PRODUCCIÓN DE LAS DIRECCIONES DE SALUD CONSTRUIDO EN EL GRUPO SOL, PARA PERSONAS QUE VIVEN CON VIH/SIDA

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ABSTRACT

Objective: to give visibility to the production of health directions constructed as a group for people living with HIV/AIDS (PLWHA). Method: an exploratory and descriptive study of qualitative approach, accomplished with 23 PLWHA participants from at least 15 group meetings at the Antônio Pedro University Hospital, Fluminense Federal University, especially in the outpatient HIV/AIDS, where it has developed a strategy to host a “technology” called “SOL Group”. There were semi-structured interviews, taken individually, analyzed according to the Content Analysis Technique. Results: categories emerged from the speeches of the deponents: Life Power Technology and Construction of belonging in health production in the SOL Group. Conclusion: from the emergence of participants' speech, there was a strong contribution that the potentiating of the involved processes of individuation, as well as the possibility of working modus operandi being in a social technology in the health field. Descriptors: Medication Adherence; Acquired Immunodeficiency Syndrome; Individualization; User Embracement; Attitude to Health.

RESUMO

Objetivo: dar visibilidade à produção dos sentidos de saúde construídos, em grupo, para pessoas que vivem com HIV/AIDS (PVHA). Método: estudo exploratório e descritivo, de abordagem qualitativa, realizado com 23 PVHA participantes de, pelo menos, 15 reuniões e no Hospital Universitário Antônio Pedro, da Universidade Federal Fluminense, em especial, no ambulatório de HIV/AIDS, onde se tem desenvolvido uma estratégia de acolhimento, uma “técnologia”, designada por “Grupo SOL”. Realizaram-se entrevistas semiestruturadas, capturadas de modo individual, analisadas de acordo com a Técnica de Análise de Conteúdo. Resultados: as categorias emergiram das falas dos deponentes: A tecnologia de potência de vida e Construção do pertencimento na produção de saúde no Grupo SOL. Conclusão: a partir da emergência das falas dos participantes, houve uma forte contribuição daquele na potencialização dos processos de individuação dos envolvidos, assim como a possibilidade do modus operandi do trabalho constituir-se numa tecnologia social, no campo da saúde. Descriptors: Adesão à Medicação; Síndrome de Imunodeficiência Adquirida; Individuação; Acolhimento; Atitude Frente à Saúde.

RESUMEN

Objetivo: dar visibilidad a la producción de los sentidos de salud construido en grupo, para personas que viven con VIH/SIDA (PVVS). Método: estudio exploratorio e descritivo, con enfoque cualitativo, realizado con 23 participantes de PVVS al menos 15 encuentros en grupo, en el Hospital University Antônio Pedro, de la Universidad Federal Fluminense, en clínica particular ambulatoria VIH/SIDA, donde se ha desarrollado una estrategia, una "tecnología" llamada "Sol". Se realizaron entrevistas semiestructuradas, capturadas individualmente, que fueron analizadas según la técnica de análisis de contenido. Resultados: las categorías surgieron de los discursos de los deponentes: la tecnología de potencia de vida y construcción del pertenecimiento en la producción de salud en el grupo SOL. Conclusión: a partir de la emergencia de los discursos de los participantes, hubo una fuerte contribución en la potencialización de los procesos de individuación de los envueltos, así como la posibilidad del modus operandi de la obra constituye una tecnología social en el campo de la salud. Descriptores: Cumplimiento de la Medicación; Síndrome de Inmunodeficiencia Adquirida; Individualización; Acogimiento; Actitud Frente a la Salud.
INTRODUCTION

The public health policy in Brazil for Acquired Immunodeficiency Syndrome (AIDS) has been guided by strategies based on three intervention pillars: surveillance, prevention and assistance. The relationship of these objective axes the search of integrated care, as a characteristic of the Brazilian AIDS program, pulverizing the performances not only with people living with HIV/AIDS (PLWHA) and their treatment, but also reaching those around you, whether it is the partners, whether it is their social networks.¹

In Brazil, “the inseparability of prevention and treatment” is proclaimed, in contrast to the international policy guidelines that point to prevention as a key public response to an epidemic.¹

Studies that guide the new guidelines for prevention put in front of the need to demystify the prejudice and vulnerability, pointing data for the use of antiretroviral therapy (ART) in containing the epidemic, either by reducing the viral circulation (VC) in PLWHA, either with the prophylactic use of antiretroviral therapy in the exposed person, in case of cutting perforating accident and sexual abuse, and more recently expanding to PLWHA partners or in the case of sexual exposure at imminent risk, as recommended by the post-exposure protocol (PEP ), which prescribes the use of ARV medication for 28 days, if the risk criteria. Ever think about the use of pre-exposure HIV protocol (PrEP) for people who are on frequent display.² ³

After advances in antiretroviral therapy and new virus detection techniques which framed AIDS as a chronic disease, treatment adherence has become the villain to control and minimize the effects of the disease. Be inserted in the health services have the relevant information or access to treatment, is not the same to adhere to treatment. The pain of discovering HIV, aggregate, often, personal and social blame, brings isolation from society. This triggers also, in many cases, a process of chronic loneliness, that breaks the weakness in dealing with everyday issues.

By observing such a context, we set out to examine whether such issues when horizontally worked in a group, can promote adhesion and constitute a social technology. Group activities provide discussion and socialization of the difficulties inherent in living with HIV/AIDS, and widen these discussions to all those who participate in the action. Participation in a group allows the speech of others, may be an ‘insight’ what ails everyone and thus encourage other group members to expose their fears, anxieties. Thus, new forms can be sought to overcome their difficulties, thus forming a support network in times of sorrow, despondency, wanting or not to fight for life. The shares of the achievements glosses over the others to oxygenate their hopes and believe in its potential.

The object of this study arises from the master’s thesis on the work that has been developed since 2002 with PLWHA group, which has the purpose to present the group dynamics, operated with the participants of the SOL Group, constituting a host of technology , which aggregates to treatment interferes properly in the construction of adherence to treatment.⁴

OBJECTIVE

- To highlight the production of health directions constructed as a group for people living with HIV / AIDS / PLWHA.

METHOD

An exploratory and descriptive study of qualitative approach, conducted with 23 individuals, SOL Group participants, aiming to learn and put in question their perceptions about the relationship between experimentation in the SOL Group - with extramural activities - and the adherence of PLWHA to treatment.

The data was produced from semi-structured individual interviews, recorded audio, which were transcribed and analyzed by content analysis. The results were analyzed by the categories listed, not at first, but after, in an imminent way, from the recorded speeches, to discuss and verify that indicated an effective contribution of the SOL Group in treatment adherence. In this sense, this production occurred in the field of construction of meaning and not in the unveiling of meanings.

Exploratory experiments allowed the researchers to assess and give preference to theories and their most appropriate concepts, in this case the thought of Spinoza, Foucault, Deleuze and Guattari, as theoretical tools to be used and deployed, which ended up favoring the contact with ideas, perspectives and unprecedented insights, so that they can move their own way of thinking.

This study was involved in the production of descriptive data about individuals, territories and interactive processes, produced through direct researcher agency with the chosen social field, where the
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researcher sought to discuss and understand the studied phenomenon from the perspective of the participants themselves forming social research fields. Therefore, the descriptive process aimed at identifying, recording and analysis of the qualities, characteristics, factors linked to the phenomenon or empirical processes in question.

The social field of research was the HUAP, UFF, in particular outpatient HIV/AIDS, which has developed a strategy to host a “technology” called “SOL Group”, together with PLWHA, which began in this hospital organization on the 14th of April 2002.

Only respondents who were older than 18 years living with HIV/AIDS, that have civil majority. The age range of participants although it is also seasonal in recent meetings due to the reduction of sick leave and reintegration into the labor market, in most cases has varied between 30 and 70 years, with more frequent presence of males, According to the survey done in register books.

The study included 23 PLWHA, first contacted by telephone after raising participation through the meetings register book, and then selected all who participated in at least 15 meetings of the SOL Group, so that they had the opportunity to share “formally” their experiences, not being accounted for the extramural meetings because these are activities in which the contacts occurred individually, through parallel conversations.

The interviews began on September 19, 2013 and were completed on February 18, 2014. Because it is impossible to do them during outpatient visits, due to the interviewer accumulating the nurse role in the care clinics, as with prior appointment of other patients, it was necessary for attendance of respondents out of their routine consultation, which takes around four months, or after the meetings of the SOL Group.

It was not possible to interview four people, for although they were contacted and invited, they did not attend. Two alleged impossibility for work activities, and two, while revealing desire to participate, did not attend the scheduled or outside time, and were distant from the group at the time, were led to believe that they would not be available to participate in the study. The period that formalized the request for permission to research the Board of Ethics and Research / HUAP with the number CAAE 15571513.7.0000.5243 until approval had a loss by death, as a result of a heart attack.

Some lines were selected and presented with the informants called by stone names as a way of their non-identification.

Though underexplored, the group host is of paramount importance, both in the construction of autonomy and empowerment of the user, how to excel at their care in various health bodies that makes use, as to face their PLWHA reality in their daily life and its intersection with the social, as also for sharing responsibilities as citizens in controlling the epidemic.

You cannot avoid observing that in Brazil, public policies for coping with AIDS have their weight and deliberation by the involvement of key people in the scientific community and civil society and the “lobby” of non-governmental organizations who are active in the AIDS field, revealing a historic building process, thickened by the strong organization of population segments in the construction and implementation of public policies for the AIDS fight since the beginning of the epidemic, which shows how the social control can be powerful in forming social policies; provoke citizenship and encourage people to be agents of their whole life, subjects who choose and decide; adjust the guides and proposed their reality and are supported in this way; They allow people to reflect and change their ways of life, an attitude or behavior, aware of the web that engenders its vulnerability.

At the beginning of the AIDS epidemic in HUAP, there was a group called AIDS Interdisciplinary Study Group (AISG) which proposed to discuss with the patients, the finitude marked by HIV infection. It was a sharing space where another health professionals, PLWHA and family expressed their pain and suffering, in an attempt to draft them and support in the best way, the interaction with a grievance, under the stigma of death.

With another configuration and formatting goals after the advances of ARVs, tests and another look at the treatments, they graduated from the SOL Group, a meeting space and shared exchange, the result of desire, voiced by PLHIV during the first consultations by nurses and social workers, and the belief of some doctors who we directed to group of people they serve. Created a space for meeting and shared exchange between PLWHA also an attempt to mitigate the impacts experienced by professional front to situations themselves, diverse and adverse, which emerged in individual assistance (serum disagreement, loneliness and abandonment, social prejudices, sharing serostatus, work, rights...
and duties ...) with a view to the possibility of listening to the activation by these professionals, their wants and needs and that helped to build another tool model to account for the issues they are worked on, functioning also as a social living space and recognition of PLWHA and the demands that come with the diagnosis of serum positive for HIV.

This space intercessor of professional-user meetings, which takes place as hosts establishing the search for new processes, not always conflicting, but bring with it the confrontation, which can enhance the individual in pursuit of meeting their needs. For this meeting to happen we need to let us affect the others, making it a good meeting, not only in the sense of work, but the ability to potentiate the individuals involved in them.

This care space is characterized by listening to what the other wants. In the transformation generated by the inter-subjective encounter, the construction bond, should anchor the technology of relations and come to meet production citizenship, generating an increase of autonomy, greater co-responsibility and the reconstruction of life projects, not just because the therapeutic success, but also considering the history and the user's desire, the recognition of the group members as subjects of law, however, not enough to make a proper diagnosis and provide free medication. You have to work the issues that influence adherence to treatment or not, being entirely tangent, the development of viral resistance, leading to treatment failure and the emergence of multidrug-resistant viral strains, which, by genetic mutations do not respond to antiretroviral therapy. So all the huge investment in research, development of antiretroviral drugs and technology needed to meet the efficacy of this therapy can be lost. To avoid this it is necessary to build strategies to promote adherence to treatment for PLWHA and the adoption of their therapeutic regimens as proposed to prevent and reduce damage to the vulnerable, and the construction of citizenship as a co-participant in controlling the epidemic.

The groups facilitate the exercise of self-determination and independence, as they can act as a support network that mobilizes people in the quest for autonomy and meaning in life, self-esteem and even in improving the sense of humor, which are essential in expanding resilience and reducing vulnerability. In the interaction between people, they create links that enable the emergence of organizations or at least the incentive promoting social inclusion.

It happens in the time of words - gestures - build that builds the fabric of the new subjective possibilities, decentralized and crystallized, the dispossession paths previously constructed and closed themselves, in most cases, a source of suffering. The individual is not only a result, but the middle of individuation. To think individuation is necessary to consider being, not as substance, matter or form, but as a tense system, supersaturated. So much so that, in this understanding, the individual-means tension emerges becoming a resolution of the first voltages and the conservations of these first forces under structure, gives the individual.

Groups derive other modes of subjectivity, there are other ways of experiencing other affects, and move the experience of individual anxieties into collective flows that transform individual stories and ghosts in coletives. Arising unforeseen unconscious elements and / or not said who will be present, sometimes difficult, sometimes contributing to the evolution of the group, with strong affective characters, building a new vision that allow dialectic growth.

**RESULTS**

The categories emerged from the speeches of the deponents: The power of life and Construction of belonging technology in health production in the SOL Group.

- **Life Power Technology**

Social technology is a promising strategy, it seeks to overcome the limits of standard / model of science and technology, in tune with the demands of society in the search for models focused on social inclusion, the main actors in society itself.

There is genesis, but has no owner, no matter the volume of services offered, but the ability to generate some new methodology that can be replicated in other social contexts, to conquer life.

It implies a commitment to social transformation through the creation of a discovery and listening a space of social needs, relevant and effective, with a pedagogical process of appropriation for all involved in the dialogue between different knowledge, educational activities and participatory planning processes, monitoring and evaluation in citizens building democracy. It begins by building their own instruments, their own work tools, depending on the dialogue to improve the living conditions of the population.
The concept of social technological innovation is described and understood as "products, techniques and/or replicable methodologies", developed in interaction with the community and represent effective solutions for social transformation. 19,20

For not having given topics previously we are open to discussion of any topic that has been proposed by a participant, is motivated by a complaint, question or a report, informal media news, for a new protocol proposed by MH, or any subject that brings nuisance or questioning by any member present. Even in recipes exchanges we took the opportunity to address the optimization of power in order to comply with nutritionist guidelines accompanying the PLWHA in service.

An article reporting experience of medical students in TCS1 discipline, the field observation on multi-professional work in CAIDS / HUAP (Coordination of AIDS Services / HUAP), cites the SOL Group as:

A chat room on their personal difficulties with treatment, relationships with family and friends. At other times, the subjects were derived for everyday things of any adult, as debates on violence or problems of urban centers. In this space, because of the long time that some members attend, they also organized social activities and militance.21

In addition to the meetings, we organize some activities within the HUAP in order to increase the socialization of PLWHA and disclose the existence of the group to others who might be interested in the activity. Some are outside the traditional space group meetings. In order to give greater visibility to the activities, they are placed in small posters of PLWHA care clinics, pharmacies and CAIDS.

These activities are described in the book of minutes as cutting hair - DIP / CM, newspaper mural confection; crafts workshops: gossip, paper baskets, paper flowers; monthly birthdays and SOL Group; Christmas parties; Movie session, Popcorn with movies: Cazuza, Central do Brasil, Alternativas Transfusionais, Tainã in partnership with PETROBRAS; Training workshops: female condoms, information Tree, counseling; Educational lectures: facial lipoatrophy, lipodystrophy prevention by physical activity, cardiovascular changes in PLWHA and commemorative.

In order to expand the listening field and partnerships, we see the extramural activities promoting user input on discussion sites and training such as seminars, network meetings Education and Health for Prevention of STDs / AIDS Niterói (REDSUAIDS) and the Municipal

Health Council and non-governmental organizations (NGOs), that purport to support PLWHA. Such participation enhances and develops the critical, bringing, albeit in a very incipient manner, the power of vision, as a citizen, to exercise social control, recommended device for the National Policy of Humanization (NPH), but also a bit of distant practice of citizenship and strengthening of SUS.

Initiated at the 28th meeting, the extramural activity, with the purpose of updating the vaccination card and socialization of adults, adolescents and children, also contributed to all their passes, because in most encounters we use.

Are found described as follows:

Post-vaccination and cultural tours: Parque Lage, ZOO Niterói, ZOO Tour RIO, Botanical Garden, mood Festival - RIO Corcovado official Press, Contemporary Art Museum, Historical Museum, Archaeological Museum Itaipu, UFF Farm in Iguaba and Cachoeira de Macacu, Fort Jurujuba, popular Niterói Theatre - the play "the assumed" in the Theatre of UFF, the Bank of Brazil Cultural Center: Japan 100 years and Yves Saint Lorran, Circuit RIO churches (St. Jude Church, Church N.Sª Aparecida, Convento Santo Antonio, Color and Light Show, Gavea Planetarium, France Brazil House, Cinemaisds shows, Fiocruz, Paqueta, Carmen Miranda Museum, Rio Art Museum, Claudio Coutinho Way - Urca, Brazil France House, woman's day Salesian / Niterói, pontoon rides in Guanabara Bay.


In the interviews, the construction of the meaning of “health” by the group's
participation appears in some biases and space to talk, share experiences and stories...

Personal life in the eyes of respondents

We learn a lot from people here in the group, like this one has, I think you should have on other services, I speak very well of our group elsewhere. (Espectrolite)

In the bias of accession:

Help demystifying the person when you receive diagnosis, we think you'll die the next day, will deteriorate and die slowly, the group helps to show that people can live as normally as possible, that the more you better care for the quality of their lives . (Agate)

It helps a lot, we comment they're going through and will see the difference from one another and see that there are people who are not living right why they do not support, we feel seeing the stories and being precautious, will compare our history with the them and seeing what is good what is not. (Emerald)

In the bias of the host:

You feel milder opening up because you identify with the person who is no stranger and know you have someone to open up to, let go, is not alone, she has the group when she wants. (Chrysoberyl)

Sometimes people are afraid to talk to people on the street here not in the group: we hear the stories identify with them and end up dropping too, then someone else hears and also ends up spilling their story. (Chrysoberyl)

Much when we speak, we are free, we vent things we cannot speak for others. In the group we can speak, everyone understands why you are going through the same problem. (Azurite)

In the bias of sharing life stories, knowing yourself:

It really helps to know how to deal with the situation, who goes through HIV must have spirit and soul to know how to deal with the situation and not to judge each other. In sharing, people have to want to be helped and embraced because it is part of the treatment, understanding. The affection and understanding helps a lot to understand and deal with a disease that has no cure. (Alabaster)

In personal life, help at the time of venting: we report, we take questions, to dealing in personal life; the guide to have notion of what should and should not do, as you put yourself at risk and thus put other people at risk; discussions help in our relationships. (Aquamarine)

When I tell my life story, to me it is good, because I help others see the world differently, there are people who think it's the end of the pit and is not so. (Benitoite)

Some cite to share experiences with others living with the same disease, they influenced them in membership:

Others report their importance to deal with everyday life as follows:

It was a great experience, I learned from people how to deal with each other, not previously discussed or shared. (Diamond)

Talking to people who have the same problem, we see that not only is that there are people with the same problems and can live with. (Jasper)

It was a fantastic experience, as you renew your life in order to live socially, discuss ideas, narrate and vent the problems facing this chronic disease. (Aquamarine)

It was great, you live with people with the same problem, you can talk more freely, can understand each other better when the other says "I'm tired of it"; when not taking medication … I'm already beginning to

Yes, it helps, because we see the other and does the same; it's in the stories we see what can, and whether it will have a long life. (Morganite)

In the bias sharing as support:

You can share and can help each other and automatically be helped: it is an exchange. (Tanzanite)

Not only help as we pick up experience, to move to another who acquired the disease in less time that we, as I got the disease from 92: I have experience and I can go to those recently discovered illnesses. (Heliodoro)

Construction of belonging technology in health production in the SOL Group

When talking about AIDS, I always wanted to understand, here I received knowledge and understanding of what was going on. (Marble Landscape)

It was great because a lot of things we did not know who found it difficult to talk to others in the group are easier because people are in the same situation as mine. It is easier to explain them because they are more experienced; it was a good experience yes. (Goshenite)

It was wonderful, I found very old people and found that I was not going to die and that the remedy was not going to let me die. (Morganite)

It was great, gave me the strength to deal with, if not the group, I do not know ... I got a lot of experience, I saw others walk, the age of the others walking with the disease, it became easier for me. (Golden Beryl)

Here I began to learn and understand the disease. After the group began I take my medicine straight and take it up to today. It was here I found out I could make adherence to medication. (Emerald)

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understand what they are feeling. (Tanzanite)

Some describe the importance of building emotional ties, where they can discuss their difficulties of living with the grievance:

Very important: I made friends who are friends to this day. (Blue Agate)

FINAL CONSIDERATIONS

The study aimed to contribute to those interested in knowing the possibilities of building other types of aid groups and memberships, so that they can share this writing experience, related to the use of technologies that facilitate the adhesion, so little reported in the literature, but possible to be applied to any service, for they do not need a high cost of devices or large investments, providing opportunities for contact with other experiences and instilling creativity in the construction of care.

The objective is also to determine whether the social technology, built in the SOL Group daily with the interest of enhancing the PLWHA to seek, in the exchange of experiences, better ways of living and adherence to treatment, encouraging participation in activities improving the quality of life, promoting socialization and even the generation of income.

The proposed objective initially was to give visibility to the production of health meanings constructed in the SOL Group for PLWHA. In this respect, I believe that we find answers that emerged from the interviews, demonstrating the importance of the group in the construction of roads for the production of their welfare, care of themselves but also those around them, and as potentiating the gestating of individuation processes, engendering ways of being different, though, when operating the group, we were not in the course of those years in which the meetings have taken place, objectively, directed to that interest. This way of operating the SOL Group, interested in identifying and in the ways they will do, and therefore do not take the individual as something already finished and closed, but in permanent construction values the subjective processes and their singularities, when escaping from formatted reasoning provided themes. Legitimizes even in PLWHA perception and experimentation of the group, which encourages participation in the meetings, since at any time there it is open to discussion, when you can receive everything that moves the anguish and provokes questions, and allows sharing as other ways of seeing and making things happen. A production of new meanings and processing the actions of people who participate in the discussions, that make the group an appropriate strategy for the reception of PLWHA, suggesting it as a social technology, capable of producing other and new directions in subjectivity processes that make up the group.

In this sense, this group dynamic is not limited to a self-help strategy. The emphasis on individualization and not the individual, open to the idea that this individual's process, unfinished and open, bound, simultaneously, a "self" and the world that builds and it is also built so and can operate - as something that can be built - its individuation process, so that it is able to experience the sick, so that it turns out to be an effective reality condition for reinventing themselves and of their own world.

Still regarding the ability to be a social technology, it appears to be able to be conceived as such, in that it suggests the assertion of another process, another way to understand and operate a group of PVHA and can therefore be used in educational processes of professional training or even those who, wishing to develop a work with PLWHA, try a motto to bring their creative power so as to enable an approach to the unknown, enabling him to solve new problems.

The professional must generate and optimize the use of technologies that meet the needs of society inclusively. The group also has the ability to demonstrate the importance of care focused on the construction of this, personalized without being individualistic, focused on the development of social skills through cooperative attitudes, in making the team work where knowledge is decentralized, owned and serves for all.

REFERENCES


Barros AMF, Ramos VC, Silva AR et al.

Production of constructed health directions...

Bairro Centro
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Available from:
http://www.proppi.uff.br/bolsasagir/edital-para-submissao-de-projetos-pibiticnpq-pibinovapdiuff-20112012
