

# *Will these drugs be worthwhile?*

## **An anthropological study of adherence to antiretroviral therapies among support groups for people living with HIV and AIDS**

*Será que esse remédio vai valer a pena mesmo?* Estudo antropológico sobre a adesão às terapias antirretrovirais entre grupos de mútua ajuda de pessoas vivendo com HIV/ aids

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### **Abstract**

Anthropological study carried out by ethnographic method within the members of two HIV support groups for people living with HIV/AIDS, in the city of Brasilia. The research aims to understand the potential benefits of these forms of social organization for facing the daily life with the virus and the contribution to antiretroviral adherence. The methodological approach focused on the development of ethnographic work which included techniques such as participant observation and interviews with members and group coaches. Results led to the identification of interacting mechanisms within health staff and people living with HIV/AIDS, the adoption of attitudes to deal with the drug prescription, and input provided by the group to improve adherence to ARV by highlighting the role of networking and peer support.

**Keywords:** Adherence; Aids; Ethnography; Support Groups.

## Resumo

A partir de uma perspectiva antropológica e do desenvolvimento de um registro etnográfico entre grupos de mútua ajuda de pessoas vivendo com aids do Distrito Federal, o estudo busca compreender o funcionamento e os potenciais benefícios dessas tecnologias para a vivência com o vírus, em particular para adesão à medicação antirretroviral. A abordagem metodológica envolveu um processo de observação participante em um dos grupos e entrevistas com frequentadores e facilitadores. Como resultados do estudo, pode-se melhor compreender os mecanismos de interação dentro dos grupos, além de concluir pelo seu potencial para a melhoria dos níveis de adesão à terapia antirretroviral a partir do encontro entre pares.

**Palavras-chave:** Adesão a Medicação; Aids; Etnografia; Grupos de Mútua Ajuda.

## Adherence and antiretroviral therapies: advances and challenges

The invention of antiretroviral combination therapy (ART), a mix of three types of antiretroviral (ARV) drugs that is very effective in inhibiting the reproductive cycle of the HIV virus, revolutionized the treatment of AIDS and brought notable changes to the lives of people affected by the disease. Significant effects were observed in decreased rates of hospitalization due to opportunistic diseases, particularly the reduction of morbidity and mortality levels of the infected (Carvalho et al., 2003; Cordeiro et al., 2010).

In a cutting edge strategy, the new medications were made available in Brazil in 1996 through the Law 9.313 (Brasil, 1996), which decreed free access to ARV in the Brazilian Unified Health Systems (SUS). The emergence of these therapies, as a result of the policy of free and universal distribution by the Brazilian government, caused a shift in the profile of the disease. Before the 1990s there were only palliative care options intended to deal with the opportunistic diseases arising from HIV/AIDS infection. The debilitating physical aspects of the ailment made it impossible for those infected to maintain their daily routines, thereby rupturing their roles in society and condemning them to a “social death”, all this without even considering the brief amount of time left to them in their lives (Jordan et al., 2000; Seidl, 2001; Sontag, 1989). The universal access to ARV in Brazil caused AIDS to pass from a highly lethal affliction to the profile of a controllable chronic disease. In an ethnographic study regarding the Brazilian response to AIDS, Biehl (2007) outlines a framework of the system of values and the political and economic contexts that guide the policies regarding the control of AIDS in the country. The author investigates the conditions which have permitted the sustainability of universal access to ART and, in a certain way, how this response constitutes a social good.

The added life expectancy brought about by ART provides possibilities of a reworking or reinvention of the societal roles and life projects of people affected by AIDS. A firm adherence is essential to the therapeutic success of the treatment; on the

contrary, a patient not adhering to their individual treatment plan threatens its effectiveness and presents a risk of disseminating viral strains resistant to therapeutic treatment, making it more difficult to control the epidemic (Jordan et al., 2000; Bangsberg et al. apud Nemes, 2009). Despite significant advances in the quality of life of people living with HIV/AIDS, correct compliance with ART and the accruing effects of its uninterrupted long term use are still quite complicated, considering, furthermore, other factors such as aging and pregnancy, as well as the existence of limited evidence regarding therapy adherence in some of the more vulnerable populace (Carvalho et al., 2003; Nachege et al., 2012; Ghiddei et al., 2013; Scanlon and Vreeman, 2013).

Various studies point to the difficulties of therapies adherence and associated factors as reasons for a low compliance rate or abandonment of the treatment.<sup>1</sup> From a biomedical point of view the concept of adherence to an antiretroviral therapy is associated with the act of following a medical prescription, in respect to the quantity and dosage schedule of the prescribed medicines (Adão and Merighi, 2000; Lignani Júnior et al., 2001). However, apart from this definition, which strongly suggests that the patient should “obey” the doctor, the term adherence could be understood in a more comprehensive form as being not only conformance to the medical prescription, but also involving aspects subjective to the patient with regard to the medical guidance given (Lignani Júnior et al., 2001; Cardoso and Arruda, 2004).

It is recognized now that adhering to a medication and the treatment as a whole is a complex process, which involves factors on various levels: organizational, related to the access and service of the health system, socioeconomic, emotional and affective, apart from those associated with the physical effects.

Socially mitigating factors in regards to health, such as low family income (Carvalho et al., 2003), low level of education and lack of information regarding the risk of non-adherence, are factors associated to lower levels of compliance to the therapy (Carvalho

et al., 2003; Bonolo et al., 2010; Nemes et al., 2000; Lignani Júnior et al., 2001). Studies done with a psychological inclination point out that people living with HIV/AIDS are particularly vulnerable to depressive processes, which in turn is associated with failures in therapy adherence (Nemes et al., 2000; Slama et al., 2006). The fear of discrimination and the imagining of death and guilt which AIDS can raise may interfere with their self esteem, and often leads to social isolation (Souza and Vietta, 2004).

In contrast, the availability of social help networks is positively associated with lowering the chances of becoming depressed. The presence of family, friends, health institutions, organized groups and the belief on the part of the individual that they are cared for, valued, and belong to those groups can play a significant part in the continuation of the therapy (Seidl, 2001; Slama et al., 2006; Cardoso and Arruda, 2004; Fernandes et al., 2010). Knowing that the scope of care that chronic disease patients receive is giving important insight into the format of that care, including the structure and arrangement of home-life by the people closest to the patients (Das e Das, 2007). Experiences related by Kleinman (2008, 2012) acknowledge the importance of understanding meaning, values, life events, age, and other contexts that, from a heuristic point of view, should be considered in the configuration of a cultural and historical guideline during the illness process.

Faced with the identification of questions that an extended life expectancy with HIV/AIDS raises and the complexity of the adherence process as a whole, psycho-educative initiatives and social organizations emerged, which we will call here “support groups for people living with HIV/AIDS”. This type of social arrangement can take different names - “adherence groups”, “mutual aid groups”, “experience groups”, “action groups”, “friendship groups”, and working procedures. It is said that the first support groups emerged at the beginning of the 1990s (Galvão, 2002) and had their origins in the public health system, civil society organizations or the gathering of personal networks of the people

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<sup>1</sup> See, among others, Carvalho et al. (2003), Slama et al. (2006), Cardoso and Arruda (2004), Malta et al. (2005), Jordan et al. (2000) and Nemes et al. (2004).

affected by the disease. These group formats are considered strategic actions with regards to adherence to antiretroviral medicine and are recommended by the Brazilian Ministry of Health (Brasil, 2007).

At the same time, they have also been recognized as important places for insight which help health professionals in understanding the factors which can help mitigate life with HIV/AIDS (Paiva, 2000). In a survey conducted in 2000 and 2001 by the public health services, 18.3% of the services surveyed indicated that they routinely conducted “adherence groups”. However, little is known about the benefits of these groups, seeing as there is no assessment available regarding their effectiveness, costs and coverage in Brazil (Nemes, 2009). In the national arena, few studies can be found with data useful in analyzing the group interactions of people living with HIV/AIDS.<sup>2</sup>

## Anthropological look at support groups

From a social science viewpoint, Katz (1981) - in the 1970s and 1980s - describes the emergence and proliferation of support groups in North America and Europe. The rapid expansion and the diversity of subsets of these groups - groups of homosexuals, of single mothers, of carriers of physical ailments or psychological issues - began to interest the investigators of social structures, social relations and public policies. Faced with this diversity, Katz and Bender (apud Katz, 1981) describe characteristics common to the functionality of these diverse groups. For the authors, they are small, volunteer structures that emphasize face-to-face interaction, aimed at reaching an objective which, in general, is to promote changes and progress in the states of the participants. They are groups formed of peers, in the sense that they share something in common and are focused on a similar cause, sharing similar concepts of the world and values. In comparison with

other institutions, the groups are structured with little bureaucracy and hierarchy. Godbout (1999), resuming the trinity of giving-receiving-repaying developed by Mauss (2003), points to that the act of identifying, sharing, and circulating experiences between people stricken by the same condition plays a therapeutic role. The author references Alcoholic Anonymous, considered pioneers in the format of support groups, and inspiring the templates of more recent initiatives.

This present report can be added to the current debates about therapy adherence, at the same time it proposes to contribute to a better understanding of the results produced in the ambit of support groups for people living with HIV/AIDS and the possible contributions of these group interactions to the processes of medical compliance and treatment adherence, as well as for living, in general, with being HIV positive. In addition, it looks to understand the operational format of these group initiatives and measure the type of relationships that are woven between health professionals and people living with AIDS, as well as the relationships within the latter.

The anthropological view of health considers that the concepts of health and sickness involve not only an organic dimension, but also they bring together biological, social, cultural, and economic factors, perceived differently by the people that are experiencing the illness process (Uchôa and Vidal, 1994; Helman, 2006). According to Taïeb et al. (2005), every malady generates speculation regarding its causes and meaning, and stimulates the organization of response mechanisms: religious beliefs, treatment options and the legitimate social status of the infected person. Bringing these facts to the current issue, AIDS is not, therefore, only a biological process confined to the body of the person who is sick; it is also a cultural event, subject to symbolic constructions that impose on the individual in question (Paim, 1998). A health anthropologist must broaden the horizons of the analysis when

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<sup>2</sup> Silveira and Ribeiro (2005) make a theoretical speculation regarding the techniques for creating well-being in adherence groups in a general way. Tunala et al. (2000) bring up some considerations in relation to an experience in their work with a psycho-educational group of women living with HIV. There are also the accounts in Adão and Merighi (2000) and Souza and Vietta (2004), which relate that the experience of creating an adherence group in a health care service as the best way of understanding the questions related to the introduction of the antiretroviral treatment and working through the difficulties of adherence.

studying processes of well-being and infirmity, illuminating the cultural aspects of biological phenomenon and the symbolic constructions affecting the people living through these events (Good, 1994; Uchôa and Vidal, 1994; Helman, 2006). In this line of thought, the theoretical speculations of Kleinman (2012, 2009), himself having been a caregiver<sup>3</sup> in his family context, contribute towards thinking about the elements which cause these social interaction processes to grow exponentially in this aspect, bringing an air of tension to the scene, of conflict and of morality in existential cycles loaded with emotion, meaning, and the necessities of the patients, caregivers, professional workers and the institutions involved.

## Ethnographic study

Based on the premise of voluntary agreement of the subjects to contribute to the study, we identified two groups which operate in the city of Brasilia: the non-governmental organization Arco Íris and the Grupo de Convivência Flor de Lótus. The method of approach regarding the two groups was different. At the NGO Arco Íris we conducted an ethnographic study of approximately three months, by observing and participating in the activities developed in the scope of the group. We participated in the meetings of one of the support groups which function in the NGO and in the “information meetings”, the latter serving as a point of encounter with health professionals, in the form of lectures and workshops. We also conducted semi-organized interviews with six participants of the group and four of the involved health professionals, one being a psychologist, another a project coordinator and two social workers. The material analyzed in reference to the Arco Íris group is composed of ten interviews, as well as a written register of the personal accounts and stories collected during group meetings.

In the Flor de Lótus group, despite the agreement to contribute to our research, there was not

a consent to carry out an ethnographic study. In response to this denial, our interaction was mediated by a “collaborator”, that being the title he gave himself. In this group, the itinerary of the interview was sent by email to our interlocutor, who then took it the members of the group. The itinerary of the interviews replied to by the group goers were returned to us by the collaborator. In total we received ten interviews from participants of the group and we had the opportunity to have more frequent personal contact with the collaborator, which in the end resulted in an interview.

The interview itinerary was the same for both groups, combining closed- and open-ended questions. It contained, apart from items relative to the socioeconomic profiles of the participants, open-ended questions that looked to uncover their perceptions regarding possible changes, benefits and meaning of their participation in a group for people living with HIV/AIDS and for the following of an antiretroviral treatment. The open-ended questions were aimed at evoking the memory of the interviewees so that they could recall parts of their lives related to participation in the groups, prompting them to reflect on their condition before and after their participation.

Group goers with at least six months of participation in the group were interviewed. All of the interviewees had been taking antiretroviral medication for at least one year. The interviews were conducted with the presence of the health professionals involved and sought to understand their perceptions regarding changes and benefits for the participants as a consequence of their participation in the groups.

## Description of the groups

Both of the groups studied were organized in a different manner and reflected distinct identities between them. The support groups operating within the NGO Arco Íris were only one of the activities that the organization offers to the participants. Created

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<sup>3</sup> The healthcare experience became quite impersonal with the expansion of bureaucracy specialized in the workings of the public health system. In counterpoint, it is suggested that the quality of health care is not linked only to these factors, but also the relationships between the health professionals themselves and the patients. The “caregiver” creates personal networks of attention and care. In the words of Kleinman (2012), the caregiver represents “the very definition of how families and friendship networks cope with sickness or disability among their own”.

in 1990, the NGO undertakes a multifaceted role; apart from the weekly meetings of support and information, it offers individualized psychological assistance, leisure activities, insertion of people into income-generating projects and distribution of “basic food and necessities baskets”. The participants belong to the working-class and come from poorer regions of Brasília. In contrast the group Flor de Lótus, which has its origins in the year 1999, is a self-managed group. There are various “leaders”, the participants themselves propose, plan and organize the activities and facilitate the meetings, with the help of collaborators, who can be HIV positive or negative. Its principal activity is the bimonthly meeting of people living with HIV/AIDS who are interested in exchanging experiences, information and building a social network that takes full advantage of the meeting place. The participants belong to medium to high income tiers of society. In general, they also possess a higher level of education than the participants of the group Arcos Íris. In relation to the timing of an HIV positive diagnosis, both are heterogeneous, sheltering people with a large range in this variable.

Apart from the construction of group life in the form of “meetings”, “lectures”, “workshops”, both groups conduct extramural activities, in which there is “no speaking about AIDS”, such as outings to parks, restaurants, the cinema or to the house of one of the other participants.

## Aspects of a new time period in the HIV condition

When asked if participation in the support group had changed something in their personal life in relation to the disease, the great majority of participants - 14 of the 16 interviewed - referred to positive changes. The two interviewees that expressed to having not perceived changes justified this absence with distinct reasons. One of them declared to have always had a good relationship with the disease, the same as before their participation in the group; the second said that they were unable to evaluate the isolated impact of the group in their life.

Of the 14 participants that affirmed having experienced changes after entering the group, nine referred to the existence of a temporal delineation using the ranges *before* and *after* the group, in a type of transition as a result of their experiences in the group. In the words of these participants, the *before* constitutes an interval marked by feelings of “emptiness”, “solitude”, “death”, “sadness”, “depression”. The *after* corresponds to new feelings, such as a period of “strength”, “self-esteem”, “self-care”, “friends”, “life”, “information”, and new ways of “viewing” HIV positivity.

Before the group: *imminent death. After the group: strength to perceive life* (Interviewee 10).

*Before I thought that I was the only person that had the virus, I felt alone and weighed down, not to mention the enormous loneliness. After the group, I could see that I'm not alone and that the problems that I face, sometimes, are identical to other peoples'* (Interviewee 7).

The image of living with HIV/AIDS separated into the categories of *before* and *after* the group could have been induced by the interview questions themselves that were given to the interviewees.<sup>4</sup> Despite acknowledging this methodological aspect, a recurring theme in the interviews was the phrase that *the beginning* (of the disease) *is the most difficult*, as put by Jordan et al. (2000), and that participation in the group took on the role of a transition towards a phase of better existence. Although our objective is situated in collective spaces, the background of the narratives highlighted what Biehl et al. (2007) denominated individual subjectivity as a strategy for existence, which permits the unveiling of inner life and a look at the operation of existential conditions and the significance given to experiences related to the disease. Furthermore, according to these authors, the path of the people who adhere to the treatment satisfactorily is a story of overcoming difficulties in connection to the therapy, to the stigma which persists regarding the disease, and to daily life with the virus. Cardoso and Arruda (2004) also mention, in their study about the social portrayal of being HIV positive, the existence of two different

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4 “Has participation in the group brought any changes to your personal life in relation to the disease?”



time periods for people considered adherents: the start, perceived as a difficult beginning, linked to death, and the afterwards, understood as a period of better adaptation to the new condition.

The testimonies and narratives collected indicate that the group has been, for most participants, a foundation in the transition between a phase of intense suffering to another phase, of acceptance and the search for strategies for an existence with HIV/AIDS. This first statement suggests that the interaction groups have a positive influence over adherence to the therapies. It can be seen through Das (1997) that the accounts about the disease show a world of difference between the biomedical approach and the experience and inner emotions of the patients.

Through the accounts of the participants and the stories of the facilitators that were interviewed, we can understand the potential contributions of these groups and their impact on the following of the treatment. As found in the work of Souza and Vietta (2004), the words of our interlocutors that affirmed that the group had a transformative role in their lives relate an initial state of seclusion, and little to no activity or hope. The solitary condition and inactivity of many of the people living with HIV/AIDS is the result of the enduring portrayal which links AIDS to death and also the stigma that falls upon infected people. From the beginning of the epidemic, a mass of depictions about the disease have been socially and culturally established, and, coercively, have been imposed on the individuals (Valle, 2002; Seffner, 1995). These depictions “[...] have an important role in the process of identity construction, in the formation of groups and in the ways in which health and sickness are being experienced” (Valle, 2002, p. 197).

The predominance of the association of AIDS and death unfolds in the experiencing of situations of “heralded death” and “civil death” by the persons stricken by the virus. The “heralded death” is described as being a continuous reminder of the brevity of life, finally near at hand. In contrast the “civil death” implies a reduction of citizenship duties, a lessening of pressure from society and the State in the sense of a curtailment of possibilities of life for a person living with AIDS (Seffer, 1995). Furthermore, within the predicaments of the per-

sonifications regarding AIDS, that of the *AIDS patient* (which emerged towards the end of the 1980s) still persists and is constituted by a stigmatized personification, in the words of Goffman (1988). The plight of being characterized as marked for death, however, is confined only to a known carrier of the disorder (Valle, 2002). The recurring fear of people living with AIDS is the moment of revelation of being HIV positive and the resulting retreat of others in a society known to be discriminatory, as showed by statements of participants of both groups.

There was an almost unanimous opinion that the groups were places to make new friends and even start amorous relationships between others who are HIV positive members, this after a period of disruption, and voluntary and/or secret isolation. Some participants and most facilitators declared the groups a “*family*”, sometimes filling in for the help and acceptance that people were not finding at home. In a general way, as with any disease, social bonds become more burdened, generating disruptions and increased social isolation; compounded by the fact that the acceptance of pain is conditioned by social and cultural factors, this can be an aggravating circumstance in the suffering. In the case of AIDS, the suffering can become more intense because the pain and the state of being HIV positive are played out in the patient’s private life (Castro and Silva, 2009). The first and clearest contribution of the group interactions that we highlight is, therefore, the possibility of (re)constructing social networks and a greater degree of availability of social support for the carrier, in contrast with the isolation and withering of the social bonds experienced by people with AIDS. As we can see, the availability of social support networks (friends, family, organized groups) bears a relation to the proper compliance to the antiretroviral treatment (Slama et al., 2006).

Participants positively valued the fact that the group not only provided new bonds of affection, but also the possibility of living together with equals, that they could *speak the same language*. For the interlocutors of Arco Íris and Flor de Lótus, the group constitutes a privileged space for dialogue about aspects of being HIV positive, which would not normally be possible at home, at work, in religious institutions and in other places of socialization

previously mentioned.

The emergence of the Flor de Lótus group is the response to a demand by its founding participants to spend time with others experiencing difficulties similar to what living with AIDS imposes. According to the description of our interlocutor, to fight the virus there was treatment with drugs; however, the drugs did not cover all the effects that AIDS produced in the lives of these people. In relation to the groups within the NGO Arco Íris, it is known that non-governmental organizations, in general, have contributed as central hubs in the redirection of people living with HIV/AIDS to new social networks (Castro and Silva, 2009). Katz (1981), when speaking about the emergence of support groups in general, points out that their core is in the perception on the part of its initiators that their needs are not being met by existing social institutions.

We can infer, in accordance with what we know regarding the biomedical model of health care, that people have not found a space to express the complex internal struggle of living with AIDS in the traditional health care services. The health field has been marked by interventions using the correct application of technical knowledge, resulting in the idea that the patient undergoing intervention is not a subject of the relationship. The subject is thereby deprived of any singularity, of desire, knowledge and history (Pinherio and Guizardi, 2004). Medical interest, since the discovery of pathological anatomy, has become focused on the internal structures of the body (Foucault, 2004). The relationship between doctor and patient is based on the degree to which the latter is the bearer of an injury, the importance of the subject himself being secondary.

The second contribution of the groups that we studied spoke with respect to its educational and informative nature. The groups were recognized as educational spaces and for providing incentive to continue treatment. The informational interventions of both groups revolve around themes such as physical processes that happen to an individual affected by the virus, diet, sexuality, rights of people living with HIV, medication and prevention of ailments, among others. The dissemination of information is one of the essential initiatives for the autonomy of the individual throughout their health

trajectory. Varying definitions portray it as a process in which an individual strengthens their control over factors which affect their health, augmenting the possibilities of altering their trajectory (Riger apud Carvalho and Gastaldo, 2008; Teixeira, 2002). In the case of people living with AIDS, this process is related to proper adherence to the treatment. According to Paiva et al. (2000), adherence implies appropriation of the treatment on the part of the infected person. The adherent patient is committed to the treatment; involved in that which aids in the comprehension of what the medication and the corresponding care mean, apart from their effectiveness.

This pedagogical work appears to be of extreme importance at the NGO Arco Íris, given the profile of its participants: the majority has low income and education, which increases the possibilities of a low rate of adherence to the treatment (Reynolds et al., 2004). In the Flor de Lótus group this educational work is also cited as an important contribution of the group, given that, according to the participants, the health services do not have places with access to this type of information.

When we asked directly whether they perceived any impact on group participation regarding using ARV, a good part of the group spoke of some type of benefit. Some descriptions showed an initial disbelief or doubt in the efficiency of the medication regarding their well-being, transforming, later, into clear concordance in taking it. Participants who said they were good adherents before entering the group agreed that it helped motivate and support their commitment to take the medication.

*[...] I thought like this: Will these drugs be worthwhile? What is they aren't? But after entering the group I saw that the drugs were worth it and that if you don't take them, you'll die. From the examples that I saw here, the people that didn't take it died, people here from this group. After that I believed that the group provides a strong support for you, in adhering to the drugs. And here there are also lectures about adherence to the drugs, that the drugs do well for you (Interviewee 1).*

In the field of psychology, it is known that when faced with an HIV positive diagnosis some individuals respond with the idea of confronting the



disease head on, understood as the construction of original responses and behaviors, getting nearer to the stress factor that was previously unknown. Others respond by evading and hiding from everything which reminds them that they are carriers of AIDS (Seidl, 2001; Faustino and Seidl, 2010). We know that the denial of having the disease is related to lower level of adherence and abandoning treatment; on the other hand, proximity and familiarity with HIV/AIDS are characteristics of people who are considered adherent (Cardoso e Arruda, 2004; Faustino and Seidl, 2010). In this sense, we consider that the dynamic of the groups studied - informative work combined with peer support - operates as an approximating factor between the people and their disease, which can have positive effects on treatment adherence. Although the groups may not use strategies of confrontation based on the religiousness professed by some participants - in which the cure and well-being come through faith (Seidl, 2001) - there is a predominance in the ambit of the groups with confronting and focusing on the disease itself.

In cases of denial of having AIDS, the groups showed themselves to be adept in handling subjective elements which hinder a good start and the adherence to treatment. The benefit most mentioned by professionals and participants in the group was the recuperation of self-esteem, of a better self-image after entering the group. According to Vasconcellos et al. (2003), self-esteem is an element which aids in the organization of responses against depression and in favor of self-care, and is part of a proper observance of the treatment. We also listened to stories of people who resumed lifelong dreams and professional careers within the group, after a period of inactivity or the renouncement of these activities, collaborating the results of Souza and Vietta (2004):

*[...] I finished school thanks to the motivation of friends in the group (Interviewee 7).*

*I returned to my studies with the support of the group (J., in one of the Arco Íris group meetings).*

Participation in the group represents for some participants a transformation that goes above and beyond the vigilance of the disease. As put by Godbout (1999) with respect to the work done by Alcohol-

ics Anonymous, some of the people interviewed lived through transformations comparable to initiation rituals described by anthropologists. The *after* being a period not only of increased attention to their health and acceptance of the disease, but also a new mental attitude and new personal undertakings, extrapolating from the gains produced by their newfound well-being. On the other hand, it can be seen that in these groups they refocus the attitudes of victimization or guilt that are attributed to these patients by the construction of new identification processes in which individual voices and collective voices redefine the condition of being HIV positive. The notion of “critical events” by Veena Das and Ranendra Das (Das e Das, 2007) can shed some light on redefining life with AIDS in support groups and moments of their disruption attributed to the existence of suffering in their social lives.

## Interaction groups as alternative places for healthcare

Besides pointing out the contributions of the groups, it is important to expound upon various considerations regarding the features of procreation of well-being in the group interactions that were studied. These interactions refer to, overall, the Arco Íris group, in which we were able to undertake an ethnographically significant encounter.

The support meetings are conducted by a psychologist or a social worker. In some meetings there are predefined topics, whereas others are focused on talking about personal life in a less organized way. The facilitators introduce the topic of the meeting or question the participants about personal events related to the illness since the last meeting. From there personal stories about daily life with AIDS begin to appear.

In this group, we saw participants and facilitators sharing experiences about themselves and others regarding the different topics related to living with AIDS and other subject matter which extrapolated on the disease. Its pedagogical dynamic involves storytelling and relating examples. As we saw in the Arco Íris meetings, when the participants elaborated on their difficulties and problems in respect to a subject there is always a mobilization by

the group to find alternatives to classify or resolve them. In this moment, an environment exists that is composed of various “therapists”. This shift makes the group a space where everyone can teach and everyone can learn. A place to find solutions and answers together, which suggests a remodeling of the traditional educational dialogue of Paula Freire (Silveira and Ribeiro, 2005). To sum up, it utilizes the resources and the experiences of the participants themselves in the confrontation of the disease, in a space for contribution and reciprocation.

Godbout (1999) suggests that, far from being restricted to ancient societies, “making offerings”, or making contributions for the greater good has a place in contemporary society and support groups would be one of the places where this “circulation system of good and services” that opts for logic and reasoning as its unit of trade, can be observed. It can be seen in these groups the cycle of “give-receive-repay” between strangers (in the sense that they were not kin or friends *a priori*) without financial interests or any such equivalent in the exchanges between peers or between participants-facilitators. This cycle of contribution is the product of relationships between participants, and, so it appears, what maintains the actual existence of the group. Groups like Arco Íris or Alcoholics Anonymous, cited by Godbout (1999), are directed more towards finding solutions and dialogue regarding problematic conditions than the pleasure of bonding with others. However, according to the author, many times it is in the bonding itself that the solution is found, as illustrated by the stories about the perceived importance of social support and the (re)creation of social networks in regards to elements which help produce self-care. The participation in support groups promotes new identifications which can function as stress relievers for the participants (Souza and Vietta, 2004).

The facilitators seem to play a double role in the groups. On some occasions, they benefit from their professional know-how to guide the behavior and the perceptions of the participants, indicating a dividing line between the “therapist” and the patient. At other times, they describe personal situations to help in the search for solutions by using concrete examples. There were cases in which the personal

situations-problems of the facilitators generated a collective reaction and mobilization of the group to understand and find an answer. In these moments, the hierarchy of the facilitator-participant became very fluid.

As to the impact of the presence of professionals related to health care in the groups studied - differently than in the cases of the AA groups studied by Godbout (1999) - it can be said, at least with regard to the dynamics of Arco Íris, the doctor-patient hierarchy is mitigated. There is not always a clear line, with the patient-client on one side, and on the other the one who cures, the wise man. These roles alternate and it can be said that contributions clearly circulate among the participants, but also among them and the facilitators at times. Also worth mentioning is that there are moments in which the facilitators play the role of conversation mediators between participants, strengthening and promoting points they have raised, clearly aimed at guiding behaviors. Nonetheless, there are moments in which the interchanges - and the contributions - circulate without interference or participation by the professionals in question.

The sick patient, little present in a traditional medical encounter, retakes importance together with their words in the process of stimulating wellbeing within the group, which, it is believed, facilitates the creation of bonds of trust and comprehension of the necessities of each participant (Silveira and Ribeiro, 2005). In this group we could also perceive in the relationship established between the facilitators and the participants that there was room for affection. Smiles, hugs, informal conversations about everyday topics between facilitators and participants were constant during the time we spent with the group.

In contrast to the health care model institutions in the field - reductionist and fragmenting - the dynamic in the support groups contributed to a more holistic concept of a human being, by accounting for their personal experience with the disease. Understanding the work of the groups that are the object of study here, the focus of Kleinman (1980) on the individual experience of illness brings important insights. The concepts of *disease* and *illness* contribute to the understanding of the objective and

subjective aspects of the disease. The definition for the term *disease* as conceived by modern medicine: an abnormality in the functioning of organs or organic systems. On the other hand *illness* refers to the experiences and perception of the patient regarding the disease. This concept takes into consideration the significance that an individual attributes to the symptoms experienced and is a reminder that the cultural environment exercises a strong influence in the interpretations of these signals. The dynamic of the groups studied is able to encompass the personal experiences of life with the AIDS virus - the *illness* - the perceptions about the disease and the treatment. An HIV positive person is not only a “medicine taker”. It is important to the dynamic of the groups what the participants think of the medication, if they are able to take it as prescribed by the doctor and how they live with AIDS.

The “program” (Katz, 1981) of the groups studied is not only focused on adherence to the medication, but adherence to the self-care attitude, which involves the treatment as a whole. The sharing of information and the incentives for self-care, provided by the dynamic of the groups, gives the participant the possibility to make informed choices (Paiva et al., 2000). The facilitators of the Arco Íris group recognize that it encompasses people considered adherent, and also others with more difficulties or even reluctance to accept the treatment. What the group does is guarantee access to quality information that is less imposing than other types of health intervention, stimulating a restructuring in the way in which participants understand their condition as a person living with HIV/AIDS - which involves ideological elements - and helps the subject find ways to get engaged with the treatment. *There is no magic solution*, points out a facilitator of the group Arco Íris.

The persistence of the stigma *in the world outside* and the more onerous citizenship that AIDS imposes (Sontag, 1989) characterize limiting factors for better living with AIDS and adherence to the medication. In all of the meetings of the Arco Íris group we saw that another point of the “program” (Katz, 1981) is the promotion of a constant association with AIDS and life, to the contrary of the more

propagated view of AIDS and death. Deconstructing the negative metaphors that exist regarding AIDS is encouraged by the more veteran and active participants. Together with the facilitators, they promote the affirmation of “clinical identities” (Valle, 2002) that are more positive than the terms *AIDS patient*, *HIV positive* or *person living* - as apposed to *dying - with HIV/AIDS*.

The object of this study was not to find an exact measurement of the behavioral changes in relation to the medication. Using the accounts of participants and facilitators we were able to grasp the potential contributions of groups with regards to compliance with treatment. Considering the current health care model, we agree with Souza and Vietta (2004) in the affirmation that the people living with AIDS in these groups have extra resources in their confrontation with the disease. Through the contributions we were able to observe and analyze, we believe that the support groups are potentially beneficial places for adherent patients or those with great difficulties to adhere; for the engaged and committed with a new normative (Cardoso and Arruda, 2004); and for those who still find themselves struggling with denial. Living with the differences in perceptions, experiences, successes and challenges, the difficult moments seem to be mobilizing agents for both cases. In other words, we perceived that the fact of *seeing the others well, happy* or *seeing others sick, in the hospital* has an impact on their actions. On the other hand, those who are already experiencing a new normative are strengthened by helping others and have support in difficult moments along their extended lifespan with AIDS (Souza and Vietta, 2004).

The groups in question take into account the dynamics of adherence in order to make room for the treatment during difficult moments, when an individual is vulnerable to non-adherence or abandonment, such as in times of personal conflict, or health problems. It is known that both adherence to the medication as well as health services involves an ongoing challenge, from situation to situation, as much from the point of view of the individual as the services that support them (Paiva, 2000). We believe that the participation of people living with HIV/AIDS in support groups soon after diagnosis

can aid in the early-on construction of a protagonist and healthy experience with the disease, avoiding opportunistic infections and the “burn-out” on medication regimens soon after beginning.

As such, we affirm the groups surveyed as alternative health care, reinforcing a support network which fits in with the advice given in public health services. We understand that the great trait of the work done by these groups is that they have shown themselves capable of embracing the complexity of living with AIDS, working on the disease not only as a physical phenomenon, but also as a phenomenon that affects the individual in their personal projects and in their social relations. Initiatives such as the groups surveyed are strategies to strengthen a multidisciplinary approach, which goes beyond service centered on clinical rationality and compartmentalization of care for people living with HIV/AIDS.

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