

An updated review on burden on caregivers of schizophrenia patients

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Abstract

Background: Schizophrenia is a debilitating mental illness that has a significant impact not only in the patient but also in the entire family as well. Caregivers assume almost the totality of the patient care. This responsibility exposes caregivers to an intense burden with negative consequences for them and the rest of the family system. This is an updated review of existing literature about burden on families with schizophrenia patients. **Method:** An electronic search of articles from MEDLINE, EMBASE, APA, EBSCO, and Cochrane databases was conducted for articles published between 2008 and 2013. **Results:** A systematization of information and frequency analysis revealed the existence of eight factors related to burden that were present in almost all the reviewed literature: Programs of family treatment, Ethnic group, Expressed Emotion, Stress and Burden, Preoccupations of the caregiver, Kind of caregiver, Social networks, Social support, Finances and Coping Strategies. **Conclusions:** This study supports the statements of different theories reflecting the complexity of schizophrenia caregivers' burden and these, in turn, may be related to the above factors.

Keywords: Burden, schizophrenia, caregivers, family, review.

Resumen

Una revisión actualizada sobre la sobrecarga en cuidadores de pacientes con esquizofrenia. Antecedentes: la esquizofrenia es una enfermedad mental grave que no solo tiene un impacto significativo en el paciente, sino también en la familia. Los cuidadores asumen casi la totalidad de los cuidados de los pacientes. Esta responsabilidad expone a los cuidadores a una intensa sobrecarga con consecuencias negativas para ellos y el resto del sistema familiar. Este estudio se trata de una revisión actualizada de la bibliografía existente acerca de la sobrecarga en familias con pacientes con esquizofrenia. **Método:** se realizó una búsqueda electrónica de artículos de bases de datos MEDLINE, EMBASE, APA, EBSCO y Cochrane para artículos publicados entre 2008 y 2013. **Resultados:** una sistematización de la información y un análisis de frecuencia reveló la existencia de ocho factores relacionados con la sobrecarga que se presentaron en casi toda la literatura revisada: programas de tratamiento familiar, grupo étnico, Emoción Expresada, estrés y sobrecarga, preocupaciones del cuidador, tipo de persona que lo cuida, redes sociales, apoyo social, finanzas y estrategias de afrontamiento. **Conclusiones:** este estudio evidencia el apoyo a las diversas teorías planteadas sobre el tema, reflejando la complejidad de la relación de los factores mencionados anteriormente en la sobrecarga de los cuidadores de pacientes con esquizofrenia.

Palabras clave: sobrecarga, esquizofrenia, cuidadores, familia, revisión.

Schizophrenia is a serious mental disorder that has a dramatic impact not only in patients suffering from it but in their families as well (Weisman, 2005). Due to the move from traditional institutional care to community care of psychiatric patients, relatives have become the most important caregivers for adults with major psychiatric disorders (Solomon, 1996). Nowadays, there is evidence suggesting that the course of the disorder is also highly associated with patient psychosocial factors and home atmosphere (Weisman, 2005). Muela and Godoy (2001) established that there is "something" in family interaction that seems to cause a patient relapse, and it seems to influence the course of the disease rather than the origin of it.

The impact of caring for psychiatric patients on relatives has been studied to a lower extent. Martens and Addington (2001)

noted that family members were significantly distressed by the fact of having one of their members suffering from schizophrenia. Ivarsson Sidenvall and Carlsson (2004) agreed that burden on a family caregiver is complex and includes many areas, such as daily life, preoccupations, and social pressure. Dillehay and Sandys (1990) defined *burden of the caregiver* as a psychological state that ensues the combination of physical, emotional work, and social pressure, such as economic restrictions that arise from taking care of the patients. There is empirical evidence confirming that caring for a schizophrenia patient implies a burden on their families. Gutiérrez, Caqueo-Urizar and Kavanagh (2005) carried out a study with a Chilean sample and pointed out that burden sets out independently of the development level of the country. The Chilean study showed high levels of burden on schizophrenia patients' caregivers, and similar findings were discovered in Nigeria (Ohaeri, 2001).

A subject of great concern in schizophrenia patients' relatives relates to social networks. In a study by Kuipers (1993), researchers already mentioned that caregivers are more likely to experience constraints in social activities, reducing themselves to their own social networks and remaining isolated in their homes with few

social contacts. Mental illness stigma in families is still frequent and can contribute to social isolation (Kuipers, MacCarthy, Hurry, & Harper, 1989). In this line, Thara, Kamath and Kumar. (2003) concluded that patients and their families experience discrimination due to mental illness and burden.

Three large studies showed that about one fifth to one third of the family members reported consternations and distant relationships with the rest of the family group because of the mentally ill relative (Ostman & Kjellin, 2002; Shibre et al., 2001; Struening, Perlick, Link, Hellman, Herman, & Sirey, 2001). Magliano, Fiorillo, Malangone, Marasco, Guarneri and Maj (2003) stated that it is possible, when relatives have limited social sources, to develop more pessimistic attitudes towards certain topics such as opportunities, schizophrenia patients keeping their civil rights and reaching effective goals. This can generate a negative influence on patient expectations regarding their social possibilities.

Theoretical background of family burden

In order to attain an integral conceptual frame for the concept of family burden, different theories have been used, incorporating quantitative as well as qualitative aspects.

The *role theory* states that every person is considered as an actor of social relationships. There are categories of persons more or less similar in some aspects. These categories are called *positions*: father, mother, son, and others. A person in a certain position displays expectations about the form in which she is going to behave with other persons in the same position. This set of expectations is called *role sector*. Addition to different role sectors is defined as a set of expected behaviors between two persons taking in consideration the positions of each other. In many occasions, schizophrenia makes family expectations regarding the patient, unfulfilled. This produces discomfort in all family members implied (Martínez, 2002).

The *stress theory* establishes that hardships associated with the disorder function, as environmental stressing factors or chronic tensions, originate the subjective aspects of burden. This produces a number of changes in the caregiver as the result of the interaction among the assessment of their coping strategies (Rose, 1998; Veltman, Cameron, & Stewart, 2002).

The *systemic theory* establishes that although burden refers to a family phenomenon, it is necessary to consider family in its social context to understand this concept. Hierarchically, the following subsystems can be recognized: individual, familiar, social network, and community and/or culture. Each subsystem has its own features and dynamics. Family would be a dynamic system affected by its subsystems and by external systems with a continuous input and output of information. In some cases, family burden generates a closure in its external and internal limits to prevent family from changing.

The aim of this study was to review the literature, to describe the factors most frequently related to caregivers' burden and to discuss them using the theoretical background stated above.

Method

Methods for inclusion/exclusion of studies for literature review

A systematic search from MEDLINE, EMBASE, reference lists of APA, EBSCO (Psychology and Behavioral Sciences

Collection, CINAHL Plus with Full Text, Academic Search Complete, Fuente Académica Premier, PsycINFO & Health Source: Nursing/Academic Edition) and Cochrane databases was carried out for articles published between January 2008 and May 2013, considering that Awad & Voruganti performed last review in 2008. Key words included in the research were: schizophrenia, burden, families, relatives, caregivers, carers, impact, review, quality of life and a combination of them. Potential studies were included if they considered a primary family caregiver and focused on caregiver's burden related to schizophrenia. Cross-sectional, longitudinal, reviews, qualitative and case reports studies were included.

A total of 810 hits was retrieved. Titles and abstracts by two authors were reviewed independently, and irrelevant articles were discarded for the following reasons: when the article had low statistical power in addition to those studies that showed mixed diagnoses because that was considered only patients with a diagnosis of schizophrenia. The full text of those studies considered relevant by either reviewer were obtained and assessed independently. Any discrepancy was solved by discussion. Finally, 42 studies with samples of different nationalities were included in the review.

Results

Methodological aspects

Over one half (64.3%) of the reviewed studies had a "cross-sectional" design, showing a low level of evidence available. Twenty-one percent of the manuscripts were longitudinal studies. Six (12%) studies used a qualitative methodology, and four (9.6%) were literature reviews. To assess caregiver's burden, different methods and instruments were used; therefore, comparison among studies was difficult. The amount of caregivers interviewed ranged from 10 to 286. It is likely that some studies were not sensitive enough to detect any significant association with caregiver burden.

The correlations between different variables and caregiver's burden included in the discussion came mainly from quantitative descriptive studies. In order to summarize the results taking into account the heterogeneity and the quality of the studies, the authors agreed that an association between any factor and caregiver's burden was considered in the discussion when it was found statistically significant in the original paper ($p \leq 0.05$) and/or was present in at least 10% of the papers reviewed. This allowed us to discuss those associations that were significant from a statistical point of view and more frequently studied.

Factors associated with caregiver burden

Table 1 shows the Profile of studies on Burden of Schizophrenia Caregivers.

- 1. Family interventions:** There is evidence about the positive results obtained by psychosocial interventions with family caregivers, allowing a decrease in the burden they deal with and in the number of relapses and hospitalizations of the patients (Awad & Voruganti, 2008; Barrio & Yamada, 2010; Gutiérrez-Maldonado, Caqueo-Urizar, & Ferrer-García, 2009; McLeod, Elliott, & Brown, 2011; Nasr &

Kausar, 2009; Sharif, Shaygan, & Mani, 2012; Tariverdi & Ekinci, 2012). In addition, family intervention programs increase the perception of social support, self-efficacy and satisfaction with treatment among caregivers (Chan, Yip, Tso, Cheng, & Tam, 2009; Kulhara, Chakrabarti, Avasthi, Sharma, & Sharma, 2009; Riley, Gregory, Bellinger, Davies, Mabbott, & Sabourin, 2011). Literature indicates that best results were obtained after three months of treatment (Barrio & Yamada, 2010; Nasr & Kausar, 2009; Sharif et al., 2012). Nevertheless, some studies show these results may disappear after a few months of its implementation without undertaking a maintenance therapy (Chan et al., 2009; Koolae & Etemadi, 2010).

Discrepancy arises regarding the kind of treatment offered to caregivers. While some programs implemented individual treatments (Sharif et al., 2012), other studies established group therapy sessions with similar levels of effectiveness (Barrio & Yamada, 2012; Gutiérrez-Maldonado et al., 2009; Koolae & Etemadi, 2010). The review elaborated for McLeod et al. (2011) established that single-family home and multiple-family treatment formats have the same level of efficacy.

2. **Ethnic group and cultural aspects:** Sociocultural and ethnic characteristics play an important role in the perception of family caregivers' burden (Caqueo-Urizar, Gutiérrez-Maldonado, Ferrer-García, & Darrigrande-Molina, 2012; Sefasi, Crumlish, Samalani, Kinsella, O'Callaghan, & Chilale, 2008; Tan et al., 2012). In recent years, reported levels of burden in Asia and Africa show similarities in frequency of the burden with populations of Europe and US, but there are differences in magnitude, manifestations and dimensions (Hosseini, Sheykhoumnesi, & Shahmohammadi, 2010; Nirmala, Vranda, & Reddy, 2011; Papastavrou, Charalambous, Tsangari, & Karayianni, 2010; Zahid & Ohaeri, 2010).
3. **Expressed emotion (EE):** Expressed emotion is assessment of the interactions and emotional climate in the family environment, which includes the caregiver' attitude to the patient and particularly focuses on the negative interactions that may be stressful to the individual. It involves variables like criticism, hostility, lack of warmth and emotionally overinvolved. EE is apparently the best predictor for relapse in schizophrenia patients, thus a high EE in parents induces distress in patients (Hanzawa et al., 2013; Moller-Leimkuhler & Wiesheu, 2012; Nirmala et al., 2011). Furthermore, Breitborde, López, Chang, Kopelowicz and Zárate (2009) suggest that expressed emotion is associated with high levels of burden, less instrumental support, and deterioration in the health of American-Mexican family caregivers of patients with schizophrenia.
4. **Stress and burden:** Stress and burden of schizophrenia patient family caregivers are directly associated to positive symptoms of the patients. These visible symptoms generate feelings of discrimination from their social networks in caregivers (Goncalves-Pereira, Xavier, van Wijngaarden, Papoila, Schene, & Caldas-de-Almeida, 2013; Hanzawa et al., 2013; Knock, Kline, Schiffman, Maynard, & Reeves, 2011). Nevertheless, negative symptoms, like impaired functioning, impaired working memory and executive functioning, can increase burden levels (Hjarthag, Helldin,

Karilampi, & Norlander, 2010). In addition, a review of current literature showed that caregiver demographic factors such as gender, employment and time devoted to patient care are directly related to caregiver's burden (Rafiyah & Sutharangsee, 2011).

Caregiver's stress and burden have also been associated with low quality of life expressed through body pains, decrease in vitality and health in general (even developing depressive and anxiety disorders), restrictions in physical role and social categories (Boyer, Caqueo-Urizar, Richieri, Lancon, Gutiérrez-Maldonado, & Auquier, 2012; Caqueo-Urizar, Gutiérrez-Maldonado, & Miranda-Castillo, 2009; Gutiérrez-Maldonado, Caqueo-Urizar, Ferrer-García, & Fernández-Dávila, 2012; Moller-Leimkuhler & Wiesheu, 2012; Osman, Alipah, Tutiiryani, & Ainsah, 2010). In a study with Taiwanese populations, Huang, Hung, Sun, Lin and Chen (2009) reported high levels of burden associated with helping the patient, lack of professional support and family conflicts.

5. **Preoccupations of the Caregiver:** This variable is predicted by patient's restlessness and excitement symptoms (McCann, Lubman, & Clark, 2011; Ochoa et al., 2008; Tang, Leung, & Lam, 2008). Main preoccupations reported by caregivers are: having the ability to influence the patient and having the capacity to help them to move on (Knock et al., 2011). Additionally, Jagannathan, Thirthalli, Hamza, Hariprasad, Nagendra and Gangadhar, (2011) found that managing patients' behavior and social-vocational problems, added to their own health issues and education about schizophrenia; were reported as common preoccupations by caregivers. Finally, the future of the patients is a long-lasting preoccupation for caregivers, particularly when patients are no longer capable of taking care of themselves (Knock et al., 2011).
6. **Kind of caregiver:** Those who take care of mentally ill persons are mainly the parents (mothers), followed by spouses and siblings (Hanzawa, Tanaka, Inadomi, Urata, & Ohta, 2008; Moller-Leimkuhler & Wiesheu, 2012; Nirmala et al., 2011). However, studies in Chile caregivers were mostly husbands, particularly in the case of the Aymara etnia (Caqueo-Urizar, Gutiérrez-Maldonado, Ferrer-García, & Darrigrande-Molina, 2012; Caqueo-Urizar, Gutiérrez-Maldonado, Ferrer-García, Peñaloza-Salazar, Richards-Araya, & Cuadra-Peralta, 2011).
7. **Social networks or social support:** Relatives of schizophrenia patients perceive a higher level of burden when they have low levels of social support (Awad & Voruganti, 2008; Barrio & Yamada, 2010; Goncalves-Pereira et al., 2013). High levels of social support have been found to be associated with better well-being (Gutiérrez-Maldonado et al., 2012). It is likely that, as a result of caregiving tasks, primary caregivers stay away from their social networks. Thus, burden is significantly related to limited social networks (Grandón, Jenaro, & Lemos, 2008). In a recent literature review, Chien and Norman (2009) concluded that there is great benefit in the perception of social support in caregivers who participate in psychosocial groups.
8. **Finances:** It has been found that financial issues contribute to family burden not only because schizophrenia tends to affect patient's labor capacity, but also because family

income decreases when the adults taking care of the patient are prevented from getting a job out of home (Boyer et al., 2012).

- 9. Caregiver Coping:** Several studies have mentioned the connection between coping strategies used by caregivers and their level of burden (Hanzawa et al., 2010; Huang et al., 2009; Loughland et al., 2009; McCann et al., 2011; Nitsche, Koch, & Kallert, 2010; Ramírez-García, Hernández, & Dorian, 2009). These investigations have identified coping styles correlated with levels of mental health deterioration, mainly with emotional distress, which is considered a strong predictor of caregiver burden (Goncalves-Pereira et al., 2013). Moreover, caregiver burden was significantly associated with a reduction of social interests, coercion, avoidance and resignation (Hanzawa et al., 2010).

Discussion

Evidence found from the review of the literature supports the statements of different theories reflecting the complexity of schizophrenia caregivers' burden, and this, in turn, may be related to the above factors.

According to the role theory, having a member of the family with schizophrenia disorganizes the familiar dynamics. The roles of each member are affected by caring for the patient. Evidence shows that many of the roles of the caregivers are annulled or handicapped, and an important part of the caregivers do not work outside of the home, they lose their friends and their social networks (Grandón et al., 2008; Rafiyah & Sutharangsee, 2011). In addition, caregivers indicate that patients do not fulfill their expectations, generating personal and familiar dissatisfaction (Huang et al., 2009; Knock et al., 2011; Riley et al., 2011). Role theory relates to Factor 4 (Stress and Burden), Factor 6 (Kind of Caregivers), Factor 7 (Social Networks or Social Support) and Factor 8 (Finances).

Considering the stress theory, the literature indicates that caregivers go through high levels of stress because they feel that their capacity of action is overwhelmed, or because the patient absorbs most of their time. In addition, caregivers' stress increases due to communication difficulties, lack of appropriate intervention strategies for patient's symptoms, and financial problems (Chien & Norman, 2009; Hanzawa et al., 2010; Huang et al., 2009; Jagannathan et al., 2011; Loughland et al., 2009; McCann et al., 2011; MacLeod, 2011; Nitsche et al., 2010; Ramírez-García et al., 2009; Riley et al., 2011). Working outside the home, generating incomes and maintaining other activities aside from patient care can protect caregivers' mental health. Therefore, the stress theory

covers Factor 1 (Family Interventions), Factor 3 (Expressed Emotions), Factor 5 (Preoccupations of the Caregiver) and Factor 9 (Caregiver Coping).

Finally and considering the systemic theory, schizophrenia is understood as an individual, familiar, social and cultural phenomenon. Cultural and racial aspects have significant importance. Being part of an ethnic minority originates the feeling of disadvantage in caregivers, due to the reduction of social networks, aid or access to benefits from the government (Caqueo-Urizar et al., 2012; Sefasi et al., 2008). Thus, the systemic theory may include Factor 2 (Ethnic Group and Cultural Aspects), some aspects of Factor 7 (Social Networks or Social Support) and some aspects of Factor 9 (Caregiver Coping). In this way, caregiver's burden is not guaranteed to be independent of the culture. The systemic theory emphasizes the existence of coordination between the diverse subsystems, which is an essential issue, considering the need to establish public policies of investment aimed at providing a holistic treatment for the patient with schizophrenia, which should comprise not only pharmacological or psychotherapeutic attention, but should also include caregivers' social networks and communitarian support. As confirmed by Pharoah, Mari, Rathbone and Wong (2012), family intervention may reduce the number of relapse events and hospitalizations and would therefore be of interest to people with schizophrenia, clinicians and policy makers.

This current study has certain limitation. Due to the language criteria, relevant information published in languages other than English may have been missed. The literature search terms were selected to be as inclusive as possible, but some articles could have been omitted, including studies that did not mention key words.

This review is considered a contribution to the literature, presenting the nine most frequent factors related to caregivers' burden. The relationship of these factors with the different theories (Role, Stress and Systemic) provides guidelines for future interventions, in the sense of knowing what, with whom and when to deal.

It is necessary to include the prevention of the burden instead of the intervention of caregivers' burden. Future research is suggested to consider this point. Also, we encourage the study of the caregivers' burden of ethnic groups, given the importance of cultural exchange.

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Table 1
Factors related to research about burden on relatives of schizophrenia patients

Authors	Family interventions	Ethnic group & cultural aspects	E.E.	Stress & burden	Preoccupations of the caregiver	Kind of caregiver	Social support	Finances	Coping strategies
Awad & Voruganti, 2008 Narrative review		X		X				X	
Grandón et al., 2008 Cross-sectional and correlational study 101 sample: patients and caregivers dyads				X			X		X
Hanzawa et al., 2008 Cross-sectional and correlational study 57 caregivers				X	X		X		X
Ochoa et al., 2008 Cross-sectional and correlational study 147 caregivers				X	X				
Sefasi et al., 2008 Randomized controlled trial 180 sample: patients and caregivers dyads		X		X					
Tang et al., 2008 Cross-sectional and correlational study 402 sample: patients and caregivers				X	X				
Breitborde et al., 2009 Longitudinal study 74 sample: patients and caregivers dyads			X	X			X		
Caqueo-Urizar et al., 2009 Narrative review				X			X	X	
Chan et al., 2009 Randomized controlled trial 146 sample: patients and caregivers dyads	X	X		X					
Chien & Norman 2009 Gutiérrez-Maldonado et al., 2009 Systematic review	X			X	X		X		
Huang et al., 2009 Qualitative study 10 caregivers		X		X			X		X
Kulhara et al., 2009 Randomized controlled trial 152 sample: patients and caregivers dyads	X	X		X					
Loughland et al., 2009 Cross-sectional and correlational study 106 caregivers				X		X			X
Nasr & Kausar 2009 Randomized controlled trial 108 sample: patients and caregivers dyads	X	X		X					

Table 1 (continued)
Factors related to research about burden on relatives of schizophrenia

Authors	Family interventions	Ethnic group & cultural aspects	E.E.	Stress & burden	Preoccupations of the caregiver	Kind of caregiver	Social support	Finances	Coping strategies
Ramírez-García et al., 2009 Cross-sectional and correlational study 31 sample: patients and caregivers dyads				X					X
Barrio & Yamada 2010 Qualitative study 59 sample: patients and caregivers dyads	X	X		X					
Hanzawa et al., 2010 Cross-sectional and correlational study 190 sample: patients and caregivers dyads		X		X					
Hjärthag et al., 2010 Cross-sectional and correlational study 99 caregivers				X					
Hosseini et al. 2010 Cross-sectional and correlational study 190 sample: patients and caregivers dyads		X		X					
Koolae & Etemadi 2010 Randomized controlled trial. 62 caregivers.	X	X	X	X					
Nitsche et al. 2010 Cross-sectional and correlational study 163 sample: patients and caregivers dyads				X			X		X
Osman et al. 2010 Cross-sectional and correlational study 243 sample: patients and caregivers dyads				X					
Papastavrou et al., 2010 Cross-sectional and correlational study 113 sample: patients and caregivers dyads		X		X					
Zahid & Ohaeri 2010 Cross-sectional and correlational study 130 sample: patients and caregivers dyads		X		X					
Caqueo-Urizar et al., 2011 Cross-sectional and correlational study 41 caregivers		X		X	X				
Knock et al., 2011 Qualitative study 10 caregivers	X			X			X		X
McLeod et al., 2011 Systematic review				X	X		X		X

Table 1 (continued)
Factors related to research about burden on relatives of schizophrenia patients

Authors	Family interventions	Ethnic group & cultural aspects	E.E.	Stress & burden	Preoccupations of the caregiver	Kind of caregiver	Social support	Finances	Coping strategies
McCann et al., 2011 Qualitative study 10 caregivers				X		X			X
Nirmala et al., 2011 Cross-sectional and correlational study 113 sample: patients and caregivers dyads			X	X					
Rafiyah & Sutharangsee 2011 Narrative review				X		X			X
Riley et al., 2011 Qualitative study 10 caregivers				X			X		X
Boyer et al., 2012 Cross-sectional and correlational study 286 caregivers		X		X			X	X	
Caqueo-Urizar et al., 2012 Cross-sectional and correlational study 45 caregivers		X		X					
Gutiérrez-Maldonado et al., 2012 Cross-sectional and correlational study 45 sample: patients and caregivers dyads				X			X		
Jagannathan et al., 2011 Cross-sectional and correlational study 30 caregivers		X		X	X				
Moller-Leimkuhler et al., 2012 Cross-sectional and correlational study 102 caregivers		X	X	X			X		
Sharif et al., 2012 Randomized controlled trial 70 sample: patients and caregivers dyads	X	X	X	X					
Tan et al., 2012 Cross-sectional and correlational study 150 caregivers		X		X					X
Tanriverdi et al., 2012 Quasiexperimental 31 caregivers	X	X	X	X					
Goncalves-Perreira et al., 2013 Cross-sectional and correlational study 108 sample: patients and caregivers dyads		X		X					X
Hanzawa et al., 2013 Cross-sectional and correlational study 116 caregivers		X		X					X

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