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Factors related to the perceived stigmatization of people living with HIV

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Fatores relacionados com a estigmatização percebida de pessoas vivendo com HIV

Factores relacionados con la estigmatización percibida de personas viviendo con VIH

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ABSTRACT

Objective: Analyzing the factors related to perceived stigmatization of people living with HIV. **Method:** A cross-sectional study conducted from September of 2014 to December 2015 with users from a specialized service in Minas Gerais. Data were collected through individual instrument application, organized in Microsoft Office Excel® 2010 spreadsheets and processed on IBM® SPSS 23.0. Descriptive statistics and multiple linear regression method were used for data analysis, adopting statistical significance set at 5.0% (p≤0.05). The study development met research ethics standards. **Results:** 258 users participated in the study. Most were males between 40 and 49 years of age, single, with low educational level and income. Being between 40 and 49 years of age and having been hospitalized for complications related to HIV were positively associated predictors to increased stigmatization; while not having comorbidities and not being aware of exposure to HIV were predictors associated to reduced stigmatization. **Conclusion:** Given these results, we highlight that stigmatization can have an impact on the lives of people living with HIV, strengthening their feelings of guilt and shame, which can lead to depression, social isolation and abandoning treatment and clinical follow-up.

DESCRIPTORS

Acquired Immunodeficiency Syndrome; HIV; Social Stigma; Depression; Public Health Nursing.

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INTRODUCTION

With the appearance of AIDS in the 1980s as an epidemic apparently restricted to homosexuals, drug users and sex workers, a stigma against people living with human immunodeficiency virus (HIV) also emerged[1-3].

A stigma is considered a defect or a label that defines others, diminishing them through negative stereotypes, discriminatory and prejudiced labels[1,3-4]. Thus, in addition to the clinical changes that HIV can bring to people's lives, the stigma can also cause serious social and psychological damage due to feelings of inferiority[1,4-5], which significantly increase anxiety, loneliness, depression and the desire to die, reducing self-esteem and self-confidence, which lead to social and sexual isolation of people living with HIV[4,6].

It is estimated that 36.9 million people live with HIV worldwide[2]. Brazil is among 30 countries that comprise 89% of HIV world registries[7] with 798,366 cases[7]. Despite this significant number, a decrease in social impacts of HIV have been observed in many regions of the world[8] since 2004, including in Brazil, with a 42% decrease in AIDS-related deaths[2].

Despite epidemiological indicators pointing to a reduction in the number of cases of the disease in the country and in other regions, its stigma is still seen as a major barrier for infection control[6]. In fact, in addition to causing financial deficits due to the risk of employees being fired[4-5], the disease can also interfere with affective and social relationships due to feelings of guilt and shame which leads to the isolation of these individuals[1,4-5,9], affecting adherence to clinical and antiretroviral follow-up by many HIV positive persons[1]. In view of the above and the need for understanding aspects related to stigmatization, the objective of this study was to analyze factors related to the perceived stigmatization of people living with HIV.

METHOD

This is a cross-sectional and analytical study carried out in an outpatient clinic for people living with HIV from the State health network, a reference to 24 municipalities in the southwestern region of Minas Gerais. Since its creation in 1992 until September 2014, 758 cases of HIV positive people had already been registered in the region.

Study participants were service users who met the inclusion criteria: being aged 18 or older; being on antiretroviral therapy (ART) for at least 6 months; and being under regular outpatient clinical follow-up. Thus, Pharmacy Service records, monthly withdrawal of antiretrovirals, as well as the data in the attendance records at the medical appointments every 3 months in the unit were considered. Exclusion criteria were: individuals in situations of confinement such as inmates, those institutionalized or residents of support homes enrolled in the service, since they do not attend the outpatient clinic.

Of the total of 338 registered users in the service from September 2014 to December 2015, 278 were eligible and agreed to participate in the study. Of these, 20 were part of the pilot study and 258 (76.3%) were study participants.

All participants were interviewed in a private room at the outpatient clinic using a semi-structured questionnaire prepared after a literature review, consisting of the variables associated with HIV stigmatization: sociodemographic variables (gender, age, education level, income, work situation, religion and relationship with family members with HIV), affective-sexual life (sexual orientation and sexual partnership), drug use, epidemiological variables (diagnosis time, who knows about the diagnosis and exposure to HIV), treatment discontinuation and clinical variables (hospitalization and comorbidities). We chose to analyze the presence of sexual partnerships and drug use in the last 12 months in order to avoid participants' memory bias. Next, the HIV Stigma Scale[10] was applied, which is composed of 40 items distributed into the following domains: Personalized Stigma, Disclosure, Negative self-image and Public Attitudes. It is a four-point Likert scale of: I totally disagree (1), I disagree (2), I agree (3) and I totally agree (4); so that Stigma Scale dimensions are measured in scores ranging from one (lesser experienced stigma) to four (the most experienced stigma).

Data were analyzed using the IBM® SPSS program version 23.0. Population variables were presented as frequency distributions. The reliability analysis of the Stigma Scale was performed using the Cronbach alpha coefficient and the scores were calculated following the mean of the scale domain items.

The multiple linear regression method with two adjustments was applied for the combined influence of population variables on the Stigma Scale using only the significant variables in both. The linear regression assumptions were met and a statistical significance of 5.0% was adopted ($p<0.05$).

The project was approved by the Research Ethics Committee (CAAE 31107614.2.0000.5112) in compliance with the ethical requirements established by resolution 466/12 of the National Health Council.

RESULTS

Of the 258 participants, 145 (56.2%) were males, 93 (36.0%) were between 40 and 49 years old, 126 (48.9%) reported having 0 to 5 full years of education, 163 (63.2%) received up to one minimum wage per month, 73 (28.3%) reported being unemployed or taking time off work, 195 (75.6%) mentioned having a religion, and 72 (27.9%) lived with relatives with HIV.

Regarding their affective-sexual life, 50 (19.4%) reported being homosexual or bisexual and 148 (57.4%) reported having sexual partners in the last 12 months. Of the total, 74 (28.7%) confirmed consumption of licit or illicit drugs in the last 12 months, and 202 (78.3%) believed that they were sexually infected. It was found that 198 (76.7%) participants disclosed the diagnosis of HIV infection only to their family, and 95 (36.8%) had lived with this diagnosis for over 10 years.

Regarding antiretroviral treatment, 180 (69.8%) reported never having stopped using ART. Comorbidities were reported by 45 (17.4%) participants and nearly one-third reported hospitalizations due to HIV/AIDS-related complications.

For Stigma Scale dimensions (Table 1), the domains that presented the lowest median and mean values were Personalized Stigma (Md=2.3, M=2.3) and Negative Self-image (Md=2.4; M=2.4), while the domain Disclosure had the highest median and mean values (Md=2.8, M=2.8).

Table 1 - Distribution of the Stigma Scale domain scores applied to people living with HIV from a specialized outpatient clinic - Passos, MG, Brazil, 2014-2015.

Score - Domains	*OI	*Md	*M	*SD	*Alpha
Personalized stigma	1.0 - 4.0	2.3	2.3	0.7	0.960
Disclosure	1.0 - 4.0	2.8	2.8	0.6	0.845
Negative self-image	1.2 - 4.0	2.4	2.4	0.6	0.837
Public attitudes	1.0 - 4.0	2.5	2.6	0.6	0.933
Overall scale	1.1 - 4.0	2.5	2.5	0.6	0.953

*OI=Obtained Interval (minimum – maximum); *Md=median; *M=mean; *SD= standard deviation; *Alpha= Cronbach's Alpha. Note: (n=258).

In the multivariate analysis (Table 2), the predictors that were positively associated with the mean increase in stigmatization were age between 40 and 49 years (β=0233; p=0.006) and the presence of hospitalizations due to HIV complications (β=0.156, p=0.042). The predictor that was negatively associated with stigmatization was the absence of comorbidities (β=-0.264, p=0.004).

The domain Personalized Stigma, which evaluated the experience of stigma through negative attitudes of other people towards themselves, showed that the predictors that contributed to the average increase of the personalized stigma score were age between 40 and 49 years (β=0.390, p=0.000) and hospitalization due to HIV complications (β=0.234, p=0.018). The predictor absence of comorbidities (β=-0.321; p=0.007) was negatively associated with stigmatization.

The regression model that used the disclosure domain as a dependent variable evaluated how the person copes and how they feel about the disclosure or the possibility of revealing their seropositivity, where not being aware about the form of HIV exposure (β=-0.367; p=0.034) was associated with a decrease in stigmatization.

As for the negative self-image domain evaluating feelings of self-devaluation and self-exclusion, the predictors associated with mean increase of stigmatization were age between 40 and 49 years (β=0.232; p=0.005) and previous hospitalization (β=0.152; p=0.042). On the other hand, absence of comorbidities (β=-0.310; p=0.001) was a predictor that was associated with a mean decrease in stigmatization.

In analyzing the predictors associated to the public attitudes domain which evaluated the respondent's perception of how people consider those who are HIV-positive, we found that being between 40 and 49 years of age (β=0.267, p=0.005) influenced the mean increase in stigmatization, and not presenting comorbidities (β=-0.292; p=0.004) decreased the mean of stigmatization by negatively influencing it.

Table 2 - Statistically significant variables with overall scores and domain scores of the Stigma Scale in multiple linear regression analysis - Passos, MG, Brazil, 2014-2015.

Stigma Scale	Variables	β*	95% CI**	p-value	R²***
Overall score					0,105
	Constant	2.574	2.296/2.852	0.000	
	Age (years)				
	20|–|29	0.135	-0.109/0.380	0.277	
	30|–|39	0.106	-0.083/0.395	0.269	
	40 |–|49	0.233	0.069/0.398	**0.006**	
	≥ 50		Reference		
	Hospitalization due to HIV/aids				
	No		Reference		
	Yes	0.156	0.048/0.373	**0.042**	
	Comorbidities				
	No	-0.264	-0.443/-0.085	**0.004**	
	Yes		Reference		
Personalized Stigma					0.101
	Constant	2.350	2.102/2.599	0.000	
	Age (years)				
	20|–|29	0.095	-0.221/0.412	0.554	
	30|–|39	0.093	-0.150/0.336	0.453	
	40 |–|49	0.390	0.178/0.603	**0.000**	
	≥ 50		Reference		
	Hospitalization due to HIV/aids				
	No		Reference		
	Yes	0.234	0.041/0.428	**0.018**	

…continuation

Stigma Scale	Variables	β*	95% CI**	p-value	R²***
	Comorbidities				
	No	-0.321	-0.553/-0.089	**0.007**	
	Yes		Reference		
Disclosure					0,027
	Constant	2.988	2.739/3.238	0.000	
	Exposure to HIV				
	Sexual	-0.102	-0.354/0.154	0.426	
	Non-sexual		Reference		
	Not sure	-0.367	-0.706/-0.029	**0.034**	
Negative Self-image					0.086
	Constant	2.498	2.310 — 2.686	0.000	
	Age (years)				
	20|–|29	0.131	-0.109/0.370	0.284	
	30|–|39	0.155	-0.029/0.339	0.098	
	40 |–|49	0.232	0.071/0.393	**0.005**	
	≥ 50		Reference		
	Hospitalization due to HIV/aids				
	No		Reference		
	Yes	0.152	0.006 — 0.299	**0.042**	
	Comorbidities				
	No	-0.310	-0.485 — -0.134	**0.001**	
	Yes		Reference		
Public attitudes					0.059
	Constant	2.675	2.474 — 2.876	0.000	
	Age (years)				
	20|–|29	0.062	-0.206 — 0.330	0.373	
	30|–|39	0.128	-0.082 — 0.337	0.130	
	40 |–|49	0.267	0.083 — 0.450	**0.005**	
	≥ 50		Reference		
	Comorbidities				
	No	-0.292	-0.491 — -0.093	**0.004**	
	Yes		Reference		

*Adjusted linear regression coefficient; **95%CI – 95% Confidence Interval; ***Coefficient of determination.

DISCUSSION

The characteristics found in this population were similar to those of other national and international studies with people living with HIV, being predominantly adult males with low education and income[9,11-12], heterosexual[2,7], with the presence of sexual partners[13], low drug use[13], with good adherence to ART[13-14] and low incidence of comorbidities[14], where the majority chose to disclose the diagnosis of HIV infection only to family members[4,14].

In relation to the Stigma Scale, the highest mean distribution values of means and medians in the disclosure domain were similar to those of another study with adults living with HIV[10], and one performed with young American adolescents and young adults recently diagnosed with HIV[15], showing that seropositivity disclosure is still an important difficulty experienced by HIV positive people[4,9]

marked by fear of non-acceptance, as well as feelings of guilt and shame[5,9].

In the analysis stratified by domain, we found that the age group between 40 and 49 years of age and previous hospitalization due to complications from HIV/AIDS contributed to stigmatization in the overall score, and for the "personalized stigma" and "negative self-image" domains. In the "public attitudes" domain, the age group 40-49 years was the only positive predictor. On the other hand, not presenting comorbidities contributed to a reduction of stigmatization in the overall score and in the "personalized stigma", "negative self-image" and "public attitudes" domains. Finally, not being aware of how they were infected also contributes to stigmatization reduction in the "disclosure" domains.

Regarding the increase in perceived stigmatization among people aged between 40 and 49 years, seeing as this

is an age group that involves adults at a productive age, it is expected that the increase in stigmatization is related to economic, affective and social factors, which are probably linked to increased feelings of devaluation, depression, and social isolation responsible for the high morbidity and mortality found in this age group[9,11].

Thus, because they are economically active, people can be confronted with the fear of not being socially accepted and let go from their jobs, as seropositivity is still a cause of high unemployment rates, and can be even higher than in the general population[4,11]; or fear of becoming ill and unable to maintain their respective work activities, since work in addition to representing the source of income is also seen as a source of support in allowing the individual to feel economically active, in face of feeling socially disqualified[1,10]. Another persistent complaint is the difficulty of relating the disease and work due to the fear of negative attitudes from colleagues and employers with the disclosure of their diagnosis, which leads many people living with HIV who are economically active, to a feeling of self-devaluation and self-exclusion due to seropositivity[5].

The increase in stigma can also be linked to the fear of disrupting affective relationships[11-12,14,16]. A study carried out with adult women in the northeast of the country[15] highlighted how the discovery of HIV can change a person's life, disorganizing affective relationships. This leads many people to fear disclosure of the diagnosis to their spouses due to fear of abandonment[4-5,12]. In disclosing HIV, there is also the fear of people's negative attitudes towards those living with HIV, since accusations of promiscuity, prostitution and even infidelity are associated with HIV which can lead people to social isolation through shame, fear and depression[12,15-16].

Regarding the increase in perceived stigmatization in the presence of hospitalizations due to HIV complications, a study of patients in Argentina[17] and health professionals in Brazil[18] revealed the negative representation of hospitalization for family members and people living with HIV. Despite the specialized and necessary care for the treatment, patients may be isolated from their social environment during the period of hospitalization, and thus are at a higher risk of having to disclose their HIV positive diagnosis to health professionals and other patients[17-18].

A study conducted in southern Brazil with 15 family caregivers of hospitalized children living with HIV identified that in addition to feelings of isolation and abandonment during hospitalization, family members still mentioned the stigma and prejudiced behavior of health professionals, reinforcing the feelings of error and guilt for seropositivity[19]. Thus, during hospitalizations due to HIV complications, in addition to a sense of powerlessness in the face of AIDS, people still face hopelessness and anguish over living with HIV[17].

The low incidence of comorbidities was an expected outcome in this study, as most participants did not use drugs, had not stopped ART, and had not been hospitalized due to HIV complications. The absence of comorbidities predictor was related to a decrease in the stigmatization mean, since in addition to a lack of pathological signs and symptoms being a good health indicator, it helped hide the diagnosis by

maintaining the confidentiality of HIV infection, preserving people from discriminatory situations[18,20].

In a study carried out in Mozambique, women who had signs and symptoms suggesting AIDS such as weight loss and fever, in addition to feelings of hopelessness in the face of the "bad", "incurable" disease that leads to death[20], also felt guilty and devalued because they were labeled in the community and strongly stigmatized for presenting signs that exposed their condition of seropositivity[21].

Thus, avoiding illness and correctly adhering to ART does not only depend on information and on the individual's posture, but also on many structural factors which are linked to the stigma and perceptions of the disease, and affect individuals regardless of their will[4,14]. As comorbidities weaken the image of the individual, they can also lead to social isolation, feelings of anguish and depression, negatively impacting the life of this individual[4,9,18].

Not being aware about the category of HIV exposure was also related to a decrease in stigmatization mean. When people were unable to identify the environment in which the viral infection occurred, they felt "victimized" and felt less guilty for having contracted HIV[20].

Thus, in the stigmatization process, individuals linked to the spread of HIV at the beginning of the epidemic such as homosexuals, prostitutes and drug users in addition to spouses with an extramarital sex life, are seen as deserving it by law due to morally reprehensible behavior, being guilty for having HIV even before the infection; while children, hemophiliacs, faithful spouses, and marital relationships are seen as innocent people who do not deserve to be infected[11,21].

Despite being closely linked to the stigmatization sensations of people living with HIV, other variables in this study such as having a religion, sexual orientation, drug use and discontinuing ART were not significant with the participating population.

We found that most had a religion, similar to other studies of people with HIV[14,22-23] and other studies with people living in similar situations such as cancer patients[24] and chronic renal disease patients[25], so that clinical evolution and the course of serious illnesses lead to the rediscovery of the importance of spirituality, strengthening hope in enduring physical and emotional distress related to the disease and treatment[24-25].

Although most participants in this study were heterosexual, which can be justified by the stimulus to early sexuality and the possibility of paid sex[26], homosexuals are the ones who are strongly stigmatized and linked to large manifestations of exclusion and blamed for HIV infection[22,27]; this is similar to what happens with drug users, being labelled and socially excluded[6,18,22,27].

We found that interruption of ART was not predominant in this study. However, we are aware that the fear of being stigmatized and being excluded from their affective relationships lead many to abandon treatment as a way to omit disclosure of their HIV positive status[5,16].

CONCLUSION

The results show that being aged between 40 and 49 years and having been hospitalized for HIV complications

were positively associated predictors for increased stigmatization, while not presenting comorbidities and not being aware of HIV exposure were predictors associated with decreased perceived stigmatization.

Thus, the analyzes suggest that stigmatization can impact the lives of people living with HIV by generating feelings of guilt and inferiority that can lead to depression and social isolation, impacting adherence to treatment and clinical follow-up of these people.

Thus, in addition to the possibility of sensitizing health professionals directly linked to the care of people living with HIV, studies of this nature can also contribute to reforming the work process organization of health professionals, subsidizing policies for user embracement and health promotion

of HIV positive people, and offering a new perspective of the problems faced, thus helping to minimize stigma and positively impact the improvement of ART adherence.

Although some studies address the impact of stigmatization on the lives of people living with HIV, only a few use instruments to assess this construct in the population. Thus, despite investigating stigmatization in four important domains, the use of specific scales such as the scale used in this study do not consider a recent period which can have repercussions on responses tainted by memory bias.

The results presented portray the reality of the study population, and therefore due to the scarcity of studies of this nature in the national literature, further studies on HIV-related stigmatization in various social contexts are needed.

RESUMO

Objetivo: Analisar os fatores relacionados com a estigmatização percebida de pessoas vivendo com HIV. **Método:** Estudo transversal realizado de setembro de 2014 a dezembro de 2015 com usuários de um Serviço de Assistência Especializado em Minas Gerais. Os dados foram coletados por meio da aplicação individual do instrumento, organizados em planilhas do Microsoft Office Excel® 2010 e processados no IBM® SPSS 23.0. Para a análise dos dados utilizou-se de estatística descritiva e método de regressão linear múltipla, adotando significância estatística fixada em 5,0% (p≤0,05). O desenvolvimento do estudo atendeu às normas de ética em pesquisa. **Resultados:** Participaram do estudo 258 usuários. Predominaram os homens, a faixa etária de 40 a 49 anos, solteiros, de baixa escolaridade e renda. Ter idade de 40 a 49 anos e ter sido internado por complicações do HIV foram preditores associados positivamente ao aumento da estigmatização, e não apresentar comorbidades e desconhecer a exposição ao HIV foram preditores associados à diminuição da estigmatização. **Conclusão:** Diante destes resultados, evidencia-se que a estigmatização pode impactar a vida de pessoas vivendo com HIV reforçando sentimentos de culpa e vergonha, o quais poderão acarretar depressão, isolamento social e interrupção do tratamento e seguimento clínico.

DESCRITORES

Síndrome da Imunodeficiência Adquirida; HIV; Estigma Social; Depressão; Enfermagem em Saúde Pública.

RESUMEN

Objetivo: Analizar los factores relacionados con la estigmatización percibida de personas viviendo con VIH. **Método:** Estudio transversal realizado de septiembre de 2014 a diciembre de 2015 con usuarios de un Servicio de Asistencia Especializado en Minas Gerais. Los datos fueron recolectados mediante la aplicación individual del instrumento, organizados en planillas del Microsoft Office Excel® 2010 y procesados en el IBM® SPSS 23.0. Para el análisis de los datos, se utilizó la estadística descriptiva y el método de regresión lineal múltiple, adoptando significación estadística fijada en el 5,0% (p≤0,05). El desarrollo del estudio atendió a las normas de ética en investigación. **Resultados:** Participaron en el estudio 258 usuarios. Predominaron los hombres, el rango de edad de 40 a 49 años, solteros, de baja escolaridad y renta. Tener edad de 40 a 49 años y haber sido hospitalizado por complicaciones del VIH fueron predictores asociados positivamente con el aumento de la estigmatización, y no presentar comorbilidades y desconocer la exposición al VIH fueron predictores asociados con la disminución de la estigmatización. **Conclusión:** Ante esos resultados, se evidencia que la estigmatización puede impactar la vida de personas viviendo con VIH reforzando sentimientos de culpa y vergüenza, los que podrán ocasionar depresión, aislamiento social e interrupción del tratamiento y seguimiento clínico.

DESCRIPTORES

Síndrome de Inmunodeficiencia Adquirida; VIH; Estigma Social; Depresión; Enfermería en Salud Pública.

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