

A SYSTEMATIC REVIEW OF FAMILY CAREGIVERS' BURDEN HAVING PARENT LIVING WITH MENTAL ILLNESS

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ABSTRACT

Background: Family caregivers play a crucial role in providing care and support for people with mental health conditions, such as schizophrenia. The purpose of this study was to integrate and summarize the current studies of family caregivers' burden having parents living with mental illness. **Method:** This systematic review followed Cochrane Collaboration and PRISMA guidelines. Three databases were searched using relevant keywords relating to parents, mental illness, burden, and family members. Three Databases included SCOPUS, Science Direct, and PubMed. The expanded version of Critical Appraisal Skills Program was used to assess the article quality. Thematic synthesis was conducted on the included papers. **Result:** Fifteen papers were identified. Most of Family caregivers of parents with mental illness experiences medium to high burden. The study identified 10 sub-themes associated with burden to substitute care. These themes were divided into five themes: Caregiving burden, emotional burden, social alienation, school/work performance difficulties, and economic burden. **Conclusion:** This review found that additional research is necessary to understand the family caregiver of parent with mental illness experience and how healthcare teams can support them. Further, the findings may help to inform health care policymakers to shift of treatment focus from the patient to the entire household that support family caregivers.

Keyword: Children; Family burden; Family caregiver; Mental disorder

INTRODUCTION

Mental disorders have become a global problem. Data showed that 970 million people around the world struggle with some mental illness or drug abuse and the prevalence of all mental disorders increased by 50% worldwide from 416 million to 615 million between 1990 and 2013 (Hopechest, 2022). Along with the increasing prevalence of psychiatric

diseases, the care for psychiatric patients who are treated at home compared to getting treatment at the hospital is also higher, which can inadvertently increase the burden on caregivers for these psychiatric patients.

Mental disorders in individuals do not only affect sufferers but also affect those who care for them. Care for people with mental disorders at home is carried out



by informal caregivers which are provided by unpaid non-professional caregivers, most commonly family members (Ignatova et al., 2019). The family caregivers are spouse, children, family members, friends, or relatives of the sick, disabled, and dependent individuals who are not paid for providing care (Hejazi et al., 2021).

Family caregivers play a crucial role in providing care and support for people with mental illness. Caring for an individual with disability is burdensome and stressful to family members (Settineri et al., 2014). Caregiving burden is defined as the stress that derives from caring for others, while caregiver burden is the sensation of emotional or physical tension felt by caregivers. Caregiver burden is defined as a negative reaction to the impact of providing care on the caregiver's social, occupational, and personal roles (Fu et al., 2021). Caregiver burden can be defined as "the level of multifaceted strain perceived by the caregiver from caring for a family member and/or loved one over time (Liu et al., 2020). Caregiver burden includes both subjective and objective aspects (Liu et al., 2020).

Differences in position in a family produce different levels of burden, as previous research has shown that adult children experience a heavier burden in caring for family members with mental

disorders than couples (Chappell et al., 2014). This condition suggests that different types of informal caregivers need to be investigated separately to better characterize the differences that exist in their needs and the challenges they face when caring for family members with mental illness.

Caregivers most disadvantaged are those who indicate as a reason of care the sense of duty rather than the affection. Finally, the sons and daughters, differently from the parents, showed a greater burden of required time and a lower quality of life. The purpose of this study was to integrate and summarize the current studies of family caregivers' burden having parents living with mental illness.

METHOD

Study selection

This systematic review followed Cochrane Collaboration and PRISMA guidelines. Three databases were searched using relevant keywords relating to parents, mental illness, burden, and family members. Three Databases included SCOPUS, Science Direct, and, PubMed. Databases were searched from inception 2013 to 31 March 2023. Both qualitative and quantitative studies were eligible, so no study design filters were applied during the searches.

Table 1. Search terms and strategy used in SCOPUS, Science Direct, and, PubMed

#1	mental illness OR mental disorder OR mental issues OR schizophrenia OR psychiatric disorder OR psych* problem OR bipolar disorder OR psychiatric illness OR depression OR anxiety OR psychotic disorder OR behavior disorder
#2	burden* OR caregiver burden* OR burnout OR exhaustion OR strain OR overload* OR frustrate* OR stress
#3	caregiver* OR family caregiver OR carer*

Terminology and definitions

For the purposes of this review, caregiver burden included objective and subjective burden. The subjective burden refers to the personal perception and personal evaluation of the extent of caregiving burden arising from caring for a

frail or disabled relative can lead to emotional, mental, and physical health problems for caregivers (Fu et al., 2021; Raj et al., 2016). Subjective burden describes the psychological reactions which caregivers experience e.g., a feeling of loss, sadness, anxiety, and embarrassment in



social situations, the stress of coping with disturbing behaviors, and the frustration caused by changing relationships (Raj et al., 2016). The objective burden of caregiving assesses the quantitative aspects that involve tangible currencies (eg, hours of care provided or tasks performed) and finances devoted to care (Fekete et al., 2017; Flyckt et al., 2015).

Eligibility criteria

The Inclusion criteria for this review included qualitative or quantitative data studies on the experiences of family caregivers to parents with mental illness. Articles were included if they reported data on caregiver burden, as defined above. Studies that report data collected from family caregiver are eligible to this review. Exclusion criteria included: studies not specific to mental disorder; studies discussing family caregiver experience indirectly (for example, data collected from patients or health professionals); studies that contained only data from a second-order analysis. Studies reporting interventions in caregivers were not eligible, as experiences and outcomes may be impacted by the intervention. Articles that were in a language other than English, case reports, editorials, opinion articles and review articles and conference abstracts were also excluded.

Quality appraisal

Quality appraisal was undertaken independently by two authors (RD and RE). Third author (AY) were reviewed when there are any disagreements. Qualitative studies were appraised using the Critical Appraisal Skill Program (CASP) Qualitative Checklist (Critical Appraisal Skills Programme, 2022). The CASP Qualitative Checklist contains 10 questions based on three broader questions: ‘are the

results of the study valid?’, ‘what are the results?’ and ‘will the results help locally?’. Quantitative studies were assessed using the Methodological Index of Non-randomized Studies (MINORS) includes eight items for assessment of non-comparative studies (i.e. studies which do not include a control or comparator population) and twelve items for comparative studies.

Data extraction and synthesis

Data were extracted by two authors (RD and RF). The extracted data included study aim, study design, data collection method(s), caregiver age and gender, disease characteristics and data on caregiver experience associated with caregiver burden. RD and AY conducted the data synthesis. The aim of this study is to assess caregiver burden. as such, these key areas formed our themes, using the definitions above, and data was coded using deductive thematic analysis. This analysis has enabled us to provide a summary of the current research available on family caregiver burden in parents with mental illness.

RESULT and DISCUSSION

Search results

The screening process was detailed by A PRISMA flowchart shown in Fig. 1. The systematic search of three databases returned 2948 citations. Full texts of 48 citations were reviewed after removing duplicates and screening the remainder of articles by title and abstract. Of these, 33 full texts were excluded. Fifteen studies (six qualitative study, seven quantitative study and two mixed-method study) were included in this review.

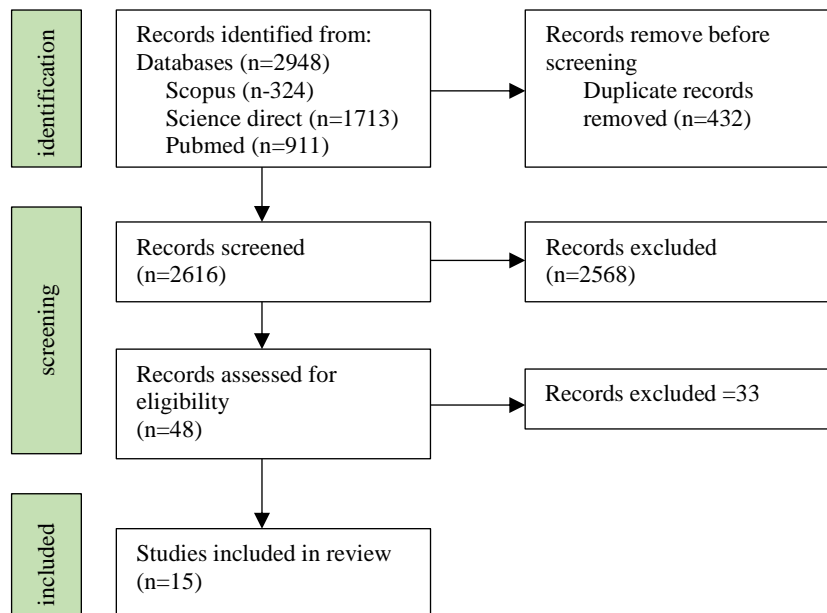


Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram of the literature screening process

Descriptions of the studies

The fifteen studies were published between 2013 and 2022 (Table 1). A total of 456 and 3013 family caregivers were included in the qualitative and quantitative studies respectively. The studies reviewed were conducted in develop country namely 8 countries: Canada (Herbert et al., 2013; Law et al., 2023), Italy (Roncone et al., 2023), Germany (Bauer et al., 2015; Kettemann et al., 2020; Theurer et al., 2019), Finland (Juntunen et al., 2018), Japan (Kageyama et al., 2021), Swedish (Widemalm & Hjärthag, 2015), United States (Bacharz & Goodmon, 2017), and Denmark (Dam et al., 2018). Four studies were conducted in developing countries namely: Iran (Rahmani et al., 2022), Cambodia (Phoeun et al., 2022), Taiwan (Hsiao & Tsai, 2015), and Indonesia (Buanasari et al., 2018).

Family Caregiver Burden Characteristics

Family caregiver of parent with mental illness were varied from school age, adolescent and adult children. The range of age was 4-49 years old totally 1,366.

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Children of parents suffering from bipolar or depressive disorder show high levels of burden (Bauer et al., 2015) and reported more burdensome aspects when they were either younger than 11 or older than 20 years old at the onset of their parent's disorder (Bauer et al., 2015). Highly involved caregivers reported less psychological distress than less involved caregivers (Bacharz & Goodmon, 2017).

Family caregiver of parent with mental illness lacked clear understanding of the legal definition and limitation of being a caregiver, and carried out the role intuitively as an extension of their being a caretaker and advocate. Many, though dedicated to their role, often expressed frustration with the lack of authority (Law et al., 2023)

Family Caregivers Burden Measurement

The caregiver burden measurement used: The family caregiver burden was measured using the version of the Family Problem Questionnaire (FPQ) (Roncone et al., 2023), economic burden (Roncone et al., 2023), The 9-item Patient Health



Questionnaire (PHQ-9; The 7-item Generalized Anxiety Disorder (GAD-7), The 21-item Depression, Anxiety, and Stress Scale (DASS-21) (Phoeun et al., 2022), Child Behavior Checklist (CBCL/4–18) (Kettemann et al., 2020), the COPE Index (Juntunen et al., 2018), The 18-item Caregiver Burden Scale-Brief (CBS-B) (Hsiao & Tsai, 2015), The Chinese version of the 10-item Family Stressors Index and the 10-item Family Strains Index, and The Chinese version of the 20-item Family Hardiness Index (FHI) (Hsiao & Tsai, 2015), the 10-item K10 Psychological Distress Scale (Bacharz & Goodmon, 2017).

Family Caregiver burden

Caregiving burden

The caregiving burden of children of parent with mental illness in areas such as taking responsibilities (Herbert et al., 2013). A study describe that children were acting as surrogate parents in took care of chores in the home, went shopping and helped with practical matters, and take care of younger siblings (Dam et al., 2018). Children also help to take care parent for their disease: helping their parents to get up in the morning, ensuring that they took their pills (Dam et al., 2018). They spend most of their time to take care of their parents with mental illness. The children had to put aside their own life, especially when the parents had bad days. Then, it happened that they stayed home from school to take care of the family. Also, already in early life, they were fearful of the effect of the mental illness on their parent and on family life (Dam et al., 2018).

There are several different research results regarding gender and the caregiving burden. A study found that the female adult child caregivers had more the negative impact of caregiving than the caregiver mothers (Juntunen et al., 2018). Daughters are more had higher acceptance of the caregiving situation than sons (Theurer et al., 2019). Other study found that there was

no significant differences between gender, role, and location (Roncone et al., 2023).

Emotional burden

Children of parent with mental illness experience emotional burden (Bauer et al., 2015) such as: feeling sorry and guilt (Dam et al., 2018; Rahmani et al., 2022) for their sick and tired parent, pain (Roncone et al., 2023), feel loneliness (Dam et al., 2018; Herbert et al., 2013), ongoing worries receiver (Phoeun et al., 2022; Rahmani et al., 2022), somatic complaints (Kettemann et al., 2020), having fearfulness and lack of sense of peace and happiness (Herbert et al., 2013). Children of parent with mental illness had a clinically relevant fearful-avoidant attachment style (Kettemann et al., 2020)

Daughters scoring substantially higher across all scale scores than son for depression (Hsiao & Tsai, 2015; Phoeun et al., 2022). a relatively low subjective burden in the caregiver sample, with a statistically significant higher burden for women than men (Roncone et al., 2023). However, a few of children of parent with mental illness reported having positive experiences such as becoming more independent, developed positive relationships in the process of taking and giving help which made them more selfless (Herbert et al., 2013).

Social alienation

Children of parent with mental illness experiencing some problems in social life such as fear of discrimination, prejudice and stigma (Rahmani et al., 2022), lacking close relationships (Dam et al., 2018), and had negative experiences while going out with parents or guests visiting them (Herbert et al., 2013). They also feelings of embarrassment and shame (Rahmani et al., 2022), feelings of helplessness in relation to health care (Widemalm & Hjärthag, 2015), and being ignored, bullied and laughed (Dam et al., 2018). Children of parent with mental



illness spent less time with their friends, had no leisure time (Widemalm & Hjärthag, 2015)

School/work performance difficulties

Children of parent with mental illness could not concentrate in school, and their grades dropped (Widemalm & Hjärthag, 2015). Their parents did not visit the school or talk to teachers, being bullied, forgetfulness, absenteeism, arriving late for school, and academic deterioration (Kageyama et al., 2021). Children feel lack of support and guidance in studies and emotional support from their parents (Herbert et al., 2013) and aware of teachers' prejudice, discriminatory behavior, and lack of consideration for privacy. and had an inadequate consultation environment or were unprepared to consult (Kageyama et al., 2021) during the school.

Economic burden

Children of parent with mental illness experience burden because of direct costs (professional, alternative medicine, drugs, and all non-reimbursable expenses) which range for professionals (psychiatrists, neurologists, psychologists, nurses) and other services (Roncone et al., 2023). The majority of children of parent with mental illness experienced severe financial issues (Phoeun et al., 2022)

CONCLUSIONS

This systematic review sought to identify reported burden experiences of children when a parent had mental illness. Majority of children reported spend most of their time to take care of their parents with mental illness and had to put aside their own life, though a few others experienced positive experiences such as becoming more independent and developed positive relationships. Children were emotionally impacted by family disruption and their parent behavior when had bad days. Children experience lack of support on their study and had academic deterioration, some

problems in social life and also financial problems.

Children caregivers who had role as primary caregiver or secondary caregiver tend to place their caregiving role as a higher priority than other life goals. Caregivers tend to place the needs of others before their own and need to be educated about the importance of preventive self-care (Champlain, 2012). Although many studies illustrate that caring for parents with mental illness has reduced children's time in activities and also increases children's burdens, there are two studies which illustrate that children have positive experiences while caring for their parents.

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Table 2. Study characteristics of eligible studies

Title (author, year)	Method	Result
“Everyone means well but the one person who’s really going to go to bat” - experiences and perspectives of substitute decision makers in caring for their loved ones with serious mental illness (Law et al., 2023)	D: qualitative research S: 13 interviews with 14 family member SDMs (with one joint parent interview). V: <i>experiences and perspectives from acting as an SDM for people with serious mental illness</i> I: interview guidance A: thematic analysis	1) Varied subjective understanding of the responsibility and authority of the SDM role; 2) Varied role demands and impact on SDMs' lives; 3) Challenges in dealing with the mental health system; 4) Leveraging decision making status to promote patient care; and 5) SDM role impact on family relationships.
Family functioning and personal growth in Italian caregivers living with a family member affected by schizophrenia: Results of an add-on study of the Italian network for research on psychoses (Roncone et al., 2023)	D: add-on study S: 136 caregivers V: socio-demographic data; Family functioning; Burden of care I: Family Problem Questionnaire (FPQ) A: Chi-squared test and <i>t</i> -test	low objective burden in the sample of caregivers. No statistically significant differences were found based on gender, role, and location. Subjective burden: relatively low subjective burden with a statistically significant higher burden for women than men
Caregiver or care receiver: Adolescents' experience of caregiving to a parent with severe mental illness: A qualitative study (Rahmani et al., 2022)	D: A qualitative research S: 18 caregiving adolescents V: experiences of living with and providing care to a parent with a severe mental illness I: interview guideline A: thematic analysis	(1) emotional exhaustion with associated subthemes of ‘ongoing worries’, ‘fear of loneliness’, ‘feeling of shame and guilt’ and ‘fear of discrimination and stigma’; (2) being trapped in a difficult situation with subthemes of ‘living a compromised life’, ‘alienating from peers’ and ‘caregiver rather than care receiver; and (3) adapting to the situation with subthemes of developing new skills and growing accountability
‘I feel hopeless’: Exploring the psychosocial impacts of caring for mentally ill relatives in Cambodia (Phoeun et al., 2022)	D: a convergent mixed-methods study design S: The FGDs included 37 participants (6–9 per group), and 115 participants provided quantitative survey data (20 children and age 18-19=16) V: qualitative= problems impacting caregivers of people with serious mental illness; Demographic data; I: A semi-structured FGD guide. The 9-item Patient Health Questionnaire (PHQ-9); The 7-item Generalized Anxiety Disorder (GAD-7); e 21-item Depression, Anxiety, and Stress Scale (DASS-21) A: multiple linear regression models.	Financial burden: her lost their job or cannot work because their caregiving and help-seeking responsibilities are too time-consuming. encompassing a range of physical, somatic, psychological, and emotional symptoms Burden of distress among relative caregivers
Burden of Children of Patients with Mental Illness-A High Risk Population that Needs Selective and Indicated Prevention? (Kettemann et al., 2020)	D: cross sectional S: 399 children 4-18 years V: Child Behavior I: Child Behavior Checklist (CBCL) A: SPSS	Children of mentally ill parents showed significantly more behavioral problems than children of healthy parents. behavioral problems were similar with respect to “social problems” (4–11 year-old boys, 12–18 year-old girls) and “somatic complaints” (12–18 year-old boys and girls)
Perceived burden among spouse, adult child, and parent caregivers (Juntunen et al., 2018)	D: cross-sectional study S: 2 388 caregivers V: Caregiver burden I: COPE Index	No significant differences were observed between daughter and son caregivers. significant factors of burden were being bothered by depressive symptoms, poor perceived health, care recipient’s low level of



Title (author, year)	Method	Result
	A:t-test; Mann-Whitney	cognitive function, and care recipient's physical immobility. High quality of support was associated with lower caregiver burden
Growing up with a parent having schizophrenia: Experiences and resilience in the offsprings (Herbert et al., 2013)	D: exploratory study S: 45 offsprings of parents with diagnosis of schizophrenia according to ICD-10 V: Resilience I: A semi-structured interview; Connor–Davidson Resilience Scale (CD-RISC) A: Frequency distribution, Mean and standard deviation	they had negative experiences in social aspects of life such as while going out with parents or guests visiting them and difficulties in emotional aspects such as having fearfulness, loneliness, and lack of sense of peace and happiness. Burden in areas such as taking responsibilities and financial and emotional aspects was reported by 66% of them. However, a few of them (2%) reported having positive experiences.
Previous experiences of Japanese children with parents who have a mental illness, and their consultation situation at school: A survey of grown-up children (Kageyama et al., 2021)	D: web-based questionnaire survey S: 120 grown-up children V: experience of grown-up children with parents suffering from mental illness during their elementary, junior high, and high school years, I: survey A: simple tabulation	the respondents provided emotional care, did household chores, most recognized adult fights, and experienced attacks by parents. Signs that others could have noticed included the fact that parents did not visit the school or talk to teachers, being bullied, forgetfulness, absenteeism, arriving late for school, and academic deterioration
The forum as a friend: parental mental illness and communication on open Internet forums (Widemalm & Hjärthag, 2015)	D: survey S: 35 selected forum threads that, in all, contained 301 comments and amounted to 166 pages of text for analysis (13–49 year) V: communication content in forum I:- A: A thematic analysis	a pressure directly related to their parents' illness: his pressure led to different types of stress reactions that affected many areas of their everyday lives, such as education, social networking, responsibilities, and their health. The forum writers often ventilated both the frustration they experienced in regard to the care provided and their frustration with the lack of care that they thought should have been provided for their parent. Many times, they had fought hard for their parent to receive adequate health care, and they often felt powerless when they could not control the situation
Experiences of adults who as children lived with a parent experiencing mental illness in a small-scale society : A Qualitative study (Dam et al., 2018)	D: a qualitative semistructured interviewstudy S: Eleven participants, eight women and three men, aged 18 till 49 years, were recruited. V: experiences I: An interview guide b A: manifest and latent content analysis	hese children were acting as surrogate parents.They took care of chores in the home, went shopping and helpedwith practical matters. Those who had younger siblings had to takecare of them too. Taboo as barrier refers to memories that many of the adult childrenrecalled, such as lack of openness in the family, at school and in the society at large regarding their parent's mental illness.
Factors of caregiver burden and family functioning among Taiwanese family caregivers living with schizophrenia (Hsiao & Tsai, 2015)	D: A cross-sectional descriptive study S: 137 primary family caregivers V: caregiver burden and family functioning I: Chinese versions of the Family Stressors Index, Family Strains Index, 13-item Sense of Coherence Scale, 18-item Caregiver Burden Scale, Family Hardiness Index and Family Adaptability, Partnership, Growth, Affection, and Resolve Index	Female caregivers, additional dependent relatives, increased family demands and decreased sense of coherence significantly increased caregiver burden, whereas siblings as caregivers reported lower degrees of burden than parental caregivers.



Title (author, year)	Method	Result
	A: descriptive statistics, Pearson's product-moment correlation coefficients, t-test, one-way analysis of variance and a stepwise multiple linear regression	
Care of parents with dementia: comparison of caregiving sons and daughters (Theurer et al., 2019)	D: survey S: 322 caregiving relatives V: style of caregiving, the feeling of stress and burden and the utilization of support offers. I:- A: t-tests, Mann-Whitney tests and χ^2 -tests.	Daughters scored on average higher than sons only with respect to the acceptance of the caregiving situation. Overall caregiving daughters and sons did not differ with respect to caregiving experiences as strongly as previously assumed
Burden, reward, and coping of adult offspring of patients with depression and bipolar disorder (Bauer et al., 2015)	D: qualitative study S: 30 adult children V: predictors of burden I: Freiburg Questionnaire of Coping with Disease (<i>Freiburger Fragebogen zur Krankheitsverarbeitung, FKV</i>) A: Regression analysis	Predominately, adult children of parents suffering from bipolar or depressive disorder show high levels of burden and are in urgent need of professional support. Emotional burden (reported by 100%), burden due to impaired family life (90%), burden due to the patient's symptoms (76.7%), burden due to dissatisfaction with the patient's therapy/professional staff (73.3%), burden due to impaired free-time activities (63.3%), burden due to impaired functioning in school/job (46.7%), burden due to own health problems (43.3%), and burden due to problems in the child's relationship/own family (30.0%)
The caregiver's burden: Psychological distress in the younger adult caregiver adult caregiver (Bacharz & Goodmon, 2017)	D: Cross-sectional study S: 44 young adult children V: financial support, social support, symptoms of distress I: The 12-item Multidimensional Scale of Perceived Social Support, the 10-item K10 Psychological Distress Scale A: univariate ANOVA	significantly higher distress scores than caregivers who were not financially supporting their loved one. no significant correlation between level of caregiving support and psychological distress or between financial distress and psychological distress.
The experience of adolescents having mentally ill parents with pasung (Buanasari et al., 2018)	D: Qualitative study S: 6 adolescences V: experience in caring for parent with pasung I: The interview guide A: Thematic analysis	economic burden felt by families is greater if it is associated with the decreased of occupational functions of mentally ill parents that hinder them to work and contribute to the fulfillment of the financial needs of the family