Quality of Life in Aymara Patients with Schizophrenia in the Central-Southern Andes^{*}

Calidad de vida en pacientes con esquizofrenia de origen Aymara en la zona Centro-Sur de los Andes

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ABSTRACT

The study aimed to compare the quality of life (QoL) of patients with schizophrenia belonging to the Aymara ethnic group from the Central-Southern Andes, with Non-Aymara patients. This cross-sectional study was conducted in three mental health clinics in Chile, Peru, and Bolivia. The data included sociodemographic, clinical characteristics and the QoL was assessed using the S-QoL18. Comparative analyses explored QoL differences between Aymara and Non-Aymara patients. Two hundred and fifty-three patients participated. Aymara had lower QoL scores compared to Non-Aymara patients, for total Index, family relationships, and sentimental life dimensions. Monthly family incomes and disorder duration were significantly lower for Aymara patients. Our study supported the hypothesis of poor QoL in Aymara patients with schizophrenia, after considering other socio-demographic and clinical variables such as the attitude to medication.

Keywords

quality of Life; S-QoL18; schizophrenia; ethnicity; ethnic minorities; Aymara; Andes.

RESUMEN

El objetivo de este estudio consistió en comparar la calidad de vida (CV) de pacientes con esquizofrenia pertenecientes al grupo étnico aymara de los Andes Centro-Sur, con pacientes no Aymara. En este estudio transversal participaron 253 pacientes de tres clínicas de salud mental en Chile, Perú y Bolivia. Se recogieron datos sociodemográficos y características clínicas. La calidad de vida se evaluó utilizando el Cuestionario S-QoL18. Los análisis comparativos exploraron las diferencias de QoL entre los pacientes Aymara y no Aymara. Los participantes de origen Aymara tuvieron puntuaciones de CV más bajos en comparación con los pacientes no Aymara para el Índice total, las relaciones familiares y la dimensión de vida sentimental. Los ingresos familiares mensuales y la duración del trastorno fueron significativamente

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Palabras clave

calidad de vida; S - QoL 18; esquizofrenia; etnicidad; minorías étnicas; aymara; andes.

Migration is defined as the process by which people move from one society to another with the intention of settling there (Giddens, 2006). In recent decades, South American populations have moved within the context of international migration processes, motivated by labor as well as social, political, and economic factors (Machín, 2011; Organización Mundial para las Migraciones, 2012; Pellegrino, 2003; Villa & Martínez, 2000).

However, to this type of migration must be added the migration of people who have also migrated massively from rural areas in the Highlands of the Andes to cities on the coast. In particular, Aymara individuals are composed of around two million people and have systematically migrated during the last decades (Gundermann, 2000; Köster, 1992; Núñez & Cornejo, 2012; Van Kessel, 1996a; Zapata, 2007).

Cultural, social and economic changes that this population has had to cope with often conflicts with the concept of balance and harmony of the Andean worldview. For the Aymara population, the world is ordered based on three dimensions: social relationships, relationships with "divinities," and relationships with nature. These three dimensions are closely related and Aymara understanding of the universe is based on the cyclical rhythms of nature and the ritual calendar that they adapted to these natural rhythms. (De Munter, 2010; Van Kessel, 1996b). Thus, Aymara behavior relies on the community experience that conflicts with the Western culture built on individualism and personal achievement. These intercultural dynamics have led to an identity crisis among the Aymara migrant group. Consequently, a large number of people who could be identified as Aymara by heritage or because of the use of Aymara traditions, no longer identify themselves as belonging to this ethnic group (Zapata, 2007). Actually, there is a growing body of literature interested in migration consequences on health, especially in the field of mental disorders (Patel et al., 2017). Especially, migration confers an increased risk for schizophrenia and there is an increasing interest in assessing this extremely vulnerable population (Selten, Cantor-Graae, & Kahn, 2007).

Schizophrenia, in addition to the clinical symptoms characteristic of the disorder, implies an important economic and social cost for the sufferer and their relatives, as well as a high degree of stigmatization that severely affects their quality of life (QoL) (De Toledo & Blay, 2004). Considering this, it has become necessary to contemplate the QoL as part of the evaluation of the results of the treatment administered to patients with schizophrenia (Cavieres & Valdebenito, 2005).

QoL has an essentially subjective nature, and there are a number of factors associated with this construct, including physical and emotional health, psychological and social wellbeing, fulfillment of personal expectations and goals, economic security, and functional capacity to develop in a standardized way the activities of daily living (Awad & Voruganti, 2008; Bobes & González, 2000; Pinikahana, Hapell, Hope, & Keks, 2002).

Patients with schizophrenia disorder have a significantly poorer standard of living than others in their community (Pinikahana et al., 2002). A number of factors negatively influence their quality of life, such as: being a man (Browne et al., 1996; Caron, Mercier, Diaz, & Martin, 2005); older (Browne et al., 1996); unemployed (Hofer et al., 2004); without a partner (Salokangas, Honkonen, Stengard, & Koivisto, 2001); with a higher number of hospitalizations (Browne et al., 1996); with low social support (Górna, Jaracz, Rybakowski, & Rybakowski, 2008); with a higher disorder severity (Rudnick, 2001); and with greater medication side effects (Awad & Hogan, 1994; Bobes, Garcia-Portilla, Bascaran, Saiz, & Bousono, 2007).

Studies lacks on the extent to which cultural factors among ethnic minorities are related to

QoL (Boyer et al., 2013; Gray, Rofail, Allen & Newey, 2005; McCrone et al., 2001; Ruggeri et al., 1994; Ruiz, 1998; Zendjidjian et al., 2014). Patients with mental disorders belonging to an ethnic minority experience a double stigma: stigma attributable to illness and the one attributable to their lower socioeconomic status. Ethnic minority patients also tend to be less aware of community resources, possess less social support, face language difficulties (Kung, 2003), and are more likely to discontinue mental health treatment (Haas et al., 2008; McLafferty, 1982; Rice, 1987; Smith et al., 2007; Thompson, Carrasquill, Gameroff & Weissman, 2010; Vicente, Kohn, Rioseco, Saldivia & Torres, 2005; Williams & Collins, 2001).

The understanding of the QoL of ethnic minority patients should therefore lead to improved strategies to lower the treatment discontinuation rates (Vicente et al., 2005) and improve functional outcomes (Caqueo-Urízar et al., 2016).

This study aims to describe the QoL of outpatients with schizophrenia belonging to an Aymara ethnic group in the Andean region in Latin-America and compare that population with Non-Aymara patients receiving treatment in the same mental health system. Because this culture presents a different worldview from the Western culture and due to the disadvantages that ethnic minority patients face, we hypothesize that Aymara patients will have a lower QoL than Non-Aymara patients.

This study is based on a secondary analysis of a broader research whose main objective was addressed in a previous publication (Caqueo-Urízar, Breslau, & Gilman, 2015).

Method and materials

Study participants

The study sample included patients with schizophrenia who were receiving services from three mental health clinics in the Central-Southern Andean regions of northern Chile (Arica), southern Peru (Tacna), and centralwestern Bolivia (La Paz). The sample included both Aymara and Non-Aymara patients. Both 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, but the Aymara speak both Spanish and Aymara.

Recruitment of Aymara and Non-Aymara patients took place in three public health sector clinics in Peru, Chile, and Bolivia. We selected the largest public health clinic in each region. The first author reviewed the lists of patients who were attending each center in each country and the research team made assessments over a three-month period in each country. Aymara patients were identified by Aymara surnames as established by legislation regarding indigenous peoples in the three countries, or by Aymara self-identification. Patients were invited to participate as they came to their monthly follow-up visits. Most of the people agreed to participate.

We applied a small set of exclusion criteria to the patient groups to ensure ability to participate fully in the interviews. We excluded those in a state of psychotic crisis or having a sensory or cognitive type of disorder preventing evaluation. The final sample included 253 patients with an ICD-10 diagnosis of schizophrenia (World Health Organization [WHO], 1992), (33.6% from Chile, 33.6% from Peru, and 32.8% from Bolivia). In relation to each specific institution in this study, the three clinics shared similar characteristics in terms of size, type of treatment given to patients, professionals, and free access of care.

Interview Procedures

The study was approved by the Ethics Committee of the University of Tarapacá and the National Health Service of Chile. Two psychologists, who were part of the research team and supervised by the main researcher, conducted the patients' evaluations under the auspices of the mental health services of each of the three countries. They evaluated the patients during 30 to 45 minutes.

Before the start of the survey, we requested and received informed consent from the patient. We explained the objectives of the study as well as the voluntary nature of participation. We offered no compensation for study participation.

Measures

Schizophrenia Quality of Life Questionnaire (S-QoL18) (Boyer et al., 2010): The S-QoL18 is a self-administered QoL questionnaire designed for people with schizophrenia that has been used extensively in Europe (Auquier et al., 2013; Baumstarck et al., 2013; Boyer et al., 2013). It has been adapted to the Spanish in Latin American countries, with $\alpha = \geq 0.7$ for the Total Index of QoL. Also the subscales present satisfactory Cronbach's alpha (the reader can review the published study Caqueo-Urízar et al., 2014).

The aforementioned questionnaire is a multidimensional instrument that assesses the patient's view of his or her current QoL. It is made of 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). Dimensions and Index scores range from 0, indicating the lowest QoL, to 100, the highest QoL.

Positive and Negative Syndrome scale for Schizophrenia (PANSS) (Kay, Fiszbein, & Opler, 1987) This is a 30-item, rating scale administered to clinicians that is developed to assess psychotic symptoms in individuals with schizophrenia and which comprises 5 different subscales: positive, negative, cognitive, depressive, and excitement scales (Fresán et al., 2005). The PANSS was translated and validated in Spain by Peralta and Cuesta (1994) and in Mexico by Fresán et al. (2005). In this study, we focused on the PANSS total score ($\alpha = 0.93$), which provides a general measure of the severity of the disorder. Drug Attitude Inventory (DAI-10) (Hogan, Awad, & Eastwood, 1983) This 10-item patient self-report scale was developed to assess attitudes, experiences, and beliefs about antipsychotic drugs. The DAI-10 is considered to be a good predictor of adherence to treatment in schizophrenia (Hogan et al., 1983; Nielsen, Lindström, Nielsen, & Levander, 2012). Scores ranged from -10 (very poor attitude) to +10 (best possible attitude). It has been adapted to Spanish by Robles García, Salazar Alvarado, Páez Agraz and Ramírez Barreto in 2004. The Cronbach's alpha coefficient of the DAI in this study was α = 0.7.

Demographic and clinical characteristics: Participant demographic characteristics included sex, age, ethnicity (Aymara and Non-Aymara), educational level (low or high), marital status (with a partner or without a partner), employment status, and family income (measure of the total salary per month for all members of the family, expressed in US dollars). Clinical characteristics covered information about duration of the disorder, number of hospitalizations, and type of treatment.

Data analysis

Data were expressed as proportions or as the means with standard deviations. The data were assessed for normal distribution using the Shapiro-Wilk test and for homogeneity of variance with the Levene test. Comparative analyses were performed to assess differences between Aymara and Non-Aymara (i.e. origin profiles) patients. Associations between patients' origin and the qualitative variables (gender, marital status, educational level, employment status, and type of mental health treatment) were analyzed using Chi-Square tests; associations between patients' origin and the quantitative variables (age, monthly family income, duration of disorder, number of hospitalizations, PANSS total score, S-QoL18 Index and its 8 dimensions) were calculated using Student ttests for normally distributed data or using nonparametric Mann Whitney tests in case of nonnormal distributions.

Multivariate analyses using multiple linear regressions (simultaneous model) were then performed to confirm the link between ethnicity and QoL levels. The S-QoL18 index and each of its 8 dimensions were considered as separate dependent variables. The variables relevant to the models were selected from the comparative analyses, based on a threshold p-value ≤ 0.2 . The final models incorporated the standardized β coefficients, which represent a change in the standard deviation of the dependent variable (QoL) resulting from a one-standard-deviation change in the various independent variables. The independent variables with the higher standardized β coefficients are those with a greater relative effect on QoL.

This study was a confirmatory analysis. The hypothesis was that belonging to an ethnic group (i.e. Aymara vs Non-Aymara) was associated with QoL of schizophrenic patients, based on the results of previous analyses (Caqueo-Urízar et al., 2017a). In this last research, the aim of the study was thus to determine whether caregivers' QoL is a determinant of patients' QoL, while considering other important determinants such as sociodemographic and clinical characteristics.

In our study, no correction for multiple testing has been carried out, consistent with recommendations (Bender & Lange, 2001).

Findings

Sample characteristics

Two hundred and fifty-three patients with schizophrenia were enrolled in the present study. The mean age of patients was 35.6 years (SD=12.5), 164 patients (66.4%) were men and 117 patients (46.2%) were Aymara. The patients had moderately severe symptoms with a total PANSS score of 71.3 (SD=28.2). Description of the total sample characteristics are reported in Table 1.

Comparisons between Aymara and Non-Aymara patients

The differences between Aymara and Non-Aymara patients are presented in Table 1. Concerning socioeconomic characteristics, monthly family income level (US dollar) was significantly lower for Aymara patients (M=329.5, SD=277.4) than for Non-Aymara patients (M=490.2, SD=512.4), U=4352, p=0.001. Other sociodemographic characteristics were similar.

For clinical factors, Aymara patients had a significantly shorter duration of disorder (M=12,SD=9.7) compared to Non-Aymara patients (M=16.7, SD=12.9), t(240)=3.3, p=0.001. As expected, Aymara patients reported poor QoL, compared to Non-Aymara patients: Aymara patients had significantly lower QoL scores (M=52.3, SD=14.2) than Non-Aymara patients (M=56, SD=14.5) for the total QoL score (S-QoL18 Index), t(250) = 2.04, p = 0.042, and both for the Family relationships (RFa) dimension (M=59.8, SD=25.5 for Aymara vs M=66.2,SD=20.8 for Non-Aymara), U=6895.5 p=0.031and for the Sentimental Life (SL) dimension (M=40.4, SD=27.1 for Aymara vs M=49.4,SD=27.4 for Non-Aymara), t(250)=2.6 p=0.01.

In the multivariate analyses (Table 2), the relationships between ethnicity and QoL remained significant even after adjusting for other confounders (including age, location, monthly family income, duration of disorder, DAI-10, and PANSS negative), for the RFa and SL dimensions (β =-0.213, p=0.003 and β =-0.175, p=0.012, respectively). The association between ethnicity and the relationships with friends (RFr) dimension became significant (β =-0.179, p=0.012). A trend was observed for the S-QoL18 Index (β =-0.117, p=0.089).

TABLE 1

Quality of Life of Aymara and Non-Aymara patients

		Total sample Ayman patien		Non- Aymara patients	p-value	
		(N=253)	(n=117)	(n=136)	<i>p</i> -value	
		$M \pm SD$ or	$M \pm SD$ or	$M \pm SD$ or		
		n (%)*	n (%)*	n (%)*		
Age (years)		35.6 ± 12.5	34 ± 11.5	37 ± 13.1	0.056 ^a	
Gender	Women	83 (33.6)	39 (33.9)	44 (33.3)	0.923 ^b	
	Men	164 (66.4)	76 (66.1)	88 (66.7)		
Location	Peru	85 (33.6)	38 (32.5)	47 (34.6)	0.02	
	Chile	85 (33.6)	31 (26.5)	54 (39.7)		
	Bolivia	83 (32.8)	48 (41)	35 (25.7)		
Marital Status	Without a partner	237 (93.7)	109 (93.2)	128 (94.1)	0.756	
	With a partner	16 (6.3)	8 (6.8)	8 (5.9)		
Educational level	Low (< 12 years)	40 (15.8)	101 (86.3)	112 (82.4)	0.246	
	High (≥ 12 years)	213 (84.2)	16 (13.7)	24 (17.6)		
Employment status	With employment	78 (31.2)	36 (31)	42 (31.3)	1	
	Without employment	172 (68.8)	80 (69)	92 (68.7)		
Monthly family income		$417.6 \pm$	$329.5 \pm$	$490.2 \pm$	0.001 °	
(US dollars)		429.4	277.4	512.4	0.001	
Duration of disorder (years)		14.6 ± 11.8	12 ± 9.7	16.7 ± 12.9	0.001	
Number of hospitalizations [#]		1.2 ± 1.5	1.4 ± 1.4	1.1 ± 1.5	0.269	
Type of mental health treatment	Integrated	31 (12.3)	17 (14.5)	14 (10.3)	0.306	
	Only pharmacological	222 (87.7)	100 (85.5)	122 (89.7)		
DAI-10		3.0 ± 4.8	2.6 ± 4.9	3.4 ± 4.6	0.194	
Symptoms severity	PANSS total score	71.3 ± 28.2	73 ± 29.3	69.9 ± 27.4	0.408	
Quality of life	S-QoL18 Index	54.3 ± 14.4	52.3 ± 14.2	56 ± 14.5	0.042 °	
	PsW		46.9 ± 24.3	48.2 ± 25	0.68	
	SE		56 ± 22.5	58.4 ± 22.2	0.399	
	RFa		59.8 ± 25.5	66.2 ± 20.8	0.031 °	
	RFr		32.9 ± 28.4	41 ± 44.8	0.094	
	RE		68.4 ± 19.5	68.4 ±15.7	0.711°	
	PhW		57.6 ± 22.3	58.6 ± 20.9	0.699	
	AU		56.2 ± 23.5	57.7 ± 21.8	0.594	
	SL		40.4 ± 27.1	49.4 ± 27.4	0.01 °	

 $*M \pm SD$: mean \pm standard desviation, n (%): number (percentage). ^a Student T test. ^b Chi-square test. ^c Mann-Whitney test Significant results are in bold. at significance level p < 0.05. # (Since the last 3 years before present hospitalization) DAI-10:Drug Attitude Inventory. PANSS:Positive and Negative Syndrome Scale for Schizophrenia, total score and dimensions. 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 wellbeing; AU: autonomy; SL: sentimental life. Source: own work.

TABLE 2

Multivariate analysis. Factors associated with S-QoL18 index and dimensions

	S-QoL18 index	PsW	SE	RFa	RFr	RE	PhW	AU	SL
	B#	ß	ß	ß	ß	ß	ß	ß	ß
Ethnicity (Ref.: Non-Aymara)	-0.117	0.048	-0.002	-0.213**	-0.179*	0.141	0.005	0	-0.175*
Age (years)	-0.099	0.044	-0.029	-0.281*	0.094	-0.436**	-0.151	0.085	-0.013
Location (Ref.: Peru)	-0.237**	-0.32**	-0.056	0.102	-0.17*	0.03	-0.063	-0.116	-0.261**
Monthly family income (US dollars)	0.092	0.195**	0.092	0.02	-0.095	0.088	0.044	0.051	0.124
Duration of disorder (years)	0.003	0.032	0.069	0.064	-0.226	0.367**	0.19	-0.083	-0.103
DAI-10	0.016	-0.157*	0.015	0.102	0.087	-0.032	-0.004	-0.028	0.025
PANSS Negative	-0.311**	-0.321**	-0.213**	0.023	-0.17*	-0.043	-0.226**	-0.222**	-0.226**

β : standardised beta coefficient (β represents the change of the standard deviation in OoL score resulting from a change of one standard deviation in the independent variable); Significant results in bold. * p≤0.05. ** p≤0.01. S-QoL:Schizophrenia Quality of Life questionnaire; PsW: psychological wellbeing; SE: self-esteem; RFa: family relationships: RFr: relationships with friends; RE: resilience; PhW: physical wellbeing; Au: autonomy; SL: sentimental life. DAI-10:Drug Attitude Inventory. PANSS:Positive and Negative Syndrome scale of Schizophrenia. Source: own work.

Discussion

The aim of our study was to describe the OoL of outpatients with schizophrenia belonging to an Aymara ethnic group in the Andean region in Latin-America and compare that population to Non-Aymara patients. Our results supported the hypothesis that Aymara patients had a significantly lower level of QoL than Non-Aymara patients, especially for relationships dimensions: family relationships (RFa), relationships with friends (RFr) and sentimental life (SL) QoL dimensions, even after adjusting the model for confounders. These results were consistent with literature. Indeed, previous studies reported Aymara patients to cope with psychological distress, showing the importance of subjective aspects of quality of life among this population (Caqueo-Urízar, Boyer, & Gilman, 2017b). Research from multiple societies revealed that ethnic minorities tend to be exposed to discrimination, these stressful experiences adversely affecting physical and mental health (Haas et al., 2008; Kung, 2003; Smith et al., 2007; Thompson et al., 2010; Vicente et al., 2005; Williams & Collins, 2001). For the poor RFa scores found in Aymara patients, the mass migration phenomenon and the rapid abandonment of rural settlements in the Andean foothills might have affected the family dynamics, being perhaps one of the most difficult experiences for the Aymara patients. Often the family members are separated; the elderly remain in the Highlands while other members move to the nearest towns. Some young people even migrate to the city without their parents, to continue their education. Migration is a complex phenomenon that does not necessarily involve a departure without return, as evidenced by the number of simultaneous residencies and linkages that are maintained with the native communities (Gundermann, González, & Vergara, 2007). Still, in this adaptation process, Aymara families have abandoned, to some extent, traditional cultural patterns and are slowly adopting new and increasingly intercultural lifestyles (Gavilán et al., 2006; Zapata, 2007). These intercultural dynamics may be associated with distance from relatives who stayed in rural Highlands, and might affect their QoL at family level. Furthermore, altered QoL in the family relationships dimension could also be related to higher levels of perceived burden and impaired QoL of Aymara caregivers, as reported in previous studies (Caqueo-Urízar et al., 2012). This could be partially due to scarcity of national social welfare and community rehabilitation programs for relatives of psychiatric patients in these countries (Caqueo-Urízar & Gutiérrez-Maldonado, 2006; Caqueo-Urízar et al., 2014). Families may have become a substitute when facing the scarcity of therapeutic, occupational, and residential resources. The impact of this shift on the family is high, having both an emotional and economic toll (Caqueo-Urízar et al., 2017c). These results highlight the need to better considerate the key role of family relationships in the patients' care and well-being.

Concerning relationships with friends and sentimental life, Aymara patients reported lower QoL scores in SL dimension than Non-Ayamara

patients did. This result should be considered knowing the fact that our total sample of patients with schizophrenia was in its majority alone and without any partner, as described before (Arsova & Barsova, 2016; Chou, Yang, Ma, Teng, & Cheng, 2015). However, previous studies reported that patients who do not have a partner tend to have a lower quality of life (Salokangas et al., 2001). In this case, it may be even harder for Aymara patients to get a partner and social life because of the double stigma that they experienced in discriminations, based both on their Andes phenotype and on their mental disorder (Kirberg, 2006; Urzúa, Heredia, & Caqueo-Urízar, 2016). Furthermore, family support and social support were reported to improve the ability for personal and social contacts of patients with schizophrenia (Arsova & Barsova, 2016).

Another finding shows that sociodemographic variables also have an important role, and socio-economic circumstances should be taken into account when assessing these patients. In this study, monthly family income level was significantly lower for Aymara patients than for Non-Aymara patients. 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 (Browne & Courtney, 2005; Marwaha & Johnson, 2004; Ruggeri et al., 2005; Schomerus et al., 2007). 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" (Wagstaff, 2002, p 97). On the contrary, a recent systematic review described that mental health interventions were associated with improved economic outcomes in lowincome and middle-income countries (Lund et al., 2011). Moreover, poverty worsens the health of patients with schizophrenia, and increases the burden of their caregivers (Butzlaff & Hooley, 1998; Caqueo-Urízar & Gutiérrez, 2006; Karanci, 1995), thus leading to poor QoL scores (Caqueo-Urízar et al., 2017a). This reinforces the need for comprehensive care and special attention should be paid to both objective and

subjective quality of life indicators (Boyer et al., 2014).

In relation to clinical variables, these findings show that Aymara patients had a significantly shorter duration of disorder than Non-Aymara patients. The underlining assumption of this result should be taken cautiously as it could be explained by a delay in the clinical diagnosis in Aymara patients due to specific cultural beliefs. Indeed, traditionally, the Aymara family tends to first lead the patient to the healer of the community (Yatiri), who performs a series of rituals to cure the mental disorder (Leiva, 2008). However, after a period of time without major improvement, they finally decide to rely on public mental health services. Another explanation could be that Aymara patients tended to be slightly younger than Non-Aymara patients in our sample, even if comparative results were not statistically significant.

It should also be considered that ethnic minority patients tend to be less aware of community resources, possess less social support, and face language difficulties (Kung, 2003), delaying the start of the treatment.

This study had some limitations that should be noted.

First, we cannot extrapolate our findings to the whole Aymara population, and especially not to those Aymara people for whom the problem of access to care is the main problem. Many of these individuals still reside in the rural Highlands. However, our sample of Aymara patients is likely to be representative of the Aymara patients with schizophrenia in our countries, because most Aymara go to public health services and not to private physicians.

Second, our study used only one type of QoL instrument using S-QoL18. It would be interesting to determine whether our findings could be replicated with QoL instruments that use other conceptual models and dimensional constructs.

Third, this study used cross-sectional data, thus relationships between ethnicity and the

different variables, including QoL scores, were not addressed according to time and were not supported to be causal. Further investigations with longitudinal studies are needed in the future.

In conclusion, our study found that Aymara patients have lower QoL than Non-Aymara patients and some of the reasons that may explain this result are the migration process experienced by the families, as well as socio-cultural and economic factors.

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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.

We obtained consent to publish from the participant. The data can't be shared because it belongs to the Universidad de Tarapacá through its postdoctoral research proyect of A. Caqueo-Urízar. Conception and design: AC-U, LB and MA. Data collection and analysis of data: AC-U, LB and MA. Interpretation of data: AC-U, LB and MA. Drafting and writing the manuscript: AC-U, LB and MA.

References

- Arsova, S., & Kopacheva Barsova, G. (2016). Patients with Schizophrenia and Social Contacts. Open Access Macedonian Journal of Medical Sciences, 4(3), 388-391. https:// doi.org/10.3889/oamjms.2016.084
- Auquier, P., Tinland, A., Fortanier, C., Loundou, A., Baumstarck, K., Lancon, C., & Boyer, L. (2013). Toward Meeting the Needs of Homeless People with Schizophrenia: The Validity of Quality of Life Measurement. PLoS ONE, 8(10), e79677. http:// doi.org/10.1371/journal.pone.0079677

- Awad, G., & Voruganti, L. (2008). The Burden of Schizophrenia on Caregivers: A Review. *Pharmacoeconomics*, 26(2), 149-162.
- Awad, A.G., & Hogan, T.P. (1994). Subjective response to neuroleptics and the quality of life: implications for treatment outcome. *Acta Psychiatrica Scandinavica*, 89(s380), 27-32.
- Baumstarck, K., Boucekine, M., Klemina, I., Reuter, F., Aghababian, V., Loundou, A., & Auquier, P. (2013). What is the relevance of quality of life assessment for patients with attention impairment? *Health and Quality of Life Outcomes*, 11(1), 70. https:// doi.org/10.1186/1477-7525-11-70
- Bender, R., & Lange, S. (2001). Adjusting for multiple testing—when and how? *Journal of Clinical Epidemiology*, 54(4), 343-349.
- Bobes, J., & González, G. (2000). Calidad de vida en la esquizofrenia. In H. Katschnig, H. Freeman, & N. Sartorious (Eds.), *Calidad de vida en los trastornos mentales* (pp. 157-169). Barcelona: Masson.
- Bobes, J., Garcia-Portilla, M. P., Bascaran, M. T., Saiz, P. A., & Bouzoño, M. (2007). Quality of life in schizophrenic patients. *Dialogues in Clinical Neuroscience*, 9(2), 215-226.
- Boyer, L., Baumstarck, K., Iordanova, Τ., Fernandez, J., Jean, P., & Auquier, P. (2014). A poverty-related quality of life questionnaire can help to detect health inequalities in emergency departments. Journal of Clinical Epidemiology, 67(3), 285-295. https:// doi.org/10.1016/j.jclinepi.2013.07.021
- Boyer, L., Lançon, C., Baumstarck, K., Parola, N., Berbis, J., & Auquier, P. (2013). Evaluating the impact of a quality of life assessment with feedback to clinicians in patients with schizophrenia: Randomised controlled trial. *The British Journal of Psychiatry*, 202(6), 447-453. https://doi.org/10.1192/ bjp.bp.112.123463
- Boyer, L., Simeoni, M.-C., Loundou, A., D'Amato, T., Reine, G., Lançon, C., & Auquier, P. (2010). The development of the S-QoL 18: A shortened quality of life questionnaire for patients

with schizophrenia. *Schizophrenia Research*, *121*(1-3), 241-250. https://doi.org/10.1016/j.schres.2010.05.019

- Browne, G., & Courtney, M. (2005). people social support and Housing, with schizophrenia: A grounded theory study. Issues in Mental Health Nursing, 26(3),311-326. https:// doi.org/10.1080/01612840590915694
- Browne, S.R., Lane, A., Gervin, M., Morris, M., Kinsella, A., Larkin, C., & O'Callaghan, E. (1996). Quality of life in schizophrenia: Relationship to socio-demographic factors, symptomatology and tardive dyskinesia. Acta Psychiatrica Scandinavica, 94(2), 118-124. https://doi.org/10.1111/ j.1600-0447.1996.tb09835.x
- Butzlaff, R.L., & Hooley, J.M. (1998). Expressed emotion and psychiatric relapse: A metaanalysis. Archives of General Psychiatry, 55(6), 547-551. https://doi.org/10.1001/ archpsyc.55.6.547
- Caqueo-Urízar, A., Alessandrini, M., Urzúa, A., Zendjidjian, X., Boyer, L., & Williams, D. R. (2017a). Caregiver's quality of life and its positive impact on symptomatology and quality of life of patients with schizophrenia. *Health and Quality of Life Outcomes*, 15, 76. http://doi.org/10.1186/s12955-017-0652-6
- Caqueo-Urízar, A., Boyer, L., & Gilman, S. (2017b). Needs of patients with schizophrenia among an ethnic minority group in Latin America. *Journal of Immigrant and Minority Health*, 19(3), 606-615.
- Caqueo-Urízar, A., Rus-Calafell, M., Craig, T. Κ. J., Irarrazaval, M., Urzúa, A., Boyer, L., & Williams, D. R. Schizophrenia: (2017c). Impact on Family Dynamics. Current Psychiatry 19(1). https://doi.org/10.1007/ Reports, s11920-017-0756-z
- Caqueo-Urízar, A., Alessandrini, M., Zendjidjian, X., Urzúa, A., Boyer, L., & Williams, D. R. (2016). Religion involvement and quality of life in caregivers of patients with schizophrenia in Latin-America. *Psychiatry Research*,

Alejandra Caqueo-Urízar, Marine Alessandrini, Laurent Boyer.

246, 769-775. https://doi.org/10.1016/ j.psychres.2016.07.063

- Caqueo-Urízar, A., Boyer, L., Boucekine, M., & Auquier, P. (2014). Spanish crosscultural adaptation and psychometric properties of the Schizophrenia. Quality of Life short-version questionnaire (SQoL18) in 3 middle-income countries: Bolivia, Chile and Peru. Schizophrenia Research, 159(1), 136-143. https://doi.org/10.1016/ j.schres.2014.08.013
- Caqueo-Urízar, A., Breslau, J., & Gilman, S. (2015). Beliefs about the causes of schizophrenia among Aymara and non-Aymara patients and their primary caregivers in the Central-Southern Andes. *International Journal of Social Psychiatry*, 61(1), 82-91.
- Caqueo-Urízar, A., Gutiérrez-Maldonado, J., Ferrer-García, M., & Darrigrande-Molina, P. (2012). Sobrecarga en Cuidadores Aymaras de pacientes con Esquizofrenia. Revista de Psiquiatría y Salud Mental, 5(3), 191-196. https://doi.org/10.1016/ j.rpsm.2011.07.001
- Caqueo-Urízar, A., Miranda-Castillo, C., Giráldez, S. L., Maturana, S. L., Pérez, M. R., & Tapia, F. M. (2014). An updated review on burden on caregivers of schizophrenia patients. *Psicothema*, 26(2), 235-243.
- Caqueo-Urízar, A., & Gutiérrez-Maldonado, J. (2006). Burden of Care in Families of Patients with Schizophrenia. *Quality* of Life Research, 15(4), 719-724. https:// doi.org/10.1007/s11136-005-4629-2
- Caron, J., Mercier, C., Diaz, P., & Martin, A. (2005). Socio-demographic and clinical predictors of quality of life in patients with schizophrenia or schizoaffective disorder. *Psychiatry Research*, *137*(3), 203-213. https://doi.org/10.1016/ j.psychres.2005.07.002
- Cavieres, F., & Valdebenito, V. (2005). Funcionamiento cognitivo y calidad de vida en la esquizofrenia. *Revista chilena de neuro-psiquiatría*,

43(2), 97-108. https://doi.org/10.4067/ S0717-92272005000200003

- Chou, C.-Y., Yang, T.-T., Ma, M.-C., Teng, P.-R., & Cheng, T.-C. (2015). Psychometric validations and comparisons of schizophrenia-specific health-related quality of life measures. *Psychiatry Research*, 226(1), 257-263. https://doi.org/10.1016/ j.psychres.2014.12.059
- De Munter, K. (2010). Tejiendo reciprocidades: John Murra y el contextualizar entre los aymara contemporáneos. *Chungará (Arica)*, 42(1), 247-255. https://doi.org/10.4067/ S0717-73562010000100033
- De Toledo, E., & Blay, S. L. (2004). Community perception of mental disorders. Social Psychiatry and Psychiatric Epidemiology, 39(12), 955-961. https://doi.org/10.1007/ s00127-004-0820-y
- Fresán, A., De la Fuente-Sandoval, C., Loyzaga, C., Garci#a-Anaya, M., Meyenberg, N., Nicolini, H., & Apiquian, R. (2005).
 A forced five-dimensional factor analysis and concurrent validity of the Positive and Negative Syndrome Scale in Mexican schizophrenic patients. Schizophrenia Research, 72(2), 123-129. https:// doi.org/10.1016/j.schres.2004.03.021
- Gavilán, V., Vigueras, P., Carrasco, A., Cabezas, R., Madariaga, V., Escobar, M., & Mamani, C. (2006). Pautas de crianza aymara. Estudio 'Significaciones, actitudes y prácticas de familias aymara en relación a la crianza y cuidado infantil de los niños y niñas desde la gestación hasta los diez años'. Iquique, Chile: Universidad Arturo Prat.
- Giddens, A. (2006). Sociología. Madrid: Alianza Editorial.
- Górna, K., Jaracz, K., Rybakowski, F., & Rybakowski, J. (2008). Determinants of objective and subjective quality of life in first-time-admission schizophrenic patients in Poland: a longitudinal study. *Quality* of Life Research, 17(2), 237-247. https:// doi.org/10.1007/s11136-007-9296-z
- Gray, R., Rofail, D., Allen, J., & Newey, T. (2005). A survey of patient satisfaction with and subjective experiences of treatment

with antipsychotic medication. Journal of Advanced Nursing, 52(1), 31-37.

- Gundermann, H. (2000). Las organizaciones étnicas y el discurso de la identidad en el norte de Chile, 1980-2000. Estudios Atacameños, 19, 75-91.
- Gundermann, H., González, H., & Vergara, J. I. (2007). Vigencia y desplazamiento de la lengua aymara en Chile. *Estudios filológicos*, 42, 123-140.
- Haas, J. S., Earle, C. C., Orav, J. E., Brawarsky, P., Neville, B. A., & Williams, D. R. (2008). Racial Segregation and Disparities in Cancer Stage for Seniors. *Journal of General Internal Medicine*, 23(5), 699-705. http://doi.org/10.1007/s11606-008-0545-9
- Hofer, A., Kemmler, G., Eder, U., Edlinger, M., Hummer, M., & Fleischhacker, W.W. (2004). Quality of life in schizophrenia: The impact of psychopathology, attitude toward medication and side effects. *The Journal of Clinical Psychiatry*, 65(7), 932-939.
- Hogan, T. P., Awad, A. G., & Eastwood, R. (1983). A self-report scale predictive of drug compliance in schizophrenics: Reliability and discriminative validity. *Psychological Medicine*, 13(1), 177. https:// doi.org/10.1017/S0033291700050182
- Karanci, A. N. (1995). Caregivers of Turkish schizophrenic patients: causal attributions, burdens and attitudes to help from the health professionals. Social Psychiatry and Psychiatric Epidemiology, 30(6), 261-268.
- Kay, S. R., Fiszbein, A., & Opfer, L. A. (1987). The positive and negative syndrome scale (PANSS) for schizophrenia. *Schizophrenia Bulletin*, 13(2), 261.
- Kirberg, A. (2006). La salud del niño aymara. *Revista chilena de pediatría*, 77(6), 608-609. https://doi.org/10.4067/ S0370-41062006000600009
- Köster, G. (1992). Los Aymaras: Características demográficas de un grupo étnico indígena antiguo en los Andes centrales. In H. Van den Berg, & N. Schiffers (Eds.), *La cosmovisión Aymara* (pp. 81-111). La Paz, Bolivia: Hisbol-UCB.

- W. (2003). Kung, The Illness, Stigma, Culture. or Immigration? Burdens on Chinese American Caregivers of Patients With Schizophrenia. Families in Society: The Journal of Contemporary Social Services, 84(4), 547-557. https:// doi.org/10.1606/1044-3894.140
- Leiva, I. C. (2008). Acercamiento antropológico del concepto de salud mental en los aymaras del sector Isluga. *Revista Cultura y religión*, 2(3), 2.
- Lund, C., De Silva, M., Plagerson, S., Cooper, S., Chisholm, D., Das, J., & Patel, V. (2011). Poverty and mental disorders: breaking the cycle in low-income and middleincome countries. *The Lancet*, 378(9801), 1502-1514.
- Machín, M. (2011). Los Derechos Humanos y la Migración en Chile: Desafíos y Oportunidades para una Convivencia Intercultural. Resumen Ejecutivo, Informe Migrantes Noviembre 2011. Retrieved from http://www.iom.int/files/live/sites/iom /files/pbn/docs/Panorama_Migratorio_de_ America del Sur 2012.pdf
- Marwaha, S., & Johnson, S. (2004). Schizophrenia and employment. Social Psychiatry and Psychiatric Epidemiology, 39(5), 337-349. https://doi.org/10.1007/ s00127-004-0762-4
- McCrone, P., Leese, M., Thornicroft, G., Schene, A., Knudsen, H. C., & Vázquez-Barquero, J. L., EPSILON Study Grp. (2001). A comparison of needs of patients with schizophrenia in five European countries: The EPSILON Study. Acta Psychiatrica Scandinavica, 103(5), 370-379. https:// doi.org/10.1034/j.1600-0447.2001.00207.x
- McLafferty, S. (1982). Neighborhood characteristics and hospital closures: A comparison of the public private and voluntary hospital systems. Social Science & Medicine, 16(19), 1667-1674.
- Nielsen, R. E., Lindström, E., Nielsen, J., & Levander, S. (2012). DAI-10 is as good as DAI-30 in schizophrenia. *European Neuropsychopharmacology*, 22(10),

Alejandra Caqueo-Urízar, Marine Alessandrini, Laurent Boyer.

747-750. https://doi.org/10.1016/ j.euroneuro.2012.02.008

- Núñez, R. E., & Cornejo, C. (2012). Facing the Sunrise: Cultural Worldview Underlying Intrinsic-Based Encoding of Absolute Frames of Reference in Aymara. Cognitive Science, 36(6), 965-991. https:// doi.org/10.1111/j.1551-6709.2012.01237.x
- Organización Mundial para las Migraciones. (2012). Panorama Migratorio de América del Sur. Retrieved from http://www.observa torio.cl/sites/default/files/biblioteca/inform e migrantes final editado1.pdf.
- Patel, K., Kouvonen, A., Close, C., Väänänen, A., O'Reilly, D., & Donnelly, M. (2017). What do register-based studies tell us about migrant mental health? A scoping review. Systematic Reviews, 6, 78. http:// doi.org/10.1186/s13643-017-0463-1
- Pellegrino, A. (2003). La migración internacional en América Latina y el Caribe: tendencias y perfiles de los migrantes, (Vol. 35). Santiago de Chile: Naciones Unidas.
- Peralta, V., & Cuesta, M. J. (1994). Validación de la Escala de los Síndromes Positivo y Negativo (PANSS) en una muestra de esquizofrénicos españoles. [Validation of the positive and negative syndrome scale (PANSS) in a sample of Spanish schizophrenic]. Actas Luso-Española de Neurología, Psiquiatría y Ciencias Afines, 22(4), 171-177.
- Pinikahana, J., Happell, B., Hope, J., & Keks, N. A. (2002). Quality of life in schizophrenia: A review of the literature from 1995 to 2000. International Journal of Mental Health Nursing, 11(2), 103-111.
- Rice, M.F. (1987). Inner-city hospital closures/ relocations: Race, income status, and legal issues. Social Science & Medicine, 24(11), 889-896.
- Robles García, R., Salazar Alvarado, V., Páez Agraz, F., & Ramírez Barreto, F. (2004). Evaluación de actitudes al medicamento en pacientes con esquizofrenia: Propiedades psicométricas de la versión en español del DAI. Actas Españolas de Psiquiatría, 32(3), 138-142.

- Rudnick, A. (2001). The impact of coping on the relation between symptoms and quality of life in schizophrenia. *Psychiatry*, 64(4), 304-308.
- Ruggeri, M., Dall'Agnola, R., Agostini, C., & Bisoffi, G. (1994). Acceptability, sensitivity and content validity of the VECS and VSSS in measuring expectations and satisfaction in psychiatric patients and their relatives. Social Psychiatry and Psychiatric Epidemiology, 29(6), 265-276.
- Ruggeri, M., Nose, M., Bonetto, C., Cristofalo, D., Lasalvia, A., Salvi, G., ... & Tansella, M. (2005). Changes and predictors of change in objective and subjective quality of life: Multiwave follow-up study in community psychiatric practice. *The British Journal of Psychiatry*, 187(2), 121-130.
- Ruiz, P. (1998). The role of culture in psychiatric care. American Journal of Psychiatry, 155(12), 1763-1765.
- Salokangas, R. K. R., Honkonen, T., Stengard, E., & Koivisto, A. M. (2001). To be or not to be married- that is the question of quality of life in men with schizophrenia. Social Psychiatry and Psychiatric Epidemiology, 36(8), 381-390.
- Schomerus, G., Heider, D., Angermeyer, M. C., Bebbington, P. E., Azorin, J.-M., Brugha, T., & Toumi, M. (2007). Residential area and social contacts in schizophrenia: Results from the European Schizophrenia Cohort (EuroSC). Social Psychiatry and Psychiatric Epidemiology, 42(8), 617-622. https:// doi.org/10.1007/s00127-007-0220-1
- Selten, J. P., Cantor-Graae, E., & Kahn, R. S. (2007). Migration and schizophrenia. *Current Opinion in Psychiatry*, 20(2), 111-115.
- Smith, D. B., Feng, Z., Fennell, M. L., Zinn, J. S., & Mor, V. (2007). Separate and Unequal: Racial Segregation And Disparities In Quality Across U.S. Nursing Homes. *Health Affairs*, 26(5), 1448-1458. https://doi.org/10.1377/hlthaff.26.5.1448
- Thompson, A. B., Carrasquillo, O., Gameroff, M. J., & Weissman, M. M. (2010). Psychiatric Treatment Needs Among the

Medically Underserved: A Study of Black and White Primary Care Patients Residing in a Racial Minority Neighborhood. *Primary Care Companion to The Journal of Clinical Psychiatry*, 12(6), e1-e7. http:// doi.org/10.4088/PCC.09m00804whi

- Urzúa, A., Heredia, O., & Caqueo-Urízar, A. (2016). Salud mental y estrés por aculturación en inmigrantes sudamericanos en el norte de Chile. *Revista Médica de Chile*, 144(5), 563-570.
- Van Kessel, J. (1996a). La cosmovisión Aymara. In J. Hidalgo, F. Schiappacasse, F. Niemeyer, C. Aldunate, & P. Mege (Eds.), Etnografía: Sociedades indígenas contemporáneas y su ideología (pp. 169-187). Santiago, Chile: Editorial Andrés Bello.
- Van Kessel, J. (1996b). Los Aymaras contemporáneos de Chile. In J. Hidalgo, F. Schiappacasse, F. Niemeyer, C. Aldunate, & P. Mege (Eds.), Etnografía: Sociedades indígenas contemporáneas y su ideología (pp. 47-67). Santiago, Chile: Editorial Andrés Bello.
- Vicente, B., Kohn, R., Rioseco, P., Saldivia, S., & Torres, S. (2005). Psychiatric disorders among the Mapuche in Chile. *International Journal of social psychiatry*, 51(2), 119-127.
- Villa, M., & Martínez, J. (2000). Tendencias y patrones de la migración internacional en América Latina y el Caribe. In United Nations (Ed.), La migración internacional y el desarrollo en las Américas. Simposio sobre migración internacional en las Américas, serie Seminarios y conferencia (pp. 19-141). Santiago, Chile: Naciones Unidas.
- Wagstaff, A. (2002). Poverty and health sector inequalities. Bulletin of the World Health Organization, 80(2), 97-105.
- Williams, D. R., & Collins, C. (2001). Racial residential segregation: a fundamental cause of racial disparities in health. *Public Health Reports*, 116(5), 404-416.
- World Health Organization [WHO] (Ed.). (1992). ICD-10 Classifications of Mental and Behavioural Disorder: Clinical Descriptions and Diagnostic Guidelines.

Geneva, Switzerland: World Health Organization.

- Zapata, C. (2007). Memoria e historia: El proyecto de una identidad colectiva entre los aymaras de Chile. *Chungará* (Arica), 39(2), 171-183. https://doi.org/10.4067/ S0717-73562007000200002
- Zendjidjian, X.-Y., Baumstarck, K., Auquier, P., Loundou, A., Lançon, C., & Boyer, L. (2014). Satisfaction of hospitalized psychiatry patients: why should clinicians care? Patient Preference and Adherence, 2014(8), 575-583. http://doi.org/10.2147/ PPA.S62278

Notes

* Research article.