

Caregiver Burden in Diagnosed Patients with Schizophrenia: A Systematic Review

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Abstract - Journals peer reviewed consisting of adequate, accurate, comprehensive data records and interpretation in relation to schizophrenia and caregiving experienced have been analysed with the method of systematic review. The aim was to design a structured study to understand the nature, causation, riskburden associated with the clinical disorder of schizophrenia and the possible measures to derive appropriate treatment place for efficient outcomes. Based on the PRISMA model, top-tier journals from 2004 – 2020 were searched in Pubmed and PsycINFO. The selection of data records was completed and the data was extracted, reviewed and the PRISMA table was designed. Theoretical analysis was undertaken and conclusion was stated based on the findings of the review. The results are suggestive of the inclusion of standardized psychological, psycho-educational and medical aid to families of the patients with symptoms of psychosis and schizophrenia to achieve positive caregiving experience. The need for psychological intervention would cater to improved daily function of the patients alongside their formal and informal caregivers.

Key words: Schizophrenia, Psychosis, Caregiver Burden, Emotional Distress, Expressed Emotions

Introduction

History and Origin

The first half of the 20th Century viewed Schizophrenia as a genetic deficit originating from Eugenics, the act of selective mating among individuals with rare desirable genetic traits. Benedict Augustine Morel (1809-1873) coined the term “démence précoce” associated with melancholia. In 1863, Karl Ludwig Kahlbaum described “catatonia”. In 1871, Ewald Hecker integrated the term “Hebephrenia”. Emil Kraepelin (1856-1927) popularized the modern concept of schizophrenia in Kraepelin's Textbook of Psychiatry, 6th edition (1899-1900) into a single disorder. Schizophrenia identified 36 “psychic” symptoms and 19 “bodily” symptoms. The poor prognosis showed existence of hallucination affecting all the sensory modalities, the common symptom being “hallucination of hearing”. The psychiatric classification distinguished “dementia praecox” and manic-depressive disorder. He identified 10 different forms of “dementia praecox”: dementia simplex, silly deterioration (hebephrenia), depressive deterioration, depressive deterioration with delusional manifestations, circular, agitated, periodic, catatonic, paranoid, and schizophasia. Finally, in the eighth edition of his textbook, Kraepelin (1913) described 10 different end states of the disease: cure; cure with defect; simple deterioration; imbecility with confusion of speech; hallucinatory deterioration; hallucinatory insanity; paranoid deterioration; flighty, silly deterioration; and dull, apathetic dementia. In 1911, Eugen Bleuler replaced “dementia praecox” with the term “schizophrenia” meaning “a mind that is torn asunder”. The core indicators according to Bleuler were “fragmented” disturbed associations termed as cognitive disturbances, psychosis or split, ambivalence, cognitive features of “loose associations,” avolition, inattention, and autism

Classification and Diagnostic Criteria

In account of the clinical practice, the diagnostic classification of Schizophrenia has been significantly addressed in mainly the ICD 10 and DSM V

In accordance to ICD 10 (International Classification of Disease) Code F20, states psycho-pathological phenomena of Schizophrenia include thought echo, thought insertion or withdrawal, thought broadcasting, delusional perception and delusions of control and hallucinations. ICD 10 has recognised 5 categories of Schizophrenia

F20.0: Paranoid Schizophrenia

Symptoms include Stable, paranoid delusion, auditory hallucination, perceptual disturbances, and disturbances of affect, volition and speech.

F20.1: Hebephrenic Schizophrenia

Symptoms include Unpredictable behaviour and mannerism, thought disorganised, fragmentary hallucination, tendency towards social isolation. Normally diagnosed in adolescents and young adults.

F20.3: Undifferentiated Schizophrenia

Symptoms of acute schizophrenia like psychotic disorder, not exhibiting more than one features of schizophrenia.

F20.5: Residual Schizophrenia

Symptoms include psychomotor slowing, under activity, passivity and lack of initiative, poor quality of speech, poor non-verbal communication, poor self-care and social skills.

F20.6: Simple Schizophrenia

Symptoms include decline in overall functioning, difficulty in maintaining social conduct, blunting affect and psychotic symptoms generally progressive in nature.

In accordance to DSM V, Schizophrenia is characterised by a range of cognitive, behavioural and emotional dysfunction. Under Code 295.90, the criteria for schizophrenia as stated – Prevalence of two or more of the following symptoms during 1 month period of time

- Delusion
- Hallucination
- Disorganized Speech
- Catatonic Behaviour
- Negative Symptoms, i.e., diminished emotional expression

Disturbances in the level of functioning in one or more significant areas

- Work
- Interpersonal Relations
- Self-Care

For children and adolescents, difficulty is prevalent in achieving expected level of interpersonal academic and occupational functioning.

Onset of Schizophrenia

During 6 months and above the residual periods, is prevalent of two or more negative symptoms.

Disturbance cannot be attributed to physiological effects of a substance (drug of abuse or medication)

Episodes

- First Episode, in partial remission –Individual has improved after a previous episode. Criteria partially met.
- First Episode, currently in full remission –No symptoms present after previous episode
- Multiple episodes – showing minimum two acute symptoms
- Multiple Episodes in partial remission
- Multiple Episodes in full remission
- Continuous
- Unspecified

Epidemiology

Schizophrenia appears in about 1.5 per 10,000 people. The age of onset is from adolescence, childhood and late-adulthood (over 45 years). Comparatively men are significantly diagnosed with schizophrenia than women. Age of onset between men is 18 – 25 years and for women between 25-35 years, with peak chances around menopause. On an average a women fall ill 3 to 4 years later than men, probably because of a protective effect of estrogen.

Studies have found the ecological factors like low standard of living and social disintegration. There also has been a significant relation between social class the morbidity risk and subtypes of schizophrenia. Psychiatric co morbidities are common in case of schizophrenia. Anxiety, depressive symptoms, panic disorder, post-traumatic stress disorder, obsessive – compulsive disorder and substance abuse disorder.

Therapeutic Intervention

Psychotherapy – is a treatment for psychological, emotional, behavioural disorders aimed in improving well-being and mental health. Guided by mental health professionals the technique facilitates routine care, supportive counselling with a problem-solving approach.

Psycho-education

- Family Education– a collaborative approach involving families of patients affected with schizophrenia. Techniques of family psycho-education like reducing distress, improving family relations, decoding family strength and resilience.
- Self Help Groups–Peer group of individuals with similar mental issues who meet at regular intervals where they interact, share their experiences, strategies, recovery progress.
- Coordinated Specialty Care – is a recovery-oriented treatment program for individuals with first episode psychosis. Generally suited 2-3 years after the psychosis onset.
- Assertive Community Treatment (ACT) – is a community based mental health care to enhance their ability to live in the community. ACT aims on reducing reliance on hospitals, and outcomes of mental illness such as homelessness and substance abuse.
- Social Recovery Therapy–is an individual psychosocial therapy for psychosis. The therapy aims to improve social recovery by engaging the individual in purposeful concrete activities. SRT aims to promote hope, values and positive schema.

Psycho-social Therapy

- Art Therapy – is a form of expressive therapy that involves increasing awareness of self through identifying non-verbal symbols and metaphors. It is used to relieve stress or tension and can be used as a mode of self-discovery.
- Social Skills training – is a type of behavioural therapy used to facilitate social behaviours involving role play and practicing new skills.
- Rehabilitation–involves utilizing psychosocial interventions to promote highest level of independent functioning by working on cognitive impairment and re-establish social adequacy.

Cognitive Behaviour Therapy (CBT)–is a psycho social intervention challenging cognitive distortions, and their associated behaviours to improve emotional regulations and develop targeted problem-solving behaviours and personal coping strategies

Cognitive Enhancement Therapy (CET) – is a recovery phase cognitive rehabilitation program for adults with schizophrenia aimed to improve neuro-cognition, cognitive styles, social adjustment and social cognition.

Review of Literature

An array of past research studies is analysed and reviewed to draw inference between the significant roles of caregivers of schizophrenic patients

Peng (2022) highlighted psycho-social interventions for family caregivers of schizophrenic patients. The study also suggested the role of cultural effects like high and low to middle income is an important determinant to address the care-givers burden in the families. Velligan (2019) reported schizophrenic patients with persistent positive symptoms were comparatively affected with higher levels of stress and anxiety. Multiple family group treatment was effective to reduce care-givers distress during the period of psychiatric care. (Hazel,McDonell,Short,Berry,Voss,Rodgers,Dyck 2004). Worakul (2007) stated psycho-educational programs were credible in increasing knowledge and shaping the attitude of caregivers. Findings also suggested psychological distress or burden of care-givers is associated with poor quality of care. Higher level of burden in emotional care was observed in the caregivers. A significant need for interventions is suggested to identify and control the problem. The relationship the patient shared with the care-givers also act as an important predictor for emotional burden experienced by the care-givers (Ozen, 2018). Yazici (2015) analysed care-giver burden was negatively correlated with income level and functionality of the patient. Findings suggested there was a positive correlation between caregiver burdens, age of the caregiver, time spend with the patient and number of hospitalizations of the patient. McCann (2009) stated caregivers often feel responsible for young patient illness during the first episode of psychosis (FEP). During the period, the relationship between caregiver and care recipient becomes closer and deeper. Results also suggested the important role of FEP services for improving support among first time caregivers during the period. Kumar (2014) stated the level of disability experienced by the patient, age of the family caregiver and gender of the patient are certain factors affecting burden faced by caregivers. Kate and Grover (2013) using the WHOQOL-BREF facets and domains highlighted coercion as a coping strategy had a negative correlation between the spiritual strength facet of WHOQOL-SRPB. Seeking social support as a coping strategy had a negative correlation with all the domains of WHOQOL-BREF. Collusion as a coping skill negatively correlated with the domains of physical health, social relationship, environment and the total WHOQOL-BREF score. Stanley (2021) suggested care-giving experience can also be viewed as rewarding. Factors like hope, perceived social support significantly predicted reward perception in caregivers. Singh and Desousa (2011) proposed depression to be commonly found in caregivers of schizophrenic patients. Determinants like duration of illness, recurrent hospitalization and religion acted as important predictors of depression in caregivers. Koschorke (2017) reported care-givers felt uncomfortable in disclosing conditions of their family members living with schizophrenia. Knowledge and awareness about schizophrenia could influence the caregiver stigma in negative or positive way. Suryani (2019) suggested increase in the frequency of health education among families with schizophrenic patients might regularize care-givers knowledge, burden and perception. Laine (2021) examined in cases of schizophrenia spectrum disorders (SSDs) a web-based psycho-education course for care-givers is beneficial. Caregiver well-being can be facilitated through regular support and cooperation from health care professional. Gater (2014) highlighted caregivers lacked time for them and showed detrimental effect in domains of physical aspect like fatigue and sickness and emotional well-being like depression and anxiety. Witarso (2018) observed a decrease in care-giver burden and psychological distress between the stages of pre-intervention and post-intervention. Caregivers showed better understanding in coping with patients, reduction of stress and self-care during the end of intervention. Quality of life was related positively to the duration of illness. Negative symptoms act as a predictor of care-givers burden. Low quality of life was found in care-givers while using the Schizophrenic Caregiver quality of life scale (Bhat, Dar, Mir and Hussain 2020). Mikkilineni (2019) stated psychological distress was prevalent in caregivers due to severity in caregiving burden. Age, Total caregiving hours, negative symptoms were highly associated with psychological distress. Ebrahim (2020) proposed psycho-education is highly recommended for family caregivers. The stigma and high level of burden suffered by caregivers is marginalized and undervalued. Ners and Yultasari (2019) indicated a significant relationship between the self-efficacy of Schizophrenia care-givers and their quality of life. Self-efficacy of schizophrenic caregivers is reportedly found in the 'strong' category.

Methodology

The systematic review is analysed through the following segments. Each segment is categorically studied in accordance to which the inference has been drawn.

Data Sources: The studies selected for the research have been exported mainly from PsychINFO and Pubmed. Only English language-based research papers were taken into consideration for systematic review analysis.

Search Strategy: The articles were searched with the usage of specific keywords. The keywords used for the selection of appropriate publications were “Schizophrenics” “Caregivers” “Schizophrenia” and “Role of Caregivers”

Selection Criteria: The articles selected ranged from the year of 2000 to the year of 2022. A total of 717 research articles were retrieved using the above-mentioned selected keywords (Figure1).

Database Details: From 717 records, 150 texts are available in complete version. 13 data were excluded from selection due to the publication year criteria. 129 data were excluded due to search criteria which included “Title”, “Scale Validation”, “Qualitative Study”, “No Relevance”, “Review”, “Comparative Study”, “Lack of Information”, “Duplicity”

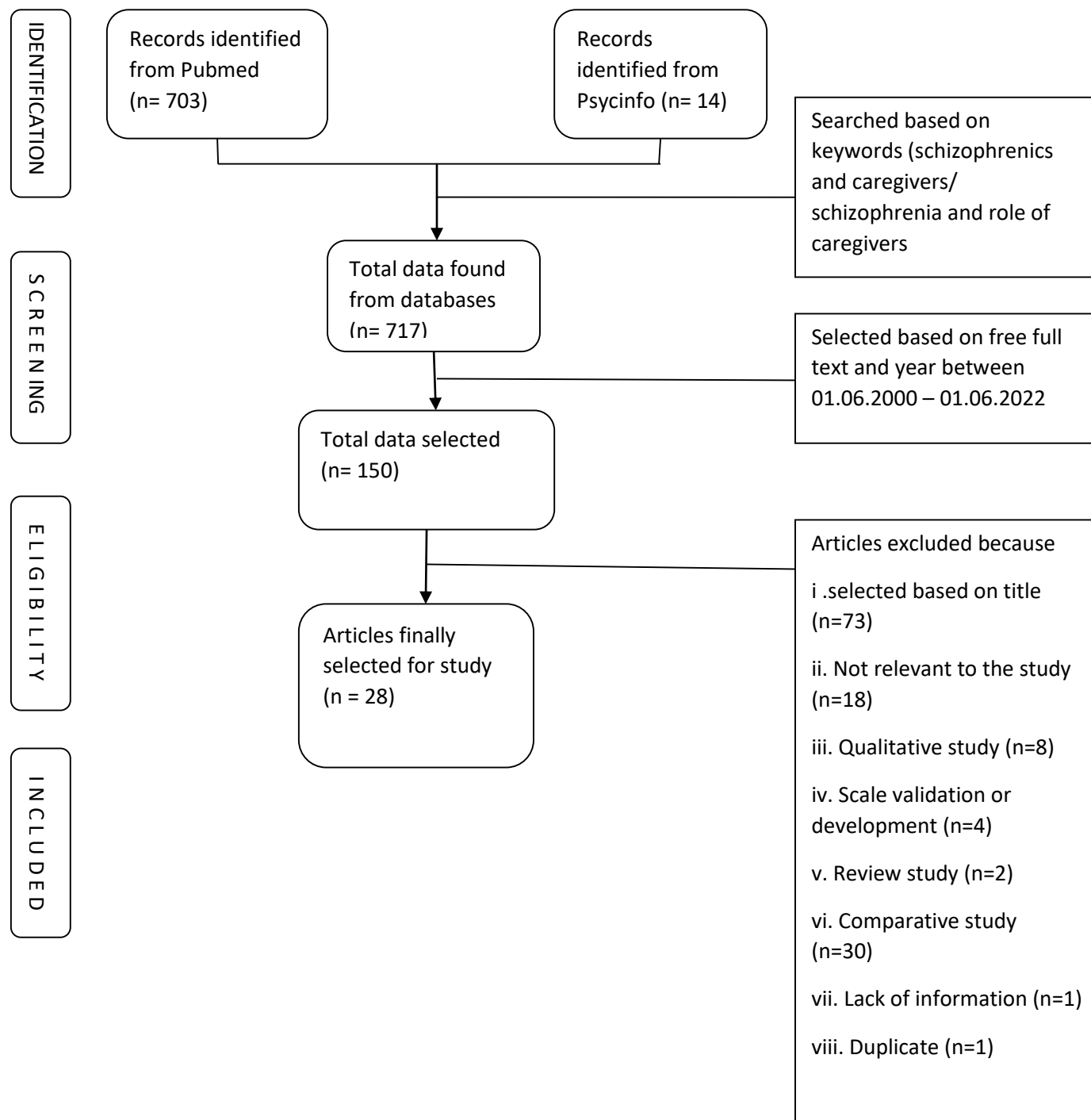


Figure 1. Flowchart of the selection and inclusion procedure.

Eligibility Criteria: The studies were eligible for selection (i) if they mainly focused on schizophrenics and caregivers role, (ii) if the study published between 01.06.2000 – 01.06.2022, (iii) if free full text available, and (iv) if journal articles are in English language. Articles were rejected if (i) free full text are not available, (ii) if title was not relevant, (iii) if topic was not relevant to the study, (iv) if study based on scale validation or development, (v) if the study was a review study, (vi) if the study is a comparative study, (vii) if lack of information, (viii) if duplicate, and (ix) if the study was qualitative.

Table 1. Characteristic of Study: A table depicting the characteristics of the study selected for systematic review analysis (n = 28)

SL NO	AUTHOR & YEAR	STUDY DESIGN	SAMPLE SIZE		LOCATION
			SP	PCG	
1	Ahmad Hajebi et al. (2019)	NM	170	170	IRAN
2	Ozlem Devrim Balaban et al. (2017)	CS	190	190	TURKEY
3	Miftahul Janah et al. (2021)	CS	NM	87	INDONESIA

4	Patricia Dias Francisquini et al. (2020)	CS	NM	117	SOUTHERN BRAZIL
5	Yaw Nyarko Opoku-Boateng et al. (2017)	CS	NM	442	GHANA
6	Alejandra Caqueo-Urizar et al. (2015)	NM	253	253	BOLIVIA, CHILE, PERU
7	Disha Geriani et al. (2015)	NM	NM	110	MANGALORE
8	Po See Chen et al. (2004)	NM	NM	57	TAIWAN
9	Dominic Ukpong et al. (2012)	NM	NM	101	NM
10	Neelam Ehsan et al. (2018)	CS	NM	50	ISLAMABAD
11	Na Meng et al. (2021)	CS	NM	147	HELSINKI
12	Tien Chen Lee et al. (2006)	NM	61	61	TAIWAN
13	B P Nirmala et al. (2011)	NM	35	35	BANGALORE
14	Farshid Shamsaei et al. (2015)	CS	225	NM	IRAN
15	Alejandra Caqueo-Urizar et al. (2017)	NM	253	NM	BOLIVIA , CHILE, PERU
16	Lucas M Mantovani et al. (2016)	NM	31	31	BRAZIL
17	Shu-Ying Hou et al. (2008)	NM	126	126	TAIWAN
18	Nanda Sari Nuralita et al. (2019)	CS	NM	86.02	NORTH SUMATRA PROVINCE
19	Tamaki Sono et al. (2008)	NM	NM	224	ICHIKAWA & MATSUDO
20	Mercedes Hernandez et al. (2013)	NM	NM	54	LATIN AMERICA
21	Kao Ching Chen et al. (2005)	NM	31	NM	TAIWAN
22	Muhammad A Zahid et al. (2010)	NM	NM	121	ARAB
23	Setsuko Hanzawa et al. (2008)	NM	NM	11	JAPAN
24	Aleksandra Skotnik et al. (2018)	NM	NM	34	SZCZECIN
25	Joseph Guada et al. (2012)	NM	NM	93	AFRIC
26	Lopez, Daisy et al. (2020)	NM	100	NM	NM
27	N Kate et al. (2013)	NM	100	100	NORTH AMERICA
28	Abdullah Burak Uygur et al. (2019)	NM	94	NM	TURKEY

Note:- NM= Not mention, CS= Cross sectional, SP= Schizophrenic patient, PCG= Primary caregiver

Discussion

The thorough analysis of research resources dated from 2004 to 2020 have led to an exploratory finding based on caregiving experience of schizophrenia

Hajebi(2019) stated primary care givers experienced higher level of burden. A direct link was found between expressed emotions of the caregivers and the level of burden they experienced. Balaban(2017) suggested interventions based on social support and coping strategies when imparted to caregivers' results in bringing a positive change in their lives. Janah (2021) also suggested a collaborative approach from health and social service professionals is an essential way for care givers to deal with their stressors with healthy approaches. Francisquini (2020) findings stated the caregiver's well-being, quality of life and hope are negatively influenced. Better education caters to better quality of life in caregivers. Male caregivers reported having better quality of life comparatively. Severity of clinical disorders like anxiety, depression was associated with higher caregiver burden and lower quality of life (Nyarko & Boateng 2017). Urizar (2015) highlighted patients with religious beliefs experienced positive symptoms of schizophrenia and developed less favourable attitude towards medication and medical aid. Geriani (2015) suggested personality traits of psychoticism and environmental factors like living in a joint family are associated risk factors which increases care-giver burden. Chen (2004) findings suggested caregivers of patients diagnosed with schizophrenia had poor psychological well-being. Psychiatric morbidity and life quality were dependent on the caregiver's awareness about schizophrenia and its causes. Ukpong (2012) suggested unemployment was an important determinant of caregiver burden. Lower education level of caregivers resulted in higher stress experienced by the

caregivers. Female caregivers reportedly experienced higher emotional distress comparatively. Ehsan (2018) reported higher depression and poor psychological well-being were experienced by informal caregivers comparatively. Meng (2021) highlighted multiple episodes of schizophrenia, closer kinship with the patient, lower education level were crucial factors that catered to poor physical health of family caregivers. Results also suggested improvement in family functionality can be improved by focussing on improving mental health of family members. Lee (2006) stated caregivers mental health is negatively impacted by the psychological severity of the patient. As per the Measure of Support Function (MSF) perceived crisis support (PCS) is a direct determinant of caregiver's mental health whereas routine crisis support (RCS) has an indirect affect on the mental health of the caregiver.

Nirmala (2011) observed a relationship between high level of relapse among the patients and caregiver burden associated with high level of expressed emotions. Shamsei (2015) highlighted caregiving duration, duration of the prolonged illness, age, gender, education level, relation to the diagnosed patient were important determinants that influenced caregiver burden. Urizar (2017) focussed on the importance of the need of family interventions to improve the quality of life among both the caregivers and patients. Mantovani (2016) findings resulted in objective caregiver burden being associated with cognitive impairment and subjective caregiver burden being impacted by the patient's onset and age of illness. Hou (2008) suggests a multidisciplinary intervention plan for improvement of physical and mental health symptoms of the caregiver and the patient. Attention towards meeting the patient need would reduce caregiver burden and facilitate healthy family participation during treatment. Nuralita (2019) reported caregiver burden affects physical, emotional, social life as well as financial status of the family. A significant relationship was observed between expressed emotions and stress due to burden among caregivers. Sono (2008) suggested Assertive Community Treatment (ACT) as a beneficial approach for the improvement of the caregiver and their family. ACT is suggestive of facilitating ordinary routine of their family life during the treatment process. Hernandez (2013) observed caregiver's increased hope was dependent on severity of the symptoms faced by the individual and individual's length of illness. Decreased family burden will result in the increase of family members hope for the future.

Chen (2005) predicted schizophrenic patient's insight were not dependent on environmental factors like caregiver's perception but rather were dependent on their own global functioning especially cognitive factors like memory index. Zahid (2010) reported non-involvement of the patient in outdoor activities, lower level of caregiver's educational level, female gender, patient's lower quality of life, disruptive behaviour was observed as global determinants for increased higher care burden in the family. Hanzawa (2008) stated general health status and difficulty in life had direct association with the burden of care. Skotnic (2018) suggested a relationship of avoidant and assertive behaviour were observed in order to cope with underlying stress. The tendency for seek social diversion during stressful situation to avoid problem solving actions were detected. Guada (2012) proposed greater family participation have led to the betterment of psychosocial functioning like work life, social life and independent living whereas family dysfunctionality has negatively impacted the psycho-social functioning. Higher caregiving criticism was associated with higher suicidal ideation in the family whereas greater family cohesion resulted in lesser tendency of suicidal ideation in the family. Family cohesion was found to be dependent on emotional distress experienced by caregivers (Lopez & Daisy 2020). Kate (2013) reported positive caregiving experiences resulted in higher quality of life faced by caregivers. Uygur (2019) stated money and intimate relations to be globally prevalent problematic domains causing distress to the patient and the caregiver.

Conclusion

The findings of the analysis indicated age, gender, educational level, family participation during illness, caregiver's educational level, patient's insight level, patients involvement in outdoor activities, closer relationship of caregiver with the patients, expressed emotion of the caregivers, caregiver's and patient's perception associated with religious beliefs, caregiver criticism, severity of the symptoms, onset of the illness have significant influences affecting lives of the caregivers and the patient. The determinants irrespective of affecting the physical and emotional health of the family members also affects the financial status and need of stable employment in the family to meet the demands during the crisis period. Appropriate holistic approach based on medical, mental aid to impart psycho-education as well as assess the needs of the patient and caregiver is required to be undertaken to enhance normal functioning in the family and work towards the reduction of emotional distress experienced during the grave phase.

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