



Sidaction at the 9th Aids Impact Conference – Gaborone, Botswana 22-25th September 2009

Created in 1994, Sidaction is a collective of researchers, healthcare professionals, and HIV-AIDS associations, in France and in developing countries, who all share a common goal: the development of scientific and medical research programs and the support of prevention and assistance programs for those living with HIV-AIDS. Sidaction is an interdisciplinary body, which over the years has acquired a respected expertise in all aspects of HIV-AIDS, enabling it to reinforce and build on existing methods used to fight the illness. Sidaction also defends the critical role played by patients and their support networks in the day-to-day battle against HIV-AIDS and, as such, focuses its support on community-based health programs.

In developing countries and countries in transition, Sidaction is supporting approximately 75 organizations, in more than 30 countries, mainly in sub-Saharan Africa but also in Eastern Europe and Asia. This support consists in a sustainable financial aid together with an appropriate technical assistance. (To learn more about Sidaction, please go to www.sidaction.org)

Sidaction's satellites and conference

Tuesday 10.00 – 13.00

An international scale of Quality of Life specific to People living with HIV/AIDS

Tuesday 10.00 - 13.00

The ethics of HIV related research in Africa: Mobilizing civil society

Friday 11.00 – 13.00

Veronica Nosedá: *Science and Community*

40.2 – 40 Future pathways – Plenary

Presentation of programs supported by Sidaction:

16.3 Jean-Paul Moatti, **Sylvie Boyer**, Sophie Rasson, Renée-Cécile Bonono, Lionel Fugon, Sandrine Loubière, Josiane Tantchou, Fabienne Marcellin, Pierre Ongolo-Zogo, Marie Préau, Maria Patrizia Carrieri, Bruno Spire, Jean-Paul Moatti

Decentralization of access to HIV treatment in Cameroun: impact on knowledge, practices, attitudes and working conditions among physicians involved in HIV care (Wednesday 14.00 – 16.00 – 16 Economics and HIV)

30.4 Fanny Chabrol

Multiple ways of caring for patients in an ARV clinic in Botswana (Thursday 14.00 – 16h00 – 30 Treatment and alternative treatments)

39.6 Caroline Desclaux, Alice Desclaux, Marie De Cenival

Providing adapted information to participants in medical research: an experiment to move from advocacy towards experience-based implementation (Friday 08.30 – 10.30 – 39 Late Breakers)

7.43 Morenike Ukpog, Kris Peterson, Olayide Akanni

Review of the reports from the community voices in the field involved with the tenofovir controversy (Wednesday, Poster Session A)

23.15 Judith Hermann – Mesfen

From the ministry of souls to the ministry of bodies? The position of the Ethiopian Orthodox Church (EOC) towards sexual behaviour, between HIV/AIDS and American donation (Thursday, Poster Session B)

23.26 Cécile Chartrain

Mobilization against AIDS and contemporary transformations of activism: the case of Solidarité Sida (Thursday, Poster Session B)



Purpose – Aim

Quality of life – QoL – is not a recent issue: it has been an important issue for many years for doctors and it has been defined as the impact of the disease and the treatment on a patient. Since the 90's, the development of instruments aimed at measuring QoL based on patient reported outcomes has enabled the identification of standards for evaluating therapeutics.

Based on the example of the PROQOL – HIV study, we will discuss:

- Why is it important to measure QoL and how can it be done?
- What are the different instruments to measure QoL in HIV?
- Why is there a QoL scale specific to HIV?
- The methodology of instrument validation
- What are the possible uses of this scale? Who will use it? Will it benefit PLWHIV/AIDS, doctors, Pharmaceutical firms?
- Why a transnational scale? Is it possible to compare the QoL of people living in countries where the access to care and HAART is not the same?
- What is the scope of this kind of scales? Is it possible to isolate factors that have an impact on QoL? Are they different depending on contexts?
- What are the perspectives depending on countries and settings?

Presentation

The PROQOL-HIV questionnaire was developed to measure the health-related quality-of-life (HRQL) of People living with HIV/AIDS (PLWHA) in different cultures in the highly-active antiretroviral therapy era. This study presents the psychometric validation and, the conceptual model: the psychosocial and clinical factors impacting on HRQL.

Methods: 830 patients were included in a cross-sectional survey in 8 countries: Australia, Brazil, Cambodia, China, France, Senegal, Thailand and USA. Item reduction was based on content, distribution of responses and factorial analysis. Reliability, construct and clinical validity with reference to biological markers and socio-demographic data.

Results: The 39-item questionnaire (and 4 individual items including Care Satisfaction and Financial Impact) demonstrates consistent psychometric properties (60% variance explained, Cronbach alpha above 0.8, intrascale correlations above 0.5). Concurrent validity was demonstrated (MOS- HIV, EQ-5D). From 9 dimensions, 4 subscores were derived: Physical Health and Symptoms, Treatment Impact, Social and Intimate Relationships, Emotional Distress. Significant differences in HRQL scores according to symptoms, comorbidities, CD4 and CDC stage support our endpoint model. PROQOL-HIV dimensionality across countries is consistent with previous qualitative research. Western countries (early diagnosis and treatment, higher income) and emerging countries like Thailand and Brazil had better HRQL than China and Cambodia. Chinese and Khmer had lower HRQL scores ($p < .001$), particularly on physical health and symptoms, health concerns, and stigma dimension, which was highest in Senegal. Between-country differences are also reflected by significant correlations between PROQOL scores and external factors: frequency of symptoms (higher in Cambodia, China and Thailand), comorbidities (higher frequency of psychiatric disorders in Cambodia), and CD4 count (low in Chinese and Khmer patients).

Speaker

Martin Duracinsky, MD, PhD, Hôpital de Bicêtre, Internal Medicine and Infectious Diseases (Pr Delfraissy), France

Discussants

Cindy Kelemi, national coordinator at BONELA, Botswana Network on Ethics, Law and HIV/Aids, Gaborone, Botswana

Nthabiseng A. Phaladze, RN, PhD, Rho and Tau Lambda-at-Large, Lecturer, University of Botswana, Department of Nursing Education, Gaborone, Botswana

Bruno Spire, président of AIDES, French NGO, researcher in public health, INSERM – Institut National de la Santé et de la Recherche Médicale – ORS – Observatoire Régional de Santé, Marseille, France

Tonya Taylor, medical anthropologist, Columbia University, New York, USA

Chairs

Vincent Douris, v.douris@sidaction.org, +331 53 26 45 84

Veronica Nosedá, v.nosedá@sidaction.org, +331 53 26 49 61



The ethics of HIV related research in Africa: Mobilizing civil society

Ethique de la recherche sur le VIH en Afrique : quel engagement de la société civile ?

Tuesday 22nd September 2009 – 10.00 - 13.00

The Informed Consent Program

10.00 – 10.20

Claire Magone, Director of International Department,
Sidaction

Ways to get involved in research ethics

10.20 – 10.50

Information and awareness raising

Presentation and debate led by Caroline Desclaux,
CRCF Ethics Project, Senegal

10.50 – 11.20

Building the capacity of key players

Presentation and debate led by Kasabati,
Burkina Faso

11.20 – 11.50

Community involvement in research ethics: is there a model?

Presentation and debate led by Calice Talom, REDS,
Cameroon

11.50 – 12.20

Monitoring research sites

Presentation and debate led by Morenike Ukpong,
Nhvm, Nigeria

Round table

12.30-13.00

The impact and limits of community mobilization

How far can we interact with the world of research?

Facilitated by Marie de Cenival, coordinator of
the Ethics / Research program – Sidaction, France

- Is research ethics only for experts?
- How much can awareness, training and expertise help?
- What is ideal when it comes to organization's defending the rights and interests of target populations?
- Can African AIDS organizations affect the course of HIV/AIDS research in Africa?

Le programme *Informed consent*

10.00 – 10.20

Claire Magone, Directrice des Programmes
Internationaux, Sidaction

Mobilisation associative et éthique de la recherche

10h20 – 10h50

Sensibiliser les publics concernés

Présentation et débat animés par Caroline Desclaux,
CRCF, Sénégal

10h50 – 11h20

Renforcer les compétences des acteurs

Présentation et débat animés par Kasabati,
Burkina Faso

11h20 – 11h50

Quelles structures pour quelles ambitions ?

Présentation et débat animés par Calice Talom,
REDS, Cameroun

11h50 – 12h20

Les activités de veille éthique autour des sites de recherche.

Présentation et débat animés par Morenike Ukpong,
Nhvm, Nigeria

Table ronde

12h30 – 13h00

Impact et limites de la mobilisation associative vis-à-vis de la recherche

Quel interlocuteur face au monde de la recherche ?

Table ronde animée par Marie de Cenival,
coordonnatrice du programme Ethique / Recherche
de Sidaction

- L'éthique dans la recherche est-elle seulement une affaire de spécialistes ?
- Sensibilisation, formation, expertise : et après ?
- Quelle structure est la plus adaptée pour défendre les intérêts des populations ciblées par les recherches ?
- Le monde associatif en Afrique peut-il avoir une influence sur le cours de la recherche en Afrique ?

Contact

Claire Magone, c.magone@sidaction.org