

## Symbolic aspects involved in group activity for persons who live with HIV<sup>1</sup>

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This is a qualitative and descriptive work, which has used the clinical and qualitative method. The sample was composed of nine patients living with HIV. We used the interview technique with semi-structured questions to collect data. The data were analyzed using the method of content analysis. Our objective was to describe the symbolic representations that emerged during the group activity, assigned to patients with HIV/AIDS. We conclude that the symbolic is very strong and representative in the life of this population. The myth surrounding HIV can be overcome by knowledge acquired during meetings in groups. Alternatives that offer care aimed at populations that tend to social isolation and exclusion should be encouraged by health professionals and their managers.

Descriptors: HIV; Symbolism; Qualitative Research.

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## Aspectos simbólicos envolvidos em atividade grupal para pessoas que convivem com HIV

Trata-se de um trabalho qualitativo e descritivo, que se utilizou do método clínico e qualitativo. A amostra foi composta por nove pacientes que vivem com HIV. Utilizamos a técnica de entrevista com perguntas semiestruturadas, para coletar os dados. Estes foram analisados pelo método da análise de conteúdo. Nosso objetivo foi descrever as representações simbólicas emergentes durante a atividade em grupo, atribuídas a pacientes portadores de HIV/AIDS. Concluímos que o simbólico é muito forte e representativo na vida desta população. O mito que cerca o HIV pode ser rompido pelo conhecimento adquirido durante encontros em grupos. Alternativas que ofereçam atenção dirigida a populações com tendência a isolamento e exclusão social devem ser incentivadas por parte de profissionais da saúde e seus dirigentes.

Descritores: HIV; Simbolismo; Pesquisa Qualitativa.

## Aspectos simbólicos envueltos en actividad grupal para personas que conviven con VIH

Se trata de un trabajo cualitativo y descriptivo, que se utilizó del método clínico y cualitativo. La muestra fue compuesta por nueve pacientes que viven con VIH. Utilizamos la técnica de entrevista con preguntas semiestruturadas, para coleccionar los datos. Éstos fueron analizados por el método del análisis de contenido. Nuestro objetivo fue describir las representaciones simbólicas emergentes durante la actividad en grupo, atribuidas a pacientes portadores de VIH/AIDS. Concluimos que lo simbólico es muy fuerte y representativo en la vida de esta población. El mito que envuelve el VIH puede ser rompido por el conocimiento adquirido durante encuentros en grupos. Alternativas que ofrezcan atención dirigida a poblaciones con inclinación a aislamiento y exclusión social deben ser incentivadas por parte de profesionales de la salud y sus dirigentes.

Descriptores: VIH; Simbolismo; Investigación Cualitativa.

### Introduction

The emergence of the Human Immunodeficiency Virus (HIV) in a society based on cultural stereotypes has raised in its core a series of moral questions and the reorganization of sexual conducts.

The Acquired Immunodeficiency Syndrome (AIDS) became a disease that led to physical deformity and was associated to groups considered as discriminated and marginalized, such as homosexuals, injecting

drug users and sex workers. This way to represent it mobilized rooted feelings and prejudices, evoking discriminatory behaviors and policies<sup>(1-2)</sup>.

The HIV carrier experiences a set of concerns and feelings such as fear, death and guilt, in addition to the entire discriminatory context carried within because of the life in society, which reinforces the habits and expectations that are deeply rooted in a prejudiced society. The individual becomes weakened, permeated by suffering, as he experiences situations

that threaten his physical, emotional and social integrity. Such a situation requires answers and the pressing need for the creation of economic, political, social and psychological resources that take care of a problem of such magnitude<sup>(3-5)</sup>.

The reflections of HIV in the world prompted new ways to handle a disease filled with inaccurate and captious symbols, meanings and images that stimulate unreasonable acts of panic, denial and intolerance to those affected by them. When some actions are implemented to demystify the disease, responses rise up, myths are clarified and new technologies are developed and used in the treatment of the disease.

Even though we are at the beginning of the fourth decade of the AIDS epidemic, the discovery of the positive diagnosis for HIV continues provoking reactions similar to those of the beginning of the epidemic, in which patients express feelings of sadness, fear and a sense of finiteness. The fear of revealing this new condition to the family and the network of relations appears, because of judgments to which they may be submitted. These persons begin to live with a determined death sentence, fostering personal doubts about their existence and family plans<sup>(6)</sup>. Such issues prompt these persons to isolate themselves socially, making their path a lonely and silent one, without access to information that would enable a better understanding of the disease, in addition to mechanisms that provide preparation in the face of this problem<sup>(7)</sup>.

Persons living with HIV, and who also directly live with this stigma, take on symbolic considerations for themselves, becoming one of the major obstacles that prevent them from revealing their serological condition. The fear of abandonment, judgment and hostile or negative reactions, coming from other persons, makes them feel as if they were not free to access health services and, therefore, improve their quality of life<sup>(3)</sup>.

Contamination and socialization with HIV seropositivity are seen as a threat to the physical integrity of the human being, resulting in mental operations, abstract symbols, codes, signs and the formation of individualized concepts. This activity results in an empathic response expressed by the fear of the unknown, a generator of individual values and beliefs of the population, showing the symbolic meanings of the disease. This symbolism is proved

in several studies aimed at the HIV seropositive population<sup>(1,7-8)</sup>.

Even before verbal language, man had symbolic means to construct, interact and interpret reality. Otherness in itself has always been, in the eyes of the human being, the first representation, image and sign taken as an extension of the self, that is, the subject is in itself and in the other, interacting and constructing reality<sup>(8)</sup>.

Being the social model based on continuous interactions that are established on a daily basis, among which roles are defined between individuals and symbolic relationships are sustained in an open process for reassurances or changes according to the individual interpretation of every being, symbolism is only constituted through the direct relationship of two or more persons, basing their actions on what the collective is composed<sup>(9)</sup>.

Symbolism and the continuous interactions of beings are also observed in some activities carried out by health professionals. As clear examples, we can mention group activities as a therapeutic tool. The group is a restricted set of persons, linked by time and space constants and articulated by their mutual representation of a task, which is its purpose, interacting for this end through complex mechanisms of adjunction and assumption of roles, being possible the existence of the person because of his group relations<sup>(9-10)</sup>.

Interventions aimed only to the recovery of the biological body do not fully respond to the health needs of persons living with HIV in modern society, as this demand goes beyond the division of the human being in his various dimensions, the quality of life and the promotion of health, increasingly leading professionals to seek new care alternatives that take into consideration their integrity.

The development of groups in the nursing practice is not exactly a novelty. Various professionals develop their work as a group, both in care and in activities together with multiprofessional teams, being this practice widely used in Public Health and in the hospital and ambulatory context<sup>(10-11)</sup>.

Observing the complexity involving HIV/AIDS carriers as social members, works that offer new alternatives, establish new thoughts related to scientific advances, enable professionals to know the representations of HIV in their daily lives and contribute

to improve their quality of life through adequate and satisfactory health actions are justified. In this regard, we have adopted the objective of describing the symbolic representations that have emerged during the group activity, assigned to HIV/AIDS carriers and their monthly meetings.

## Method

This is a qualitative and descriptive work, which was carried out through the clinical and qualitative method, collecting data in the STD/AIDS clinic that works next to the social services of a Public University Hospital located in a city in the countryside of São Paulo, Brazil. The group studied was formed ten years ago and has monthly meetings. It is composed of HIV carriers, and men are the majority. As it is a joint and open operating group, the invitation and adhesion of the patients are free.

The participants were chosen intentionally, that is, the choice was deliberate by those who showed the ability to provide rich and sustainable data in relation to the research objectives according to their experience of life and disease.

We included patients living with HIV and who use antiretroviral drugs (ARV), of both gender, adults, who frequent the outpatient group of the STD/AIDS Clinic, with attendance of at least five meetings, and we excluded from the study non-dedicated patients, who amounted to nine participants. In this group, there was a predominance of female persons, aged between 30 and 51 years of age and men aged between 49 and 62 years of age, with elementary education, followed by individuals who have complete high school. Most of them have no profession or occupation and take care of household chores. Regarding the time of diagnosis, and not the time of contamination with the virus, it ranged from three to eighteen years. The length of stay in the group as a member, following our inclusion criterion, occurs from five meetings up to seven years of participation.

We used the interview technique with semi-structured questions to collect the data. This type of interview allows open-ended questions, however with specific focus on a given subject, allowing the respondent to bring important data on the subject of interest and avoiding elusive answers. The questions addressed issues such as the representation of being HIV positive in their life and experience in participating

in groups aimed at their condition. Data were analyzed by the method of content analysis<sup>(12)</sup>, by following these steps: readings of all the collected material, selection of the thematic units, coding of the reports and creation of thematic categories.

Being this work a part of the master's thesis involving research with human beings, it was approved by the Research Ethics Committee of the School of Medical Sciences of UNICAMP, under No. 0069.0146.000-09. All participants signed an Informed Consent (IC) after being informed about the content and purpose of the research.

## Results and Discussion

To present the result and discuss the data analysis, we seized, in the speech of the subjects, their experiences and emotions and their relationships with the participating members of the study in the group context. After reading all the collected material, selecting the thematic units and coding the reports, we created the following thematic categories:

### Learning, Meeting, Knowing

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*[...] It instructed me, helping me open my mind[...] (E6-P7). [...] I have a lot of baggage, I'm learning with them, taking lessons for my life[...] (E1-P4). [...] People don't have an open mind... (E6-P6).*

The knowledge that persons bring with them about the disease, taking into account their epidemiological, virological or infectious aspects, showed a dark dimension that could be illuminated by a phenomenon that was named as "opening the mind", that is, something that was not understood, that was not part of the whole and became a constant in itself. The knowledge consciously enters and is internalized in thoughts, and it attaches itself to parts of a whole; that which was not there is now inserted and becomes acceptable because of the fateful understanding that surrounds it. Being a set of knowledge all the information describing the world, it predicts and explains reality, making it scrutinized and easy to understand.

*The group helps people open up their mind, explain, tell other people[...] (E6-P7).*

Opening the mind and learning more about their disease denote certain conformity caused by this approach with the reality described by science, knowing their true limits and discarding the myths created by

the discriminatory contact imposed by them and by society. The subjects recognize themselves modified by knowledge, by a growth in their “being”, reproducing this knowledge in their everyday attitudes<sup>(13)</sup>.

The function of the group, considered as the component that promotes the act of “opening the mind”, is linked to information provided by health professionals and experiences lived by the members of the group, being it a space which allows these exchanges, which are only accepted and adhered by the participants because of the brotherly ties created between them.

### The symbolism of the blood

*[...]what's in his blood is in mine. (E5-P4).* The blood that flows in the veins of all us may seem common, but it is an essential fluid, extremely precious to our life and its maintenance. Symbolically, blood has a narrow link with affection and brotherhood, in this moment used in rituals of connection. It is the symbol of the emotional part of the human soul, and it also represents pacts between individuals, being the representations of blood numerous in the psychological, social and physiological spheres<sup>(14)</sup>.

We can say that consanguineous links go from father to son and between brothers, i.e. the natural or consanguineous link between persons descended from the same ancestor, connected by the same blood<sup>(14)</sup>.

In this case, consanguineous connections are outdated, the similarities attributed by the blood strengthens the bonds of trust and equality. Where personal differences are nonexistent, the subject feels protected, belonging to a place, away from their differentiation as being HIV positive, a search for self-affirmation as a condition of primordial equality in the sense of the human condition inherent to life, health and dynamism. He is reflected in the other, inside his complex of equality, where his most intimate part becomes thus visible to the other; the identification of these symbols makes he aware of the meanings produced, occurring exchanges between individuals<sup>(15)</sup>. These situations are only possible because they have adhered, are part of this group of equals, in which problems are similar and the solutions are practical among all.

*[...]when I have a problem the whole group has it, we try to solve together[...] (E5-P5).* These exchanges are evident

during the speech, and the life experience of each one is assimilated, absorbed, taken and incorporated by the other, who takes partial responsibility for the solution of the problem in a complex of equality of hard measurement, in which everything is simplified or possible for this equity.

### The need of dialogue

*[...]the group is closed, nobody goes outside to talk to other people about what I have or not[...] (E5-P4). [...]I can really open myself here[...] (E7-P4).*

The subjects report their serological condition as an inviolate secret, which make them prisoners of an inner world, surrounded, closed by walls of prejudice that can befall on them, and the group coexistence becomes a protection in some ways.

This “fortress” which is formed around them makes them vulnerable and open to the stigmatization given by society. In the following lines we can observe that the representative factor of the stigma comes from society in a general way, and not from small social groups, such as close persons, family and friends.

*[...]I don't comment to anyone, I do my best so they don't find out... because I think there is still a lot of prejudice[...] (E7-P4). [...] here I say what I don't say on the streets[...] (E4-P5).* Only few persons can be considered as deserving, chosen to share this secret, and they are someone who in some way is common in their way of life or social placement and they are not always persons connected by family or friendship ties. They are defined<sup>(16)</sup> as a set of individuals from which the stigmatized person can expect support; they are persons who share their stigma and because of this they are known and defined as “their peers”.

These persons regarded as “equal” are seen as normal, but their special situation has led them to participate intimately and secretly as carriers, which allowed the stigmatized person to sympathize with them, resulting in a certain acceptance.

Another way to define persons that are less closely connected, but who share this secret, is by using the term “informed”. They are those who know the secret, and the carrier does not have to be ashamed or self-controlled near these persons, because they know that they will be considered as a common person. A type of “informed” person is one whose information comes from his work and actions undertaken by society in relation to them, such as nurses, therapists and social

workers. Thus, empathy with health professionals is so striking and evident that the subject creates strong links with these professionals, so strong that they can overcome the institutional walls<sup>(16)</sup>.

*[...]I talk to my husband, but it's hard sometimes, because he doesn't have it, so it's tough (E4-P5). [...]Here I started talking because I was quiet, I didn't talk to anybody, I saved a year for myself, a year! Only for myself, you know? (E4-P4). [...]Nobody knows my problem (E7-P4).* Carriers demonstrate a real fear in being "discovered", in having their secret revealed, thus some spend part of their life avoiding touching the subject, even when their serology condition is known by those around them.

Carriers protect themselves, often from their own conscience, from accepting themselves as HIV positive, spending a long time avoiding the affirmation of their condition by hearing their own voice when making such a claim, as it is not real what only they know, an illusion that does not require statements, generating great distress.

The respondents have demonstrated a great need to express their anxieties at being HIV carriers, in keeping this a secret, even from their own conscience. When talking about their condition, they reach a therapeutic level characterized in the speech about their welfare, of feeling better.

Unanimously, the respondents of the research say that the group is the place elected to talk about any subject relating to HIV or not. Similar to the literature, they have attributed this attitude to the assurance that they are in a place protected by the equality of the class<sup>(16-17)</sup>.

*[...]In the group it is cool, the group has what I have [...] here I can really open myself[...] (E7-P4). [...]Here, I know everybody has it[...] I feel safe[...] (E5-P4).* Said safety about being able to talk, without fear, without limits imposed by society through ethical and moral concepts, and the quality of being in a place where everyone belongs to a same class of stigmatized persons comforts the members who participate in it.

The bond created by the diagnosis reinforces notions of natural habitat. The statement of confidence in the members of the group and the safety of belonging to it is very strong, specific and striking. The notion of safety can be compared to related concepts such as confidence, because both are related to the perception of protection, of being protected from risks, dangers and losses<sup>(17)</sup>.

*[...]Here I find myself open to talk as if I was a psychologist, as if I were a social worker, a gynecologist with whom we can talk to[...] (E5-P4).* From the perspective of carriers, they belong to a place without inhibitions, without fear of making mistakes and at the same time affirming the safety that they feel and that other members of the group attribute to them.

Their personal perception changes and passes to acquire a position equated to that of a professional, because of their visibility in relation to the group and confidence in their knowledge, which again demonstrates a group perception without a hierarchy level in the face of the health professional within the group<sup>(11)</sup>.

The support from the group is crucial for the acceptance of oneself as a carrier and, at the same time, as member of a social group. The subjects took possession of the personal accounts of the other members of the group about their experiences of life, reproducing the experience of others in their daily lives and reframing it as part of their learning in handling situations related to the disease and everything related to it. In other words, they assimilate these experiences and repeatedly use them as a means of reproducing knowledge. It is similar to the way of handling something new, yet unknown, that their entire life experience was not enough to answer.

Some changes observed during the conversations cannot be explained only by the formulation of conscious thought. This is a change in the entire behavior and body placement, including the perception of the self in itself, built through several internal changes, leading to the disruption of the "I":

*I felt like a little girl, I liked everything, had vanity, wore short clothes, thought about living, traveling, working hard; after I found out I died, I'm like this, a styrofoam, so it is horrible to feel that you aren't that person anymore[...] (E2-P1).* This separation between different beings is eloquent. On the one hand, a healthy person, born in a family free of evils, away from carnal and mundane evils, however HIV seronegative. On the other hand, a HIV seropositive, deserver of divine punishment and malignancies because of their status as HIV-positive.

## Therapeutic Adherence

The concept of "therapeutic adherence" is aimed primarily to the adherence to treatment of some specific illness. It involves the use of at least 80% of

the prescribed drugs or other procedures, observing schedules, doses and duration of treatment<sup>(18)</sup>.

A broader and more comprehensive definition notes that adherence is a dynamic and multifactorial process, which includes physical, psychological, social, cultural and behavioral aspects, and it requires shared decisions and co-responsibilization. It is a negotiation between the user and health professionals who have their specific responsibilities recognized by each party. More than just the intake of drugs, therapeutic adherence includes the recovery of the patient, access to information, clinical and laboratory monitoring and adequacy to individual and shared needs and habits<sup>(6,18)</sup>.

These concepts lead to the conclusion that therapeutic adherence is more of an introspective process than an health action. Participation in a group is part of the process of therapeutic adherence, but it becomes a vehicle that leads the carrier in a way that is directly proportional to adherence.

Adherence to treatment is directly linked to the acceptance of being HIV positive; by adhering to the treatment, the carrier is stating, even if unconsciously, his serological condition. The acceptance of the fact that he has a chronic disease means acknowledging the condition of patient. *I didn't see me like that, I knew I was a carrier, but I didn't see myself taking the drug, I didn't admit the need to take the drug. Today I take the drug and I've accepted it because of the group (E5-P4). I've learned how to take the drugs, how to live with my husband, how not to miss the appointments, how not to miss the time of the drugs, everything got easier[...]* (E3-P4).

The coexistence with the group allowed the process of acceptance of the drug treatment to start settling among the subjects studied. It becomes noticeable for the individual that this process of transformation is obtained by exchanging the information and experiences of the other participants who currently have established their adherence. These experiences are, admittedly, the primary factor that leads to a change in behavior in relation to the use of medicine.

The exchange of information between the participants of the group, both their personal experiences and those provided by professionals involved in the group dynamics, denotes a stage that is different from the previous one. At first, the use of anti-retroviral drugs reminded them of the disease, now they have become the way to maintain life and an inseparable part of their everyday life.

## Social and family relationships

*I began to loosen up, to play more [...] with my children, with my husband, then I started to loosen up[...] (E4-P4). Now it's normal, I have a normal relationship with my husband like anybody else, like a normal person (E4-P1).*

Family relationships have great importance in the life of persons. Family bonds are responsible for establishing the first space of coexistence for the human being and they serve as a fundamental reference for the incorporation of ethical values. In this space, persons are born, grow and acquire their moral values. It is in family relationships that persons experience situations of affectivity and build their representations, judgments and expectations.

The cohabitation of spouses acquires a special sense in some cases, as marriage serves as a tool for construction, with the social function of creating a particular order, capable of giving new meaning to life<sup>(19)</sup>.

The diagnosis of HIV changes the concept of how to place oneself in relation to the other, leading the carrier in the search to adapt himself to his new condition or to relocate himself in relation to the family and partner. Such consideration could be linked to the guilt that he takes to himself, as he contracted the virus. Family relationships are shaken and restructured in a continuous process until acceptance, revealing new meanings throughout this process<sup>(3,20)</sup>.

In the case of the HIV carrier, relationships can be ruptured because of the fear of contamination, especially in the case of serodiscordant couples. In the beginning, there may be a detachment between spouses, followed by a period of greater proximity, linked to the complicity in sharing a "secret world", narrowing the marital ties with the strengthening of the marriage ties.

*Everything changed! Everything changed, it taught me how to live with society and go back to society[...] you see how other people react on society[...]* (E5-P7).

Social isolation comes in the speeches as a result of the disruption of ties. Because of the disease, the person moves away from the family and social conviviality, thus avoiding judgment and moral condemnation, and we highlight that this is a stigmatizing disease, which crystallizes social symbolizations on HIV transmission in the imaginary<sup>(3,20)</sup>.

The feeling of inertia that arises right after the diagnosis goes away over time with the participation in

the group. The anxieties and existential uncertainties begin a maturation process, mitigating their stigmatizing potential. The person starts to feel free; their internal structures and mechanisms are prepared to face any discriminatory action linked to HIV when trying to be placed socially. The exchanges of experiences that occur in the group environment strengthen and establish this condition. Moreover, they allow the return to normal activities and to family relationships without resignations, establishing new directions and arrangements for their social placement.

As the carriers participating in the group are in the individualized acceptance stage, the experiences relating to social confrontations are differentiated, favoring the exchange of enriching experiences, which will later promote the reproduction of these confrontations in various situations.

### Final considerations

We believe that symbolic issues representatively permeate the life of this population. Part of their beliefs is based on experiences of a past and remote reality, in which the knowledge about the disease was still incipient and fragmented.

The symbolism found in group experiences is substantiated by the collective representation of a daily and constant reality in this population. The permanent coexistence with the stigma and discrimination from society is what makes these forms of representation present. Non-symbolic representations are processed and solved by the process of group interaction, offering relief to the anxieties that come from the silence and loneliness caused by the discriminatory actions experienced.

The meaning of being a HIV carrier remains idealized. Despite the medical breakthrough occurred in recent decades, the disease is still considered as fulminant. The differential of this population is marked by resignifications; the myths surrounding HIV can be modified and clarified to the carrier through knowledge acquired during group meetings about the disease. If there is a process to accept the disease, the serological condition and the personal confrontations, the patients become responsible for their treatment and health, fully adhering to the treatment proposed by the health team.

Health teams can offer alternatives that provide attention directed to persons with a tendency to social

isolation and exclusion, being always encouraged by health professionals and their managers, as group activities have a low cost and great benefits.

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