

Caregivers' perception of patients' cognitive deficit in schizophrenia and its influence on their quality of life

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Abstract

Purpose: The aim of the study was to explore the relationship between the caregivers' perception of patients' cognitive deficits (i.e., neurocognition and social cognition) and their quality of life (QoL), after adjusting on clinicians' assessment of neurocognitive deficits and sociodemographic confounding factors. **Methods:** The study included 253 patients with schizophrenia and their caregivers from public mental health clinics in Bolivia, Chile, and Peru. The caregivers' perception of patients' neurocognitive and social cognitive deficits was assessed using the GEOPTE scale, caregivers' QoL was assessed using the schizophrenia caregiver quality of life questionnaire (S-CGQoL) and clinicians' ratings of patients' neurocognitive deficits was based on the cognitive factor of the positive and negative syndrome scale for schizophrenia (PANSS). **Results:** The degree of agreement between caregivers' perception and health care professionals' assessment of cognitive deficit of patients with schizophrenia was moderate. Caregivers' perceptions of neurocognitive and social cognitive deficits were significantly associated with their QoL, contrary to clinicians' assessment. **Conclusions:** Caregivers' perception of patients' cognitive deficit was significantly associated with their QoL. The caregivers' perception regarding patients' neurocognition and social cognition may enrich the knowledge of clinicians on patients and is important to be considered by clinicians to improve caregiver's QoL.

Keywords: Caregivers, patients cognitive deficits, schizophrenia, quality of life.

Resumen

Percepción de los cuidadores del déficit cognitivo de pacientes con esquizofrenia y su influencia en la calidad de vida. Antecedentes: el objetivo fue explorar la relación entre la percepción de los cuidadores respecto a los déficits cognitivos de los pacientes (neurocognición y cognición social) y su calidad de vida (CV), una vez ajustados los modelos con variables de confusión como la evaluación neurocognitiva médica y variables sociodemográficas. **Método:** incluyó a 253 pacientes con esquizofrenia y sus cuidadores de servicios de salud pública en Bolivia, Chile y Perú. La percepción de los cuidadores respecto a los déficits neurocognitivos y cognición social de los pacientes se evaluó mediante la escala GEOPTE, la CV de los cuidadores mediante el S-CGQoL y la valoración de los médicos fue evaluado con el factor cognitivo de la Escala PANSS. **Resultados:** el grado de acuerdo entre la percepción de los cuidadores y evaluación de los profesionales respecto al déficit cognitivo de los pacientes fue moderado. La percepción de los cuidadores respecto a los déficits neurocognitivo y de cognición social presentó una asociación significativa con su CV, contrariamente a la evaluación de los médicos. **Conclusiones:** la percepción de los cuidadores respecto a los déficits neurocognitivos y de cognición social puede enriquecer el conocimiento de los clínicos, siendo de importancia para mejorar la CV del cuidador.

Palabras clave: cuidadores, déficits cognitivos de los pacientes, esquizofrenia, calidad de vida.

Schizophrenia has a significant impact not only on the patient but also on the entire family. Large-scale deinstitutionalization of these patients has resulted in a dramatic shift in the burden of caregiving from health care professionals to family members with negative consequences for their quality of life (Caqueo-Urizar, Breslau, & Gilman, 2015).

Evidence shows that there are several objective determinants of the deterioration of caregivers' quality of life (QoL), ranging from socio-demographic factors, such as being older, female (specially

the mother), with nuclear family, with medical problems, lower educational and socioeconomic status, unemployed and recent life crisis (Shulz & Sherwood, 2008; Gutiérrez-Maldonado, Caqueo-Urizar, & Kavanagh, 2005; Caqueo-Urizar & Gutiérrez-Maldonado, 2006; Zamzam et al., 2011; Kumar & Mohanty, 2007; Martin, 2009), to factors related to the patient's disorder, such as course of the illness, duration of the disorder, number of hospital admissions, level of functioning, severity of psychotic symptoms and cognitive impairment (Dyck, Short, & Vitaliano, 1999; Roik, Heider, Bebbington, & Angermeyer, 2007; Schene, Van Wijngaarden, & Koeter, 1998; Provencher & Mueser, 1997; Wong, 2000; Kuokia & Madianos, 2005; Perlick et al., 2006; Kate, Grover, Kulhara, & Nehra 2013; Veltro, Magliano, Lobraccio, Morosini, & Maj, 1994).

A criticism leveled against these studies was that caregivers' personal experiences of these objective factors are not necessarily

equivalent among individuals and may thus lead to different QoL level. From this perspective, subjective caregivers' experience may be a stronger predictor of QoL than objective factors (Boyer et al., 2014). Studies should focus on caregivers' personal experiences in addition to objective factors.

Although neurocognitive impairment is a core symptom of schizophrenia, little is known about the relationship between caregivers' QoL and their perception of patients' cognition (neurocognition and social cognition), in comparison to the clinicians' assessments of cognitive deficits (Millier et al., 2014; Caqueo-Úrizar, Gutiérrez-Maldonado, Ferrer-García, Urzúa, & Fernández-Dávila, 2013; Caqueo-Úrizar, Gutiérrez-Maldonado, & Miranda-Castillo, 2009). In addition, the differential influence of neurocognition and social cognition on caregivers' QoL is rarely studied. Contrary to neurocognitive impairment, scarce data are available concerning the impact of social cognition on caregivers' QoL. Social cognitive deficits in patients with schizophrenia "include a compromised ability to infer and interpret others' feelings, a tendency to excessively ascribe negative emotions to others" (Penn, Sanna, & Roberts, 2008).

Studies in social cognition show that it is an independent predictive factor in treatment outcomes, which considers other aspects not addressed by neurocognition (Brekke, Kay, Lee, & Green, 2005; Brune, 2005; Penn, Mueser, Spaulding, Hope, & Reed, 1995; Pinkham & Penn, 2006; Waldheter, Jones, Johnson, & Penn, 2005). Other authors have pointed out that patients' functioning is more related to social cognition than to neurocognition; so, social cognition can have significant influence on caregivers' QoL (Fett, et al., 2011; McGurk, Twamley, Sitzer, McHugo, & Mueser, 2007; Pijnenborg et al., 2009).

The aim of the study was to explore the relationship between caregivers' perception of patients' cognitive deficits (i.e., neurocognition and social cognition) and their QoL, after adjusting for clinicians' assessments of confounding neurocognitive deficits and sociodemographic factors.

Method

Participants

The cross-sectional study evaluated prospective patients and their caregivers from May 2012 to February 2013 from the Public Mental Health Services in three Latin-American countries: La Paz-Bolivia (32.8%); Arica-Chile (33.6%) and Tacna-Perú (33.6%).

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, tenth version ICD-10 (WHO, 1992). The exclusion criteria included the following: diagnosis other than schizophrenia, a state of psychotic crisis, or having a sensory or cognitive type of disorder that prevents being evaluated. 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.

Instruments

GEOPTE Scale of Social Cognition for Psychosis (Sanjuán et al., 2003): We used this 15-item scale designed to measure social cognition in schizophrenia. Each item was scored on a 5-point

scale from (1) *none*, (2) *a little*, (3) *normal*, (4) *fairly much*, and (5) *a lot*, with higher values indicating a higher level of functional impairment. Items 1 to 7 measure neurocognitive functions and items 8 to 15 measure social cognitive function; for this study, each set of factors was assessed separately to compare neurocognitive deficit (GEOPTE 1-7, range 1-35) and social cognitive impairment (GEOPTE 8-15, range 1-40).

Positive and Negative Syndrome Scale for Schizophrenia (PANSS) (Kay, Fiszbein, & Opler, 1987): This is a 30-item 7-point (1-7) rating scale that was specifically developed to assess psychotic symptoms in individuals with schizophrenia and which comprises three subscales: positive, negative and general psychopathology. For the purposes of this study, we only considered the cognitive factor (range 3 to 21) of this instrument consisting of the items of disorientation, poor attention and difficulty of abstract thinking.

Schizophrenia Caregiver Quality of Life Questionnaire (S-CGQoL); Richieri et al., 2011): Self-reported instrument to measure of QoL. Its application takes about 5 minutes. It has 25 items that describe seven dimensions: physical and psychological well-being, psychological burden and loss, relationship with spouse, relationship with psychiatric team, material burden, relationship with family and relationship with friends. The S-CGQoL presents satisfactory psychometric properties; its structure explains 74.4% of the total variance, while its internal consistency has a Cronbach alpha coefficient ranging from .79 to .92 in the sample. Dimension and index scores range from 0, indicating the lowest QoL, to 100, the highest QoL.

Demographic and clinical data: for patients, we collected sex, age, ethnicity (Aymara/Non-Aymara), educational level (low/high), marital status (with a partner or without a partner). For caregivers, we collected sex, age, ethnicity, educational level, marital status, employment status, family income (measure of the total monthly income per household, expressed in US dollars). Regarding ethnicity, the Aymara culture, with a population of 2 million people, has lived in the Andes Mountains for centuries. However, recent generations of Aymara have undertaken a massive migration, moving from rural towns in the highland to large cities (Köster, 1992; Van Kessel, 1996; Gundermann, González, & Vergara, 2007).

Procedure

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 the caregivers. The length of time of the evaluation was between 20 and 30 minutes.

Before the start of the survey, informed consent was requested and received from the caregivers. The objectives of the study were explained as well as the voluntary nature of participation. No compensation was offered for participating in the study. Most of the people agreed to participate.

Data analysis

Associations between QoL (S-CGSQoL index), caregivers' perceptions of patients' neurocognitive deficit (GEOPTE 1-7), caregivers' perceptions of patients' social cognitive deficit

(GEOPTTE 8-15) and clinicians' ratings of patients' neurocognitive deficit (PANSS cognitive) were explored using Pearson correlation coefficients. Then, eight multiple linear regression models were fitted considering the index and each of the seven subscales of the S-CGQoL as dependent variables, and caregivers' perceptions of patients' neurocognitive deficit (GEOPTTE 1-7), social cognitive impairment (GEOPTTE 8-15), PANSS cognitive and sociodemographic characteristics as independent variables. The assumptions underlying regression analysis were controlled (e.g., linear relationship, multivariate normality, no or little multicollinearity and homoscedasticity). All statistical analyses were performed using the SPSS version 18.0 software package (SPSS Inc., Chicago, IL, USA).

Results

Two hundred and fifty-three patients and caregivers were enrolled in the study (table 1).

Table 2 shows the intercorrelations of caregivers' perception of patients' neurocognitive deficit (GEOPTTE 1-7), patients' social cognitive impairment (GEOPTTE 8-15), clinicians' ratings of patients' neurocognitive deficit (PANSS cognitive) and QoL (S-CGQoL18 index). The correlation between caregivers' perception of patients' social cognitive deficit (GEOPTTE 8-15) and the clinicians' ratings of the patients' cognitive deficits (PANSS cognitive) was moderate (.49), which indicates that there is medium degree of agreement between the neurocognitive deficits reported by the caregiver and the clinician. On another hand, the correlation between caregivers' perception of patients' neurocognitive deficits (GEOPTTE 1-7) and patients' social cognitive impairment (GEOPTTE 8-15) was higher (.63).

Table 3 shows the results of linear regression analyses of the S-CGQoL. Caregivers' perceptions of cognitive deficit, including neurocognitive and social cognitive deficits, were significantly associated with their QoL, contrary to clinicians' assessment of the patients' neurocognitive deficits, which was not statistically significant. More precisely, caregivers' perception of patients' neurocognitive deficits were related to the area of Relationship with the spouse ($\beta = -0.22, p = .02$) and Relationship with Family ($\beta = -0.26, p < .01$). Caregivers' perception of patients' social deficit were associated with QoL in the area of Psychological and Physical well-being ($\beta = -0.35, p < .01$) and also with the QoL index ($\beta = -0.37, p < .01$).

Concerning patient characteristics, being female, younger, and having low educational level were associated with lower caregivers' QoL levels.

Concerning caregiver characteristics, being female, older, unemployed, Aymara and having a low family income were associated with lower QoL levels.

Discussion

Our study found that, first, the degree of agreement between caregivers' and health care professionals' perceptions of cognitive deficit of patients with schizophrenia was moderate. One explanation could be that caregivers are witnesses of cognitive disorders and of their impact in 'real life', contrary to clinicians who performed an assessment of cognition in an 'experimental' situation. Previous studies have shown the discrepancy between

Table 1
Sample characteristics (N = 253)

Patients		M (SD)
Gender (men): N (%)		164 (66.4)
Age in years		35.6 (15.5)
Aymara: N (%)	Yes	117 (46.2)
	No	136 (53.8)
Educational level \geq 12 years: N (%)		40 (15.8)
Marital Status: N (%)	Married	16 (6.3)
	No-married	237 (93.7)
Duration of disorder in years		14.6 (11.8)
Severity - PANSS	Cognitive factor	7.28 (3.97)
Caregivers		
Gender (women): N (%)		170 (67)
Relationship with the patient N (%)		
Mother		115 (45.5)
Father		57 (22.5)
Sibling		40 (15.8)
Partner		13 (5.1)
Son/Daughter		12 (4.7)
Other		16 (6.3)
Age in years		54.7 (14.4)
Aymara: N (%)	Yes	130 (51.4)
	No	123 (48.6)
Educational level \geq 12 years: N (%)		66 (21.1)
Employment status: N (%)	Employed	144 (56.9)
	Unemployed	109 (43.1)
Monthly family income (US dollars)		417.6 (429.4)
M (SD): mean and standard deviation; N (%): effective (percentage). PANSS Cognitive = Positive and Negative Syndrome scale for Schizophrenia		

Table 2
Intercorrelations between GEOPTTE 1-7, GEOPTTE 8-15, PANSS Cognitive and S-CGQoL18 Index

	Caregivers' perception of patients' neurocognitive deficits (GEOPTTE 1-7)	Caregivers' perception of patients' social cognitive deficits (GEOPTTE 8-15)	Clinician ratings of neurocognitive deficits (PANSS cognitive)
GEOPTTE 1-7	-		
GEOPTTE 8-15	0.63*	-	
PANSS cognitive	0.48*	0.49*	-
S-CGQoL	-0.26*	-0.41*	-0.32*
GEOPTTE 1-7 = Caregivers' perception of patients' neurocognitive deficit; GEOPTTE 8-15 = Caregivers' perception of patients' social cognitive impairment; PANSS cognitive = clinicians' ratings of patients' neurocognitive deficit; S-CGQoL = Caregiver-reported index of their quality of life.			
* $p < .01$			

Table 3
Linear regression model of caregivers' Quality of Life

	Total Index S-CGQoL β [#]	Psychological and Physical well-being β	Psychological burden and loss β	Relationship with spouse β	Relationship with psychiatric team β	Material burden β	Relationship with family β	Relationship with friends β
Patient' Gender Women Men (Ref)	-0.01	-0.02	-0.064	0.03	-0.00	-0.18**	0.00	0.03
Patient' Age	0.18*	0.19*	0.24**	-0.12	-0.08	0.27**	0.03	0.08
Patient' Ethnicity Aymara Non-Aymara (Ref)	-0.03	-0.02	0.05	-0.09	0.11	-0.02	0.04	0.03
Patient' Marital status Without a partner With a partner (Ref)	-0.04	-0.05	0.02	0.10	-0.03	0.05	0.05	0.08
Patient' Educational level ≥12 years <12 years (Ref)	0.00	-0.01	-0.04	0.07	0.18*	-0.16*	0.05	0.06
Caregiver' Gender Women Men (Ref)	-0.17*	-0.20**	-0.19**	-0.26**	0.09	-0.17*	-0.07	-0.18*
Caregiver' Age	-0.01	-0.03	-0.07	-0.31	0.07	-0.10	-0.20*	-0.02
Caregiver' Ethnicity Aymara Non-Aymara (Ref)	-0.02	0.00	-0.13	-0.09	0.07	-0.16*	-0.16	-0.00
Caregiver' Educational level ≥12 years <12 years (Ref)	0.12	0.09	0.07	-0.04	-0.04	0.18	0.04	0.13
Employment status Without employment With employment (Ref)	0.03	-0.00	0.02	-0.16*	-0.02	-0.05	0.19	-0.05
Family income (US Dollars)	-0.00	-0.00	0.06	0.09	0.07	0.26**	0.00	0.00
PANSS Cognitive	-0.13	-0.08	-0.12	0.06	-0.05	-0.08	-0.00	0.04
GEOPTe 1-7	-0.00	0.00	-0.11	-0.22*	-0.02	-0.14	-0.26**	-0.00
GEOPTe 8-15	-0.37**	-0.35**	-0.13	0.14	0.00	-0.01	0.05	-0.08

[#]β: 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); Ref = reference group. Statistically significant correlations are bolded. * p≤0.05; ** p≤0.01. PANSS = positive and negative syndrome scale for schizophrenia, clinicians' ratings of patients' neurocognitive deficits; GEOPTe 1-7 = patients' subjective perceptions of their neurocognitive deficits; GEOPTe 8-15 = patients' subjective perceptions of their social cognitive impairments

the reports of patients and health professionals (Slevin, Plant, Lynch, Drinkwater, & Gregory, 1998; Boyer et al., 2013).

Second, caregivers' perception of patients' cognitive deficits including both neurocognitive and social cognitive deficits were significantly associated with QoL, contrary to clinicians' assessment. This finding suggests that clinicians should incorporate a caregivers' measure of cognitive deficit of patients to enrich their knowledge about patients' cognitive deficits and to better meet caregivers' needs.

Third, we found that caregivers' perception of patients' neurocognitive and social cognitive deficits were not associated with the same dimensions of QoL. On the one hand, neurocognitive deficits were related to the relationship with the spouse and family, probably because caregivers are closer to the patient and spend more hours on his/her care, so deficits in the cognitive area in more severe patients can make that coexistence in the family more difficult, increasing the levels of caregivers' burden. Previous studies have shown that a greater severity of the disorder and a lower functional level of the patient, increase caregivers' burden (Ochoa et al., 2008; Parabiaghi et al., 2007; Angermeyer, Kilian, Wilms, & Wittmund, 2006). On the other hand, the fact that social cognitive deficit affects caregivers' QoL in the area of psychological and physical well-being is probably related to the caregiver's constant concern about the patient's lack of integration in society and about the patient's future in the absence of the caregiver. Most caregivers perceived that the patient is highly dependent on them and therefore they do not have

enough time for themselves, which influences their psychological well-being (Caqueo-Urizar & Gutiérrez-Maldonado, 2006). In addition, our finding about social cognition is of importance because it adds new information to previous studies. Our assumption is that, to the extent that patients have better social cognition, this will allow them to participate more in the community and enjoy more social inclusion, which in turn could mean less demand for the caregiver, leading to increased caregivers' perception of their psychological and physical well-being. It seems, then, that aspects such as integration in the community, patients' social functioning and social networks outside the family would be important variables in the improvement of caregivers' QoL, in addition to patients' neurocognitive rehabilitation (memory, thinking and language). Indeed, patients who manage to establish and maintain social interactions within the community help families to conform and adapt to the disorder (Gutiérrez-Maldonado, Caqueo-Urizar, Ferrer-García, & Fernández-Dávila, 2012; Green, Kern, & Heaton, 2004).

Finally, our results also show that both patient and caregiver sociodemographic and clinical characteristics were associated with caregivers' QoL. Coinciding with previous studies, female caregivers (mainly the mothers) show lower level of QoL, they are usually the main caregiver and assume full responsibility for the patient's care, showing higher involvement (Kung, 2003; Caqueo-Urizar, & Gutiérrez-Maldonado, 2006; Kuipers, 1993; Martínez, Nadal, Beperet, Mendióroz, & Grupo Psicost, 2000; Kumar & Mohanty, 2007), which in turn affects their overall health

(Alonso, Prieto, & Antó, 1995). Socioeconomic level seems to play an important role in caregivers' QoL, as suggested by several variables. Financial and social difficulties have been reported on other contexts, such as: India (Thara, Kamath, & Kumar, 2003), China (Li, Lambert, & Lambert, 2007) and Nigeria (Ohaeri, 2001). Economy is affected because of the loss of potential income from the patient (Kuipers, 1993) and also because, in many cases, the main caregivers quit their jobs because of their caring obligations (Caqueo-Urizar & Gutiérrez-Maldonado, 2006). Related to patients' age, our results are similar to other studies that show that older patients positively influence caregivers' QoL. This might be explained by an improvement in caregiver coping strategies over the years (Magliano, et al. 2002) and also because younger patients are related to higher caregiver psychological distress (Thornicroft, et al., 2002; McDonnell, Short, Berry, & Dyck, 2003).

Several limitations should be considered in our study. First, the study is cross-sectional and thus, cannot establish the temporality between social cognition or neurocognition and caregivers' QoL. Second, the sample may not be representative of the entire Latin American population of caregivers of patients with schizophrenia. Larger studies of more diverse and larger groups of caregivers are needed to confirm our findings. Third, future studies should explore important variables such as the years of evolution of the disorder and the severity of disorder that we could not include in our analyses because of the problem of colinearity with variables such as patients' age, caregivers' age and cognitive PANSS. Fourth,

we considered only cognitive PANSS, so future studies should consider more appropriate cognitive assessment, and finally, we did not have an assessment of social cognition by a provider.

Acknowledgements

This research was funded by CONICYT and BECAS-CHILE Postdoctorado en el Extranjero (number 74140004) and also by the Convenio de Desempeño UTA-MINEDUC.

We thank Felipe Ponce and Jorge Escudero for their assistance in the study and also the following people and facilities: Dr. Hugo Sánchez, Dr. Ricardo Alvites, Dr. Andrés Collado, Gladys Coaquira, and Vilma Liendo; and we extend our special thanks to Dr. José Revilla from Hipólito Unanue Hospital in Tacna, Perú, Dr. Marcio Soto from Arequipa, Perú, Dr. Fernando Garitano, Dr. Mauricio Peredo, and Dra. Mabel Romero from Centro de Rehabilitación y Salud Mental San Juan de Dios, and the Director of Hospital Psiquiátrico de la Caja Nacional de Salud from La Paz, Bolivia.

We also thank Dra. Magdalena Gardilic, Ester López, and Alejandra Lagos from Servicio de Salud de Arica, Chile, and extend our special thanks to all the patients and caregivers who participated in this study.

Finally, a special thanks to Dr. Stephen Gilman and Dr. David Williams from Harvard University who assisted in the research project.

References

- Alonso, J., Prieto, L., & Antó, J. (1995). La versión española del SF-36 Health Survey (Cuestionario de Salud SF-36): un instrumento para la medida de los resultados clínicos [The Spanish version of the SF-36 Health Survey (SF-36 Questionnaire Health): An instrument for measuring clinical outcomes]. *Medicina Clínica (Barcelona)*, *104*, 771-776.
- Angermeyer, M. C., Kilian, R., Wilms, H. U., & Wittmund, B. (2006). Quality of life of spouses of mentally ill people. *International Journal of Social Psychiatry*, *52*, 278-285.
- Boyer, L., Baumstarck, K., Boucekine, M., Blanc, J., Lançon, C., & Auquier, P. (2013). Measuring quality of life in patients with schizophrenia: An overview. *Expert Review of Pharmacoeconomics & Outcomes Research*, *13*(3), 343-349.
- Boyer, L., Baumstarck, K., Iordanova, T., Fernández, 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.
- Brekke, J., Kay, D. D., Lee, K. S., & Green, M. F. (2005). Biosocial pathways to functional outcome in schizophrenia. *Schizophrenia Research*, *80*(2-3), 213-225.
- Brune, M. (2005). Emotion recognition, 'theory of mind,' and social behavior in schizophrenia. *Psychiatry Research*, *133*(2-3), 135-147.
- Caqueo-Urizar, A., & Gutiérrez-Maldonado, J. (2006). Burden in families of patients with schizophrenia. *Quality of Life Research*, *15*(4), 719-724.
- Caqueo-Urizar, 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-Urizar, A., Gutiérrez-Maldonado, J., & Miranda-Castillo, C. (2009). Quality of life in caregivers of patients with schizophrenia: A literature review. *Health and Quality of Life Outcomes*, *7*, 84.
- Caqueo-Urizar, A., Gutiérrez-Maldonado, J., Ferrer-García, M., Urzúa, A., & Fernández-Dávila, P. (2013). Typology of schizophrenic symptoms and quality of life in patients and their main caregivers in northern Chile. *International Journal of Social Psychiatry*, *59*(1), 93-100.
- Dyck, D., Short, R., & Vitaliano, P. (1999). Predictors of burden and infectious illness in schizophrenia caregivers. *Psychosomatic Medicine*, *61*, 411-419.
- Fett, A. K., Viechtbauer, W., Dominguez, M. D., Penn, D. L., van Os, J., & Krabbendam, L. (2011). The relationship between neurocognition and social cognition with functional outcomes in schizophrenia: A meta-analysis. *Neuroscience & Biobehavioral Reviews*, *35*(3), 573-588.
- Green, M. F., Kern, R. S., & Heaton, R. K. (2004). Longitudinal studies of cognition and functional outcome in schizophrenia: Implications for Matrics. *Schizophrenia Research*, *72*, 41-51.
- Gundermann, H., González, H., & Vergara, J. (2007). Vigencia y desplazamiento de la lengua aymara en Chile [Force and displacement of the aymara's language in Chile]. *Estudio filológico*, *42*, 123-140.
- Gutiérrez-Maldonado, J., Caqueo-Urizar, A., & Kavanagh, D. J. (2005). Burden of care and general health in families of patients with schizophrenia. *Social Psychiatry and Psychiatric Epidemiology*, *40*, 899-904.
- Gutiérrez-Maldonado, J., Caqueo-Urizar, A., Ferrer-García, M., & Fernández-Dávila, P. (2012). Influencia de la percepción de apoyo y del funcionamiento social en la calidad de vida de pacientes con esquizofrenia y sus cuidadores [Influence of perceived social support and functioning on the quality of life of patients with schizophrenia and their caregivers]. *Psicothema*, *24*(2), 255-262.
- Kate, N., Grover, S., Kulhara, P., & Nehra, R. (2013). Relationship of caregiver burden with coping strategies, social support, psychological morbidity, and quality of life in the caregivers of schizophrenia. *Asian Journal of Psychiatry*, *6*(5), 380-388.
- Kay, S. R., Fiszbein, A., & Opler, L. (1987). The positive and negative syndrome scale (PANSS) for schizophrenia. *Schizophrenia Bulletin*, *13*, 261-276.

- Köster, G. (1992). Los Aymaras: características demográficas de un grupo étnico indígena antiguo en los Andes centrales [The Aymara: Demographic characteristics of an ancient indigenous ethnic group in the Central Andes]. In H. Van den Berg & N. Schiffers (Eds.), *La cosmovisión Aymara* (pp. 81-111). La Paz: UCB/Hisbol.
- Koukia, E., & Madianos M. G. (2005). Is psychosocial rehabilitation of schizophrenic patients preventing family burden? A comparative study. *Journal of Psychiatric and Mental Health Nursing*, 12(4), 415-422.
- Kuipers, L. (1993). Family burden in schizophrenia: Implications for services. *Social Psychiatry and Psychiatric Epidemiology*, 28, 207-210.
- Kumar, S., & Mohanty, S. (2007). Spousal burden of care in schizophrenia. *Journal of the Indian Academy of Applied Psychology*, 33(2), 189-194.
- Kung, W. (2003). The Illness, Stigma, Culture or Immigration? Burden on Chinese American Caregivers of Patients with Schizophrenia. *Families in Society: The Journal of Contemporary Social Services*, 84, 547-557.
- Li, J., Lambert, C., & Lambert, V. (2007). Predictors of family caregiver's burden and quality of life when providing care for family member with schizophrenia in the people's republic of China. *Nursing & Health Sciences*, 9, 192-198.
- Magliano, L., Marasco, C., Fiorillo, A., Malangone, C., Guarneri, M., Maj, M., & Working Group of the Italian National Study on Families of Persons with Schizophrenia (2002). The impact of professional and social network support on the burden of families of patients with schizophrenia in Italy. *Acta Psychiatrica Scandinavica*, 106, 291-298.
- Martin, N. (2009). *Quality of life as defined by people living with schizophrenia & their families. QOL Summary Report*. Schizophrenia Society of Canada. Retrieved from: <http://www.schizophrenia.ca/docs/FINALSSCQOLReport.pdf>
- Martínez, A., Nadal, S., Beperet, M., Mendióroz, P., & Grupo Psicost. (2000). Sobrecarga de los cuidadores familiares de pacientes con esquizofrenia: factores determinantes [Burden of family caregivers of patients with schizophrenia: Determinants]. *Anales del Sistema Sanitario de Navarra*, 23, 101-110.
- McDonell, M. G., Short, R. A., Berry, C. M., & Dyck, D. G. (2003). Burden in schizophrenia caregivers: Impact of family psychoeducation and awareness of patient suicidality. *Family Process*, 42, 91-103.
- McGurk, S. R., Twamley, E. W., Sitzer, D. I., McHugo, G. J., & Mueser, K. T. (2007). A meta-analysis of cognitive remediation in schizophrenia. *American Journal of Psychiatry*, 164(12), 1791-1802.
- Millier, A., Schmidt, U., Angermeyer, M. C., Chauhan, D., Murthy, V., Toumi, M., & Cadi-Soussi, N. (2014). Humanistic burden in schizophrenia: A literature review. *J Psychiatry Research*, 54, 85-93.
- Ochoa, S., Vilaplana, M., Haro, J. M., Villalta-Gil, V., Martínez, F., Negredo, M. C., Casacuberta, P., Paniego, E., Usall, J., & Dolz, M. (2008). Do needs, symptoms or disability of outpatients with schizophrenia influence family burden? *Social Psychiatry and Psychiatric Epidemiology*, 43, 612-618.
- Ohaeri, J. (2001). Caregiver burden and psychotic patient's perception of social support in Nigerian setting. *Social Psychiatry and Psychiatric Epidemiology*, 36, 86-93.
- Parabiaghi, A., Lasalvia, A., Bonetto, C., Cristofalo, D., Marrella, G., Tansella, M., & Ruggeri, M. (2007). Predictors of changes in caregiving burden in people with schizophrenia: A 3-year follow-up study in a community mental health service. *Acta Psychiatrica Scandinavica*, 116, 66-76.
- Penn, D. L., Mueser, K. T., Spaulding, W., Hope, D. A., & Reed, D. (1995). Information processing and social competence in chronic schizophrenia. *Schizophrenia Bulletin*, 21(2), 269-281.
- Penn, D., Sanna, L., & Roberts, D. (2008). Social cognition in schizophrenia: An overview. *Schizophrenia Research*, 34(3), 408-411.
- Perlick, D. A., Rosenheck, R. A., Kaczynski, R., Swartz, M. S., Canive, J. M., & Lieberman, J. A. (2005). Components and correlates of family burden in schizophrenia. *Psychiatric Services*, 57(8), 1117-1125.
- Pijnenborg, G. H., Withaar, F. K., Evans, J. J., van den Bosch, R. J., Timmerman, M. E., & Brouwer, W. H. (2009). The predictive value of measures of social cognition for community functioning in schizophrenia: Implications for neuropsychological assessment. *Journal of the International Neuropsychological Society*, 15(2), 239-247.
- Pinkham, A. E., & Penn, D. L. (2006). Neurocognitive and social cognitive predictors of interpersonal skill in schizophrenia. *Psychiatry Research*, 143(2-3), 167-178.
- Provencher, H. L., & Mueser, K. T. (1997). Positive and negative symptom behaviors and caregiver burden in the relatives of persons with schizophrenia. *Schizophrenia Research*, 26, 71-80.
- Richieri, R., Boyer, L., Reine, G., Loundou, A., Auquier, P., Lançon, C., & Simeoni, M. (2011). The schizophrenia caregiver quality of Life questionnaire (S-CGQoL): Development and validation of an instrument to measure quality of life of caregivers of individuals with schizophrenia. *Schizophrenia Research*, 126(1-3), 192-201.
- Roick, C., Heider, D., Bebbington, P. E., & Angermeyer, M. C. (2007). Burden on caregivers of people with schizophrenia: Comparison between Germany and Britain. *British Journal of Psychiatry*, 190, 333-338.
- Sanjuán, J., Prieto, L., Olivares, J. M., Ros, S., Montejo, A., Ferre, F., Mayoral, F., González-Torres, M. A., & Bousño, M. (2003). Escala GEOPTE de cognición social para la psicosis [GEOPTE Scale of social cognition for psychosis]. *Actas Españolas de Psiquiatría*, 31, 120-128.
- Schene, A. H., Van Wijngaarden, B., & Koeter, M. W. (1998). Family caregiving in schizophrenia: Domains and distress. *Schizophrenia Bulletin*, 4, 609-618.
- Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *Journal of Social Work Education*, 44(3), 105-113.
- Slevin, M.L., Plant, H., Lynch, D., Drinkwater, J., & Gregory, W.M. (1988). Who should measure quality of life, the doctor or the patient? *British Journal of Cancer*, 57, 109-112.
- Thara, R., Kamath, S., & Kumar, S. (2003). Women with schizophrenia and broken marriages-doubly disadvantaged? Part II: Family perspective. *International Journal of Social Psychiatry*, 49, 233-240.
- Thornicroft, G., Leese, M., Tansella, M., Howard, L., Toulmin, H., Herran, A., & Schene, A. (2002). Gender differences in living with schizophrenia. A cross-sectional European multi-site study. *Schizophrenia Research*, 57, 191-200.
- Van Kessel, J. (1996). La cosmovisión Aymara [Aymara worldview]. In J. Hidalgo, F. Schiappacasse, F. Niemeyer, C. Aldunate & P. Mege (Eds.), *Etnografía: sociedades indígenas contemporáneas y su ideología [Ethnography: Contemporary indigenous societies and their ideology]* (pp. 169-187). Santiago de Chile: Editorial Andrés Bello.
- Veltro, F., Magliano, L., Lobraccio, S., Morosini, P. L., & Maj, M. (1994). Burden on key relatives of patients with schizophrenia vs neurotic disorders: A pilot study. *Social Psychiatry and Psychiatric Epidemiology*, 29, 66-70.
- Waldheter, E. J., Jones, N. T., Johnson, E. R., & Penn, D. L. (2005). Utility of social cognition and insight in the prediction of inpatient violence among individuals with a severe mental illness. *Journal of Nervous and Mental Disease*, 193(9), 609-618.
- Wong, D. F. (2000). Stress factors and mental health of carers with relatives suffering from schizophrenia in Hong Kong: Implications for culturally sensitive practices. *British Journal of Social Work*, 30, 365-382.
- World Health Organisation (1992). *ICD-10 Classifications of Mental and Behavioural Disorder: Clinical Descriptions and Diagnostic Guidelines*. Geneva: World Health Organisation.
- Zamzam, R., Midin, M., Hooi, L. S., Yi, E. J., Ahmad, S. N., Azman, S. F., Borhanudin, M. S., & Radzi, R. S. (2011). Schizophrenia in Malaysian families: A study on factors associated with quality of life of primary family caregivers. *International Journal of Mental Health Systems*, 5, 16.