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Caregiver's quality of life and its positive impact on symptomatology and quality of life of patients with schizophrenia

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Abstract

Background: Although the quality of life (QoL) experienced by patients with schizophrenia has been recognized, few studies have assessed the relationship between the caregivers' QoL and patients' QoL.

Methods: The study included 253 stabilized outpatients with schizophrenia and their caregivers from 3 Mental Health Services in Bolivia ($N = 83$), Chile ($N = 85$) and Peru ($N = 85$). Caregivers' and patients' QoL were respectively assessed using two specific QoL questionnaires (S-CGQoL and S-QoL 18). We collected socio-demographic information and clinical data. Multiple linear regressions were performed to determine which variables were associated with patient's QoL. We tested the following hypothesis using structural equation modeling (SEM): caregivers' QoL may have an indirect effect on patients' QoL mediated by their influence of the severity of psychotic symptoms.

Results: In the multivariate analysis, the caregivers' QoL was not significantly associated with the patients' QoL, except for one QoL dimension about relationship with family ($\text{Beta} = 0.23$). Among patients' characteristics, being a woman and Aymara, having lower educational level, unemployment and severity of symptoms was significantly associated to a lower QoL. The SEM revealed a moderate significant association between caregivers' QoL and psychotic symptoms severity (path coefficient = -0.32) and a significant association between psychotic symptoms severity and patients QoL (path coefficient = -0.40). The indirect effect of caregivers' QoL on patients' QoL was significant (mediated effect coefficient = 0.13).

Conclusion: Improvement of caregiver's QoL may have a direct impact on the psychotic symptoms of patients and indirectly on patient's QoL, confirming the need for ongoing family interventions in these regions.

Keywords: Schizophrenia, Caregiver, Quality of life, Structural equation modeling

Background

Quality of life (QoL) measurements have become an important way to evaluate the treatments and care provided to patients with schizophrenia [1, 2]. QoL provides important information concerning the emotional and social experience of individuals which is not available for traditional assessments [3, 4]. In recent studies, QoL has been reported to be an independent predictor

for long-term symptomatic remission, functional recovery and disability [5, 6]. Knowledge of the factors that are determinants of QoL in patients with schizophrenia may assist clinicians in choosing the most appropriate and effective interventions. However, the determinants of QoL remain poorly understood in this population. Recent works have argued for the need for a better understanding of the variables that contribute to QoL [7].

Over the last decades, numerous studies have investigated the value of psychotic symptoms, depression, neurocognition and functioning as predictors of QoL

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[7–10]. These studies have unquestionably advanced our knowledge of the determinants of QoL but they did not examine the influence of the caregivers on the QoL of patients despite their central role in caring for patients with schizophrenia. The caregivers are the individuals, generally a member of the patient's family, who assume the role of care historically performed by psychiatric hospitals by providing informal care to patients since the large-scale deinstitutionalization of psychiatric patients [11, 12]. The caregiver spends most of his/her time caring for the patient, supplying support, checking medication and other aspects of the patient's daily life.

Although they play a major role in providing care, the lack of interventions for counseling, training or supporting them has been highlighted [13].

Importantly, caregivers' negative experiences may affect their ability to care for the patients and considering caregivers' QoL may be of importance both for the caregivers themselves and indirectly for patients' health. To our knowledge, no study has explored the association between the caregiver's QoL and the symptomatology and quality of life of patients with schizophrenia. Such information is important to developing better services for caregivers.

The aim of this study was thus to determine whether caregivers' QoL is a determinant of patients' QoL from three countries in Latin America, while considering other important determinants such as socio-demographic and clinical characteristics. We hypothesize that caregivers' QoL may have an indirect effect on patients' QoL mediated by their influence on the severity of psychotic symptoms. We used structural equation modeling (SEM), which is a useful statistical procedure, to test a theory involving non-straightforward relationships and is therefore well suited to the management of cross-sectional data for inferential purposes [14].

Method

Study participants

This cross-sectional study evaluated data collected through a survey of patients and their primary caregivers conducted from May 2012 to February 2013 through the Public Mental Health Services program in three Latin American cities: La Paz, Bolivia (32.8%); Arica, Chile (33.6%), and Tacna, Peru (33.6%). Patients were invited to participate as they came to their monthly follow-up visits, usually accompanied by their key caregiver, defined as the person who fulfilled the primary caring role and spent more time than anyone else with the patient in the task of caring. Most of the people agreed to participate.

The inclusion criteria for patients were the following: being over 18 years of age and having a diagnosis of schizophrenia according to the criteria of the International Classification of Diseases, 10th version [15]. The inclusion criteria for the caregivers were the following: being

identified by the individual with schizophrenia as the main caregiver and being 18 years of age or older. We applied a small set of exclusion criteria to the patient (being in a state of psychotic crisis or having a sensory or cognitive type of disorder that prevented being evaluated) and caregiver (presence of organic symptomatology; having a psychoactive substance abuse disorder; having a sensory or cognitive type of disorder that prevented being interviewed) groups to ensure the ability to participate fully in the interviews. These criteria were applied by the treating psychiatrist.

The sample included both Aymara and non-Aymara patients and caregivers. Aymara patients and caregivers were identified by Aymara surnames as established by legislation regarding indigenous peoples in the three countries, or Aymara self-identification. Both the Aymara and non-Aymara patients live in the same urban areas, are served by the same mental health centers, and have roughly comparable socio-demographic characteristics.

Measures

Schizophrenia quality of life questionnaire (SQoL18) [16]

The SQoL18 is a self-administered QoL questionnaire designed for people with schizophrenia and has been used extensively in Europe [6, 17, 18] and Latin America [19]. It is a multidimensional instrument that exclusively assesses the patient's view of his or her current QoL. It comprises 18 items describing 8 dimensions: psychological well-being (PsW), self-esteem (SE), family relationships (RFa), relationships with friends (RFR), resilience (RE), physical well-being (PhW), autonomy (AU), and sentimental life (SL), as well as a total score (index). Dimension and index scores range from 0, indicating the lowest QoL, to 100, the highest QoL.

Positive and negative syndrome scale for schizophrenia (PANSS) [20]

This is a 30-item, 7-point (1–7) rating scale that is specifically developed to assess psychotic symptoms in individuals with schizophrenia. This instrument is clinician-rated. For the purposes of this study, we considered the five subscales of the PANSS: positive, negative, excitation, anxiety/depression and cognitive subscales [21]. The PANSS has been translated and validated in Spain by Peralta and Cuesta (1994) [22] and also Fresán et al., (2005) [23] examined the psychometric properties of this instrument in Mexico. Positive and Negative Syndrome scale for Schizophrenia (PANSS) severity score are: PANSS total score of 58 = "Mildly ill"; PANSS total score of 75 = "Moderately ill"; PANSS total score of 95 = "Markedly ill" and PANSS total score of 116 = "Severely ill".

Schizophrenia caregiver quality of life questionnaire (S-CGQoL) [24]

This instrument has 25 items and assesses QoL on seven dimensions. This questionnaire took about 5 min to

administer and has satisfactory psychometric properties. Its structure explains 74.4% of the total variance, while its internal consistency, Cronbach's coefficient alpha, ranges from 0.79 to 0.92 on the various dimensions: Psychological and Physical Well-being; Psychological Burden and Daily Life; Relationships with Spouse; Relationships with Psychiatric Team; Relationships with Family; Relationships with Friends; Material Burden and Total Index. Each dimension and the total index score range from 0, indicating the lowest QoL, to 100, the highest QoL.

Demographic and clinical data

For patients, we collected age, gender, ethnicity (Aymara and non-Aymara), marital status (with a partner/without a partner), educational level (≥ 12 years or < 12), employment status (with employment/without employment), family income (measure of the total salary per month for all members of the family, expressed in US dollars), duration of the disorder in years, number of hospitalizations (since the last 3 years before present hospitalization) and type of treatment (whether the patient received only pharmacological treatment from the mental health services or integrated treatment, meaning pharmacological plus psychotherapy, family psychoeducation, day care hospital). For caregivers, we collected age, gender, relationship with the patient (mother/other), marital status (with a partner/without a partner) and educational level (≥ 12 years or < 12).

Procedures

The study was approved by the Ethics Committee of the University of Tarapacá and the National Health Service of Chile. We also obtained the authorization of the Mental Health Services in Peru and Bolivia. Two psychologists, who were part of the research team and supervised by the principal researcher, conducted the evaluations of family members and caregivers under the auspices of the mental health services of each country. The length of time of the evaluation of the caregivers was between 15 and 20 min; the evaluation of the patients was more extensive, between 30 and 40 min.

Before the start of the survey, informed consent was requested and received from the relative and the patient. The objectives of the study were explained as well as the voluntary nature of participation. No compensation was offered for participating in the study.

Statistical analysis

Data were expressed as proportions or as the means, standard deviations, medians, and interquartile ranges (IQR). Associations between patients' QoL scores (SQoL18) and the continuous variables (caregiver: S-CGQoL and patient: age, monthly family income, duration of disorder, number of hospitalizations, PANSS total score and its five dimensions, PANSS negative, positive, anxiety/depression and

cognition) were analysed using Spearman's correlation tests. Means-based comparisons of the SQoL18 index and dimensions between various sub-groups (gender, ethnicity, marital status, educational level, employment status and type of treatment) were calculated using Student t-tests.

Multiple linear regression analyses were then performed to identify variables potentially associated with patients' QoL levels. The SQoL18 index and each of its dimensions were considered as separate dependent variables. The variables relevant to the models were selected from the bivariate SQoL18 index analysis based on a threshold p -value ≤ 0.20 . Patients' gender was included in the models owing to its clinical and socio-demographic interest. The final models incorporated the standardised β coefficients, which represent a change in the standard deviation of the dependent variable (SQoL18) resulting from a change of one standard deviation in the various independent variables. The independent variables with the higher standardised beta coefficients are those with a greater relative effect on patients' QoL.

Finally, we assessed hypothetical relationships among the significant variables of the multivariate analyses to apply structural equation modeling (SEM). We hypothesized that caregivers' QoL had an indirect effect on patients' QoL mediated by their influence of the severity of psychotic symptoms. This model was adjusted for the significant covariates of the multivariate analyses. The model tested is presented in Fig. 1. Our model was based on three latent variables, caregivers QoL, psychotic symptoms severity and patients' QoL. Socio-demographic characteristics (i.e. gender, ethnicity, educational level and employment status) are observed variables. We evaluated the model fit using the chi-squared statistic with the normed chi-square (χ^2/df), the Root Mean Square Error of Approximation (RMSEA), the Comparative Fit Index (CFI) and the Standardized Root Mean Square Residuals (SRMR). The significance of the path coefficient was assessed using the standard errors and the t-values for each coefficient. In addition to the statistical significance of the path coefficients, the strength of the relationship plays a role in determining whether the relationships are weak (< 0.2), moderate (0.2–0.5) or strong (> 0.5) [25].

All the tests were two-sided. Statistical significance was defined as $p < 0.05$. The statistical analyses were performed using the SPSS version 20.0 software package (SPSS Inc., Chicago, IL, USA) MPLUS for the SEM analyses.

Results

Sample characteristics

Sample characteristics are presented in Table 1. Two hundred and fifty three patients with schizophrenia and their primary caregivers participated in our study. The mean age of patients was 35.6 years (± 12.5 years) and 66.4% ($n = 164$) were male. The mean duration of illness

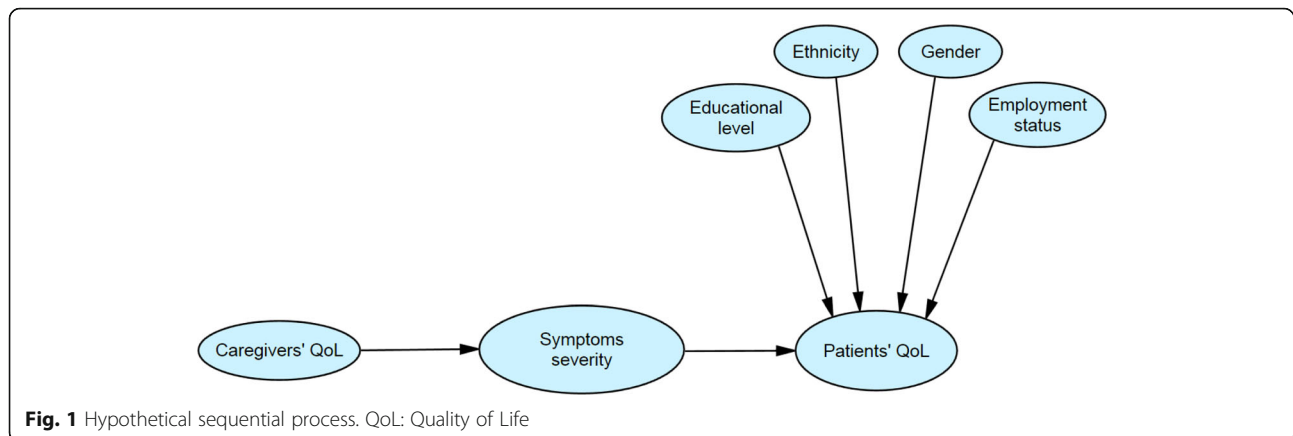


Fig. 1 Hypothetical sequential process. QoL: Quality of Life

was 11 years (IQR [5; 22]), and they had a moderate severity of psychotic symptoms with a total PANSS score of 71.3 (± 28.2).

Factors associated to patient's QoL

The results of the univariate and multivariate analyses are provided in Table 2. In the multivariate analysis, the caregivers' QoL was not significantly associated with the patients' QoL, except for the RFa dimension ($r = 0.23$). Among patients' characteristics, being a woman and Aymara, having lower educational level, unemployment and higher severity of symptoms was significantly associated with a lower patients' QoL.

Structural equation model

The SEM is presented in Fig. 2 confirming our hypothesis. The SEM showed good fit with $\chi^2/df = 1.66$, root mean square error of approximation RMSEA = 0.05, comparative fit index CFI = 0.88 and standardized root mean square residuals SRMR = 0.05. The SEM revealed a moderate significant association between caregivers' QoL and psychotic symptoms severity (path coefficient = -0.32) and a significant association between psychotic symptoms severity and patients QoL (path coefficient = -0.40). The indirect effect of caregivers' QoL on patients' QoL was significant (mediated effect coefficient = 0.13). The psychotic symptoms severity was not equally associated with caregivers' and patients' QoL. The PANSS excitation was the most important factor loaded (0.87) while the PANSS depression was the least important (0.53).

Discussion

First, at the patient level, as in previous studies, socio-cultural and economic factors were associated with patient's QoL in this sample: being female, having a lower educational level, being unemployed and belonging to an ethnic minority (i.e., Aymara) was associated with lower reports of QoL [26–28]. These results are also consistent with previous studies indicating that a higher level of

education facilitates employment, thus improving patients' level of income and QoL [29–32]. An explanation of the results for QoL associated with ethnic minority status can relate to the fact that this population, with 2 million people, have participated in a massive migration from the Andes Mountains to large cities searching for a brighter future; it is likely that in this process they encountered discrimination based on their Andes phenotype [33–38]. Prior researches from multiple societies revealed that ethnic minorities are exposed to discrimination and that these stressful experiences adversely affect physical and mental health and therefore their QoL [39–44]. Symptoms severity was also associated with patient's QoL. Several studies including meta-analyses have reported this association although the percentage of variance explained by symptoms remains moderate in comparison to socioeconomic factors [45–50]. The analyses from this sample show that the control of symptoms remains an important need for patients with schizophrenia living in Latin America. This finding may be not surprising in Latin America where the WHO Report on mental health systems identified the absence of universal social security coverage for mental disorders, the lack of capacity for some patients to purchase antipsychotic medications and the limited role of primary care in the mental health area [51].

Second, in relation to caregiver level, it is necessary to mention that the change in the way patients with schizophrenia are treated (de-institutionalization) has resulted in a dramatic shift in the burden of caregiving from health care professionals to family members [52]. The chronic illness of a family member can be a source of stress for the caregiver who can appraise this stressor as one with a high level of demands in relation to caregiving. The stress-appraisal-coping model suggests that during this process, the family member takes into consideration the nature of the stressor and the resources to cope [53, 54]. The impact of the caregiver's role depends on the characteristics of the patient, the family member, their relationship and the environment [55].

Table 1 Sample characteristics (N = 253)

Patients		Mean \pm SD, median [IQR] or n (%) ^a
Age in years		35.6 \pm 12.5
Gender	Women	83 (33.6)
	Men	164 (66.4)
Ethnicity	Non-Aymara	136 (53.8)
	Aymara	117 (46.2)
Marital Status	Without a partner	237 (93.7)
	With a partner	16 (6.3)
Educational level	\geq 12 years	40 (15.8)
	<12 years	213 (84.2)
Employment status	With employment	78 (31.2)
	Without employment	172 (68.8)
Monthly family income (US dollars)		331.3 [144.9; 517.9]
Duration of disorder in years		11 [5; 22]
Number of hospitalizations (since the last 3 years before present hospitalization)		1 [2; 0]
Type of mental health treatment	Integrated	31 (12.3)
	Only pharmacological	222 (87.7)
Symptoms severity	PANSS total score	71.3 \pm 28.2
	PANSS negative	18.6 \pm 8.4
	PANSS positive	8.3 \pm 4.6
	PANSS excitation	11.5 \pm 5.9
	PANSS anxiety/ depression	6.4 \pm 3.7
Quality of life	S-QoL 18 index	54.3 \pm 14.4
	Caregivers	
Age in years		54.7 \pm 14.4
Gender	Women	170 (67.7)
	Men	81 (32.3)
Relationships with patient	Others	138 (54.5)
	Mothers	115 (45.5)
Marital Status	Without a partner	132 (52.2)
	With a partner	121 (47.8)
Educational level	\geq 12 years	66 (26.1)
	<12 years	187 (73.9)
Quality of life	S-CGQoL index	47.8 \pm 15.7

^aMean \pm SD: mean \pm standard deviation; median [IQR]: median [Inter Quartile Range]; n (%): effective (percentage)

PANSS positive and negative syndrome scale for schizophrenia, total score and dimensions

S-QoL18 schizophrenia quality of life questionnaire

S-CGQoL schizophrenia caregiver quality of life questionnaire

The results of this study show that there is a significant association between caregivers' QoL and patients' QoL mediated by psychotic symptoms severity. Previous studies have shown that patients' clinical variables are those that most significantly affect caregivers' QoL, such as: duration of the disorder, patient's disruptive behavior, lower social functioning, higher level of disability, positive and negatives symptoms and general psychopathology [4, 56–62]. For the first time, this study shows that caregivers' QoL may have a positive association with psychotic symptoms severity and patients' QoL, confirming the central role of caregivers in the treatment of patients.

While the majority of studies in this substantive area have been conducted in European and North American countries, there have been few prior research studies in Latin America. Thus, these findings are a contribution to the existing evidence on the importance of considering the caregiver as an ally and indispensable agent in the treatment of the patient. However, especially in low and middle-income countries, there is a lack of systematic intervention to enhance the capacity and provide resources to these families. Once the psychoeducation program is completed, studies show that effective treatment for patients with schizophrenia needs further monitoring and involvement of health professionals because both family and patients will face long-term challenges, needing support and strategies to cope with these difficulties, and hence the service to the patient and family should be permanent [63]. However, one of the biggest barriers to achieve this type of family treatment is of an economic nature, both, at the *macro* level (such as the lack of professionals in public health services), as well as *micro* level, where even when there are family interventions as a part of the mental health services, caregivers may lack resources to take advantage of them, such as not having enough money for transportation to these services [64].

Family interventions can improve caregivers' QoL, however, they may also benefit from programs to reduce the level and chronicity of poverty [65], which influence directly patient's QoL as previously reported in our findings. Indeed, growing international evidence shows that mental illness and poverty interact in a negative cycle: "poverty breeds ill-health, and ill-health keeps poor people poor" [66, 67]. Poverty worsens the health of patients with schizophrenia, and increases the burden of caregivers, which in turn may affect the caregivers' health and their ability to care for the patients, so improvement of caregivers' QoL should be a multidisciplinary, comprehensive effort [68–70].

This study had some limitations that should be considered. First, the sample is not representative of the entire Latin American population of caregivers and patients with schizophrenia. Larger studies with more diverse

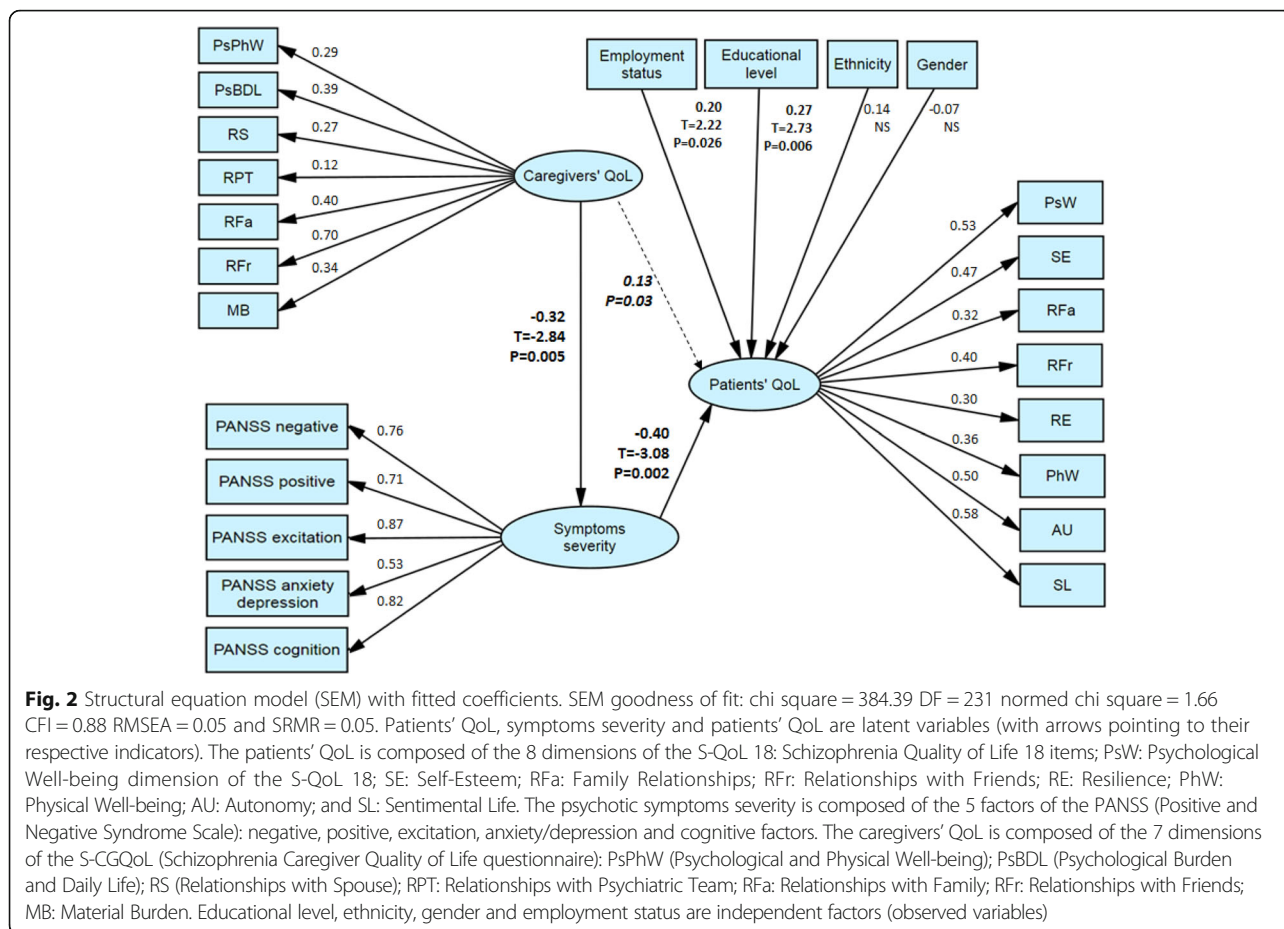
Table 2 Factors associated with S-QoL18 index and dimensions

Univariate analysis		S-QoL18 index	<i>p</i>	Multivariate analysis								
				S-QoL18 index	PsW	SE	RFa	RFr	RE	PhW	AU	SL
		<i>M</i> ± <i>SD</i> ^a or <i>R</i> ^b		β ^c	β	β	β	β	β	β	β	β
Caregivers												
Quality of life	S-CGQoL	0.14	0.032	0.05	0.09	-0.12	0.23**	0.10	-0.15	-0.10	-0.09	0.11
Patients												
Age in years		-0.09	0.142	-0.12	-0.17	0.09	-0.14	-0.12	-0.16	0.02	0.14	-0.16
Gender	Women	52.7 ± 15.7	0.208	-0.20*	0.11	-0.07	-0.45**	-0.10	-0.17	-0.10	-0.19	-0.03
	Men (Ref)	55.1 ± 13.8										
Ethnicity	Non-Aymara	58.7 ± 17.2	0.035	0.19*	0.13	0.00	0.00	0.28**	0.04	0.00	0.00	0.22*
	Aymara (Ref)	52.3 ± 14.2										
Marital status	Without a partner	54.2 ± 14.6	0.794	-	-	-	-	-	-	-	-	-
	With a partner (Ref)	53.2 ± 13.4										
Educational level	≥12 years	62.5 ± 11.5	<0.001	0.14	0.31**	0.05	-0.04	0.05	0.05	0.04	0.06	0.12
	<12 years (Ref)	52.7 ± 14.4										
Employment status	With employment	59.2 ± 13.4	<0.001	0.15	0.082	0.15	0.02	0.12	0.18*	0.06	0.09	0.01
	Without employment (Ref)	52.1 ± 14.5										
Monthly family income (US Dollars)		0.08	0.246	-	-	-	-	-	-	-	-	-
Duration of disorder in years		-0.05	0.399	-	-	-	-	-	-	-	-	-
Number of hospitalizations		-0.09	0.168	-0.03	0.05	0.03	0.11	-0.15	-0.04	-0.01	0.11	-0.11
Type of treatment	Integrated	58.6 ± 11.8	0.076	0.06	0.11	0.13	-0.07	-0.01	0.12	0.15	-0.01	-0.07
	Only pharmacological (Ref)	53.7 ± 14.7										
Symptoms severity - PANSS total score		-0.37	<0.001	-0.23*	-0.27**	-0.15	-0.10	-0.11	-0.01	-0.12	-0.22*	-0.10
	PANSS negative	-0.35	<0.001	-	-	-	-	-	-	-	-	-
	PANSS positive	-0.26	<0.001	-	-	-	-	-	-	-	-	-
	PANSS excitation	-0.24	<0.001	-	-	-	-	-	-	-	-	-
	PANSS anxiety/depression	-0.17	0.006	-	-	-	-	-	-	-	-	-
	PANSS cognition	-0.30	<0.001	-	-	-	-	-	-	-	-	-

^a*M* ± *SD*: mean ± standard deviation; ^b*R*: Spearman's correlation coefficient; ^cβ: standardised beta coefficient (β represents the change of the standard deviation in QoL score resulting from a change of one standard deviation in the independent variable); **p* ≤ 0.05; ***p* ≤ 0.01
 S-QoL18 schizophrenia quality of life questionnaire, *PsW* psychological well-being, *SE* self-esteem, *RFa* family relationships, *RFr* relationships with friends, *RE* resilience, *PhW* physical well-being, *AU* autonomy, *SL* sentimental life
 Number of hospitalizations: since the last 3 years before present hospitalization
 PANSS positive and negative syndrome scale for schizophrenia, total score and dimensions
 S-CGQoL schizophrenia caregiver quality of life questionnaire

groups of patients and caregivers are needed to confirm our findings. Second, our study used only one type of QoL instrument for each participant. It would be interesting to determine whether our findings would be replicated with QoL instruments that utilize other conceptual models and dimensional constructs. Third, this study only provided information about the main clinical characteristics of our sample, and did not report further details concerning clinical stability and prescribed

medication, for example. Fourth, the data are cross-sectional and even though we use SEM, we are unable to make causal claims. Fifth, it was not statistically possible to test simultaneously in our SEM model the existence of the indirect effect of caregivers' QoL on patients' QoL and the existence of a bilateral association between caregivers' QoL and severity of symptoms. We thus tested another model with a bidirectional association between caregivers' QoL and severity of symptoms (but



without testing the indirect effect of caregivers' QoL on patients' QoL). This model confirmed that a bidirectional association is probable (path coefficient = -0.4, $p < 0.001$).

Nonetheless, the limitations of the study should be considered in the light of its strengths. This was the first study carried out in Latin America that considers the relationship between caregiver' QoL and patient' QoL. Moreover, in this multicentric, international study, we confirmed the key role of the caregiver in patient treatment and the necessity to consider his/her health and QoL in a comprehensive assessment of the needs of the patient.

Conclusion

Improvement of caregivers' QoL may have a direct impact on the psychotic symptoms of patients and indirectly on patients QoL. So caregivers' QoL is a major concern and mental health professionals and policy makers should consider the establishment of routine and ongoing family interventions in Latin America.

Abbreviations

AU: Autonomy; CFI: Comparative Fit Index; MB: Material Burden; PANSS: Positive and Negative Syndrome scale for Schizophrenia; PhW: Physical well-being; PsBDL: Psychological Burden and Daily Life; PsPhW: Psychological and Physical Well-being; PsW: Psychological well-being; QoL: Quality of life; RE: Resilience;

RFa: Family relationships; Rfa: Relationships with Family; Rfr: Relationships with Friends; Rfr: Relationships with friends; RMSEA: Root Mean Square Error of Approximation; RPT: Relationships with Psychiatric Team; RS: Relationships with Spouse; S-CGQoL: Schizophrenia Caregiver Quality of Life questionnaire; SE: Self-esteem; SEM: Structural equation modeling; SL: Sentimental life; S-QoL 18: Schizophrenia Quality of Life Questionnaire; SRMR: Standardized Root Mean Square Residuals; χ^2/df : chi-squared statistic with the normed chi-square

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Availability of data and materials

The data can't be shared because it belongs to the Universidad de Tarapacá through its postdoctoral research project of A. Caqueo-Urizar.

Authors' contributions

Conception and design: AC-U, LB and DRW. Data collection and analysis of data: AC-U, LB, MA, AU and XZ. Interpretation of data: AC-U, LB, MA, AU and XZ. Drafting and writing the manuscript: AC-U, LB and DRW. All authors read and approved the final manuscript.

Competing interests

The authors declare that they have no competing interests.

Consent for publication

We obtained consent to publish from the participant.

Ethics approval and consent to participate

The study was approved by the Ethics Committee of the University of Tarapacá and the National Health Service of Chile. Before the start of the survey, informed consent was requested and received from the relative and the patient.

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