The role of family caregiving in the management of individuals with mental illnesses and the outcome of family-based interventions for mental illnesses in China: a scoping review

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Summary

The effects of China's rapid economic development and urbanisation on family caregivers' responsibilities for providing essential practical, social, and psychological support to family members with mental illnesses are unclear. This scoping review identified 176 relevant studies published from 1 January 2000 to 31 December 2023 in six English-language and three Chinese-language databases. Most studies focus on family caregiving for individuals with schizophrenia (63 studies), autism (40 studies), or dementia (39 studies). Family caregiving—subclassified as informational, concrete, or psychological—was beneficial both for patients and their family members, but providing support often necessitated substantial sacrifices by family caregivers, many of whom experience psychological distress and financial difficulties. The type and intensity of the support provided are influenced by the severity of the patient's symptoms, financial and other resources of the patient's family, community members' beliefs about mental illnesses, and the local availability of mental health and social welfare services. Results from intervention studies indicate that different methods of enhancing family caregiving improved outcomes for individuals with mental illnesses. However, the methodological quality of the intervention studies was poor, and most of the studies were conducted in inpatient settings, so the benefits of these family-based strategies remain uncertain. Rapid economic development and urbanisation in China are resulting in fundamental changes in the relative responsibilities of different stakeholders for providing social welfare services—individuals, families, communities, and governmental agencies. Understanding and enhancing the role that families play in the support of community members with mental illnesses will require improving the quality of research about this issue, expanding the range of mental health conditions considered, and, most importantly, developing a dynamic overarching theoretical framework that integrates the many factors influencing ongoing changes in the structure and functioning of Chinese families.

Keywords: Family caregiving; Mental illness; China; Scoping review

Introduction

Background

Mental illness is a global public health problem. The global age-standardized 12-month prevalence of mental illness was 12,262 per 100,000 in 2019[1]; the most prevalent mental illnesses were anxiety (3780/100,000) and depression (3440/100,000). The mortality caused by mental illness is relatively low, but the disability associated with mental illnesses is substantial.[2,3] The overall burden of mental illnesses—including that due to premature death and years lost due to disability—is assessed in terms of 'Disability Adjusted Life Years' (DALYs) lost, a measure used to compare the burden of all types of illnesses and injuries over time, by region and cohort. Based on this measure, mental illnesses were the thirteenth most important health condition globally in 1990 (1510 DALYs lost per 100,000 population); this increased to the seventh most important health condition in 2019 (1620 DALYs lost per 100,000 population). When limiting the analysis to disability due to health conditions (excluding premature death), mental illnesses were the second most important cause of 'Years Lived with Disability' (YLD) both in 1990 (10,048 YLD per 100,000 population) and 2019 (11,127 YLD per 100,000 population).[2] The estimated burden of mental illnesses in China in 2019 was somewhat lower than the global average—1427 DALYs lost per 100,000 population—but mental illnesses were the country's fifth most important health condition. Given its large

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population, China has the highest national number of individuals with mental illnesses and the greatest total health burden due to mental illnesses.[4] In 2017, there were an estimated 243 million individuals with mental illnesses in China and over 16 million with severe mental illnesses.[5]

Family caregiving has always played a significant role in managing individuals with mental illness, particularly children with mental illnesses and adults with serious mental illnesses that compromise their ability to make rational decisions about their own care. In countries that had previously institutionalised many individuals with chronic mental illnesses, the de-institutionalisation movement that started in the 1960s refocused attention on the central role of family members in the monitoring and management of community-dwelling individuals with severe mental illnesses.[6,7] Family caregiving addresses three primary needs of individuals with mental illness: informational support about help-seeking and medication usage, instrumental (tangible) support to address daily concerns, and emotional support to provide positive emotional nurturance.[8] The importance of family caregiving in managing individuals with mental illness has been reported in studies around the globe.[6,7,9–14] Family members act as gatekeepers, enabling earlier identification of mental illness symptoms and more immediate medical attention.[10] They also help individuals with mental illnesses manage their symptoms, improve their social functioning, and enhance the quality of their lives.[6,12,14] However, family caregiving is influenced by a wide range of sociocultural factors, factors that can change dramatically over time, particularly in rapidly developing low- and middle-income countries like China.[6,15–17] For example, the availability of essential public health services (particularly in rural communities),[14,18] community-level mental health literacy, and the stigmatisation of mental illnesses,[15] all directly affect the type and effectiveness of family support provided to individuals with mental illnesses.

Chinese society and its Confucian-based cultural values have traditionally considered extended patriarchal families the most important social unit.[19,20] In the Confucian worldview, individual self-identity, duty, and responsibility are constrained by the power dynamics of rigorously ordered family relationships: children obey parents, wives obey husbands, and younger siblings obey older siblings. Since the Zhou Dynasty (1046-771 BCE), the family has been the central social unit regulating all aspects of social participation, including economic, political, and daily life.[21] Unlike in Western cultures, relationships among individuals in China are maintained by social contracts primarily defined in terms of blood ties.[22,23] People linked by blood have similar economic prospects and a shared family-wide social status.[24] Given the centrality of the family unit in the culture, extended family members generally lived in the same locality and took responsibility for helping each other when necessary. Even as the increased mobility of the modern era has dispersed many extended families, the family remains primarily responsible for managing its sick members, including those with mental illness.[25–27] Largely based on Confucian ethical tenets, family members are identified within the family as the primary decision-makers who make most decisions for individuals with serious illnesses, such as help-seeking, career development, and marriage arrangements.[28,29]

In China, the intensity and type of stigma related to mental illness have changed as urban and—to a lesser extent—rural community members have been exposed to Western conceptions of mental illness, which started with the introduction of Western psychiatry at the end of the 19th century.[30] Earlier beliefs attributing mental illness to supernatural events or karma persisted into the 1990s, leading some family members to seek help from Chinese shamans for mentally ill parents, siblings, or children rather than seeking help from the formal health care system. Many families prohibited or restricted family members with severe mental illnesses from participating in social life; their main goal was to avoid the shame and discrimination that would affect the entire family, such as limiting the marriage prospects of unmarried family members.[28,31] Due to the limited mental health literacy of family members, individuals with severe mental illnesses and disruptive behaviours were sometimes kept in isolation, locked in cages, or (more recently) sent to long-term psychiatric hospitals.[32,33]

In recent decades, rapid urbanisation and economic development have dramatically changed the structure, values, and resources available to Chinese families, particularly those living in urban centres. This, in turn, has transformed the types of support families provide to their ill members.[34,35] Gradual improvements in mental health literacy have decreased the stigmatisation of the mentally ill and their family members.[36,37] An "unlock (the mentally ill) movement" in the 2000s re-integrated many chronically mentally ill individuals into their families and communities. The government's re-branding of mental illness as a public health problem and substantial investments in community-based mental health services greatly expanded access to affordable services.[38,39] China's 2013 National Mental Health Law highlighted the centrality of family care in the management of individuals with mental illnesses.

Urbanisation and economic development have also made it more difficult for families to support family members with severe mental illnesses. The nuclear family has become the main family structure, replacing the extended family network,[40] so there is a smaller pool of potential caregivers when needed. With the gradual relaxation of the national household ('hukou') registration system (which required individuals to live and work

in their location of birth) and the consequent massive rural-to-urban migration of labour, elderly parents and other vulnerable groups, including young children and persons with severe physical or mental illnesses, have been left behind in rural areas.[41–43] In urban communities, many young adults move from small- or medium-sized cities to larger cities or overseas for studies or work, resulting in long separations from their parents and an inability to help each other when a health crisis arises.[44] These changes have significantly decreased the accessibility of family support when a family member develops a mental illness.

These dynamic changes in family structure and function and the availability of mental health services are not unique to China, but they may be happening more quickly in China than elsewhere. Ongoing monitoring of these changes will be needed to develop programs that most effectively engage families caring for mentally ill individuals in ways that maximise positive outcomes both for patients and their family caregivers. Previous studies of family support for mentally ill individuals in mainland China have been limited in focus,[45–47] and a recent review of family-based interventions in Chinese families primarily considered Chinese individuals living outside of mainland China.[48] A comprehensive scoping review of family care for mentally ill individuals in mainland China is needed to clarify the current status, provide new research directions, and act as a baseline against which future changes can be compared.

Objectives

This scoping review will identify all relevant research in English-language and Chinese-language databases to provide a comprehensive overview of available information about the content, outcomes, and moderating factors of family caregiving for individuals with any type of mental illness in mainland China. It will also assess the methodological quality of the available studies and identify any critical gaps in the literature about this important issue.

Methods

Protocol registration

We conducted a systematic search to identify literature on family support for managing individuals with mental illness in mainland China. Our scoping review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) guidelines.[49] The protocol is registered with the Open Science Framework (DOI: 10.17605/OSF.IO/H4CJX).

Selection criteria

Included publications met the following criteria: 1) empirical study; 2) study subjects were persons with any type of mental illness or their family members; 3) the study described or assessed any type of support provided by family members to persons with mental illnesses; 4) study subjects were Chinese residents in mainland China; 5) the article was published in Chinese or English; and 6) the article was published between 1 January 2000 and 31 December 2023. There was no restriction on the design of the study. We excluded reports that 1) described caregiver burden or interventions aimed at reducing caregiver burden without considering the effect of caregiving on mentally ill family members; 2) described family therapy interventions for individuals with mental illnesses; 3) focused on mental health problems caused by or co-morbid with physical health problems; or 4) were only published as abstracts without any full-text articles.

Search strategy

We (MH, XL, YZ, ZC) searched six English electronic databases (PubMed, Embase, PsycINFO, Web of Science, the Cochrane Library, and Scopus) and three Chinese electronic databases (CNKI, CBM, and Wanfang). We used variants and combinations of search terms relating to family, mental illness, and China. We pilot-tested several sets of search terms to identify the most efficient method for locating relevant articles. Finally, we decided to use a broad search strategy that would require screening a large number of articles but would capture virtually all articles of interest. The final search strategies for each of the nine databases are provided in Supplementary Table S1. All databases were searched on 24 January 2024 for entries from 1 January 2000 to 31 December 2023. We also manually searched references of the included publications to identify relevant publications not captured by the electronic search strategies.

Selection of publications

We imported research results into the reference management software EndNote 20 and deleted duplicates. Two reviewers screened each record's title and abstract independently (XL, YZ, ZC, RL, CL). The same two reviewers then conducted full-text reviews of the selected papers separately. Discussions between the two reviewers resolved uncertainty regarding whether publications met the inclusion criteria. If there was disagreement about including a publication, a third senior reviewer (MH) made the final decision.

Data extraction

The data charting process was based on recommendations and guidelines from the Joanna Briggs Institute and related literature.[50,51] We (MH, XL, YZ, ZC, RL, CL) extracted and recorded data from six aspects of the included articles.

a) *characteristics of the study* (author, full citation, date of publication, study design, geographic region, study setting, and location);

b) *characteristics of participants receiving family support* (diagnostic group, diagnostic criteria, sample size, age, gender, duration of illness, and severity of disease);
c) *characteristics of family members providing support* (age, gender, kinship, co-residency, work, and financial status);
d) *types of support provided by the family members*;
e) *costs and benefits of family support*; and
f) *factors that influenced the type and level of family support*.

Two reviewers independently extracted data from each paper; discrepancies between reviewers about how to code specific items were resolved by group discussions among the entire review team.

Quality assessment

We adopted four instruments to evaluate the quality of the reports of included studies based on the study design. 1) The 37-item CONSORT—Consolidated Standards of Reporting Trails—was adopted for intervention studies such as randomised controlled trials (RCTs) and non-randomized controlled studies.[52] 2) The 34-item STROBE—The Strengthening the Reporting of Observational Studies in Epidemiology—was used to evaluate the quality of reports of descriptive studies such as cohort, case–control, and cross-sectional studies.[53] 3) The 32-item COREQ—Consolidated Criteria for Reporting Qualitative research—was used to evaluate the quality of reports of qualitative studies.[54] 4) The 17-item GRAMMS—Good Reporting of A Mixed Methods Study—was used to evaluate the quality of reports of mixed-methods studies.[55]

Following the method used in a previous scoping review, the quality of the reports of the four types of studies were classified as 'low', 'low-to-moderate', 'moderate-to-high', or 'high' based on the number of recommended items in the reporting guidelines that are provided in each report.[56] Details of the appraisal tools and criteria are provided in Supplementary Table S2. Two reviewers (YZ and XL) independently evaluated the quality of the studies' reports. Discrepancies between the two reviewers were resolved through discussion; if a consensus was not reached, a third senior reviewer (MH) made the final decision.

Most of the identified intervention studies assessed the effectiveness of family-based interventions for improving patient outcomes. To determine the robustness of the results of these studies, we evaluated the quality of evidence in the studies using the Grading of Recommendations, Assessment, Development and Evaluations (GRADE) criteria[57] and, based on these assessments, classified the quality of evidence of each study as 'very low', 'low', 'moderate' or 'high'. Details of the GRADE criteria are provided in Supplementary Table S3.

Findings

Search results

Fig. 1 shows the flowchart of the search results. In total, 228,051 records were identified in the electronic searches of English-language and Chinese-language databases. After removing duplicates and screening the abstracts and full-text articles, 171 eligible articles were identified. Five additional articles were identified among the 4637 references in these 171 eligible articles. Thus, 176 articles were included in the review, 49 published in English and 127 in Chinese.

Characteristics of publications included in this scoping review

The 176 publications included 79 descriptive studies and 97 intervention studies. The descriptive studies (including 60 qualitative studies,[58–80,27,81–116] and 19 quantitative studies [15 cross-sectional studies,[117–131] 3 cohort studies,[132–134] and 1 mixed method study[135]]) described the characteristics of family support provided to patients with mental illnesses in China. The intervention studies (including 59 RCTs,[136–159,160–194] 23 controlled trials,[195–217] and 15 pre-post studies[218–232]) assessed the effectiveness of family-based interventions for mental illnesses in China. As shown in Fig. 2, the number of reports about family-related issues has increased over time: among the 79 descriptive studies, 21 (26.6%) were published in the twelve years from 2000 to 2011, while 58 (73.4%) were published in the twelve years from 2012 to 2023; and among the 97 intervention studies, 26 (26.8%) were published from 2000 to 2011 while 71 (73.2%) were published from 2012 to 2023. As shown in Fig. 3, the types of patients considered in the 176 studies included individuals with schizophrenia (63 studies), autism (40 studies), dementia (39 studies), attention-deficit/hyperactivity disorder (4 studies), depression (2 studies), intellectual development disorder (2 studies), mild cognitive impairment (2 studies), and one study each about anxiety, obsessive-compulsive disorder, and bipolar disorder (14 studies include participants with unspecified 'mental illness' and 7 studies included participants with unspecified 'serious/severe mental illness'). The detailed characteristics of the 176 studies included in this scoping review are presented in Supplementary Table S4.

Quality of identified reports and of the evidence provided in intervention studies

The quality of the reports of all 176 identified studies is shown in the last column of Supplementary Table S4.

We used three different instruments to assess the quality of the reports of the 79 descriptive studies: COREQ, STROBE, and GRAMMS. Using COREQ to assess the quality of the reports of the 60 qualitative studies, 2 studies were classified as 'low quality',[79,113] 13 studies as 'low-to-moderate quality',[60,62,65,68,71,73,78,81,88,98,99,101,102]

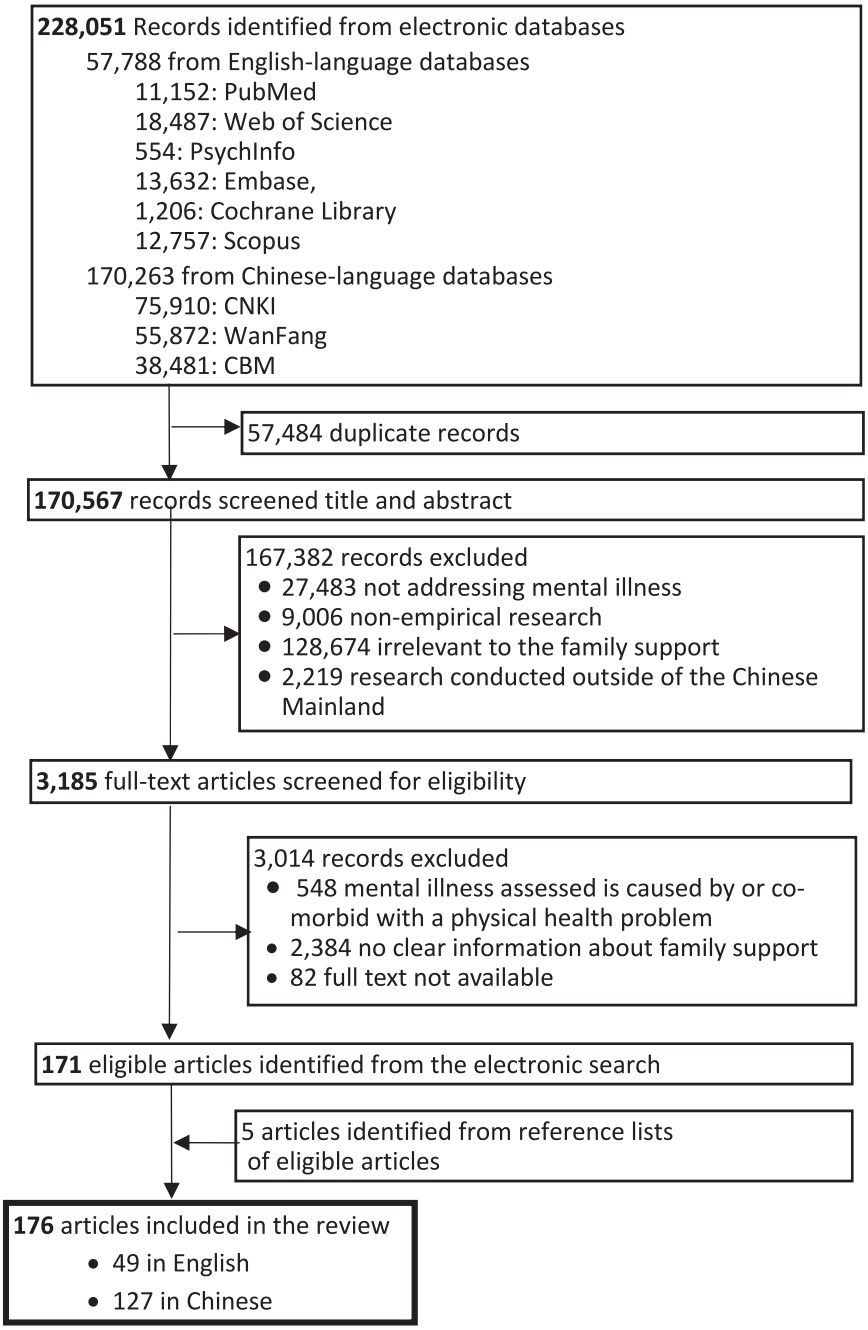

Fig. 1: **PRISMA Flowchart of identification of eligible articles**.

30 as 'moderate-to-high quality',[27,59,61,63,64,66,67,69,70,72,73,75,77,80,84–87,90,93,97,100,103,105–110,115] and 15 as 'high-quality'.[82,83,89,91,92,94–96,104,111,112,114,116] The quality of qualitative studies was most commonly downgraded due to failure to report the following study characteristics: 1) personal characteristics of the individuals who conducted the interview, such as gender and occupation, 2) presence at the interview (or not) of extraneous individuals, 3) whether transcripts of the interview were provided to participants for comment, 4) provision of feedback about the findings by the participants, and 5) description of contradictory elements and minor themes that emerged during the interview. Using STROBE to appraise the quality of the reports of 15 cross-sectional studies and 3 cohort studies, 1 was classified as 'low quality',[118] 6 as 'low-to-moderate quality',[117,119–122,132] 8 as 'moderate-to-high quality',[123,124,127–130,133,134] and 3 as

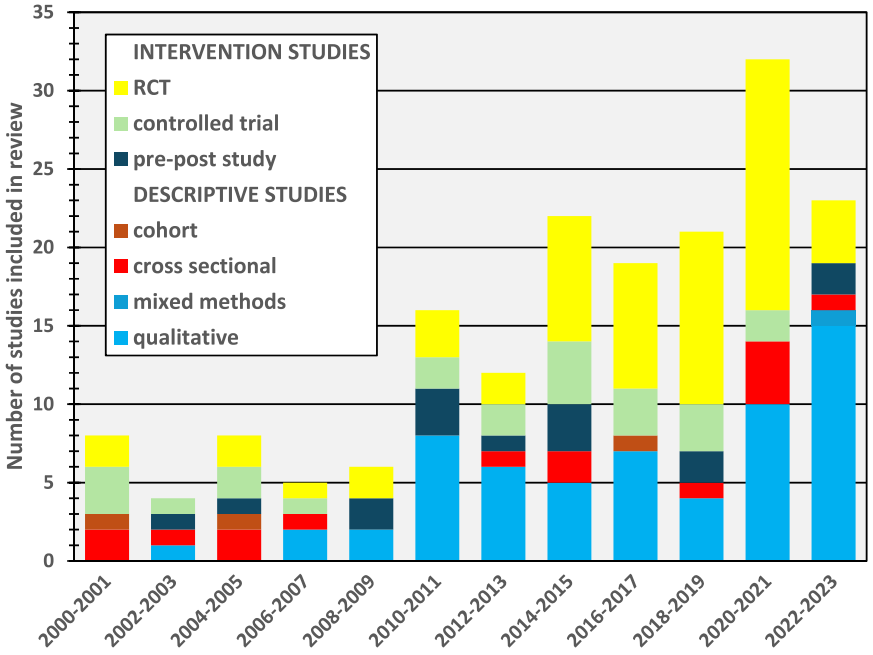

Fig. 2: **Number of different types of studies about family caregiving of mentally ill individuals in China: 2000–2023.**

'high-quality'.[125,126,131] The important information most commonly missing from these reports included 1) descriptions of the matching criteria or potential sources of bias, 2) study size estimates, 3) details of the statistical methods, 4) reasons for non-participation at different stages of the intervention, 5) a flow diagram about the status of participants throughout the study, and 6) sensitivity analyses. Using GRAMMS to assess the quality of the single mixed-methods study identified,[135] the quality of the report was classified as 'moderate to high'. The main shortcomings were the failure to describe 1) sampling methods, 2) how the integration of different methods occurred, and 3) the study's limitations.

The quality of the report of the 97 intervention studies was assessed based on the number of recommended items from the CONSORT checklist reported: 10 studies were 'low quality',[146,163,174,197,199,218,221,226,229,230] 75 'low-to-moderate quality',[136–139,142–145,147–149,151,153,155–162,164–172,175–185,187–196,198,200–205,207–212,214,217,219,220,223–225,227,228,231,232] and 12 'moderate-to-high quality'.[140,141,150,152,154,173,186,206,213,215,216,222]

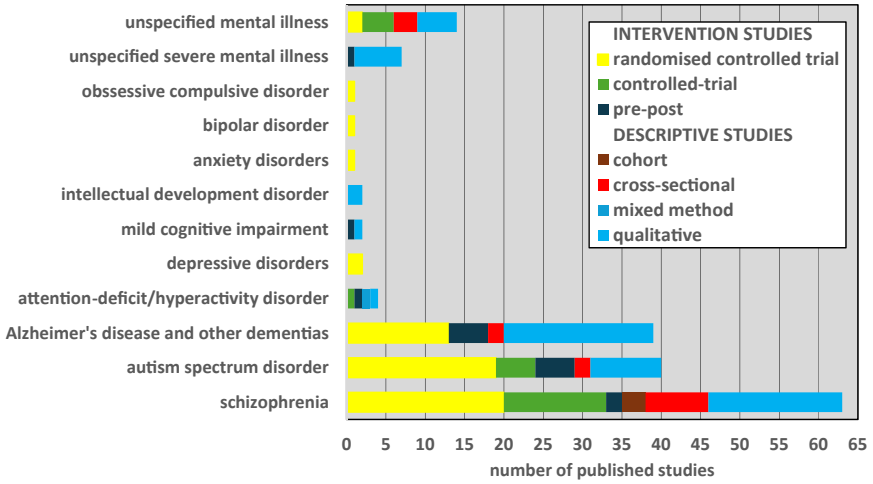

Fig. 3: **Number of different types of studies about family caregiving of individuals with mental disorders in China: 2000–2023.**

Important study characteristics not reported in more than 75% of the 97 studies included 1) the method of estimating sample size, 2) the method of randomising participants, and 3) the study's limitations.

Based on GRADE criteria, the quality of the evidence of the effectiveness of the intervention was rated as 'very low quality' for 96 of the 97 intervention studies and 'low quality' for one study.[186] None of the studies reported the mechanism for concealing group allocation. Only one study blinded the evaluation of the outcome.[186] Sixteen studies did not use validated outcome measures,[160,161,163,164,172,174,177,179,187,216–219,221,223,226] and 13 studies did not report the numbers of participants who completed the intervention.[139,142–144,146,163,175,180,190,208,212,214,220] Moreover, 41 of the 59 RCT intervention studies did not describe the method of randomisation.[136,138–149,152–159,161–167,173,174176,177,180,181,183,184,186–188,190,191,193] Details about the risk of bias in the reported evidence about the effectiveness of the intervention in the 97 intervention studies are provided in Supplementary Table S5.

Family support for persons with mental illnesses in China

Family support is defined as the social support provided by families. Classical social support theory divides social support into informational, instrumental, and emotional categories.[233] Kahn and Antonucci proposed a fourth category—appraisal support — focusing on how families enhance family members' self-affirmation.[234] In this analysis of family support for family members with mental illnesses, we classify family support into three categories: informational, concrete (including instrumental support), and psychological support (including both emotional and appraisal support).

The type of family member who becomes the primary caregiver for a family member with a mental illness was largely determined by the age of the ill individual. In almost all cases the providers were immediate family members of the ill individual: for children with autism, attention-deficit/hyperactivity disorder, or intellectual development disorder, parents were the primary family caregivers[60,63,88,103,135]; for adults with mental illness, parents and spouses were the primary family caregivers, while siblings played a complementary role[68,81,82,114]; and for older adults with dementia or mild cognitive impairment spouses and offspring were the primary family caregivers.[65,72,77,87]

Content of family support for individuals with mental illnesses in China

Among the 176 included studies, 79 described the content of family support for individuals with different types of mental illnesses (including 60 qualitative studies,[58–80,27,81–116] 15 cross-sectional studies,[117–131] 3 cohort studies,[132–134] and 1 mixed-method study[135]). Thirty-eight (48.1%) of these studies were conducted in community settings,[27,58,61–63,65,72,74,78,82–84,88,90,95,98,100,101,103,105–114,119,120,125–127,130,131,133,134] 19 (24.1%) in hospital inpatient settings,[60,67,68,70,71,79,85–87,89,91,116–118,121,122,124,129,132] 14 (17.7%) in hospital outpatient settings,[64,66,73,75–77,81,97,99,102,104,123,128,135] and 8 (10.1%) in both inpatient and outpatient hospital settings.[59,69,80,92–94,96,115] Twenty-eight studies focused on family support for individuals with schizophrenia,[58,62,67–70,75,81,86,89–92,96,102,104,110,118–121,124,126,127,129,132–134] 21 for older adults with dementia or mild cognitive impairment (MCI),[59,65,66,71–73,76–78,80,83,85,87,93,94,97,107–109,115,123,128] 13 for children with autism or attention-deficit/hyperactivity disorder (ADHD),[61,63,74,78,99,103,105,106,112,113,130,131,135] 2 for children with intellectual development disorder,[60,84] and 14 for individuals with unspecified mental illnesses.[27,64,79,82,95,98,100,101,111,114,116,117,122,125] The specific content of family support varies between the different patient groups and over the course of the illness due to 1) the different psychosocial limitations associated with different types of mental illnesses, 2) the trajectory of patient needs over the course of the illness, and 3) the types of internal and external resources available to family members trying to support the daily needs and long-term rehabilitation of their ill family member.

Informational support. Informational support refers to the provision of information to family members with mental illness. We include homeschooling and skills training by family caregivers in this category. Fifteen out of 79 studies reported informational support to individuals with mental disorders.[61,63,68,75,81,82,84,88,96,97,99,108,109,124,125] For children with autism, ADHD, or intellectual development disorder, informational supports mainly include skills training, such as sensory integration, self-care and socialisation, and homeschooling.[61,63,68,84,88,99] For individuals with schizophrenia or other severe mental illness, informational support focuses on providing them with knowledge about treatment or referral information.[75,81,82,96,124,125] For older adults with dementia, informational support focuses on memory training through the use of old photos and reminiscing about past experiences.[97,108,109]

Concrete support. Concrete support is the provision of material goods, services, or tangible aid. All 79 studies that provide information about the content of family support report the provision of concrete support.[27,58–8990–119120–135] We subcategorised this type of family support into 'medical-related support' and 'non-medical-related support'. Detecting the early signs of symptoms, accompanying the patient when seeking professional treatment, and managing and monitoring medication use were the three most commonly reported types of medical-related concrete support provided by family members across all types of mental illness.[58,59,61,62,64,68,70,71,73–75,79,81] For patients with schizophrenia or dementia living in the community, family members are often responsible for monitoring the

patient's symptoms.[68,75,95,125] For hospitalised patients with severe mental illnesses, family members accompany them to the hospital when needed and visit them while they are inpatients.[116] Some studies report that families also seek non-professional care (e.g., from shamans or faith healers) for people with schizophrenia or other severe mental illnesses.[62,119,125] Meeting patients' daily needs, providing financial support, and guaranteeing patients' safety were the three most commonly reported types of non-medical-related concrete support provided by family members across all types of mental illness.[98,100–103,106–108] Some family members also promote the social engagement of their ill family members.[27,58,61,64,77,84,97] For children with autism or ADHD, parents may apply for disability support from the government[106] or make special arrangements for their child to attend school,[61,99,105] including accompanying their child during in school.[88,103,113] In one study, parents of children with ADHD provided massage therapy (tuina, 推拿) to help alleviate their symptoms.[135] For young adults with severe mental illnesses, some parents actively help them find employment and marriage partners.[82] For older patients with dementia, some families hire external help to care for the patient[59,62,71,72]; this includes hiring a visiting (or live-in) caretaker or placing the elderly family member in a long-term care facility.

Psychological support. Psychological support includes caregivers' provision of empathy, love, trust, respect, and affirmation to the mentally ill family member. Among the 79 studies that reported the content of family support, 15 reported that families provided different types of psychological support to individuals with mental illnesses.[63,74,80,84,96,97,108,113,117,118,120,124,125,129,133] The psychological support family members provide to individuals with schizophrenia includes acceptance of the illness and encouragement.[96,120,134,198] Psychological support for children with autism or ADHD involves providing companionship for the child to reduce their loneliness.[103] The psychological support families provide to patients with dementia or MCI was the most wide-ranging: it included acceptance of the illness, companionship to reduce loneliness, respect for the individual, and encouragement.[73,80,97,108]

Outcomes of family support

Among the 79 studies that describe different types of family support for mentally ill individuals in China, 53 reported the outcome of family support, including 37 qualitative studies,[58–63,65–72,76,78,79,81,84,86,88,91,92,94,96,97,99–101,103,107,109,110,112–114,116] 12 cross-sectional studies,[117–123,125–127,129,131] 3 cohort studies,[132–134] and 1 mixed-method study.[135] These studies reported both positive and negative outcomes of providing family support for both the mentally ill individual and, in some cases, the family caregivers who provide the support.

Benefits for recipients. Eleven studies (including 5 cross-sectional studies, 3 cohort studies, and 3 qualitative studies) about individuals with schizophrenia,[58,91,110,118–121,129,132–134] 1 cross-sectional study about children with autism,[131] 1 mixed-method study about children with ADHD,[135] and 3 cross-sectional studies about unspecified mental illnesses[117,122,125] reported benefits to the recipients of family support. The outcomes of the quantitative studies were assessed using investigator-constructed questionnaires, medical records, and standardised scales, such as the General Self-Efficacy Scale (GSES) for individuals with schizophrenia.[129] The assessment of the outcomes of family support in qualitative studies relied on information gathered through interviews conducted with family members.[58,91,110] For community-dwelling individuals with schizophrenia or other severe mental illnesses, the most commonly reported benefits of the emotional support, economic support, and medication supervision provided by family members were a higher rate of treatment adherence and a lower relapse rate.[117–121,125,132–134] Family support for patients in inpatient settings (i.e., emotional support during hospital visits and family caregiving in open ward settings) resulted in shorter hospital stays and less frequent re-hospitalisations.[132] One study reported an association of family support with higher rates of survival and lower rates of homelessness.[134] For children with autism and ADHD, the reported benefits of family support included improved perception and behaviour.[131,135]

Negative impact on recipients. Three studies described the adverse effects of inappropriate activities of family caregivers on their mentally ill family members.[62,101,122] A cross-sectional study reported that improper (high-intensity) family visits to hospitalised individuals with mental illness can worsen their condition, increase negative emotions, and lead to adverse events, such as treatment refusal, elopement, and suicide.[122] Due to the stigma associated with mental illness, some family members refuse to seek professional treatment for individuals with schizophrenia, instead opting for shamanic exorcism, which can have detrimental effects.[62] Furthermore, some family caregivers give their ill family members strong medications obtained from non-professional sources or restrict their use of prescribed medications, resulting in a worsening of symptoms.[101]

Benefits for family caregivers. Nine studies reported benefits to the family members who supported their mentally ill relative.[61,67,84,94,97,100,109,126,127] Two quantitative studies assessed the effects on family caregivers of providing support to mentally ill family members using the Family APGAR and the Caregiving Rewarding Feelings (CRF) scale,[126,127] and seven qualitative studies conducted structured interviews with family members

to assess the effects on family caregivers.[61,67,84,94,97,100,109] When non-ill family members provided support to family members with mental illnesses, relationships within the family improved, and the emotional ties with the ill family member became closer.[61,84,94,97] Providing support to family members with mental illnesses also improved family caregivers' understanding of their ill family members, increased their feelings of being responsible for the welfare of their ill family members, and strengthened their love for their disabled family members.[94,109]

Caregiver burden. Supporting mentally ill family members also incurred costs. Thirty-eight studies reported costs to caregivers who supported their mentally ill family members.[59–63,65–72,76–79,81,84,86,88,92,94,96,97,99,101,103,107,109,112–114,116,122,123,126,127] The methods used to assess these costs included interviews with family members in qualitative studies,[59–63] and administering the Zarit Burden Interview (ZBI) in cross-sectional studies.[126,127] The identified costs include psychological distress (negative emotions, stigma, and worry about the future),[84,86,88] financial burden,[68–72] social impairment,[63,68,69] conflicts between the demands of caregiving and maintaining other parts of their life,[68,69,72] physical exhaustion,[59,62,65] interpersonal strain among family members,[81,86] and difficulties sustaining regular employment.[61,92,113]

Factors that influence family caregiving provided to individuals with mental illnesses

Among the 79 studies that describe different types of family caregiving, 18 reported factors influencing the provision of family caregiving to family members with mental illnesses.[62–66,74,76–78,82–85,91,93,109,119,128] We classified these moderating factors into four types: recipient-related factors, provider-related factors, health service-related factors, and sociocultural factors.

Recipient-related factors. The recipient's age and the type and severity of mental illness were related to the kinds of family caregiving provided. Help in accessing treatment and rehabilitation services, daily care, and emotional support were provided regardless of the recipient's age.[63,76,78,84] Homeschooling, arrangement for schooling, and accompanying the patient while at school was an age-specific type of support families provided to children with autism or ADHD.[61,84] Arranging a marriage was a type of support families primarily provided to young adults with serious mental illnesses.[82] Concrete support related to the practical problems of daily life was the primary type of support families provided to individuals with schizophrenia or dementia,[77,126] while family caregiving for children with autism focused on skills training aimed at promoting the child's psychosocial development.[63,97] Among family members of individuals suffering from the same type of mental illness, the degree to which the individuals' symptoms affected the psychosocial functioning of the individual (and of the family) determined the type and intensity of family caregiving provided for daily care and the urgency (or lack of urgency) caregivers felt about the need to seek help from the health care system.[69,82]

Provider-related factors. Family members' mental health literacy, health status, financial status, and working status significantly affected their ability and willingness to care for a mentally ill family member. Limited mental health literacy among family members was associated with decreased symptom detection, help-seeking, and adherence to professionally recommended treatments.[64,74,78,82,83] Family caregivers' poor health and poverty were also associated with limited family caregiving for mentally ill individuals.[76,78,82,97,128] If all potential adult co-resident family caregivers are employed in occupations that take up most of their time and energy, the ability of family caregivers to simultaneously provide close supervision and support to their mentally ill family member is limited.[91]

Health service-related factors. Access to mental health services affected the amount and effectiveness of family caregiving for mentally ill individuals. Lack of mental health expertise among general physicians (the healthcare providers most commonly consulted by family members of individuals with mental illnesses) and the distance to specialised mental health services (particularly for rural residents) increased the difficulty family members had to overcome to obtain professional help for managing their mentally ill family member.[74]

Sociocultural factors. Sociocultural factors both hinder and facilitate the provision of family caregiving to community-dwelling individuals with mental illnesses in China. Stigma and discrimination about mental illnesses, both by community members and within the family (and, occasionally, by mentally ill individuals themselves), are significant barriers limiting family caregiving for mentally ill individuals and preventing help-seeking for family members with mental illnesses. These negative attitudes about mental illnesses can result in family members denying the problem's existence, indifference towards the issue, or maltreatment of the ill individual.[84,93] On the other hand, some aspects of Chinese culture promote family caregiving for persons with mental illnesses. Several studies reported that supporting a family member with a mental illness was considered a moral imperative for family members based on the Confucian tenets of filial piety (孝),[66,93,109] collective responsibility, and kinship in Chinese traditional culture.[84,93] Moreover, China's marriage law (published in 1950) requires family members to care for

a spouse with a mental illness,[119] and China's National Mental Health Law (promulgated in 2013)[235] stipulates that family members should care for each other, create a good and harmonious family environment, and raise awareness to prevent mental illness. The mental health law also specifies that when a family member has a mental illness, the family should help them seek timely medical treatment, appropriately monitor the management of the illness, and provide for the ill individual's daily needs.

Family-based interventions for individuals with mental illnesses in China

The 97 intervention studies identified in this scoping review assessed the effectiveness of interventions for individuals with mental illnesses that included enhanced family caregiving as part of the intervention strategy. Among these studies, 13 (13.4%) were conducted in community settings,[137,141,148,159,193,207,222,226–229,231,232] 60 (61.9%) conducted interventions during the hospitalisation of mentally ill individuals,[138,139,142,146,147,151–156,158,161–167,170–173,175–182,184,185,187–189,191,192,194,196,198–206,208–214,216,217,220,221] 23 (23.7%) recruited participants and conducted interventions in outpatient settings,[136,140,143,145,149,150,157,160,168,169,174,183,186,190,195,197,215,218,219,223–225,230] and one study (1.0%) recruited samples from both inpatients and outpatients in a hospital setting.[144] These studies mainly focused on three mental illnesses: schizophrenia, autism, and dementia.

Family-based interventions for individuals with schizophrenia

Thirty-five intervention studies focused on individuals with schizophrenia, including 20 RCTs with sample sizes (of the intervention group) ranging from 15 to 120 individuals (average, 58),[136–142,145,148,155,160,162,166,175,176,178,181,182,189,193] 13 controlled trials with sample sizes (of the intervention group) ranging from 18 to 145 individuals (average, 64),[196–198,200,201,203,204,206,207,209–212] and 2 pre-post studies with sample sizes of 36 and 59 individuals, respectively.[220,221] The types of family caregiving assessed in these intervention studies were similar to those identified in the descriptive studies.[58,62,67–70] Interventions focused on informational support assessed the effectiveness of providing family caregivers with detailed treatment and referral information and training them to enhance their ill family member's life skills and social skills.[178,181,182,189] The effectiveness of medical-related concrete support was assessed by evaluating the effect of training family members to monitor and manage their ill family member's medication, monitor symptoms, and encourage them to regularly visit the patient while hospitalised.[139–142] Non-medical concrete support strategies were assessed by evaluating the effectiveness of encouraging family caregivers to support their ill family member's daily needs and social engagement.[140,141,176,178] The potential benefits of providing psychological support were assessed by training family caregivers to demonstrate respect and provide emotional support to their ill family member.[145,176,181] These interventions lasted from nine days to three years[197,198] (in 9 studies[162,166,176,178,182,193,200,209] the duration of the intervention varied depending on the length of the hospitalisation and in 4 studies[119,193,203,207] the duration of the intervention was not specified). Scores on the Brief Psychiatric Rating Scale (BPRS),[141,142,155] Insight and Treatment Attitudes Questionnaires (ITAQ),[138,139,142] Social Disability Screening Schedule (SDSS),[148,175,201] Personal and Social Performance Scale (PSP),[162,165,176] and Positive and Negative Syndrome Scale (PANSS) were the most commonly used outcome measures.[138,178,202,207] Compared to individuals with mental illnesses from families that did not receive a family-based intervention, individuals from families that received interventions focusing on enhancing family caregiving had significantly decreased symptom severity, relapse, and rehospitalisation[138–140]; They also had better medication adherence,[137,138] social functioning,[141,142,148] and quality of life.[146,150,159] One inpatient study reported that systematic training of family caregivers of hospitalised individuals with schizophrenia leads to better outcomes for the patient.[209]

Family-based interventions for children with autism

Twenty-nine studies that assessed family-based interventions for children with autism included 19 RCTs with sample sizes (of the intervention group) ranging from 20 to 60 individuals (average, 41)[151–154,158,161,164,165,167,170,172,173,177,184,186–188,190,191]; 5 controlled trials with sample sizes ranging from 9 to 76 (average, 40)[195,213,215–217]; and 5 pre-post studies with sample sizes ranging from 1 to 51 individuals (average, 12).[222,224,226,229,232] These interventions focused on enhancing one or more of the three types of family caregiving—informational, concrete, or psychological. In studies focused on strengthening informational support, medical staff trained parents to improve their children's sensory integration skills, life skills, and social skills.[151–153] Studies focused on enhancing concrete support instructed parents to monitor and manage their child's medication use, provide for their child's daily needs, and assist in their child's social engagement.[161,164–166] Studies focused on enhancing psychological support trained family caregivers to show respect for the child, create happiness in the parent–child interactions, encourage the child's socialisation, and provide emotional support.[165,166,172] The duration of the interventions varied from 6 weeks to 18 months[195,232] (in 6 studies[161,164,165,177,187,188] the duration of the intervention varied depending on the length of the hospitalisation and in 5 studies[172,184,191,226,229] the duration of the intervention was not specified). Scores on the Autism Treatment Evaluation Checklist (ATEC),[152,154,158,164,170] Autism Behavior Scale (ABC),[170,173,186] and Childhood

Autism Rating Scale (CARS) were the most commonly used outcome measures in these studies.[154,158,167] All studies reported significant improvements in one or more areas: severity of disease,[151–153] quality of life,[164,177] and social functioning.[161,166]

Family-based interventions for older adults with dementia

Eighteen intervention studies focused on older adults with Alzheimer's disease and other dementias, including 13 RCTs with sample sizes (of the intervention group) ranging from 24 to 56 individuals (average, 39),[143,146,150,156,159,163,168,169,171,174,180,183,185] and 5 pre-post studies with sample sizes ranging from 25 to 78 individuals (average, 52).[218,219,223,227,228] The effectiveness of informational support strategies was assessed in studies that trained family caregivers on how to improve the social skills of their ill relative.[146,150,156] In contrast, the concrete and psychological family caregiving measures assessed in intervention studies were similar to those reported in the descriptive studies: concrete support strategies involved training family caregivers about meeting the patient's daily needs,[156,169] guaranteeing their safety,[169,174,180] and promoting their social engagement[181]; psychological support strategies involved training family caregivers to demonstrate respect and provide emotional support.[150,156,159,163] The interventions lasted from one month to two years[150,159,219] (in 1 study[156] the intervention persisted throughout the hospitalisation and in 5 studies[146,163,171,185,227] the duration of the intervention was not specified). Scores on the Activities of Daily Living Scale (ADL),[143,147,148] the Mini-Mental State Examination (MMSE),[143,159,169,180] and the 36-Item Short Form Health Survey (SF-36) were the outcome measures used in these studies.[143,164,177,189] Patients from families participating in these enhanced family caregiving interventions had significantly higher quality of life,[150,159] better cognitive function,[169,171,180] and fewer adverse events than those in the control groups.[169,218,219]

Family-based interventions for individuals with other mental illnesses

Fifteen intervention studies focused on other types of mental illnesses. These included: 2 RCTs about family support for individuals with depression (with sample sizes of 40 and 90 individuals in the intervention group)[179,194]; 2 studies about family support for children with ADHD (including 1 controlled trial with 65 individuals in the intervention group and one pre-post study with three participants)[205,231]; 1 RCT about family support for individuals with anxiety disorder (with 31 individuals in the intervention group)[144]; 1 RCT about family support for individuals with bipolar disorder (with 41 individuals in the intervention group)[192]; 1 RCT about family support for individuals with obsessive-compulsive disorder (with 35 individuals in the intervention group)[149]; 1 pre-post study about family support for individuals with MCI (with 70 participants)[230]; 6 studies about family support for individuals with unspecified mental illnesses (including 3 RCTs with 25–210 individuals in the intervention groups, and 3 controlled trials with 25–56 individuals in the intervention groups)[147,157,199,202,204,218]; and 1 pre-post study with 200 participants about family support for individuals with unspecified types of 'severe mental illness'.[225] The types of family caregiving provided to these individuals were similar to those mentioned above for schizophrenia, autism, and dementia. The interventions lasted from four weeks to one year[199,225] (in 4 studies[147,202,205,214] the duration of the intervention varied depending on the length of the hospitalisation and in 4 studies[157,179,192,231] the duration of the intervention was not specified). Scores on the Self-rating Anxiety Scale (SAS),[144,147] Self-rated Depression Scale (SDS),[157,160] Activity of Daily Living Scale (ADL),[147,208] and Generic Quality of Life Inventory 74 (GQOLI-74) were the most common outcome measures in these studies.[144] Significant improvements were observed in individuals receiving family support, as indicated by measures of symptom severity, quality of life, and daily living.

Discussion

Summary of main findings

This is the first known scoping review from mainland China that systematically assessed available literature pertaining to the role of family support in managing mental illnesses and the results of intervention studies that aim to enhance the effectiveness of family support for mental illnesses. We identified 176 empirical studies published from 2000 to 2023 in English and Chinese peer-reviewed journals that met the inclusion criteria for the scoping review,[27,58–99100–129130–149150–179180–209210–232] including 63 about schizophrenia, 40 about autism, 39 about dementia, and 34 about other mental illnesses. Among these 176 studies, 79 described the status of family caregiving for individuals with mental illnesses, and 97 explored the effectiveness of family-based interventions. The descriptive studies identified the different types of informational, concrete, and psychological support family caregivers provide to their mentally ill family members. These studies report that family caregiving benefits both patients and their family members but can also incur substantial financial, social, and psychological costs for family caregivers. The type and intensity of family caregiving vary between families and over time depending on the characteristics of patients and family caregivers, the available mental health services, and various sociocultural factors (e.g., stigma and discrimination). The 97 intervention studies—including 60 RCTs, 22 non-randomized controlled trials, and 15 pre-post studies with a mean of 50 individuals in the intervention group—assessed the effectiveness of a wide range of family-based interventions aimed at enhancing family-centred informational, concrete, and

psychological support for patients with schizophrenia, autism, dementia, and some other mental illnesses. All intervention studies reported significant improvements in patients' disease severity, social functioning, or quality of life. However, based on the GRADE criteria, the strength of evidence for the effectiveness of 96 of the 97 interventions was rated as 'very low quality'.

Family caregiving varied according to the different types and severity of mental illnesses

For adult patients with severe mental illnesses such as schizophrenia or dementia, the primary focus of family caregivers is to manage the limitations resulting from impaired cognitive and social functioning, so concrete support to meet their daily and medical needs was the primary type of support caregivers provided.[64–68] Moreover, the more serious the impairment, the more likely the ill family member would receive needed concrete support from family caregivers. For children and adolescents with mental illnesses, the focus of family caregiving is to help them meet age-appropriate developmental goals. For example, for children with autism, family caregivers focus on supporting training in life skills, sociability, and sensory integration and, if necessary, arrange for schooling by either accompanying their child at school or providing homeschooling.[61,63,88]

The types of family caregiving provided to individuals with severe mental illnesses in China (i.e., informational, concrete, and psychological support) are similar to those reported in Western countries, but the methods and motivations for providing the support differ.[236–238] Family members in China are pragmatically focused on achieving concrete goals for the patient, so providing psychological support is less important. Unlike the Western focus on fostering patients' autonomy and self-sufficiency,[237] traditional Chinese culture—which continues to influence current attitudes and behaviour—stipulates that families should paternalistically assume responsibility for all aspects of the lives of family members who become seriously ill or disabled.[236] Families in China often make treatment decisions and other care decisions without consulting their mentally ill family members, and doctors and other service providers often negotiate treatment alternatives with family members without involving the patient. Involving patients in these decisions is viewed as adding to their stress when they are psychologically fragile, so family caretakers assume these responsibilities for them.

Another difference between China and the West is families' motivation for assisting mentally ill family members in negotiating social and occupational activities. In the West, these activities are seen as central to rehabilitating patients of all ages, helping to ensure the retention of their social skills and promoting their self-esteem.[77,164,238] In China, the promotion of patients' social and occupational activities is a primary focus of families of children and young adults with mental illnesses but not a focus of families of older adults with mental illnesses; the family's primary goal is to fulfil their responsibility of ensuring a stable future for their ill family member (i.e., educational attainment, marriage, and a job), *not* the recovery of their mental illness.[84]

Effects of family caregiving

Despite using somewhat vague definitions of 'family caregiving' and a wide variety of measures to assess the outcomes of family caregiving, most studies identified in this scoping review reported that family caregiving was beneficial to family members with severe mental illnesses, resulting in decreased symptom severity, fewer relapses and rehospitalisations, better social functioning, and improved quality of life. Given the limited number of mental health conditions considered and the methodological weakness of some of the studies, the validity and generalizability of these uniform results are uncertain. Nevertheless, the findings are consistent with results from studies about family caregiving of the mentally ill in other countries.[239–241] Western studies also report potential negative aspects of family caregiving, for example, when families try to control patients' behaviour instead of encouraging patients' self-sufficiency, ignoring the needs and rights of their ill family member.[242] Given the paternalistic slant of family caregiving in China, this may also be an issue in Chinese families with mentally ill family members, but none of the identified studies reported this kind of adverse effect of family caregiving for ill family members. Despite the more controlling nature of family caregivers in China, similar to their Western counterparts,[241] families' caregiving efforts in China include promoting social skills training and other independence-enhancing strategies in their mentally ill family members. However, some studies did report negative financial, health, psychological, and social consequences for family caregivers and the negative impact on patients of inappropriate management of their illness by family caregivers.

Changes over time in family caregiving for individuals with mental illness in China

In China, community members' notions of 'mental illness' were traditionally limited to adults with severe mental illnesses such as schizophrenia or other chronic psychosis. The understanding of what constitutes a mental illness has more recently expanded to include less severe mental illnesses and mental illnesses among children, a change that has been more rapid in urban communities than in rural communities. In parallel with these changes, the types of family caregiving provided to mentally ill family members have changed, particularly in urban communities. In earlier periods,

family caregiving was primarily limited to providing food and shelter; mentally ill family members were almost always secluded at home, hidden from society, and, if their behaviours were disruptive, they may have been locked up or chained.[243] Some patients from families with financial or other resources would be sent to chronic care psychiatric hospitals where they could spend the remainder of their lives without family visitations.[244]

Our findings show that over the last two decades, families have provided more positive, diverse support to their mentally ill family members. Family caregivers are now much more likely to seek professional mental health care, help monitor psychiatric medication, encourage patients' participation in social activities, and, in some cases, promote patients' self-esteem and provide emotional support. Despite these positive changes, the primary focus of family caregiving for mentally ill family members in China remains the provision of concrete, practical assistance; the provision of informational and psychological support remains underdeveloped.

Gaps in the literature and problems with the available literature about family caregiving for mentally ill individuals in China

Despite our comprehensive search of multiple English-language and Chinese-language databases, 80.7% (142/176) of the available literature from 2000 to 2023 refers to family caregiving for persons with only three disorders—schizophrenia, autism, or dementia—conditions that are more severe but much less common than depressive and anxiety disorders. Moreover, 34.2% (27/79) of the available descriptive studies and 62.9% (61/97) of the intervention studies were conducted in inpatient settings, locations where patients have more severe symptoms, where families only have occasional contact with patients, and where the daily routines of family life are absent; the relevance of the findings of such studies to less severely ill patients living in the community with their families is doubtful.

There were also problems with the quality and comprehensiveness of the available reports. Descriptive studies about family support and caregiving for individuals with mental disorders only rarely describe the prevalence, intensity, and duration of the different categories of support provided (i.e., informational, concrete, psychological); this limitation makes it impossible to identify the mechanisms through which family caregiving influences changes in patients' outcomes. All studies assess family caregiving within the nuclear family, ignoring significant caregiving contributions made by extended family members, a common situation in China. The most glaring problem was with the methodological quality of the intervention studies; despite having reasonable sample sizes, the quality of the evidence supporting the effectiveness of the assessed interventions (based on GRADE criteria) was 'very low' for 96 out of 97 studies, primarily due to the lack of blinding of the outcome assessment.

Future directions

Given the central importance of families in the identification, treatment, rehabilitation, and social support of persons with mental illnesses in China, the limited information available about this issue and the poor scientific quality of the information that is available is a serious problem. The scope and quality of research about family caregiving for mentally ill individuals must overcome several challenges before it can provide up-to-date, actionable information that governmental agencies and communities can use to develop policies and programs that will strengthen this important component of the mental health delivery system.

First and foremost, there needs to be a concerted effort to operationally define 'family caregiving' and develop standardised measures to describe and characterise family caregiving in both urban and rural China. At the same time, a theoretical framework including the many factors that moderate the relationship between family caregiving, other sources of support for persons with mental disorders, and the key outcomes of mental illness (i.e., diagnosis, symptom severity, social functioning, quality of life, etc.) needs to be developed and used to test hypotheses about the mechanisms that connect different types of family caregiving with the outcomes of interest. Based on the information identified in this scoping review, we developed the dynamic model shown in Fig. 4, which can be revised as future (hopefully better quality) information about this important topic accumulates.

Research about family caregiving needs to move out of the psychiatric hospital, focusing on both psychiatric outpatients and the community-dwelling individuals with mental illnesses identified in China's frequent psychiatric epidemiological studies (many of whom are untreated). Given the greater social needs of children and adults with severe mental illnesses, it is reasonable to focus research efforts on understanding the role of family caregiving in these situations and on how health institutions and governmental agencies can help reduce the burden of these family caregivers. However, family support (particularly psychological support) is also crucial in the identification, treatment seeking, adherence to treatment, and recovery of less severe but more common conditions such as depressive disorders, anxiety disorders, and bipolar disorder, so these more prevalent conditions also need to be included in this expanded research effort.

Given the very poor methodological quality of the available intervention studies and the unrepresentativeness of the individuals included in the studies, there is no convincing evidence that any of the proposed strategies

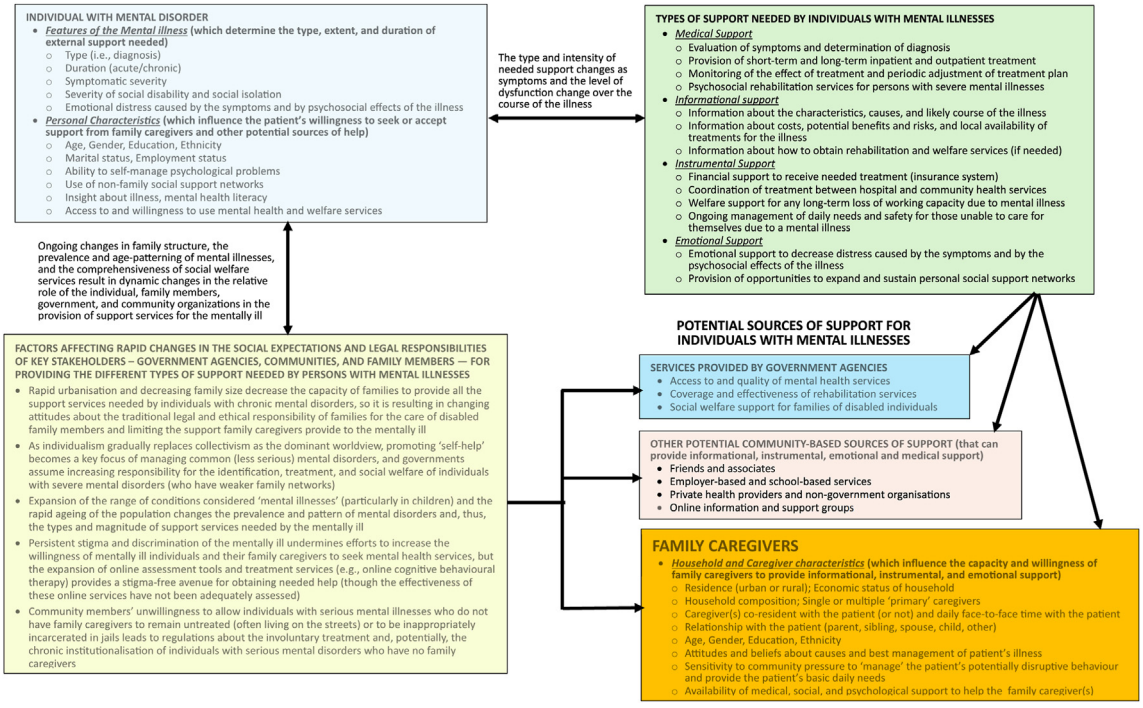

Fig. 4: **Proposed model of types of support provided by different stakeholders to individuals with mental disorders.**

for enhancing the effectiveness of family caregiving actually benefit patients. Two of the main problems in conducting RCTs about strategies for enhancing family caregiving is that in the absence of a mock 'placebo treatment' that can be used in the control group, it is difficult to conceal group assignment and, thus, blind the outcome evaluation. These problems are common when conducting RCTs of any social (i.e., non-medication) interventions. Typical solutions are to 1) provide the control group with the same number of clinical/informational contacts as the intervention group without administering the intervention of interest (e.g., discussing a topic that is unrelated to family caregiving in the control group), and 2) use pre- and post-intervention evaluators who do not administer the intervention and are both unfamiliar with the group assignment of participants and with the overall goals of the study. Despite the increased difficulty, adopting these methodological steps will be essential to identifying effective family-based interventions.

These methodological improvements in intervention studies about family caregiving will be essential to identify the most cost-effective, evidence-based strategies for maximising the utility of family caregiving for the mentally ill. Subsequent implementation research will be needed to: 1) promote the translation of these scientific findings into specific local and national policies and programs that provide structural support for family caregivers; 2) adapt the programs for different types of mental illnesses, cohorts (e.g., old versus young patients), and geographies (particularly urban versus rural settings); 3) periodically assess the fidelity of the implementation and outcomes of the programs; and 4) flexibly update the policies and programs as socioeconomic conditions change.

Conclusions

As China's rapid urbanisation replaced large multi-generational rural households with small nuclear urban households, the familial resources available to families for supporting family members with serious illnesses—including mental illnesses—have decreased, and the financial, social, and psychological burden on the remaining family caregivers has increased. Developing social welfare services to help families adapt to this major social transformation requires a detailed understanding of how families currently care for their ill family members. This study systematically searched available literature about the role of family caregiving in managing individuals with mental illnesses in China and research studies that assessed family-based interventions for mental illnesses in China. The 176 identified studies included 79 descriptive studies and 97 intervention studies. Among these studies, 142 (80.7%) were about schizophrenia, autism, or dementia; there is currently little published research about the characteristics and effects of family caregiving for other, more

common, mental disorders in China, such as depressive disorders and anxiety disorders. The 79 descriptive studies reported that family caregiving—including informational, concrete, and psychological support—benefited individuals with mental illnesses and their families, though providing these types of support often required family caregivers to make substantial sacrifices. All 97 family-based intervention studies reported significant post-intervention improvements in patient functioning, but 61 (62.9%) of these studies were conducted in inpatient settings, and all 97 studies had serious methodological problems, so the validity and generalizability of these results are uncertain.

Given the centrality of family caregiving in the management of mental illnesses in China (a fact highlighted in China's 2013 national mental health law), a clear operational definition of 'family caregiving' for family members with mental illnesses and standardised methods for assessing the presence, type, and effects of family caregiving are urgently needed. Future intervention studies aimed at enhancing the effectiveness of family caregiving for mentally ill individuals need to be more methodologically rigorous. Future descriptive studies of family caregiving need to expand the types of mental illnesses considered, and most of the studies should be conducted in outpatient and community settings (*not* inpatient settings). Regular monitoring of the characteristics and outcomes of family caregiving for a wide range of mental illnesses in representative locations around the country is needed to assess the effects of policies and programs, such as China's national Mental Health Law and to periodically update these policies and programs in response to ongoing changes in the structure and functioning of Chinese families.

Contributors

MP and SX conceived the idea of this scoping review and developed the rationale. MH designed the methodology. XL led the searches and initial screening of the study articles. XL, YZ, ZC, CL, and RL screened all full-text articles and verified the eligibility of included articles. YZ and XL evaluated the quality of the included articles. Any discrepancies in assessing the eligibility of potential articles were reviewed by MH. MH, XL, and YZ drafted the manuscript. All study authors provided revisions, offered critical feedback on the manuscript and approved the final version.

Declaration of interests

All other authors declare no competing interests.

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Appendix A. Supplementary data

Supplementary data related to this article can be found at https://doi.org/10.1016/j.lanwpc.2024.101184.

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