<u>Illness Perception Mediates the Effect of Illness Course on the Quality of Life of Mexican</u> <u>Patients with Psychosis</u>

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Gómez-de-Regil, L., Kwapil, T.R., & Barrantes-Vidal, N. (2014). Illness perception and functioning mediate the effect of illness course on the quality of life of psychosis patients. *Applied Research in Quality of Life*, 9(1), 99-112. doi: 10.1007/s11482-013-9211-4

The final publication is available at Springer via <u>http://dx.doi.org/10.1007/s11482-013-9211-4</u>

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Abstract:

Learning about possible factors influencing, positively or negatively, the Quality of Life (QoL) of patients with psychosis is an important task for both, research and treatment. The study examined the association of illness course with QoL in a sample of Mexican patients with psychosis. It was hypothesized that illness perception would mediate the relation of illness course to QoL. Sixty-one (56 % female) patients were interviewed and assessed for illness course (relapses, residual symptoms, and diagnosis), QoL, and illness perception. Mediation analyses (simple and multiple) with bootstrapping procedures were applied, including residual symptoms as the predictor of QoL, and illness perception dimensions as candidate mediators. Residual symptoms, rather than a relapsing course or a diagnosis of schizophrenia, have a diminishing effect in the subjective QoL. This effect is fully mediated by illness perception, particularly by the cognitive and the emotional representations. Results underscore the importance that patients' beliefs have on their perceived QoL, encouraging further research and development of interventions targeting illness perceptions.

Keywords: Psychosis | Illness perception | Quality of life | Illness course | Mexican

Article:

Introduction

Patients' quality of life (QoL) has become an important issue in patient care and, in consequence, in research, reflecting a re-emerging biopsychosocial perspective of health. The concept of QoL has long been applied in medical conditions, and more recently expanded to psychiatric disorders (Awad and Voruganti *2000*).

Even though schizophrenia spectrum psychoses can be considered as the most disabling of all mental disturbances, advances in treatment approaches, including antipsychotic medication, have

made clinical stability achievable for patients and meant that QoL is a feasible aim in the patient's process of reintegration to family and community life. Despite some methodological limitations (Browne et al. 2000; Gladis et al.1999), research indicates that people with schizophrenia suffer significantly poorer QoL (Pinikahana et al. 2002). Moreover, impaired QoL has been observed in patients with a first-episode of psychosis (Bechdolf et al. 2005; Browne et al. 2000; Theodore et al. 2011), prodromal (Bechdolf et al. 2005; Ruhrmann et al. 2008) and even psychosis-vulnerable subjects (Svirskis et al. 2007). Nevertheless, follow-up studies have shown that after a first psychotic episode is treated, QoL might plateau (Górna et al. 2008) and even improve (Foldemo and Bogren 2002; Malla et al. 2001; Ritsner et al. 2003).

Various sociodemographic (Pinikahana et al. 2002), clinical (Gaite et al. 2002; Malla and Payne 2005; Ritsner et al. 2003), social (Caron et al. 2005; Gaite et al. 2002; Ritsner et al. 2003) and treatment factors (Pinikahana et al. 2002) have been identified as reliable predictors of QoL, although their effect might be influenced by cultural issues (Gaite et al. 2002; Pinikahana et al. 2002). The course of psychotic illness might be an important factor related to QoL. Although not all evidence concurs (Almond et al. 2004), a relapsing course might lead to functional deterioration and diminished stability in employment and relationships (Nasrallah and Lasser 2006), in turn affecting QoL. Also, residual psychopathology might diminish QoL (Malla and Payne 2005; Savilla et al. 2008; Thorup et al. 2010), disrupting functioning and causing distress (Rudnick 2001); particularly negative symptoms (Hirschberg 2006; Narvaez et al. 2008; Pinikahana et al. 2002). In regard to diagnostic course, although schizophrenic psychoses show a poorer global outcome (Möller et al. 2000; Ritsner et al. 2003). Improving our understanding of factors mediating the effect of illness course on the QoL of patients with psychosis should improve patient care and increase the likelihood of satisfactory recovery beyond symptom remission.

The concept of "illness perception" or "illness appraisal" (Leventhal et al. *1984*) has attempted to explain how people create a private representation of their illness in order to make sense of and respond adequately to the situation. Attribution and perception of mental illness might prompt or delay help-seeking, determine pathways to mental health care and affect prognosis (Burns et al. *2011*). Whether seen as an illness or otherwise, the experience of psychosis raises individual's beliefs involving not only the acknowledgement of health status, but also the appraisal of personal and social consequences (Watson et al. *2006*). Among mental health patients, it is not unusual to find partial awareness of their illness that might be addressed as "personal difficulties," "stress" or "nervousness." This might be due to denial, a limited educational level, or even to mildness of symptoms. Illness perception does not require acknowledging the condition as a disorder; thus, patients can recognize being affected (or not) regardless of their comprehension of and insight into mental illness. Illness perceptions involve cognitive and emotional representations (Broadbent et al. *2006*; Leventhal et al. *1984*; Moss-Morris et al. *2002*) that have been related to QoL in various medical conditions (Miglioretti et al. *2008*; Scharloo et al. *2007*) and in psychosis as well (Lobban et al. *2004*; Stainsby et al.*2010*; Theodore et al. *2011*;

Watson et al. 2006). Patients with psychosis are undeniably in risk of temporary or chronic deterioration; however, focus must be placed not only on the mere amelioration of symptoms and prevention of relapses, but also on the achievement of satisfactory levels of QoL. Learning about possible factors influencing, positively or negatively, the QoL of patients with psychosis is an important task for both, research and treatment. Reports of patients with psychosis from Mexico are limited; data from this population might not only help to corroborate or refute the findings of previous research from other countries, but would also provide valuable clues in regard to predictive and mediating variables of QoL that might be proper to this culture. The present study examined the association of illness course with QoL in a sample of Mexican patients with psychosis. Although both illness course and illness perception have been reported to have a significant effect on the QoL of patients with psychosis, to the best of our knowledge these two variables have not been yet simultaneously studied. The present study undertakes this task and further proposes a model where illness perception might play a mediating role between illness course and its effect on QoL.

Methods

Sample

Participants for this study were patients who have received mental health care in the adult service of the Hospital Psiquiatrico Yucatan in Mexico. This hospital does not have a delimited catchment area as it offers attention for mental health to all in need regardless of residence and availability of medical insurance. Sampling was restricted to the inhabitants of the city of Merida, where the hospital is located. After obtaining formal authorization and ethical approval from the Hospital Committee, clinical files were reviewed in search of patients who would meet the following criteria: i) occurrence of a first episode of psychosis between 1999 and 2005; ii) age at onset 16–45 years; and iii) a primary current DSM-IV-TR (American Psychiatric Association—APA 2000) diagnosis of schizophrenia or other schizophrenia-spectrum psychotic disorder. Exclusion criteria were: i) a DSM-IV-TR diagnosis of psychosis of affective, organic, or toxic type (APA 2000), ii) an evident intellectual disorder, and iii) inadequate contact information.

From a total of 158 potential cases, 55 had moved away and could not be located. From the remaining 103, 66 (64 %) agreed to be interviewed (with no economic compensation involved) signing informed consent. Five participants were unable to provide reliable data due to high symptom severity; thus, the final sample included 61 patients (56 % female). Thirty-four (56 %) participants had secondary or lower education (up to 9th grade) and the remaining 27 (44 %) had partial/complete medium or higher education. At the time of the assessment, no participant was hospitalized. In terms of current DSM-IV-TR diagnoses, 41 patients had schizophrenia (14 paranoid, 2 disorganized, and 25 residual) and 20 patients had other types of schizophrenia-spectrum psychoses (8 schizoaffective, 7 delusional, 2 schizophreniform, 2 brief, and 1 not otherwise specified). Mean illness course was 6.7 years (SD = 1.9, range 3.8–11.2). Current

mean age was 35.9 years (SD = 10.0). Mean age at onset was 29.1 years (SD = 9.8); although an atypical value it is consistent with previous studies in Mexican samples (Apiquián et al. *1997*). There were no significant sex differences for either current ($t_{(59)} = -1.06$, p = 0.29) or onset ($t_{(59)} = -1.01$, p = 0.32) age. Gender, educational level, current and onset age were not significantly related to QoL. Of the total sample, 25 patients (41 %) were not currently receiving outpatient treatment. Four of them (2 with brief psychosis and 2 with schizophreniform disorder), had received medical discharge. The remaining 21 had dropped out from regular outpatient follow-up. However, these 21 patients did not show any difference in our outcome variable, QoL, compared to the 36 who followed out-patient treatment (CSCV-Favorable, $t_{(55)} = -1.37$; CSCV-Disfavorable, $t_{(55)} = 1.21$). Therefore, current treatment status was not considered for the analyses.

Measures

Based on both, information from clinical files and SCID-I (Structured Clinical Interview for DSM-IV-TR Axis I Disorders; (First et al. 1995) interviews with patients, the illness course of each patient at the time of assessment was established for three dichotomously scored criteria: i) any recorded relapse (i.e. exacerbation of psychotic symptoms requiring hospitalization and/or increase in medication (Rosen and Garety 2005) in the time period from the first episode to participation in the study), ii) the current presence of residual symptoms (only negative symptoms or two or more positive symptoms present in an attenuated form (APA 2000)) and, iii) the current primary psychotic diagnosis according to the DSM-IV-TR criteria (APA 2000; First et al. 1995). Even though the complexity of illness course is undeniable, simplifying it into two categories for research purposes has provided significant results (Altamura et al. 2001; Gómez-de-Regil et al.2010; Rosen and Garety 2005; Vázquez-Barquero et al. 1999).

QoL was assessed with the Sevilla Quality of Life Questionnaire (CSCV, Cuestionario Sevilla de Calidad de Vida), a 59-item self-rated questionnaire developed in Spanish for patients with schizophrenia (Giner et al.1997). This questionnaire has two subjective QoL scales: the Favorable-aspect scale (CSCV-Favorable) composed of vital satisfaction, self-esteem and harmony factors; and the Disfavorable-aspect scale (CSCV-Disfavorable) composed of lack of cognitive apprehension, loss of energy, lack of inner control, difficulty with emotional expression, difficulty with cognitive expression, oddness, fear of losing control, restrained hostility, and automatism factors. The instrument has satisfactory levels of reliability and validity (Ibañez et al. 1997) that have been replicated in samples from Latin America (Alvarado and Muñoz 2006).

Illness perception was measured with the Brief Illness Perception Questionnaire (Brief-IPQ) (Broadbent et al.2006). This 8-item self-report scale assesses three dimensions of illness perception: cognitive representation (beliefs about illness' severity, consequences, and duration, personal control over illness and usefulness of treatment), emotional representation (negative emotions about illness) and comprehensibility (understanding of the disorder). Higher scores of

cognitive and emotional representations indicate a negative perception of illness, whereas higher scores on comprehensibility indicate a favorable perception. The instrument has shown good levels of validity and reliability (Broadbent et al. 2006) and although it is not exclusive for people with a mental illness, it has been satisfactorily applied to patients with psychosis (Broadbent et al. 2008). All scales were presented in a 4-point scale.

Statistical Analysis

First, the QoL of groups defined by the dichotomous illness course criteria (relapses, residual symptoms, and diagnosis) were compared with t-tests and the association of QoL with illness perception was estimated with Pearson correlations. Next, bivariate and partial correlations were applied to observe the direct and mediated effect (controlling for illness perception dimensions) of illness course on QoL. Following Preacher and Hayes (2004), simple mediation bootstrapping procedures were used to determine the significance of each mediator individually. Finally, following Preacher and Hayes (2008), the resulting significant mediators were entered simultaneously to confirm their effect.

Results

Regarding QoL levels, 82 % (n = 50) of participants scored in average above the 2.5 midpoint value (possible score range: 1 to 4) for CSCV-Favorable and up to 85 % (n = 52) below 2.5 for CSCV-Disfavorable. Descriptive data for illness perception and QoL measures are presented in Table 1. No significant differences by sex or educational level were found on any variable so the values are presented for the total sample. Onset and current age were not significantly correlated with any of the described variables. Cognitive representation was significantly correlated with the emotional representation (r = 0.50, $p \le 0.001$).

Scales	Mean (SD)	Range				
Illness perception (Brief-IPQ)						
Cognitive representation	10.7 (2.9)	5.0 - 17.0				
Emotional representation	5.0 (2.1)	2.0 - 8.0				
Comprehensibility	2.9 (1.1)	1.0 - 4.0				
Quality of life (CSCV)						
Favorable	3.0 (0.7)	1.5 - 4.0				
Disfavorable	1.7 (0.6)	1.0 - 3.4				

Table 1 Mean and standard deviation of illness perception and quality of life scores (n = 61)

Possible score range for cognitive representation: 5.0 - 20.0; for emotional representation: 2.0 - 8.0; for comprehensibility: 1.0 - 4.0

Brief-IPQ Brief Illness Perception Questionnaire; *CSCV* Cuestionario Sevilla de Calidad de Vida (Sevilla Quality of Life Questionnaire)

Data for illness course and its effect on QoL are presented in Table 2. Following Cohen (*1992*), a d-value of .2 indicates a small effect, .5 a medium effect, and .8 a large effect size. As it can be seen, the presence of residual symptoms was robustly associated with impaired QoL.

Qualit	Relapses				Residual symptoms				Diagnosis			
y of life subscal												
es (CSCV	Anv	Single-		Coh				Coh		Other		Coh
) mean	relapse	episode	t (5	en's	Present	Absent $n = 31$	t (59	en's	Schizophre	psychose	t (5	en's
(SD) Favora	$\frac{n-37}{2.9}$	<i>n</i> – 24	- 1.	u	n - 30	$\frac{n-31}{3.3}$	-2.9	u	111an - 41	5n - 20	9)	u
ble	(0.7)	3.2 (0.6)	33	0.46	2.8 (0.7)	(0.6)	9**	0.77	2.9 (0.7)	3.2 (0.5)	59	0.49
Disfav	1.8		1.2			1.5	2.90				-0.	
orable	(0.6)	1.6 (0.5)	9	0.36	1.9 (0.7)	(0.4)	**	0.70	1.7 (0.6)	1.7 (0.7)	19	0.00

Table 2 Differences in quality of life according to illness course (n = 61)

Medium effect sizes in bold

CSCV Cuestionario Sevilla de Calidad de Vida (Sevilla Quality of Life Questionnaire)

 $p \le 0.05; p \le 0.01; p \le 0.001$

Data for the association of QoL with illness perception are presented in Table <u>3</u>. Overall, negative cognitive and emotional representations were significantly related to poorer QoL, whereas higher understanding of illness was related only to the favorable QoL score. Following Cohen (*1992*), a correlation of .10 represents a small effect, .3 a medium effect, and .5 a large effect.

Table 3 Pearson correlations of quality of life with illness perception (n = 61)

Quality of life subscales	Illness perception (Brief-IPQ)					
(CSCV)	Cognitive	Emotional	Comprehensibility			
	representation	representation				
Favorable	-0.59***	-0.42***	0.30*			
Disfavorable	0.62***	0.45***	-0.18			

Significant results in bold

Brief-IPQ Brief Illness Perception Questionnaire; *GAF-F* Global Assessment of Functioning Scale, Functioning Score; *CSCV* Cuestionario Sevilla de Calidad de Vida (Sevilla Quality of Life Questionnaire)

 $p \le 0.05; **p \le 0.01; ***p \le 0.001$

The residual symptom criterion was selected as the most reliable predictor of poor QoL, above diagnosis and relapses. Therefore, the final mediation analysis included residual symptoms as the predictor of QoL (CSCV-Favorable and CSCV-Disfavorable), and illness perception dimensions

as candidate mediators. Results are shown in Table 4. A significant direct effect of residual symptoms on both QoL dimensions can be observed by bivariate correlations. However, the effect seemed fully mediated by the negative emotional representation of illness, as it was no longer significant when this mediator was entered in partial correlations. Negative cognitive representation and comprehension of illness failed to partially mediate the effect of residual symptoms on either QoL measure. Nevertheless, following Preacher and Hayes (2004), bootstrapping procedures revealed that both cognitive and emotional representation were individually significant mediators. Finally, by bootstrapping multiple mediation analysis (Preacher and Hayes 2008), only the statistically significant mediation effect of cognitive representation was corroborated.

Table 4 Tests of mediation of the association of residual symptoms and quality of life by illness

 perception dimensions

Predictor	Outcome	Direct effect	Mediator	Mediated effect	Simple mediation Bootstrap 95 % CI	Multiple mediation Bootstrap 95 % CI
Residual	CSCV-	36 **	Cognitive	27*	3900	3802
symptoms	Favorable		representation			
			Emotional	25	3237	1906
			representation			
			Comprehensibility	32*	1802	-
	CSCV-	.35 **	Cognitive	.26*	.00 – .34	.02–.35
	Disfavorable		representation			
			Emotional	.23	.04 – .32	0419
			representation			
			Comprehensibility	.33*	0514	_

Direct effect is the bivariate correlation of Residual Symptom rating with the outcome measure; Mediated effect is the same correlation with the mediator partialed out. Simple mediation indicates the significance of mediation analyzed individually. Multiple mediation indicates the significance of mediation with the mediators entered simultaneously. Significant results in bold

CSCV Cuestionario Sevilla de Calidad de Vida (Sevilla Quality of Life Questionnaire)

* $p \le 0.05$; ** $p \le 0.01$; *** $p \le 0.001$

Discussion

This is the first study not only reporting on the QoL of mental health patients from a particular Mexican population, but also analyzing the mediating role of illness perception between illness course and QoL. Our results not only corroborate the association between residual psychopathology and poor QoL (Jabs et al.2004; Malla and Payne 2005; Rudnick 2001; Theodore et al. 2011), but also provide a clear picture of the impact of residual symptoms above

that of relapsing course and diagnosis. Additionally, the study also replicates the evidence in favor of an association between a diminished QoL and illness perception (Lobban et al. 2004; Stainsby et al. 2010; Theodore et al. 2011).

The major finding of this study was that cognitive and emotional representations of illness, rather than comprehensibility, fully mediate the effect that residual symptoms have on the QoL of patients with psychosis. These results converge with Theodore et al. (2011) who found, in a sample of patients with early psychosis, that illness perception was significantly associated with QoL, particularly the cognitive (treatment control, negative consequences) and emotional dimensions; and that the former was the strongest predictor of QoL over and above symptomatolgy. Patients conceiving their illness as severe and long-lasting, unmanageable by treatment or personal control, and seriously affecting their lives, experience a diminished QoL. An illness perceived as uncontrollable and highly intrusive might compromise QoL by reducing gratification from psychologically valued activities and, by diminishing personal control as the ability to obtain positive outcomes and/or to avoid negative ones becomes limited (Devins 2010). The adversity of psychopathology comes not only from the psychological distress it causes, but also, and mainly, from how it affects the social dimension, by limiting the attainment of "personal projects" (Shahar and Davidson 2009). Evidence supports that family and social dimensions of life, which might provide attachment and reassurance of worth, are very important to patients' QoL (Caqueo-Urízar and Lemos-Giráldez 2008; Caron et al. 2005; Lundberg et al. 2008; Pitkänen et al. 2009) and might even reduce the risk of suicide in patients with schizophrenia (Kao et al. 2011). Patients' sense of recovery does not unfold in isolation, but within a social and interpersonal context (Harvey et al. 2007; Ng et al. 2008; Schön et al. 2009; Topor et al. 2011). The reintegration of patients' to their daily family and community roles might can be hindered by persistent and intrusive residual symptoms and the resulting negative cognitive perception of illness, restringing their opportunities to obtain social reinforcement and improve QoL. Although this possibility cannot be directly drawn from our results, it is an idea worth of further study.

The emotional representation (concerns and emotions) of illness is also an important mediator of the effect of residual symptoms on the QoL. Illness perception has been related to positive and negative symptoms (Lobban et al. 2005) as well as anxiety and depression (Huppert and Smith 2001; Priebe et al. 2000) in patients with schizophrenia; yet studies suggest that the ability to cope with symptoms (Ritsner et al. 2003) and the associated distress (Lasalvia et al. 2002; Ritsner et al. 2003), substantially contribute to QoL in schizophrenia, even more than symptom severity (Lasalvia et al. 2002; Ritsner et al. 2003). Therefore, reducing the negative emotional impact of psychosis and enhancing abilities to emotionally cope with illness may be at least as important as controlling symptoms (Stainsby et al. 2010).

The link between the illness perception and QoL comes forward as a compelling target for research, and an important factor to be considered in clinical interventions. Learning how illness perceptions of a mental health problem relate to psychological and treatment outcomes would

improve our understanding of behavior in patients with psychological disorders, leading to new applications and approaches to facilitate patients' adjustment to their illness. Interventions addressing illness perceptions may encourage adherence to therapy, reduce inappropriate service use, and improve family and significant other relationships through analysis and therapy around aligning illness perceptions (Petrie et al. 2008). Likewise, targeting beliefs of young adults, in risk of or with mental health problems, about mental illness may prompt timely help-seeking (Vanheusden et al. 2009) reducing the gap between illness onset and treatment, in favor of outcome.

Regardless of the limitations in mental health provision, our sample did not show markedly poor levels of QoL. This might well, at first, call into question the validity of the results; however, from a more positive approach towards psychotic illness other arguments must be considered. Results from the World Health Organization International Study of Schizophrenia (Jablensky et al. 1992) revealed that although the outcome of patients in the developing countries was not uniformly better as compared to the outcome in developed countries, high rates of complete clinical remission were significantly more common in the former. Furthermore, patients in developing countries experienced significantly longer periods of unimpaired functioning in the community, although only a small proportion (16%) of them were on continuous antipsychotic medication (Jablensky et al. 1992; Jablensky and Sartorius 2008). For our sample, enrollment in treatment at the time of assessment did not have any significant impact on QoL. However, it must be underlined the fact that all patients had, at some point in time, received treatment; therefore, concluding that treatment makes no difference in terms of QoL would be erroneous. Moreover, the sample included not only schizophrenia cases but also those who have experienced milder types of psychoses (e.g. brief, delusional) and participation was not limited to patients still in need of treatment, but also cases that have achieved a satisfactory level of recovery. As our study did not focus exclusively on patients with an overall poor clinical status, results might well reflect the possibility of achieving a satisfactory level of recovery.

The cultural background of the sample is an important factor to consider in relation to outcome, as data from Mexican general population have shown social- rather than monetary-oriented indicators to be core domains of QoL (Felix and Garcia-Vega 2012). Despite access to costly biomedical treatment, high rates of disability are more likely in high income countries, suggesting that the highly competitive standards common in these cultures might diminish social support and negatively affect patients' outcome (Jablensky and Sartorius2008). Caregivers of Mexican origin seem particularly accepting of their relative's psychotic illness, showing non-blaming and low aversive responses to patient's behavior (Dorian et al. 2008). These conditions might play a core role in the patients' functional reintegration and perception of QoL; thus, the social factors favoring satisfactory levels of outcome in this culture (e.g. family attitudes) come forward as an important focus of future research.

The uniqueness of our sample and the restrictive selection criteria may be of concern when discussing the implications of our results. Nevertheless, research with not well-known

populations might well contribute to replicate previous findings from other countries and to cue on particular characteristics of patients that might be highly influenced by culture.

Including patients with other types of psychoses and even other mental disorders, as well as patients from other locations would enrich future studies. A prospective design would strength the reliable assessment and control of important outcome predictors to be considered such as treatment compliance, medication adherence and substance abuse. Furthermore, the measurement of a more ample number of potential sociodemographic, clinical, social and treatment factors previously associated with QoL, must be considered.

Conclusions

Residual symptoms, rather than a relapsing course or diagnosis of schizophrenia, have a diminishing effect in the subjective QoL of Mexican patients with psychosis. This effect is fully mediated by illness perception, particularly by negative cognitive and emotional representations. Results underscore the importance that patients' beliefs have on their perceived QoL, encouraging further research and development of interventions targeting illness perceptions.

Acknowledgments

LGR thanks the Consejo Nacional de Ciencia y Tecnología (CONACyT), Mexico, for funding number 187498. NBV and TRK are supported by the Spanish Ministry of Science and Innovation (PSI2008-04178), the Generalitat de Catalunya, Suport als Grups de Recerca (SGR2009672), and La Fundació La Marató de TV3 (091110). We thank the Hospital Psiquiátrico Yucatán (México) for its support and all who kindly took part as participants.

Conflict of interest

All authors declare that they have no conflicts of interest.

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