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Original

# Experiences about HIV-AIDS preventive-control activities. Discourses from non-governmental organizations professionals and users

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## ABSTRACT

*Objectives:* The main aim of this study was to identify the experiences of professionals in nongovernmental organizations (NGO) in Catalonia (Spain) working in HIV/AIDS prevention and control activities and potential areas of improvement of these activities and their evaluation. A further aim was to characterize the experiences, knowledge and practices of users of these organizations with regard to HIV infection and its prevention.
*Methods:* A phenomenological qualitative study was conducted with the participation of both professionals and users of Catalan nongovernmental organizations (NGO) working in HIV/AIDS. Theoretical sampling (professional) and opportunistic sampling (users) were performed. To collect information, the following techniques were used: four focus groups and one triangular group (professionals), 22 semi-structured interviews, and two observations (users). A thematic interpretive content analysis was conducted by three analysts.
*Results:* The professionals of nongovernmental organizations working in HIV/AIDS adopted a holistic approach in their activities, maintained confidentiality, had cultural and professional competence and followed the principles of equality and empathy. The users of these organizations had knowledge of HIV/AIDS and understood the risk of infection. However, a gap was found between knowledge, attitudes and behavior.
*Conclusions:* NGO offer distinct activities adapted to users' needs. Professionals emphasize the need for support and improvement of planning and implementation of current assessment. The preventive activities of these HIV/AIDS organizations are based on a participatory health education model adjusted to people's needs and focused on empowerment.

## Experiencias sobre la prevención y el control del VIH-sida. Discursos de los profesionales y usuarios de las organizaciones no gubernamentales

*Palabras clave:*
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Entrevistas como asunto
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## RESUMEN

*Objetivos:* Identificar las experiencias y actividades de las organizaciones no gubernamentales (ONG) que trabajan en la prevención y control del VIH/sida, las posibles áreas de mejora de las actividades y de su evaluación, e identificar las experiencias, conocimientos y prácticas de sus usuarios sobre el VIH y su prevención.
*Métodos:* Estudio cualitativo fenomenológico en el que participan los profesionales y usuarios de las ONG que trabajan en VIH. Se realizó un muestreo teórico (profesionales) y un muestreo opinático (usuarios). Se utilizaron cuatro grupos focales y uno triangular (profesionales), 22 entrevistas semi-estructuradas y dos observaciones (usuarios). Se realizó un análisis de contenido temático realizado por tres analistas.
*Resultados:* Los profesionales de las ONG ofrecen un enfoque holístico, confidencialidad, competencia cultural y profesional, y aplican los principios de igualdad y empatía. Los usuarios tienen conocimientos sobre el VIH/sida y comprenden el riesgo de infección. Existe una separación entre conocimiento, actitud y conducta.
*Conclusiones:* Las ONG ofrecen diversas actividades adaptadas a las necesidades de los usuarios. Los profesionales destacan la necesidad de apoyo y mejora de la planificación y ejecución del proceso de evaluación actual. Las actividades preventivas de las ONG que trabajan en VIH/sida se basan en un modelo de educación sanitaria participativa ajustado a las necesidades de la población, basada en el empoderamiento.

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## Introduction

A number of HIV-related nongovernmental organizations (NGO) work to promote prevention and health (AIDS-NGO) and provide care and help to persons with HIV. The role of these organizations has been critical in the fight against HIV since the onset of the epidemic[1].

In many countries, AIDS-NGO have led the initiative against HIV. These organizations are the largest providers of preventive activities against HIV-AIDS, particularly among groups showing high-risk behavior: commercial sex workers, injecting drug users, men who have sex with men, youths in high-risk situations, persons living with HIV/AIDS, prisoners and immigrants[2,3]. The activities of AIDS-NGO are complementary to those in the public health sector and these entities act as a bridge or as "communicative spaces" between marginalized communities or immigrants and health services[4–7].

Since the start of the of the AIDS Prevention and Care Program in Catalonia (Spain), the importance of promoting and coordinating the activities of the various NGO in the field of HIV/AIDS has been highlighted[8] and the preventive, health promotion and care activities of AIDS-NGO have increased[3,8,9].

The core activities of AIDS-NGO are as follows: providing HIV prevention peer education; distributing educational materials; promoting health education and safe sex activities; participating in commemorative AIDS acts, providing counselling and rapid testing of HIV and syphilis; receiving health services and referrals, when necessary; promoting adherence to antiretroviral treatments; conducting emotional support sessions and individual psychological therapies; and providing legal advice and advocacy[10,11]. These organizations have interdisciplinary teams, usually consisting of psychologists, physicians, social workers, social educators, nurses, experts and volunteers.

Information on the preventive activities of AIDS-NGO is only available in the technical or yearly reports of these organizations[3,8]. Few studies have been published on the experiences and opinions of AIDS-NGO to fully understand their preventive programs and their needs and challenges[3] or to describe the dearth of financial and human resources of NGO[12]. The present study reports the experiences and practices of AIDS-NGO to describe how these organizations work and how their activities are perceived by users.

This study is part of a major study aiming to identify a set of valid and reliable indicators to facilitate assessment of the activities carried out by AIDS-NGO. The main objective of this study was to identify the experiences of professionals in Catalan NGO working in HIV/AIDS preventive and control, the potential areas for improvement of these activities, and their evaluation. A further aim was to identify the experiences, knowledge and practices of users of these programs related to HIV infection and its prevention.

## Methods

We carried out a qualitative study using a phenomenological approach to identify and interpret discourses (professionals and users) on individual experiences in the social world expressed through language[13].

### *Sampling*

Professionals and users from 36 out of the 40 AIDS-NGO funded by the Department of Health agreed to take part in this study. For the professionals, a theoretical sampling based on prior definition of participants' characteristics was carried out to obtain optimal variety and discursive wealth to reach data saturation. The variables used to define the informant profile of AIDS-NGO professionals were as follows: AIDS-NGO target population (commercial sex workers, injecting drug users, men who have sex with men, youth in high-risk situations, persons living with HIV/AIDS, prisoners and immigrants), age, sex, professional profile, setting (urban or rural) and years of experience.

Due to the difficulties of theoretical sampling, opportunistic sampling was finally performed for the AIDS-NGO users. However, heterogeneity criteria were taken into account. The variables used to define the users were AIDS-NGO target population, age, sex, nationality, serostatus, and length of relationship with the organizations.

Tables 1 and 2 describe informants' sociodemographic characteristics.

Professionals were recruited by the research team through informative telephone calls requesting participation.

To identify users, key informants of AIDS-NGO were ask to provide information about the study and to request participation via news boards and web pages. The group of youths at high-risk was selected according to their availability in terms of time and location.

### *Techniques to generate information*

Distinct techniques were used[14]. For professionals, focus groups[15] and triangular groups were employed[16]. In the focus groups, the instrument used to stimulate individual speech was interaction[15]. For users, semi-structured interviews were employed because sensitive issues may arise[17] during their the course of the interview. Open, focused and non-systematic observation of theater performances in teenagers and young adults was also employed[18].

The use of the different techniques was justified by the feasibility and accessibility of the informants and the triangulation of information collecting techniques[19,20].

Four focus groups and one triangular group took place among the AIDS-NGO professionals. Twenty-two semi-structured interviews for users were completed, as well as two observations of youth and teenager groups. For the group interviews, professionals were segmented according to their target group. The number of personal interviews was determined by examining the discursive representativity of users' high-risk activities and data saturation.

Forty-two professionals from 36 AIDS-NGO were invited to participate in the focus groups and 36 participated. Six professionals could not attend due to incompatibility with their work schedules.

### *Setting and data collection*

Data collection was performed between February and June 2008. Focus groups were held in a neutral place (Jordi Gol Institute of Research in Primary Care) and included a moderator and an observer. The semi-structured interviews took place in the users' work place or at the AIDS-NGO venues. The observations were made in two secondary schools.

To explore the various topics, an outline was used in the development of the focus groups, the triangular group and users' interviews (Table 3). During these techniques, field notes were taken. Group interviews lasted for 90-120 minutes, semi-structured interviews for 30 minutes and observations for 60 minutes. In the group and individual interviews, data saturation was reached[3,19,21,22]. All the informants verified the information.

### *Ethical aspects*

This study was conducted according to the Helsinki Declaration and Good Clinical Research Practice. Participants signed informed consent forms at the beginning of each focus group or interview. The confidentiality and anonymity of the data was ensured through a code given to each informant [23]. This code was used to identify