

Author Accepted Manuscript (11.08.2016)

Citation: Stanley, S., Balakrishnan, S. & Ilangovan, S. (2017) Psychological distress, perceived burden and quality of life in caregivers of persons with schizophrenia, *Journal of Mental Health*, 26(2): 134-141.

Psychological distress, perceived burden and quality of life in
caregivers of persons with schizophrenia

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Abstract

Background: Caregiving in schizophrenia is a demanding and exhausting activity that challenges the physical and emotional resources of family caregivers. In traditional societies such as India, this is further compounded by illiteracy, ignorance and religious and cultural explanations attributed to mental illness.

Aims: This study aimed to assess primary caregivers of persons with schizophrenia in terms of their perceived burden, manifestation of psychological distress and quality of life (QOL).

Methods: The study used a quantitative cross-sectional design and survey methodology to collect data from caregivers in a hospital setting in Thanjavur, India. Standardized instruments were used to collect data from patients and their caregivers.

Results: High perceived burden and lower QOL were seen in the majority of caregivers. They also manifested high levels of anxiety and depression. Patient characteristics such as age, gender, symptoms and duration of illness did not influence the perceived burden of caregivers, while positive and negative symptoms and the duration of illness were correlated with their QOL.

Conclusions: Findings indicate the need for intervention for family caregivers to enable them cope more effectively with the demands of caregiving. Psychoeducation and participation in peer support groups are advocated as low resource and effective outcome strategies for caregivers in India.

Caregiving in mental illness is a demanding and exhausting activity that typically involves a considerable amount of time, energy and money over potentially long periods of time, in tasks that may be unpleasant or uncomfortable and could be psychologically stressful and/or physically exhausting (Schulz & Martire, 2004). This could be particularly challenging in traditional societies such as India. The close knit family structure and lack of adequate State resources to support people with mental illness place the onus of care on the family which is perceived to be the “natural” caregiver. Sociocultural expectations see the caregiving function as typically being discharged by either parents, children or the spouse and as an obligation that has morally binding undertones (Stanley et al., 2016). Religious-cultural attributions often causally implicate supernatural factors in the manifestation of mental illness.

Patients’ symptoms are attributed to witchcraft, ghosts, spirit intrusion, divine wrath, planetary influences and bad deeds in previous life or karma (Grover et al., 2014). Such beliefs frequently drive families to faith healers and charlatans who perform elaborate (and often expensive) rituals to “cure” the person, and modern psychiatric treatment is usually the last resort (Stanley & Shwetha, 2006). Ignorance, illiteracy and superstition colour the perception of mental illness, and stigma and oppression become hard realities that families encounter in everyday life.

Schizophrenia is a severe mental disorder that typically begins in late adolescence or early adulthood, and is characterized by profound disruption in thinking, language, perception and the sense of self, and often includes psychotic experiences, such as hearing voices or delusions (World Health Organisation, 2016). The volatile nature of the disorder and its accompanying debilitating consequences pose a considerable burden on family caregivers owing to its physical, social, emotional and financial implications. The burden experienced by family caregivers is a complex phenomenon that includes many areas, such as daily life, worries and social pressure (Ivarsson et al., 2004). Caregivers are also likely to experience constraints in social activities due to the stigma associated with mental illness that can further their social isolation (Kuipers et al., 1989). Several studies worldwide have reported high levels of burden experienced by caregivers of people with schizophrenia (Adeosun, 2013; Gutierrez-Maldonado et al., 2005; Mitsonis et al., 2012; Ozlu et al., 2015). Similar findings have also been attested by researchers from India (Gururaj et al., 2008; Jagannathan et al., 2014; Kate et al., 2013).

Mirowsky and Ross (2002) define psychological distress as a state of emotional suffering characterized by symptoms of depression (e.g. loss of interest, sadness and hopelessness) and anxiety (e.g. restlessness, feeling tense). It is known that the caregiving experience takes a toll on the mental health of the caregiver (Harvey et al., 2001; Martens & Addington, 2001), and this is an issue not adequately addressed in the Indian literature on caregiving in mental illness. Studies from elsewhere indicate that depression has been frequently reported by caregivers of people with mental disorders (Magliano et al., 2007). Caregiver stress has also been associated with anxiety, psychiatric disorders and poor mental and physical health (Etters et al., 2008; Lavela & Ather, 2010). It is important to understand the mental health status of caregivers, as care recipients experience positive health outcomes when their carers do not feel burdened or depressed (Liu et al., 2015). Caregiver depression can influence their behaviour towards the recipient by resulting in physical (MacNeil et al., 2010) or verbal abuse (Smith et al., 2011).

Although studies have been conducted on specific issues in caregiving such as burden and coping, not much has been done to explore quality of life (QOL) issues in caregivers of people with schizophrenia. It is seen from the literature that these caregivers are at risk of having a lower QOL due to mental health problems and higher caregiver burden (Chen & Greenberg, 2004). Those who experience high levels of distress are more likely to have a lower QOL (Geriani et al., 2015; Li et al., 2007). This is particularly so when they experience restricted roles and activities, and increased psychosomatic, anxious or depressive symptoms (Awad & Voruganti, 2008; Schulz & Beach, 1999).

This study was framed to understand the caregiving experience with regard to the mental health status of the caregiver, their QOL and the extent and nature of burden perceived by them in caring for a family member having a diagnosis of schizophrenia. We were also interested in ascertaining whether patient symptoms did influence any of these key variables of the study.

Methods

Design

A quantitative cross-sectional survey design was used to assess respondents utilizing standardized self-report instruments to elicit data pertaining to the key variables.

Setting of the study

Thanjavur (also known as Tanjore) is a temple town in Tamilnadu state in South India. Data for the study were collected at the Thanjavur Medical College Hospital which is a multi-speciality teaching cum treatment centre established in 1964. It has a bed-strength of 678 and caters to people predominantly from the adjoining rural districts. It offers treatment in 18 specialisms including the Department of Psychiatry, where data for this study were collected.

Instruments

(1) The Positive and Negative Syndrome Scale (PANSS) by Kay et al. (1987) is a 30-item instrument. Of these, 7 items constitute a Positive Scale (symptoms such as delusions, hallucinations, grandiosity), 7 items a Negative Scale (symptoms such as blunted affect, stereotyped thinking, emotional withdrawal), and the remaining 16 a General Psychopathology Scale (symptoms such as anxiety, depression, guilt). Items for component scales are rated from 1 to 7 according to symptom severity from 1 for “absent” to 7 for “extreme”. This instrument was administered only to the person with schizophrenia.

(2) The Schizophrenia Caregiver Quality of Life questionnaire (S-CGQoL) is a self-administered, multidimensional instrument developed by Richieri et al. (2011). It contains 25 items describing seven dimensions (Psychological and Physical Well-Being; Psychological Burden and Daily Life; Relationships with Spouse; Relationships with Psychiatric Team; Relationships with Family; Relationships with Friends; and Material Burden). Items are rated using a 6-point Likert scale, with options scored from “Never” to “Always” for each of the seven dimensions as well as a cumulative QOL score.

(3) The Zarit Burden Interview (ZBI) by Zarit et al. (1980), a popular caregiver self-report measure that contains 22 items and assesses the perceived burden of

rendering care, using a 5-point scale. Response options range from 0 (Never) to 4 (Nearly Always). A cumulative burden score has been used in this study. Though the instrument was initially developed to assess caregiver burden in dementia, it has been used extensively in relation to mental illness (e.g. Adeosun, 2013; Hanzawa et al., 2010).

(4) The Depression, Anxiety and Stress Scale (DASS-21) consists of three self-report scales developed by Lovibond and Lovibond (1995), and was used to assess psychological distress with regard to the emotional states of depression, anxiety and stress. Each of the three scales contains seven items, and scores for each scale are calculated by summing the scores for the relevant items.

Respondents

Data were collected from 75 caregivers who were caring for a family member diagnosed (according to ICD-10) and undergoing treatment for schizophrenia as inpatients in the Department of Psychiatry of the Medical College. Respondents were chosen consecutively on inpatient admission based on their willingness to participate.

Ethical considerations

The study received ethical clearance from the Ethics Review Panel of the medical college. Participation was voluntary, and informed consent was obtained from the patients and their caregiver. They were told that they had the option to drop out of the study at any point without any implications in terms of the treatment being availed of.

Statistical analysis

SPSS version 20 (Statistical Package for Social Sciences; IBM Software, Armonk, NY) was used for data analysis and for generating the results of this study.

Independent t tests were used to compare caregivers on background factors (such as patient's gender) and caregivers' characteristics (gender, relationship to patient) in terms of the manifestation of the key variables of the study. Pearson's correlation coefficients were obtained to examine the relationship among the key variables and

also with background factors. A multiple regression analysis was finally executed to identify predictor variables that influence the manifestation of caregiver burden.

Results

Respondents' profile

All caregivers were married and their age ranged from 28 to 60 years (mean = 49.4). The majority of them were men (62.5%) and Hindus by religion (88%). They came from a rural setting and were predominantly farmers (73%) with a monthly income up to Rs. 4000 (82%) (about \$60). Educational background was low with most having attended school at various levels. The family size for the majority was two or three members (60%) (mean family size = 3.6). They provided care in their capacity of either being parents (72%) or the spouse (28%) of the person undergoing treatment for schizophrenia.

Care recipients' profile

The persons undergoing treatment for schizophrenia were between 17 and 54 years of age (mean = 31.4), and the majority were unmarried (59.7%) men (63.6%). They had a low level of education at different levels of school; 45.5% were unemployed and 18.2% said they were housewives. The others mentioned working as farmers, tailors, weavers, mechanics and being engaged in small trades. About 63.6% did not have an income and those who did, earned up to Rs. 3000 per month (about \$45). The duration of their illness ranged from 5 to 15 years (mean = 5.67). They had all been in treatment previously and said that the illness had an insidious onset and was progressive in nature with deterioration of symptoms over time.

PANSS profile of care recipients

The majority of patients scored up to 30 (maximum score 49) on the positive symptoms scale, much lower than the other two domains of the PANSS.

Insert Table 1 about here

Table 1 shows that scores for the negative scale are distributed at all levels with the majority having scored up to 40 out of a maximum possible 49.

The third PANSS domain constitutes a general psychopathology scale and the majority have scored between 31 and 50 (maximum score 112) on this scale. In accordance with the scoring guidelines, a “Composite Scale” was also obtained by subtracting the negative score from the positive score. This yields a bipolar index that ranges from –42 to+42, which is essentially a difference score reflecting the degree of predominance of one syndrome (positive or negative) in relation to the other. Frequencies plotted for the composite scale reveal that the majority of care recipients (68%) had a predominance of positive symptoms over negative symptoms (32%).

Insert Table 2 about here

DASS profile of caregivers

Table 2 depicts the DASS profile of the caregivers in terms of the severity of the manifestation of its respective components, graded according to the norms provided by the authors of the scale. It is seen that while the majority of caregivers experienced a “moderate” level of stress, in terms of depression and anxiety, they have been classified as being “severe” and “extremely severe”, respectively.

Insert Table 3 about here

Burden and QOL profile of caregivers

This profile was generated by using the median to classify respondents into “low” and “high” groups in terms of their burden and QOL scores. It is seen from Table 3 that the majority of respondents have been rated as being “high” on the burden perceived by them. It is worth mentioning that according to scoring instructions, scores above 60 are classified as “severe burden” and that all caregivers in this study met this criterion. It is also seen that based on the median, with regard to the total QOL score as well as all the seven dimensions of the S-CGQoL, that the majority have been classified as being “low”.

Comparisons based on background factors

In order to compare the relationship status of the caregivers on the key domains, t tests were carried out. No significant difference was seen based on parent/spouse status in terms of the ZBI scores ($t = 0.64$; $p = 0.43$) and the total QOL scores ($t = 1.18$; $p = 0.24$) except for the psychological burden and daily life component of the QOL scale ($t = 2.78$; $p = 0.01$).

Mean scores indicated higher burden in spouses (mean = 83.10) than in parents (mean = 82.20) and lower QOL in spouses (mean = 91.86) than parents (mean = 93.41). Kinship status also did not differentiate caregivers in terms of their depression ($t = 1.31$; $p = 0.19$), anxiety ($t = 0.12$, $p = 0.90$) and stress scores ($t = 0.03$; $p = 0.98$).

The next comparison was based on the gender of the caregivers, and t tests were run to compare male and female caregivers on the key dimensions. No statistically significant differences were obtained in this comparison on the ZBI ($t = 1.62$; $p = 0.10$), depression ($t = 1.06$; $p = 0.29$), anxiety ($t = 1.27$; $p = 0.21$) or stress ($t = 0.17$; $p = 0.86$) scores.

However on the overall QOL score, significant difference was seen in terms of the gender of the caregivers ($t = 2.19$; $p = 0.03$), and mean scores indicate higher QOL for male caregivers (mean = 93.9) than for females (mean = 91.2). In terms of the sub-dimensions of the QOL scale, significant differences were obtained for psychological and physical well-being ($t = 3.20$; $p = 0.002$) and psychological burden and daily life domains ($t = 3.17$; $p = 0.002$), with higher mean scores for men on both.

Comparison was then made in relation to the gender of the care recipient also using t tests. No statistically significant differences were obtained in this analysis for any of the subject dimensions on either the ZBI ($t = 0.95$; $p = 0.35$), depression ($t = 0.20$; $p = 0.84$), anxiety ($t = 1.09$; $p = 0.28$), stress ($t = 1.53$; $p = 0.13$) and QOL scores ($t = 0.83$; $p = 0.41$).

Insert Table 4 about here

Correlations among variables

While it is not surprising to obtain correlations among dimensions of the same scale (PANSS or DASS) as portrayed in Table 4, it is seen that the total QOL score of the caregivers is negatively correlated with the general psychopathology domain of the PANSS score of the patient. Similarly the anxiety scores of the caregivers are negatively correlated with the negative symptoms of the patient.

With regard to correlations of the key variables with background factors, it was seen that the duration of the illness was not correlated with caregiver burden scores ($r = 0.01$, $p > 0.05$) but correlated negatively with the QOL of the caregiver ($r = -0.25$; $p <$

0.05) and with the manifestation of positive symptoms ($r = -0.48, p < 0.01$) and positively with negative symptoms ($r = 0.55, p < 0.01$). The size of the family correlated negatively with the QOL of the caregiver ($r = -0.34, p < 0.01$) and also with their burden score ($r = -0.34, p < 0.01$). The age of the caregiver or that of the patient however did not enter into any significant correlations with any of the subject dimensions.

Predictors of caregiving burden

A multiple regression was conducted to see if the scores of any of the DAS and PANSS subscales and the total QOL score predicted the extent of burden (ZBI score) perceived by the caregivers. The ZBI scores of the caregivers were treated as the dependent variable and the analysis performed by treating the depression, anxiety, stress, negative symptoms, positive symptoms, general psychopathology and total QOL scores, as independent variables. Using the enter method, it was found that together the independent variables explained a significant amount of the variance in the extent of burden perceived ($F_{(7, 67)} = 2.37, p = 0.02, R^2 = 0.14, R^2_{\text{Adjusted}} = 0.05$). However, the depression ($\beta = -0.27, t(74) = 2.17, p = 0.03$) and stress scores ($\beta = -0.26, t(74) = 2.16, p = 0.03$) were the only two key variables that significantly predicted the burden perceived by the caregivers.

Discussion

The composite PANSS score shows that the majority of care recipients predominantly exhibited positive symptoms. The Type I or positive syndrome is composed of florid symptoms, such as delusions, hallucinations and disorganized thinking, which are superimposed on the mental status of the person (Kay et al., 1987). It is to be expected that those with a predominance of positive symptoms would experience more disorientation, disorganization and distortion of reality, thus posing a greater difficulty in management. Positive symptoms create a sense of powerlessness, helplessness and heightened fears in others (Magliano et al., 1998), and severity of positive symptoms has been associated with higher levels of caregiver burden (Chen et al., 2004).

This study has however not found any significant statistical correlation between any of the three subscales of the PANSS and caregiver burden, and none of these have been elicited as predictors of caregiver burden through regression analysis.

This is in agreement with the findings of Aydin et al. (2009). Previous studies have however found a positive relationship between PANSS scores and caregiver burden (Adeosun, 2013; Perlick et al., 2006; Ponangi et al., 2014). The general psychopathology scores of PANSS showed a negative correlation with the QOL scores of the caregivers. The general psychopathology subscale consists of 16 symptoms that include disorientation, disturbance of volition, poor impulse control, unusual thought content and social avoidance. It seems that these symptoms create difficulty in patient management and impact the QOL of the caregivers.

The finding of high perceived burden in caregivers of persons with schizophrenia in this study is in agreement with several studies from India (Ampalam et al., 2012; Ganguly et al., 2010; Kate et al., 2013; Mandal et al., 2014) and also those from the West (Lowyck et al., 2004; Roick et al., 2006; Wolthaus et al., 2002). Disruption in family life and in family interaction, financial burden and adverse consequences in terms of well-being and health are some consequences of caregiving burden reported by earlier studies from India (Chakrabarti et al., 1995; Talwar & Matheiken, 2010; Thara et al., 1998). Patient characteristics (such as age, gender, symptomatology and duration of illness) did not influence the burden of caregivers in this study. In terms of gender, the literature reports an association between family burden and patients being male (Roick et al., 2007) and greater burden in female caregivers (Thunyadee et al., 2015). Based on the gender of the patients, no difference was seen in terms of caregivers' burden and this is in agreement with an earlier study from India (Sreeja et al., 2009).

The adverse consequence of caregiving on the mental health status of caregivers has been evidenced by several other studies (Gater et al., 2014; Gupta et al., 2015; Mitsonis et al., 2012; Stanley et al., 2016; Suro & De Mamani, 2013). High scores obtained for depression, anxiety and stress in this study are indicative of heightened psychological distress in caregivers. Depression and stress levels also emerged as significant predictors that influence caregiver burden. A high prevalence of depressive symptoms and anxiety has been reported in caregivers of patients with chronic mental illnesses (Maganã et al., 2007; Perlick et al., 2007).

Caregivers with higher psychological distress have been found to have a heavier caregiving burden (Cw Lam et al., 2013). Caregivers of persons with schizophrenia experience more stress due to the nature of the symptoms as well as the prolonged duration of illness (Raj et al., 2016). Spending more time with the patient, being assaulted by the patient, interruption to work, disputes with children and other relatives and feelings of increased psychological burden are factors associated with caregiver depression (Rodrigo et al., 2013).

Low QOL on various dimensions has been seen in the caregivers in this study, and this agrees with findings from earlier studies (Awadalla et al., 2005; Li et al., 2004; Margetic´ et al., 2013). Previous studies reveal a negative correlation between caregivers' age and their QOL (Awadalla et al., 2005; Margetic´ et al., 2013), but this has not been evidenced in our study. Correlations between low QOL and high burden in caregivers reported by Foldemo et al. (2005) have also not been established in our study. In terms of kinship status, we did not find any significant difference between parents and spouse on QOL. However other studies have indicated that parents show lower QOL than other family members (Awadalla et al., 2005; Margetic´ et al., 2013). We found gender differences and lower QOL in female caregivers, and this is in consonance with an earlier study from India (Rammohan et al., 2002). We obtained significant relationships between patient characteristics such as the duration of their illness, their positive and negative symptoms and the QOL of their caregivers. This indicates that chronicity of illness and symptom severity does adversely impact caregivers' QOL (Jagannathan et al., 2014). Based on the gender of the patients, no difference was seen in terms of the QOL of caregivers, and this is congruent with another study from India (Sreeja et al., 2009).

Implications for intervention

The evidence relating to dealing with caregiving issues conclusively demonstrates the usefulness of family-based interventions in lessening negative outcomes for caregivers (Chakrabarti, 2016). While the focus of clinical intervention has been on the patient (and rightly so), this tends to disregard and side-line the needs of caregivers with no supportive intervention strategies put in place to enable them deal effectively with the demands and challenges encountered in caregiving.

A systematic review of the efficacy of psychoeducational programmes among families of patients with schizophrenia found that they were highly effective in increasing knowledge levels and coping strategies (Sin & Norman, 2013) and to improve patient functioning (Li & Arthur, 2005). The psychoeducational approach would be relevant in the Indian context given the economics involved besides the fact that illiteracy and ignorance play a huge role in understanding the nature of mental illness. Orientation of caregivers to aspects such as the nature of schizophrenia, its prognosis, relapse and the importance of adherence to medication would enable more favourable family attitudes towards the patient.

There is also evidence that social support is a key issue that influences the burden perceived by caregivers (Adeosun, 2013; Aggarwal et al., 2011). The provision of supportive networks would thus go a long way in mitigating caregiver burden. Peer support that involves sharing and learning from the experiences of other caregivers could also provide comfort in the knowledge that one is not alone in facing distressful situations.

Participation in peer support groups is beneficial and associated with caregivers' ability to cope, improved performance in the caregiving role and thereby exerts a positive influence on the care recipients' mental status and functioning (Chien et al., 2006; Kung, 2005; Saunders, 2003).

We are of the opinion that clinical settings such as the one where this study was done need to have an active caregivers' management plan that kicks in once a patient is registered for treatment. At the least, this could incorporate a family psychoeducation approach combined with facilitating participation in a peer support group. These measures would provide the necessary care and support that caregivers of people with schizophrenia currently lack in the Indian context.

Limitations

The cross-sectional nature of the study does not capture the changing dynamics related to caregiving that is experienced at different points of time. Further caregiving burden has been treated as a unidimensional variable, whereas it has been widely acknowledged to be a multi-faceted concept. Our analysis thus does not provide an insight into the different areas where caregivers experience heightened burden.

Studies of caregiving burden in schizophrenia also underline the fact that coping strategies used influence the perception of burden (Grover & Chakrabarti, 2015), and this has not been considered in this study. Cultural considerations also limit wider generalizations of our findings. In spite of these limitations, this study deals with a wide array of variables, not often explored together, and provides an understanding of caregivers from a low socio-economic and predominantly rural background and thus adds to the extant literature in this area.

Conclusions

Consistent with the literature, this study indicates high levels of burden, greater psychological distress and a poor QOL in caregivers of people with schizophrenia. We did however find differences relating to our analysis of socio-demographic factors, in a manner not always consistent with other similar studies. Patient characteristics such as age, gender, symptoms and duration of illness did not influence the perceived burden of caregivers in this study, while positive and negative symptoms and the duration of illness were correlated with the QOL of caregivers. Kinship status of caregivers did not differentiate between parents and spouse on perceived burden, QOL or their mental health. We suggest that family interventions involving psychoeducational approaches and the provision of support groups for caregivers be envisaged as integral components of management and care of people with schizophrenia.

Declaration of interest

This study did not receive any funding. The authors declare no conflict of interest.

References

- Adeosun II. (2013). Correlates of caregiver burden among family members of patients with schizophrenia in Lagos, Nigeria. *Schizophrenia Research and Treatment*, 2013, 353809.
- Aggarwal M, Avasthi A, Kumar S, Grover S. (2011). Experience of caregiving in schizophrenia: A study from India. *International Journal of Social Psychiatry*, 57, 224–36.
- Ampalam P, Deepthi R, Vadaparty P. (2012). Schizophrenia - insight, depression: A correlation study. *Indian Journal of Psychological Medicine*, 34, 44–8.
- Awad AG, Voruganti LN. (2008). The burden of schizophrenia on caregivers: A review. *Pharmacoeconomics*, 26, 149–62.
- Awadalla WA, Ohaeri JU, Salih AA, Tawfiq AM. (2005). Subjective quality of life of family caregivers of community living Sudanese psychiatric patients. *Social Psychiatry and Psychiatric Epidemiology*, 40, 755–63.
- Aydin A, Eker SS, Cangur S, et al. (2009). The relationship between demographic variables and disease characteristics of depression and anxiety in caregivers of patients with schizophrenia. *Archives of Neuropsychiatry*, 46, 10–4.
- Chakrabarti S. (2016). Research on family caregiving for mental illness in India and its impact on clinical practice: Are we doing enough to help families? *Indian Journal of Social Psychiatry*, 32, 19–24.
- Chakrabarti S, Raj L, Kulhara P, et al. (1995). Comparison of the extent and pattern of family burden in affective disorders and schizophrenia. *Indian Journal of Psychiatry*, 37, 105–12.
- Chen F-P, Greenberg JS. (2004). A positive aspect of caregiving: The influence of social support on caregiving gains for family members of relatives with schizophrenia. *Community Mental Health Journal*, 40, 423–35.
- Chen PS, Yang YK, Liao YC, et al. (2004). The psychological well-being and associated factors of caregivers of outpatients with schizophrenia in Taiwan. *Psychiatry and Clinical Neurosciences*, 58, 600–5.

Chien W-T, Chan SWC, Thompson DR. (2006). Effects of a mutual support group for families of Chinese people with schizophrenia: 18-month follow-up. *British Journal of Psychiatry*, 189, 41–9.

Cw Lam P, Ng P, Tori C. (2013). Burdens and psychological health of family caregivers of people with schizophrenia in two Chinese metropolitan cities: Hong Kong and Guangzhou. *Community Mental Health Journal*, 49, 841–6.

Etters L, Goodall D, Harrison BE. (2008). Caregiver burden among dementia patient caregivers: A review of the literature. *Journal of the American Academy of Nurse Practitioners*, 20, 423–428.

Foldemo A, Gullberg M, Ek AC, Bogren L. (2005). Quality of life and burden in parents of outpatients with schizophrenia. *Social Psychiatry and Psychiatric Epidemiology*, 40, 133–8.

Ganguly K, Chadda RK, Singh TB. (2010). Caregiver burden and coping in schizophrenia and bipolar disorder: A Qualitative Study. *American Journal of Psychiatric Rehabilitation*, 13, 126–42.

Gater A, Rofail D, Tolley C, et al. (2014). “Sometimes It’s Difficult to Have a Normal Life”: Results from a qualitative study exploring caregiver burden in schizophrenia. *Schizophrenia Research and Treatment*, 2014, 368215.

Geriani D, Savithry KS, Shivakumar S, Kanchan T. (2015). Burden of care on caregivers of schizophrenia patients: A correlation to personality and coping. *Journal of Clinical and Diagnostic Research*, 9, VC01–4.

Grover SP, Chakrabarti S. (2015). Coping among the caregivers of patients with schizophrenia. *Indian Psychiatry Journal*, 24, 5–11.

Grover SP, Nebhinani N, Chakrabarti S, et al. (2014). Relationship between first treatment contact and supernatural beliefs in caregivers of patients with schizophrenia. *East Asian Archives of Psychiatry*, 24, 58–67.

Gupta S, Isherwood G, Jones K, Van Impe K. (2015). Assessing health status in informal schizophrenia caregivers compared with health status in non-caregivers and caregivers of other conditions. *BMC Psychiatry*, 15, 162.

Gururaj GP, Math SB, Reddy J, Chandrashekar CR. (2008). Family burden, quality of life and disability in obsessive compulsive disorder: An Indian perspective. *Journal of Postgraduate Medicine*, 54, 91–7.

Gutiérrez-Maldonado J, Caqueo-Urizar A, Kavanagh DJ. (2005). Burden of care and general health in families of patients with schizophrenia. *Social Psychiatry and Psychiatric Epidemiology*, 40, 899–904.

Hanzawa S, Bae JK, Tanaka H, et al. (2010). Caregiver burden and coping strategies for patients with schizophrenia: Comparison between Japan and Korea. *Psychiatry and Clinical Neurosciences*, 64, 377–86.

Harvey K, Burns T, Fahy T, et al. (2001). Relatives of patients with severe psychotic illness: Factors that influence appraisal of caregiving and psychological distress. *Social Psychiatry and Psychiatric Epidemiology*, 36, 456–61.

Ivarsson AB, Sidenvall B, Carlsson M. (2004). The factor structure of the Burden Assessment Scale and the perceived burden of caregivers for individuals with severe mental disorders. *Scandinavian Journal of Caring Science*, 18, 396–401.

Jagannathan A, Thirthalli J, Hamza A, et al. (2014). Predictors of family caregiver burden in schizophrenia: Study from an in-patient tertiary care hospital in India. *Asian Journal of Psychiatry*, 8, 94–8.

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, 380–8.

Kay SR, Fiszbein A, Opler LA. (1987). The Positive and Negative Syndrome Scale (PANSS) for schizophrenia. *Schizophrenia Bulletin*, 2, 261–76.

Kuipers L, MacCarthy B, Hurry J, Harper R. (1989). Counselling the relatives of the long-term adult mentally ill. II: A low cost supportive model. *British Journal of Psychiatry*, 154, 775–82.

Kung WW. (2005). Cultural adaptations of family Intervention for patients with schizophrenia in China. *International Social Work*, 48, 409–18.

Lavela S, Ather N. (2010). Psychological health in older adult spousal caregivers of older adults. *Chronic Illness*, 6, 67–80.

- Li Z, Arthur D. (2005). Family education for people with schizophrenia in Beijing, China: Randomised controlled trial. *British Journal of Psychiatry*, 187, 339–45.
- Li J, Lambert CE, Lambert VA. (2007). Predictors of family caregivers' burden and quality of life when providing care for a family member with schizophrenia in the People's Republic of China. *Nursing Health Science*, 9, 192–8.
- Li TC, Lee YD, Lin CC, Amidon RL. (2004). Quality of life of primary caregivers of elderly with cerebrovascular disease or diabetes hospitalized for acute care: Assessment of well-being and functioning using the SF-36 health questionnaire. *Quality of Life Research*, 13, 1081–8.
- Liu C, Wang L, Qun Zhao Q. (2015). Factors related to health-related quality of life among Chinese psychiatrists: Occupational stress and psychological capital. *BMC Health Services Research*, 15, 20.
- Lovibond PF, Lovibond SH. (1995). The structure of negative emotional states: Comparison of the Depression Anxiety Stress Scales (DASS) with the Beck Depression and Anxiety Inventories. *Behaviour Research and Therapy*, 33, 335–43.
- Lowyck B, De Hert M, Peeters E, et al. (2004). A study of the family burden of 150 family members of schizophrenic patients. *European Psychiatry*, 19, 395–401.
- Macneil G, Kosberg JI, Durkin DW, et al. (2010). Caregiver mental health and potentially harmful caregiving behavior: The central role of caregiver anger. *Gerontologist*, 50, 76–86.
- Magan˜a SM, Garcı´a JI, Herna´ndez MG, Cortez R. (2007). Psychological distress among latino family caregivers of adults with schizophrenia: The roles of burden and stigma. *Psychiatric Services*, 58, 378–84.
- Magliano L, Fadden G, Madianos M, et al. (1998). Burden on the families of patients with schizophrenia: Results of the BIOMED I study. *Social Psychiatry and Psychiatric Epidemiology*, 33, 405–12.
- Magliano L, McDaid D, Kirkwood S, Berzins K. (2007) Carers and families of people with mental health problems. In: Knapp M, McDaid D, Mossialos E, & Thornicroft G, eds. *Mental health policy and practice across Europe: The future direction of mental health care*. Berkshire: Open University Press, 374–96.

- Mandal P, Prakash S, Sagar R. (2014). Primary caregivers of schizophrenia outpatients: Burden and its correlates. *Delhi Psychiatry Journal*, 17, 343–8.
- Margetic´ BA, Jakovljevic M, Furjan Z, et al. (2013). Quality of life of key caregivers of schizophrenia patients and association with kinship. *Central European Journal of Public Health*, 21, 220–3.
- Martens L, Addington J. (2001). The psychological well-being of family members of individuals with schizophrenia. *Social Psychiatry and Psychiatric Epidemiology*, 36, 128–33.
- Mirowsky J, Ross CE. (2002). Measurement for a human science. *Journal of Health and Social Behaviour*, 43, 152–70.
- Mitsonis C, Voussoura E, Dimopoulos N, et al. (2012). Factors associated with caregiver psychological distress in chronic schizophrenia. *Social Psychiatry and Psychiatric Epidemiology*, 47, 331–7.
- Ozlu A, Yildiz M, Aker T. (2015). Burden and burden-related features in caregivers of schizophrenia patients. *Journal of Psychiatry and Neuro Sciences*, 28, 147–53.
- Perlick DA, Miklowitz DJ, Link BG, et al. (2007). Perceived stigma and depression among caregivers of patients with bipolar disorder. *British Journal of Psychiatry*, 190, 535–6.
- Perlick DA, Rosenheck RA, Kaczynski R, et al. (2006). Components and correlates of family burden in schizophrenia. *Psychiatric Services*, 57, 1117–25.
- Ponangi CD, Thatiseti VPK, Dronamraju PB. (2014). Caregiver burden in patients with schizophrenia. *Andhra Pradesh Journal of Psychological Medicine*, 15, 117–21.
- Raj EA, Shiri S, Jangam KV. (2016). Subjective burden, psychological distress, and perceived social support among caregivers of persons with schizophrenia. *Indian Journal of Social Psychiatry*, 32, 42–9.
- Rammohan A, Rao K, Subbakrishna DK. (2002). Burden and coping in caregivers of persons with schizophrenia. *Indian Journal of Psychiatry*, 44, 220–7.
- Richieri R, Boyer L, Reine G, et al. (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, 192–201.

Rodrigo C, Fernando T, Rajapakse S, et al. (2013). Caregiver strain and symptoms of depression among principal caregivers of patients with schizophrenia and bipolar affective disorder in Sri Lanka. *International Journal of Mental Health Systems*, 7, 2.

Roick C, Heider D, Bebbington PE, et al. (2007). Burden on caregivers of people with schizophrenia: Comparison between Germany and Britain. *British Journal of Psychiatry*, 190, 333–8.

Roick C, Heider D, Toumi M, Angermeyer MC. (2006). The impact of caregivers' characteristics, patients' conditions and regional differences on family burden in schizophrenia: A longitudinal analysis. *Acta Psychiatrica Scandinavia*, 114, 363–74.

Saunders JC. (2003). Families living with severe mental illness: A literature review. *Issues in Mental Health Nursing*, 24, 175–98.

Schulz R, Beach SR. (1999). Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *JAMA*, 282, 2215–19.

Schulz R, Martire LM. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *American Journal of Geriatric Psychiatry*, 12, 240–9.

Sin J, Norman I. (2013). Psychoeducational Interventions for family members of people with schizophrenia: A mixed-method systematic review. *Journal of Clinical Psychiatry*, 74, 1145–62.

Smith GR, Williamson GM, Miller LS, Schulz R. (2011). Depression and quality of informal care: A longitudinal investigation of caregiving stressors. *Psychology of Aging*, 26, 584–91.

Sreeja I, Sandhya G, Rakesh I, Singh M. (2009). Comparison of burden between family caregivers of patients having schizophrenia and epilepsy. *International Internet Journal of Epidemiology*, 6. Available at: <http://ispub.com/IJE/6/2/9378>.

Stanley S, Metilda GB, Bhakyalakshmi S. (2016). Mental health status and perceived burden in caregiving spouses of persons with psychotic illness (A study from India). *Social Work in Mental Health*, 14, 530–544.

Stanley S, Shwetha S. (2006). Integrated psychosocial Intervention in schizophrenia: Implications for patients and caregivers. *International Journal of Psychosocial Rehabilitation*, 10, 113–28.

Suro G, De Mamani WAG. (2013). Burden, Interdependence, ethnicity, and mental health in caregivers of patients with schizophrenia. *Family Process*, 52, 299–311.

Talwar P, Matheiken ST. (2010). Caregivers in schizophrenia: A cross cultural perspective. *Indian Journal of Psychological Medicine*, 32, 29–33.

Thara R, Padmavathi R, Kumar S, Srinivasan L. (1998). Burden Assessment schedule: Instrument to assess burden on caregivers of chronic mentally ill. *Indian Journal of Psychiatry*, 40, 21–9.

Thunyadee C, Sitthimongkol Y, Sangon S, et al. (2015). Predictors of depressive symptoms and physical health in caregivers of individuals with schizophrenia. *Nursing Health Science*, 17, 412–9.

Wolthaus JE, Dingemans PM, Schene AH, et al. (2002). Caregiver burden in recent-onset schizophrenia and spectrum disorders: The influence of symptoms and personality traits. *Journal of Nervous and Mental Disease*, 190, 241–7.

World Health Organisation. (2016). Schizophrenia. Available from: <http://www.who.int/topics/schizophrenia/en/>.

Zarit SH, Reever KE, Bach-Peterson J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *Gerontologist*, 20, 649–55.

Table 1. Distribution of care recipients by PANSS profile.

Score	Positive symptoms	Negative symptoms	General psychopathology
11–20	14 (19.2)	49 (64.7)	–
21–30	60 (79.5)	6 (8.8)	–
31–40	–	17 (22.6)	38 (49.9)
41–50	1 (1.3)	3 (3.9)	36 (48.8)
51–60	–	–	1 (1.3)
Total	75 (100)	75 (100)	75 (100)
Mean	24.9	21.9	40.2
SD	5.5	10.4	4.7
Range	14.0–41.0	14.0–55.0	32.0–60.0

Figures in parentheses are percentages.

Table 2. DASS profile of caregivers.

Severity	Depression	Anxiety	Stress
Normal	-	-	-
Mild	-	-	1 (1.33)
Moderate	36 (48)	1 (1.33)	74 (98.67)
Severe	39 (52)	2 (2.67)	-
Extremely severe	-	72 (96)	-

Figures in parentheses are percentages.

Table 3. Burden and QOL profile of caregivers.

Variable	Low	High	Median	Mean	SD	Range
Total burden score	38 (25.3)	112 (74.7)	85.0	82.5	5.4	68–91
Total QOL score	44 (58.7)	31 (41.3)	92.0	92.9	5.1	79–105
Psychological & physical well-being	73 (97.3)	2 (2.7)	21.0	20.4	1.4	16–22
Psychological burden & daily life	61 (81.3)	14 (18.7)	32.0	31.5	1.8	25–34
Relationship with spouse	66 (88.0)	9 (12.0)	5.0	5.1	0.7	4-8
Relationship with psychiatric team	64 (85.3)	11 (14.7)	12.0	12.2	1.5	9-15
Relationship with family	60 (80.0)	15 (20.0)	4.0	4.4	0.9	2-6
Relationship with friends	58 (77.3)	17 (22.7)	6.0	6.4	1.1	2-8
Material burden	43 (57.3)	32 (42.7)	12.0	13.1	1.9	6-15

Figures in parentheses are percentages.

Table 4. Correlation matrix for key subject variables.

Variables	Positive symptoms	Negative symptoms	General psychopathology	Depression	Anxiety	Stress	Total ZBI	Total QOL
Positive symptoms	1	–	–	–	–	–	–	–
Negative symptoms	–0.75**	1	–	–	–	–	–	–
General psychopathology	–0.04	0.28*	1	–	–	–	–	–
Depression	–0.20	0.10	0.06	1	–	–	–	–
Anxiety	–0.23	–0.26*	–0.10	–0.29*	1	–	–	–
Stress	–0.02	–0.01	–0.04	–0.25*	–0.17	1	–	–
Total ZBI	–0.06	–0.01	–0.03	–0.18	–0.01	–0.19	1	–
Total QOL	0.12	–0.20	–0.31**	–0.15	–0.08	–0.15	0.18	1

$N = 75$; $p < 0.05^*$; $p < 0.01^{**}$.