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BRIEF REPORT

Quality of life of schizophrenia patients of Aymaran ethnic background in the north of Chile*

Alejandra Caqueo-Urízar^{a,*}, José Gutiérrez-Maldonado^b, Marta Ferrer-García^b, Paula Fernández-Dávila^a

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KEYWORDS

Quality of life; Schizophrenia; Aymaran ethnicity; Community

Abstract

Objective: To describe the quality of life of patients of Aymaran descent with schizophrenia and analyse the differences with patients of non-Aymaran descent.

Method: The study included 45 patients who attended the Mental Health Services in Arica, Chile. The Positive and Negative Syndrome Scale (PANSS) and the Seville Quality of Life Questionnaire (SQoLQ) were used.

Results: The patients of the study showed moderate quality of life levels, with a strong association with the negative syndrome and the general psychopathology of the disorder. No significant differences were found in the quality of life dimensions as regards ethnic background.

Conclusions: The results found demonstrate that the integration of patients in the Community Health Services is positively associated as regards their quality of life. The integration of the caregivers is considered essential in the treatments administered.

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PALABRAS CLAVE

Calidad de vida; Esquizofrenia; Etnia aymara; Comunidad

Calidad de vida en pacientes con esquizofrenia de ascendencia étnica aymara en el norte de Chile

Resumen

Objetivo: Se describe la calidad de vida en pacientes con esquizofrenia con ascendencia aymara, analizando la presencia de diferencias con pacientes de ascendencia no originaria. *Método:* Participaron 45 pacientes atendidos por los Servicios de Salud Mental de Arica, Chile. Se utilizó la Escala de Síntomas Positivos y Negativos (PANNSS), y el Cuestionario Sevilla de Calidad de Vida (CSVV).

E-mail address: acaqueo@uta.cl (A. Caqueo-Urízar).

^a Departamento de Filosofía y Psicología, Universidad de Tarapacá, Arica, Chile

^b Departamento de Personalidad, Evaluación y Tratamientos Psicológicos, Universidad de Barcelona, Barcelona, Spain

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^{*} Corresponding author.

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Resultados: Los pacientes del estudio mostraron niveles moderados de calidad de vida, con una fuerte relación con el síndrome negativo y la psicopatología general del trastorno, no hallando diferencias significativas en las dimensiones de la calidad de vida en función de la ascendencia étnica. Los resultados encontrados evidencian que la integración de los pacientes a los servicios de salud comunitarios se asocia positivamente a la valoración que hacen respecto a su calidad de vida, siendo fundamental considerar la integración de los cuidadores en los tratamientos administrados. © 2011 SEP y SEPB. Publicado por Elsevier España, S.L. Todos los derechos reservados.

Introduction

The incidence of schizophrenia in Chile can be calculated at 12 new cases per 100 000 inhabitants per year, observing that 5 out of 1000 people older than 15 years old present this pathology. The regions of Arica-Parinacota and Santiago de Chile have the greatest prevalence of schizophrenia.² The first region, located in the pre-mountain and highland strip, is where there is the greatest concentration of Aymara in the country. The Aymara are an indigenous ethnic group, dedicated mainly to agriculture and pasturing, although at present many of them have had to immigrate to the cities to seek better work opportunities.

The cultural, social and economic changes that this population has had to face in recent times often enter into conflict with the concept of balance and harmony characteristics of the Andean view of the world. For the Aymara, the world is ordered in 3 dimensions: social relationships, the relationship with the "gods" and the relationship with nature. These 3 dimensions are intimately interwoven and their understanding of the universe revolves around the cyclic rhythms of nature and the ritual calendar that the Aymara have adapted to these natural rhythms. The Aymara do not view themselves as owners of nature but as an intrinsic part of it; their concept of "the good life" is a harmonious walk. However, it is not possible to speak of "the Aymara tradition" as simply an isolated and homogeneous whole. The Aymara tradition is changing and has to adapt to the new times and new circumstances.^{3,4} Aymara ethics, based mainly on community life, enters into conflict with the ethics that have become hegemonic in the Occidental world, based on individualism and personal achievement. This process of acculturation that the people of the Aymara ethnic are going through could bring significant emotional imbalances as a consequence. Schizophrenia, in addition to the clinical symptoms characteristic of the disorder, implies a significant social and economic cost for those who suffer from it and for those closest to them. It also involves an elevated level of stigmatisation that severely affects their quality of life.⁵ Bearing this in mind, it has become necessary to study the quality of life perceived as part of the evaluation of the results from the treatment given to patients with schizophrenia.6

Quality of life is of an essentially subjective nature. There are numerous factors associated with it, including physical and emotional health, social and psychological well-being, fulfilment of personal expectations and goals, economic security and the functional capacity to develop

the activities of daily life normally, among others. 7-9 Based on this, it could be mentioned that the quality of life construct encompasses 2 qualitatively different dimensions: the objective, referring to the conditions of life, and the subjective dimension, corresponding to the personal assessment that individuals make about their conditions of life. 10

Studies on quality of life in patients with schizophrenia over the last decade^{7,8} have found that these individuals report poorer quality of life than the general population and than other patients having physical diseases. Women, young people and individuals with a high level of education report better quality of life. With respect to gender, there is evidence that married women and women living with their partners, together with men living with their partners, receiving their support, present better conditions of life and social functioning. 11,12

It has also been shown that longer development and more severe symptoms correlated poor quality of life, 13 with 3 variables involved: depression and anxiety symptoms, positive symptomatology and negative symptomatology. Among these, the presence of negative symptoms correlates most with poorer quality of life.8-13 As to how personality characteristics influence the quality of life in patients with schizophrenia, characteristics such as being "open to new things" and having high self-esteem are associated with better subjective quality of life, as they mediate between the depression and anxiety symptoms. 14,15

Turning to the patients' social conditions, the literature indicates that having a job or some type of occupation correlates to better quality of life.16 Likewise, having a good social support network of significant individuals such as family members and close friends significantly improves the patients' subjective quality of life; this is because it makes them feel that they have increased ability to cope with and adapt to daily life and stressful occurrences. 17-21

Finally, and from a more positive point of view, the combination of psychosocial and drug treatment, work and task-oriented coping strategies improve the levels of quality of life for these people. 6,13,14,16-21

Considering the fact that they belong to a native population, most of the individuals from an ethnic minority present less social support, less information about community resources, linguistic barriers and a low socioeconomic level.³ Most of the researches come from developed countries with socioeconomic characteristics different from those of the Aymara people. We consequently believe that it is necessary to assess in detail the quality of life in psychotic patients belonging to this ethnic minority. This was, in fact, the central objective of our study.

Method

The subjects participating in the study were 45 patients divided into 2 groups: Aymara ethnic group (n=26) and non-Aymara group (n=19). The patients who described themselves as belonging to the Aymara were considered to be from that ethnic group, constituting 57.8% of the total sample. The sociodemographic characteristics of patients with and without ethnic ancestry are described in Table 1.

Tools

PANSS²²: Its usefulness stems from its assessment of the severity of the symptoms and control of response to treatment. The scale is administered in a semi-structured interview, which lasts 30-40 min. There are 30 items (symptoms), scored from 1 (absent) to 7 (extreme). It consists of 3 subscales: the positive (PANSS-P), with 7 items assessing symptoms such as hallucinations and thought disorders; the negative (PANSS-N), which also has 7 items measuring symptoms of burnout and emotion flattening; and the general psychopathology (PANSS-PG), with 16 items measuring the presence of depression or anxiety. A forth scale, called compound (PANSS-C) is accepted; it is the result of subtracting the negative score from the positive. This tool was translated into Spanish and validated in Spain by Peralta and Cuesta (1994). Its psychometric properties present good interobserver and construct validity, elevated internal consistence (Cronbach's alpha of 0.73 for the positive scale, 0.83 for the negative and 0.87 for the general psychopathology) and appropriate test-retest stability. The intra-class coefficient of correlation was approximately 0.80 for the 3 subscales.

CSCV in Spanish²³: This tool is composed of 59 items, divided into 2 scales: the scale of favourable factors (CSCV-F), composed of 13 items assessing pleasant or positive aspects of quality of life, and the scale of disadvantageous factors (CSCV-D), consisting of 46 items assessing disagreeable or negative aspects of quality of life. Its response scale corresponds to 5-point Likert type scale, which goes from 1 = totally disagree to 5 = agree completely. This tool has been validated in Chile, showing elevated internal consistency within each scale (alpha de Cronbach's alpha of 0.89 and 0.95 in the dimensions of favourable and disadvantageous factors).²⁴

Procedure

In choosing the study participants, the following were considered criteria for exclusion: presence of any organ based symptoms, presence of disorder from psychoactive substance use, presence of any type of sensorial or cognitive disorder, and psychiatric disorder present in any of the caregivers.

Before we administered the tools, we gave the participants a document specifying our research goals, the fact that participation was voluntary, data confidentiality and inclusion criteria. The patients who agreed to participate

gave their informed consent. No payment was offered for participating in the study.

We collected the patients' demographic data. The participants then answered the questionnaires in the following order: CSCV and PANSS. The mean assessment time was approximately an hour. Psychologists administered both tools in the patients' homes. Initially, the Health Service and the University of Tarapacá had sent the users written invitations to their homes; however, there was no response to these invitations. Consequently, we decided to perform the assessment in their homes.

Results

The results of the Aymara patients on the different CSCV tools showed a mean of 103.5 (standard deviation [SD] = 38.2; range, 45–179) for the *Disadvantageous Factors* (CSCV-D) and a mean of 49.6 (SD = 10.80; range, 23–65) on the scale for *Favourable Factors* (CSCV-F). The results for the non-ethnic patients yielded a mean of 107.2 (SD = 36.02; range, 54–197) on the *Disadvantageous* scale and of 47.6 (SD = 13.6; range = 24–65) on the *Favourable Factors*. The total CSCV score classified both patient groups as being in a moderate level of quality of life.

As for the symptom severity measured with the PANSS, the Aymara patient results showed a mean of 10.4 (SD = 4.8; range, 7-24) for *Positive* (PANSS-P), a mean of 16.6 (SD = 7.4; range, 7-35) for Negative (PANSS-N), a mean of 31.1 (SD = 12.1; range, 16-56) for General Psychopathology, of 5.7 (SD = 3.2; range, 4-19) for the Excitation subscale, a mean of 7.2 (SD = 2.2; range, 4-12) for the Mania subscale, and of 7.9 (SD = 4.4; range, 4-18) for the Depression subscale. The PANSS results for the patients with no indigenous ancestry yielded the following means: a Positive mean of 10 (SD = 6.4; range, 7-27) (PANSS-P), a Negative of 15.2 (SD = 8.5; range, 7-44) (PANSS-N), a General Psychopathology of 31.6 (SD = 16.9; range, 17-89), an Excitation subscale mean of 5.9 (SD = 4.2; range, 4-18), a Mania subscale of 8 (SD = 2.7; range, 4-15) and a Depression subscale mean of 10.4 (SD = 6.2; range, 4-24).

We analysed symmetry and kurtosis, finding that the data distribution did not adjust to a normal distribution. Consequently, we then proceeded to use non-parametric tests in the data analysis. To analyse the relationship between the PANSS subscales and the *Favourable* and *Disadvantageous* factors of the CSCV, Pearson's chi-square independence test was applied, to see whether the differences observed in the 2 groups were attributable to chance. The *Favourable* function showed a relationship only with the PANSS *Negative* subscale score. The *Disadvantageous* factor showed a relationship with only the PANSS *General Psychopathology* subscale score (Tables 2 and 3).

To analyse the existence of significant differences in the patients' quality of life by their ethnic group, we applied Mann-Whitney U test. This contrasted whether the values obtained for a variable were similar in different groups. We did not observe any difference among the Aymara and the non-Aymara patients, on either the Favourable function (U = 224.5; P = .6) or the Disadvantageous factor subscales (U = 236; P = .8). Neither did we find any differences in the dominant type of symptoms based

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atient ethnic group	Aymara (n	= 26)	Non-Aymara (n = 19)		
ocio-demographic variables					
Age (years)	36.1 (SD, 12.6)		47.9 (SD, 13.2)		
Sex					
Male	26	100%		0%	
Female		0%	19	100%	
Civil state					
Married	2	7.7%	3	15.8%	
Single	24	92.3%	15	78.9%	
Separated		0%	0	0%	
Widow/widower		0%	1	5.3%	
Educational level					
Basic	2	7.7%	5	26.3%	
Middle	16	61.5%	7	36.8%	
Higher	6	23.1%	6	31.6%	
Technical	2	7.7%	1	5.3%	
No studies		0%	0	0%	
Occupation					
Blue-collar worker	2	7.7%	16	52.6%	
Student	4	15.4%	2	0%	
White-collar worker	1	3.8%	1	5.3%	
Professional		0%	2	0%	
Not working	19	73.1%	10	42.1%	
Religion					
Catholic	10	38.5%	13	68.4%	
Other	11	42.3%	5	26.3%	
No religion	5	19.2%	1	5.3%	
Retirement					
Retired	24	92.3%	15	78.9%	
Not retired	2	7.7%	4	21.1%	
Mental health centre					
ESSMA Norte	11	42.3%	5	26.3%	
ESSMA Sur	15	57.7%	14	73.7%	

on ethnic ancestry [Positive syndrome (U=193.5; P=.2), negative syndrome (U=204.5, P=.3), general psychopathology (U=234.5, P=.8), excitation (U=219, P=.5), mania (U=219, P=.5) and depression (U=181, P=.1)].

Discussion

The patients who formed the sample analysed in this study presented a dominance of negative symptomatology, related with a more unfavourable disorder course, longer periods of hospitalisation, delay in recovery and poor treatment results. These symptoms are related to the social, economic and professional dysfunctions^{25–28} that diminish the quality of life perceived by the patients in different areas of their lives.

Likewise, the participants showed elevated indices of general psychopathology, specifically symptoms of depression and anxiety—symptoms both also associated with unfavourable aspects of quality of life. While depression symptoms are not a central element of the disorder, they are highly prevalent in patients diagnosed with schizophrenia

during long periods. This, in turn, is associated with precarious functioning and a reduction in the subjects' quality of life. 26,29,30

Despite the symptomatology found and in agreement with previous studies performed in the same geographical location, ²¹ these study participants presented moderate levels of quality of life, with no differences derived from ethnic origin being seen. Given these results, it is worth considering if the specific variables as to region or its socio-cultural conditions (such as the barely competitive rhythm of life and the moderate life span) could explain the differences between the results found in this research and the data from other studies performed in developed countries where patients with schizophrenia perceive a lower quality of life. ^{25,27,28,31-34} It seems that the social and cultural context in which the patients are immersed can have significant influence over the course of the disorder.

With respect to the influence of psychosocial factors on the quality of life of patients with schizophrenia, there is evidence that subjects who have an occupation possess greater social networks and more social support stemming

Table 2 Pearson's chi-square coefficients for the favourable function of the Seville Quality of Life Questionnaire and the PANSS negative symptom subscale.

	Value	Degrees of freedom	Asymptotic significance (bilateral)
Pearson's chi-square	451.562a	480	0.820
Likelihood ratio	191.412	480	1.000
Linear by linear association	7.683	1	0.006
Valid cases (No.)	45		
a 25 boxes (100.0%) had an expect	ed frequency less thar	5. The minimum expected frequ	ency was 0.02.

Table 3 Pearson's chi-square coefficients for the unfavourable function of the Seville Quality of Life Questionnaire and the PANSS general psychopathology subscale.

	Value	Degrees of freedom	Asymptotic significance (bilateral)
Pearson chi-squared	1012.500a	1.008	0.454
Likelihood ratio	269.779	1.008	1.000
Linear by linear association	4.295	1	0.038
Valid cases (No.)	45		

^a 1073 boxes (100.0%) have an expected frequency less than 5. The minimum expected frequency was 0.02.

from this, being associated positively with their subjective well-being. ^{35,36} Social functioning, defined as the capacity to adopt social roles such as wife or worker, thus constitutes the main predictor for the patients' quality of life. ^{31–35} Consequently, comprehensive treatment for patients with schizophrenia should be continued and improved, taking the family in consideration as well.

In spite of the interest of the data provided, this study does have some limitations: (1) because the data were collected from the patients' homes, it was difficult to control the environmental variables that could interfere with or bias the information; (2) during our data collection, a significant percentage (20.3%) of the patients did not agree to participate in the study, probably due to the social stigma associated with the disorder, which could have influenced willingness to participate.

Future research should focus its study on the treatment modes currently administered to patients with schizophrenia and analyse the measurements of success produced, considering the integration of the caregivers as an essential criterion.

Ethical disclosures

Protection of human and animal subjects. The authors declare that the procedures followed were in accordance with the regulations of the responsible Clinical Research Ethics Committee and in accordance with those of the World Medical Association and the Helsinki Declaration.

Confidentiality of data. The authors declare that they have followed the protocols of their work centre on the publication of patient data and that all the patients included in the study have received sufficient information and have given their informed consent in writing to participate in that study.

Right to privacy and informed consent. The authors have obtained the informed consent of the patients and/or

subjects mentioned in the article. The author for correspondence is in possession of this document.

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Conflict of interest

The authors have no conflict of interest to declare.

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