

LINKING RESEARCH AND INTERVENTION: A COMMUNITY RESEARCH PROGRAM ON SEROSTATUS DISCLOSURE IN FIVE COUNTRIES (Mali, Morocco, DRC, Ecuador, Romania)

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Background

Disclosing one's serostatus is still a great burden for People Living With HIV (PLWHIV) due to related stigmatization and discrimination. Most studies have been carried out in Northern countries, data for the South being sparse. Few suitable interventions have been proposed or evaluated on the ground.

Methods

A mixed (researchers/NGO members) and international research consortium developed a research program to study the phenomenon of serostatus disclosure in order to inform policies and to propose suitable interventions.

Following an exploratory qualitative study, a standardized questionnaire was developed and pre-tested on the ground. Eligibility criteria for participation were as follows: being aged 18 or older, living with HIV, knowing one's HIV status for at least six months. Study participants were administered a 125-item questionnaire during face-to-face interviews with trained community-based interviewers in the five countries of the study between May and October 2011.

The questions explored history with HIV, serostatus disclosure, representations of HIV/AIDS and associated treatments, social and affective life, sexuality, quality of life, relationships with community-based organisations as well as psychological construct including self-efficacy.

Results

Process

The Partages study group, composed of "paired" community actors and researchers for each country, developed a collaborative working methodology. Training and capacity-building workshops were proposed so that everyone could play an active role in all stages of the project. The complementary expertise and experience of the research teams and the community actors were particularly useful in the data analysis stage.

The research team experience had been described in a recent publication: Demange, E., Henry, E., Préau, M. *From collaborative research to community-based research. A methodological toolkit.* Paris. ANRS/Coalition PLUS. Coll. Sciences sociales et sida. 2012

Main characteristics of participants (n= 1500)

Variables	n(%) or median [IQR]
Age (years) :	36 [27 -44]
Number of years since HIV diagnosis	5 [2 - 8]
Women	813 (54)
Main source of money	Personal activity 703 (47) Structural or institutional 368 (25) Family network 398 (27)
Activity	Jobless 384 (26) Formal sector 631 (42) Informal sector 198 (13) Housewife 233 (16)
HAART	1360 (91)
Health perception	Bad 91 (6) Poor 268 (18) Good 839 (56) Very good 240 (16) Excellent 59 (4)

Variables	n(%) or median [IQR]
Disclosure to main sexual partner	637 (42)
Having experienced sympathy and social support after disclosure	1184 (79)
Having experienced rejection after disclosure	236 (16)
Having experienced physical violence	63 (4)
Having stopped sexual intercourses	481 (32)
About sexual life, you are	Insatisfied 378 (25) Rather insatisfied 112 (8) Rather satisfied 184 (12) Satisfied 721 (48)
Do you feel lonely ?	Sometimes 466 (31) Everyday 218 (15)

n= 1500 PLWHIV (300 per country) answered the questionnaire.

Conclusions

The study has furthered universal similarities in terms of suffering and impact on people's quality of life. The results are currently being used in several countries to propose suitable interventions to respond to the problems associated with the question of disclosure and to develop strong advocacy messages, promoted by the NGOs involved in the project.

Coalition PLUS is an international union of 10 NGOs fighting the AIDS pandemic in their respective country (Ecuador, Burkina Faso, Burundi, Canada, France, Mali, Morocco, the Democratic Republic of the Congo, Romania, Switzerland). They decided to join forces to promote together community-based approach in the fight against HIV through advocacy, research and technical support programs.

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Scientific coordination



Study group



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