



## The experience of overcoming the stigma associated to HIV/AIDS: a call for collaboration with community Psychology.

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### **Abstract**

After more than 20 years of the HIV/AIDS epidemic, it is noticed an intense connection with different forms of discrimination. The evolution of the epidemic has revealed that it stressed other forms of prejudice related to sexual orientation, to gender, race and social class. In Brazil, where the social inequality is very severe, the social exclusion is even a more important feature, once it exposes a bigger number of people to the infection by the virus and other sexual transmitted diseases. This situation generates an intense suffering, inhibiting emancipatory actions to face the stigma for a better quality of life of people who live with HIV/AIDS. By the practice of the Community Psychology at Cruzeiro do Sul University, in a Non-Governmental Organization (NGO), with poor communities in the periphery of São Paulo, it was intended to strengthen the psychological aspects of these people as an instrument for constructing more active citizens in the communities. The procedures were: 1 – Community and Institutional Diagnosis, by means of interviews and participative observation; 2- Group work, focusing on the exchange of experience between soropositive and soronegative women; 3- Elaboration and discussion of the group meetings, registered in weekly reports over a 10-month-period. The results have demonstrated that the suffering, resulting from a little tolerant society and culture, can be transformed by group practices focused on the strengthening of intersubjective exchanges which 1 – discuss the living experience of stigmatization and discrimination as a result of the articulation of subjective experiences with cultural background and social, political and economical aspects; 2- promote healthy mental aspects (affective and cognitive) related to the ability of noticing, in spite of the difficulties, the public space of an NGO as place for overcoming the stigma; 3- stimulate the strengthening of friendship between the participants and the social nets for support.

**Key words:** Community Social Psychology, HIV/AIDS, Non-Governmental Organizations (NGO), Stigma, Social Exclusion, Strengthening Communities.

### **Introduction**

The process of globalization of the capitalism is quite complex and unequal. In countries such as Brazil the consequences are related to: the increase in social inequality; the increasing concentration of income; the increment of structural unemployment; flexibilization of the social rights and increase of the feeling of insecurity in work and life; the weaken of the old identity and solidarity of social class; the growth of international migratory current; the uncontrolled consumption geographically expanded; increased the scope and global environmental degradation; the reactive fundamentalism affirmation

of identities of the non – included people (Mancebo, 2003).

In this context, Psychology has been requested, as well as other areas of knowledge, to contribute to change that social reality. Throughout its history, we can see different political positions. At some stages the Psychology underwrote a more conservative position, for example, developing technical and interventions that sought a passive adaptation of the subject to the social environment; in other times, has taken a more critical position, looking for instrumental to understand the subject as complex beings resulting from the interaction between

psychological, biological and social factors. (Lane, 1984; Bock, 2003).

Among some of the theoretical and practical approaches, we highlight the Community Social Psychology, which has as a scope the construction of the most active subjects in their social environment, and for which citizenship and autonomy are guiding parameters of actions that promote the development and changes of the communities (Campos, 1996; Montero, 2003).

In this direction the Community Social Psychology which guided many of the discussions of the Psychology Community course taken by the students of the fifth year of Psychology at Cruzeiro do Sul University, we bring some of the results achieved over approximately 10 years with the non-governmental organizations (NGOs) that act in the AIDS field in Eastern and Central São Paulo. These areas have high social vulnerability and they have few public resources available to people. In this way AIDS-NGOs concentrate many of the demands of this population, resulting from social exclusion of basic rights, such as education, health and work.

This kind of intervention in communities is guided by action search, according to Montero (2007), it is a method based on ethics and committed as well with the production of knowledge and social change. The main steps of this method consist of: Get familiar with the community; identification of needs (held with the community); meeting with leaders and members of the community and the development of collective actions.

Therefore this article builds itself by the documentation of everything that we could learn (supervisor and students) with the experience of the process of an intervention through the training in Community Psychology. Emphasizing the politization of the people involved and their social links, i.e. of the people that are living with HIV/AIDS (PHA) and are engaged in activities of NGOs/AIDS, mainly in reference to coping with the psychosocial consequences of the disease, highlighting the stigma and discrimination.

### **The Praxis of Community intervention: some of the psychosocial aspects of social exclusion.**

According to Gomes & Pereira (2005), the term social exclusion includes temporal and spatial meanings: a social group is excluded according to specific geographical area or in relation to the economic and social structure of the country. In Brazil, this term is mainly related to poverty, since

the people in this condition are groups in social exclusion, because they are at personal and social risk, i.e. excluded from social policies (work, education, health, housing, food). Poverty cannot be defined in a single way, but it is clearly a part of the population that is not capable of generating enough income to have sustainable access to basic features that ensure a decent life.

In her turn, for Sawaia (2002), the social exclusion is a complex and multi-faceted process, a setting of material, political, relational and subjective dimensions. It is a subtle and dialectical process, because it exists only in relation to its contrary part, i.e. the inclusion. It is not a thing or a state, but a process that involves the human and its relations with the other. It does not have a single form neither it means a system failure nor, and it should not be defeated as something that disturbs the social order, on the contrary it is the product of the system.

In addition, Sawaia (2002) discusses the process of social exclusion based on affectivity, in particular by the suffering arising from unfair living conditions, which is called suffering of ethical-political. The manipulation of the affection is an important factor in the understanding of the maintenance of authoritarian and undervalued relations of the potential citizen of the people.

For this author to question about suffering and happiness in the study of social exclusion is to overcome the view that only worry of the poor people is solely the survival, and there is no explanation to deal with the emotion when going through hunger. Epistemologically, this means to put the idea of humanity in the center of the discussion about social exclusion. This way, to talk about social exclusion, means talking about desire, temporality and affectivity, at the same time of power, economy and social rights.

Also the author speak of potency of action and explains that, from its research carried out with residents of street, she could know different ways of thinking, feeling and actions caused by social exclusion. The potency of action of an individual shows when he/she copes with the exclusion.

For Montero (2003), to review the origin of the Community Psychology, in Latin America, as well as in the United States and Canada, we will see that, although there are trends oriented at paternalism, there is an attention focused on the organization of the members in the Community and its development, supporting the positive qualities of these people, so that they achieve by themselves changes that improve

their quality of life and access to goods and services of their community.

According to the same author (2003) the definition of Community Psychology includes to develop, to promote, to maintain the control and the power in people that form a community, and this control and power should keep focused in the community and not be taken as something from outside. Thus, activity, control, participation and decision are important conducts to achieve fundamental changes, and for that reason they require strengthening processes.

In addition Montero (2003), taking into consideration several other authors, sets this strengthening process as a strategy by which the members of a Community together develop capabilities and resources to control their lives, acting in a critical, conscious and committed way to achieve the social and collective transformation, according to their needs and aspirations, at the same time transforming themselves.

In this way the institutions are privileged places for community actions and for the development of the most active subject in society. From the point of view of the Community Social Psychology the institutions can be used as means of access to communities. Campos (1996) defines institutions as everything that is recognized by all as being part of a broad social system. In general, we can say that everything that became established, accepted as having materialized existence in social life is considered an institution.

Campos (1996) stresses the importance of the institution as the access way to the community, since the communities are studied as organized elements functionally in a system of intricate interdependence and continuously changing. The institution presents itself as a space of mediation between what is from the nature of the social and what is from nature of the individual.

In this context, Bleger (1984) emphasizes that the Institutional Psychology inserts itself both in a History of social needs, as in the History of Psychology and, in this last one, it does not only deal with one field of application of Psychology, but fundamentally, with a field of research, highlighting that the Institutional Psychology is not a field of the Applied Psychology, which can mean in itself an extraordinary advance on the investigation and on the development of Psychology as a profession.

To the author, Institutional Psychology covers, then, the set of the physical existence of the organizations that has a certain degree of permanence in any field

or specific sector of the activity of the human life, in order to study in all of them the human phenomena as a result of the relation with dynamic, structure, functions and objectives of the institution.

Thus, these theoretical and political approaches contribute to a broader and contextualized understanding of the work in Community Social Psychology with groups in the situation of social exclusion, specifically those who are living with HIV/AIDS and that are engaged in NGOs/Aids.

### **Human rights and HIV/AIDS- related stigma-reduction approaches**

On the very beginning of the AIDS epidemic, stigma and discrimination have been associated with PHA (UNAIDS, 2005). Based on Goffman's Stigma (1988), Parker and Aggleton (2001) interpretation the stigmatization is an underestimate of social and cultural relations. Moreover, these authors suggest that we must understand stigmatization and social discrimination within the context of power relations and domination.

Thus, the more obvious manifestation of stigma associated with HIV/AIDS may reveal masked social and cultural relationships. In addition, the stigma associated with HIV/AIDS often can be to overcome beginning with a much deeper social transformation. Therefore it represents just the top of the iceberg revealing a small fraction of the visible elements of a culture deeply rooted in conservative moral values, expressed through a lack of solidarity and a progressive increase in individualism.

Indeed, the stigma and discrimination associated with HIV/AIDS, and its resulting social exclusion, have a long history. It is connected with other social exclusion mechanisms that affect PHA, such as poverty, gender discrimination, sexuality, race, and ethnicity (Parker & Aggleton, 2002).

This social discrimination and stigmatization leads to several consequences for PHA, including: unemployment, the disintegration of social relationships, and negative public labeling. From this exclusionary framework, it becomes clear that social vulnerability is one factor that may expose far too many people to HIV. At the same time, it may also suggest some viable pathways to confront it. (Ayres et al. 1999; Gostin & Tarantola, 1999). For instance the strengthening of the Human and Civil Rights becomes an important strategy in the reduction of the stigma and discrimination connected with HIV/AIDS. The fight to achieve and retain human rights contributes for the PHA to comprehend their

citizenship; that is, they strive to exist with dignity, autonomy and better quality of life.

To illustrate some actions that are working to reduce HIV/AIDS stigma we may consider some information from a recent UNAIDS report. This report presents a number of case studies illustrating approaches to stigma reduction. The report's authors present three points that are relevant in appreciating the relationship between stigma, discrimination, and human rights: "preventing stigma; challenging discrimination when it occurs, and promoting and protecting human rights, including monitoring and readdressing human rights violations." (UNAIDS, 2005, p.13) These approaches have been in various degrees of development in Africa, Latin America, and Asia.

According to the report activities relating to the reduction of stigma it suggests multiple strategies for prevention and treatment. These initiatives aim to achieve these goals through improving the quality of life for PHA through integrated care, including home-based care; mobilizing religious leaders to foster respect and compassion for people living with HIV; addressing broader inequalities through participatory education; creating a supportive and confidential space for the discussion of sensitive topics; providing comprehensive HIV treatment and HIV/AIDS care, including access to antiretroviral therapy; empowering people living with HIV to take the lead in diverse support and advocacy activities; mobilizing community leaders to encourage greater openness around sexuality and HIV-related issues within communities by building on positive social norms; and raising awareness. In addition, the report asserts that the implementation of these programs is a vital element in proactively addressing discrimination and developing laws and policies that defend PHA.

The development and effectiveness of these approaches rely upon a number of factors including volunteer training, enrollment of community and PHA, and establishing partnerships between the government and the civil society.

The Shanga Metta Project in Thailand, for example developed activities from Buddhist doctrine to raise awareness and compassion among monks, nuns, and novices enrolled within this project. One of the factors that contributed to the effectiveness of this action was related to the recognition of the attitudes and cultural values of the local population. Furthermore, these monks, working as a bridge between PHA and their communities, increased the willingness of that community to get involved with

PHA. For example, HIV positive children that were previously denied admission to school are now admitted

In Brazil, the HIV-AIDS movement originated from the context of a broader social movement. On the 1980s, the social movement has worked as a setting where people may fight for improvements in their lives, such as, urban infrastructure, and sharing situations of social oppression, mainly gender, race and sexuality (Sader, 1995). In this way the NGO setting promotes personal development and enhances citizenship.

Since the beginning of HIV/AIDS epidemic AIDS-NGOs have been playing important role in giving material and social-emotional support to PHA. As such, providing concrete assistance to HIV-AIDS patients and their families, these groups have focused on building and strengthening the rights of patients; including their rights of citizenship. (Parker, 1994; Altman, 1995)

In this way, the AIDS-NGOs may create new meanings for the suffering shared by PHA, and emphasize the psychosocial dimensions related to the stigmatization and discrimination process. These institutions provide support to people who identify with social oppression; and through their political participation, the construction of a common identity becomes far stronger. Therefore, the comprehension of political participation may help PHA to develop and consolidate changes that started from grassroots movements, NGOs and related social actions.

Through such approaches we may consider, from the relationship between actions taken and report outcomes, that there have been significant changes, which may have resulted from the implementation of these projects. These changes are, in fact, improvements in policies relating to HIV/AIDS, which emphasizes both the social and cultural aspects of the disease.

#### **The building of a method: step by step of a community intervention**

From above theoretical-practical and political statements we developed the following steps of intervention in the community, including the process of institutional / communitarian diagnosis and the practice with PHA groups at AIDS/NGO:

1. Analysis of official documents, in order to know the status, mission of the institution, its resources, among other information about infrastructure and its social role.

2. Interviews with the coordination of the institution to get acquainted with the history and work done. At that time, also visits were carried out to the institution, in the participant observation model, to better understand its dynamic and activities.
3. Individual semi- structured interviews with the PHA that are users, and in many cases, participants of the institution, in order to deeply know the demand, including personal data, socio-economic conditions, and the coping with HIV/ AIDS.
4. Creation of the intervention proposal, which referred mainly to programming the PHA group activities to happen in meetings of two hours per week, in order to provide a space for the exchange of the experience of living with HIV/AIDS and their relationship with the social context in which they are inserted, on their lives and relationships. The method used were group dynamics, texts readings and thematic phrases for group reflection, free drawing, and themes brought by the participants.
5. The registering of the weekly meetings happened through transcription and discussion, each in supervision. And these reports, delivered weekly, were made of the following parts: description of the meetings, in-depth analysis, highlighting the main points and a preliminary summary, which sought to develop the theoretical and practical hypothesis that guided the interventions.

**The description of a psychosocial intervention: the process of coping with the experience of living with HIV/AIDS-related stigma and discrimination**

The development means the beginning of the Group activities with the participants who went through the sorting process, highlighting that such process, including visits to the institution and interviews, privileged an important rapport important for the beginning of activities.

The description of this experience wants to highlight some aspects that were important in the course of this type of intervention which targeted the strengthening psychological and community capacity for PHA. The task (with a view of working group led by Pichon-Riviere) was to create an area of conversation, drafting and actions that help the PHA to deal with the new condition of living with HIV soropositive. In

that sense we highlight three aspects, from a psychosocial point of view, which contributed to the development of this intervention:

*1. The recovery of history and path of life beyond the living with HIV / AIDS*

The history of most of these PHA suffers a great transformation with the news of HIV-positive. The impact of this news in our days, takes the experiences of imminent death and deep anguish. The situation becomes more difficult when the life of these people is beginning to be negatively affected, because when required a change in their routine to go frequently to treatments at Reference Centers of HIV/AIDS (CRT/AIDS) and diet changes, among other requests. The personal and working routine are drastically changed. Moreover, because many of these people discover the disease from a symptom, sometimes from a serious illness as pneumonia or tuberculosis (so-called opportunistic diseases).

The effects on the people of their everyday living are unpredictable, accenting in the family and at work, but generally in these two settings reproaches and charges are harder. The PHA feel abandoned and betrayed by the people who were mostly close to them.

The search for an NGO/AIDS happens at this moment of intense solitude and many doubts about the disease and treatment, besides administration of the antiretroviral drugs varies widely from person to person even because of their emotional susceptibility

From that moment on, the participation in NGO activities- from self-help group, passing through income-generating activities until participation in actions of political pressure towards the Government- allow people to broaden their understanding of the disease, i.e. understand HIV/AIDS linked to their social economic and cultural dimensions. This process helps to reduce the feelings of guilt and shame in the light of the perception of themselves as a subject in interaction and influenced by the social environment that imprint an individualistic understanding of the PHA.

However the ability to tackle the stigma and discrimination varies according to the intensity of the psychosocial impact of HIV/AIDS in their lives, in most of these cases added by other forms of oppression already in progress. This situation generates deep sequel, conducting the person to hopelessness, social isolation and difficulties to reorganize their lives.

In this context the setting of the Group contributed for the rescue of their life histories with achievements and expectations that have been obfuscated or stifled by psychosocial negative repercussions of the disease. On the group activities were encouraged to facilitate the reporting of life histories which showed other aspects of identity of these PHA. Many of these stories were about personal achievements, such as migrants telling about the effort and struggle to arrive in a big city as São Paulo, or women who tackle the oppression of the family and their husbands to fulfill their professional wants.

Thus to contribute for the new meaning of these life histories triggers other potential that were blocked by HIV/AIDS-related to stigma and discrimination, causing divisions that increase feelings of powerlessness and unhappiness.

### 2. *The focus on healthy psychosocial aspects*

From the perspective to make the group a place of conversations about stories and experiences of life, new meanings and unique strategies to manage their lives have been started.

The recovery of psychological healthy aspects refers to the prospect that in the middle of feelings of helplessness, expressed many times by symptoms of depression, preserved emotional resources are valued, as for example, desire of changes and build of new friendships, among others.

In this sense we are promoting the empowerment of these PHA by building a therapeutic space that not focuses on only on the symptom, on the contrary the impact of living with HIV / AIDS would generate more resistance and defenses reaffirming feelings of guilt and shame.

The empowerment acquired is part of a dialectical process where the institutional setting serves as connection with the community and the construction of citizenship. Through which the feelings of empowerment increase in a context of welcoming and respect. It is important to highlight the role of the group coordinator as the one who facilitate the exchange and preserves the welcoming feeling in the group. Moreover, the coordinator contributes to a greater engagement of PHA with the institution. This as a setting that promotes alternative life projects associated with the enhancement of public space and coexistence.

The friendships built in this institutional setting act as an important affective support giving PHA new life dimension. This kind of support generates

opportunities to develop group cohesion and consequently more chances of this group to continue.

### 3. The Politization of new friendships in public space

In this work of following up the activities of NGOs/AIDS, the affective aspect is a main factor in the quality of the relationship bond and tackling of HIV/ AIDS-related to stigma and discrimination. It is through the welcoming and an attentive listening and without prejudices that the PHA can diminish the anguishes and feelings of guilt and solitude. The possibility of building a friendship in this public space (NGO) brings a great potential of the disease politization.

The concept of friendship seen as a political exercise, for instance, experimenting with new forms of sociability and community (Arendt, 2003 and Ortega, 2000), helps us to understand this type of public space that is not restricted to the area of family intimacy. Friendship promotes meetings that instigate changes, and the friend, in this line of thought, is not a mirror in which we search a reproduction of our image. Nietzsche (apud Ortega, 2000) was the first to break with this tradition of the friendship concept in which the proximity, equality and agreement, place the friend not as an unconditional adhesion, but like the one that encourages and challenges us to transform ourselves.

To bring out the moments of asymmetry and emotional non-reciprocity provides a space where the heterogeneity and otherness in relation to the other is preserved (Ortega, 2000). Nevertheless, we are not thereby enhancing the disagreements and conflicts, but mainly put ourselves away from the consensus. The care of another implies certain detachment, because, when it is possible, the affection can help, otherwise, suffocate.

This prospective of friendship helps us to understand the relationship that NGOs can promote, i.e. type of relationships that strengthens identification among equals, protecting themselves from a common enemy promoting coping and emancipation. Friendship would preserve a field of distinction in which a subject keeps his/her singularity. It is necessary the maintenance of certain distance, in order to preserve some solitude inherent to human existence. An excessive intimacy leads to feelings of possession and lack of differentiation between people.

Therefore, the NGO setting can express the possibility of sharing and giving new dimension through symbolic elaboration of the life experience of

PHA. At some point of their personal struggle against HIV/AIDS, the PHA perceive that their suffering, concern and indignation can be giving new meanings by the interactions that were built from the engagement with the NGO (Castro-Silva, 2004). Spink (1996) reminds us that the institution is nothing but permanent expression of the various actions of people. Then to link the impact of HIV/AIDS in the life of PHA and the dilemmas of their participation in an NGO/AIDS can contribute to the strengthening of the solidarism and citizenship of social networks.

### Final considerations

We consider that the psychology can be an important tool for psychological and community strengthening of subjects that repeatedly suffer with the consequences of social exclusion. It can contribute for the transformation of reality shown and this is possible through a look that gives privilege to a subject in bio-psycho-social dimensions and capable to transform their social environment, i.e. more than dealing with symptoms, often triggered by unfair social situations that lead to feelings and perceptions of low self-esteem, humiliation, shame and other feelings constructed and reinforced by prejudices. Therefore, the Community Social Psychology proposes a more comprehensive intervention with a differentiated work in favor of communities (Montero, 2003; Sawaia, 2002).

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