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.

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

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 opinativo (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.

Conclusions: 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, basado 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 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 and the preventive, health promotion and care activities of AIDS-NGO have increased.

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. 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. Few studies have been published on the experiences and opinions of AIDS-NGO to fully understand their preventive programs and their needs and challenges or to describe the dearth of financial and human resources of NGO. 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.

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

The use of the different techniques was justified by the feasibility and accessibility of the informants and the triangulation of information collecting techniques.

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’ workplace 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. 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. This code was used to identify
the selected verbatim-transcripts. The transcripts were anonymous and made by trained external personnel. The project was approved by the Ethical and Clinical Research Committee of the Jordi Gol Institute of Research in Primary Care.

Data analysis

The analysis was based on notes from the observations and from the literal and systematic transcriptions of the data. A thematic interpretive content analysis was carried out with the support of Atlas.ti and Nvivo software. Three researchers independently analyzed the data. The results were subsequently discussed and a consensus was reached.

The analysis took place as follows: a) careful reading of all the transcripts, b) identification of the relevant subjects and texts, c) fragmentation of the text in units of meaning, d) text codification with a mixed strategy through emerging codes and predefined codes, e) creation of categories by grouping the codes by the criterion of analogy, according to pre-established analytical criteria in the objectives of the study and new elements from the comments, f) identification of emerging categories not initially planned, g) analysis of the points of agreement and disagreement, h) triangulation of the results.

Results

The results are structured according the comparison between professionals’ and users’ discourses. Verbatim records of informants’ discourse are shown in Tables 4 and 5. The quotations were translated from Catalan, Spanish and Portuguese to English.

Characteristics of HIV/AIDS prevention and control activities: professionals’ and users’ experiences

1) Holistic approach

AIDS-NGO professionals reported that they offer services that target the whole person rather than focusing on preventing HIV infection. The professionals attend to users’ basic needs before tackling HIV/AIDS-related issues. AIDS-NGO users agreed with...
of congruent behaviors, attitudes, and policies that come together with highly diverse needs. Cultural competence is defined as a set of skills required social, legal and work-related services.

were observed: the autochthonous population mainly required professionals but some differences in the use of AIDS-NGO services were observed: the autochthonous population mainly required activities related to HIV prevention, while immigrants initially required social, legal and work-related services.

2) Cultural competence

AIDS-NGO currently provide care for a multicultural population with highly diverse needs. Cultural competence is defined as a set of congruent behaviors, attitudes, and policies that come together in an organization to enable it to work effectively in cross-cultural situations.

The professionals also underlined an important change in the approach to users. In the 1980s, talking about sexual relationships or condoms was still taboo, whereas currently the main problem is communication, language barriers, and knowing the degree of information assumed, due to cultural differences.

3) Confidentiality

Confidentiality pervades every AIDS-NGO activity. Professionals apply strategies to bring the organization and its users closer and create a bond.

4) Creation of horizontal relations between AIDS-NGO users and professionals

Professionals working with men who have sex with men, injecting drug users, or persons living with HIV/AIDS considered that the creation of horizontal relations based on equality and empathy was essential. Such relations were believed to facilitate accessibility and bonding between the professional and user and contribute to eliminating prejudices that are often held by health professionals. Users highlighted the perception of accessibility and availability and felt accompanied, emphasizing the human component of these interactions.

Table 4
Categories emerging in focus groups, the triangular group and semi-structured interviews from AIDS-NGO professionals and users.

<table>
<thead>
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<th>Category</th>
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| Holistic approach | Professional “their priorities are food and housing; when you offer them care, workshops, the test...you are offering services based on the person, the HIV activities are not the priority” (group 2).
User “When my partner died they always told me: “Remember that we are here if you need us”. It was not the fact of being infected and affected, but that I felt I was treated as a person” U13. “It has meant a lot to me to be able to become like everybody else...to have a job. They help you to improve, to have your house, your own stuff” U10
| Cultural competence | Professional “We see many cultures and different needs. The information given has to be adapted and reconsidered. We constantly need to look for new ways of working” (group 1).
“Language is not the only problem...but the basis of the concepts you talk about...if we start talking about a virus maybe they do not understand the same thing...” (group 3)
| Confidentiality | Professional “We ask them their name and they tell us, later they get a card with a code to preserve confidentiality” (group 1)
| Creation of horizontal relations between the NGO users and professionals | Professional “They have not been able to talk and share their worries even in their closest circle. This is the value of the organization, you can talk with somebody that understands you and shares the same problem as you” (group 5)
| Evaluation of the objectives and activities of AIDS-NGO | Professional “And the girl that you take to the doctor...and you are with her...three or four hours. At the end, an infection is diagnosed. You have been with her many hours. How would you consider that?” (group 4).
“Some of them wait in very dangerous locations. Prevention in these cases means that the client stops further away...not only for them, but also for the client. Prevention of accidents before AIDS prevention” (group 1)
“They know that to share the syringe is a risk for HIV, but the sense of urgency and the need prompt them to do it again. The objective is not to stop drug use, but for the injecting drug user to feel more integrated” (group 1).”
“We are trying to establish coordination between departments, Work, Social and Citizenship. Everyone says that HIV does not belong to them... only the Health Department, but it is task requiring coordination” (group 2)
“In the online consultations we get more questions about sexuality by young users than in the face-to-face consultations, in which sexuality issues are rare (group 4).
Listen
| Challenges and opportunities for improvement | Professional “X has explained many things that have helped not only in HIV, but also in many other areas. The workshops are very useful, they are the only HIV talks in the prison” U17
“I think the information is available but lots of people still get infected, you have all the information and people still get infected” U4
“I tell the clients that I do not have sex without a condom. This is non-negotiable and more money does not change my decision, because my health is the priority” U11. When you have the drug the only thing you want is to get a shot and you do not care if the syringe is clean or dirty. You only want to get a shot” U19.

Table 5
Categories emerging about knowledge and beliefs on HIV by AIDS-NGO users in semi-structured interviews.

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<th>Verbatim</th>
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| Knowledge and beliefs on HIV | Professional “X has explained many things that have helped not only in HIV, but also in many other areas. The workshops are very useful, they are the only HIV talks in the prison” U17
“I think the information is available but lots of people still get infected, you have all the information and people still get infected” U4
“I tell the clients that I do not have sex without a condom. This is non-negotiable and more money does not change my decision, because my health is the priority” U11. When you have the drug the only thing you want is to get a shot and you do not care if the syringe is clean or dirty. You only want to get a shot” U19.
| User “I’d like to think that the NGO will not only remain a good NGO and that it will incorporate more people, because at the moment I always see the same people, it is a sort of private club” U14.
| Acknowledgement of the AIDS-NGO | Professional “We offer an outstanding service that provides help in aspects not covered by the administration, but it is not valued. Furthermore, the evaluation has funding consequences” (group 2)
“We offer an outstanding service that provides help in aspects not covered by the administration, but it is not valued. Furthermore, the evaluation has funding consequences” (group 2)
“The people are acknowledged with us. You see they are because they feel it...” |
5) Interdisciplinary approach
NGOs have professionals from distinct disciplines, which facilitates an interdisciplinary approach when addressing users’ overall and specific needs. Some users reported that the AIDS-NGO had several, well-defined roles and provided assistance appropriate in each case. For instance, when diagnosis of HIV was made, the need to meet some other seropositive people and to receive psychological support was perceived as essential.

6) Evaluation of the objectives and activities of AIDS-NGO
In most group meetings, concerns about the difficulties of evaluating the work of AIDS-NGO were voiced. Some activities required a strong effort and dedication and quantitative indicators, such as the number of cases, were insufficient to evaluate them.

To improve assessment of the activities and objectives of AIDS-NGO, professionals suggested looking for quantitative and qualitative indicators that would provide a reliable measure of the process and its results.

7) Challenges and opportunities for improvement
Professionals reported that multiple activities required high mobility, the ability to adapt, creativity, imagination and innovation. The enquiries and requests for information received through the internet and e-mail from youths in high-risk situations and men who have sex with men were highly regarded. Therefore, these new technologies should be strengthened. Youths in high-risk situations reported that it was essential to be able to communicate their sexual concerns through the internet or via e-mail. Boys found it easier to consult via the internet and chose AIDS-NGO offering online services.

Another challenge was the need to reach invisible groups such as older men who have sex with men and commercial sex workers, the latter linked to illegal organizations and tending to work on the roadside where opportunities to assist them are very limited.

A major challenge for professionals was integrating users into the community, particularly in the case of injecting drug users. The informants explained that it is important to decrease drug consumption, to promote social integration, lower self-exclusion and aim at more controlled abuse.

Some users point out major challenges to improving AIDS-NGO services. These users stated that these organizations have limited resources available and cannot offer help in extreme situations. For them, AIDS-NGO need more funding or to join efforts with other related NGO to be able to offer more services. In addition, these users report that the locations of AIDS-NGO are unevenly distributed, with a need to reach the population outside the Barcelona area.

8) Acknowledgment of the AIDS-NGO
NGO professionals complained that other health and social providers did not sufficiently acknowledge their work. In reports, these professionals were required to continuously justify what they do and the result had an impact on funding.

Importantly, professionals’ felt valued by the users who requested their help and recommended them to other users. They felt satisfied with their work and pointed out that AIDS-NGO promoted participation and self-healing.

9) Knowledge and beliefs on HIV infection among AIDS-NGO users
Adult users reported having good knowledge of HIV-AIDS infection, transmission and prevention and recognized the contribution of AIDS-NGO to their knowledge.

However, there were still contradictions among individuals. Despite being aware of the information, some people believed that infection does not occur in unprotected sex. Commercial sex workers often need strategies to convince people in their social context to use condoms. Moreover, an ex-injecting drug user explained that when you are addicted to drugs it is difficult to think about prevention. Youths in high-risk situations explained that condoms are often not used due to unplanned opportunities to have sex. At the same time, drug or alcohol abuse increase vulnerability and affect cognitive and emotional ability, which can influence the use of preventive measures.

Discussion
This qualitative study improves knowledge of the activities, attitudes and practices of AIDS-NGO professionals and users. NGO professionals working in HIV/AIDS adopt a holistic approach in their activities, maintain confidentiality, have cultural and professional competence and follow the principles of equality and empathy. Users have HIV/AIDS knowledge and understand the risk of infection and feel satisfied with the AIDS-NGO services.

These results agree with those obtained by Convisier and Pounds, which emphasize the importance of offering ancillary services to people in need of HIV/AIDS prevention or treatment. Estrada et al show that a holistic person-based approach is essential to achieve a change in behaviour.

The preventive activities of AIDS-NGOs are based on a participatory health education model adjusted to people’s needs. This model focuses on empowerment and knowledge and skills. This educational strategy follows the principles put forward by the World Health Organization, highlighting the impact of person-based care in health improvement, quality of life, user trust and treatment adherence. In this educational model, professionals take into account the users’ values and perspectives and incorporate them in the decision-making process.

Users are satisfied with the AIDS-NGO activities because of empathic relationships, person-based care and the various activities organized. However, some feel that more resources and services are required to cover their demands.

The results confirm that AIDS-NGO target most of their activities at groups at risk of social exclusion or groups of socially vulnerable individuals to reduce social inequalities due to socioeconomic position, gender and social orientation. Our results also confirm the role of AIDS-NGO as a bridge and “space and communication” for health services and the population as well as with other services (legal, social, legal, employment, etc.). This evidence is consistent with the applicability of specific programs that require a community approach to adjust them to match the needs of the target population.

The increase in the immigrant population, which is more socially vulnerable and shows high cultural diversity, requires the incorporation of other professionals, such as mediators. A greater degree of creativity and cultural competence is required to design workshops with contents adapted to the distinct audiences, translation of informative materials and the creation of materials adapted to immigrants’ linguistic and cultural needs. The importance of these roles justifies the inclusion of these professionals in the AIDS-NGO team, although their presence or availability in these teams varies.

The professionals regarded confidentiality as essential. The emerging virtual forums or web pages, as platforms to prevent and provide information on HIV-AIDS, contribute to inter-user support and to improving bonding with AIDS-NGO while preserving personal anonymity. Internet-based HIV-AIDS preventive interventions have been shown to be as effective as personal-based interventions. In our study, on-line consultations and web pages were more frequently used by young people. However, a recent
study by Bull et al. shows that internet-based interventions need to be more intensive to maintain young people’s attention over several sessions in order to be more effective.37 Despite the several strategies and activities performed by AIDS-NGO, there are still beliefs that hamper HIV-AIDS prevention: a) the time gap between a risky sexual encounter and the onset of the disease; b) unprotected sex facilitates closeness and intimacy with the partner and is perceived as a risk-free practice; c) risk perception is still based on the partner’s external appearance, which implies unprotected sex with people “that look healthy.”29,38 The triangulation of techniques in this study highlights the gap between knowledge and behavior with regard to HIV prevention. While more information is available than previously, this increase has not been followed by changes in risk behavior, particularly in the autochthonous population.

During the two observations, not all topics included in the focus groups and interviews were included and therefore data saturation in this population sector was not achieved. However, the results agree with those of other studies in the same group.39 Caution is needed before extrapolating these results to other settings. However, the similarity with other studies suggests the applicability of our results.

Another limitation was that we did not study the views of other health providers working with HIV-AIDS prevention or control programs (primary care, public health and reproductive and sexual health) due to practical impediments and lack of resources. Our study increases understanding of the role of AIDS-NGO. To date, few studies have analyzed the role of these organizations from the perspective of both professionals and users. Some studies in primary care have analyzed the point of view of professionals and patients;40 but none refer to AIDS-NGO.

This study adhered to the following quality criteria of qualitative research:14,19,25,42,43: (i) methods, data and analysis were triangulated; (ii) the analysis of triangulation established substantial agreement;44 (iii) the participants had access to the summary of the transcripts to verify their contents.

In conclusion, AIDS-NGO offer distinct activities adapted to users’ needs. Users are satisfied and feel comfortable with this education and health promotion model. This participatory model seems to be that which the user will subsequently use to facilitate HIV/AIDS prevention. When basic needs are solved, HIV/AIDS prevention activities become more effective. However, greater efforts seem to be required to create strategies that would close the gap between knowledge, attitudes and behavior. However, in the near future, more efforts should be made to improve services and cooperation between AIDS-NGO and other organizations or health services working in HIV/AIDS.

Authors’ contribution

A Berenguera, E Pujol-Ribera, C Violan, A Romaguera, R Mansilla, A Giménez and J Almeda, have been involved in drafting the manuscript or revising it critically for important intellectual content and have given final approval of the version to be published. A Berenguera, E Pujol-Ribera, J Almeda, C Violan and A Romaguera have made substantial contributions to conception and design. A Berenguera and E Pujol-Ribera have been made the field work and the analysis and interpretation of data. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

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Competing interests

The authors declare that they have no competing interests.

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