

A Systematic review of Caregiver burden in Mental Health Issues

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Abstract

Background: Mental illness is portrayed by disability in social, emotional, work, and other significant areas of functioning. Several studies have been reported that subjective caregiver burden is related to stress, depression and financial crisis. However, there is no systematic review quantified with reviewing overall burden for caregiver.

Objective: The purpose of this systematic review is to identify the burden of caregivers of people with mental illness including mood disorder, schizophrenia and anxiety disorders specifically who undergone treatment in psychiatry hospital.

Methods: The investigator searched major databases such as PubMed, PsycINFO, Scopus, Google Scholar and ISI Proceedings article from the year of 2005 to April 2020, and conducted a detailed review based on selection criteria.

Results: The results revealed that the majority of the studies included in the review were descriptive nature and studied anxiety disorders, bipolar disorder, schizophrenic patients' caregivers. They used variety of tools used to measure mental illness. It revealed that the burden perception of caregivers was moderate to severe and was influenced by different variables which are related to mental illness.

Conclusion: This review suggests that caregivers of patients with mental illness experiences burden moderately. The limited evidence does not allow conclusions to be drawn. Further research is needed, given the salience of mental illness and burden of caregiver.

Key words: *Mental Illness, Burden, Caregiver.*

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Introduction

Chronic dysfunctional behaviours impair the emotional, thought and intellectual competences of people; also change personal and individual characteristics and cause social and economic losses (Gultekin, 2010; Buldukoglu, Bademli, Karakaya, Goral, & Keser, 2011; Yuku, & Derleme, 2017). Of individuals with chronic psychological maladjustments, ten percent of people only need to care in the long term hospitalization and rest of them mostly live with their families (Duman, & Bademli, 2013; Yuku, & Derleme, 2017). Hence, at least one family member needs to take care of the affected person and the member is distanced from social life as well as experience physical, mental, emotional, social and economic problems (Magliano, Fiorillo, Malangone, De Rosa, & Maj, 2006; Duman, & Bademli, 2013; Yuku, & Derleme, 2017).

The primary investigations of caregivers have been conducted during the 1950s with individuals encountering mental illness and with their family members (Schulze & Rossler, 2005; Aslan, & Aylaz, 2018; Yuku, & Derleme, 2017). The idea of burden perceived by caregivers was characterized by Grad and Sainburg toward the start of the 1960s to describe problems experienced by caregiver with psychological maladjustment as well as mental illness (Isik, 2013; Yuku, & Derleme, 2017).

The concept of “caregiver burden” is rather complicated and multidimensional perspective. Caregiver burden refers to adverse events when caregivers assume an unpaid and unanticipated responsibility for a care recipient with disabling mental problems (Schene, Tessler, & Gamache, 1994). Also, referred as the degree to which a carer’s emotional or physical health, social life or financial status had suffered as a result of caring for their relative (Zarit, Todd, & Zarit, 1986). Further, it emphasises that caregiver burden involves physical, social and financial conditions of caregivers. Caregivers not only provide direct

caring but also giving psycho social support to the patients. Hence, it is reviewed that caregiver burden refers to high level of physical, psychological, emotional, behavioural and financial burden experienced by caregivers or family members with mental health patients.

To reducing caregiver burden, the first most things that should be done are to determine the perceived burden. Also, to determining caregivers' needs and planning effective interventions, it is significant to know the studies that have been conducted to determine the burden of caregivers for patients with chronic diseases specifically mental illness. Hence, this systematic review has been conducted to specify studies which was conducted with caregivers for chronic mental illness including mood disorder, schizophrenia and anxiety disorders in India and globally, also to determine their perceived burden and the factors that affect it, furthermore, to determine the kind of studies that are needed in this sector. In addition to the present article, the results of a review of the research literature with respect to caregiver burden with mental issues.

Material and methods

Design

The researcher followed guidelines on methodology of reviews (Roe, 2007), as well as Cochrane Handbook guidelines (Higgins et al., 2019).

Search strategy and selection criteria

Electronic databases viz., PubMed, PsychINFO, Scopus-Elsevier, ISI Proceedings, Cochrane Central Register of Controlled Trails, CTRI registry in India, and Shodhganga were searched with time limit between 2005 and February 2020 as well as limits with English language only. It also categorized into two such as India and rest of the world. The search terms in databases were "caregiver", "burden", "mental illness", "psychotic disorders", and

“psychiatry”. The combination of 5 key words was used as searching strategy in this review article. Further, all the articles which were come under the inclusion criteria were examined and reviewed.

Inclusion and exclusion criteria

In the present study has been followed carefully about the following inclusion criteria: (1) have published between 2005 and February 2020, (2) has been published in English, (3) participants must be caregiver, or family member who have a patient with psychiatric problem, (4) subject of the studies must be caregiver burden, (5) descriptive, observational (prospective or retrospective cohort study, case-control study, cross-sectional study), experimental or quasi-experimental, and randomized controlled trial were considered eligible.

The following exclusion criteria have been adopted in this study: (1) caregiver burden in chronic illness other than mental illness, (2) psychometric studies developing or testing burden scales or tests, and (3) studies lacking full text accessibility.

Search results

While entered the keywords into databases, 18 studies were found and the selected articles were reviewed under two phases. In the first phase, researcher reviewed the abstract of articles and removed the articles which were not matched in the inclusion criteria. At the end of the first phase, researcher finalized 13 studies. Further, in the second phase, researcher read the full-texts of selected articles and those articles that did not meet the inclusion criteria were excluded again. Hence, finally, 10 articles only met with the required criteria which include 3 reviews article in different disorder. Such articles have been selected for further research process. All the selected articles have been published in English language which was listed in Table 1.

Table 1:

Author(s)	Purpose	Sample size	Data collection methods	Research Design	Instrument	Outcomes
Stanley, Balakrishnan, & Ilangovan (2017)	To assess caregivers with schizophrenia in terms of their perceived burden, distress and QOL.	75	Self-report	Cross-sectional survey design	The Positive and Negative Syndrome Scale (PANSS)	Low QoL has been seen in the caregivers with schizophrenia. High scores in depression, anxiety and stress are indicative of heightened psychological distress in caregivers. Depression and stress levels also emerged as significant predictors that influence caregiver burden. Caregivers with higher psychological distress have been found to have a heavier caregiving burden.
					The Schizophrenia Caregiver Quality of Life Questionnaire (S-CGQoL)	
					The Zarit Burden Interview (ZBI)	
					The Depression, Anxiety and Stress Scale (DASS-21)	
Gupta, & Sharma (2013)	To assess and compare the burden and coping styles of caregivers of psychiatric and cancer patients	150	Self-report	Cross-sectional survey design	Family Burden Interview Schedule	There were significant differences in all areas of family burden in caregivers of psychiatric and cancer patients.
					Coping check list	

						Study also revealed that caregivers of cancer patients were more used “Problem focused and Social support” and caregivers of psychiatric patients used “Avoidance as well as Collusion and Coercion”.
Beentjes, Goossens, & Poslawsky (2012)	To know the existing knowledge about caregivers burden of patients with bipolar disorder in hypomanic and manic episodes	-	Database Search	Systematic Review	Used Instruments of Burden, depressive and manic symptom check list	Bipolar mania is extremely burden for informal caregivers.
Bauer et al., (2011)	To qualitatively assess the burden on caregivers of patients with bipolar affective disorders	32	Semi-structured interview	Qualitative content analysis	Statements used in the interview	Patients’ helplessness of the caregivers in interaction with the depressive and manic symptoms of the ill family members emerged as serious burdens on the caregivers.
Kalra, Kamath, Trivedi, & Janca	To review the available evidence on caregiver’s	-	Database Search	Systematic Review	Used Instruments of anxiety related	Caregivers of patients with OCD and PTSD experience a

(2008)	burden in different anxiety disorders.				disorders	significant degree of burden. This burden affects several domains of interpersonal functioning and relationships with impact on family functioning and strain for caregivers.
Chien, Chan, & Morrissey (2007)	To examine the level of perceived burden of the families caring for a relative with schizophrenia	203	Self-report	Cross-sectional descriptive study	Family Burden Interview Schedule	The families who perceived a higher level of caregiver burden were those who lived in a family with poorer functioning, worse health status and less satisfaction of social support. Social support was the best predictor of caregiver burden.
					Family Assessment Device	
					Social support Questionnaire	
Gutierrez-Maldonado, & Caqueo-Úrizar (2007).	To explore the effectiveness of a psycho educational family intervention program for reducing burden in caregivers of patients with	45	Interventional	Quasi Experimental study	Psycho educational family program	Psycho educational family intervention program reducing caregiver burden in caregivers of patients with schizophrenia.
					The Zarit Caregiver Burden Scale (ZCBS)	

	schizophrenia					
Voort, Goossens, & Bijl (2007)	To highlight the factors which influence burden, coping and needs for support of caregivers for patients with a bipolar disorder	-	Database Search	Systematic Review	Used Instruments of Burden, coping scale for caregivers of patients with bipolar disorder	Caregivers of patients with a bipolar disorder experience high burden and try to cope in different ways. Little research is available on coping styles and needs for support.
Perlick, Hohenstein, Clarkin, Kaczynski, & Rosenheck (2005)	To evaluate the relationship of the level of burden caregivers report experiencing to their use of health services, controlling for level of distress and health status	264	Mixed Method	Descriptive study	The Social Behaviour Assessment Schedule	Burdens experienced by family caregivers appear to increase use of health services, and presumably cost.
					The Centre for Epidemiologic Studies – Depression Scale (CES-D)	
					The Cornell Medical Index	
					Brief Psychiatric Rating Scale (BPRS)	

Nehra, Chakrabarti, Kulhara, & Sharma (2005).	To compare caregiver coping in Bipolar affective disorder and schizophrenia and exploring the determinants of coping	100	Mixed Method	Cross-sectional survey design	Family Burden Interview Schedule	High levels of patient-dysfunction and caregiver-burden, low awareness of illness and low perceived control over patient's behaviour were characteristic of both bipolar affective disorder and schizophrenia. Coping and other elements of the caregiving experience in bipolar affective disorder are no different from schizophrenia.
					Dysfunction Analysis Questionnaire	
					Patient's Experience of Hospitalization	
					PGI Health Questionnaire- N2 Version	
					Social Support Questionnaire	
					Caregiver Coping check list	

Discussion

The caregivers' burden of patients with mental illness tends to be high as compare to other chronic illness. Also, the symptoms of bipolar disorder are associated with the depressive, manic as well as inter-episodic nature of such an illness place a considerable burden on caregivers. Further, most of the relevant caregiving research involves patients with schizophrenia and only minor differences were found on caregiver burden, coping mechanisms and support seeking as well as patients with bipolar disorder. Hence, noticeable findings were made from the review as caregiver burden is highly associated with severity of symptoms only rather than diagnosis (Perlick, Hohenstein, Clarkin, Kaczynski, & Rosenheck, 2005; Nehra, Chakrabarti, Kulhara, & Sharma, 2005).

There is significant involvement in caregiving is associated with poor quality of life in caregivers. Significant low quality of life of patients with obsessive compulsive disorder in the domains viz., physical, psychological, and social relationship has also been reported. Obsessive Compulsive Disorder (OCD) also has an adverse effect on the quality of life of relatives or family members of patients with OCD. Hence, educating family members or caregivers have a significant effect on the patients' outcome and enhancing their coping mechanism (Stanley, Balakrishnan & Ilangovan, 2017).

The finding of this review also revealed that high perceived burden in caregivers of persons with schizophrenia is in agreement with several studies from India (Ampalam et al., 2012; Ganguly et al., 2010) as well as those from the Western countries (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. Patient characteristics viz., age, gender, symptoms and duration of illness have not influence the burden of caregivers.

The literature reports that the burden perceived by caregivers is associated with variables such as depression, anxiety, burn-out, impairment in physical health and social support. However, it is not possible to be clear on that care provision leads to the development of physiological and psychological problems or causes these problems, or that these problems make it difficult to provide patient care.

Of the 10 studies included in this review study, 4 were conducted with caregivers for patients with schizophrenia. Schizophrenia is a chronic mental illness that has direct effects on both patients and family members who live with them, because it begins at early ages, affects emotions, thoughts and behaviours and considerably impair adaptation to the environment. Hence, it has been revealed from the studies conducted with caregivers of patients with schizophrenia showed that this chronic mental disorder is one of the most important illnesses which causes burden for caregivers.

A limitation of this review is the eligibility criteria of only including literature with recent years on caregiver burden with mental illness. Not included chronic illness such as Alzheimer diseases, dementia or any other degenerative disorders. Sometimes it was likely that citations could not directly relate to caregiver burden, so it was left out. Therefore, some specific mental illness based burden study might have been ignored.

Conclusion

This systematic analysis of the studies conducted to determine the burden of caregivers for patients with mental illness. It was found that the majority of the studies were cross-sectional and few were review studies in the recent past. Out of them, most were carried out with caregivers for bipolar, schizophrenia and only one study for anxiety disorder. In the overall, the caregivers have moderate to severe levels of burden. More experimental and qualitative studies with different sample group in India, specifically Tamil Nadu should

be needed in future. Furthermore, interventional studies for family members, caregivers as well as informal caregivers with patients of mental illness should be needed at large. These would be reducing not only the burden of caregivers but also improving their quality of life.

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