



DESCRIPTIVE FLOWCHART OF THE MEANINGS OF HEALTH FOR PEOPLE LIVING WITH HIV/AIDS IN THE SOL GROUP

FLUXOGRAMA DESCRITOR DE SENTIDOS DE SAÚDE DE PESSOAS VIVENDO COM HIV/AIDS NO GRUPO SOL

FLUJOGRAMA DESCRIPTIVO DE LOS SIGNIFICADOS DE LA SALUD PARA PERSONAS QUE VIVEN CON VIH/SIDA EN EL GRUPO SOL

Ana Maria Ferraz Barros¹, Mauro Leonardo Salvador Caldeira dos Santos²

ABSTRACT

Objective: to provide visibility - through the construction of a descriptive flowchart - to the different meanings of health for people living with HIV/AIDS (PLWHA) who participate in the SOL group. **Method:** Qualitative, exploratory, descriptive study. Data will be collected through literature review, review of the minutes book and interviews with participants of the SOL Group, which was created in 2002 in an university hospital. The research project was submitted to the Ethics Committee on Research (CAAE 155715137000052430). **Expected results:** we expect that, in the final assessment, the use of support groups is found to be a social technology that facilitates the adherence to treatment of people living with HIV/AIDS. Furthermore, we hope that it will serve as an empowerment tool for health professionals who would like to work in the care of PLWHA. **Conclusion:** the meanings of health extracted from the interviews are varied, but unanimous in affirming the importance of the group to the acceptance of disease and adherence to treatment. **Descriptors:** Adhesion; Long-Term Survivors of HIV infection; AIDS; HIV infection.

RESUMO

Objetivo: dar visibilidade, por meio da construção de um fluxograma descritor, à produção dos diferentes sentidos da ideia de saúde construídos, no Grupo SOL, por pessoas que vivem com HIV/AIDS (PVHA). **Método:** estudo exploratório e descritivo, de abordagem qualitativa. OS dados serão coletados por meio de revisão de literatura, da consulta ao livro de atas e de entrevistas aos participantes do grupo Grupo SOL, que foi criado em 2002, em um hospital universitário. O projeto de pesquisa foi submetido ao Comitê de Ética em Pesquisa, com CAAE 15571513700005243. **Resultados esperados:** que na avaliação se encontre o uso do acolhimento grupal como tecnologia social facilitadora da adesão de pessoas vivendo com HIV/AIDS ao tratamento AIDS. Além disso, espera-se que ele sirva como ferramenta de empoderamento para o profissional de saúde que pretenda trabalhar na atenção de PVHAs. **Conclusão:** os sentidos de saúde que aparecem nas entrevistas são variados, mas unânimes em afirmar a importância do grupo para a aceitação da doença e adesão ao tratamento. **Descritores:** Adesão; Sobreviventes de Longo Prazo ao HIV; AIDS; infecção pelo HIV.

RESUMEN

Objetivo: proporcionar visibilidad a la producción de los diferentes significados de la idea de salud construidos en Grupo SOL por personas que viven con VIH/SIDA (PVVS). **Métodos:** estudio cualitativo, exploratorio y descriptivo. Los datos serán recolectados a través de la revisión de la literatura y del libro de actas, y de entrevistas con los participantes del grupo SOL, que fue creado en 2002 en un hospital universitario. El proyecto de investigación fue sometido al Comité de Ética en Investigación (CAAE 15571513700005243). **Resultados esperados:** se espera que, en la evaluación final, el uso de grupos de ayuda pruebe ser una tecnología social que facilita la adhesión de las personas que viven con el VIH/SIDA al tratamiento. Por otra parte, se espera que sirva como herramienta de empoderamiento para los profesionales de la salud que deseen trabajar en el cuidado de las PVVS. **Conclusión:** los significados de salud que aparecen en las entrevistas son múltiples, pero unánimes en afirmar la importancia del grupo para la aceptación de la enfermedad y la adhesión al tratamiento. **Descriptor:** Adhesión; Supervivientes a Largo Plazo de la Infección por VIH; SIDA; Infección por VIH.

¹Nurse, Specialist in Collective Health, UFF, Professional Master's Degree Program in Assistential Nursing, Fluminense Federal University /UFF, Niterói (RJ) Brazil. E-mail: aferrazbarros@bol.com.br; ²Nurse, PhD in Nursing, Professional Master's Degree Program, Fluminense Federal University /UFF, Niterói (RJ) Brazil. E-mail: mcaleo@uol.com.br

INTRODUCTION

In Brazil in the 80's the beginning of the AIDS epidemic struck mainly white, upper or middle-class homosexual and bisexual men living in large metropolitan areas. Progressively all social classes became affected.¹ Nowadays, there is no longer a profile for the target population. All races, sexes, social classes, and age groups are affected. "In 2011, 608,230 cases of AIDS (Acquired Immunodeficiency Syndrome) were reported in Brazil". Prevalence is concentrated among 15-49-year-old adults".²

The Brazilian public health policy for AIDS is based upon three pillars of intervention, namely: epidemiological surveillance, prevention and care. Aim is the articulation of these three pillars, in order to achieve the integrality of actions in the AIDS program. Health actions should not only be aimed at people living with HIV/AIDS (PLWHA) and their treatment, but also at their partners or social network members. Currently, there is the advocacy for "the indissociation between prevention and treatment", contrary to policy guidelines that define prevention as the essential public response to the epidemic.³

These issues further add to the multifaceted character of the epidemic, and flatten society into one single mass. Nevertheless, the everyday lives of PLWHA are still affected by issues of prejudice and discrimination. These generate social and personal conflicts that culminate in the difficulty of correctly adhering to treatment. Given the complexity, intensity and tension of the questions raised, it was perceived the urgent need for support to PLWHA and their families, especially in regards to their reception. We believe that the treatment of PLWHA should not be limited to medical consultations and the prescription of medications.

The desire to have a private place for sharing anxieties, experiences, news and needs was expressed by most of the patients during their nursing consultations. Many of them had been seeing each other at the hospital's corridors for years, but had never engaged in conversation due to the fear of exposing HIV status and experiencing prejudice.

It is important to mention that the disclosure of the HIV/AIDS diagnosis may bring great difficulties to the everyday lives of these individuals, because of the way their lives as citizens is affected. In this sense, the support group showed to be a valuable tool for the empowerment, socialization and

"capacity building" of both participants and the person caring and/or being held responsible for the group.⁴

The possibility of the professional practice in this field reveals the importance of supporting groups and the influence of nursing care activities. It meets the recommendations of the National STD/AIDS Coordination and is an important tool for improving adherence. These groups help to improve the quality of life of PLWHA in their daily lives, in society, and as users of different health care services. It also improves their social participation by sharing responsibility for the control of the epidemic.⁴

The National Humanization Policy (NHP) was created in 2003 as a proposal for achieving integrality of actions, outlining ways to improve team interaction and prepare professionals to deal subjectively and horizontally with relationships in health care practice. It also empowers and brings healthcare professionals and users closer together in the discussion and construction of public health policies, i.e., in a form of co-management. The formation of ethical-aesthetic-political attitudes is encouraged for the construction of a permanent citizen's network. This causes the destruction of knowledge borders and demystifies the territories of power established in the constitution of labor relations, through transversality and inseparability. The user is seen as a subject with rights. Demands are analyzed together with the possibility of meeting the unique psychosocial needs of each individual, with his/her life histories and vulnerabilities, in a care freed from judgments and prejudices.⁴

In every health care approach, there is a process of relations constructed through live work in action. In this coming together of expectations and productions, intersubjective moments (speaking, listening, interpreting) are created. If the intentions of the people involved are understood, it results in complicity and accountability for the problem to be faced. These are moments of hope and reliability that create bonds and relationships of acceptance.⁵

The mutual support group tends to be a very productive space, decentralizing technical and professional knowledge and (re)producing information. It also seems to have a better acceptance by better acceptance by patients, because in the group several versions of a given topic are created, creating new ways of thinking and living. Moreover, it is a rich space for socialization and to live new experiences, gain knowledge

and get updates... Because they all have the same HIV status, they feel more comfortable in freeing themselves from their prejudices and talking about their anxieties, sorrows, expectations and difficulties, as well as their victories, achievements and strivings. This has a positive impact on adherence to treatment, since in the peer groups there is a different logic other than the medicalized one.⁵

Although science has evolved and succeeded in transforming AIDS in a chronic disease (due to the further development of antiretroviral drugs and specific tests), adhesion, which means much more than swallowing pills, remains the most important element for the treatment of PLWHA. It is through adhesion that they can control the effects of disease and medications, prevent themselves from coinfections, and improve their self-esteem and quality of life. In this view, the use of a technology of support groups as an aid tool greatly helps in this process due to the sharing of experiences.⁵ In this sense, the nursing professional, in order to be able to host a group and discuss the various biopsychosocial, spiritual and religious aspects experienced by the PLWHA, needs to be aware of, understand and know how to apply these technologies. Thus, he/she can collaborate to the adherence of PLVH to treatment. The idea of constructing a flowchart of the meanings of health for people living with HIV/AIDS in the SOL Group came up as an attempt to build strategies for facilitating adhesion.

The SOL Group was started on April 14th, 2002, with the presence of 12 PLWHA. It was created due to requests received during the first consultations performed by the nurse and social worker. There was the need for the creation of a meeting place for the exchange of experiences. The group is also in an attempt to mitigate the impacts of various situations that usually arise in individual care (lack of adherence, HIV sero-discordancy, social prejudices, sharing of HIV status, loneliness and abandonment, work, rights and duties...). There is no agenda of topics to be covered during the meetings. We try to discuss any subject related to citizen life and not just focus on the antiretroviral therapy, because the PLWHA is, above all, a member of society. The PLWHA should be privileged with the access to information and ultimately share it with those around him/her. These are elements of right established by law that promote the solidification of the unified health system (UHS). The importance of participation in social control in all spheres of civic life, as well as the access tools for such

participation are always brought into discussion as a way of strengthening the UHS and controlling the epidemic .

In order to expand partnerships and enhance the field of listening, we also perform external activities, promoting the insertion of users in discussion and formation sites that try to support PLWHA, such as seminars, meetings of the health network, the city council and non-governmental organizations (NGOs). The participation in discussions creates empowerment and critical consciousness. It brings, though in a very incipient way, the idea of building up power as a citizen by exercising social control, as envisaged by the NHP.

OBJECTIVES

- To provide visibility - through the construction of a descriptive flowchart - to the different meanings of health constructed by individuals living with HIV/AIDS.
- To show how the technology used in the SOL Group constitutes an appropriate strategy in supporting people living with HIV/AIDS.
- To construct a descriptive flowchart of the different meanings of health for people living with HIV/AIDS in the SOL Group.

METHOD

Qualitative, exploratory, descriptive study. Data was collected through literature review, review of the minutes book and semi-structured interviews with participants who attended at least 15 meetings of the SOL Group. Data will be subjected to thematic content analysis (Bardin).

The research is being carried out at the HVI/AIDS outpatient unit of the Antonio Pedro University Hospital (HUAP), Federal Fluminense University (UFF). The SOL Group, a low-technology strategy conducted by a nurse, started on April 14th, 2002. Meetings take place fortnightly from 11am to 1pm in the meeting room of the CAIDS/HUAP.

Data will be extracted from semi-structured, individual, audio-recorded and transcribed interviews that will be examined using the content analysis technique. Results will be analyzed according to categories that will not be listed a priori, but posteriorly and in an immanent way. This will be done in order to verify whether an effective contribution of the SOL group to treatment adherence can be found. In this sense, the aim of this study is to construct meanings, not to unveil significations.

With regard to ethical and legal issues, the research project was approved by the Ethics

Committee on Research of the Antonio Pedro University Hospital, Fluminense Federal University (CAAE number: 1557151370005243). Each survey participant will have to sign a free and informed consent form, as established by Resolution 466/1213 of the National Health Council (NHC) regarding regulations for research involving human subjects.¹⁰

Anonymity will be preserved by adopting names of gemstones selected by the participants before the interview.

EXPECTED RESULTS

To be inserted in health care services, have relevant information and access to treatment is not the same as adhering to treatment. The disclosure of an HIV positive diagnosis is painful and often associated with personal and social culpability. It develops in isolation from social life and leads to feelings of chronic loneliness. These feelings, which result in difficulties in dealing with everyday situations, together with the side effects of medications further hinder adherence to treatment.

With this research we expect to determine whether the discussion of such issues in mutual support groups can improve adherence to treatment, and become a social technology. The group works as a tool that enables the discussion and socialization of difficulties inherent to living with HIV/AIDS. It brings these discussions to all those who participate in the group. The testimonial of one person can give an insight of what may be distressing other participants and encourage them to expose their fears and anxieties, and look for new ways of overcoming their difficulties. Thus, it works as a supporting net in times of pain, despair, or conflicting feelings; of wanting or not wanting to fight for their lives. Moreover, it enables participants to share their achievements, which helps others to renew their hopes and believe in their own power to produce successful outcomes.

Participating in the SOL Group seems to lead to a greater adhesion to treatment, according to the users' speech in the interviews. By dealing with everyday life issues after the disclosure of diagnosis, we have been noting the expansion of social and affective bonds, and an increased motivation to live.

REFERENCES

1. Rachid M & Schechter. Manual de HIV/AIDS. Rio de Janeiro: Editora REVINTER, 9th ed. 2008; p. 5.
2. Carta Magna da Constituição Brasileira de 1988
3. Vidal ECF; Braga, VAB; Silva, MJ; Pinheiro, AKB. Políticas públicas para pessoas com hiv: discutindo direitos sexuais e reprodutivos. Rev Rene [Internet] 2009 apr/june [cited 2013 Apr 20];10(2):166-74. Available from: <http://www.revistarene.ufc.br/revista/index.php/revista/article/viewFile/504/pdf>.
4. Brasil- MS . Política Nacional de Humanização. Brasília; 2003
5. Merhy EE . A perda da dimensão cuidadora na produção da saúde/ publicado no livro O SUS em Belo Horizonte. SP: Editora Xamã, SP; 1998.
6. De Marchi MC, Padoin SMM, Zuge SS, De Paula CC, Langendorf TF, Rodrigues AP. Adultos em terapia antirretroviral para o hiv/aids: implicações no cotidiano. J Nurs UFPE on line [Internet]. 2013 May [cited 2013 Apr 20];7(6):4528-34. Available from: <http://www.revista.ufpe.br/revistaenfermagem/index.php/revista/article/view/4160>
7. Brito AM; Szwarcwald CL; Castilho EA. Fatores associados à interrupção de tratamento antirretroviral em adultos com AIDS: Rio Grande do Norte, Brasil, 1999-2002. Rev Assoc Med Bras [Internet]. 2006 Mar/Apr [cited 2013 Apr 20];52(2):86-92. Available from: <http://dx.doi.org/10.1590/S0104-42302006000200017>
8. Carvalho CV; Merchán-Hamann E; Matsushita R. Determinantes da adesão ao tratamento antirretroviral em Brasília, DF: um estudo de caso-controle. Uberaba: Rev Soc Bras Med Trop [Internet]. 2007 Oct [cited 2013 Apr 20];40(5):555-65. Available from: <http://dx.doi.org/10.1590/S0037-86822007000500013>

Barros AMF, Santos MLSC dos .

Descriptive flowchart of the meanings of health...

Submission: 2013/12/04
Accepted: 2013/03/12
Publishing: 2014/06/01

Corresponding Address

Ana Maria Ferraz Barros
Hospital Universitário Antonio Pedro
Rua Marques do Paraná, 303 / Centro
CEP 24230 370 – Niterói (RJ), Brazil