Does perceived control mediate the relationship between stigma and well-being for individuals with Parkinson's disease?

Dani Verity[1], Fiona J R Eccles[1*], Amanda Boland[2], Jane Simpson[1]

[1]Division of Health Research, Lancaster University, Lancaster, LA1 4YT, UK

[2]Cheshire & Wirral Partnership NHS Foundation Trust, Soss Moss Hospital Site, Chelford Road, Alderley, Macclesfield, SK10 4UJ, UK

*Corresponding author:

Fiona J R Eccles, Division of Health Research, Lancaster University, Lancaster, LA1 4YT, UK; +44(0)1524, 592807, f.eccles@lancaster.ac.uk

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Abstract

Introduction: Stigma is a known correlate of well-being for many neurological conditions. Perceived control is also an important variable in models of adaptation to living with a health condition. The purpose of this study was to investigate whether the perception of control mediates the relationship between stigma and well-being in people with Parkinson's disease.

Methods: Two hundred and twenty-nine individuals completed quantitative measures of stigma and perceived control, and a full exploration of the concept of well-being (including health-related quality of life, depression, anxiety, stress and positive affect). A series of mediation models investigated whether perceived control mediated the relationship between stigma and each measure of well-being.

Results: Mediational regression analyses indicated that the perception of control mediated the relationship between stigma and health-related quality of life, depression and positive affect. Perceived control did not, however, mediate the relationship between stigma and anxiety nor between stigma and stress.

Conclusions: These findings suggest that in people with Parkinson's disease, perceived control may play an important role in explaining the relationship between stigma and some aspects of well-being. Both stigma and perceived control should be considered within clinical and everyday environmental settings for individuals with Parkinson's disease. Interventions which focus on both reducing stigma and increasing perceived control are outlined.

1. Introduction

People with Parkinson's disease (PD) often have visible physical differences (e.g., tremor, rigidity, dykinesias) as well as difficulties with cognition and communication. Such differences have long been known to attract stigma [1]. Classic accounts of stigma suggest it occurs in response to characteristics that deviate from the social norm and are considered to be of less value [e.g. [2]. Stigma can involve direct acts from others (e.g. being called derogatory names, or being stared at), known as enacted stigma as well as being felt as a result of anticipating such reactions and internalising negative societal stereotypes, known as felt stigma [3]

People with PD describe a variety of stigmatising experiences, including feeling shame and embarrassment due their difficulties, increased social isolation due to worries regarding others' perceptions and feeling a burden to others [4]. However, the relationship between stigma and psychological well-being is complex. For some individuals with PD, there appears to be an association between stigma experiences and high anxiety and depression e.g. [5, 6]. For others, the experience of stigma does not appear to correlate with anxiety [7] nor positive affect [6]. Therefore, there may be other factors that influence the effect of stigma on indices of well-being.

One variable which might explain the differing effects of stigma on measures associated with well-being is perceived control, understood as the level of control felt by an individual generally (i.e. over their life) or, as is more relevant in this context, in health-related domains. Control as a concept has been extensively used as both a predictor and outcome measure [8], is included in a number of theoretical models on adaptation to chronic illness (e.g. self-regulatory model [9]) and has been shown to predict well-being, with higher levels of control generally (although with some

important caveats) predicting higher levels of well-being. For individuals with chronic health conditions, high levels of perceived control are generally associated with high scores of health-related quality of life (HRQoL) and low levels of anxiety, depression and negative affect [10, 11].

Obtaining a sense of perceived control over PD is challenging due to the chronic, unpredictable and degenerative nature of the condition, with people with PD reporting loss of self-efficacy and autonomy [4]. However, it is possible for individuals with PD to gain a sense of control over some aspects of treatment and/or over other aspects of their lives [8, 12]. Given the significance of perceived control for individuals with PD, it could be hypothesised that perceived control underpins the relationship between stigma and well-being and so acts as an important mediating variable.

It is accepted that well-being is a well-used term with no fixed and agreed definition e.g. [13] but is operationalised in this study by both the absence of mental health difficulties (i.e. as measured by depression and anxiety scales) and by the presence of positive affect. Consequently, the models tested whether perceived control mediates the relationship between stigma and measures of well-being. Specifically, it was predicted that low levels of stigma would be associated with high levels of well-being and perceived control and that perceived control would mediate the relationship between stigma and well-being.

2. Methods

2.1 Participants

All participants were recruited from a large UK-based PD charity (Parkinson's UK). The study was advertised online by the charity from September 2017 to

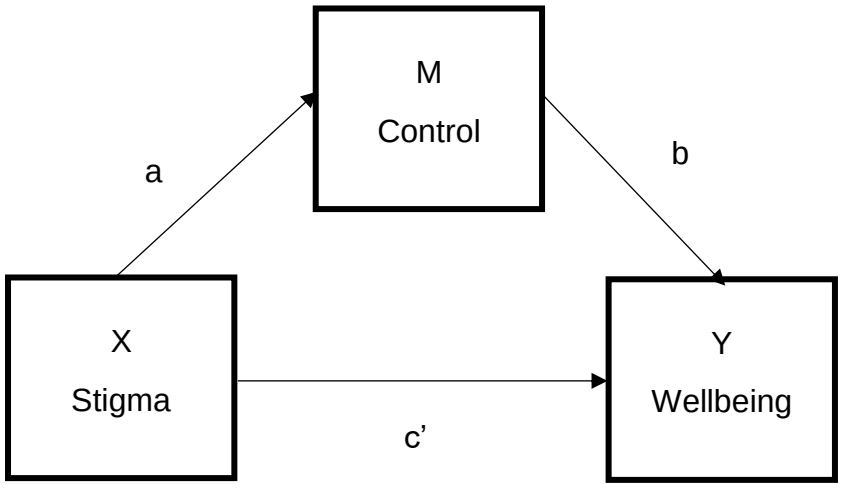
December 2017. While online recruitment methods have some limitations (e.g., inability to confirm diagnosis definitively), they have been used extensively elsewhere – e.g. in studies validating quality of life [14]. Individuals who met the following inclusion criteria were eligible to participate in the study:

- Self-reported a diagnosis of PD.
- Aged 18 years or above.
- Sufficient knowledge of written English to take part.
- Could complete the survey measures either alone or with support.

2.2 Design

The study was a cross-sectional survey comprised of quantitative measures. The data were examined using mediation analysis conducted using Hayes PROCESS tool [15] to examine whether perceived control mediated the relationship between stigma and well-being. A path diagram is shown in figure 1.

Figure 1. Path diagram



Parameters a, b and c' denote path (regression) coefficients.

Ethical approval was given by the researchers' host academic institution (Reference: FHMREC16123). All participants provided consent to participate in the study. At least 71 participants were required to provide 80% power (p <.05) [16].

2.3 Materials

The survey included demographic and clinical questions alongside validated measures. The demographic variables collected were age, gender, ethnicity, work status, relationship status and living arrangements (alone, co-habiting, residential/nursing home). The clinical variables collected were age of symptom onset, age of diagnosis and whether taking medication.

2.4 Validated Measures

2.4.1 Predictor Variable

The 24-item Stigma Scale for Chronic Illness (SSCI) [17] measures both perceived (or felt) stigma and enacted stigma and has been validated for use with individuals with neurological conditions such as PD. The scale consists of two subscales which measures the two stigma concepts. The perceived stigma subscale contains 13 items about an individual's feelings regarding their condition, focusing on any worries or feelings of embarrassment. The enacted subscale consists of 11 items and questions relate to an individual's objective experience of stigma such as noticing people staring. Scores on the two subscales are summed to create a total stigma score. Higher scores indicate higher experiences of stigma.

2.4.2 Mediator Variables

The 15-item Parkinson's UK Scale of Perceived Control (PUKSoPC) was developed with Parkinson's UK members and has been comprehensively validated [18]. The scale consists of five subscales: Think positive, Get informed, Do things, Make plans, and Be involved, which are summed to give the total score, used here. Higher scores indicate greater perceived control.

The 10-item General Self-Efficacy Scale (GSE) [19] was used as a general/non-health specific measure of perceived control. It assesses individuals' general beliefs in their ability to respond to and problem solve situations; higher scores indicate higher self-efficacy. It was used as a comparator measure to the above scale.

2.4.3 Outcome Variables

The 8-item Parkinson's Disease Questionnaire short form (PDQ8) was used to measure HRQoL [20, 21]. Lower scores indicate higher HRQoL.

The Depression Anxiety and Stress Scale-21 (DASS-21) [22] is a well-validated short-form version of the original 42-item scale. It consists of three subscales: depression, anxiety, and stress, with higher scores indicating more severe depression, anxiety or stress.

The 10-item positive subscale of the Positive and Negative Affect Schedule (PANAS) [23] was used to measure positive affect in the last few weeks (the DASS already provided an assessment of negative mood). Higher scores indicate greater positive affect.

2.5 Missing data

The missing data within the dataset were minimal (less than 5%). Twenty entries provided only demographic information and/or limited completion of measures and were removed [24]. Given the small amount of missing data, methods of mean imputation and pro-rating of individual cases was used for n = 14 [24]. One extreme data point was removed, leaving 229 participants in the overall data set.

2.6 Inferential analysis

Normality of the data was assessed and as some variables (particularly the DASS) were skewed, Spearman's correlation coefficients were conducted between each outcome variable and demographic/psychosocial variables. The data were then statistically examined using a mediational regression and only significant correlations ($p < .05$) were entered into the model [24]. Hayes PROCESS tool [15], which implements a bias-corrected bootstrap model, was utilised to conduct the mediation regression (with 1000 replications). Each regression which formed part of the mediation was tested to ensure assumptions of linearity, and normality and homoscedasticity of residuals were met.

3. Results

3.1 Descriptives

Demographic and clinical details can be seen in Table 1 and means, standard deviations (SD) and Cronbach's alpha of psychometric measures in Table 2. The mean of the sample indicated generally low levels for depression (in the mild range); the mean for anxiety fell within the moderate range; and the mean for stress fell

within the normal range [25]. The means were somewhat higher (indicating greater distress) than some previous Parkinson's disease studies [26, 27]. Using cut-offs in the manual [25], the proportions of the sample in the different categories were as follows: depression (normal 55%, mild 13.1%, moderate 17.5%, severe 6.1%, very severe 8.3%), anxiety (normal 32.8%, mild 13.5%, moderate 26.6%, severe 10.5%, very severe 16.6%) and stress (normal 61.6% , mild 14.8%, moderate 9.2%, severe 9.6%, very severe 4.8%). The mean PDQ8 was moderately low compared to the validation sample (indicating a higher HRQoL) but comparable to those in the validation sample at Hoehn and Yahr stage 2 [21, 28]. On the PANAS, positive affect was comparable to a UK general population validation sample [29], comparable to some previous Parkinson's disease samples [30, 31] but higher than others [27].

Table 1 Descriptive statistics of the sample

	Value	Range
Age: mean (SD)		
Age in years	65 (8.00)	29-90
Age of symptom onset	57 (9.74)	26-90
Age of diagnosis	60 (9.32)	29-90
Gender: n (%)		
Female	116 (51)	-
Male	113 (49)	-
Ethnic group: n (%)		
White	227 (91)	-
Asian	2 (9)	-
Partnership status: n (%)		
Single	18 (8)	-
Married	191 (83)	-

Divorced	10 (4)	-
Widowed	10 (4)	-
Living arrangements: n (%)		
Alone	37 (16)	-
With others (partners, family and friends)	190 (83)	-
Residential/nursing home	1 (0.5)	-
Other	1 (0.5)	-
Work Status:		
Employed	42	-
Other (including retired)	187	-

SD = standard deviation. Percentages are rounded to the nearest whole number, except for percentages less than one, which are rounded to the nearest 0.5%.

Table 2: Mean, standard deviation and correlates of variables

	SSCI	PUKSoPC	GSE	PDQ	DASS-D	DASS-A	DASS-S	PANAS
Mean	50.13	56.53	29.42	31.11	10.56	11.39	14.07	32.56
SD	15.70	10.18	6.33	20.63	10.13	7.78	9.51	9.27
Cronbach's alpha	0.94	0.89	0.94	0.85	0.92	0.72	0.88	0.93
Age	-0.11	0.12	0.05	0.04	-0.03	-0.09	-0.10	0.06
Gender	0.10	0.04	-.016*	0.00	-0.01	0.02	0.01	-0.02
Work status	-0.06	.202**	0.02	0.05	-0.02	-0.10	0.00	0.10
Relationship status	0.11	-.15*	-0.11	0.11	.15*	.15*	.18**	-0.13
Living status	-0.07	0.16*	0.11	-0.05	-0.14*	-0.13*	-0.15*	0.12
Age of symptom onset	-0.24**	0.07	0.14*	-0.15*	-0.11	-0.14*	-0.14*	0.09
Age of diagnosis	-0.25**	0.09	0.14*	-0.14*	-0.12	-0.13*	-0.11	0.09
Disease duration	0.24**	0.118	-0.12	0.28**	0.10	0.11	0.07	0.01
Prescribed medication	-0.10	0.00	0.09	-0.12	-0.08	-0.03	0.01	0.05

SSCI	-	-0.37**	-0.37**	0.68**	0.61**	0.49**	0.54**	-0.41**
PUKSoPC	-		0.51**	-0.37**	-0.50**	-0.22**	-0.30**	0.66**
GSE	-	-	-	-.005**	-0.50**	-0.30**	-0.36**	0.66**

SSCI = Stigma Scale for Chronic Illness; PUKSoPC = Parkinson's UK Scale of Perceived Control; GSE = General Self-Efficacy Scale. *p value is less than .05. **p value is less than .01. DASS-21 scores are doubled to allow comparison with the full 42 item DASS [25].

3.2 Correlational analyses

Prior to mediation regression, bivariate Spearman's correlations were carried out on the demographic and psychosocial variables (see Table 2 for details).

The stigma scale, the SSCI, correlated in the expected direction with the measures of depression, anxiety, stress, HRQoL and positive affect (DASS; PDQ; PANAS); higher stigma was associated with lower well-being. Significant negative correlations were found between the SSCI and both measures of perceived control (PUKSoPC; GSE); thus higher stigma scores were associated with lower scores of perceived control. Significant relationships in the predicted direction were found between both measures of perceived control (PUKSoPC; GSE) and all psychological outcomes variables, i.e. higher control correlated with higher well-being.

A number of demographic variables correlated with the outcome variables. Depression correlated with relationship status (those currently with a partner were less depressed than those not currently with a partner) and living status (those living with other/s were less depressed than those alone); anxiety correlated with relationship status (those with a partner were less anxious), age of symptom onset and diagnosis (higher age of onset/diagnosis, less anxiety); stress correlated with relationship status (those with a partner were less stressed), living status (those living with other/s were less stressed) and age of symptom onset (higher age of onset, less stress); and HRQoL correlated with age of symptom onset and diagnosis

(higher age of onset/diagnosis, higher HRQoL) and disease duration (shorter duration, higher HRQoL). These demographic variables were consequently controlled within the regression models.

3.3 Mediation analyses

Given the support from examination of the correlational analysis for the hypothesised mediation model, full mediational regression analyses were performed and then re-examined while controlling for covariates. As the outcomes controlling for covariates were very similar, for clarity only the results of the unadjusted analyses are shown in Tables 3 (with PUKSoPC as control variable) and 4 (with GSE as control variable).

3.3.1 Mediation with PUKSoPC as mediator

Table 3: Mediation Models with stigma as predictor (X) and PUKSoPC as mediator (M)

	Model 1 Y = HRQoL	Model 2 Y = anxiety	Model 3 Y = depression	Model 4 Y = stress	Model 5 Y = positive affect
A CI	-0.26** -0.34, -0.18	-0.26** -0.34, -0.18	-0.26** -0.34, -0.18	-0.26** -0.34, -0.18	-0.26** -0.34, -0.18
B CI	-0.09* -0.16, -0.03	-0.01 -0.11, 0.09	-0.26** -0.37, -0.15	-0.08 -0.19, 0.03	0.52** 0.43, 0.62
c' (direct effect) CI	0.26** 0.22, 0.31	0.23** 0.16, 0.29	0.32** 0.25, 0.39	0.30** 0.22, 0.37	-0.13** 0.19, 0.07
ab (indirect effect) CI	0.02 0.01, 0.05	0.003 -0.03, 0.03	0.07 0.03, 0.11	0.02 -0.01, 0.06	-0.14 -0.19, -0.09

CSIE	0.06	-	0.11	-	-0.23

CI = confidence interval; CSIE = completely standardised indirect effect. * $p < .05$ ** $p < .001$.

Mediation analyses indicated that perceived control was found to be a significant mediator between stigma and HRQoL (ab = 0.02, 95% CI [0.01, 0.05]). The direct effect between stigma and HRQoL remained significant when controlling for the effect of the mediational variable of perceived control (c' = 0.26, 95% CI [0.22, 0.31], $p < .001$). The completely standardised indirect effect indicated that as stigma scores increased by 1 SD, HRQoL scores increased by 0.06 SD due to the effect of perceived control. When controlling for age of symptom onset and age of diagnosis, all pathways of the model remained significant and the completely standardised indirect effect remained the same (0.06).

Similarly, perceived control was a significant mediator for the relationship between stigma and depression (ab = 0.07, 95% CI [0.03, 0.11]). The direct effect between stigma and depression remained significant when controlling for the effect of the mediational variable (c' = 0.32, 95% CI [0.25, 0.39], $p < .001$). The completely standardised indirect effect was 0.11. When adjusting for relationship status and living arrangements, all pathways of the model remained significant and the completely standardised indirect effect reduced slightly to 0.10.

Perceived control also mediated the relationship between stigma and positive affect (ab = -0.14, 95% CI [-0.19, -0.09]). The direct effect between stigma and positive affect remained significant when controlling for the effect of the mediator (c' = -0.13, 95% CI [0.19, 0.07], $p < .001$). The completely standardised indirect

effect was -0.23. There were no significant demographic and clinical covariates for positive affect so an adjusted model was not required.

Perceived control was not a significant mediator of the relationship between stigma and anxiety (ab = 0.003, 95% CI [-0.03, 0.03]). When adjusting for covariates symptom onset and relationship status, the non-significant finding remained. Similarly perceived control was not a significant mediator of the relationship between stigma and stress (ab = 0.02, 95% CI [-0.01, 0.06]). When adjusting for covariates living arrangements and relationship status and age of symptom onset, the non-significant finding remained.

3.3.2 Mediation with GSE as mediator

Table 4 Mediation Models with stigma as predictor (X) and GSE as mediator (M)

	Model 1 Y = HRQoL	Model 2 Y = anxiety	Model 3 Y = depression	Model 4 Y = stress	Model 5 Y = positive affect
A CI	-0.16** -0.21, -0.11	-0.16** -0.21, -0.11	-0.16** -0.21, -0.11	-0.16** -0.21, -0.11	-0.16** -0.21, -0.11
B CI	-0.27** -0.37, -0.17	-0.14 -0.29, 0.02	-0.46** -0.63, -0.29	-0.17 -0.35, 0.01	0.89** 0.74, 1.03
c' (direct effect) CI	0.25** 0.21, 0.29	0.21** 0.15, 0.27	0.31** 0.24, 0.38	0.29** 0.22, 0.36	-0.12** -0.18, -0.07
ab (indirect effect) CI CSIE	0.04 0.02, 0.07 0.10	0.01 -0.01, 0.03 -	0.07 0.03, 0.12 0.07	0.02 -0.01, 0.07 -	-0.14 -0.20, -0.09 -0.24

CI = confidence interval; CSIE: completely standardised indirect effect. * $p < .05$. ** $p < .001$.

As can be seen from Table 4, the finding using the GSE scale as a measure of control were very similar to those using the PUKSoPC. Again, perceived control mediated the relationship between stigma and health-related quality of life, depression and positive affect. It did not mediate the relationship between stigma and anxiety or stress. The findings when controlling for covariates were similar (the same paths remained significant).

4. Discussion

This study examined whether the perception of control played a mediating role in the relationship between stigma and a broad conceptualisation of well-being including HRQoL and standard indices of mood and positive affect. Stigma significantly correlated with all outcome measures in the expected direction (greater stigma, poorer well-being), with moderate effects between stigma and perceived control, positive affect and anxiety and large ones between stigma and stress, depression and HRQoL. Perceived control significantly mediated the relationship between stigma and HRQoL, depression and positive affect. All pathways within these models were significant, including when covariates were controlled. The largest completely standardised effect size was for the mediated relationship between stigma and positive affect. However, perceived control did not mediate the relationship between stigma and anxiety and stress.

The mediating effect of perceived control supports the importance placed upon it within health behaviour models such as Leventhal's self-regulatory model [11]. This model provides a framework of understanding how an individual's health

beliefs may facilitate adjustment to a health condition. Control is an important component of these beliefs and the model cumulatively can explain the various influences on and responses to a chronic condition such as PD [see [10] for review]. In addition, the current findings provide further support to the growing literature that emphasises the role of perceived control particularly for those with PD [8].

From a theoretical perspective, the association between (perceived) (un)controllability and depression has long been established. For example, learned helplessness may arise as a result of having limited or no control and this state has been associated with negative affect and is often considered to lead to depression [32]. However, both measures of perceived control (PUKSoPC; GSE) were more weakly associated with anxiety. While initially surprising, these findings are consistent with some previous research which reports a weak or no association between perceived control and anxiety when measured cross-sectionally [27, 33]. However Evans and Norman [33] found perceived control at baseline predicted anxiety six months later, when controlling for baseline anxiety, and therefore the relationship between perceived control and anxiety may be more complex and involve longitudinal effects.

Given the findings, interventions should acknowledge the effect of stigma, through the direct pathway and the indirect pathway, via perceived control. Reducing stigma is complicated and requires coordinated effort on a number of levels including intrapersonal, interpersonal, community, organisational and governmental change [34]. Intrapersonal interventions can target a variety of factors including knowledge, attitudes, emotions and behaviour as well as improving coping skills [34] which may both reduce stigma and improve perceived control. For example, cognitive-behavioural therapy (CBT) involving these factors has been effective in reducing

stigma in other conditions [34] and, while the stigma reduction has not been proven in PD, such intrapersonal factors are also targeted in CBT for people with PD [35]. More generally, psychological therapy has been shown to increase self-efficacy (and therefore perceived control) for people with other neurological conditions, including when used in groups [36]. Furthermore, self-help and advocacy groups may also be beneficial to target these intrapersonal factors, alongside working with local communities and families to increase social support [34].

However, individual interventions are frequently criticised for proposing the stigmatised individual as the agent of change, rather than placing the responsibility for such change into society. Indeed it can be society which has actively lead to the stigmatisation and diminution of control [37]. Thus there are calls for more research into interventions at wider organisational, community and societal levels [34]. Educational campaigns are needed to increase understanding in communities along with societal and legal changes which promote social inclusion and reduce discriminatory practices [34].

By measuring HRQoL in more depth, future research could examine whether one of the components of stigma predicts certain dimensions of HRQoL (e.g. enacted stigma could predict activities of daily living). With a greater understanding of stigma (i.e. its separate forms and how these are related to the individual components of HRQoL) interventions may be tailored more appropriately, at either an individual or societal level. For example, if enacted stigma plays a significant role in HRQoL, it may be more appropriate to increase awareness and understanding of the nature of PD through various media channels.

The study has a number of limitations. It used online recruitment and was advertised through Parkinson's UK. This may have selected a sample of individuals

who may be highly literate and/or motivated due to the fact that they have proactively become a member of a third-sector organisation. Therefore, the findings could be different for individuals with PD who do not have computer access or are not members of a charity. The study was only available in English, and although individuals were permitted to complete the survey with support, comprehending the survey and the concept of stigma may not be translatable to other languages or cultures.

Given the cross-sectional design of the study, the findings provide a snapshot of how perceived control may affect the relationship between stigma and variables of HRQoL. However, as it is cross-sectional, the direction of the relationships is not assured. Relationships may be bi-directional whereby, for example, lower mood also leads to reduced perceived control and an increased sensitivity to notice discrimination as well as a feeling of increased stigmatisation. Lower perceived control may also lead to greater feelings of stigma and hence lower wellbeing. Longitudinal studies would be needed to tease out further the temporal nature of these interactions. Furthermore, with a progressive condition, such as PD, the condition may become more visible and therefore more visible to others. Increasing visibility may result in higher experiences of stigma [1]. The experience of perceived control may also change over time with a changing course of the condition [11]. Longitudinal studies may also provide a more detailed picture of how these relationships may change over time.

5. Conclusion

Both stigma and perceived control are associated with quality of life and psychological distress (whereby greater stigma predicts greater distress and reduced

quality of life and greater control predicts less distress and improved quality of life). Furthermore, perceived control plays an important role in mediating the relationship between stigma and HRQoL, stigma and depression and stigma and positive affect. Interventions should target both control and stigma, not just at an individual level but also systemically to help enhance individuals' HRQoL and aspects of emotional well-being. Future research should further examine stigma and its defined forms with the individual components of HRQoL, to elucidate the relationships further. In addition, larger samples would enable the examination of more complex relationships and longitudinal studies would help clarify the nature of the relationships over time.

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