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How does the issue of research knock on a PLWHA organization's door?

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RACINES Presentation

- Research, Community Actions, Initiatives for New Hope
- Beninese NGO started in 1999
- 2 areas of activity :
 - Education
 - Health : fighting against HIV/AIDS in 2 places (Cotonou and Savalou)



The issues of ethics and research in Bénin

- Bénin, virgin territory for clinical trials
- Retrospective and prospective research is conducted
- Lack of good clinical and academic trials
- Nonetheless, small trials are conducted in various areas:
 - Traditional medicine
 - New products from the West with specific/alternative methods of payment (food support, immune boosters, vitamins, supplements, products that “cure” HIV?...)
- Heavy media involvement, especially radio in advertising traditional medicine products....



Community group involvement

- They are solicited more frequently by those conducting this kind of « informal » research
- Because the process is more complicated on the state level for trials
- Traditional healers and vendors of new Chinese and Western products inundate community organizations



Organizations' involvement

- Healers and product vendors
 - No training on clinical trials
 - Feel threatened by modern medicine and the State (formula theft ...)
 - Think that they can be better understood by and collaborate better with community organizations
 - Want to work in a context of total anonymity and secrecy
 - Suggest alternative payment methods



Organizations' involvement

- RACINES receives many requests for participation in trials on various products
- Most of these requests are from people who have little to no knowledge of HIV pathology
- Claim success in other places but do not offer proof
- Patients are used at their own expense and told us that they also pay for the products themselves



Case 1

- Mr. D.P comes to RACINES in June of 2006 and asks to meet with the doctor to try out his new product on People Living with HIV
- He is based in Lomé, claims that patients in Togo et Burkina Faso became HIV negative
- Product's active ingredient is men's urine
- Cost =7.100FCFA/month for 9 months for the patient and 3.000F/month/patient for the doctor
- Blood sample for rapid test has to be taken 18 months later
- Requests secrecy especially from the PNLs



Case 2

- Madame B.J, a teacher on ARVs since 2004
- Discovered a traditional healer "able to cure HIV"
- 60.000FCFA /month for an 8-month cure with the patient becoming HIV negative
- Came to take her ARVs every month
- Drop in CD4 after 6 months of traditional treatment, new HIV test: HIV+
- Confided in us after the results



Conclusions / Perspectives

- Need for training and information equally great for healers, product vendors, journalists and patients
- Summarize the products currently in use in Benin
- Meet patients who have already used these products and document their experiences