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Short communication

Objective and subjective burden in relatives of patients with schizophrenia and its influence on care relationships in Chile

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ABSTRACT

This study examined the burden on family members of patients with schizophrenia in a Chilean community. Sixty-five caregivers underwent the Subjective and Objective Family Burden Interview. The results showed moderate to high levels of subjective burden and low levels of support from others in providing care. Burden and containment of disturbed behaviour were correlated with worse relationships between patients and caregivers, with the latter spending less time working outside the home. The assessed sample showed a similar pattern of burden to that of caregivers from developed countries; however, the extent of the burden tended to be higher in Chilean caregivers.

1. Introduction

Most patients with schizophrenia cannot fulfil their personal and social obligations, leaving primary caregivers, who are often relatives, to do so on their behalf (Pereira et al., 2007). They require significant assistance during their daily lives; in addition, the type of care provided and the need to contain behavioural difficulties result in changes in family dynamics (Martínez et al., 2000). This change leads to an overload of stress in family members living with the patient and reduces their ability to provide care and support for other relatives (Martens and Addington, 2001; Ochoa et al., 2008).

Studies have shown that the factors that exert the greatest impact on caregiver burden include the following: emotional distress, general concerns and symptomatic behaviour in the patient, poor social relationships in caregivers, lack of leisure activities, and financial difficulties (Gutiérrez-Maldonado et al., 2005; Lowyck et al., 2004; Pariante and Carpiniello, 1996).

There are two dimensions to burden: objective and subjective. Objective burden refers to changes in the home, finances, work, social life, and leisure in relation to patient care, whereas the subjective burden refers to the subjective reaction of the caregiver in coping with the tasks performed in patient care (Magliano et al., 2000; Martínez et al., 2000).

Various tools have been developed, based on this definition of burden, to examine the effects of caring for schizophrenia patients. The Subjective and Objective Family Burden Interview (SOFBI-II) is available in Spanish and was developed based on the Family Burden Interview Schedule-Short Form (Vilaplana et al., 2007).

This scale has been used with caregivers of patients with schizophrenia (Martorell et al., 2011; Ochoa et al., 2008) and intellectual disability in Spain (Irazábal et al., 2012) and chronic viral hepatitis in China (Ren et al., 2014). The findings of such studies have demonstrated high levels of caregiver burden, which affected daily activities and routines and led to disruptions in behaviour (Martorell et al., 2011; Ochoa et al., 2008). In addition, researchers using the SOFBI II in the southern region of Chile, which has an ethnically different population (Mapuches), observed low levels of caregiver burden and moderate levels of general concern (Grandón et al., 2008).

Previous international studies have shown that caregiver burden was associated with reduced quality of life and exerted a significant impact on caregivers' health and functioning (Caqueo-Urízar and Gutiérrez-Maldonado, 2006; Fadden et al., 1987; Kuipers et al., 1992; Martínez et al., 2000; Suro and Weisman de Mamani, 2013), and they emphasized families' need for support from mental health services (Karanci, 1995).

With respect to ethnicity, some studies have shown better outcomes and lower burden in African-American and Latino caregivers (Farran et al., 1997; Haley et al., 2004; Magaña et al., 2007; Skarupski et al., 2009).

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In most studies examining burden, schizophrenia patients' mothers provide care and experience the highest levels of burden, even if they share the task with other relatives (Bloch et al., 1995; Cassidy and O'Callaghan, 2001; Castilla et al., 1998; Thara et al., 2003). Economic burden has also been shown to be significant in developing countries (Gutiérrez-Maldonado et al., 2005; Ohaeri, 2001; Thara and Srinivasan, 2000).

In South America, most patients with psychotic disorders live with a family caregiver because of a lack of community resources (residences, day centres, and psychiatric hospitals; Caqueo-Urízar and Gutiérrez-Maldonado, 2006). Research has shown that mental illness and poverty interact within a negative cycle (Caqueo-Urízar et al., 2015; Lund et al., 2011) and acoording to Wagstaff: 'poverty breeds ill-health, and ill-health keeps poor people poor' (Wagstaff, 2002, p. 97). Poverty worsens the health of patients with schizophrenia and increases caregiver burden, which could affect caregivers' health and their ability to care for patients (Butzlaff and Hooley, 1998; Caqueo-Urízar et al., 2015; Caqueo-Urízar and Gutiérrez-Maldonado, 2006; Karanci, 1995).

In Chile, people with low incomes receive public health insurance (Fondo Nacional de Salud, FONASA), which is provided for approximately 80% of the population. A communitarian approach has been implemented during the last decade, to improve care for psychiatric patients. Patients could benefit from a short stay in a public hospital during the acute phase of their illness, with outpatient care involving monthly medication delivery by nurses. As mentioned previously, the care received by these patients is mainly provided by their relatives. However, there is no systematic support for family members, who turn to informal support networks, such as churches or self-help groups, for assistance (Boyer et al., 2012). Some patients receive monthly government assistance (145 USD), which constitutes very low levels of economic support relative to the minimum wage of 408 USD per a month (Ministerio de Economía, Fomento y Turismo de Chile, 2013).

The aim of the study was to use the SOFBI-II to examine objective and subjective burden experienced of 65 relatives of patients with schizophrenia, who used mental health services in Arica, Chile, and define a burden profile. We hypothesized that the burden profile presented by Chileans caregivers would differ from that of caregivers from developed countries, and we expected to observe higher burden in Chilean caregivers because of the economic difficulties experienced in the north of Chile.

2. Methods

2.1. Subjects

The sample consisted of 65 family members (16 men and 49 women) of patients with schizophrenia treated by the mental health service in Arica, a Chilean city with around 200,000 inhabitants, located in the north of the country. The Arica economy is based on fishing and agriculture, and the area has been in deep economic crisis for the last 30 years. In addition, as it is a border town, it has high rates of Peruvian and Bolivian immigration.

The sample characteristics are shown in Table 1. The inclusion criteria were living with a patient with schizophrenia and being the patient's key caregiver, which was defined as the person who was most involved in caring for the patient and spent the highest number of hours in this role. All participants were caregivers for outpatients diagnosed with schizophrenia according to the criteria of the International Classification of Diseases, 10th version (ICD-10) (WHO, 1992). Family members with mental illness or cognitive impairment were excluded.

2.2. Instruments

2.2.1. SOFBI II

The SOFBI-II includes different aspects of caregiver burden and is divided into 8 modules:

Table 1
Sociodemographic characteristics of caregivers and patients ($N=65$).

	Caregivers *n* (%)	Patients *n* (%)
Sex		
Male	16 (24.6)	44 (67.7)
Female	49 (75.4)	21 (32.3)
Age		
Average	55.22	33.09
Standard deviation	13.219	9.107
Marital status		
Married/Attached	38 (58.5)	
Single	10 (15.4)	
Widowed/Separated	17 (26.1)	
Educational level		
No schooling	0	0
Primary school	32 (49.2)	12 (18.5)
High School	22 (33.8)	38 (58.5)
Bachelor's degree	11 (17)	15 (23.1)
Current occupation		
Employed	28 (43.1)	7 (10.8)
Unemployed	37 (56.9)	58 (89.2)
Financial assistance from the government		
Yes		23 (35.4)
No		42 (64.6)
Caregiver–patient relationship		
Spouse	1 (1.5)	
Mother	40 (61.5)	
Father	11 (16.9)	
Daughter	1 (1.5)	
Sister	9 (13.8)	
Other	3 (4.6)	

- Module A records assistance with activities of daily living, subjective burden (worry and distress) related to this assistance, and objective burden (frequency and duration of care provision).
- Module B records the supervision of behavioural problems and related burden (subjective and objective).
- Module C gathers information concerning out-of-pocket expenses related to care and daily living.
- Module D explores the impact of care on functioning in the primary caregiver's life domains (work, social relationships, and leisure).
- Module E is assessed using a 7-item self-report scale and rates the subjective burden (such as worry about well-being, quality of life, and the patient's future) experienced by the primary caregiver and
- Module F provides information concerning dedication to care and replacement of the primary caregiver by other carers.
- Module G provides information regarding the impact of care provision on the caregiver's health (health status, use of health services, and days lost at work because of health problems).
- Module I involves the interviewer's overall assessment.

The interview includes 45 items, with responses provided using dichotomous or Likert-scale format for all modules, with the exception of Module C, which requires registration of the money spent. Each of these modules is quantified via yes/no questions or combined numerical and verbal scales. A total score is obtained to reflect total burden. Higher scores reflect higher levels of burden (Martorell et al., 2011).

The SOFBI-II is used with primary caregivers of patients with schizophrenia living in the community and involves either self-report or reports from the informant. In this study, we used the self-report version of the SOFBI-II translated into Spanish and validated (Vilaplana et al., 2007).

The SOFBI-II scale was initially developed for English-speaking populations and was extended by the PSICOST Group to assess family burden. The interview was initially aimed at principal caregivers of people with schizophrenia living in the community (Vilaplana et al., 2007) and has been used and validated in Spain