

MESTRADO INTEGRADO EM MEDICINA

The impact of self-stigma in people with diagnosis of severe mental illness: a pilot study from a community psychiatry unit

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The impact of self-stigma in people with diagnosis of severe mental illness: a pilot study from a community psychiatry unit

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Dedicatória

“Ah, que ninguém me dê piedosas intenções!

Ninguém me peça definições!

Ninguém me diga: "vem por aqui"!

A minha vida é um vendaval que se soltou.

É uma onda que se alevantou.

É um átomo a mais que se animou...

Não sei por onde vou, Não sei para onde vou - Sei que não vou por aí!”

José Régio – Cântico Negro

in 'Poemas de Deus e do Diabo

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Resumo

Introdução: O auto-estigma refere-se a um processo de transformação em que uma pessoa internaliza estereótipos, crenças e preconceitos enraizados na sociedade sobre a sua doença mental e adota uma visão estigmatizante de si mesma. De facto, a doença mental grave é uma das condições clínicas mais estigmatizantes entre a sociedade. A internalização do estigma está associada a mau prognóstico clínico e funcional, sentimentos de desvalorização, desmoralização, discriminação, isolamento e alienação da sociedade.

Objetivos: Em Portugal a investigação sobre o estigma associado à doença mental é ainda muito reduzida. Neste estudo, pretendemos avaliar o impacto do auto-estigma em pessoas com diagnóstico de doença mental de uma unidade de psiquiatria comunitária. Os principais objetivos foram i) avaliar a prevalência de auto-estigma entre pacientes com diagnóstico de doença mental grave; e ii) investigar as variáveis associadas a níveis elevados de auto-estigma.

Método: Cinquenta e um participantes com diagnóstico de doença mental grave, foram recrutados de uma unidade de psiquiatria comunitária do Porto, Portugal. Após consentimento informado, foram aplicados questionários para a recolha de dados sociodemográficos e clínicos dos pacientes, bem como medidas de avaliação do estigma internalizado (ISMI), auto-estima (RSES) e qualidade de vida (WHOQOL-Bref).

Resultados: 31.4% dos participantes do estudo reportaram um nível moderado a elevado de auto-estigma. Os indivíduos desempregados ou de baixa devido à doença apresentaram níveis de auto-estigma mais elevados. Na análise de correlações entre as variáveis em estudo, foi observada uma correlação negativa entre o auto-estigma e autoestima ($\rho = -0,745$; $P < 0,001$), bem como entre o auto-estigma e a qualidade de vida ($\rho = -0,585$; $P < 0,001$). Foi também observada uma associação positiva entre a autoestima e a qualidade de vida ($\rho = 0,551$; $P < 0,001$).

Conclusão: O presente estudo reporta níveis elevados de auto-estigma entre as pessoas com diagnóstico de doença mental severa que participaram no projeto de investigação. Para além disso, corrobora a evidencia de que o estigma internalizado está significativamente associado à diminuição da autoestima e da qualidade de vida em pacientes com doença mental. Em conclusão, é importante criar estratégias e intervenções que visem diminuir o prognóstico do auto-estigma na doença mental severa.

Abstract

Background: Self-stigma refers to the process in which a person internalizes negative stereotypes, beliefs and prejudices about mental illness and adopts a stigmatised view of themselves. Severe mental illness is one of the most socially exclusive stigmata. It is associated with poor clinical and functional outcomes, devaluation, discrimination, isolation, and alienation from society that result from misconceptions about the disease.

Objectives: In Portugal, research towards self-stigma in mental health is still scarce. In this study, we aimed to evaluate the impact of self-stigma among people with mental illness in a community-based psychiatry unit. For this goal we i) assess the prevalence of self-stigma among patients with diagnosis of severe mental illness; and ii) investigate the correlates of elevated self-stigma levels.

Method: Fifty-one outpatients with severe mental illness diagnosis, were recruited from a community psychiatry unit from Porto, Portugal. After informed consent, evaluations included sociodemographic data, illness characteristics, and self-reported standardized scales. Self-stigma (ISMI), self-esteem (RSES) and quality of life (WHO-QoL) were assessed.

Results: Moderate to high self-stigma levels was found in 31.4 % of the total sample of the study. Unemployed and individuals retired due to illness had higher levels of internalized stigma. In the correlations analysis between the study variables, a negative correlation between self-stigma and self-esteem ($\rho = -0.745$; $P < 0.001$), as well as, between self-stigma and quality of life ($\rho = -0.585$; $P < 0.001$) was reported. A positive relationship between self-esteem and quality of life ($\rho = 0.551$; $P < 0.001$) was also found.

Conclusion: These results suggest that elevated levels of self-stigma are common among outpatients with diagnosis of severe mental illness from a community psychiatry unit. Moreover, our findings corroborate that internalized stigma was significantly associated with diminished self-esteem and quality of life. Therefore, targeting internalized stigma and self-esteem is a major health priority to improve prognosis in patients with mental illness.

Abbreviation List

ISMI – Internalised Stigma of Mental Illness

QoL – Quality of life

Ns – Not significant

RSES – Rosenberg Self-Esteem scale

SMI – severe mental illness

WHO – World Health Organization

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1. Introduction

In 1963, Goffman adopted the term stigma as an attribute, behaviour, or reputation that was socially discrediting, “an undesired differentness”, that reduced the bearer “from a whole and usual person to a tainted, discounted one”. It caused an individual to be mentally classified by others in undesirable, rejected stereotype.¹ Three elements compose stigma: knowledge (stereotypes), a problem of attitudes (prejudice), and a problem of behaviour (discrimination).²

Public stigma refers to the stereotypes, prejudices or discriminatory attitudes that large social groups have about mental illness.³ The effects of public stigma on individuals include perceived stigma (one’s recognition of public prejudices and stereotypes about themselves); experienced stigma (experience of discrimination), anticipated stigma (expectation that one will be discriminated) and self-stigma or internalized stigma.⁴ The latter, reflects the degree in which a person has internalized societally endorsed stigmatizing beliefs, based on their individual experience and through anticipation of negative social attitudes about mental illness.^{5, 6} Link and Phelan (2001) focus at both individual and societal levels and described stigma as the co-occurrence of its components - labelling, stereotyping, separation, status loss, and discrimination.³ In this sense, self-stigma holds a process of identity transformation in which a person’s social identity is progressively replaced by a devalued and stigmatized view of oneself, accepting and agreeing with public stigma and ultimately applying it to themselves. This is known as “illness identity” and leads to self-prejudice and self-discrimination.^{4, 6, 7}

Growing body of evidence has focus on the effects of public and internalized stigma among individuals with Severe Mental Illness (SMI).⁴ Most people with severe mental illness face stigma due to societal related misperception of risk and unpredictability of the disease.⁸ Studies involving participants with SMI have reported that internalized stigma is associated with lower levels of self-esteem and self-efficacy, hopelessness, high perceived discrimination and devaluation, shame, lowered empowerment, isolation, decreased social support/integration as well as poor neurocognitive function.^{6, 9-15} Regarding psychiatric variables, it was suggested that self-stigma is associated with psychiatric symptom severity and worsen disease prognosis, depression and anxiety symptoms, suicidal ideation, and is negatively related with overall mental and physical health outcomes, recovery, treatment adherence or seeking for help.^{4, 6} Moreover, internalized stigma was associated with social withdrawal and impaired adaptation, unemployment, income loss and limited social support.^{16, 17}

Quality of Life (QoL) and self-esteem have been widely used as important outcome measures for mental health. In 2010, a meta-analysis, reported that higher levels of internalized stigma were

associated with decreased self-esteem and subjective QoL. ⁶ Oliveira S.E.H. *et al.* (2016) addressed self-esteem as a core element in reducing the negative effects of internalized stigma on QoL among people with mental illness. ¹⁸ In addition, Mashiach-Eizenberg *et al.* (2013), suggested that self-esteem mediated the relationship between internalized stigma and hope. ¹⁹ Recently, it has been further reported that alienation and stereotype endorsement contributed to the decrease of QoL in schizophrenic patients, through a self-esteem mediating process. ²⁰

Self-stigmatization is a maladaptive biopsychosocial phenomenon distressing a significant number of psychiatric patients and impairing their global functioning. Over the last years, a growing awareness of the impact of stigma on mental illness is evident. ⁴ Yet, in Portugal, studies on mental illness stigma are scarce and, it is essential to better understand the impact of self-stigma among people with diagnosis of SMI. In this study, we aimed to evaluate internalized stigma from a sample of outpatients from a community psychiatry unit. For this goal we i) assessed the prevalence of self-stigma among people with diagnosis of SMI; and ii) investigated the correlates of elevated self-stigma in severe mental disorders, including socio-demographic data, social and professional network, clinical variables as well as self-esteem and quality of life assessment.

2. Material and methods

2.1 Study design, participants, and procedure

A cross-sectional study was conducted among outpatients with diagnosis of severe mental illness from a community psychiatry unit from Porto metropolitan area, Portugal. Official approval was obtained by Ethics Committee and Education, Training, and Research Department from Centro Hospitalar Universitário do Porto (REF:2022.038(029-DEFI/030-CE)) (Annex 1). The study was conducted in agreement with the latest version of the Declaration of Helsinki and the standards of Good Clinical Practice.

People with diagnosis of severe mental disorders were recruited from a community psychiatry unit by the coordinating psychiatrist. The researcher explained the aim of the study and an individual and voluntary informed consent for participation was obtained from all participants (Annex 2). The researcher was available to assist the participant with aspects of completing the survey. The inclusion criteria for the sample were as followed: i) aged between 18 and 65 years old; ii) outpatients with diagnosis of SMI that were clinically stable under psychiatric treatment (implying an informed consent according to psychiatric and to ensure that patients did not have acute symptomatology, did not required recent hospitalization, nor changes in medication or other

therapeutic intervention). The exclusion criteria were as followed: i) severe acute symptomatology and comorbidity with substance abuse, organic brain disease, and severe somatic disease; ii) patients suffering from moderate to severe cognitive impairment; iii) patients with recent changes in the medications (at least one month).

After recruitment, patient's clinical files were consulted to obtain missing information regarding sociodemographic and clinical variables including diagnosis (based on DSM-V, American Psychiatric Association), data and age of diagnosis, duration of illness, family history of mental illness and hospital admissions.

2.2 Measures

The following questionnaires (Annex 2) were conducted: i) socio demographic questionnaire, including age, gender, area of residence, education, type of family, status of marriage, employment status; ii) Portuguese version of internalized stigma scale; iii) Rosenberg self-esteem scale; and iv) Quality of Life questionnaire (WHOQOL-BREF).

The Internalised Stigma of Mental Illness Scale (ISMI)

The Portuguese version of the ISMI scale is a 28-item questionnaire ²¹, translated from ISMI 29-item scale. ²² Author's authorization for using the ISMI scale was obtained. ISMI scale assesses individual's personal experience of stigma or internalized stigma in relation to mental illness. It is composed of five subscales measuring alienation, stereotype endorsement, social withdrawal, and stigma resistance. Each item is rated on a four-point Likert scale from 1 (strongly disagree) to 4 (strongly agree). Items are summed to provide a mean total score; higher values indicate higher levels of self-stigma stigma. A score above 2.5 indicates a moderate to high level of self-stigma. ¹⁷

The Rosenberg Self-Esteem scale (RSES)

The most used tool for measuring self-esteem is the Rosenberg Self-Esteem Scale (RSES). ²³ The Portuguese version of the RSES ²⁴ is a self-report measure composed by 10 items, in which five are positively oriented (e.g.: I feel that I have a number of good qualities) and five are negatively oriented (e.g. I feel I do not have much to be proud of). Items are scored on a four-point Likert scale from 1 (strongly agree) to 4 (strongly disagree). Higher scores indicate higher levels of self-esteem whereas lower scores indicate lower levels of self-esteem.

World Health Organization Quality of Life Bref–WHOQOL

The WHOQOL-Bref is one of the most widely used instruments to evaluate QoL. The Portuguese version of the World Health Organization Quality of Life-Bref ²⁵ is a 26-item self-report

questionnaire to assess QoL. It measures four domains: physical, psychological, environment and social relationships. Each item of the WHOQOL-Bref represents one aspect of QoL and is rated on a five-point Likert scale from 1 (highly dissatisfied) to 5 (highly satisfied). Higher scores indicate higher QoL.

2.3 Statistical analysis

The reliability of the tests was verified using Cronbach's α coefficient. Cronbach's α reliability coefficient for the IMSI scale was 0.97 and for the RSES scale was 0.88, indicating a good internal consistency for both tests. Categorical variables were expressed as counts and frequencies/percentages, and continuous variables as mean and standard deviation (or median and interquartile range). Due to ordinal scales and non-normal variables distribution, nonparametric statistics were used. The Mann-Whitney U test was used to compare the stigma scores medians between groups: marital status (single/divorced/widowed vs. married/civil union); level of education (basic education – until 9th grade vs. upper education); employment status (active vs unemployed/unoccupied or retired) and number of hospitalizations (less than two vs. equal or higher than 2). Association between categorical or categorized variables (namely, scores above 2.5 indicating a moderate to high level of self-stigma and less than 2.5 indicating a minimum to low self-stigma level) was assessed by Fisher's exact test. The correlation between self-stigma scores and quantitative variables was assessed using the Spearman correlation coefficient (ρ). Data analyses were performed using the SPSS version 28.0 (IBM Corp., Armonk, NY). p -values < 0.05 were considered significant.

3. Results

3.1 Sample characteristics

Fifty-one outpatients with SMI from a community psychiatry unit participated in this study. The demographic and clinical characteristics of the participants are presented in Table 1 and Table 2, respectively. From the study sample, 66.7% were male, with mean age of 44.8 ± 11.0 . Most participants were single (56.9%). 33.1% reported living with their parents while 31.4% were living with a partner/spouse. Concerning the level of education, 58.8% completed basic education, and 23.5% achieved upper secondary education. The majority of patients were retired due to illness (62.7%) whereas only 19.6% were employed. Considering clinical variables, most of individuals had a diagnosis of schizophrenia (60.8%), followed by specific personality disorders (13.7%),

schizoaffective disorders (7.8%) and unspecified nonorganic psychosis (7.8%). The mean duration of the disease was 15.6 ± 9.5 years among all participants, and the mean age at diagnosis was 29.2 ± 10.9 years.

3.2 Associations between categorical variables and self-stigma categories

Table 3 presents the results of grouping self-stigma (ISMI), as minimal-low and moderate-high self-stigma categories. Moderate to high self-stigma levels were found in 31.4% of participants, whereas 68.6% reported minimal to low levels of internalized stigma. A significant association was found with occupational status. Proportion of elevated self-stigma was significantly higher in patients that were unemployed/retired vs. those who were active (39.0% vs. 0%; $P = 0.021$).

3.3 Correlates of self-stigma scores

No significance differences were found in stigma median scores between gender, marital status (single/divorced/widowed vs. others), level of education (basic education vs upper education) nor number of hospitalizations (< 2 vs. ≥ 2) (Table 4). Table 5 presents the correlates between self-stigma score and continuous variables (age, levels of education, number of hospitalizations, age at diagnosis and time since diagnosis). No correlations were found between self-stigma scores and age, level of education, number of hospitalizations, age at diagnosis and duration of illness.

3.4 Correlations between self-stigma, self-esteem and QoL scores

Spearman's correlations were used to analyse the associations between the study variables: self-stigma, self-esteem and QoL (total score and specific domains) as shown in Table 5. A robust negative correlation between internalized stigma and self-esteem was found ($\rho = -0.745$; $P < 0.001$). As expected, it was also observed a negative correlation between self-stigma and QoL ($\rho = -0.586$; $P < 0.001$) and, specifically, in all domains that constitute QoL. Higher levels of self-stigma were associated with the lowest levels of QoL in the psychological domain ($\rho = -0.545$; $P < 0.001$), followed by physical ($\rho = -0.497$; $P < 0.001$), social relationships ($\rho = -0.473$; $P < 0.001$) and environment ($\rho = -0.471$; $P < 0.001$) domains. As predicted, it was also found a positive association between self-esteem and QoL ($\rho = 0.551$; $P < 0.001$). Higher levels of self-esteem were significantly correlated with high levels of QoL in the physical domain ($\rho = 0.542$; $P < 0.001$) and psychological domain ($\rho = 0.545$; $P < 0.001$). Moderate associations were observed between self-esteem, social relationships, and environment domains ($\rho = 0.346$; $P < 0.001$ and $\rho = 0.379$; $P < 0.001$; respectively).

4. Discussion

Self-stigma is an individual and subjective process, embedded within a socio-cultural context, that reflects undesirable feelings about self, a maladaptive behaviour, or stereotype and prejudice endorsement resulting from a person's discrimination experience towards mental illness.⁶ World Health Organization (WHO) has declared that the stigma and discrimination toward persons suffering from mental and behavioural disorders is one of the most important barriers to overcome in the community.²⁶ In Portugal, there is a lack of research regarding stigma and mental illness. The present study aimed to investigate the correlates and the impact of self-stigma among outpatients with SMI from a community psychiatry unit from Porto, Portugal. The prevalence of moderate to high self-stigma levels was 31.4%, whilst 68.6% of participants reported minimal to low levels of internalized stigma. These results corroborate the literature depicting that around one-third of people with mental disorders report moderate-to-high ISMI scores.^{15, 27} In a systematic review of 272 articles, Dubreucq J. *et al.* (2021) found an average of 31.3% of high self-stigma among patients with SMI, and the highest frequency was found in schizophrenia disorder (35.8%).⁴ An evaluation of self-stigma in people with schizophrenia from 14 European countries (GAMIAN-Europe study), reported that 41.7% of the patients had moderate or high levels of internalized stigma.¹⁷ Albeit, studies showed that the prevalence of self-stigma significantly varied between countries, which might be explained by social, cultural, and political contexts or setting-related differences.^{4, 15}

In the literature, contrasting studies correlate self-stigma among patients with mental illness and socio-demographic and illness-related variables.^{4, 14, 17, 27} In the present study, we reported that employment status may be related to self-stigma. A significant association between elevated self-stigma and being unemployed or retired was found, in comparison with those employed. No significant correlations were found with age, level of education, age at diagnosis, duration of illness, number of hospitalizations nor family history of psychiatric disease, which corroborate certain results.^{4, 27} Findings from the REHABase national psychiatric rehabilitation cohort study (2020) found correlations between internalized stigma and female gender, older age at diagnosis, illness duration, number of psychiatric hospitalizations, as well as history of suicide attempt,¹⁴ which is in accordance with other studies.^{15, 28} They also observed that higher insight into illness significantly predicted the level of self-stigma¹⁴, that is suggested elsewhere.^{29, 30} On the contrary, other authors found no significant differences between gender, employment, and marital status and internalized stigma, but rather a correlation between illness duration and internalized stigma.^{27, 31} In line with our study, the Pan European stigma study (2013) found that employment may protect people with a mental illness from self-stigma.¹⁵ This is in accordance to another study⁶, but contrasts with

others that found no correlations between employment status and self-stigma.^{14, 17} In addition, it has been suggested that both tertiary education and employment could protect against self-stigma.^{15, 17, 32} The observed disparities in the before-mention studies may rely on different methodologies used, sample characteristics, different inclusion/exclusion criteria and scales used. Also, conceptual variability of findings may also arise from the complexity of the self-stigma phenomenon.³

A meta-analysis from Livingston and Boyd (2010) has reported that a higher level of self-stigma was associated with diminished levels of hope, self-esteem, empowerment, self-efficacy, social support, as well as a greater severity of psychiatric symptoms and poorer treatment adherence.⁶ Dubreucq J. *et al.* (2021), further suggested that a reduction in self-stigma was related to better recovery-related outcomes, improved depression, suicidality, attitudes towards medication, self-esteem, QoL, and psychosocial functioning.⁴ In the present study, we found a robust negative relationship between internalized stigma, self-esteem and QoL. Self-esteem is related to the ability to hold positive attitudes and beliefs towards oneself and it echoes general life satisfaction, depending on self-evaluation and social feedback.³³ Our findings are supported by several studies in the literature implying that internalized stigma is significantly associated with decreased self-esteem.^{11, 14, 18, 34, 35} QoL reflects the overall patient functioning and well-being and several studies have established a causal relationship between individual's self-stigma and QoL.^{19, 35, 36} It has been further suggested that internalized stigma may have a detrimental effect on the psychological, physical, social relationships and environment aspects of QoL.¹⁸ Aligned with these studies, we reported that elevated self-stigma was correlated with low levels of all QoL domains. Furthermore, our findings suggested a positive correlation between self-esteem and QoL, especially in relation to the physical and psychological domains. On this regard, Oliveira S.E.H. *et al.* (2016), proposed that self-esteem fully mediated the relationship between internalized stigma and the physical and social relationship domains of QoL.¹⁸ Barbalat G. *et al.* (2022) recently suggested that the most QoL domains related to self-esteem included physical and psychological well-being, autonomy, and resilience.³⁷ This study also highlighted self-esteem as core aspect beneath quality of life of patients with mental disorders.³⁷ In schizophrenic patients it has been reported that alienation and stereotype endorsement directly contributed to the lower QoL, through a process mediated by self-esteem.²⁰ These and other studies are in accordance with the previous model proposed by Mashiach-Eizenberg *et al.* (2013) suggesting that the effect of internalized stigma upon hope and QoL may be closely related to self-esteem levels.^{19, 35}

Limitations

Despite of the contribution this study may extend to stigmatization research and clinical practice, it displays some important limitations that will be highlighted. Firstly, the number of participants included in the study (n= 51) is small to infer definite correlates and may limit the generalization of the results. Also, neither severity of the symptoms nor the insight into illness were taken into consideration, which may impact the assumptions. Secondly, the sample of study is composed by outpatients of a community psychiatric hospital and might therefore not be representative of all patients with SMI. Also, the data collection methodology, conducted in the presence of the researcher, cannot guarantee that social desirability did not bias the answers. Since this study was of a cross-sectional design, causality relations cannot be inferred and, in this way, it is possible that longitudinal studies have a higher contribute. Future studies will be endorsed with larger samples and to further include other clinical important measures, such as psychiatric symptom severity related to SMI.

5. Conclusion

People with diagnosis of severe mental illness not only have to cope with the often-overwhelming effects and disabilities of their illness, but also experiment stereotypes, discrimination, social exclusion, isolation and prejudice. WHO has further asserted self-stigma among patients with SMI as a major public health issue. Nevertheless, in Portugal, the investigation on mental illness stigma is scarce. Therefore, it is imperative to underpin the underlying correlates of self-stigma in order to establish individual interventions to tackle self-stigma. The current study reports a high prevalence (31.4%) of elevated self-stigma among outpatients from a community psychiatry unit. Moreover, our findings support previous evidence that internalized stigma is strongly associated with diminished self-esteem and impairs QoL, in particular, those aspects related to physical and psychological complaints. Targeting internalized stigma and self-esteem among patient with SMI will likely improve their quality of life, besides providing more effective and efficient care, and improving their clinical and functional outcomes.

6. Annexes

Annex 1 - Official approval obtained by Ethics Committee and Education, Training, and Research Department from Centro Hospitalar Universitário do Porto.

Exma. Sra. Marta Almada

Estudante do ICBAS

ASSUNTO: Trabalho Académico - MIM - “The impact of self-stigma in people with diagnosis of severe mental illness: a pilot study from the community psychiatry unit of Centro Hospitalar Universitário do Porto.” – N/ REF.ª 2022.038(029-DEFI/030-CE)

O Conselho de Administração do CHUPorto autoriza a realização do estudo acima mencionado, a realizar no Serviço de Psiquiatria e Saúde Mental – Unidade de Psiquiatria Comunitária desta Instituição e tendo como Investigador Principal Marta Almada, estudante do ICBAS.

O estudo foi previamente analisado pela Comissão de Ética do CHUPorto|ICBAS, pelo Serviço de Investigação Clínica, pela Direção do Departamento de Ensino, Formação e Investigação do CHUPorto e pelo Presidente do Conselho de Administração, tendo obtido parecer favorável.

Cumprimentos,

04/05/2022

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* Em todas as eventuais comunicações posteriores sobre este estudo é indispensável indicar a nossa ref.ª.

APRECIAÇÃO E PARECER PARA A REALIZAÇÃO DE TRABALHO ACADÉMICO - MIM

Título: "The impact of self-stigma in people with diagnosis of severe mental illness: a pilot study from the community psychiatry unit of Centro Hospitalar Universitário do Porto."		Ref.ª: 2022.038(029-DEFI/030-CE)
		Investigador: Marta Almada Estudante do ICBAS

DIREÇÃO DE ENFERMAGEM: ☒ NÃO SE APLICA ☐ PARECER FAVORÁVEL ☐ PARECER NÃO FAVORÁVEL Data: 03 MAIO 2022 _____	PRESIDENTE DO CONSELHO DE ADMINISTRAÇÃO: ☐ PARECER FAVORÁVEL ☐ PARECER NÃO FAVORÁVEL Data: 03 MAIO 2022 _____ Dr. PAULO BARBOSA Presidente do Conselho de Administração do CHUP
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PARECER FAVORÁVEL


Dr. SEVERO TORRES
Assessor do Presidente do Conselho de Administração

Em conformidade. Pode ser autorizado.


Ref.ª **Doutora Luísa Lobato**
Diretora do DEFI
Luísa Lobato
Diretora do DEFI
02/05/2022

COMISSÃO DE ÉTICA CHUPorto / ICBAS

APRECIÇÃO E VOTAÇÃO DO PARECER

Deliberação	Data: 9/3/22	Órgão: Reunião Plenária
Título: "The impact of self-stigma in people with diagnosis of severe mental illness: a pilot study from the community psychiatry unit of Centro Hospitalar Universitário do Porto."		Ref.ª: 2022.038(029-DEFI/030-CE)
Protocolo/Versão: MIM	Promotor: o(a) próprio(a)	Investigador / Local: Marta Almada Serviço de - CHUPorto

A Comissão de Ética CHUPorto / ICBAS, ao abrigo do disposto no Decreto-Lei n.º 80/2018, de 15 de Outubro, em reunião realizada nesta data, apreciou a fundamentação do relator sobre o pedido de parecer para a realização do **MIM** acima referenciado:

Ouvido o Relator, o processo foi votado pelos Membros da Comissão de Ética CHUPorto / ICBAS presentes:

Presidente: Prof. Doutor João Nuno Melo Beirão

Vice-Presidente: Dr.ª Paulina Aguiar

Dr. Aníbal Albuquerque, Prof.ª Doutora Carla Teixeira, Dr.ª Cármen de Carvalho, Dr.ª Fernanda Manuela Costa, Dr. Gonçalo Senra, Prof. Doutor José António Pinho, Prof.ª ~~Doutora Margarida Araújo~~, Prof.ª Doutora Maria Strecht, Prof.ª Doutora Susana Magalhães.

Resultado da votação:

PARECER FAVORÁVEL

A deliberação foi aprovada por unanimidade.

Pelo que se submete à consideração superior.

Data 9/3/22

O Presidente da Comissão de Ética CHUPorto / ICBAS



Prof. Doutor João Nuno Melo Beirão

Annex 2 - Survey applied to patients with SMI – including informed consent, survey pack containing sociodemographic questionnaires, and self-reported scales which measured self-stigma, self-esteem, and quality of life.

Informação aos Participantes sobre o Estudo

O impacto do auto-estigma em pessoas com diagnóstico de doença mental: um estudo piloto numa unidade de psiquiatria comunitária

Este é um estudo em desenvolvimento no Serviço de Psiquiatria do Centro Hospitalar do Porto e tem como objetivo principal, compreender o impacto do auto-estigma ou estigma internalizado em pessoas com diagnóstico de doença mental, e conhecer o peso relativo de cada componente do estigma. Desta forma, pretendemos contribuir para o aprofundamento do conhecimento do auto-estigma na população portuguesa, que poderá facilitar o desenvolvimento de futuras intervenções na área do estigma e da Saúde Mental, de forma a prevenir o seu potencial impacto deletério.

A investigadora responsável por este estudo é a Dra Ana Sofia Pinto, médica psiquiatra no serviço de Psiquiatria deste Hospital. Este trabalho será desenvolvido no contexto do Programa Doutoral da Dra Ana Pinto, e do Mestrado Integrado em Medicina do ICBAS da estudante, Marta Almada.

Farão parte deste estudo, as pessoas com diagnóstico de Doença Mental seguidos no Serviço de Psiquiatria deste Centro Hospitalar.

Pedimos assim, que preencha um questionário, com o objetivo de recolher alguns dados pessoais; um questionário sobre qualidade de vida e dois questionários sobre auto-estigma na doença mental. O preenchimento destes questionários demorará cerca de 20 minutos.

Salientamos que toda a informação será confidencial e apenas os elementos da equipa de investigação a ela terão acesso. O armazenamento dos dados recolhidos será realizado de forma segura e o seu nome não estará presente.

Não é obrigado a participar, e caso decida não o fazer, não terá qualquer tipo de penalização.

Agradecemos desde já a sua participação, e os Investigadores estão ao seu dispor para qualquer esclarecimento de dúvidas e para qualquer outra informação pertinente.

Termo de Consentimento Informado

Participação na dissertação de Mestrado em Medicina “The impact of self-stigma in people with diagnosis of severe mental illness: a pilot study from a community psychiatry unit”

Eu, abaixo-assinado, _____, declaro ter entendido a informação que me foi fornecida sobre o estudo. Estou consciente dos objetivos e procedimentos do mesmo, bem como do papel do investigador e do meu papel como participante do mesmo, tendo-me sido dada a oportunidade para esclarecimento de dúvidas.

Foi-me dada garantia de confidencialidade de identificação em todo o estudo, assim como poderei recusar a participar em qualquer fase de estudo, e que é garantida a confidencialidade e o anonimato da informação obtida, que servirá apenas para o estudo em questão.

Aceito, que recolham a informação pretendida do processo clínico e que a minha participação é inteiramente voluntária e livre.

Porto, ____, de _____ de 202__

Assinatura do Participante

Assinatura do responsável legal

Assinatura do(a) investigador

Questionário socio demográfico

Data de avaliação: _____

1- Data de nascimento: __/__/____ Local de Nascimento (concelho): _____

Local de residência atual (concelho): _____

2- Género

a. Masculino

b. Feminino

c. Outro: _____

3- Grau de Escolaridade

a. Ensino Primário incompleto

b. Ensino Primário

c. 2º ciclo (6º ano)

d. 3º ciclo (9º ano)

e. Ensino Secundário

f. Ensino superior

g. Nenhum

4- Estado Civil

a. Solteiro (a)

b. União de facto

c. Casado (a)

d. Divorciado (a)

e. Viúvo (a)

ID: _____

5- Profissão: _____

a. Ativo

b. Desempregado (a)

c. Baixa médica

Devido à doença?: Sim ☐ Não ☐

d. Reformado

Devido à doença?: Sim ☐ Não ☐

e. A frequentar um curso profissional

Se sim, qual: _____

6- Com quem vive atualmente:

a. Pais

b. Cônjuge

c. Companheiro (a)

d. Filho (a)

e. Irmão (ã)

f. Sozinho (a)

g. Institucionalizado

h. Outras pessoas: _____

ID: _____

WHOQOL-BREF

Instruções

Este questionário procura conhecer a sua qualidade de vida, saúde, e outras áreas da sua vida.

Por favor, responda a todas as perguntas. Se não tiver a certeza da resposta a dar a uma pergunta, escolha a que lhe parecer mais apropriada. Esta pode muitas vezes ser a resposta que lhe vier primeiro à cabeça.

Por favor, tenha presente os seus padrões, expectativas, alegrias e preocupações. Pedimos-lhe que tenha em conta a sua vida nas duas últimas semanas.

Por exemplo, se pensar nestas duas últimas semanas, pode ter que responder à seguinte pergunta:

	Nada	Pouco	Moderadamente	Bastante	Completamente
Recebe das outras pessoas o tipo de apoio que necessita?	1	2	3	4	5

Deve pôr um círculo à volta do número que melhor descreve o apoio que recebeu das outras pessoas nas duas últimas semanas. Assim, marcaria o número 4 se tivesse recebido bastante apoio, ou o número 1 se não tivesse tido nenhum apoio dos outros nas duas últimas semanas.

Por favor leia cada pergunta, veja como se sente a respeito dela, e ponha um círculo à volta do número da escala para cada pergunta que lhe parece que dá a melhor resposta.

		Muito Má	Má	Nem Boa Nem Má	Boa	Muito Boa
1 (G1)	Como avalia a sua qualidade de vida?	1	2	3	4	5

		Muito Insatisfeito	Insatisfeito	Nem satisfeito nem insatisfeito	Satisfeito	Muito Satisfeito
2 (G4)	Até que ponto está satisfeito(a) com a sua saúde?	1	2	3	4	5

As perguntas seguintes são para ver até que ponto sentiu certas coisas nas duas últimas semanas.

		Nada	Pouco	Nem muito nem pouco	Muito	Muitíssimo
3 (F1.4)	Em que medida as suas dores (físicas) o(a) impedem de fazer o que precisa de fazer?	1	2	3	4	5
4 (F11.3)	Em que medida precisa de cuidados médicos para fazer a sua vida diária?	1	2	3	4	5
5 (F4.1)	Até que ponto gosta da vida?	1	2	3	4	5
6 (F24.2)	Em que medida sente que a sua vida tem sentido?	1	2	3	4	5
7 (F5.3)	Até que ponto se consegue concentrar?	1	2	3	4	5
8 (F16.1)	Em que medida se sente em segurança no seu dia-a-dia?	1	2	3	4	5
9 (F22.1)	Em que medida é saudável o seu ambiente físico?	1	2	3	4	5

As seguintes perguntas são para ver até que ponto experimentou ou foi capaz de fazer certas coisas nas duas últimas semanas.

		Nada	Pouco	Moderadamente	Bastante	Completamente
10 (F2.1)	Tem energia suficiente para a sua vida diária?	1	2	3	4	5
11 (F7.1)	É capaz de aceitar a sua aparência física?	1	2	3	4	5
12 (F18.1)	Tem dinheiro suficiente para satisfazer as suas necessidades?	1	2	3	4	5
13 (F20.1)	Até que ponto tem fácil acesso às informações necessárias para organizar a sua vida diária?	1	2	3	4	5
14 (F21.1)	Em que medida tem oportunidade para realizar actividades de lazer?	1	2	3	4	5

		Muito Má	Má	Nem boa nem má	Boa	Muito Boa
15 (F9.1)	Como avaliaria a sua mobilidade [capacidade para se movimentar e deslocar por si próprio(a)]?	1	2	3	4	5

As perguntas que se seguem destinam-se a avaliar se se sentiu bem ou satisfeito(a) em relação a vários aspectos da sua vida nas duas últimas semanas.

		Muito Insatisfeito	Insatisfeito	Nem satisfeito nem insatisfeito	Satisfeito	Muito Satisfeito
16 (F3.3)	Até que ponto está satisfeito(a) com o seu sono?	1	2	3	4	5
17 (F10.3)	Até que ponto está satisfeito(a) com a sua capacidade para desempenhar as actividades do seu dia-a-dia?	1	2	3	4	5
18 (F12.4)	Até que ponto está satisfeito(a) com a sua capacidade de trabalho?	1	2	3	4	5
19 (F6.3)	Até que ponto está satisfeito(a) consigo próprio(a)?	1	2	3	4	5
20 (F13.3)	Até que ponto está satisfeito(a) com as suas relações pessoais?	1	2	3	4	5
21 (F15.3)	Até que ponto está satisfeito(a) com a sua vida sexual?	1	2	3	4	5
22 (F14.4)	Até que ponto está satisfeito(a) com o apoio que recebe dos seus amigos?	1	2	3	4	5
23 (F17.3)	Até que ponto está satisfeito(a) com as condições do lugar em que vive?	1	2	3	4	5
24 (F19.3)	Até que ponto está satisfeito(a) com o acesso que tem aos serviços de saúde?	1	2	3	4	5
25 (F23.3)	Até que ponto está satisfeito(a) com os transportes que utiliza?	1	2	3	4	5

ID: _____

As perguntas que se seguem referem-se à frequência com que sentiu ou experimentou certas coisas nas duas últimas semanas.

		Nunca	Poucas vezes	Algumas vezes	Frequentemente	Sempre
26 (F8.1)	Com que frequência tem sentimentos negativos, tais como tristeza, desespero, ansiedade ou depressão?	1	2	3	4	5

ID: _____

ISMI – ESTIGMA INTERNALIZADO EM PESSOAS COM DOENÇA MENTAL

Neste questionário será usada a expressão “doença mental”, mas por favor, interprete-a usando o termo que acha que melhor se aplica.

Assinale em cada questão se Discorda totalmente, Discorda, Concordo ou Concordo Totalmente

		Discordo Totalmente	Discordo	Concordo	Concordo Totalmente
1	Sinto-me deslocado/a no mundo porque tenho uma doença mental.				
2	As pessoas discriminam-me porque tenho uma doença mental.				
3	Procuo não me aproximar de pessoas que não têm uma doença mental de modo a evitar a rejeição.				
4	Sinto-me embaraçado/a ou envergonhado/a por ter uma doença mental.				
5	As pessoas com doença mental não devem casar.				
6	As pessoas com doenças mentais dão um contributo importante à sociedade.				
7	Sinto-me inferior àquelas pessoas que não têm doença mental.				
8	Não socializo tanto como anteriormente, por causa da minha doença mental, que pode fazer com que eu pareça ou reaja de forma “estranha”.				
9	As pessoas com uma doença mental não conseguem viver uma vida boa e gratificante.				
10	Não falo muito de mim mesmo/a porque não quero sobrecarregar as outras pessoas com a minha doença mental.				
11	As ideias negativas ou estereótipos sobre as doenças mentais fazem com que me isole do mundo dito “normal”.				
12	Estar com pessoas que não têm doença mental faz com que me sinta deslocado/a ou inadequado/a.				
13	Não me sinto à vontade ao ser visto/a em público com uma pessoa que tem manifestamente uma doença mental.				
14	As pessoas muitas vezes tratam-me com um ar condescendente ou tratam-me como uma criança só porque tenho uma doença mental.				
15	Estou desiludido/a comigo por ter uma doença mental.				
16	Ter uma doença mental estragou a minha vida.				
17	As pessoas conseguem ver que tenho uma doença mental pela aparência que tenho.				
18	Devido à minha doença mental preciso que os outros tomem a maioria das decisões por mim.				
19	Evito situações sociais para proteger a minha família e amigos de embaraços.				
20	As pessoas que não têm doença mental não iriam conseguir compreender-me.				

		Discordo Totalmente	Discordo	Concordo	Concordo Totalmente
21	As pessoas ignoram-me ou não me levam tão a sério só porque tenho uma doença mental.				
22	Não consigo contribuir em nada para a sociedade porque tenho uma doença mental.				
23	Viver com uma doença mental tem feito de mim um/a lutador/a sobrevivente.				
24	Ninguém iria querer aproximar-se de mim porque tenho uma doença mental.				
25	De um modo geral consigo viver a minha vida da maneira que eu quero.				
26	Não me sinto realizado/a ou satisfeito/a e bem com a vida, por causa da minha doença mental.				
27	As pessoas pensam que não consigo alcançar muita coisa na vida porque tenho uma doença mental.				
28	As ideias negativas ou estereótipos sobre as pessoas com doença mental aplicam-se a mim.				

ID: _____

RSES - Escala de Avaliação Global da Auto Estima de Rosenberg

Segue-se uma lista de afirmações que dizem respeito ao modo como se sente acerca de si próprio(a). À frente de cada uma delas assinale com uma cruz (X), na respetiva coluna, a resposta que mais se lhe adequa.

		Concordo completamente	Concordo	Discordo	Discordo completamente
1	Globalmente, estou satisfeito(a) comigo próprio(a).				
2	Por vezes penso que não sou bom/boa em nada.				
3	Sinto que tenho algumas qualidades.				
4	Sou capaz de fazer as coisas tão bem como a maioria das pessoas.				
5	Sinto que não tenho muito de que me orgulhar.				
6	Por vezes sinto-me, de facto, um(a) inútil.				
7	Sinto-me uma pessoa de valor, pelo menos tanto quanto a generalidade das pessoas.				
8	Gostaria de ter mais respeito por mim próprio(a).				
9	Bem vistas as coisas, inclino-me a sentir que sou um(a) falhado(a).				
10	Adoto uma atitude positiva para comigo.				

ID: _____

Annex 3

Table 1 - Sociodemographic characteristics of the participants

		N (%)
		Total sample (n = 51)
Age; M (SD)		44.78 (11.0)
Min - Max		24-65
Gender	Male	34 (66.7)
	Female	17 (33.3)
Marital Status	Single	29 (56.9)
	Married/Civil union	14 (37.4)
	Divorced	5 (9.8)
	Widowed	3 (5.9)
Highest level of education	No former education	3 (5.9)
	Basic education (first cycle)	5 (9.8)
	Basic education (5 th – 9 th grade)	30 (58.8)
	Upper secondary education (12 th grade)	12 (23.5)
	Higher education	1 (2.0)
Employment status	Active (full or part time)	10 (19.6)
	Unemployed/Unoccupied	7 (13.7)
	Retired (because of illness)	34 (66.6)
Age (min – max)		24 - 64
Cohabitants (living with)	Alone	9 (17.6)
	Parents (with or without brother/sister)	17 (33.3)
	Grandparent	1 (2.0)
	Brother/Sister	4 (7.8)
	Married (with or without son/daughter)	16 (31.4)
	Son/Daughter	4 (7.8)
	Institutionalised	1 (2.0)

Annex 4

Table 2 - Clinical characteristics of the participants

		N (%)
		Total sample (n = 51)
Diagnosis (DSM V)		
Schizophrenia n = 31	Paranoid Schizophrenia (F20.0)	27 (52.9)
	Hebephrenic Schizophrenia (F20.1)	1 (2.0)
	Residual Schizophrenia (F20.5)	2 (3.9)
	Simple Schizophrenia (F20.6)	1 (2.0)
Unspecified nonorganic psychosis n = 4	Psychosis NOS (F29.0)	4 (7.8)
Persistent delusional disorders n = 2	Delusional disorder (F22.0)	1 (2.0)
	Persistent delusional disorder (F22.9)	1 (2.0)
Schizoaffective disorders n = 4	Schizoaffective disorder, manic type (F25.0)	n = 4
Bipolar affective disorder (BAD) n = 2	BAD, current episode hypomanic (F31.0)	1 (2.0)
	BAD, current episode manic with psychotic symptoms (F31.2)	1 (2.0)
Specific personality disorders n = 7	Paranoid personality disorder (F60.0)	5 (9.8)
	Emotionally unstable personality disorder (F60.3)	2 (3.9)
Family history of psychiatric illness	Yes	22 (43.1)
	No	29 (56.9)
Age at diagnosis; M (SD)		29.2(10.9)
Min – Max		15 – 56
Duration of illness in years; M (SD)		15.6 (9.5)
Min – Max		1 – 43
Number of hospitalizations in years; M (SD)		2.4 (1.5)
Min - Max		0 – 6

Annex 5

Table 3 - Association between categorical variables and self-stigma categories

		Low self-stigma (n = 35; 68.6 %)	Elevated self-stigma (n = 16; 31.4%)	P value
Gender	Male	24 (70.6%)	10 (29.4%)	<i>P</i> = 0.753
	Female	11 (64.7%)	6 (35.3%)	
Marital status	Single/Divorced/	26 (70.3%)	11 (29.7%)	<i>P</i> = 0.742
	Widowed			
	Married/Civil union	9 (64.3%)	5 (35.7%)	
Highest level of education	Basic education	25 (65.8%)	13 (34.2%)	<i>P</i> = 0.753
	Upper education	10 (76.9%)	3 (23.1%)	
Employment status	Active	10 (100%)	0 (0.0%)	<i>P</i> = 0.021
	Unemployed/Retired	25 (61.0%)	16 (39.0%)	
Family history of psychiatric illness	Yes	16 (72.7%)	6 (27.3%)	<i>P</i> = 0.559
	No	18 (64.3%)	10 (35.7%)	
Number of hospitalizations	> 2	12 (69.6%)	14 (30.4%)	<i>P</i> = 1.000
	<= 2	20 (69.0%)	9 (31.0%)	

Bold values refer to statistically significant correlations.

Annex 6

Table 4 – Stigma scores medians comparison between groups (gender, marital status, level of education, employment status and number of hospitalizations)

		N	Mean Rank	Sum of Ranks	U	P value
Gender	Male	34	25.51	867.50	272.50	<i>P</i> = 0.740
	Female	17	26.97	458.50		
Marital Status	Single, divorced or widowed	37	26.24	971.00	250.00	<i>P</i> = 0.848
	Married/Civil union	14	25.36	355.00		
Level of education	Basic education	38	25.88	983.50	242.50	<i>P</i> = 0.922
	Upper education	13	26.35	342.50		
Employment status	Active	10	14.75	147.50	92.50	<i>P</i> = 0.007
	Unemployed/Retired	41	28.74	1178.50		
Number of hospitalization	> 2	17	23.47	682.00	246.00	<i>P</i> = 0.991
	<= 2	29	23.52	399.00		

Bold values refer to statistically significant correlations.

Anex 7

Table 5 - Spearman's coefficient correlations between internalized stigma, self-esteem, QoL domains scores and continuous variables

	Self-stigma (total score) ISMI	Self-esteem RSES	Quality of Life (total score)
Self-esteem (RSES)	rho = - 0.745 (P < 0.001)		rho = 0. 551 (P < 0.001)
Physical (QoF)	rho = - 0.497 (P < 0.001)	rho = 0.542 (P < 0.001)	rho = 0. 710 (P < 0.001)
Psychological (QoF)	rho = - 0.545 (P < 0.001)	rho = 0.545 (P < 0.001)	rho = 0. 841 (P < 0.001)
Social Relationships (QoF)	rho = - 0. 473 (P < 0.001)	rho = 0.346 (P < 0.001)	rho = 0. 864 (P < 0.001)
Environment (QoL)	rho = - 0.471 (P < 0.001)	rho = 0.379 (P < 0.001)	rho = 0. 837 (P < 0.001)
QoL (total score)	rho = - 0.586 (P < 0.001)	rho = 0. 551 (P < 0.001)	
Age	rho = 0.191 (ns)	rho = - 0.209 (ns)	rho = - 0.091 (ns)
Level of Education	rho = 0.001 (ns)	rho = 0.100 (ns)	rho = - 0.186 (ns)
Age at diagnosis	rho = - 0.095 (ns)	rho = 0.111 (ns)	rho = 0.130 (ns)
Time of illness	rho = 0.217 (ns)	rho = - 0.259 (ns)	rho = - 0.181 (ns)
Number of hospitalizations	rho = - 0.028 (ns)	rho = - 0.145 (ns)	rho = - 0.045 (ns)

Bold values refer to statistically significant correlations. Abbreviation: ns, not significant.

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