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# Social protagonism: meetings between nursing graduates of Salvador and activists living with HIV

**ABSTRACT** | Objective: This work aims to report the experience of undergraduate nursing students during meetings with people living with HIV and participating in an organized social movement. Method: The idea of integrating the meetings promoted by the group arose from the need to approach people who work in the Bahian scenario, proposing discussions about prevention, diagnosis and coping with the HIV epidemic, objects of the Bonde Universitário extension project: young participation in the prevention of Sexually Transmitted Infections, of which the students are a part. Result: The meetings triggered rounds of monthly conversations with themes suggested by the participants: prejudice, perspective of the future and leadership. The action promoted the integration among the participants and gave the undergraduate students a rich practice of health care. Conclusion: Participation provided the organization of educational activities and mutual learning, with the development of innovative actions that have the potential to produce effects on the sexual practices of the subjects.

**Keywords:** Health education; Sexually Transmitted Diseases; Nursing.

**RESUMEN** | Objetivo: Este trabajo tiene como objetivo reportar la experiencia de estudiantes de enfermería durante encuentros con personas que viven con el VIH y que participan en un movimiento social organizado. Método: La idea de integrar los encuentros promovidos por el grupo surgió de la necesidad de acercarse a las personas que trabajan en el escenario bahiano, proponiendo discusiones sobre prevención, diagnóstico y afrontamiento de la epidemia de VIH, objetos del proyecto de extensión Bonde Universitário: jóvenes participación en la prevención de Infecciones de Transmisión Sexual, de la cual los estudiantes son parte. Resultado: Los encuentros desencadenaron rondas de conversaciones mensuales con temas propuestos por los participantes: prejuicio, perspectiva de futuro y liderazgo. La acción promovió la integración entre los participantes y brindó a los estudiantes de pregrado una rica práctica del cuidado de la salud. Conclusión: La participación proporcionó la organización de actividades educativas y de aprendizaje mutuo, con el desarrollo de acciones innovadoras que tienen el potencial de producir efectos en las prácticas sexuales de los sujetos.

**Palabras claves:** Educación en Salud; Enfermedades de Transmisión Sexual; Enfermería.

**RESUMO** | Objetivo: Este trabalho objetiva relatar a experiência de graduandas de enfermagem durante encontros com pessoas que vivem com o HIV e participam de um movimento social organizado. Método: A ideia de integrar os encontros promovidos pelo grupo surgiu da necessidade de se aproximar de pessoas que atuam no cenário baiano propondo discussões sobre prevenção, diagnóstico e enfrentamento da epidemia do HIV, objetos do projeto de extensão Bonde Universitário: participação jovem na prevenção de Infecções Sexualmente Transmissíveis, do qual as estudantes fazem parte. Resultado: Os encontros desencadearam rodas de conversas mensais com temas sugeridos pelos participantes: preconceito, perspectiva de futuro e liderança. A ação promoveu a integração entre os participantes e conferiu às graduandas uma prática rica de atenção à saúde. Conclusão: A participação proporcionou a organização de atividades educativas e um aprendizado mútuo, com elaboração de ações inovadoras que tenham potencial para produzir efeitos sobre as práticas sexuais dos sujeitos.

**Palavras-chaves:** Educação em saúde; Doenças Sexualmente Transmissíveis; Enfermagem.

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## INTRODUCTION

The appearance of the Human Immunodeficiency Virus (HIV) was experienced, initially in the 1980s, with great suffering, given the process of illness and discrimination suffered

by the people affected. Infection with the virus usually occurs through sexual intercourse, with fluid exchange when not using a vaginal or penile condom, in addition to vertical transmission and contamination with sharp objects such as syringe sharing.

Currently, this epidemic affects people of different identities of gender, race/color, social classes and generations that were not previously considered to be susceptible to this infection.<sup>1</sup>

Given this, there were many strategies implemented to face the infection by HIV / AIDS and among these, it is worth mentioning, the involvement of the population demanding access to information, crea-

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tion of public policies and the inclusion of the Unified Health System (SUS - Sistema Único de Saúde) as an excellence service to meet the demands related to the epidemic.<sup>2</sup> The Joint United Nations Programme on HIV/AIDS (UNAIDS) identified that the number of new infections by Human Immunodeficiency Virus (HIV) has fallen 47% since the peak in 1996 in Brazil.<sup>3</sup>

However, despite advances, people living with HIV/AIDS often face exclusionary systems, leaving them in a vulnerable condition. For Ayres and his collaborators, vulnerability occurs to a minority that, due to individual, social and programmatic motivation, leads to a greater susceptibility to illness due to the different opportunities of access to information and available services.<sup>4</sup> In view of this statement, it is understood that the health needs of some populations are often not heard or taken into account to the detriment of the stigmas that permeate this group.

In this way, social, collective movements of a socio-political and cultural character appear, which add forces to transform this reality, with the objective of organization, inclusion, empowerment and expression of demands.<sup>5</sup> From the inefficiency of the government in creating strategies to fight AIDS, Social Organizations appear and help to strengthen public policies and struggles for the right to improve the quality of life.<sup>6</sup>

Based on this, recognizing the importance of the theme, the following research question was outlined: What is the experience of nursing students in encounters with people living with HIV and participating in an organized social movement?

In view of this, the present study aimed to report the experience of nursing students during meetings with people living with HIV and participating in an organized social movement. The idea of integrating the meetings promoted by the support group arose from the need to get closer to people working in the Bahian scenario, proposing discussions about the prevention, diagnosis and coping with the HIV epidemic, as these

are also objects of the Bonde Universitário extension project: youth participation in the prevention of Sexually Transmitted Infections (STIs), of which the students are part.

#### METHOD

This is an experience report based on activities developed by the extension group Bonde Universitário of the School of Nursing of the Federal University of Bahia (EUFBA), linked to the research project Health Conditions of Women in the Municipality of Salvador-BA, approved by the Research Ethics Committee, under opinion No. 3.919.332. The meetings that originated this report started in March 2019 to March 2020, weekly, from 2 pm to 5 pm, in a reference service located in the city of Salvador-Bahia.

After the elaboration of the extension project, teachers and students established an agenda for discussion and knowledge sharing on the themes of prevention, diagnosis, STI/ HIV/ AIDS treatment, health needs and social markers.<sup>7</sup> Concomitant to this, contact was made with people from the social movement in search of information on spaces for discussion and meetings between activists.

The Bonde Universitário project was introduced to activists, who showed interest in a partnership. The meetings, at first, took place with few interventions by the listeners, but it was an important space for bonding with the Social Movement and newcomers. Then, the meetings were open to the public and counted on the participation of undergraduate students from Higher Education Institutions (HEIs), activists, professionals and users of the service. This insertion was favorable for holding conversations, organizing preventive actions on the streets, events, in addition to educational activities and new proposals that emerged during the meetings.

The service where the meetings took place provides outpatient care for individuals with suspected or diagnosed STI/ HIV/ AIDS, Medical Assistance, Nursing Assistance, Social Assistance, Nutrition, Den-

tistry, Occupational Therapy, among other specialties. It also develops activities such as theater and dance.

The study was developed based on the ethical aspects of the research, involving human beings recommended by Resolution 466/2012 of the National Health Council of the Ministry of Health, which addresses the duties and rights of the researcher and subject.<sup>8</sup>

#### RESULTS

The meetings take place at the referral health service for the care of people with HIV. They are organized by activists, who take political stances, use the space as a source of learning and denouncing the restricted rights of people living with the virus. Most members have been living with HIV for many years, had experiences in multiple treatments, hospitalizations and their reports served as an example for many people.

Due to the awareness and recognition for the learning promoted by the students when participating in the meetings, they proposed to include, once a month, some theme suggested by the members or identified as relevant by the group, as an agenda. The group welcomed the proposal and, based on that, a schedule was drawn up, content and meetings were listed in the format of Conversation Wheels.

Each action was thought of in a group, all aspects discussed in the circles were carried out from the previous reading of scientific articles that allowed updating and expansion of knowledge. In view of the above, three central themes to be worked on were listed: prejudice, perspective of the future and leadership.

On the subject of prejudice, we started with the development of a dynamic for approximation and integration in which the participants received a blank sheet. On the one hand, they represented the way they thought people and society saw them as individuals living with HIV and on the other hand how they saw themselves. The activity made it possible to promote speeches

in relation to the experience of stigmas of people living with HIV.

It was identified that the representations of how the participants believed to be seen by society, for the most part, were symbolized by drawings. When provoked to justify them, many talked about the prejudice faced in the family environment during the 90s, a time when society was unaware of the infection. In addition to different opinions on whether or not to reveal seropositivity. Some said they did not disclose to family and friends to protect themselves from stigma, others felt it was better to comment in the first contacts as a way of coping, avoiding the violence of these people.

In contrast, the way the participants saw themselves was mostly represented by words that outlined positive feelings such as affection, happiness and family, signaling how much they were loved and that their prejudice was broken with love and information over time. At the end of this first moment, users were invited to build a speech related to the theme.

One of the activists suggested making a song, a presentation with life projects and plans for the future. The composer did not attend the conversation about the prospect of the future, however, the other subjects highlighted dreams, struggles and verbalized that living with HIV is no longer a major influence on life decisions, as other individual and social factors interfered more in their existence.

At the end of this second round, everyone wrote on paper about how they would like to be in the future and pasted the words on a similarity tree, made by the students, for better visualization. Most participants considered healthy aging and death without suffering as the main factor for the future. In view of these explanations, it was emphasized that they could exercise control of their lives, in addition to ways to organize each step towards the future.

Based on this assumption, the next round of conversation was thought together: leadership. The approach of the theme was very desired by the students due to the re-

cognition of the need to change the organization of the movement due to the overload of tasks of some members.

For this purpose, dynamics were used, the participants were subdivided into groups and chose a representative to lead the activity. The leader of each group in this circle mediated the activity to solve the proposed problem. Through this, it was noticed several ways to integrate, lead and share demands.

## DISCUSSION

It was observed that there was a fluid communication channel between the service and the movement, since professionals from different sectors participated in the meetings and doubts were clarified about different areas such as health, law and social issues. But occupying that space is a daily struggle for permanence, in the face of a fragile SUS scenario, with disputes over the expansion of the private service and withdrawal of transportation and food aid that was provided by the service. However, the gains of this articulation were diverse, the voices of the movement were heard by the institution, as well as they fight for improvements in the service.

At the meetings, several participants spoke about the therapeutic itinerary, the trajectory to achieve what they were looking for, they provided guidance on sickness benefits, disability retirement or continued benefits.<sup>9</sup> In addition, it is important to highlight that the movement's participation in the service is important, as it develops, together with the unit, information campaigns, prevention and control of STIs. This form of collaboration with non-profit civil entities is regulated by Law no. 9.637/1998.<sup>10</sup>

It was also observed that most of the participants were older than 40 years, which is different from the epidemiological profile of the infection. A study carried out between January 2012 and May 2016, in 112 medical records of patients diagnosed with HIV / AIDS, in the municipality of Pas-

sos in Minas Gerais, observed the predominance of cases in men and in the age group of 20 to 39 years.<sup>11</sup> This experience among older people, although important, may be of little interest to young people, as there is no identification and they do not recognize themselves as peers.<sup>12</sup>

The action promoted integration and reflection among the participants. In the first round of conversation, many reports outlined emotions and, above all, emphasized the importance of the role of activists to extinguish printed discrimination against people living with HIV. Many reported that they felt loved by family and friends and that it strengthened them to fight prejudices and to build the future. Because, conversation circles can expand discussions and identify new directions for the group.<sup>13</sup>

This initial discussion was based mainly on studies by Goffman on the stigmatized subject, the one who goes from being an ordinary individual to being diminished by society.<sup>14</sup> And for the second round, Robayo and collaborators based it on how the members of the group wanted to be in 10 years, in order to build or share the perspectives of life.<sup>15</sup>

During the third round, activists were encouraged to redistribute roles, share roles and responsibilities with autonomy for change. It was realized that there was an important role in awakening them to individual potentials, the magnitude that collective practices have to impact changes. It reflected on the spaces and the multiple ways of carrying out ethical, virtuous, authentic and positive leadership. The practice of leadership charged with intention, but with prudence.<sup>16</sup>

The discussions showed the ignorance of the majority about the leadership exercised in their daily lives, they believed that being the leader of the movement was a great responsibility which they were unable to exercise. Such a perception resulted in the burden on a minority, from the administrative burden to a few activists, who are seen as indispensable and irreplaceable for the existence and maintenance of the movement.

It was noted that the interaction with the group was positive and surprising. Throughout the activities, the exchange of experiences showed that learning was mutual, the availability of everyone to think and develop collective STI prevention actions united and motivated them to implement innovative approach strategies that could produce effects on the subjects' sexual practices.

The partnership between the academy and the organized social movement gave the undergraduate students a practice of real health care, brought them closer to subjects and experiences that had hitherto been new. The reports about the infection, care and social relations aroused the undergraduate students to the subjective needs of each subject involved.

## CONCLUSION

The rapprochement between nursing students, activists and users of the specialized health care service for people living with HIV favored the exchange of popular and scientific knowledge and produced an interaction between the university and the community. Participation in the group brought undergraduate students closer to diverse subjects, endowed with desires and individual trajectories loaded with aspirations beyond infection and enabled the recognition of activism as a social tool for the occupation of spaces and collective struggles capable of changing not only the existing scenarios, but lives.

This report allowed us to address practical, social and subjective issues that involve emotion. The entire description of what ha-

ppened along the Conversation Wheels arises from contexts and life stories, so the limitation of the study may be a report imbued with impressions, individual perceptions, but which were shared by the executing team.

The contribution of this article is to expose the possibilities arising from an immersion in the practical field, which can also be theoretical. Learning arises from doing, but also from reflection, discussion and detailed description of what has been done. The construction of the text strengthened the knowledge acquired.

It was possible to think critically about the stigmas and understand the individual strategies of daily defense to survive. Every experience provided learning about the health context, the use of active methodologies to promote welcoming, listening, caring, and the bond to establish relationships between subjects. 🍀

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