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# Internalized stigma and its impact on schizophrenia quality of life

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#### ABSTRACT

The internalization of schizophrenia-related stigma highly affects people living with this disease, hindering their recovery process. The aim of this work is to study the effect of alienation and stereotype endorsement on the specific dimensions of schizophrenia-specific quality of life (SQoL), through the damage on selfesteem and self-efficacy. The model was tested in 167 patients with schizophrenia by path analysis using maximum likelihood procedure. The data fit the proposed model, but not all hypothesized predictions were met. A negative effect of alienation on selfesteem and self-efficacy was shown, while the negative effect of stereotype endorsement on these self-concept-related variables was non-significant. Self-esteem significantly contributed to the variance of the three dimensions of SQoL, while self-efficacy seems not to be involved in the model. Our results suggest that both alienation and stereotype endorsement have a direct effect on psychosocial SQoL and physical SQoL, while motivation and energy-related SQoL is affected only indirectly by alienation (through the decrease of self-esteem). Finally, we found that selfesteem significantly mediates the negative effect of alienation on the three dimensions of SQoL. We propose that the strengthening of self-esteem would mitigate the damage on SQoL, protecting specially the motivation and energy dimension, which may favor recovery.

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#### **KEYWORDS**

Self-stigma; alienation; stereotype endorsement; self-esteem; self-efficacy; quality of life; internalized stigma; schizophrenia

### Introduction

The internalization of mental illness stigma is the process by which people diagnosed endorse and apply to themselves the negative stereotypes related to the diagnosis (Corrigan, Larson, & Rüsch, 2009). It has been suggested that this internalization indirectly reduces the probabilities of recovery from the disease (Garay, Pousa, & Pérez, 2014; Livingston & Boyd, 2010) and increases suicide risk (Campo-Arias & Herazo, 2015). As a direct consequence of internalization, the person suffers a deterioration of his self-esteem and self-efficacy (Corrigan et al., 2009; Corrigan & Rao, 2012), which are essential components of positive self-concept. This deterioration of the self-concept may trigger some negative consequences. On the one hand, it has been shown that the patients tend to adopt a passive attitude that will lead them to not getting involved in the consecution of life goals (Corrigan et al., 2009). On the other hand,

CONTACT Clara I. Morgades-Bamba 🖾 claramorgades@cop.es 🖃 Avda. Valencia, 13, 6°C, Zaragoza 50005, Spain © 2019 Informa UK Limited, trading as Taylor & Francis Group they may suffer a deterioration of their affective well-being - this is, and increase of the frequency of experiencing negative affects, and a decrease of the frequency of experiencing positive affects (Morgades-Bamba, Fuster-Ruizdeapodaca, & Molero, 2017). Specifically, people with schizophrenia and their family caregivers had the highest internalized stigma among the different mental illnesses (Chang, Wu, Chen, & Lin, 2016; Chang, Yen, Jang, Su, & Lin, 2017). Concretely in these patients, it has also been shown that internalized stigma deteriorates well-being through the negativization of self-concept (Morgades-Bamba, Fuster-Ruizdeapodaca, & Molero, 2019). It has been claimed that studies about the sociocultural factors that could affect the quality of life (QoL) of patients with schizophrenia are needed (Caqueo-Urízar & Lemos-Giráldez, 2008), and we wondered whether such deterioration of positive self-concept - result of internalizing the schizophrenia-related stigma - could also affect QoL. There are two types of factors that predict QoL in schizophrenia patients: those which affect perception and those which affect expectations (Pinikahana, Happell, Hope, & Keks, 2002). Internalized stigma meets both requirements, since it affects self-perception and expectations about self-capacity and own future. QoL includes different dimensions as physical and mental health, psychological and social well-being, and the ability to carry out activities of daily life (Caqueo-Urízar & Lemos-Giráldez, 2008). In people with severe mental illnesses, it has been found a negative effect of internalized stigma on QoL - measured as satisfaction with own life - and that self-esteem mediates this effect (Corrigan, Sokol, & Rüsch, 2013; Mashiach-Eizenberg, Hasson-Ohayon, Yanos, Lysaker, & Roe, 2013). Specifically, in people with schizophrenia, Sibitz et al. (2011) found that empowerment which included self-esteem and self-efficacy - mediates the effect of stigma (as latent variable composed by public stigma and self-stigma) on QoL. Moreover, recently, it has been found that internalized stigma negatively impacts the different dimensions of QoL (social, psychological and physical) in schizophrenia patients, and that self-esteem is mediating these effects (Huang, Chen, Pakpour, & Lin, 2018). Nevertheless, the specific impact of the different dimensions of internalized stigma on the distinct dimensions of schizophrenia-specific quality of life (SQoL) has not been studied yet.

Most studies in patients with schizophrenia use generic QoL instruments, as the Short Form-36 Health Survey (SF-36; Ware & Gandek, 1998) or the World Health Organization Quality of Life (WHOQOL-BREF; Whoqol Group, 1998). Recently, it has been shown that SQoL instruments had more sensitivity as compared with those generic QoL instruments (Su, Yang, & Lin, 2017a, 2017b). Concretely, it has been recommended to use the Schizophrenia Quality of Life Scale (SQLS; Wilkinson et al., 2000) which has shown its psychometric solidity (Su et al., 2017a). Further, this measure of SQoL assesses items very close conceptually to symptomatology and it has been widely used to evaluate symptomatology and social function of these patients (Lysaker & Davis, 2004). Thus, it was considered necessary to carry out a research on the effect of internalized stigma, through self-esteem and self-efficacy deterioration, on each dimension of specific SQoL: Motivation and energy-related SQoL, psychosocial SQoL and physical SQoL (Wilkinson et al., 2000).

Otherwise, we wanted to study the specific effect of two dimensions of the internalized stigma proposed by Boyd-Ritsher, Otilingam, and Grajales (2003), which are the central core of internalization and that imply a modification in self-view: *Alienation* (feeling that one is

not a full member of society because of having schizophrenia), and *stereotype endorsement* (assuming and applying to oneself the negative stereotypes related to schizophrenia). Alienation and stereotype endorsement are the two dimensions associated to treatment adherence (Hajda et al., 2015) and they have been identified as the predictors of the damage on positive self-concept (Boyd-Ritsher & Phelan, 2004; Morgades-Bamba et al., 2017). The other dimensions of internalized stigma proposed by Boyd-Ritsher et al. (2003) were not of our interest because, as we and other authors see it, *perceived discrimination* would be a cause of the internalization process, while *social withdrawal* would be a consequence of it (Morgades-Bamba et al., 2017; Yanos, Roe, Markus, & Lysaker, 2008). For its part, *stigma resistance* – which measures the experience of being unaffected by the public stigma – is understood as an obstacle for internalization but not a part of the process, and it has been identified as a separate construct (Brohan, Elgie, Sartorius, & Thornicroft, 2010; Lysaker, Tsai, Yanos, & Roe, 2008; Sibitz, Unger, Woppmann, Zidek, & Amering, 2009).

According to the literature, we hypothesized a predictive model of SQoL. As shown in Figure 1, internalization of stigma (alienation and stereotype endorsement) would contribute to the decrease of positive self-concept (self-esteem and self-efficacy), which in turn would improve the three dimensions of SQoL (motivation-energy, psychosocial and physical). This is, alienation and stereotype endorsement would negatively affect SQoL dimensions through the deterioration of self-esteem and self-efficacy.

#### Method

#### **Participants**

Sample was composed of 167 people diagnosed with schizophrenia (73.6% men, 26.4% women), aged 24 to 70 (M = 44.38; SD = 9.69). They had been diagnosed between 1 and 40 years ago (M = 18.32; SD = 9.62). The only exclusion criterion was not to suffer cognitive impairment, which was determined by their clinician. All of them were users of 12 associations (non-profit organizations) spread throughout six Spanish autonomous communities: Andalucía, Aragón, Canarias, Cantabria, Comunidad Valenciana, y Galicia.



Figure 1. Hypothesized model.

#### Instruments

#### Internalized stigma

Two subscales of the Spanish version of the Internalized Stigma of Mental Illness (ISMI, Boyd-Ritsher et al., 2003; Muñoz, Sanz, Pérez-Santos, & De-Los-Ángeles-Quiroga, 2011) were used. These subscales assess the two most important dimensions of internalization of the stigma: a) *Alienation*: Six items like 'I feel inferior to others who don't have schizophrenia' or 'I feel out of place in the world because I have schizophrenia', and b) *Stereotype endorsement*: Seven items like 'I can't contribute anything to society because I have schizophrenia' or 'Because I have schizophrenia, I need others to make most decisions for me'. This scale was rated with a Likert scale from 1 (*strongly disagree*) to 4 (*strongly agree*).

#### Self-esteem

Spanish version (Expósito & Moya, 1999) of the 10-item Rosenberg's self-esteem scale (Rosenberg, 1965) was used. Five items are indicators of a high level of self-esteem (like 'I take a positive attitude towards myself '), while the other five indicate low self-esteem (for example, 'I wish I could have more respect for myself ') – which must be reverse-coded -. This scale was rated with a Likert scale from 1 (*strongly disagree*) to 4 (*strongly agree*).

#### Self-efficacy

The Spanish validation (Sanjuán-Suárez, Pérez-García, & Bermúdez-Moreno, 2000) of the general self-efficacy scale (Schwarzer, 1992) was used. This scale includes 10 items like 'I can manage to solve difficult problems if I try hard enough'. This scale was rated with a Likert scale from 1 (*strongly disagree*) to 4 (*strongly agree*).

### Schizophrenia Quality of Life

Schizophrenia Quality of Life scale (SQLS, Wilkinson et al., 2000), in its Spanish version (Calvo, Pedraza, & Solano, 2012) was used. This 30-item scale was originally created to assess symptomatology in schizophrenia, and it has been widely used to study social function among these people (Lysaker & Davis, 2004). It is divided into three subscales, each of which measures a dimension of QoL in schizophrenia: a) *Motivation and energy:* Seven items like 'I tend to stay at home' or 'I lack the energy to do things'; b) *Psychosocial SQoL:* Fifteen items like 'I find it difficult to mix with people', 'I feel that people tend to avoid me', 'I take things people say the wrong way', 'I find it hard to concentrate', or 'My feelings go up and down'; and c) *Physical SQoL:* Eight items like 'My sleep is disturbed' or 'My muscles get stiff '.

This scale was rated with a Likert scale from 1 (*never*) to 4 (*always*). Scores on this scale (except three of them that were already positive) were inverted to be indicators of a good SQoL.

#### Procedure

Scales were administered to participants when they were clinically stable (based on the opinion of their clinician). Data collection was carried out in silent rooms of the associations, with the collaboration of the psychologists who work there. The average time to complete the scales was 40–45 min.

#### Statistical analyses

To assess the exploratory model, path analysis was conducted in AMOS 24 (Arbuckle, 2016) using maximum likelihood parameter estimation procedure. Regarding sample size, it 'should exceed 100 observations regardless of other data characteristics to avoid problematic solutions and obtain acceptable fit concurrently' (Nasser & Wisenbaker, 2003, p. 754). Our sample complies with the recommendation of 10 to 20 cases per parameter (Kline, 2011), and good fit can be reached despite having a sample size of less than 200 (Hayduk, Cummings, Boadu, Pazderka-Robinson, & Boulianne, 2007; Markland, 2007).

To determine model fit, several goodness-of-fit indexes were taken into account, as recommended (Hu & Bentler, 1999). The  $\chi^2$  statistic, the goodness-of-fit index (GFI), the root mean square residual (RMR), the standardized root mean square residual (SRMR), the comparative fit index (CFI) and the root mean square error of approximation (RMSEA) were used. The Akaike information criterion (AIC) and the consistent Akaike information criterion (CAIC) were also used to compare different models.

Models are considered to have a good fit when the  $\chi^2$  statistic is non-significant; GFI and CFI are greater than .90; SRMR and RMSEA are .08 or less and RMR is less than .05 (Hu & Bentler, 1999). However, when the sample size is small and the model have few degrees of freedom, the RMSEA too often falsely indicates a poor fit (Hu & Bentler, 1999; Kenny, Kaniskan, & McCoach, 2015). Lower values of AIC and CAIC indicate a better model.

To test for the statistical significance for the hypothesized mediations in the model, bias-corrected confidence intervals (95%) were calculated through the bootstrapping procedure (1,000 samples), as recommended by Shrout and Bolger (2002). Additionally, Sobel test was conducted for each mediation.

#### Results

#### Descriptive statistics and correlations

No differences were found in any variable according to sex, age or length of time diagnosed, except for a very low correlation between age and Motivation & Energy SQoL (r = .18; p < .05), so, in subsequent analyses, this effect was controlled for.

Cronbach's alphas, mean scores, standard deviations and bivariate correlations for all variables in the model are displayed in Table 1. All expected relationships were met except for the association between self-efficacy and physical SQoL. Thus, this prediction was not included in subsequent analysis.

#### Path analysis

Although all of the indexes show that the model fit the data well (see Table 2, Model 1), some of the hypothesized predictions were not met (see Figure 2). Specifically, the paths from stereotype endorsement to self-esteem and self-efficacy, as well as the paths from self-efficacy to SQoL dimensions, were found to be non-significant. For this reason, we decided to test an alternative model in which: 1) self-efficacy was removed, and 2) direct paths from stereotype endorsement to the three SQoL dimensions were added, based on the correlations found and the theoretical sustenance. Finding then that the path from

Table 1. Descriptive statistics			relations		ables in	the mou	ici.	
Variables	а	M SD	1	2	3	4	5	6
1. Alienation <sup>a</sup>	.78	2.23 .67	-					
2. Stereotype endorsement <sup>a</sup>	.74	1.92 .56	.54**	-				
3. Self-esteem <sup>a</sup>	.77	2.81 .47	52**	37**	-			
4. Self-efficacy <sup>a</sup>	.82	2.58 .50	32*	21*	.51**	-		
5. Physical SQoL <sup>b</sup>	.85	3.70.83	49**	40**	.38**	.15	-	
6. Psychosocial SQoL <sup>b</sup>	.89	3.14 .73	63**	41**	.56**	.34**	.68**	-
7. Motivation & Energy SQoL <sup>b</sup>	.67	3.27 .60	36**	29**	.50**	.25*	.43**	.55**

Table 1. Descriptive statistics and bivariate correlations for all variables in the model.

Note. SQoL = schizophrenia quality of life. <sup>a</sup> Rated on a Likert scale from 1 to 4. <sup>b</sup> Rated on a Likert scale from 1 to 5. \*p < .01; \*\*p < .001.

Table	2.	Goodness-of-Fit	indexes	for	the	tested	models
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	χ²	df	р	GFI	RMR	SRMR	CFI	RMSEA	AIC	CAIC
Model 1 (Hypothesized)	4.45	2	.108	.993	.014	.035	.994	.086	56.45	163.51
Model 2	7.09	3	.069	.987	.020	.050	.989	.091	43.09	117.22
(Re-specified)										

Note. GFI = goodness-of-fit index, RMR = root mean square residual, SRMR = standardized root mean square residual, CFI = comparative fit index, RMSEA = root mean square error approximation; AIC = Akaike information criterion; CAIC = consistent Akaike information criterion.



$$p < .05; **p < .01; ***p < .001$$

Figure 2. Results for Model 1 (hypothesized model): Standardized regression coefficients for each path, and  $R^2$  for each endogenous variable.

stereotype endorsement to motivation and energy was not significant, it was eliminated. The resultant re-specified model shows an acceptable fit and lower values of AIC and CAIC than the full hypothesized model (see Table 2, Model 2). As it can be seen in Figure 3, a considerable amount of variance of SQoL is explained by the model (motivation and energy: 25%; psychosocial: 33%; physical: 20%).

#### **Mediations**

To test for the statistical significance of the mediating role of self-esteem, a new model was conducted. In this model, alienation (as a unique predictor) was linked to SQoL dimensions, both directly and indirectly through self-esteem. Standardized total, direct



\*p < .05; \*\*p < .01; \*\*\*p < .001

Figure 3. Results for Model 2 (re-specified model): Standardized regression coefficients for each path, and  $R^2$  for each endogenous variable.

 Table 3. Test of the mediating role of Self-esteem: Direct, indirect and total effects, and associated bootstrapping bias-corrected 95% confidence intervals (CI).

	Predictor: Alienation						
Outcome	Direct effect [CI]	Indirect effect [CI]	Total effect [CI]				
Motivation & Energy SQoL	14 [30, .00]	22 [33,12] **	36 [49,22] **				
Psychosocial SQoL	47 [60,32] **	16 [26,09] **	63 [73,52] **				
Physical SQoL	40 [55,23] **	09 [18,01] *	49 [62,36] **				

Note. All the reported estimates are standardized. SQoL = schizophrenia quality of life. \*p < .05; \*\*p < .01.

and indirect effects of alienation on SQoL are displayed in Table 3. As it can be seen, all indirect effects were statistically significant. According to these results, self-esteem is partially mediating the effect of alienation on physical SQoL and psychosocial SQoL (in the latter case, in a greater extent) and totally mediating this effect on the motivation-energy dimension.

#### Discussion

The main objective of this study was to test a model of the impact of internalized stigma on SQoL, hypothesizing that self-esteem and self-efficacy are mediating this effect.

Previously it had been found that internalized stigma predicts a decrease in QoL in people with schizophrenia (Huang et al., 2018; Sibitz et al., 2011). Nevertheless, to date, there was no study about the specific impact of the different dimensions of internalized stigma on the specific dimensions of SQoL. Besides, the mediation of empowerment (Sibitz et al., 2011) and self-esteem (Huang et al., 2018) on the negative impact of stigma on QoL had been previously identified in schizophrenia patients, but the specific role of self-efficacy had not been studied. The present results support previous findings and shed light on the process of the concrete effect of alienation and stereotype endorsement on each specific dimension of SQoL. Our results indicate that both alienation and stereotype endorsement directly contribute to the decrease of SQoL.

Huang et al. (2018) found that internalized stigma impacts above all psychological QoL, and according to our results, it seems that is alienation which is causing this impact. Moreover, we have found that self-esteem (and not self-efficacy) mediates the effect of alienation on each of the three dimensions of SQoL (motivation-energy, psychosocial and physical), while the effect of stereotype endorsement on SQoL (psychosocial and physical) is not mediated by self-esteem nor by self-efficacy.

Thus, our results show that self-esteem could mitigate the impact of alienation on SQoL (especially, it may be an important protector of motivation and energy SQoL among these patients), and this seems to be a relevant finding that should be taken into account when designing and improving interventions for schizophrenia. Self-esteem had been shown as a mediator of the effect of internalized stigma on QoL – measured as satisfaction with life – in people with serious mental illness (Mashiach-Eizenberg et al., 2013), and our results suggest that is the impact of alienation which is actually being mediated. According to previous findings (Boyd-Ritsher & Phelan, 2004; Morgades-Bamba et al., 2017), we have found that alienation is the dimension of internalized stigma which diminishes self-esteem. Moreover, according to previous findings, we have found that alienation causes greater damage than stereotype endorsement, both in the variables of positive self-concept and in those of well-being (Morgades-Bamba et al., 2019). We propose that more attention should be given to the alienation process, without underestimating the importance of the other dimensions.

On the other hand, our results also suggest that self-efficacy does not contribute to SQoL, and this could be due to the fact that, in schizophrenia patients, self-efficacy might be related to grandiose delusions. The fact that we have not found a significant effect of stereotype endorsement on self-efficacy might also be explained by a probable moderating role of megalomaniac symptomatology on this relation. It has previously been found that self-esteem is the main mediator of the negative impact of the internalization of schizophrenia-related stigma (Huang et al., 2018; Morgades-Bamba et al., 2019). It has been shown that self-efficacy only seems to mediate the impact of internalized stigma on positive affect, but not on negative affect (Morgades-Bamba et al., 2019). Therefore, it could also be hypothesized that self-efficacy does not significantly impact negative variables in schizophrenia (in the present study SQoL has been measured through items that assess problems analogous to symptomatology, which punctuation must be reverse-coded in order to obtain the level of a positive variable as it is SQoL). Perhaps, it would be advisable to assess SQoL through an instrument that reflect aspects of SQoL, and not the lack of it. For example, to measure motivation and energy SQoL we could use items like 'I have energy to do things' or 'I usually leave home (to walk, to do leisure activities, to make purchases or errands, to meet someone...)' instead of 'I lack the energy to do things' and 'I tend to stay at home'. Regarding psychosocial SQoL, instead of 'I find it hard to concentrate', 'My feelings go up and down' or 'I find it difficult to mix with people', we could use items like 'I am able to concentrate', 'I have emotional balance' and 'I do not have difficulties to mix with people'. And regarding physical SQoL, instead of 'My sleep is disturbed' or 'I feel unsteady walking', we could use 'I sleep well at night' and 'I feel steady walking'.

In schizophrenia patients, Tang and Wu (2012) had found a negative relation between internalized stigma and mental health-related QoL, but not between internalized stigma and physical health-related QoL. This may be due to methodological aspects, since these authors used a general instrument of measurement (the SF-12 *World Health Organization Questionnaire of Quality of Life*), while we have used a specific one for measuring physical SQoL. As Pinikahana et al. (2002) pointed out, it is essential that it is clear what is being measured when we study QoL in schizo-phrenia, and compare findings.

According to our findings and those from other studies (Boyd-Ritsher & Phelan, 2004; Morgades-Bamba et al., 2017; Yanos et al., 2008), we could hypothesize a correspondence between the dimensions of internalized stigma (Boyd-Ritsher et al., 2003) and the four phases of the internalization process (Corrigan et al., 2015): (1) Perceived discrimination = *Aware*; (2) Stereotype endorsement = *Agree*; (3) Alienation = *Application*; (4) Social Withdrawal (in addition to deterioration of self-concept, decrement of well-being and decrement of SQoL) = *Harm*. Future research should address this issue. Regarding the *Cognitive-affective-behavioral model of self-stigma for concealable minorities* (Chang, Lin, Gronholm, & Wu, 2018; Mak & Cheung, 2010) we could hypothesize the following correspondence: (1) Perceived discrimination and stereotype endorsement = *Cognitive*; (2) Alienation and deterioration of self-concept = *Affective*; (3) Social Withdrawal = *Behavioral*. This also should be studied in future research.

We also propose that, in schizophrenia, it could exist another step between *application* and *harm*. A patient with schizophrenia might agree with negative schizophreniarelated stereotypes and be in part alienated, but feel at the same time that he is special or omnipotent (Pérez-Álvarez, 2012), which would reduce *harm* or maybe sometimes even avoid it (Smith et al., 2006). Moreover, without the presence of grandiose delusions, a schizophrenia patient might believe that he is not 'mentally ill' – or live with two opposite and simultaneous beliefs: I have schizophrenia/I do not have schizophrenia (Pérez-Álvarez, 2012). In these cases, the person could agree with stereotypes and be alienated because of being diagnosed with schizophrenia, but not suffer the same harm than others (or suffer it differently).

Otherwise, since the items on the SQoL scale are very close conceptually to symptomatology, we hypothesize that this model could also work for predicting negative and positive symptoms of schizophrenia. Schizophrenia is understood by some authors as a self-disorder (Pérez-Álvarez, 2012; Postmes et al., 2014) which implies a disturbance of reality that could be triggered by a disturbance of the self, so is possible that an additional modification of the self-concept (as a consequence of internalized stigma) could exacerbate symptomatology. Besides, it has been found that distancing behaviors – which may arise from internalized stigma – predicts a higher level of paranoid ideation (MacBeth, Schwannauer, & Gumley, 2008), and social avoidance caused by internalized stigma has been shown as a predictor of the whole positive symptomatology (Yanos et al., 2008). For these reasons, the impact of the internalization of schizophreniarelated stigma on symptomatology should be studied.

As has been claimed, it is very necessary to study how to avoid alienation (Boyd-Ritsher & Phelan, 2004; Morgades-Bamba et al., 2017), as well as developing interventions focused on reduce the important negative effects of internalized stigma on recovery-related outcomes in people with schizophrenia (Yanos et al., 2008).

As limitations of this research, it should be noted that it was a cross-sectional study that should be approached in the future with Kernel smoothing methodology (Lin, Chang, Wu, & Wang, 2016) and, if possible, with a longitudinal design. On the other hand, all the patients were receiving some type of institutional support (psychologists and psychiatrists at their disposal, occupational therapy, artistic or leisure activities...), so our results cannot be generalized to all patients with schizophrenia. Finally, our sample is relatively small, so this study should be replicated using a larger one.

In conclusion, our study provides three main contributions to the study of stigma in schizophrenia. First, alienation and stereotype endorsement seem to diminish the whole SQoL. Secondly, self-esteem seems to play an important mediating role in the process, cushioning the effect of alienation. Thirdly, self-efficacy seems not to be involved in this process. This results have practical implications for the design of interventions in order to improve QoL in people with schizophrenia.

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