et politiques du sida en Afrique du Sud*. Paris: La Découverte.
  9. CHAS, National AIDS Control Committee, Lao PDR. (2016). *Lao PDR country progress report: Global AIDS response progress country report, 2016*
  10. National AIDS Control Committee. (2010). *Lao PDR's UNGASS 2010 country progress report 2010*.
  11. Sychareun, V., Faxelid, E., Thomsen, S., Somphet, V., & Popenoe, R. (2011). Customary adolescent sexual practices among the Akha of northern Lao PDR: considerations for public health. *Culture, Health & Sexuality*, 13 Suppl 2 (December), S249–62. doi:10.1080/13691058.2011.634924
  12. Sychareun, V., Thomsen, S., Chaleunvong, K., & Faxelid, E. (2013). Risk perceptions of STIs/HIV and sexual risk behaviours among sexually experienced adolescents in the Northern part of Lao PDR. *BMC Public Health*, 13(1), 1126. doi: 10.1186/1471-2458-13-1126

Many young Laotians begin exploring their sexuality and gain sexual experience at an early age. Nearly two decades ago, the 2000 Lao Adolescent Reproductive Health Survey<sup>13</sup> found that adolescents increasingly engaged in sex before marriage, that many resort to unsafe abortion, and that many contract sexually transmitted infections (STIs).

Our intensive data collection, in both urban and rural health care settings over four years, has shed light on the situation. Fearing stigma and discrimination, many people do not want to be tested for HIV in Laos, and many die of HIV-related diseases because they arrive to antiretroviral treatment centers too late. The HIV epidemic remains a sensitive subject. However, similar to other parts of the world, Laos has also acknowledged that all HIV-positive people should be treated to break the transmission chain and hopefully see an end to the epidemic. The Center for HIV/AIDS/STIs (CHAS), working under the Ministry of Health in partnership with donors and international organizations, has implemented various activities in this area,<sup>14</sup> but access to HIV testing, prevention, and care services remains limited, especially in rural areas.

What ethical issues are raised by producing knowledge related to the prevention of mother-to-child transmission of HIV in such a context? We answer this question by considering the ethical rules governing access to data collection, HIV disclosure among couples, the management of confidentiality in health care settings, and personal ethical conduct.

As always when collecting scientific data, we also had to take various steps to gain access to information. Conducting research means first negotiating one's presence in various spaces. After obtaining authorization from the National Ethical Research Committee, we had to request authorizations at the district and village levels. For observations and interviews at the hospital level, we sought authorization at each hospital department in charge of the prevention and treatment of mother-to-child HIV transmission (antenatal care, obstetrics, pediatrics, and infectious diseases departments). While such requirements represent the basic ethical standard for any scientific research, other demands were quite challenging. For example, before interviewing caregivers, we were requested to also ask permission from their supervisors. Interviews could rarely exceed 45 minutes, and no second interviews were allowed. This constraint raised various questions in terms of classical anthropological methods that require prolonged immersion and floating observation.<sup>15</sup> Although the informants did

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13. Lao Youth Union, Japanese Organisation for International Cooperation in Family Planning & UNFPA. (2001). Adolescent Reproductive Health Survey 2000.

14. CHAS, National AIDS Control Committee, Lao PDR. (2016). Lao PDR country progress report: Global AIDS response progress country report, 2016

15. Hancart Pettet, P. (2008). Dimension éthique de la recherche en Inde du Sud. A propos d'une étude anthropologique d'un programme de prévention de la

their best to “provide accurate answers,” the hospital staff tended to state that everyone followed the official rules and medical protocols with no hurdles, questions, or doubts regarding their daily activities. The counseling team in the antenatal care department rarely admitted to any difficulties when giving HIV test results to pregnant women or when convincing those women’s husbands or partners to also get tested. At the end, we were left in an uncomfortable position when asking people questions that they felt were unfair or inappropriate.

In retrospect, our frustration during the fieldwork became an opportunity to observe *locally* how social and cultural norms influence the management of the epidemics, in terms of generation gaps, social status, gender, hierarchy, and ethnicity. It helped us to understand the development of the HIV epidemic in Lao PDR, long after its emergence in Europe and the United States. Finally, because of our work through IRD’s collaboration with the University of Health Sciences research team and our partnership with Médecins du Monde in Champassak province, we were able to better document the perceptions of various stakeholders, caregivers, and patients involved in HIV prevention and care programs in both urban and rural settings as well as the local interpretation of medical protocols.

We observed that in rural areas many women were delivering at home and received no HIV tests. Only a few pregnant women attending antenatal consultations in NGO-subsidized health care centers were tested since HIV tests were only available at provincial hospitals. However, testing raised various issues for them. Some women who were prescribed an HIV test did not go to the laboratory to be tested, others did not return to get their test results. When investigating the process caregivers followed when providing HIV test results to these women, we also felt that caregivers did not fully grasp the basic rules for managing confidentiality. For example, with no private space set up so that caregivers could return HIV test results to patients confidentially, patients feared that their result would not remain confidential because other caregivers or patients would overhear it. Also, although some women understood that they could receive treatment and limit the risk of HIV transmission to their babies during pregnancy, delivery, and breastfeeding, they found it very difficult to bear the responsibility of disclosing their HIV status to their partners and families all alone.

To comprehend the social context of HIV infection as it relates to reproductive health issues, we also had to understand the common social representations of HIV sexual risks. What do people know about HIV? Do they consider themselves at risk of getting HIV infection? How do they deal with prevention measures? We interviewed people in non-health care settings and encouraged them to share their own perceptions of HIV/STI

risks. For example, one married housewife told us that she observed that since getting a smartphone, her husband frequently contacted his friends on WhatsApp. Every night they invited him out to have fun and drink in entertainment venues. Based on her friends' stories, this woman feared that her husband may be having intimate relationships with other women. The presence of a regular mistress, a *mia noy*, in her husband's life was unacceptable, but she said she could understand and accepted the fact that her husband may want to experiment sexually with other women since they had already been married for many years. She knew about HIV; however, she did not dare to discuss infectious risks with her husband, and she wondered how to protect herself from being infected.

Another ethnographic case raises additional questions about ethical and responsible conduct.

*Jon (a pseudonym) is an 18-year-old man we met in Vientiane. He defined himself as a playboy. He is very smart, plays music with his band at weddings and events, and is successful with young women. Regarding HIV risks he stated: "I have read books at the school library. I learned that if one loses weight and has a fever and spots on the tongue, that means that he has HIV/AIDS. I don't have any of these, so I don't have HIV. Condoms? Oh no! You know, right then, it's urgent, and I'm often very drunk. If you stop and wonder about condoms, then it's over! I only have sex with very young, pretty women. I also follow them on Facebook to be sure that I'm their only one!"*

At this stage, we felt that we could not wait to complete the usually long process to publish research results. While data collection and analysis continued, we started sharing some of our results during locally held HIV meetings. We provided information that we felt could be useful for improving the delivery of PMTCT services and explaining why housewives and youth should also be targeted as at-risk populations in the public health program. We raised an ethical question shared by all researchers involved in applied research programs: how can we make the research results useful for others? How can we shape them in such a way that everyone—the general population, caregivers, and stakeholders—can learn from them? And given the extremely slow process to share results, how do we make research findings accessible faster?

After one year of negotiations, we began sharing our results on radio programs that reach 80% of Lao territory. In May 2015, with the help of Mrs. Souk Prasay Sithimolada, an expert consultant at Radio National Lao and at the Ministry of Information, Culture, and Tourism, we started a collaborative project with a team from Radio National Lao. This weekly radio program in Lao language was called "Health for You/Soukapap peua tan." These broadcasts openly addressed various themes related to our study using simple language. During the 15 30-minute radio shows, scientific data, interview extracts, and a diverse range of testimonies from lay men and



women and health professionals were woven together around a chosen topic (HIV basics, mother and child mortality, young people and HIV, risk taking, how to live with HIV, PMTCT, and children living with HIV).

Through this program we provide basic information on reproductive issues and HIV, and share the experiences and perceptions of stakeholders, caregivers, and patients involved in HIV/MTCT prevention and care programs. We also talk about prevention, stigma, and gender issues. The radio program made these research results accessible and understandable for a wide audience (the general public; public health, development, and media actors; researchers; and decision makers). Each broadcast was also linked to several digital platforms and Facebook pages (in Lao and in English) and a website (<https://healthforyouinlao.wordpress.com/>), which also posts summaries and photos from the field as well as communication materials in Lao produced by the Ministry of Health and international institutions. Through our collaboration with the organization I Care Benefits, a social enterprise based in Vietnam and active in Laos since 2012, our program has also been broadcasted in eight garment factories in Vientiane, reaching an audience of 8000 workers.

## Conclusion

This chapter presented issues related to the ethical aspects of research that arose during fieldwork conducted during prevention programs for mother-to-child transmission of HIV in Laos. First, we employed a reflexive approach to describe the initial conditions of data collection and the process used to obtain research authorization. Second, we described the steps taken by researchers while conducting the various phases of the study and the steps to meet ethical research requirements. Next, our ethnographic examples raised additional ethical questions. Our results raised confidentiality issues in health care settings and weighed people's individual responsibility to prevent HIV/AIDS transmission.

Further analysis of these findings also suggests that issues related to ethical aspects of research, professional deontology, and what meanings researchers give to knowledge production are inseparable. Once the research has begun, maintaining ethical concern for the involved actors cannot be limited to fulfilling administrative formalities or avoiding the unfortunate consequences of possible misconduct. This constant concern for "the Other" represents a challenging imperative whose *raison d'être* lies beyond a formal requirement, underlying the epistemology of our scientific discipline and how we give meaning to knowledge production.

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