



THE SELF-HELP GROUP AS A RESOURCE IN BETTER DEALING WITH HIV INFECTION. TEN YEARS OF EXPERIENCE IN ARCOBALENO AIDS

S. Patrucco, A. Siliato, P. Gusmeroli, P. Altini, G. Orofino, C. Owen

Associazione Arcobaleno Aids, Italy

Background

Thanks to HAART, HIV infection is comparable to a chronic pathology. Yet, this extraordinary result does not mean that people living with this condition no longer find themselves facing potentially painful and stressful situations also as a result of social stigma. Hence, in 2008, Arcobaleno Aids felt the need to start a new self-help group, replacing a previous experience of many years in which, however, a number of difficulties and weaknesses had emerged.

Aim

With the new self-help group, the Association's aim is to help those people living with HIV, and who wish to participate in the new group, to improve their level of wellbeing. By sharing, discussing, assisting and supporting one another, each member can:

- begin a process of personal growth aimed at accepting the diagnosis;
- formulate personal strategies to better face the difficult situations posed by HIV infection;
- give value to their acquired competences and the sense of self-efficacy.

All of this has positive effects in terms of the quality of life.

Methods

The three promoters of the project assumed the role of voluntary facilitators, and their task is that of ensuring the efficient running of the new group. Arcobaleno Aids guarantees them the supervision of a psychologist.

The base upon which the promoters began building the project was a revision of the experience of the previous group. They agreed that the group had to have a name and written rules that might identify the sense of belonging and might determine its life.

Hence, from the very first meeting, as well as facilitating the group's formation, the promoters proposed two objectives:

- the group had to find and give itself a name;
- the group had to define and establish a set of shared rules.

The name that the group gave itself is **+Positivi**. As for the rules, the group decided that they had to be set down in what is an actual contract that all new members must agree to and sign.

The contract

The contract specifically:

- sets the number of members at not more than 15 people – a number considered acceptable if all members are to have the chance to express themselves;
- allows for the participation of serodiscordant couples and people with no HIV diagnosis;
- sets the number of meetings at two per month;
- stipulates that people applying to enter the self-help group must attend an interview with the facilitators, who provide information on what a self-help group is, on what the rules of **+Positivi** are, and with whom it is possible to evaluate whether this is the best response to their needs;
- underlines that gender identity, sexual orientation, religion and political ideas must never be the cause of discrimination;
- recognises that the abuse of illegal substances or alcohol, and serious psychiatric pathologies are conditions that require different types of assistance provided by specialised personnel;
- requires members of the group to guarantee continuity in attendance and participation;
- establishes that mutual respect is the founding rule of **+Positivi**, which means guaranteeing confidentiality and punctuality, notifying possible delays or absences, listening when a member of the group is speaking and giving constructive feedback, and sharing with the group the decision to conclude the self-help experience.

Results

In 10 years of meetings, the self-help group has seen the participation of 50 people, 41 males (31 MSM) and 9 females, and overall an average age of 35. Only one serodiscordant couple and four people with no HIV diagnosis have participated. Ten of the people who asked to enter the group did not meet the conditions or have the suitable characteristics. Of the total fifty participants, 27 people have concluded positively their participation in the group; 11 people abandoned the group; 12 people are still members of the group,

The themes discussed by the group have been:

- being diagnosed personally with HIV infection, how the diagnosis was communicated, how the individual reacted;
- the relationship with the hospital and its staff;
- treatment – the fear of starting, effectiveness, side effects, lipodystrophy, adherence, changing therapy, new pharmaceutical drugs;
- telling partners, family members and friends about the diagnosis – discrimination, stigma and self-stigma;
- HIV and work;
- HIV: rights and responsibilities;
- sexuality; sexually transmissible infections;
- HIV and becoming parents.

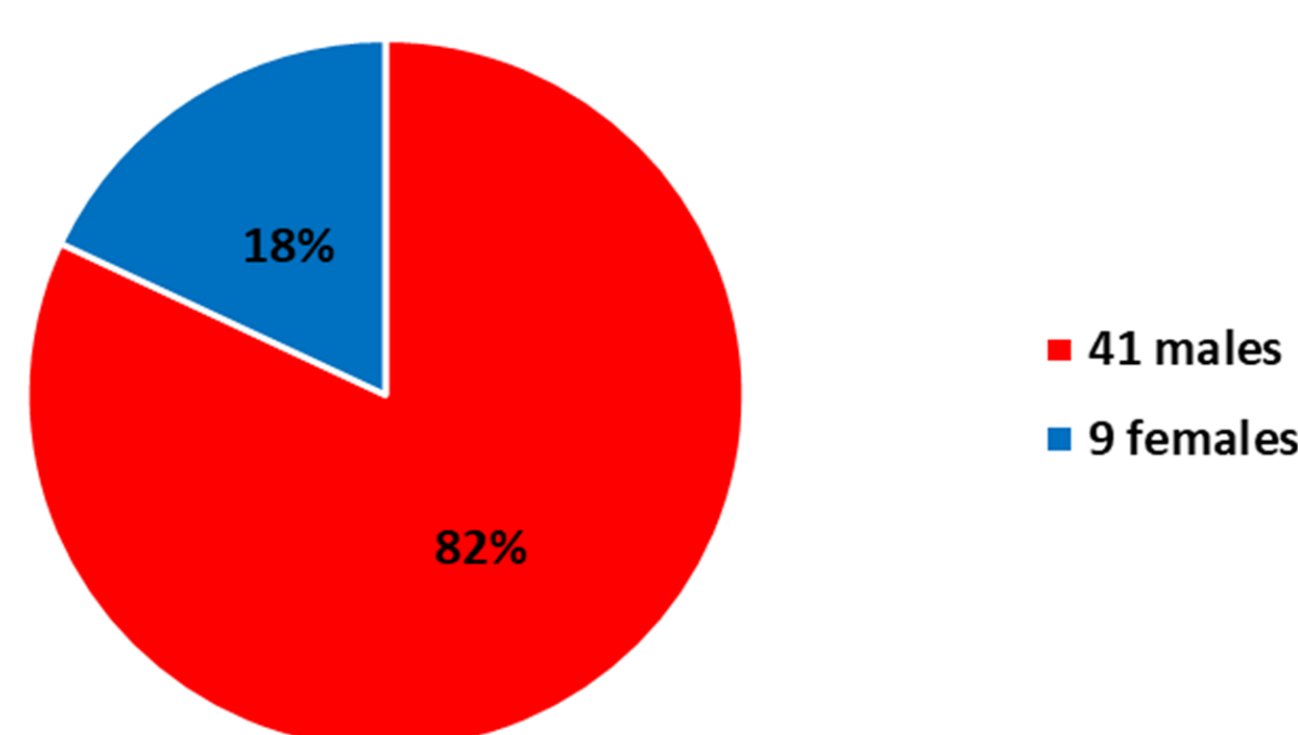
In the last year, another subject for debate has often been "Undetectable = Untransmittable".

Over the years, among the members of **+Positivi**, the need to make new friends has emerged. As a result, the group has tried to find means of answering this need by creating socialising events such as *Sede Aperta* (Open House) or *Pizza Positiva*. Such initiatives allow current members to meet old members who have concluded their participation, people who participated in the earlier self-help group, and other people living with HIV who, for various reasons do not belong to the group.

Conclusion

- For the majority, the experience has proved positive in terms of acceptance of the diagnosis, an improved adherence to treatment, overcoming self-stigma, and changing high-risk behaviour.
- For many, it has been the chance to create a network of friends that has lasted even after participation in the group has come to a conclusion.
- Some have chosen to do voluntary work with the Association and take part in informative activities, awareness and prevention events, as well as in the fight against stigma.
- On entering the group, some people have had difficulty recounting and sharing their experiences. However, in most cases, in time and thanks to the climate of trust and mutual respect, the majority have gradually been able to overcome their barriers.
- Having seronegative members has been acknowledged as a resource.

+Positivi: gender



+Positivi: sexual orientation

