

## **EXPERIENCE OF HIV- RELATED STIGMA AMONG SPANISH SEROPOSITIVE PEOPLE BETWEEN 2011 AND 2021: A SYSTEMATIC REVIEW**

**Introducción.** La población que vive con VIH/SIDA sigue hoy en día sufriendo las consecuencias del estigma social y la discriminación. Esto les influye de manera negativa en su calidad de vida y favorece a la ocultación de la infección retrasando el posible diagnóstico y su respectivo tratamiento. Ciertos ámbitos en los que se detecta la existencia de estigmatización arbitraria en España son el laboral, el sanitario, el afectivo-relacional, la justicia, en el acceso a créditos o la contratación de seguros. El objetivo de esta revisión es analizar la literatura, en la última década, sobre la experiencia del estigma en población seropositiva española. **Metodología.** Entre los meses de marzo y abril de 2021 se realizó una búsqueda electrónica a través de las bases de datos Scopus, PsycInfo, PubMed y Dialnet para identificar estudios sobre estigma social en personas que viven con VIH en población española. Se utilizaron los siguientes términos de búsqueda: "HIV", "stigma" y "Spain". Se incluyeron finalmente seis artículos en lengua inglesa en la revisión. **Resultados.** La literatura refleja que las personas con VIH es uno de los grupos más estigmatizados de la población española. Aunque los análisis muestren que las diferentes expresiones del estigma en la población hayan disminuido, los niveles de estimatización social siguen siendo preocupantes. Los factores de riesgo que contribuyen a desarrollar estigma relacionado con el VIH fueron: creencias erróneas sobre la transmisión del VIH, culpar a las personas con esta condición, la edad avanzada y el bajo nivel educativo. Además, los resultados también mostraron que el estigma tenía un impacto negativo en la calidad de vida de las personas con VIH, en su autoeficacia para hacer frente a ese estigma y en el grado de revelación del estado serológico, afectando a su vez de manera diferente entre géneros. **Conclusión.** La desinformación social sobre el VIH es la base de la estigmatización que sufren las personas que viven con esta condición, afectando de manera negativa a su bienestar emocional. Es necesario desarrollar acciones educativas para erradicar los prejuicios y conceptos erróneos sobre el VIH en la sociedad española en general, mirando más allá de un enfoque preventivo.

**Palabras clave:** VIH, estigma, España, ODS3.

**Introduction.** People living with HIV/AIDS continue to suffer the consequences of social stigma and discrimination. This has a negative influence on their quality of life and encourages the concealment of the infection, delaying possible diagnosis and treatment. Certain areas in which arbitrary stigmatisation has been detected in Spain are employment, health, affective-relational, justice, access to credit and insurance. The aim of this review is to analyse the literature, over the last decade, on the experience of stigma in the Spanish HIV-positive population. **Methodology.** Between March and April 2021 an electronic search was carried out using the databases Scopus, PsycInfo, PubMed and Dialnet to identify studies on social stigma in people living with HIV in the Spanish population. The following search terms were used: "HIV", "stigma" and "Spain". Six English-language articles were finally included in the review. **Results.** The literature shows that people with HIV are one of the most stigmatised groups in the Spanish population. Although the analyses show that the different expressions of stigma in the population have decreased, the levels of social stigmatisation are still worrying. Risk factors contributing to the development of HIV-related stigma were: erroneous beliefs about HIV transmission, blaming people with HIV, older age and low educational level. In addition, the results also showed that stigma had a negative impact on the quality of life of people living with HIV, their self-efficacy to cope with stigma and the extent of disclosure of HIV status, while affecting it differently between genders. **Conclusion.** Social misinformation about HIV is the basis of the stigmatisation suffered by people living with this condition, negatively affecting their emotional wellbeing. It is necessary to develop educational actions to eradicate prejudices and misconceptions about HIV in Spanish society in general, looking beyond a preventive approach.

**Keywords:** HIV, stigma, Spain, ODS3.

# Experience of HIV- related Stigma among Spanish seropositive people between 2011 and 2021: a systematic review

Paula González Fernández (Tutora: Cristina Giménez García)  
TFG Psicología 2020-2021 (PS1048)

## INTRODUCTION

### HIV-related stigma

#### Enacted stigma

Experiences of prejudice, and discrimination.

#### Internalized stigma

Self-concept, blame, depression, anxiety.

Impacts negatively on quality of life (Franke et al., 2010; Steward et al., 2011):

- Psychological well-being
- Social support
- Life satisfaction
- Physical health

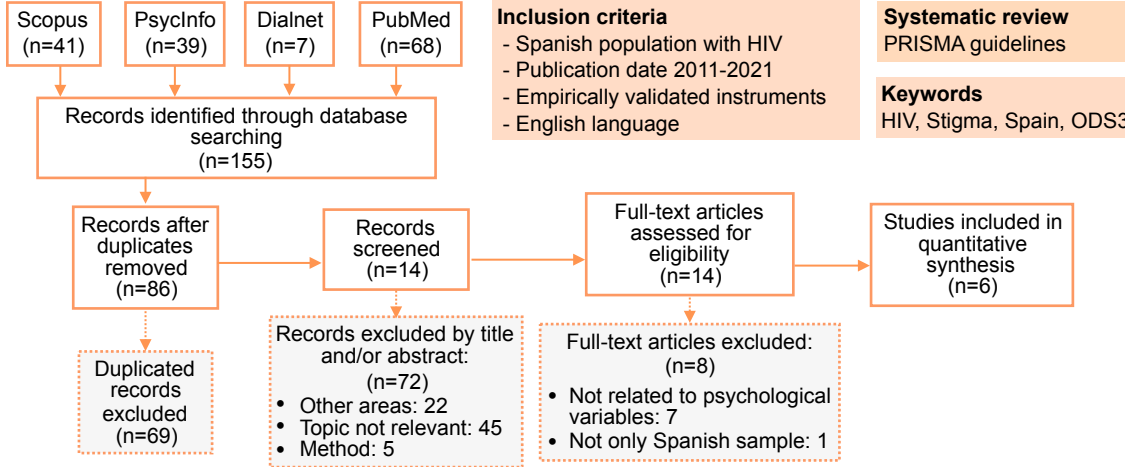
Fear of rejection encourages **concealment of the infection**, delaying diagnosis and treatment (Young & Bendavid, 2010).

Spanish legislation is **not discriminatory**, but discrimination is present in daily life areas such as (Koertin et al., 2019):

**Employment, health care, emotional-relationships, justice, education, life insurance or banking.**

**OBJECTIVE:** To analyze the empirical knowledge, of the last decade, about the experience of stigma among Spanish seropositive people and its main effects for these people.

## METHOD



## DISCUSSION

- **Fear of casual transmission** and public **rejection** and **avoidance attitudes** are still expressed at **concerning** levels in 2012.
- Main **predictors** of HIV-related stigma: **incorrect beliefs** about transmission and **blaming** people for their disease.
- **HIV-related stigma** has a **negative** influence on the **quality of life**, their **self-efficacy** to cope with stigma and the **degree of HIV status disclosure**.
- **Enacted stigma** has a **direct** and **strong** impact on the **quality of life**; **Internalized stigma** has a higher impact on **self-efficacy** to cope with stigma and the **degree of HIV status disclosure**.
- People with higher levels of **internalized stigma** tend to develop **negative affect** on **group identification** and this determines **poorer quality of life**.
- **Gender differences** in health-related **quality of life levels** of people with HIV underlying possible **biopsychosocial inequalities**.
- **Increase** in the negative impact of stigma through **subtle** forms of discrimination.

## LIMITATIONS AND PROPOSALS FOR IMPROVEMENT

- Cross-sectional survey that does not allow for an analysis of the causes of the stigma reduction.
- HIV community is heterogeneous.
- Mediating variables that influence perceived stigma levels.

*To break the stigma associated with HIV/AIDS by developing educational action to eradicate misinformation and prejudices about HIV in Spanish society at large and not only from the preventive approach.*

AUTHOR	PARTICIPANTS	INSTRUMENTS	RESULTS
Fuster et al. (2013)	- 1607 people with HIV - Age: M=41,60, SD=16,69 - Gender: 49% men; 51% women	- HIV-Related Stigma survey designed ad hoc. - Sociodemographic questionnaire designed ad hoc.	*p < 0.5; **p < .01; ***p < .001  - <b>50% discomfort and avoidance</b> - <b>20% advocacy of discriminatory policies</b> - <b>19.3% blaming</b> people with HIV. - <b>15% easy transmission</b> though social contact <b>Predictor variables</b> of HIV-related stigma: - Age, educational level, proximity to people with HIV, blaming people with HIV, incorrect belief about transmission.
Fuster et al. (2014)	- 1607 people with HIV - Age: M=45,33, SD=16,72 - Gender: 49% men 51% women	- HIV-Related Stigma (Fuster et al., 2013)	<b>Significantly decreased</b> in 2012: 2008 ≠ 2012 - Degree of discomfort *** - Advocacy of discriminatory policies *** <b>Lower</b> in 2012. - Negative feelings * - Avoidance intention * - Blaming people with HIV * <b>No significant differences</b> in 2012. - Beliefs about the transmission of HIV (NS) - Perceived severity of the disease (NS)
Fuster et al. (2015)	- 557 people with HIV - Age: M=43,43, SD=8,09 - Gender: 70,8% men, 28% women, 1,3% transsexual	- HIV Stigma Scale (Fuster et al., 2015) - Quality of Life Scale (Ruiz & Baca, 1993) - Perceived Self-Efficacy to Cope with Stigma Scale (Fuster, 2011) - Degree of HIV status disclosure (Stratchan et al., 2007)	<b>Negative relations</b> between <b>stigma</b> and: <b>Quality of life</b> . I. <b>Perceived External Stigma</b> ** II. <b>Personalized stigma</b> ** <b>Self-efficacy &amp; Degree of HIV status disclosure</b> I. <b>Internalized stigma</b> ** II. <b>Disclosure concerns</b> ** - AIDS-related opportunistic infections ↑ <b>Perceived External Stigma</b> t = 3.022**, d = 0.26
Fuster et al. (2014)	- 557 people with HIV - Age: M=43,43, SD=8,09 - Gender: 70,8% men, 28% women, 1,3% transsexual	- HIV Stigma Scale (Berger et al., 2001) - Group Identification Scale (Cameron, 2001) - Quality of Life Scale (Ruiz & Baca, 1993)	<b>Negative influence</b> of <b>enacted*</b> and <b>internalized*</b> stigma on the <b>quality of life</b> . Different paths: - <b>Enacted stigma: no mediation</b> by group identification. - <b>Internalized stigma: mediation</b> by <b>group identification</b> , mainly through <b>in-group affect</b> . The estimated model explained 21 % of the variance of quality of life.
Fumaz et al. (2019)	- 744 people with HIV - Age: IQR:44 - Gender: 72,3% men	- Sociodemographic questionnaire designed ad hoc. - Screenphiv (Remor et al., 2012) - MOS-HIV (Badía et al., 1999)	Women > men: - <b>Enacted stigma</b> ** - <b>Internalized stigma</b> ** Men > Woman: - <b>Positive coping</b> ** - <b>Body image satisfaction</b> *** - <b>Physical*/Mental health</b> **
Molero et al. (2012)	- 1016 stigmatized people (13% with HIV) - Age: M=34,97 SD=10,06 - Gender: 54,1% men, 46,4% women	- MSPD (Meertens & Pettigrew, 1992) - SCQ (Pinel, 1999) - PANAS (Watson et al., 1988) - SPWB (Ryff, 1989)	<b>Group of people with HIV</b> , perceived the <b>most discrimination</b> (M=3.47 SD=0.65); <b>Romanian group the least</b> (M=2.57 SD=0.74). Group discrimination > Individual discrimination*** Subtle discrimination > Blatant discrimination***

MSPD: Multidimensional Scale of Perceived Discrimination, SCQ: Stigma Consciousness Questionnaire, PANAS: The Positive And Negative Affect Schedule, SPWB: Scales of Psychological Well Being, MOS-HIV: Medical Outcomes Study HIV Health Survey

## BIBLIOGRAFÍA

Badía, X., Podzamczar, D., López-Lavid, C., García, M., y Grupo Español de Validación de los cuestionarios MOS- HIV y MQOL-HIV. (1999). Medicina basada en la evidencia y la validación de cuestionarios de calidad de vida: La versión española del cuestionario MOS-HIV para la evaluación de la calidad de vida en pacientes infectados por el VIH. *Enfermedades Infecciosas y Microbiología Clínica*, 17(2), 103–113.

Berger, B. E., Ferrans, C. E., y Lashley, F. R. (2001). Measuring stigma in people with HIV: psychometric assessment of the HIV stigma scale. *Research in nursing & health*, 24(6), 518–529. <https://doi.org/10.1002/nur.10011>

Cameron, J. E., y Lalonde, R. N. (2001). Social identification and gender-related ideology in women and men. *British Journal of Social Psychology*, 40(1), 59–77. <https://doi.org/10.1348/014466601164696>

Franke, M. F., Muñoz, M., Finnegan, K., Zeladita, J., Sebastian, J. L., Bayona, J. N., & Shin, S. S. (2010). Validation and abbreviation of an HIV stigma scale in an adult spanish-speaking population in urban Peru. *AIDS and behavior*, 14(1), 189–199. <https://doi.org/10.1007/s10461-008-9474-1>

Fumaz, C. R., Larrañaga-Eguilegor, M., Mayordomo-López, S., Gómez-Martínez, S., González-García, M., Ornellas, A., Fuster Ruiz de Apodaca, M. J., Remor, E., Ballester-Arnal, R., y Spanish Group for the Quality of Life Improvement in HIV or AIDS (2019). Health-related quality of life of people living with HIV infection in Spain: a gender perspective. *AIDS care*, 31(12), 1509–1517. <https://doi.org/10.1080/09540121.2019.1597959>

Fuster M. J. (2011). La percepción del estigma en las personas con VIH: Sus efectos y formas de afrontamiento. [Tesis doctoral, UNED]. <http://e-spacio.uned.es/fez/eserv/tesisuned:Psicologia-MJfuster/Documento.pdf>

Fuster-RuizdeApodaca, M. J., Molero, F., Gil de Montes, L., Agirrezabal, A., Toledo, J., Jaen, A., y Spanish Group for the Study of HIV-Related Stigma (2014). Evolution of HIV-related stigma in Spain between 2008 and 2012. *AIDS care*, 26 (1), 41–45. <https://doi.org/10.1080/09540121.2014.906557>

Fuster, M. J., Molero, F., Gil de Montes, L., Agirrezabal, A., y Vitoria, A. (2013). HIV- and AIDS-related stigma: psychosocial aspects in a representative Spanish sample. *The Spanish journal of psychology*, 16, (30). <https://doi.org/10.1017/sjp.2013.52>

Fuster-Ruizdeapodaca, M. J., Molero, F., Holgado, F. P., y Mayordomo, S. (2014). Enacted and internalized stigma and quality of life among people with HIV: the role of group identity. *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation*, 23(7), 1967–1975. <https://doi.org/10.1007/s11136-014-0653-4>

Fuster-RuizdeApodaca, M. J., Molero, F., Holgado, F. P., y Ubillos, S. (2015). Adaptation of the HIV Stigma Scale in Spaniards with HIV. *The Spanish journal of psychology*, 18, (66). <https://doi.org/10.1017/S1138741615000694>

Meertens, R. W., & Pettigrew, T. F. (1992). Le racisme voilé: dimensions et mesure. In M. Wieviorka (ed.), *Racisme et modernité* (pp. 109–126). Paris: La Découverte.

Molero, F., Recio, P., García-Ael, C., Fuster, M., y Sanjuán, P. (2013). Measuring Dimensions of Perceived Discrimination in Five Stigmatized Groups. *Social Indicators Research*, 114(3), 901-914. Retrieved May 20, 2021, from <http://www.jstor.org/stable/24720286>

Pinel E. C. (1999). Stigma consciousness: the psychological legacy of social stereotypes. *Journal of personality and social psychology*, 76(1), 114–128. <https://doi.org/10.1037//0022-3514.76.1.114>

Remor, E., Fuster, M. J., Ballester-Arnal, R., Gómez-Martínez, S., Fumaz, C. R., González-García, M., Ubillos-Landa, S., Aguirrezabal-Prado, A., y Molero, F. (2012). Development of a new instrument for the assessment of psychological predictors of well-being and quality of life in people with HIV or AIDS. *AIDS and behavior*, 16(8), 2414–2423. <https://doi.org/10.1007/s10461-012-0230-1>

Ruiz, M. Á., y Baca, E. (1993). Design and validation of the "Quality of Life Questionnaire" ("Cuestionario de Calidad de Vida", CCV): A generic health-related perceived quality of life instrument. *European Journal of Psychological Assessment*, 9(1), 19–32.

Ryff, C. (1989). Happiness is everything, or is it? Explorations of the meaning of psychological well-being. *Journal of Personality and Social Psychology*, 57, 1069–1081. <https://psycnet.apa.org/doi/10.1037/0022-3514.57.6.1069>

Steward, W. T., Chandy, S., Singh, G., Panicker, S. T., Osmand, T. A., Heylen, E., y Ekstrand, M. L. (2011). Depression is not an inevitable outcome of disclosure avoidance: HIV stigma and mental health in a cohort of HIV-infected individuals from Southern India. *Psychology, health & medicine*, 16(1), 74–85. <https://doi.org/10.1080/13548506.2010.521568>

Strachan, E. D., Bennett, W. R., Russo, J., y Roy-Byrne, P. P. (2007). Disclosure of HIV status and sexual orientation independently predicts increased absolute CD4 cell counts over time for psychiatric patients. *Psychosomatic medicine*, 69(1), 74–80. <https://doi.org/10.1097/01.psy.0000249900.34885.46>

Watson, D., Clark, L. A., y Tellegen, A. (1988). Development and validation of brief measures of positive and negative affect: the PANAS scales. *Journal of personality and social psychology*, 54(6), 1063–1070. <https://doi.org/10.1037//0022-3514.54.6.1063>

Young, S. D., y Bendavid, E. (2010). The relationship between HIV testing, stigma, and health service usage. *AIDS care*, 22(3), 373–380. <https://doi.org/10.1080/09540120903193666>