

From the stigmatizing disease to resignification of living on the streets

Clara Maria Conde Antunes¹, Anderson Silva Rosa², Ana Cristina Passarella Brêtas³

ABSTRACT

This qualitative study used the method of oral history – thematic modality – aimed to comprehend existing relationships in the process of resignification of life on the street from the diagnosis of a socially stigmatizing disease. It was developed in a Shelter Center, with five homeless people, who have a socially stigmatizing disease. From the analysis, two categories emerged: The stigmatizing disease; Resignifying life. We inferred that to have a stigmatizing disease, prejudice and fear contributes with the frailty of social bonds, it broadens personal vulnerabilities and chances to start and/or perpetuate life on the street. The self-knowledge about the disease and the reflection about one's own finitude contribute with resignification of life. The symbolisms involved in each of the discussed diseases are little sensitive to public polices interventions for this matter.

Descriptors: Social Stigma; Social Determinants of Health; Prejudice; Homeless Persons.

¹ Nurse. Master in Nursing. Nurse at the Hospital São Camilo Santana. São Paulo, SP, Brazil. E-mail: claracp@yahoo.com.br.

² Nurse, Ph.D in Nursing. Adjunct Professor at São Paulo Nursing School (EPE) from the Universidade Federal de São Paulo (UNIFESP). São Paulo, SP, Brazil. E-mail: anderson.rosa@unifesp.br.

³ Nurse and Sociologist, Ph.D in Nursing. Associate Professor at EPE/UNIFESP. São Paulo, SP, Brazil. E-mail: acpbretas@ymail.com.

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INTRODUCTION

For years, homeless people were invisible for public health policies, but through the mobilization of organized social movements, defense for health rights for this population has becoming stronger⁽¹⁾. From 2004, the city of São Paulo started to count with teams from the Special Family Health Strategy to collaborate with the homeless population, that were gradually amplified⁽²⁾. They were all incorporated to the Street Clinic – a strategy created in 2011 to care for this population – in consonance with the Primary Care National Policy⁽³⁾.

The Street Clinic foresees mobility of professionals and its assistance network outside of the comfort

zone of homecare strategies, causing strangeness from observed and felt situations to which the teams not always have answers. It has propitiated new configurations of these assistencial networks, replacing challenges to the effectiveness of the Unified Healthcare System⁽⁴⁾.

However, while these assistance strategies are constituted, homeless people still suffer with prejudice and lack of prepare from some services and professionals, resulting in no assistance to their demands, or still, they are victims of hygiene actions focused on social separation, not considering life dignity and human rights. To advertise knowledge in this area denounces an unjust reality, at the same time that it contributes with professional training for an assistance compromised with peculiarities of the ways of life and needs from this people.

A homeless situation is not disconnected from social living at the urban space. It is in this context of conflicts and social contradictions that stigmas and prejudice linked to those living on the streets are enhanced. Judgements come from a simplistic view about the complexity of social relations established on the street, many times anchored to the aesthetic and physical appearance strangeness from a parcel of the population who cannot or does not want self-care, and the association of this life condition to urban violence.

There are two types of stigma holders: the individual that has an invisible stigma and who has the possibility to manipulate or not the information about it; and the one visually stigmatized, vulnerable to the tension generated in social living that creates discomfort and awkwardness in the interaction⁽⁵⁾. The stigmatized person as well as the person stigmatizing tend to develop protective mechanisms manifested as withdraw conducts⁽⁵⁾. The homeless person is subject to stigma in their social condition and ways of life, as well as the stigma of diseases that they can develop. "Individuals who experience situations of discrimination are more vulnerable because, with higher probability, they cannot count on a social, emotional, affective, and practical social support network, they do not trust in institutions or people with whom they interact with"⁽⁶⁾.

A study in a health service for people living on the street in Boston⁽⁷⁾ to identify the main causes of death, identified 1,302 deaths in a period of 15 years caused by: drug overdose (219), cancer (206) and heart diseases (203). The last two causes are predominant among people of 45-64 years, representing 16% each from a total of death studied, showing an average two or three times higher than in the general population.⁽⁷⁾

In Brazil, most homeless people have health problems: hypertension, HIV/AIDS, psychiatric disorders, vision disorders - blindness⁽⁸⁾. When ill, most patients search for an emergency room at first, after, a primary care unit⁽⁸⁾. A study conducted in São Paulo⁽⁹⁾, identified a disproportional prevalence of HIV in the homeless population (4.9%) when compared to the general population (0.6%). In proportion, the levels of infection can oscillate between three to more than 20 times higher than the general population. Younger people, people with homosexual practices living on the streets and women are more vulnerable⁽⁹⁾.

The conduction of health policies for this population has given relevance to most prevalent issues, showing difficulties in relationships between the disease process, care, and ways of life on and from the streets, requiring technical competence and sensitivity of professionals who act in this segment.

We understand the disease also as a social construction. Is it unequally distributed among individuals, classes and populations, overall through the difference in access to attention, and the prejudice from those considered harmful to all others⁽¹⁰⁾.

In this scenario, this study aimed to comprehend existing relationships in the process of resignification of life on the streets from a socially stigmatizing diagnosis.

METHODS

This qualitative study is originated from a master's dissertation⁽¹¹⁾ that used oral history method in the thematic modality.

The oral history is built around people, about memories of facts and values interesting to the study, how they are experienced and remembered in the imagination⁽¹²⁾. Its thematic modality propitiates a more restrictive narrative of the deponent, directed to a theme⁽¹³⁾, in this case, the resignification process of life on the street and, from the diagnostic of a socially stigmatizing disease.

The study was conducted in a Shelter Center that shelters homeless people in São Paulo. Four Adults were heard and one elderly woman with socially stigmatizing diseases: HIV/AIDS, hanseniasis, and cancer. The narrators, three women and two men, identified in the text by the codes E-1, E-2, E-3, E-4, E-5, guaranteeing anonymity. The inclusion criteria were: to have a stigmatizing disease, to be 18 years or older, to be living on the street, to be able to keep a dialogue.

The data were collected in 2012, through interview technique with a semi-structured guide with the questions: Did something change in your life after the diagnosis of this disease? How do you deal with this disease while being on the streets? Does someone take care of you? What is death to you? What are your feelings about being on the street and about your disease?

The interviews were recorded and transcribed. We followed these steps for analysis:

- (1) sorting the data obtained from the interviews;
- (2) classifying the data obtained from the texts (empirical and theoretical), related to analytical categories (theoretical) and empirical;
- (3) re-sorting the interviews, adopting the resource used in the relational analysis;
- (4) conducting the relational critical analysis between the empirical data obtained from interviews and the selected analytical categories⁽¹⁴⁾.

In this study we worked with two categories: The stigmatizing disease; Resignifying life.

The research project was approved by the Ethics in Research Committee, process 0377/11, from the Universidade Federal de São Paulo. Participants were informed about the study objectives, methodology, and ways of advertisement; if they agreed to participate, they signed the Free and Informed Consent Term.

RESULTS AND DISCUSSION

We present here some of the characteristics from those people participating in the study.

- E-1, 60 years old, from Bahia state, came to São Paulo when 13 years old, catholic, homeless for eight years. In 2002 she was diagnosed with hanseniasis. She lost her fingers. She could not walk anymore. She has 11 siblings, never got married. She does not have contact with any family member, and does not wish to have.
- E-2, 36 years old, from Bahia state. Diagnosed with HIV/AIDS six years ago during prenatal. She stayed one year and four months hospitalized in Campos do Jordão to treat tuberculosis. She is widowed, has five children, two grandchildren and five siblings. She keeps contact with her family once a month.
- E-3, 46 years old, from São Paulo city, evangelical. She is at the shelter for two years. She was diagnosed with leukemia in 1999. She is widowed, has six children who knows she is homeless. They offered help, but she does not want to see them.
- E-4, 40 years old, from São Paulo city, catholic. He is homeless for five years. He is addicted to alcohol since 11 years old. He used weed for 29 years, and crack for one year. He is a smoker. He was arrested for three years. He was diagnosed with HIV/AIDS in 1999, while he was treating tuberculosis.
- E-5, 45 years old, catholic. He is homeless for two years. He used drugs since 15 years old, and withdrew it after a HIV/AIDS diagnosis 20 years ago. He is treating tuberculosis for the sixth time. He is widowed, has two children. He has two sisters. Little family contact.

The stigmatizing disease

Nothing is more punitive than to attribute moralist significance to a disease, especially those with an obscure cause, of an ineffective treatment, overloaded with symbolic signification. The most profound objects of fear, as corruption, decadence, pollution, anomy, weakness, are identified with the disease. The disease becomes a metaphor. It starts to give adjectives. It is said that this or that looks like the disease, with a meaning that it is disgusting or ugly⁽¹⁵⁾.

The stigma can be recognized as a marker of individual differences and social groups, but it is not a fixed attribute, but one of social and cultural construction, historical and variant, and it establishes relationships of devaluation of the other. Thus, it is inserted in contexts and socially built processes⁽¹⁶⁾.

In this study, we found diseases socially carried with stigma, prejudice, and fear of contamination that weakened family bonds, and, when associated with difficulties to keep a job, income incapacity and/or drug addiction, it increases the chances to live on the streets. The absence of social references to serve as support can lead to a social death process before the physical death⁽¹⁷⁾.

It was painful to go back to the street with HIV because I had this sister of mine as a mother. I wanted to stay close to her, but I saw that she did not accepted it. It was like five minutes of conversation and nothing more, I started to withdraw from her to don't suffer and to don't argue with her. I used to call her prejudiced, we used to argued, I preferred to get away from her. (E-2)

A complex social representation of HIV and AIDS influence in everyday lives of those affected, in a

process of group insertion, of social integration, of stigmatization, of adherence to therapy and to the condition of living with the virus and/or the syndrome. This representation, far away from being only an imaginary reconstruction about the object, presents itself as a modulator of the experienced reality and an operator of faced situations⁽¹⁸⁾.

Before knowing about this disease I was already on the streets. I said: all right, my family is not united, I'll build one for me. I'm a man to find a companion and to have children and to build a family with. So then when I found out about this AIDS problem, my life fell apart. The last hope I had, died.(E-4)

Many times, due to moral and reproving judgment expressed by society and family members, people with HIV/AIDS opt to hide the serology. It can reveal an obscure, illicit side that exposes pleasures of the body, that exceeded the social control⁽¹⁷⁾. The metaphors used to talk about HIV/AIDS are associated to proximity to death, physical suffering, fear, invalidity, social isolation, guilt, and prejudice. These symbolisms are responsible for: psychic suffering, decrease of self-esteem, loss of sense in life and, consequently, absence of stimulus for treatment.

The participants pointed prejudice and discrimination due to the disease as being superior to the fact that they are homeless. The interviewed 1 reports about the perception and reaction that people had about hanseniasis and the consequences left by the disease.

I used to notice many things, people talked, but never said on my face, they said on my back. I was with my antenna on. The ones who stayed close to me, no. It was others that used to come and say: ah let not touch close to her because her fingers are falling. (E-1)

The fear inspired by hanseniasis is not based on the speed of contamination, once the disease never had epidemic characteristics. The carrier survives long time after being infected. In this case, the fear would be related not to proximity or possibility of death, but to the type of life that it was imposed to its carrier. The stigma that permeates, accompanies the disease since leprosy times when people were retained from social living. Nowadays, although the advances in the therapeutic approach, possibility of cure and even change in taxonomy that classifies the disease, the lack of information perpetuates its stigmatizing character⁽¹⁹⁾.

I found out that I had hanseniasis in 2002, by the doctor of the basic health unit. It was really painful to me to stay without fingers. Now I'm used to it, I'm alleviated with it. Thanks to God I treated, I'm fine, only sequels stayed. (E-1)

In a paradox way, the stigma of the visible disease as the hanseniasis case, was pointed as a facilitator of practices of mendicancy on the streets. Although it creates repulse, disgust, and fear for some people, in others, it creates compassion and solidarity.

In the street cars passed, gave food, left something, covers, clothes for us, I never had difficulties on the street. I used to gain money until saying enough. I used to make a lot of money on the street. (E-1)

The metaphors permeating certain diseases increased the suffering of the carrier and from their family members and conviviality people. Those carriers anticipate that they will suffer by prejudice and stigmatizing

and, as a protection way, they opt for secrecy to impede them to trust in someone or to look for adequate healthcare, increasing their personal suffering and vulnerability to get sick⁽²⁰⁾.

We found in the narratives, moments of psychic suffering caused by the disease progress, ending in absence of meaning in life and intention to commit suicide. The suffering reported has more to do with metaphors and stigmas related to the disease than with the specific biological suffering of each disease.

When I committed suicide, at the time it was a solution for me. I didn't think like now. I had no experience, I didn't know how HIV was, I didn't know how to react to my body. For me, I was going to have a lot of holes, lot of bruises. I thought it was going to affect my breathing, my heart, that I was going to have many things in the body. For me, I was going to be deformed. So the solution was death. (E-2)

I tried to kill myself twice, after the AIDS diagnosis. See, my face was broken here. I threw myself in front of a truck; I stayed with a broken face. I was so revolted. They (doctors) wanted to operate, to put a plaque, platinum, that thing. I didn't want to. (E-4)

Such moments of lack of hope need to be identified and supported by professionals or conviviality people. The data from this study reinforce the importance to care for people in a multidimensional way, that is, in the physical dimension (control of symptoms, maintenance of functionalities), psychic (fears, guilt, anticipated mourning, anxiety, denial), social and familiar (support, financial matters, life in the street, conflicts), spiritual (relationship with God, search for meanings, rites, religious conflicts)⁽²¹⁾. For that, specific demands of care from each disease are indispensable and, to respect the peculiarities of ways of life on the street while this is the only option of life for some people.

Resignifying life

The lack of knowledge regarding the disease and to know how your body would react, the lack of people to welcome and care, and the prejudice of those around them caused them to feel lost at the time of diagnose; believing that death was close and they could harm people around them. From the diagnostic shock and reflections about their own death, the narrators started to rethink life.

Now I already understand what is HIV, before I didn't. To me, it was the worst thing in the world, now there is medication, we can live for a long time.(E-2)

To find out the HIV/AIDS diagnosis resulted in a diversity of feelings and it is common, although they are physically well, they think that contamination is synonym of death. They can experience a denial process about the disease and its severity, not searching for treatment or not adhering to it when in a follow-up⁽²²⁾. When they felt empowered about the knowledge regarding the disease, they had a new sight to the experienced reality; they perceived that although the disease, they were alive and could live with quality.

The HIV is not my death, it is a life lesson that I'm learning from my mistakes. Now I'm learning to live, because before I didn't live. I learned. To me, life was anyhow, not now: I give more value to it. (E-2)

The abuse of licit or illicit drugs of high prevalence among homeless people, makes the adherence to treatment of diseases difficult, and in HIV/AIDS cases, it is related to an increase in mortality⁽²³⁾. The

interviewed 5 had the HIV/AIDS diagnosis for more than 20 years and, even when saying that finding out about the disease did not change anything in his life, he noticed that if he kept his lifestyle he could compromise his health condition.

Since my fifteen years, I used drug. I don't want to know today. What motivated me to stop was the disease. Because if I let myself down with this drug thing, the disease accumulates even more, it let me fall and the drug is one foot to let you down there. (E-5)

This makes us think that the discovery of a socially stigmatized disease can influence the life of a person. The disease made these interviewed to remember they are finite, and death is part of life. Although experiencing situations of extreme vulnerability as the use and addiction of drugs and alcohol, violence, crime and drug dealing, it was from the knowledge of a disease full of stigma that they started to think about their lifestyle, as well as their death processes.

The interviewed 4 saw the disease as cure for a lifestyle considered threatening. He highlights that if he had not caught HIV/AIDS and tuberculosis, he would had died in consequence of other things.

AIDS came to cure me. It's the key to everything. If I haven't found it, if I hadn't gotten it, maybe I was dead already. Of drinks, of alcohol, of drug, I would have died, I put my feet on the break. One year using crack. I lost a lot, I've even saw death in front of me, all because of this. With this disease I've stopped practically with everything, I just didn't stop with the cigarette. (E-4)

The quality of the information is fundamental to minimize the stigmatizing effects and to incentivize change of mentalities and attitudes. Public policies of national coverage can serve as an important combat tool for the stigma social process and discrimination in affected populations, besides promoting prevention and assistance to sexually transmissible diseases⁽²⁴⁾. We defend such assertive to be expanded to other diseases. While there is stigma, inter-sectorial interventions are needed, that thinks about the stigmatizing process and the vulnerability of resulting diseases. This comprehension includes to not allow interferences of prejudices that label people as homeless, sick, addicted, thief, aggressive or dangerous to impede professionals to see the person, to discover what the person knows, desires, what brings one's essence⁽²⁵⁾.

The narratives bring us to the concept of resilience, because although experiencing stress and adversity situations, the interviewed were able to surpass them. Thus, stronger, they found a positive adaptation before the experienced reality, resignified their lives and discovered ways to deal with a new context according to their possibilities.

FINAL CONSIDERATIONS

The discussion of socially stigmatized diseases for homeless population should be permeated by social life contexts of these people. Many times, before thinking about their biological death, they experienced the social death first through a lost job, cut of family and, affective bonds, of not recognizing their human condition. To think death on the streets is to think many deaths – symbolic or not – that happens in a concomitant way that can be more meaningful than at the end of life. The way they experienced obstacles

throughout life brings to how they see their finitude and, when thinking the biological death, they can see how they live.

To have diseases full of stigma, prejudice and fear contributes to fragility of social bonds, it amplifies individual vulnerabilities and the chances to ingress and/or perpetuate in life on the streets. However, when empowered of knowledge regarding the disease and when reflecting about their own finitude, they could resignify life and to abandon habits evaluated as harmful to health. The proximity of death propitiates the encounter of new ways of living. The symbolism involving each one of the discussed diseases in this study are little sensible to public policies interventions for this matter, perhaps they need more time to interfere in prevalent mentalities and stigmas.

As health professionals, we should actively act in the education process, not only in the sense of disease prevention and health promotion, but, specially, in the conceptions involving disease processes and its consequences in different social contexts. Our senses need to be receptive to capture expressions of fear, anguish, and suffering emitted by people we care. We should work as supporter of the life resignification process, disease process, and death, contributing with the surpassing of prejudice and stigmas. People with fragile support networks, or even inexistent end up searching for welcoming in health professionals not only for physical matters, but also social and emotional.

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