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 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.

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-Urízar, 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 (especially the mother), with nuclear family, with medical problems, lower educational and socioeconomic status, unemployed and recent life crisis (Shulz & Sherwood, 2008; Gutiérrez-Maldonado, Caqueo-Urízar, & Kavanagh, 2005; Caqueo-Urízar & 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; Provencier & Mueser, 1997; Wong, 2000; Kuokia & Madianos, 2005; Perlick et al., 2006; Kate, Grover, Kulhara, & Nehra 2013; Veltro, Magliano, Lobraice, Morosini, & Maj, 1994).

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

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 neurocognitivos 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.
Caregivers’ perception of patients’ cognitive deficit in schizophrenia and its influence on their quality of life

The aim of the study was to explore the relationship between caregivers’ perception of patients’ cognitive deficit (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-Peru (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-CGQoL index), caregivers’ perceptions of patients’ neurocognitive deficit (GEOPTE 1-7), caregivers’ perceptions of patients’ social cognitive deficit
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...
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-Urízar & 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 networks outside the family would be important variables in the improvement of caregivers’ QoL, in addition to patients’ neurocognitive rehabilitation (memory, thinking and language).

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-Urízar, & Gutiérrez-Maldonado, 2006; Kuipers, 1993; Martínez, Nadal, Beperet, Mendióroz, & Grupo Pscost, 2000; Kumar & Mohanty, 2007), which in turn affects their overall health.

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### Table 3

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

*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.
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.

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References


