

A Systematic Review of Family Caregivers of Persons with Serious Mental Illnesses in Non-Western Countries

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Abstract

Family caregivers of individuals with serious mental illness (SMI) play an essential role in managing patient conditions. The shift towards community care for patients has resulted in transferring patient care to family members, resulting in significant challenges. Studies have documented the experiences of family caregivers in Western countries. However, a clear overview of family caregiver experiences of persons with SMI in non-Western countries is warranted. The purpose of this study was to integrate and summarize the current literature about family caregiver experiences in non-Western countries. Five databases were searched using relevant keywords for studies published in English from 2015 to 2020. The studies included in the review were qualitative and quantitative designs, representing several non-Western countries. This systematic review included 25 articles and data synthesized based on similarities and different findings. The findings of this systematic review will provide more knowledge on the experiences of family caregivers of persons with SMI in non-Western countries, including burden, coping, psychological well-being, and stigma. This review found that additional research is necessary to understand the family caregiver experience and how healthcare teams can support caregivers. Further, the findings may help to inform health care policymakers to tailor strategies that support family caregivers.

Keywords: Severe mental illness, caregiver, experiences, family, non-Western countries.

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INTRODUCTION

Serious mental illness (SMI) refers to long-term, persistent psychiatric disorders, specifically schizophrenia, bipolar disorder and major affective disorders [1]. The World Health Organization's (WHO) Mental Health Gap Action Programme (mhGAP) identifies, bipolar disorder, depression, schizophrenia, and other psychotic disorders as priority mental illnesses that need integrated management and interventions in low- and middle-income countries [2]. Mental illnesses are prevalent in low- and middle-income countries [3]. In several South Asian countries, the prevalence of depression and bipolar disorder was 28.4% and 0.6%, respectively [3]. In Africa, WHO estimated the mean prevalence rates by disorder are 0.28%, 0.37%, and 2.18% for schizophrenia, bipolar, and depression, respectively [4]. The estimated percentage worldwide of persons with SMIs is 22.1% [5]. Between 2011 and 2030, the projected economic cost associated with mental disorders is US \$16.3 trillion worldwide [6]. The recent estimates the global burden of mental illness is 32.4% and is ranked as the fifth leading cause of disability [7].

Family Caregivers

Due to deinstitutionalization in low- and middle-income countries, family members provide the highest percentage of care for persons with mental illnesses or chronic illnesses [8]. Family caregivers take care of their relative's mental state and treatment, provide emotional support, accompany them to the hospital, and help them manage their finances [9]. Families also play an important role in providing daily routine care, supervising medication, and managing patient behavior disturbances [10]. In many non-Western societies, the reliance on family caregivers is not only because of the closer family relationships, but also, due to the lack of rehabilitation professionals in developing countries, to provide family support services [11-13]. In developing countries, there is a lack of infrastructure and political and financial support for mental health services in the healthcare system, such as a comprehensive family caregiver's plan in the clinical setting and in the community [12, 14, 15].

The effects of SMI symptoms can decrease patient functionality in various ways, including inability to complete and maintain work, interruption of

education, and an inability to live independently [16]. Furthermore, most patients do not show a positive response to treatment but continue to have severe symptoms that affect them and their families' quality of life [17]. These symptoms are disabling and require extended long-term care.

Caregiving Experiences

Caregiving experiences are a broad concept influenced by factors such as coping skills of caregivers and social support [14]. Providing care to loved ones diagnosed with acute or chronic mental illness challenges the well-being of family caregivers. Caregiving roles change family priorities, lifestyles, and routines, and consequently decrease their quality of life. Caregiving for individuals with SMI can cause emotional, financial, social, and physical problems for the caregivers [18]. These negative aspects experienced by family caregivers due to their caregiving role are defined as a "burden" [19].

There are two classifications of burden: objective and subjective. Objective burden refers to "the practical problems, difficulties and concrete and observable negative effects the illness has on family life resulting in significant life changes," whereas subjective burden is "the extent to which caregivers actually feel burdened because of the situation, resulting in psychological reactions and affecting well-being" [20]. Burden has been researched and is better understood than in the past; however, in some non-Western countries, the experience of caregiving burdens goes undocumented [21].

Quality of Life

The manifestation of psychological illness can have an effect on the quality of life of familial caregivers, affecting such areas as health, social and economic condition, psychological well-being, and family dynamics. Eventually, this can lead to poor care and the caregivers' non-adherence to the treatment plan, issues that can worsen a patient's health. Accordingly, the accumulated caregiving demand on caregivers without adequate support can lead to the caregiver becoming a hidden patient or to increased hospital readmission rates. Caregivers of persons with SMI need help to cope with their challenges. Caregivers develop different types of coping skills, and a passive coping style may adversely affect caregiving functions [22]. It is important to provide family caregivers with assistance to meet their various needs.

Project Goal and Objectives

A qualitative systematic review was conducted to explore family caring experience for persons with schizophrenia [23]. This review highlighted three themes: "(a) caregivers emotional response toward their caregiving role, their relative diagnosed with schizophrenia, and relationship with health care professions, (b) the impacts of schizophrenia and

caregiving role on their health, (c) needs among both caregivers and patients" [23]. This systematic review included studies across diverse countries related to specific caregivers of individuals diagnosed with schizophrenia. An example of Western countries included in the articles were the United States, Canada, Germany, and Australia; and in non-Western countries, four areas in Africa and Asia.

The current review expanded the previous review by extending the inclusion criteria to include schizophrenia, bipolar and depression disorders, and a broader range of study designs to incorporate the findings from these studies. Further, the current review included non-Western studies only. There is a need to merge these findings to understand the complexity of caregiving beyond looking at one specific channel of information, which may lack contextual relevance. Conducting a systematic review is important to understand how the experiences of caregivers are an essential component of both the caregiver's and the patient's overall health. Therefore, this systematic review aimed to explore and summarize family caregiver experiences when providing care for their relatives with severe mental illness in non-Western countries.

METHODS

The researcher followed guidance on systematic reviews published by the Centre for Reviews and Dissemination (CRD) [24]. The CRD's review protocol developed the following methods to plan systematic reviews: formulating the review question, inclusion and exclusion criteria, searching, study selection, data extraction, quality assessment, and data synthesis [24].

The Review Questions

The following review questions were framed in terms of the population, intervention, comparator and outcomes (PICOS):

1. What are the family caregiver experiences of persons with serious mental illness in non-Western countries?
2. What are the factors associated with caregiver experiences of non-Western family caregivers of patients with SMI?

Inclusion and Exclusion Criteria for Review

The review's inclusion and exclusion criteria included the following:

Inclusion criteria: (a) studies focused on family caregivers who have experienced caring for persons with clinically-diagnosed SMI (schizophrenia, bipolar disorder, and major depression disorder), (b) studies published in theses, dissertations, and reports, (c) studies published between 2015 to 2020, (d) studies reported in English; (e) studies that explored qualitative

and quantitative data, (f) studies that were full-text accessible, and (g) studies reported in non-Western countries.

Exclusion criteria: (a) abstracts, secondary analysis studies, and systematic reviews; (b) studies focused on other caregivers and family caregivers of an adult with any other illness, including substance-induced psychosis, dementia, or Alzheimer's disease; (c) studies reported in Western countries; (d) unpublished or grey literature, books, and conference summaries; (e) studies where participants were not caregivers for family members only; (e) studies focused on caregivers of persons with SMI in inpatient facilities; and (f) studies focused on non-family caregivers such as nurses and mental health professionals.

Search Methods

The search for this review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guideline [25]. The search process included: (a) selecting the databases and key terms for the search, (b) guiding in an initial search using the key terms selected, (c) removing duplicates using a filter system of the university library databases, and (d) performing an initial screening of the articles searched based on abstracts and titles.

Literature Search

The databases used for the search included PubMed, MEDLINE, CINAHL, ProQuest, PsycINFO, and OVID. Search terms were a combination of the following keywords: "experiences," "mental illness," "severe mental illness," "schizophrenia," "bipolar," "major depression," "caregiver," "caregiving," "family," "parent," "mother," "sibling," "spouse," "non-Western countries," "Asia," "Africa," and "Middle East." The researcher searched the non-Western countries based on geographic locations, and

references from journal articles were used for locating benchmark articles.

The PRISMA flow diagram (Figure-1) for the systematic review was used to illustrate the process of review and deselection of journal articles [25]. Using advanced search techniques of the library database, the number of selecting articles with full text was 4,900 written in English between 2015 and 2020. Abstracts were assessed for eligibility and whether they addressed the inclusion criteria and topic of review. A total of 4,620 were excluded. Further, some duplicate articles were identified and excluded. A final review of abstracts and titles based on the inclusion and exclusion criteria left 74 articles, resulting in the evaluation of 25 articles for the systematic review. Of the 49 articles excluded, 25 studies not related to family caregivers only and 20 studies collected data from inpatient settings were excluded. Two studies were not related to the SMIs disorder such as intellectual disabilities and autism or not specify the types of mental illness.

Data Extraction

Quantitative data were extracted from the articles and included: publication year, country of study, setting, purpose, design, patient's diagnosis, data collection measures, and outcomes (Table-1). For qualitative data, the researcher extracted themes for each article (Table-2).

Assessing Quality of Studies

The researcher appraised the 25 studies using the Joanna Briggs Institute's critical appraisal tools [26]. The JBI has various critical appraisal tools that fit different research designs to assess the methodological quality of studies. Two appraisal tools were used to appraise the quality of studies (qualitative research and cross-sectional studies) included in this review (Table-3).

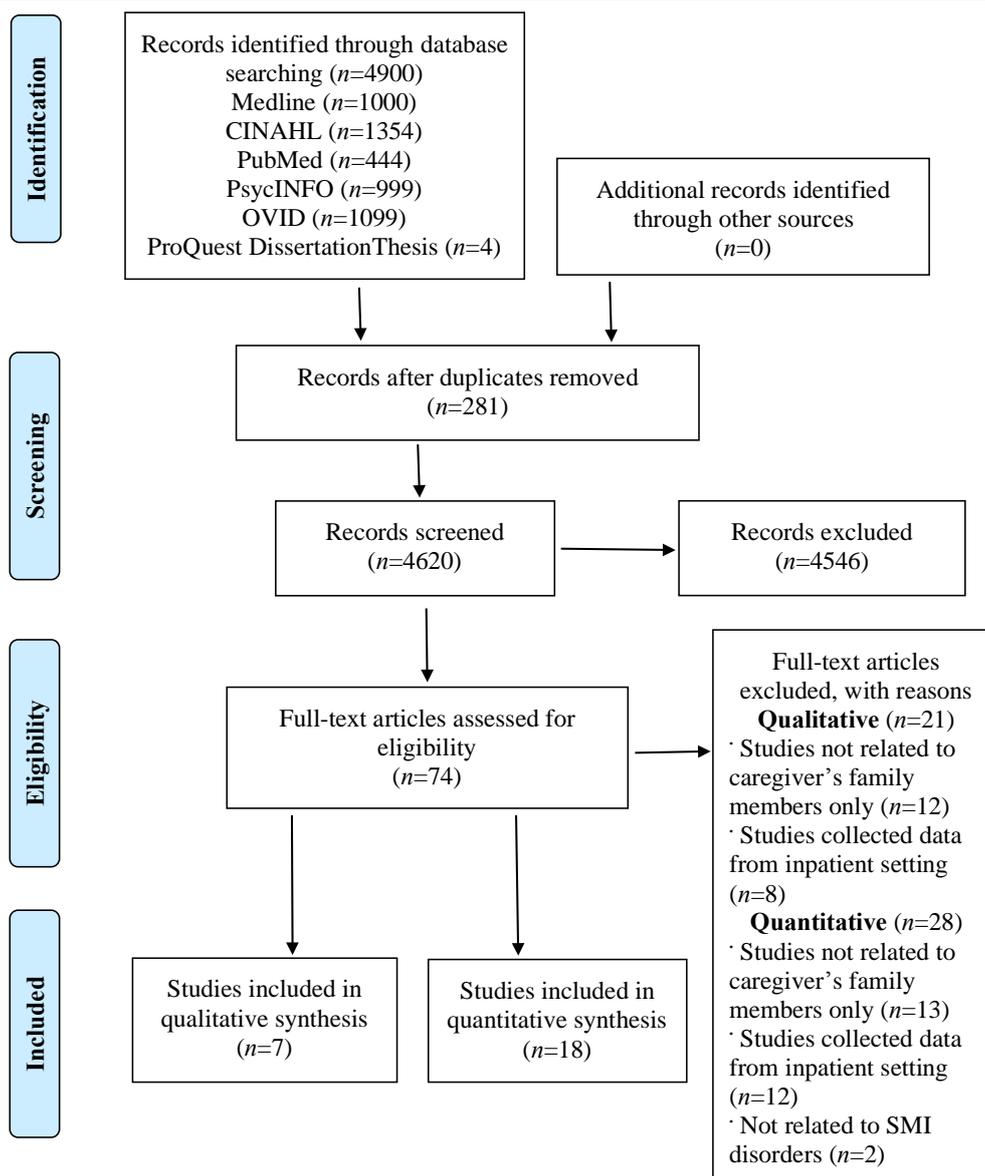


Fig-1: PRISMA Flow Diagram of Study Selection Process

Table-1: Quantitative Data on Family Caregivers of Patients with Serious Mental Illness in Non-Western Countries

Author	Topic	Sample Size/ Diagnosis	Design	Measures	Results
Shamsaei <i>et al.</i> , (2015)	Determined the family caregivers' burden.	N=225 SMI Type: Schizophrenia Setting: Iran	Correlation. Cross-sectional design	1. Zarit Burden Interview (ZBI)	Caregivers experienced moderate burden to severe burden. Factors influencing caregiver burden are age (older adult), relationship to their relative, duration of illness, and caregiving.
Chang <i>et al.</i> , (2016)	Examined the association between caregiving experiences, reactions to caregiving, and psychological distress.	N= 344 SMI Type: Schizophrenia, major depressive disorder, anxiety disorders, or dementia Setting: Singapore	Cross-sectional design	1. Patient Health Questionnaire (PHQ-9) 2. The Caregiver Reaction Assessment (CRA)	Socio-demographic correlates with CRA domains. All four dominions were significantly correlated with distress scores.

Author	Topic	Sample Size/ Diagnosis	Design	Measures	Results
Ghannam <i>et al.</i> , (2017)	Predicted the relationship of personality traits, expressed emotion, and coping strategies on caregivers' burden.	<i>N</i> =196 SMI Type: Schizophrenia and bipolar disorders Setting: Jordan	Correlation. Cross-sectional design	1. Assessment Schedule Scale (BASS) 2. The family emotional involvement and criticism scale (FEICS) 3. The Arabic version of brief COPE Inventory 4. Personality Inventory for DSM-5-Brief Form	Caregivers experienced a moderate-to-severe burden level. A negative significant relationship with coping; a positive relationship with personality dysfunction; caregivers' physical and mental health burden domain has a significant association with expressed emotion. Caregivers used low effective coping such as avoidance of coping strategies. burden were significant predicted by emotional expression, coping, and personality.
Sagut <i>et al.</i> , (2016)	Compared burden level between two group of family caregivers.	<i>N</i> =79 SMI Type: Schizophrenia Setting: Turkey	Descriptive study	The Caregiver Burden Inventory (CBI)	Caregivers of persons with chronic psychosis was higher in burden level than caregivers of persons with first episode psychosis.
Bademli <i>et al.</i> , (2017)	The relation between caregiver's anger level and the burden.	<i>N</i> =426 SMI Type: schizophrenia Setting: Turkey	Descriptive, correlational study	1. Caregiving Burden Inventory 2. Trait Anger and Anger Expression Style Scale (TAAES)	Caregiving burden and trait anger were significantly correlated. High anger levels were associated with single, male caregivers, and the duration of caregiving.
Chang <i>et al.</i> , (2017)	Compared caregivers' affiliate stigma, low self-esteem, caregiver burden, depression, and anxiety.	<i>N</i> =459 SMI Type: schizophrenia, bipolar disorder, and depressive disorder Setting: Taiwan	Cross-sectional design	1. Affiliate Stigma Scale 2. The Rosenberg Self-esteem Scale 3. The Caregiver Burden Inventory 4. The Taiwanese Depression Questionnaire 5. The Beck Anxiety Inventory	Caregivers of patients with schizophrenia had a higher level of affiliate stigma than patients with a bipolar disorder and major depressive disorder. Self-esteem, developmental and emotional burden were significant influences by affiliate stigma.
Masa'Deh (2017)	Measured the stress levels of family caregivers.	<i>N</i> =310 SMI Type: schizophrenia, bipolar disorder, major depressive and anxiety disorders. Setting: Jordan	Descriptive comparative study design	1. Arabic Version of the Perceived Stress Scale 10-Item (PSS-10)	Family caregivers of individuals with schizophrenia diagnosis had the highest stress levels compared to other diagnoses. Time of diagnosis was negatively correlated with family caregivers 'stress levels.
Alzahrani <i>et al.</i> , (2017)	Investigate the consequences of caring on family caregivers.	<i>N</i> =377 SMI Type: mental illness Setting: Saudi Arabia	Cross-sectional design	An Arabic version of the Involvement Evaluation Questionnaire (IEQ)	A higher level of burden was among caregivers caring for close relative. "Urging" was significantly higher among caregivers who were living with the patient and among those caring for female patients and families without professional support.
Kretchy <i>et al.</i> , (2018)	Examine caregivers' psychological distress and caregiver rated adherence to medications.	<i>N</i> =444 SMI Type: schizophrenia. Setting: Ghana	Cross-sectional design	1. Zarit Burden Interview (ZBI) 2. The DASS 3. Adherence Report Scale (MARS)	Poor adherence to antipsychotics was significantly related to caregiver burden and experience of anxiety. Anxiety and stress were significantly associated with poor adherence. Caregivers experiencing depressive symptoms also increased the poor adherence.
Walke <i>et al.</i> , (2018)	Assess caregivers' burden and their coping mechanisms.	<i>N</i> =320 Type of SMI: schizophrenia or a bipolar disorder	Cross-sectional design	1. The Burden Assessment Schedule (BAS) 2. Brief Cope Scale (BCS)	Caregiver burden was significantly associated with gender of the caregiver, marital status, relationship with the patient, income, and duration of care.

Author	Topic	Sample Size/ Diagnosis	Design	Measures	Results
		Setting: India			Caregivers used coping strategies: religion, planning, acceptance, instrumental support, positive reframing, self-distraction, venting, and emotional support.
Ghaith & Mohammed (2018)	Examined the relationship between caregivers' burden, psychological well-being	<i>N</i> =150 Type of SMI: Schizophrenia. Setting: Egypt.	Descriptive correlational design.	1. The Family Burden Scale 2. The Psychological Well-Being Scale 3. The Multidimensional Scale Of Perceived Social Support	The most caregivers had high and moderate level of burden. A negative correlation among social support, psychological well-being, and family burden. A positive significant correlation between social support and psychological well-being among caregivers of patients with mental illness.
Dikeç <i>et al.</i> , (2018)	Determined the relation among anxiety and family burden.	<i>N</i> =481 Type of SMI: anxiety disorder, mood disorder, and schizophrenia Setting: Turkey	Cross-sectional, descriptive design	1. Beck Anxiety Inventory (BAI) 2. Perceived Family Burden scale (PFBS)	Males caregivers perceived higher levels burden compared to female caregivers. Caregivers of persons diagnosed with schizophrenia had higher levels of burden and anxiety.
Zhang <i>et al.</i> , (2018)	Measured the relationship between affiliate stigma and quality of life (QOL).	<i>N</i> =350 Type of SMI: schizophrenia, depressive disorders, anxiety disorders and dementia. Setting: Singapore	A cross sectional design.	1. The World Health Organization Quality of Life questionnaire (WHOQOL-BREF) 2. Family Stigma Scale (FSS)	Younger aged scored significantly higher on the stigma scale. All four QOL dominions were significantly associated with affiliate stigma: psychological, social, relationship, and environment.
Yu <i>et al.</i> (2019)	Examined the association between caregiver burden and mental health, with personality, coping style, and, family functioning.	<i>N</i> =355 Type of SMI: schizophrenia and schizophrenia-related disorders, bipolar disorder, major recurrent depressive disorder Setting: China	Cross-sectional design	1. The Chinese version of the Symptom Checklist-90-R. 2. The Chinese version of Family Burden Interview Schedule 3. The Chinese version of the McMaster Family Assessment Device (FAD). 4. The Chinese version of the Simplified Coping Style Questionnaire (SCSQ). 5. The Chinese version of the Eysenck Personality Questionnaire (EPQ, adult edition)	Personality traits, coping style, and family function influenced the relationship between caregiver burden and mental health. The personality traits had effect directly on caregiver burden and family functioning. Caregivers' coping skills had a direct effect on the burden, and family functioning had a direct effect on the caregiver burden.
Madathum-kovilakath <i>et al.</i> , (2018)	Identified caregivers coping strategies.	<i>N</i> =270 Type of SMI: mood disorder, schizophrenia and schizoaffective disorder Setting: India	Correlation study	1. Modified Overt Aggression Scale (MOAS) 2. The Revised Ways of Coping	Most of caregivers perceived verbal aggression from the patient. Coping strategies used by family caregivers were: seek professional help and escape avoidance strategies, planful problem solving, and seeking social support.
Sun <i>et al.</i> , (2019)	Described the prevalence of depression among caregivers and explored the effect of care burden between social support and depression.	<i>N</i> =256 Type of SMI: severe mental illness Setting: China	Cross-sectional design	1. The Chinese version of the Social Support Rating Scale (SSRS). 2. The Zarit Caregiver Burden Interview (ZBI) 3. The Chinese version of the ten-item Center for Epidemiologic Studies Depression Scale (CES-D 10)	Care burden and social support were directly related to depression, while social support had a direct association with care burden. For the socio-demographic variables, gender, education level, and annual income had significant associations with depression. Social support is negatively associated with care burden and depression. Care burden was correlated with depression.

Author	Topic	Sample Size/ Diagnosis	Design	Measures	Results
Yu <i>et al.</i> , (2018)	Explored the differences in family burden and caregiver distress based on patient and caregiver gender.	<i>N</i> =327 Type of SMI: schizophrenia Setting: China	Cross-sectional design	1. The Global Assessment of Function (GAF) scale 2. The 24-item Family Burden Interview Schedule (FBIS) 3. The nine-item Patient Health Questionnaire (PHQ-9) 4. Caregivers anxiety was measured by the seven-item Generalized Anxiety Disorder Scale (GAD-7)	Family burden was significantly higher for male patients on physical and mental health domains, and significantly higher for female caregivers on the financial burden and effect on physical and mental health domains. Caregivers of male patients were experienced anxiety than caregivers of female patients; female caregivers were experienced depression and anxiety than male caregivers.
Yu <i>et al.</i> , (2020)	Examined family caregiving experiences between parents and spouse.	<i>N</i> =264 Type of SMI: schizophrenia Setting: China	Cross-sectional design	1. The Global Assessment of Functioning scale (GAF) 2. Specific caregiving activities were assessed by four "Yes - No" questions 4. The Family Burden Interview Schedule (FBIS) 5. The Zarit Burden Interview (ZBI) 6. The 9-item Patient Health Questionnaire (PHQ-9) 7. The 7-item Generalized Anxiety Disorder Scale (GAD-7) 8- The caregiving rewarding feelings (CRF). 9-The Family Adaptation, Partnership, Growth, Affection and Resolve Index scale (APGAR).	Both parents and spouse caregivers were engaged in similar caregiving roles and have a comparable level of objective burden. Parent caregivers had a significant higher subjective burden than spouse caregivers, depression and anxiety, and lower family functioning. Both groups of caregivers reported caregiving rewarding feeling.

Note. *N*=18.

he 19 quantitative were appraised by the Scottish Intercollegiate Guideline Network (SIGN)

Table-2: Qualitative Data on Family Caregivers of Patients with Serious Mental Illness in Non-Western Countries

Author	Purpose	Research Design and Analysis	Sample/Type of SMI/ Setting	Key Findings/Themes
Ebrahimi <i>et al.</i> , (2018)	Identified caregivers' experiences of barriers to coping strategies.	A qualitative study with semi-structured interview, using the conventional content analysis by the Graneheim and Lundman method.	<i>N</i> =16 Type of SMI: schizophrenia, schizoaffective disorders, and bipolar affective disorders Setting: Iran	The patient's isolation from everyday life, incomplete recovery, lack of support by the mental health care system, the financial strain related to the disease.
Rahmani <i>et al.</i> , (2018)	Explored the experiences of female spousal caregivers.	An exploratory qualitative with semi-structured interview, using the conventional content analysis by the Graneheim and Lundman method.	<i>N</i> =14 Type of SMI: schizophrenia, schizoaffective disorders, and bipolar affective disorders Setting: Iran	Motional detachment, emotional exhaustion, loss of interest and motivation, feeling of incompetency, loss of self.
Imkome, & Waraassawapati (2018)	Explored caregiver perspectives on long-term experiences	A qualitative study with semi-structured interview, using Braun and Clarke thematic analysis approach.	<i>N</i> =30 Type of SMI: schizophrenia Setting: Thailand	Learning to love and live with individuals with schizophrenia, life's uncertainties, uncertainty regarding the caregivers' available decisions in the future, interacting with psychiatric and mental healthcare teams and service, self-care and problem-solving, stigma and discrimination.

Author	Purpose	Research Design and Analysis	Sample/Type of SMI/ Setting	Key Findings/Themes
Attepe Özden & Tuncay (2018)	Understood burdens, coping strategies, and social support affecting the families.	A qualitative phenomenological approach, with semi-structured interview, using thematic analysis.	N=31 (members of 12 families) Type of SMI: schizophrenia Setting: Turkey	Learning and accepting the disorder, caregiving, coping with caregiver burden, and caregiving and social support.
Yuen <i>et al.</i> , (2019)	Explored family caregivers' perceptions about recovery.	Qualitative study with a semi-structured interview, using Braun and Clarke content analysis.	N=14 family members Type of SMI: Bipolar Setting: China	Understanding of the concept of recovery from the perspective of family caregivers, their experience of interactions with peer supporters, and perception of the impact of peer support services on individuals with BD and on the caregiving journey.
Amaresha <i>et al.</i> , (2019)	Explored siblings' perspectives about their affected sibling's illness and caregiving experiences.	Qualitative study with audio-recorded interviews, using the general inductive approach for analysis.	N=15 Type of SMI: schizophrenia Setting: India	Explanatory models of mental illness expressed emotion (EE), caregiving experience, and ways of caregiver involvement and coping.
Tamizi <i>et al.</i> , (2020)	Understood caregiving burden and its related factors.	A qualitative research method with semi-structured interviews using Graneheim and Lundman method for data analysis.	N=12 family caregivers Type of SMI: schizophrenia Setting: Iran	The perceived objective burden as theme included two main categories: (1) heavy involvement of caregivers and (2) challenges of the healthcare system, which include neglected educational needs of caregivers, ineffective medical and health care services and limited access to services.

Note. N=7.

Table-3: Joanna Briggs Institute Checklist for Quantitative Research

Research Studies	Criteria							
	1. Were the criteria for inclusion in the sample clearly defined?	2. Were the study subjects and the setting described in detail?	3. Was the exposure measured in a valid and reliable way?	4. Were objective, standard criteria used for measurement of the condition?	5. Were confounding factors identified?	6. Were strategies to deal with confounding factors stated?	7. Were the outcomes measured in a valid and reliable way?	8. Was appropriate statistical analysis used?
Shamsaei <i>et al.</i> , (2015)	Yes	Yes	Unclear	Yes	Unclear	Unclear	Yes	Yes
Chang <i>et al.</i> , (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Ghannam <i>et al.</i> , (2017)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Sagut & Çetinkaya Duman (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Bademli <i>et al.</i> , (2017)	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes
Chang <i>et al.</i> , (2017)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Masa'Deh (2017)	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes
Alzahrani <i>et al.</i> , (2017)	Unclear	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes
Kretchy <i>et al.</i> , (2018)	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes
Walke <i>et al.</i> , (2018)	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes
Ghaith & Mohammed (2018)	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes
Dikeç <i>et al.</i> , (2018)	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes
Zhang <i>et al.</i> , (2018)	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes
Madathum-kovilakath <i>et al.</i> , (2018)	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes
Yu <i>et al.</i> , (2018)	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes
Sun <i>et al.</i> , (2019)	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes
Yu <i>et al.</i> , (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Total of yes responses	16	17	15	17	13	6	17	17

RESULTS

Characteristics of Included Studies

In the final review, 25 studies were included, which were conducted in 11 different countries and had more than one study: Iran ($n = 4$), Turkey ($n = 4$), China ($n = 5$), Singapore ($n = 2$), Jordan ($n = 2$), Saudi Arabia ($n = 1$), Ghana ($n = 1$), India ($n = 3$), Thailand ($n = 1$), Taiwan ($n = 1$), and Egypt ($n = 1$). Of the included studies, 18 were quantitative and seven were qualitative. The majority of quantitative studies used a cross-sectional descriptive design, while qualitative studies used a descriptive design. The majority of studies included family caregivers of individuals with more than one type of SMI: schizophrenia ($n = 23$), bipolar ($n = 9$), and depression ($n = 4$). The number of participants in the 25 studies varied from 12 to 459 participants. The majority of family caregivers were

female, between the ages of 17 and 90. Most of the family caregivers were parents, followed by spouses, siblings (brother and sister), and children (sons and daughters). All studies collected data from outpatient and community settings.

Quantitative Synthesis Results

Instruments Used in Included Studies

Table-4 lists all measurement tools used to measure the following concepts: caregiver burden, caregiver coping strategies, stigma, family function, patient function, caregiver emotional well-being, caregiver stress, and social support. The majority of studies utilized a 4 to 5-point Likert scale response format. All study instruments were translated and reported based on the participant language and the reliability and validity of all scales.

Table 4: Description of Tools Used in Studies on Family Caregivers of Patients with SMI

Construct	Studies Using Scale	Name of Tools	Dimensions	Number of Items/Format
Caregiver Burden	Shamsaei <i>et al.</i> , (2015); Kretchy <i>et al.</i> , (2018); Sun <i>et al.</i> , (2019); Yu <i>et al.</i> , (2020)	The Zarit Burden Interview (ZBI)	Burden in the caregiver's health, psychological wellbeing, finances, social life, stigma details, and patient-caregiver relationship.	The ZBI consists of 22 items scored on a 5-point Likert scale.
	Ghannam <i>et al.</i> , (2017); Walke <i>et al.</i> , (2018)	The Burden Assessment Schedule Scale (BASS)	Spouse related, physical and mental health, external support, caregiver's routine, support of patient, taking responsibility, other relations, patient's behavior, and caregiver's strategy.	A 40- item on 3 points on three options such as "Not at all," "To some extent," and "Very much."
	Sagut <i>et al.</i> , (2016); Bademli <i>et al.</i> , (2017); Chang <i>et al.</i> , (2016)	The Caregiver Burden Inventory (CBI)	Time-dependency burden, developmental burden, physical burden, social burden and emotional burden.	A 24-item 5-point Likert type.
	Ghaith & Mohammed (2018)	The Family Burden Scale	Physical burden and emotional burden. Modified by researcher and add two items from Camber well Family Interview to assess familial responsibilities and financial affairs.	A 28-item 4-point Likert scale.
	Dikeç <i>et al.</i> ,	Perceived Family Burden Scale (PFBS)	The burden of the family member within the past month: The general evaluation determines current behaviors of the patient (the objective component) and at what rate these behaviors annoy the relatives (the subjective component).	A 24-item, 4-point Likert scale.
	Yu <i>et al.</i> , (2020); Yu <i>et al.</i> , (2018); Yu <i>et al.</i> , (2019)	The Family Burden Interview Schedule	Financial burden, disruption of routine family activities, family leisure, family interactions, and effect on physical and mental health of others.	A 24-item rated on a 3-point Likert scale
Coping Strategies	Ghannam <i>et al.</i> , (2017)	The Arabic version of brief COPE Inventory	Measures the ways individuals cope with stress in their life.	A 28-item scale, responses ranging from 1 to 4.
	Walke <i>et al.</i> , (2018)	The Brief Cope Scale (BCS)	Response to specific coping strategies: (1) active coping, (2) planning, (3) positive reframing, (4) acceptance, (5) humor, (6) religion, (7) using emotional support, (8) using instrumental support, (9) self-distraction, (10) denial, (11) venting, (12) substance use, (13) behavioral disengagement, and (14) self-blame.	A 28- item 4- point Likert scale.
	Yu <i>et al.</i> , (2019)	The Chinese version of the Simplified Coping Style Questionnaire (SCSQ)	To assess two areas of coping style: positive coping and negative coping.	A 20 items, a 4-point Likert scale.

Construct	Studies Using Scale	Name of Tools	Dimensions	Number of Items/Format
Psychological Distress (anxiety depression, and, anger)	Kretchy <i>et al.</i> , (2018)	The 21-item Depression, Anxiety, Stress Scale (DASS)	The DASS measures the severity of a range of symptoms common to depression, anxiety and stress.	A 21-item, 4-point Likert scale.
	Yu <i>et al.</i> , (2019)	Chinese version of the Symptom Checklist-90-R	Assess nine domains: somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism.	83 items.
	Sun <i>et al.</i> , (2019)	Chinese version of the ten-item Center for Epidemiologic Studies Depression Scale (CES-D 10)	Depressive affect and somatic symptoms, and positive affect.	A 10-tem, 4-point Likert scale.
	Yu <i>et al.</i> , (2018); Yu <i>et al.</i> , (2020)	Generalized Anxiety Disorder Scale (GAD-7)	Caregivers anxiety	A 7-item 4-point Likert scale.
	Bademli <i>et al.</i> , (2017)	Trait Anger and Anger Expression Style Scale (TAAES)	Assess anger levels of the caregivers.	A 34-item, Likert-type 4-point scale.
Stigma	Chang <i>et al.</i> , (2017)	Affiliate Stigma Scale	Affect, cognitive, and behavior.	A 22-item, 4-point Likert scale.
	Zhang <i>et al.</i> , (2018)	Family Stigma Scale (FSS)	Assess how frequently caregivers experience stigma.	A 14-item (high to low) scale.
Perceived Caregiver Stress	Masa'Deh (2017)	Arabic Version of the Perceived Stress Scale 10-Item (PSS-10)	Assess perceived stress levels in families facing different life situations.	A 10-item 4-point Likert-type scale.
Family Functions	Yu <i>et al.</i> , (2019)	The Chinese version of the McMaster Family Assessment Device (FAD)	Assess family functioning by seven dimensions: problem solving, communication, roles, affective responsiveness, affective involvement, behavioral control, and general functioning.	60- items; scores from 1 to 4 (1 = strongly disagree; 4 = strongly agree).
	Chang <i>et al.</i> , (2016)	The Caregiver Reaction Assessment (CRA)	Measure reactions from caregiving in four domains including impact on schedule and health, impact on finance, lack of family support, and caregiver esteem.	A 24-item instrument, 5-point Likert scale (1 = "strongly disagree" to 5 = "strongly agree").
	Yu <i>et al.</i> , (2020)	Family Adaptation, Partnership, Growth, Affection and Resolve Index scale (APGAR)	Assess caregiver perceived family functioning in adaptation, partnership, growth, affection, and resolve.	5-items scored in 3-point Likert scale from 0 (hardly ever) to 2 (almost always).
Patient Functions	Yu <i>et al.</i> , (2018); Yu <i>et al.</i> , (2020)	The Global Assessment of Function (GAF)	To assess patients in the person's overall social, occupational and psychological functioning during a particular time.	A100-point single-item rating scale, scores ranging from 0 (lowest) to 100 (highest)
	Ghannam <i>et al.</i> , (2017)	The family emotional involvement and criticism scale (FEICS)	Emotional expression: emotional over-involvement and perceived criticism.	a 14-item scale, response is almost never, once in a while, some, often, and almost always.
	Madathumkovilakath <i>et al.</i> , (2018)	Modified Overt Aggression Scale (MOAS)	Verbal aggression, aggression against property, auto aggression, and physical aggression.	A total range from 0–100: mild (1-25), moderate (26-50), severe (51-75) and very severe (76-100).
Caregiver Personality Traits	Yu <i>et al.</i> , (2019)	The Chinese version of the Eysenck Personality Questionnaire (EPQ)	The psychoticism scale (EPQ-P) was designed to measure aggressiveness, egocentricity, and tough minded-ness; the extraversion scale (EPQ-E) was designed to measure extraversion versus introversion; the neuroticism scale (EPQ-N) was constructed to measure emotional instability and lying (unsophisticated dissimulation and social conformity).	88 items with 1 indicating the lowest functioning and 100 the highest.

Construct	Studies Using Scale	Name of Tools	Dimensions	Number of Items/Format
	Ghannam <i>et al.</i> , (2017).	The Personality Inventory for DSM-5—Brief Form (PID-5-BF)	Assess negative effect, detachment, antagonism, disinhibition, and psychoticism.	A 25-item scale, a 4-point scale (i.e., 0=very false or often false, 1=sometimes or somewhat false, 2=sometimes or somewhat true, 3=very true or often true).
Positive Caregiving Aspects	Yu <i>et al.</i> , (2020)	The Caregiving Rewarding Feelings Scale (CRF)	Rewarding feelings of family caregiver during caregiving.	12 items, “yes” and “no” response, scored 1 or 0; higher scores indicate more positive feelings in caregiving.
Social Support	Ghaith & Mohammed (2018)	Multidimensional Scale of Perceived Social Support	Person’s perception of the social support that he or she receives from family, friends, and other.	A 12-item, 5-point Likert scale, ranging from strongly disagree (1) to strongly agree (5).
	Sun <i>et al.</i> , (2019).	The Chinese version of the Social Support Rating Scale (SSRS).	Subjective support, objective support, and use of social support.	10 items, total score ranging from 12 to 66, low (12-22), moderate (23-44) and high (45-66).
Caregivers Psychological Well-being	Ghaith & Mohammed (2018)	Psychological Well-being scale.	Autonomy, positive relationships with others, environmental mastery, self-acceptance, personal growth, and purpose in life.	42 item, 5-point Likert scale: strongly disagree (1), disagree (2), neutral (3), agree (4), and strongly agree (5).
Quality of Life	Zhang <i>et al.</i> , (2018)	The World Health Organization Quality of Life questionnaire (WHOQOL-BREF)	Physical health, psychological, social relationships, and environment	A 26-item, 5-point Likert scale ranging from 1 (not at all) to 5 (completely)
Patient Adherence to Medications	Kretchy <i>et al.</i> , (2018)	The MARS with adaptations	The caregiver-reported the extent of adherence was measured	A 5-point Likert scale, a total score of 25 indicated better adherence.
Consequences of Caring	Alzaharani <i>et al.</i> , (2017)	The Involvement Evaluation Questionnaire (IEQ-EU)	The consequences of psychiatric disorders for relatives of people with mental illness.	A 27-item, scoring based on Tension,” “Worrying,” “Urging,” and “Supervision.”
Self Esteem	Chang <i>et al.</i> , (2017)	The Rosenberg Self-esteem Scale	Self-esteem	10 items.

Ten quantitative studies measured caregiver burden using six varied tools. The most frequently used instruments were the Zarit Burden Interview (ZBI) in four studies [27-30]; the Burden Assessment Schedule Scale (BASS) in two studies [31, 32]; the Caregiver Burden Inventory (CBI) in three studies [10, 33, 34]; and the Family Burden Interview Schedule (FBIS) in three studies [30, 35-36]. The Family Burden Scale [37] and the Perceived Family Burden Scale (PFBS) [38] were also used.

Emotional distress concepts were measured by researchers using different tools to assess the severity of depression, anxiety, and anger levels among family caregivers. The Patient Health Questionnaire (PHQ-9) was used to assess depression among family caregivers in three studies [10, 30, 35]. In other studies, the researchers used different tools to measure depression, such as The Taiwanese Depression Questionnaire [39] and the Chinese version of the ten-item Center for Epidemiologic Studies Depression Scale [29] were also used. Anxiety was measured by the Generalized Anxiety Disorder Scale (GAD-7) in two studies [30, 35], and by the Beck Anxiety Inventory in two studies

[38-39]. Two studies used tools that measure depression, anxiety, and various emotional distress: The 21-item Depression, Anxiety, Stress Scale (DASS) [27], and the Chinese version of the Symptom Checklist-90-R [36]. The Trait Anger and Anger Expression scale measures the level of anger and was used in one study [33].

The concept of coping was measured by researchers in three studies [31, 32, 36] using three different scales: the Arabic version of the Brief COPE Inventory, the Brief Cope scale (BCS) and the Chinese version of the Simplified Coping Style Questionnaire (SCSQ). Similarly, two studies measured stigma by the Affiliate Stigma Scale [39], and the Family Stigma Scale (FSS) [40]. Also, social support was measured by two different tools: the Multidimensional Scale of Perceived Social Support [37] and the Chinese version of the Social Support Rating Scale (SSRS) [29]. Family and patient functions, caregiver personality traits, caregiver’s psychological well-being, quality of life, and the consequences of caring and self-esteem were measured with various tools.

Factors Associated with the Caregiving Experience of Non-Western Family Caregivers

In quantitative studies, the factors related to the caregiving experiences of non-Western family caregivers of patients with SMIs included (a) caregiver burden, (b) caregiver coping strategies, (c) caregiver affiliated stigma, and (d) psychological wellbeing. These factors were reported as significantly correlated ($p < .05$), as presented in Table 5.

Caregiver Burden

Five studies reported a high to moderate level of burden among family caregivers (28-29, 31-32, 37).

A significant factor influencing caregiver burden was caregivers who were more than 55 years old [28, 37, 39]. Greater caregiver burden levels were associated with being female caregivers [28, 32], while one study reported that perceived family burden was at higher levels in males than females [38]. The caregiver's employment status was also associated with caregiver burden [32, 37]. Further, the lower level of family caregiver education and employment status significantly impacted their financial burden [10, 32, 37, 38, 41]. High levels of caregiver burden were associated with being a parent of the patient [21, 30, 36, 37, 39] or a spouse [32] or by being a child [28].

Table-5: Synthesis of Factors Associated with Caregiving Experiences As Found in Quantitative Studies

	Caregiver Burden	Stress Level	Caregiver Coping Strategies	Stigma	Psychological		Caregiver Self Esteem	Care-giver Health	Impact on Finances
Factors					Stress (anxiety, depression, anger)	Well-being			
Socio-demographic	1								
Age	+ older adult (Shamsaei <i>et al.</i> , 2015) + older adult (Chang <i>et al.</i> , 2017) + Ghaith & Mohammed (2018)			+ Elderly risk to adjust with stigma (Chang <i>et al.</i> , 2017). + High Aged=35 (Zhang <i>et al.</i> , 2018)		+ Ghaith & Mohammed (2018)		Ages of 35-49 years (Chang <i>et al.</i> , 2016)	
Education	+ Shamsaei <i>et al.</i> , (2015)		No association Madathum-kovilakath <i>et al.</i> (2018)	+ a protector to cope with Stigma (Chang <i>et al.</i> , 2017)	High school less depression (Sun <i>et al.</i> , 2019)	+ Ghaith & Mohammed (2018)	+ high education Chang <i>et al.</i> (2016)		Lower ED perceived great impact on finance (Chang <i>et al.</i> , 2016)
	Caregiver Burden	Stress Level	Caregiver Coping Strategies	Stigma	Psychological		Caregiver Self Esteem	Care-giver Health	Impact on Finances
Factors					Stress (anxiety, depression, anger)	Well-being			
Gender	+ Women (Shamsaei <i>et al.</i> , 2015) + (Walke <i>et al.</i> , 2018) Male >Female (Dikeç <i>et al.</i> , 2018).	+Female (Masa' Deh, 2017)	No association Madathum-kovilakath		1- Anger level High in Male (Bademli <i>et al.</i> , 2017) 2- Female > Male +Femle (depression), Male (Anxiety) (Sun <i>et al.</i> , 2019) + Female (depression and anxiety) (Yu <i>et al.</i> , 2018)	- Lower in female (Ghaith & Mohammed, 2018)			High in female (Yu <i>et al.</i> , 2018)

Employment	+ (Walke et al., 2018) + Ghaith & Mohammed (2018)		No association Madathum-kovilakath et al. (2018)			+ high education (Ghaith & Mohammed, 2018)			+Unemployment perceived great impact on finance (Chang et al., 2016)
Marital status	HB Single caregivers (Bademli et al., (2017) + Walke et al., (2018)		No association Madathum-kovilakath et al. (2018)		High level Anger in single caregivers (Bademli et al., 2017)	+ Ghaith & Mohammed (2018)			
Relation to care recipient: Parent, sibling, spouse, child	+ Child (Shamsaei et al., 2015) +Parent in emotional and physical burden (Chang et al. 2017) + All Alzahrani et al. (2017) + spouse Walke, + Ghaith & Mohammed (2018) +parent (Yu et al., 2019) + parent > spouse (Yu et al., 2020) +Family function is lower with parent (Yu et al., 2020).		No association Madathum-kovilakath et al. (2018)	Parent (Chang et al., 2017). + high in parent than other (Zhang et al., 2018)	Parent high depression, anxiety > spouse (Yu et al., 2020)	+ Spouse lower than other (Ghaith & Mohammed, 2018)			
	Caregiver Burden	Stress Level	Caregiver Coping Strategies	Stigma	Psychological		Caregiver Self Esteem	Caregiver Health	Impact on Finances
Factors					Stress (anxiety, depression, anger)	Well-being			
Type of Disorder									
Schizophrenia	+ (Shamsaei et al., 2015) High level (Dikeç et al., 2018) + FG a higher level of develop-mental, physical, social, and emotional burden than others (Chang et al., 2017)	High level (Masa' Deh, 2017)		High affiliate stigma level in FC of schizophrenia than BD & MDD (Chang et al., 2017)	No difference with other (Chang et al., 2017) High level anxiety than other (Dikeç et al., 2018)				
Bipolar	High than anxiety disorder (Dikeç et al., 2018)								
Duration of Illness	+Shamsaei et al. (2015) +HB Caregivers of Pt with chronic (Sagut & Çetinkaya Duman, 2016) + (Walke, et al., 2018)	- Masa'D eh, (2017)	No association Madathum-kovilakath et al. (2018)	No association (Zhang et al., 2018)	High level Anger (Masa'Deh, 2017)				
Long Duration of Caregiving (5- 20 years)	+ Shamsaei et al., 2015 HB (Bademli et al., 2017) + Alzahrani et al. (2017) + (Walke, et al., 2018) + Ghaith & Mohammed, 2018 + (Dikeç et al., 2018)		No association Madathum-kovilakath et al. (2018)		+ Anxiety (Dikeç et al., 2018) + High anger level in caregiving (1-5 years) (Bademli et al., 2017)	+ Ghaith & Moham med (2018)			
Patient Functions and Clinical Characteristics	+ female patient Alzahrani et al., 2017 +Pt behaviors (Walke et al., 2018) +Higher in Male patient (physical/ mental), in Female patient (financial) (Yu et al., 2018). + poor anti-psychotic med. adher. (Kretchy et al., 2018)	+ poor Meds adherence Kretchy et al. (2018)	+ (Madathum-kovilakath et al., 2018) report coping style and patient's aggressive behavior	+ (Chang et al., 2017)	+ Male Patient (anxiety) (Yu et al., 2018) + poor Meds adherence (FC anxiety & depression) (Kretchy et al., 2018)				

Caregiver Burden	+ High burden (Sagut Çetinkaya Duman, 2016). + experience developmental, physical, social and emotional burdens (Bademli et al., 2017) + High physical and mental health (Walke et al., 2018) +development burden and emotional burden (Chang et al., 2017).		- Ghannam et al. (2017)		+ Predictor of depression (Sun et al., 2019)	- Ghaith & Mohammed (2018)			+ Ghaith & Mohammed (2018). +Masa'Deh (2017) + Walke et al. (2018) +low economic (Dikeç et al., 2018)
Coping Strategies	- Predict and protect - Ghannam et al., 2017) Direct effect (Yu et al., 2019)	are	- Ghannam et al. (2017) FG use avoidance strategies + Walke et al., (2018) the most used coping strategies						No association Madathum-kovilakath et al. (2018)

	Caregiver Burden	Stress Level	Caregiver Coping Strategies	Stigma	Psychological		Caregiver Self Esteem	Caregiver Health	Impact on Finances
Factors					Stress (anxiety, depression, anger)	Well-being			
Emotional Expression	+ Predictor Ghannam et al. (2017)								
Psychological Distress (anxiety depression and anger)	+ the time and dependency burden, emotional burden, social burden, and physical burden of caregivers related to anger levels (Bademli et al. (2017)								+ Chang et al. (2016) +(Dikeç et al., 2018) +Depression +annual income with depression (Sun et al., 2019)
Personality Traits	+Predictor (Ghannam et al., 2017) + physical/ mental health burden(Ghannam et al., 2017) Direct effect on family function. (Yu et al., 2019) Higher level of (personality dysfunctions) more likely have HB (Ghannam et al., 2017)								
Self Esteem				+ Chang et al. (2017)					
Stigma	Burden (Chang et al., 2017)						Significant factors (Chang et al., 2017)		
Social Support	- Ghaith & Mohammed (2018). - Sun et al. (2019) Professional support (Alzahrani et al., 2017)	+ Impact Chang et al. (2016)			Predict depression (Sun et al., 2019) + Chang et al. (2016)	+ Ghaithe & Mohammed, 2018			Low family income perceived a greater lack of family support (Chang et al., 2016)
Quality of Life				+ (Zhang et al., 2018)					

Note: + Significant positive association; - Significant negative association. Level of burden: High = HB, Moderate = MB, Low = LB. FC = family caregiver.

Studies showed that the type of SMI, such as schizophrenia [28, 38, 39], patient's functions [21, 27, 32, 35], and the long duration of caregiving [21, 28, 32, 33, 37, 38] had an effect on caregiver burden. All studies concluded that high burdens were associated with providing care for male patients. However, one study found that caregiving for a female patient was related to a higher burden [21]. Furthermore, studies showed that family caregivers had a high level of developmental, physical, social, and emotional burden [32-34, 39]. Emotional expression, coping, and a caregiver's personality dysfunctions were significant predictors of caregiver burden [31]. Simultaneously, the caregiver's personality traits (neuroticism personality traits), family functioning, and coping style affected the caregiver burden [36]. A negative association among social support, psychological well-being, and family burden was also found [29, 37]. Furthermore, the burden had a significant negative relationship with coping [31]. Further, social support directly associated with care burden [29].

Caregiver Coping Strategies

One study concluded that there was no significant relationship between the caregiver or patient characteristics and coping strategies of the caregiver [42]. However, high levels of caregiver anger were related to the duration of caregiving because a lack of social support effective and coping methods, or inability to adapt to the illness [33]. The findings of two studies revealed that the coping style of family caregivers, such as avoidance strategy, were a predictor of, and directly affected, caregiver burden [31, 36]. Two studies indicated that family caregivers used adaptive coping strategies [32, 42]. The most frequently used coping strategies were reported in one study: acceptance, religion, active coping, planning, positive reframing practices, escaping, and emotional support; while denial, self-blame, behavioral disengagement, humor, substance use were the least used coping styles [32]. Further, one study indicated that the most caregivers were used playful problem solving and seeking social support to take care of a patient's aggressive behavior [42]. However, most family caregivers did not use efficient coping strategies, and those that were used were not used appropriately [31, 36, 42].

Caregiver-affiliated stigma

Caregiver-affiliated stigma is defined as internalized stigma faced by family members who are closely related to stigmatized individuals with mental illness; this stigma is a result of the public's negative view of mental illness [39, 40]. Two studies focused on family caregiver-affiliated stigma [39, 40]. Caregivers above the age of 30 were found to be at risk of feeling stigmatized; meaning they scored high on stigma tools [39]. In contrast, one study described that primary caregivers who were 35 years or younger felt more stigmatized than caregivers aged more than 50 years [40]. However, a high level of education was reported

as a protective factor for coping with stigma [39]. Being a parent of a person with SMI had a significant highly affiliated stigma [39, 40]. No relationship was found between stigma and duration of mental illness [40]. However, the two factors that decreased the level of affiliated stigma were psychiatric hospitalization and suicide attempts by the persons with SMI [39]. The affiliated stigma of caregivers is correlated with a family caregiver's self-esteem and caregiver burden, and is higher in the families of patients with schizophrenia when compared to bipolar and major depression disorders [39]. Additionally, it was reported that all four determinants of a caregiver's quality of life, physical and psychological health, social relationships and environment were significantly associated with affiliated stigma [40].

Psychological Well-Being

Female caregivers were more likely to have depression or anxiety and low psychological well-being [29, 35, 37, 41]. However, male caregivers were associated with high levels of anger [33]. Furthermore, anger level and low psychological well-being were higher in, and more significantly associated with, single caregivers and long durations of care [33, 37]. Also, high levels of stress were negatively associated with the duration of illness [41]. The level of education and annual income of the family had significant associations with depression and low psychological well-being [29, 37]. Parent caregivers have higher levels of depression and anxiety than spouse caregivers [30]. However, a statistically significant relationship between the caregiver's low psychological well-being and being a spouse of patients was also reported [37]. Caregivers of persons with schizophrenia had higher levels of anxiety and stress than caregivers of patients with bipolar disorders and depression disorders [38, 41]. Conversely, no significant differences were found in depression and anxiety among family caregivers of various patient diagnoses (schizophrenia, bipolar, and major depression disorder) [39]. Caregiving for male patients and poor medication adherence were associated with family caregiver anxiety, depression, and heightened level of stress [27, 35]. Further, one study compared two types of caregivers (spouses and parents) who engaged in similar caregiving activities and concluded that no significant difference in a positive caregiving effect between them [30].

One study reported on caregiving reaction in four domains: "impact on schedule and health, impact on finance, lack of family support and caregiver esteem" and found that they were significantly associated with distress scores [16]. Social support had a negative relationship with care burden and depression [10, 29]. The caregiving burden and social support were predictors of depression and had an impact on stress level [10, 29]. A positive significant association was found between psychological well-being and social support [37]. Further, burden was significantly higher

among caregivers who were not receiving any kind of professional support [21].

Qualitative Synthesis Results

All articles included in the current review used a phenomenological qualitative approach. Furthermore, content analysis was the most used analysis approach in the studies. The findings of seven qualitative studies were analyzed and categorized based on similarity and differences of meaning. Two main themes emerged: the impact of caregiving on families and coping strategies adopted by caregivers (Table 6 and 7).

Impact of Caregiving on Families

The impact of caregiving on the caregivers is individualized and varies, depending on the diverse family and contextual characteristics [43]. This theme synthesizes the experiences of the family caregiver for persons with SMI based on two subthemes: the negative and positive aspects of caregiving experiences. The negative aspect of the caregiving experience theme synthesized the emotional and complicated experiences reported by family caregivers in all studies. The positive aspect of the caregiving experiences theme synthesized the positive aspects related to their role and their feelings about caring.

Table-6: Synthesis of Negative Impacts of Caregiving on Families as Found in Qualitative Studies

	Negative Aspects							
	Lack of Mental Health Care Resources	Lack of Professional Support	Financial Problem	Caregiving Responsibility	Social Isolation			Psychological Distress
Articles					Lack of Social Support	Stigma	Effect of Illness and Medications	
Ebrahimi et al. (2018)	Lack of rehabilitation program and psycho-therapeutic intervention for patients.	1- Mental health professional (MHPs) not providing education about patient medications. 2- MHPs need to educate patients about their disorders and medications. 3- lack of MHPs support. 4- lack of communication between families and MHPs. 5- MHPs excludes families from treatment plan.	1- Medical insurance may not cover certain types of treatment and recurrent nature of disease.	1- disturbance of daily	The process of care and the nature of disease cause social isolated.	A strong barrier to family caregivers' coping 2- Affect employers' practices that lead to loss of social support and increases social isolation.	Family becomes more isolated from society.	1-Feeling abundant from caregiving role by MHPs 2- Uncertainty about their caregiving role.
Rahmani et al. (2018)	No supportive resources.	Assumed responsibility for caring without education from formal services.	No financial support for the family.	1- Lack of preparation to care for patient /assume family roles. 2- Increase caring need and life issue. 3- Busy with caregiving tasks. 4- Caregiving tasks interfere with other responsibilities, 5- Caregiving tasks overlap with caregiver's personal, social, occupational or educ. task. 6- A full commitment to care/support to the patients: caregivers neglect their need.	1- Lack of support from friends and relatives.	-	-	1- Emotional detachment. 2- Loss of emotional relationships with patients. 3- Psychological distress. 4- Hopeless about patient recovery and desperate about living stations. 5- Loss of interest. 6- Incompetent, inefficient and unqualified feelings. 8- Confused and feel lonely.

Negative Aspects								
	Lack of Mental Health Care Resources	Lack of Professional Support	Financial Problem	Caregiving Responsibility	Social Isolation			Psychological Distress
Imkome, & Waraassa wapati (2018)	-	- Experienced frustration when MHP ignored their concerns.	Financial problems related to continuing the treatment programs	1- Engaged in less active lifestyles 3- Exclude themselves from activities and social interactions because of patients' situations.	Excluded by friends and the community.	1- Society not understand the mental illness. 2- Stigma and discrimination with both family and their relatives. 3- Changing jobs because people caused them to feel shame and harm. 4- Labeling disorders leads to social isolations	Symptomatic phases, emotional reaction, anti-psychotic medications side effects, and the cognitive impairment of the patients	1- Uncertain about course of illness/ patient's future. 2- Doubt and worry about sustainability of severe positive psychotic symptoms. 3- Anxiety and doubt re patients' future. 4- Worries. 5- Anxiety and fear to contact local healthcare team. 6- Sadness and anxiety by taking care in crises. 7- Caregivers regret not knowing enough re illness. 8- Exclusion and feeling different from other.
Attepe Özden, & Tuncay (2018)	Insufficient caregiving services.	Families need training, information.	Related to insufficient services of caregiving	1- Spend more time in caregiving 2- Family members' perceptions of the mental illness and the meanings they attribute to it influence caregiving process. 4- Patients become dependent on their families. 2- Difficulties to manage patients' symptoms. 5- Struggling with accepting caregiving 7- Delay learning about disease.		1-The social exclusion and stigmatization 2- Families choose to hide the disease, therefore they isolated themselves from society.	1- Providing care result in becoming socially withdrawn	1- Blamed themselves for the disorder. 2- Mothers mostly become sad and panicked 3- Fathers were shocked at first. 4- A sense of loneliness among families. 5- Wondering about who provide caregiving after they died.
Yuen et al. (2019)	1- Caregivers are negatively perceived peer support services 2- Caregiver stated that peer support is not useful.	1- Caregivers not knowing about peer support service.		1- Difficulty to manage symptoms. 2- Peer support is not useful for people who has recurrent mood changes 3- Doubtful about the training they had from peer support.				1- Concerned about patient's job to support their life.
Tamizi et al. (2020)	-Limited access to psychiatric health-care services. -Inadequacy provision of mental health services. - Issue related to hospitalization.	1- Disregarded educational needs of caregivers 2- Lack of providing appropriate education by the health care providers 3- Ineffective treatment 4- Poor health care providers' therapeutic communication		1- Helping patient to perform self-care activities, full-time care for the patient. 2- Long time caregiving influences the family caregiver burden.				

Negative Aspects							
	Lack of Mental Health Care Resources	Lack of Professional Support	Financial Problem	Caregiving Responsibility	Social Isolation		Psychological Distress
Amaresha et al. (2019) Sibling	Not reported	-	Financial burden related to patient's socio-occupational dysfunction and unemployed status	1- Sibling highly critical or overprotective toward their patients. 2- Increase responsibilities 3- Experienced objective and subjective burden. 4- Impacted caregivers' marital relationship. 5- Interfered with their daily work. 6- Sibling caregiver is involved in other important caregiving activities. 7- Relationship with the sibling with SMI has change.		In the early stage of disorders: 1- Sibling negative attitude toward mental illness. 2- Delay seeking health care professional 2- Feeling embarrassment of their siblings' illness lead to avoiding people.	Grief

Table-7: Synthesis of Positive Impacts of Caregiving on Families and Caregiver Coping Strategies as Found in Qualitative Studies

Articles	Positive Impacts of Caregiving	Five Caregiver Coping Strategies				
		1. Emotion-focused	2. Problem-focused	3. Passive Caring	4. Caregiver Self Care	5. Cultural Beliefs re Mental Illness
Ebrahimi et al. (2018)		1- Sharing their difficulties with other and becoming more resilient.				Seeking traditional healing to cope because believing that the illness was manmade or possession of evil spirit.
Rahmani et al. (2018)	Caregiving considered as a duty and as part of family's lives	1- Acceptance of caregiving role.				
Imkome & Waraassawapati (2018)			Focus on how family overcome problems rather than focusing on problems.		Adapt relaxation activities	
Attepe Özden & Tuncay (2018)		Thanked God and compared their current circumstances with the first years of the illness.	1-Religion-based activity 2- Adopted different strategies to deal with illness	1- Use Avoidance behavior in the caregiving process. 2- Use religion-based activities to isolate themselves.		
Yuen et al. (2019)		Peer support services lead to increased socialization 1- Peer support had a positive impact on caregiver's emotion. 2- Changed caregiver's perceptions about the illness.				No increase in their religious belief during the illness process.
Tamizi <i>et al.</i> , (2020)						1- Seeking treatment based on the existing cultural beliefs in the society and from religious beliefs. Beliefs that mental illness is a result of "previous deeds, black magic, or God's curse, possession of evil spirit."
Amaresha <i>et al.</i> , (2019)			Involving in or carrying out their regular work.	Avoidance.		

Negative Aspect of the Caregiving Experience

Family caregivers experience negative impacts from caregiving, including emotional stress, financial issues, a lack of community resources, and worry due to a lack of knowledge. Four authors reported the lack of availability and access to mental health care resources for caregivers and patients [11-13, 44]. However, one study addressed the negative and positive family caregiver experience with available peer support services [45]. Furthermore, the lack of professional support for family caregivers was illustrated in six studies [11-13, 44-46]. Family caregivers assumed caring without sufficient knowledge about a patient's medication or the disorder, yet had to provide care for the patient at home, managing the patient's high-risk behavior and the patient's resistance to treatment due to a lack of communication and ignorance from psychiatric healthcare providers [11-13, 44-46]. However, one study addressed how peer support services impacted family experience, such as instilling hope for patient recovery, having a positive impact on caregiver emotions, changing caregiver perceptions about the illness, and facilitating better communication between the caregiver and the service user [45].

In five studies, financial problems were related to various factors; for instance, no medical insurance coverage for all treatment or medications, recurrent episodes of disease, insufficient services of caregiving, cost of continuing the treatment programs, or no financial support for family, as well as related to the patient's socio-occupational dysfunction and unemployed status [9, 11, 12, 44, 46].

Two studies [9, 13] addressed caregiving responsibilities and included following up on medical appointments, managing medications, guiding other family members to take care of the patients, motivating the patients with their daily activities, helping patients to perform self-care activities, and spending more quality time with the patients. Additionally, many families contend with caregiving difficulties associated with such issues as managing the patient's symptoms, the patient's refusal to take medication, uncontrollable patient behavior, and the patient's lack of self-care [44, 45]. Interestingly, due to the full commitment of these care giving roles and patient dependency on caregivers, caregiving tends to interfere with a family's daily lifestyle and related responsibilities. This in turn causes caregivers to neglect issues relating to themselves and often including the exclusion of various activities and social interactions, the impact on their relationship with relatives with SMI, the affect on their quality of life both socially and economically, and the objective and subjective burden to which they are subjected [9, 11-13, 44, 46]. Also, the attitude of family members toward the mental illness and a lack of knowledge about SMI influenced the caregiving process and family relationships [9, 44].

Family social isolation was evident in five studies, and was related either to a lack of social support or stigma or to the effect of illness and medications. Families experienced isolation because of involvement in the caregiving process and the characteristics of disease [11], and experienced exclusion and lack of support from friends, relatives, and their communities [12, 46]. Family caregivers and their relatives with SMI experienced public stigma, which impacted a family caregiver's coping, employer recruitment practices, and family functioning, and caused delays in seeking professional health care, loss of social support, and increases social isolation [9, 11, 44, 46]. Furthermore, families isolated themselves or avoided people because they were hiding the disease, and felt embarrassment because of their relative's illness [9, 44]. Due to having to provide care for a patient, as well as various factors such as incomplete patient recovery, symptomatic phases, patient emotional reactions, side effects of anti-psychotic medications, and cognitive impairment, families gradually become more isolated from society and more socially withdrawn [11, 44, 46].

Psychological distress was evident in five studies and was described as the psychological disturbance experienced by family caregivers throughout their relative's illness trajectory. Frequently, this distress was described in terms of guilt, where the caregivers blamed themselves for the disorder or for failing to know about the illness [44, 46] and worried about the uncertainty of such factors as the patient's future, the caregiving process after they died, unpredictable illness, and how the patient could fit in and maintain a job in society [11, 44-46]. Additionally, feelings of loneliness were described in three studies [11, 44, 46]. Caregivers felt especially sad and anxious when taking care of patients in crisis situations [44, 46]. Furthermore, anxiety and fear were related to ambivalence to contact healthcare providers to manage the crisis situation [46]. Family caregivers also experienced feelings of hopelessness about patient recovery, feelings of being incompetent and unqualified to provide care with emotional disconnection, and feelings of loss of interest and self [12]. One study reported that siblings experienced grief about their relatives [9].

Positive Aspect of the Caregiving Experience

Families perceived themselves as the only supportive resource for their relative with SIMs in that they were accepting and assumed their caregiving role as a part of their lives [12]. A positive experience of caregiving was identified in one study as families continue to enjoy providing care to their relatives with SMI as it is as part of their responsibility and a part of their lives [12].

Coping Strategies Adopted by Caregivers

Caregivers use a broad range of coping strategies to assist and support with patient illness and caregiving necessities. Three articles addressed the most emotional focused approach; these included accepting caregiving roles, looking for emotional support, sharing their feelings and difficulties with other, and using religious and spiritual approaches [11-12, 44]. Furthermore, three studies illustrated that problem-focused approaches were used in seeking advice from family members, overcoming problems, and involving caregiving activities and regular tasks [9, 44, 46]. However, two studies reported that families used escape-avoidance as a coping strategy from the caregiving process [9, 44]. One study explained the caregiver's self-care activities; for example, engaging in leisure activities and adapting relaxation activities, including chatting with friends, listening to the radio and watching television, and enjoying meals with family [46].

Two studies revealed that cultural beliefs regarding mental illness, as well as caregiver's spiritual strategies, tend to be the primary reason for family caregivers seeking traditional, religious, and faith healing treatments to cope with their relative's disorders [11, 13]. These practices were based on existing cultural beliefs embedded in the caregiver's community that mental illness is a result of "previous deeds, black magic, or God's curse, possession of evil spirit" [9]. However, one study found no increase in family religious beliefs during the illness process [45].

The Synthesis of Findings

This systematic review synthesized the non-Western evidence of the experiences of family caregivers in providing care for persons with SMIs. The integration results from this review revealed that the quantitative studies described the most frequent factors that are associated with a family caregiver's challenges. The qualitative studies illustrated the high level of complexity associated with family caregiving experiences. These difficulties were significantly exemplified with regard to the levels of burden and stigma, and the elevated levels of emotional responses, including feeling overwhelmed and being socially isolated. Further, it was noted that families used different coping skills with their everyday activities relevant to their caregiving and in overcoming various obstacles. Overall, it is evident that throughout non-western countries, regardless of the culture, age or socioeconomic status, caregivers are experienced similar frustrations. More frequently, many caregivers find that their coping skills promote additional unmet needs and requisite support strategies.

DISCUSSION

This systematic review aimed to analyze the experiences of family caregivers of patients with SMI in

non-Western countries. Most of the studies used descriptive quantitative and qualitative studies. Therefore, it is important to develop intervention studies to improve caregiver burden, to teach family caregivers how to adapt to lower their stress, and to prepare these caregivers for their caregiving role. Further, studies used various tools with varied constructs such as burden, stigma, coping, and psychological distress to measure and overlap using different scales. Also, researchers in those studies tested relationships between caregiver burden, psychological problems, stigma, personality traits, social support, and self-esteem, and found significant relationships between or among variables. Also, the researchers tested relationships between caregiver burden, psychological problems, stigma, personality traits, social support, and self-esteem, and found significant relationships between or among variables.

All caregivers included in these studies were close family members to the person with SMI for whom they were caring. Caregivers were different ages and the majority of them in the research were parents, spouses, siblings, and adult children. The caregivers' burden of patients with mental illness tends to be high across most of the studies. Hence, findings from the review indicated caregiver burden is highly associated with female caregivers, older age caregivers, a long duration of caregiving, low education levels, unemployment, economic costs related to treatment and to the patient's illness, low health status, experience stigma, a lack of family support, their relationship with patient, and type of patient diagnosis. These findings are consistent with the study conducted in Western countries, which found a family's mental health difficulty within one year was significantly increased among female caregivers under the age of 65 [47]. Other factors included marital status (divorced, widowed, or single), a low education, a low household income, and the presence of a mental health diagnosis for families who perceived a high level of burden.

Notable factors influencing experiences were the contradictory findings of the caregiving burden for the male with SMI. In Saudi Arabia, the high level of burden is associated with caring for female patients with SMI [21]. A study explained these differences based on the Arab culture in which people handle any issue related to females with SMI in secrecy due to two reasons: limiting their chance of marriage and being incapable of caring for their children [21]. In Saudi Arabia, it was surprising to find only one quantitative study on family caregivers and no qualitative studies.

The finding of this review also revealed that perceived burden, stigma, and psychological distress detected in caregivers of persons diagnosed with schizophrenia was greater than for patients with other SMIs. This finding is consistent with several studies within Western countries; the difference may have

arisen from disease characteristics of the patient [48-49]. In addition, patients with schizophrenia have a higher rate of symptom relapse and recovery [50]. Therefore, patients with schizophrenia need a longer duration caregiving and treatment due to frequent hospitalization.

The systematic review found that the burden perceived by caregivers is associated with variables such as depression, anxiety, anger level, and social support. It was clear that caregiving responsibilities lead to the development of psychological and physiological problems or predict these problems and make it difficult to provide patient care. This finding is in agreement with a systemic review that 46% of caregivers reported depression and anxiety, which are related to the caregiving relationship [51]. Depression and anxiety were found to be related to being a female caregiver, clinical features of the illness, and duration of care [52].

The systematic review highlighted that family caregivers used different coping strategies and self-care activities to deal with caregiving activities or crisis situations. Furthermore, the review found that family coping styles were associated with caregiver burden. These finding were similar to a study [53] that family caregivers of persons with SMI used various problem- and emotion-focused coping strategies to deal with a mental health crisis and to prevent the negative impact of stigma and family burden. Furthermore, the review found that families were seeking traditional or religious and faith healers for treatment or to cope with their situations based on cultural beliefs. Therefore, healthcare professionals need to help caregivers enhance their coping skills, to support their existing skills, and to facilitate the development of new ones [54].

The systematic review revealed that family caregivers experienced a lack of formal and informal support and of mental health care resources, which had an impact on their psychological well-being, family burden, and financial issues. The findings of this review demonstrated that communication and education from health care professionals are important to caregivers. Also, caregivers experienced social isolation due to providing care, a loss of social support, stigma, illness and medication side effects, and attitudes toward their relative's illness. Social and cultural background may play a role in the burden of caregiving and caregiver perceptions. One study reported that there is a higher level of stigma and negative conceptualizations of the illness, which leads caregivers to try to keep the illness a secret and to delay seeking treatment [55].

Even though the non-Western studies shared similar findings, limited studies have examined the supports available, the needs of family caregivers of patients with SMI, and the positive aspect and rewards of caregiving experiences in non-Western countries.

Cultural differences in each country affect the burden experienced by each family as caregivers. Families need support when caring for patients and need service and support for their own mental and physical health in order to sustain their caregiving role. Limited research was found on needs of these caregivers for professional support. Caregivers need information, accessibility of care, and communication with a professional. Also, family caregivers need support in gaining confidence in their ability to cope and in managing the patient behaviors, and should not be ignored by professionals. Furthermore, due to differences in healthcare systems and culture variation, caregivers in Saudi Arabia might have different experiences. More qualitative studies of Saudi caregiver experiences with persons with SMI are warranted to gain further understanding of family caregiving experiences and to develop culturally appropriate intervention studies in Saudi Arabia.

CONCLUSION

This systematic review of the studies was conducted to synthesize the recent evidence about family caregivers' experiences of caring for patients with SMI. The review included qualitative and quantitative studies and found most were conducted on caregivers for schizophrenia, bipolar, and major depressive disorders. Despite that family caregivers of patients with SMI have moderate to severe levels of burden, the review found that there was an impact on the caregiver's health, psychological well-being, and coping skills. Many family caregivers do not report symptoms or seek mental health-specific services for help regarding their needs. Therefore, a psychiatric mental health nurse should conduct a comprehensive psychiatric evaluation of family caregivers on a regular basis. The psychoeducational and nursing interventions for caregivers based on the needs of caregivers are important.

On the other hand, the review found a few intervention studies that could uplift these burdens and improve the coping skills of caregivers. Furthermore, more experimental and qualitative studies with different sample groups in non-Western countries should be considered in the future. Further research is required to apprehend social and professional support in this context. Planning and implementing early psychosis support programs as well as long-term interventional programs such as those commonly implemented in Western countries may also provide important contributions to caregivers. The mental healthcare system must plan comprehensive interventions to meet caregiver needs. It is necessary to develop approaches that improve knowledge about mental health and mental disorders and that support best practice interventions. These would decrease not only the burden on caregivers but also improve their quality of life.

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