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Original Article

LIVING WITH HIV/AIDS IN STREET SITUATION: SOCIAL REPRESENTATIONS OF HOSPITALIZED PEOPLE

VIVER COM HIV/AIDS EM SITUAÇÃO DE RUA: REPRESENTAÇÕES SOCIAIS DE PESSOAS HOSPITALIZADAS

VIVIR CON VIH/SIDA EN LA CALLE: REPRESENTACIONES SOCIALES DE PERSONAS HOSPITALIZADAS

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Objective: to apprehend the social representations about living with HIV for homeless people hospitalized and to identify the contents, elements and structure of these representations. Method: this is a descriptive study, based on the Theory of Social Representations, conducted with homeless hospitalized people living with HIV. For data collection, a form and the Free Word Association Test were used. Data analysis occurred through descriptive statistics and EVOC software. Results: of the 65 participants, 46 were male, with a mean age of 39 years. The central core of social representations included: fear, illness and prejudice, indicating the functional proportions and related to the image of the investigated object. The investigated group represented living with HIV/aids on the street through negative words, loaded with hurt, sadness and fear. Conclusion: representations have a probable core in the word "fear".

Descriptors: Social Representation. Ill-Housed Persons. HIV. Hospitalization. Nursing.

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Objetivo: apreender as representações sociais sobre o viver com HIV para pessoas hospitalizadas em situação de rua e identificar os conteúdos, elementos e estrutura dessas representações. Método: trata-se de estudo descritivo, embasado na Teoria das Representações Sociais, realizado com pessoas hospitalizadas, que vivem com HIV em situação de rua. Para coleta de dados utilizou-se um formulário e o Teste de Associação Livre de Palavras. A análise de dados ocorreu por meio da estatística descritiva e do software EVOC. Resultados: dos 65 participantes, 46 eram do sexo masculino, com idade média de 39 anos. Observou-se como núcleo central das representações sociais: medo, doente e preconceito, indicando as proporções funcionais e relacionadas à imagem do objeto investigado. O grupo investigado representou o viver com HIV/aids na rua por meio de palavras negativas, carregadas de mágoa, tristeza e medo. Conclusão: as representações têm um provável núcleo central na palavra "medo".

Descritores: Representação Social. Pessoas Mal Alojadas. HIV. Hospitalização. Enfermagem.

Objetivo: aprehender las representaciones sociales sobre el vivir con VIH para personas hospitalizadas en situación de calle e identificar los contenidos, elementos y estructura de esas representaciones. Método: se trata de estudio descriptivo, basado en la Teoría de las Representaciones Sociales, realizado con personas hospitalizadas, que viven con VIH en situación de calle. Para recolección de datos se utilizó un formulario y el Test de Asociación Libre de Palabras. El análisis de datos se realizó por medio de la estadística descriptiva y del software EVOC. Resultados: de los 65 participantes, 46 eran hombres, con edad media de 39 años. Se observó como núcleo central de las representaciones sociales: miedo, enfermo y prejuicio, indicando las proporciones funcionales y relacionadas a la imagen del objeto investigado. El grupo investigado representó el vivir con VIH/sida en la calle por medio de palabras negativas, cargadas de dolor, tristeza y miedo. Conclusión: las representaciones tienen un probable núcleo central en la palabra "miedo".

Descriptores: Representación Social. Personas con Mala Vivienda. VIH. Hospitalización. Enfermería

Introduction

Human Immunodeficiency Virus (HIV) infection and aids continue to be an important object of social research even after more than 40 years of their discovery and given the advances in treatment obtained in recent years, because they are still a problem that produces negative images in social media[1]. Aids is one of the serious public health problems, characterized as a global epidemic, with rapid spread and worsening. At the beginning of the epidemic, it was considered a disease that affected a restricted group, the so-called "risk group", which included homosexuals, hemophiliacs, Haitians and heroin addicts, as well as sex workers. The use of this expression marked the historical, cultural, imaginary and social construction of aids in the world. Soon after, the epidemic was associated with "risky behavior". However, this model was and is strongly criticized for blaming individuals for having "failed" regarding prevention and/or protection[2].

Considering the inequalities of Brazilian society and the spread of HIV infection in the country, aids reveals itself to be an epidemic of multiple dimensions that has, over time, undergone significant changes in its epidemiological profile, being today marked by its feminization, heterosexuality, interiorization and aging[3]. Reconfigurations of the popular representation of the disease are already noticed, although in a slight reduction of its negative image, in several realities, both from the perspective of users and health professionals.

Thus, from 2007 to mid-2021, Brazil reported 381,793 cases of aids, registering an average of 36.8 thousand new cases annually in the last five years. In the Northeast, the population infected with HIV is 75,618, corresponding to 19.8% of the total cases. Although Brazil is a reference in the fight against the epidemic, the Northeast region has different epidemiological characteristics, with a higher incidence in vulnerable populations. Among them, homeless people stand out, which, along with other population segments, such as young people, blacks and Indigenous, are considered as priority populations[4].

In this context, in the daily life of living on the street, individuals end up getting involved

with alcohol and other drugs, and become more vulnerable to chronic, psychiatric and infectious diseases, such as skin conditions, infestations by pediculosis, tuberculosis, HIV and sexually transmitted infections[5]. The specificities of street life, associated with the complexity of factors, make people vulnerable to various social and health problems that challenge health professionals.

In addition to clinical care, homeless people also seek hospital care to perform hygiene habits and maintain food. Thus, these subjects adopt health care measures that align with the context in which they are inserted[6].

The Theory of Social Representations (TSR) is understood as a form of knowledge that serves for communication and participation in community discourses, which allows the production and determination of behaviors. In addition, the TSR enables the ordering and understanding of the reality of the subject or a group[7]. Social representations can reverberate in practices and behaviors by the social group, presenting a close relationship with the multiprofessional health team.

However, the literature demonstrates insufficient studies related to perceptions and subjective aspects of living with HIV/aids in street situation, which hinders the understanding of the health needs of this population and the construction of a humanized care. Therefore, it is necessary to use tools to learn the meanings attributed to living with HIV/aids for this population segment.

Given the above, this research aimed to apprehend the social representations about living with HIV for homeless people hospitalized and identify the contents, elements and structure of these representations.

Method

This is a descriptive study based on the TSR. Social representations are understood as a set of interpretation of reality that governs the relationships of individuals with their physical and social environment, determining their behaviors and practices, and a set of anticipations and expectations. They form part of the ordinary knowledge system of individuals, being understood by a grouping of beliefs, images, metaphors and symbols, with their own cultural significance, surviving independently of individual experiences[7].

The research was conducted in a state hospital, reference institution for infectious diseases and for the treatment of HIV/aids, located in the city of Fortaleza, Ceará, Brazil. The study included 65 health service users who lived with HIV/aids in street situation and were hospitalized during the data collection period. The composition of the studied group occurred by convenience and obeyed the following inclusion criteria: living in a street situation, having a positive diagnosis for HIV/aids and being hospitalized. Exclusion criteria: users underage.

Data collection took place from September 2019 to January 2020. To this end, a form with sociodemographic data and the Free Word Association Test (FWAT) were used. For the FWAT, participants were asked to verbalize words or expressions that came immediately to their mind through an inducing term. This study adopted the term "living with HIV/aids on the street", orienting the production of a maximum of four items for this term. Soon after the free evocations of the words, the participants were asked to proceed to the hierarchization of the free evocations performed, according to the importance attributed to them for the definition of each social object in question. The recording of the evocations was carried out by the researcher in a specific printed instrument.

The stage of analysis of sociodemographic data occurred through descriptive statistics. For the analysis of evocations and frame construction, the openEVOC software was used. It is a program that allows the analysis of evocations through the frequency and order that the terms were evoked, in order to identify the structure and internal organization of the representations. The elements of the representation are organized in a table of four houses, according to the frequency of the terms evoked and the mean evocation order (MEO) graphically demonstrating the

words belonging to the central core and peripheral system of social representations.

Thus, the analysis of free evocations began with the standardization of words or expressions evoked by the subjects to constitute a corpus. This was done with orthographic correction, substitution of prepositions and spaces by hyphen, standardization of terms in plural or singular form and by gender. Subsequently, the researchers sought to homogenize the evocations to reduce the dispersion of their contents, classifying under the same designation elements with common meaning. The analysis of the structural relationship between social representations about living with HIV/aids for homeless people was based on the visual presentation of the four-house chart for each social object.

The crossing allowed the identification of the relevance of the elements that are associated with the inducting term. To organize the results, the four-house quadrant was used, which has two axes, the vertical, which corresponds to the frequency of the evocation of the word, and the horizontal, which represents the order of the evocations[8].

In the division of each quadrant, the first includes the evocations that were first brought and that have the highest frequency, when compared to the others. These first evocations that have the highest frequency are part of the central core of the representations[8]. The second and third quadrants are related to evocations that have less frequency and were evoked later, considered less relevant in the structure of representation, but are considered important for the organization. In the fourth quadrant, the elements that were less frequently addressed are expressed, presenting the elements that are more related to a restricted number of subjects, being more individual evocations[8].

The research was approved by the Research Ethics Committee of the *Hospital São José de Doenças Infecciosas* (HSJ), under Opinion n. 3,484,083, respecting the recommendations of Resolution n. 466/12 of the National Health Council. All study participants signed the Informed Consent Form (ICF).

Results

The sample was composed predominantly of males with 70.8% (n=46) of the 65 participants. The age group of the population living with HIV/aids in street situation ranged from 28 to 52 years, with an average of 39.47±6.3 years. According to racial self-declaration, 43% (n=28) of the interviewees self-declared brown and 41.5% (n=27), black. Regarding schooling, 50.76% (n=33) of these subjects had incomplete elementary school. In addition, 75.4% (n=49) live in the city of Fortaleza (CE); of these, 40% (n=26) have been living on the street for more than 5 years (Table 1).

The clinical profile of the participants showed that 20% (n=13) have been diagnosed with HIV infection for less than 1 year, 58.5% (n=38) from 1 to 5 years and 21.5% (n=14) for more than 5 years. Regarding drug and alcohol use, 90.8% (n=59) reported alcohol use and 72.3% (n=47) illicit drug use. Regarding the regular use of antiretroviral therapy (ARTT) and diagnosis of aids, 61.5% (n=40) were not in regular use of antiretroviral drugs (ARTD) and 81.5% (n=53) had a positive diagnosis for aids (Table 1).

Table 1 – Distribution of socioeconomic and clinical characteristics of homeless people living with HIV/aids. Fortaleza, Ceará, Brazil – 2021. (N=65)

(continued)

Characteristics	n	%
Sex		
Male	46	70.8
Female	19	29.2
Race/Color		
Brown	28	43
Black	27	41.5

Table 1 – Distribution of socioeconomic and clinical characteristics of homeless people living with HIV/aids. Fortaleza, Ceará, Brazil – 2021. (N=65) (conclusion)

Characteristics	n	%
White	10	15.5
Marital Status		
Single	52	80.0
Married	2	3.0
Stable Union	11	17.0
Schooling		
No Schooling	13	20.0
Incomplete Elementary School	33	50.8
Complete Elementary School	14	21.5
High School	3	4.7
Incomplete College	1	1.5
Complete College	1	1.5
Religion/Belief		
Evangelical	25	38.5
Catholic	16	24.6
None	24	36.9
Alcohol Use		
Yes	59	90.8
No	6	9.2
Drug Use		
Yes	47	72.3
No	18	27.7
Years as homeless		
< 1 year	7	10.7
1 - 5 years	32	49.3
5 - 10 years	18	27.7
> 10 years	8	12.3
Years of HIV Diagnosis		
< 1 year	13	20.0
1 - 5 years	38	58.5
5 - 10 years	9	13.8
> 10 years	5	7.7
Regular use of antiretroviral therapy		
Yes	17	26.2
No	40	61.5
Never done	8	12.3
Aids diagnosis		
Yes	53	81.5
No	12	18.5
Total	65	100.0

Source: created by the authors.

Regarding the social representation of living with HIV/aids for homeless people, 260 expressions were reproduced, being 15 different. The mean evocation order, that is, the mean rang calculated, was 2.7 and the mean frequency, 8. Together, these two factors allowed the distribution of the elements by the quadrants corresponding to the structure of the representation (Chart 1).

Chart 1 – Structure of social representation about living with HIV/aids for homeless people. Fortaleza, Ceará, Brazil – 2021

1st Quadrant			2nd Quadrant		
Freq. ≥8		Rang <2.7	Freq. ≥8		Rang ≥2.7
++			+-		
12.69%	Fear	1.73	15.77%	Drugs	3.20
8.46%	Sick	2.55	10.77%	Loneliness	2.71
8.08%	Prejudice	2.33			
4th Quadrant			**3rd Quadrant**		
Freq. <8		Rang <2.7	Freq. <8		Rang ≥2.7
-+			--		
6.54%	Friendship	2.24	6.54%	Sadness	3.12
6.15%	Death	2.56	5.38%	Violence	3.00
5.77%	Abandonment	1.40	3.46%	Longing	2.78
4.23%	Hurt	2.36	2.31%	Prostitution	3.00
3.46%	Pain	1.78			
0.38%	Danger	1.00			

Source: created by the authors.

Thus, in the upper left quadrant, corresponding to the central core, the terms "fear", "sick", "prejudice" were identified. The most important word of the central core was "fear", being possible to understand that this element represents some feelings reported by this population, such as the fear of "death", the fear of "abandonment", the fear of "pain" and the fear of "danger". The second word of the central core was "sick", because when they find out they are living with HIV/aids, they already have other HIV-related infections. Finally, the central core also revealed the word "prejudice", which, in this case, is duplicated, because living with HIV/aids is associated with living in the street situation, which extrapolates all pre-judgments that are related to these social and clinical conditions.

In the first periphery of social representations, "drugs" and "loneliness" are evoked. This shows that people who use the streets as a form of housing are more exposed to drug use, and loneliness is something that accompanies their entire experience on the street, since, in many cases, family contact is broken; drug use is a form of refuge from the reality in which these people are inserted.

In the second periphery, there are the evocations "sadness", "violence", "longing" and "prostitution". The elements of this quadrant reveal that the street is an environment in which violence and prostitution are found and experienced. Sadness is present, and longing for something, or someone, are feelings configured as negative and that permeate the lives of these people.

Finally, in the lower left quadrant, which corresponds to the contrast zone, the evocations "friendship", "death", "abandonment", "hurt", "pain" and "danger" emerged. This zone shows opposition to the central core, especially the most important word, "fear". This quadrant highlights the main fears of homeless people with HIV/aids. Those involved in the enunciations of the elements show that these subjects are afraid of friendships, death, abandonment, hurt, pain and danger, which is what life on the streets provides them.

Discussion

The social representations of living with HIV/aids for homeless people are revealed by coping with their social and health context, as a person living with a chronic infectious disease and homeless. Visualizing this problem under the structural approach of social representations involves recognizing the diversity of factors that

influence living with HIV/aids for homeless people, given the importance that the subjects involved attribute to these factors.

Life on the streets is a situation in which discrimination and violence, being strongly related to each other, increase vulnerability to HIV infection and aids. The trajectories of homeless people, stigmatized by prejudice and discrimination, associated with dissident sexual orientation and gender identities, are predisposing elements for the street situation experienced and its representations[9].

When talking about dimension related to information, such as "fear" and "prejudice", this dimension portrays the social representations that are formed by previous knowledge acquired over time on a certain subject, because this knowledge is understood as something socially elaborated, shared and that helps in the construction of a reality common to these subjects[10].

Social representations are understood as variations of social thought, which is also mediated by an "affective" dimension. Thus, affections are not elements restricted to subjective private life, because the emotions experienced during collective interaction also influence the construction of representations. This can be exemplified by the fact that the central term "disease", even being guided by the knowledge acquired by the individual about the disease, is strongly connected with elements anchored in affective dimensions[11].

Living in a street situation with HIV/aids is to have continuously diverse feelings running through the mind, generating emotions that end up causing different contradictions of feelings and desires not only when living in street situation, and of several representations related to HIV/aids[11]. In this perspective, a significant part of people living with HIV/aids also used the terms "sadness" and "loneliness", which, associated with social conditions found on the street, negatively interfere with health care and make them vulnerable to the health-disease process[12].

Feelings of "fear" and "hurt" can be linked to the guilt of the subject for having been "prostituted" and contaminated by a disease that, in some cases, is characterized by being avoidable and that is interconnected to a sexual behavior. "Prostitution" and "drug use" contribute to the permanence of these subjects in the streets, because, in this space, they acquire addictions and, in this place, they find the necessary inputs for survival[13]. Living or discovering living with HIV/aids in this context can bring innumerable representations that evoke suffering, hurt and sadness for these subjects, because the intertwining of feelings end up generating guilt for being in such a situation.

Corroborating the above, a study conducted in Canada with homeless people shows that all participants expressed fear of violence and that, because of this, they rate the streets as dangerous and stressful, considering that many exchange the day for the night to protect themselves. These claim that shelters and social housing are also hazardous environments. In addition, they share feelings of loneliness due to social exclusion. This is alarming, considering that, in addition to the concern with physical health, the homeless population lives in constant concern with the fear of violence, perpetuating the feeling of loneliness and invisibility[14].

In the streets, sexual practice occurs, in addition to pleasure, in exchange for money, drugs or alcohol, shelter, food, clothing and transportation. Of these, money and drugs are the most frequent[15-16]. The use (or abuse) of psychoactive substances often precedes living on the streets. However, in this context, it is emphasized as a way to minimize difficulties and to be able to endure the suffering of the difficult conditions of life in the streets[17].

Moreover, the condition of living on the street is related to various health, social and legal vulnerabilities, which increase social marginalization. Regarding access to health, a study conducted in India with injecting drug users and homeless people shows participants' statements related to feelings of rejection by health professionals from centers providing antiretroviral therapy, fear of being identified by other people and by the police and reports of physical aggression by health service guards[18].

Violence is perceived as one of the main symptoms of social vulnerability, representing one of the major concerns for this population, submitted at all times to the fury of other individuals, especially in the night, due to decreased movement of people on the street. Especially when prevention and social support services and actions are not offered, making users more susceptible to sexual abuse[9].

Thus, the fear of suffering attacks causes protective strategies, such as sleeping in groups at night or sleeping during the day to stay awake at night and avoid aggression. Due to such strategies, bonds of friendship arise between subjects in the same situation[19].

In addition, even with the hurt they carry because of abandonment and distrust, various stimuli make people continue in street situation. This living can be a source of strength and perseverance, such as the freedom to live without the interference of their families, to conduct life as one wants and the friendships they have won[20].

The literature points out that the search for freedom, family mismatches, dependence on alcohol and illicit drugs, the presence of mental illness, migration, unemployment, extreme poverty and love disappointment are some of the reasons reported in the literature that allow people to seek the street as a place of residence[21-22]. However, the complexity of this phenomenon is emphasized and other factors can lead to such a situation.

Understanding the narratives and experiences of this population is a challenge, because while some individuals report the suffering of living on the street, the desire to transform reality and the return to domestic life, others demonstrate that they have become accustomed to the daily life on the street, relationships and wish to continue in this situation[12]. Living with HIV/aids on the street is influenced by structural and biographical elements. Thus, understanding and even facing such a reality implies the recognition of the living conditions of these subjects and the availability of social services in each city[23-24].

The limitations of this study concern the fact that it is a descriptive study, conducted in a single hospital in the state of Ceará, which hinders the generalization of the findings to the population. However, the data constructed in this investigation reveal the representation for a marginalized population group, giving voice to such people. Thus, this research contributes to support other studies involving this population, as well as deeper investigations on the different representations of living with HIV/aids for homeless people.

Conclusion

The accomplishment of this study allowed the apprehension of the contents and their disposition in the structure of the social representation related to living with HIV/aids for the homeless population. These representations have a probable core in the word “fear”. Among the elements of the periphery, the words “drugs” and “loneliness” stand out. “Friendship”, “death”, “abandonment”, “hurt”, “pain” and “danger” represent the elements of contrast.

The findings of the study refer, therefore, to the necessary work of health professionals, especially nursing professionals, in understanding the elements that permeate the lives of these subjects in relation to what it means to live with HIV/aids, considering all social and cultural aspects involved so that the necessary care and quality of life of these subjects can be offered.

It is also necessary to promote group and individual dialogical approaches to contribute to the deconstruction of negative representational facets related to living with HIV/aids, in view of the representations that guide them. Finally, the TSR is a fundamental means to understand the vision of groups about their reality and their world, focusing on the homeless population living with HIV/aids.

Collaborations:

1 – conception and planning of the project: Monalisa Rodrigues da Cruz, Paulo Victor

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2 – analysis and interpretation of data: Monalisa Rodrigues da Cruz, Beatriz Braga Leite Barbosa, Isabella Martins Camelo, Paulo Victor Avelino Monteiro, Rodrigo Everton da Silva Lopes, George Jó Bezerra Sousa and Maria Lúcia Duarte Pereira;

3 – writing and/or critical review: Monalisa Rodrigues da Cruz, Beatriz Braga Leite Barbosa, Isabella Martins Camelo, Paulo Victor Avelino Monteiro, Rodrigo Everton da Silva Lopes, George Jó Bezerra Sousa and Maria Lúcia Duarte Pereira;

4 – approval of the final version: Monalisa Rodrigues da Cruz, Beatriz Braga Leite Barbosa, Isabella Martins Camelo, Paulo Victor Avelino Monteiro, Rodrigo Everton da Silva Lopes, George Jó Bezerra Sousa and Maria Lúcia Duarte Pereira.

Competing interests

There are no competing interests.

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